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SOCIO-ETHICAL ISSUES OF PRENATAL TESTING: A CONTENT ANALYSIS OF PATIENT AND TRADE LITERATURE

by

M. Sara Rosenthal

A thesis submitted in conformity with the requirements for the degree of Master of Arts
Department of Sociology and Equity Studies in Education
Ontario Institute for Studies in Education of the University of Toronto

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ABSTRACT

Women require accurate information about the benefits and harms of prenatal testing in order to determine what is in their best interests, and the best interests of the unborn fetus they are carrying, or hope to carry in cases of assisted reproduction. When the tests are inaccurate, or women are being misinformed about the purposes of various screens and tests, healthy, wanted fetuses could be aborted; and unhealthy fetuses, who might have been aborted with accurate information, are born. Misinformation, or a lack of information, undermines a woman's right to make decisions about her own life. There are also wider moral implications of any decision made with respect to prenatal testing. If she had access to information on how her decision impacts society at large, she may make another decision. This thesis explores whether enough printed information on prenatal testing is provided to individual women offered testing.
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Choice. Rights. Do these terms have any meaning in the era of technological reproduction?
- Helen Bequaert Holmes (1992: 6)

INTRODUCTION

Although I have spent the last several years writing about women's reproductive health issues, I have only recently begun to look at these issues from a feminist bioethics perspective. This means I am taking a core feminist (Purdy, 1996) position: "women, as a group, worse off than men, because their interests routinely fail to be given equal consideration. [T]hat state of affairs is unjust and should be remedied" (Purdy, 1996:5).

With so many women's health issues demanding scholarly attention, it was initially difficult for me to select an area where all (or at least a good deal) of my concerns as a graduate student in sociology and bioethics could be addressed. Prenatal testing - and its consequences - comes pretty close; it is an area that raises profound sociological and ethical concerns for all of human health, and, of course, the future of the human species. Whether a woman is initially infertile or subfertile, and uses assisted reproductive technology to conceive, or she conceives spontaneously, her pregnant body has become a focus of medical intervention. For example, "all phases of a woman's reproductive life, from menstruation through menopause, have been medicalized and subjected to expert control by the male-dominated medical profession" (Sherwin, 1992: 25). Yet the interests of women have not been served, when one considers how many unnecessary procedures (Sherwin, 1992) have been performed. The medicalization of reproductive health has made most women seeking prenatal care in the developed world, at least partially dependent on the male-dominated medical system. This dependency begins for heterosexual women in adolescence for hormonal birth control; continues into
pregnancy and childbirth; and may continue with menopause because of hormonal replacement therapy.

Given the patriarchal bias and authoritarian nature of medicine and the fact that the new reproductive technologies further extend the potential power of male dominated institution, feminists have grounds for viewing increased medical control of reproduction with alarm. (Sherwin, 1992: 25)

When the medical system controls pregnancy and childbirth, women become powerless over their reproductive lives.

Although pregnancy and childbirth have profound social and economic effects on women, women have not been allowed control over them. Since women’s control over their own reproduction is central to all aspects of division of power between women and men, arguments about abortion must be couched in this political recognition. (Sherwin, 1992: 27)

It is therefore imperative that feminist researchers working in women’s health, explore whether a woman is fully informed about medical tests and treatments administered during her pregnancy. Bioethicists agree that informed consent is necessary in order for patients to exercise their autonomy and free will. Without information, there can be no decision, which is defined by the Oxford dictionary (1984 edition) as: “settlement of a question; conclusion, formal judgement.” The antonym to “decision” that Word 98 lists is “indetermination”. Clearly then, without information, a woman cannot be self-determined.

This thesis explores whether the patient and trade literature on prenatal testing, in the absence of counselling, facilitates or impedes informed consent. Therefore, information provided to women through verbal communication is not explored or measured in this thesis. The key research questions posed are these:
1. Does the literature provided (or available) to women/parents on prenatal testing clearly explain the purposes of each test, its limitations and risks?

2. Does the literature provided (or available) to women/parents on prenatal testing create awareness of the social implications of testing?

3. Does the literature provided (or available) to women/parents on prenatal testing coerce them into prenatal testing, or conversely, deter them from prenatal testing?

4. Does the literature provided (or available) to women/parents on prenatal testing facilitate, or impede, moral decision-making on the right to reproduce (Purdy, 1996)?

There seems to be a logical distinction between understanding the purposes, limitations, risks, and social implications of a particular test, and making a moral decision about whether to bring a potentially “harmed life” into the world. This thesis is not concerned with presenting arguments about when it is – or is not – immoral to reproduce; it is concerned with whether a woman is given enough information to answer that question to her own satisfaction. Laura Purdy notes: “A decision to procreate is surely one of the most significant decisions a person can make. So it would seem that it ought not be made without some moral soul searching” (Purdy, 1996:39).

While some women believe that we “ought to try to provide every child with something like a minimally satisfying life” (Purdy, 1996:45), other women may be more comfortable surrendering to a karmic coin toss, allowing the “Gods” to decide who will live and who will not. Still, other women may have their own interests (or the interests of other women) at heart, because:
Sometimes disability is a disaster, and I believe that it is unfair to all concerned to obscure that possibility... Who already does the bulk of caring work in this society, including childrearing? Women. And caring for a child with serious health problems can add immeasurably to a mother's burden. It is not rare for, allegedly, feminist analyses to pay scant, if any, attention to the burdens now shouldered by women caring for children with health problems... But where is a woman's right to be fully and realistically informed about the probable consequences of her decision to go forward with her pregnancy? Surely these issues need to be right up front in feminist work instead of submerged in some generalized "right to choose." (Purdy, 1996:82-83.)

Jenny Morris provides a feminist theory of disability, and points out that the politics of community care, which includes looking after disabled or aging persons, is sexist. Women's interests as both carers and the cared for, need to be taken into account. However, traditional feminist writings do not generally include disabled women in the oppressed group known as "women". Morris asserts that the "cared for" are separated out from the "carers," which is a serious problem that further isolates disabled people (Morris, 1991). Furthermore, it widens the gap between the divisions of labour between the sexes in community care (Morris, 1991). Therefore, understanding how deeply the carer role impacts on a woman's choice to bear a child with a disability is an important aspect of consenting to prenatal tests.
Explanation of Terms

There is a newer terminology for prenatal testing that reflects the increasing medicalization of pregnancy: "prenatal diagnosis". I reject this terminology because it is less specific, and assumes that the fetus is already in a diseased state. One does not normally "diagnose" a human being when s/he is in a normal state of health. When I use the term prenatal testing, I am referring to diagnostic imaging tests, such as ultrasound; blood and/or "fluid" tests, such as maternal serum alphafetoprotein, or genetic tests, performed during pregnancy, to decipher the status of the developing fetus. Although pregnant women will also be screened for diabetes, high blood pressure, or protein in their urine, this thesis does not look at literature pertaining to these tests, which some may call "prenatal tests". In my view, since these tests do not specifically "check" the fetus (although ill health in the mother will definitely affect the fetus), and do not usually result in a "termination question," I have omitted them from my analysis, and regard these tests to fall into a broader category of general maternal health, along with information on nutrition and exercise during pregnancy.

I do not wish to de-emphasize the importance of nutrition during pregnancy, either; adequate amounts of folic acid intake, for example, prior to and during the first trimester, dramatically reduces many of the birth defects these tests detect, such as open neural tube defects. Moreover, I should point out that women with gestational diabetes are often in danger of giving birth to exceedingly large babies (a condition known as macrosomia, where the fetus literally becomes "glucose gorged," and can weigh over 12 pounds at birth). Clearly, in this case, a woman would need to decide whether to continue the pregnancy or deliver prematurely. Yet deciding whether to terminate the pregnancy
would not be a reasonable or intentional goal of glucose screening or other such tests that check general maternal health.

Screening for the human immunodeficiency virus (HIV) is a different matter, and an issue so complex, it demands an entirely separate thesis. However, I do not analyze HIV screening literature in this thesis. This is because azidothymidine (AZT) treatment during pregnancy is now standard therapy in all developed countries, and in most cases, can prevent maternal-fetal HIV transmission. Current UNAIDS policy stipulates that HIV-infected women in the developed world be given AZT during the last 12 weeks of pregnancy, receive intravenous infusions of the drug during delivery, and then have the drug administered to their newborn during the first six weeks of life. The effective AZT regimen (also known as the "076 regimen," after the number assigned to the federal study that proved it effective) costs roughly US$1,000 per pregnant woman and newborn.

There are certainly different ethical and sociological issues that warrant a great deal of discussion and analysis surrounding HIV screening during pregnancy. For example, there are questions concerning distributive justice issues (who gets access to AZT treatment?) as well as third world research, such as the ethics of placebo-controlled AZT trials in poor countries. Education and informed consent issues are also enormous problems when it comes to HIV screening, particularly in the area of breastfeeding recommendations. But since, as of this writing, HIV screening during pregnancy in developed countries, does not present the "termination question" to the pregnant woman undergoing the screening, but rather the "access to treatment question," I have omitted the analysis of HIV literature from this thesis. What is not omitted from this thesis is analysis of information pertaining to genetic carrier screening. While these screens, at
first glance, seem to fall under the category of general maternal or paternal health, they are not done to specifically treat a condition in the man or woman but to prevent fetal anomalies. Finally, the term: “preimplantation diagnosis” is currently used to refer to embryos that are tested in vitro for sex selection or various anomalies prior to being implanted or transferred into the gestational carrier (who may or may not be genetically related to the implanted fetus). I reject this terminology as well, and will use the term preimplantation screening.

There are also a series of tests known as antepartum tests (meaning before delivery) which detect placental problems or amniotic fluid problems that may trigger fetal distress. The literature about these tests is not analyzed in this thesis because, again, these tests are not posing the “termination question” to the woman as much as the “when to deliver” question. I note, however, that antepartum testing has great bearing on the type of labour experience a woman can expect.

Finally, what is meant in this thesis, by the term “literature”? This refers to the following pieces of printed matter, which I have collected for analysis:

1. Patient literature distributed to pregnant women/parents by women’s health clinics or the actual facility doing the testing (in this case, the hospital) in the form of pamphlets, booklets, questionnaires, consent forms, waiting room magazines, articles, etc.
2. Trade literature on prenatal testing available for sale at retail outlets (bookstores, drug stores, etc.) which would usually take the form of chapters or sections within a larger book on pregnancy or fertility.
CHAPTER 1

LITERATURE REVIEW

Women require accurate information about the benefits and harms of prenatal testing in order to determine what is in their best interests, and the best interests of the unborn fetus they are carrying, or hope to carry in cases of assisted reproduction. When the tests are inaccurate, or women are being misinformed about the purposes of various screens and tests, healthy, wanted fetuses could be aborted; and unhealthy fetuses, who might have been aborted with accurate information, are born. Misinformation, or a lack of information, undermines a woman's right to make decisions about her own life. There are also wider moral implications of any decision made with respect to prenatal testing. If she had access to information on how her decision impacts society at large, she may make another decision.

The purpose of this thesis is to explore whether enough information on prenatal testing is provided to individual women offered testing. The purpose of this literature review is to illustrate the complexities involved with these technologies by presenting the potential harms associated with testing, critiques of prenatal testing, and counterarguments to some of these critiques.

This literature review does not expand on the perceived benefits of prenatal testing; it is obvious that Western society already perceives prenatal testing as a good, and something which can offer a higher quality of life to the potential parent and society at large. Yet unless women are exposed to the debate surrounding prenatal testing, it seems unreasonable to expect they can make truly informed decisions.
Section 1.1: Prenatal Testing and Informed Consent

Prenatal tests have been routinely available in the Western world since the early 1960s (Duster, 1990; Lippman, 1993). They now detect the physical shape of the fetus, all known chromosomal abnormalities, several developmental malformations, over 150 biochemical disorders, and fetal sex (Lippman, 1993).

Obstetrical care has become more focused on the prevention of fetal abnormalities, and much less centered on the pregnant woman herself. With each planned prenatal visit to the doctor, there is an accompanying test that is positioned as a marker or screener for various genetic diseases or fetal abnormalities (Lippman, 1993). Lippman notes that when the world is “gendered” (Lippman, 1993:46), genetic technologies cannot be neutral. In other words, when males are valued more than females in a particular culture, the potential for gender bias exists. It is all the more disturbing when none of these tests can guarantee the fetus is normal or abnormal (Capen, 1994).

What worries critics as well is that prenatal testing is being sold as a solution to “women at ‘genetic risk’ who ‘need’ some reassurance, as something women ‘choose’.” (Lippman, 1993:47.)

“The line between preventing the birth of fetuses with severe defects and improving the species begins to blur. ...And who decides which prenatal tests should be developed” (Glazier, 1993:109)?

For example, prior to a planned, unassisted pregnancy (meaning that a woman conceives without assisted conception or new reproductive technologies), women are encouraged to be screened for sex-linked disorders associated with the X chromosome
(e.g. hemophilia, various dystrophies). Other genetic diseases typically screened for prior to conception would be Tay Sachs disease in people of Jewish or French Canadian descent) (Hechtman et al, 1990) or sickle cell anemia (in people of African descent) (Lauerson, 1995; Duster, 1990). Ten weeks into the pregnancy, a woman will be encouraged to have an alpha fetoprotein test, in which a compound normally found in the liver of the fetus can be measured in the mother's blood. Current statistics on AFP screening (based on U.S. populations) show that for every 1,000 women who take this test, roughly 50 will be told that their AFP levels are high (meaning neural tube defects) or low (meaning Down's Syndrome); out of those 50, only two will have a child with defects (Lauersen, 1995).

Amniocentesis is said to be reserved for high risk cases only, or for women who have a higher likelihood of giving birth to a Down's Syndrome child because of age. It is therefore offered to women who are over 35, or who are at high risk of carrying a child with genetic problems (Lauersen, 1995). However, since there are so many women who will be referred on to amniocentesis as a result of inconclusive AFP results, amniocentesis is slowly becoming a far more routine procedure for women with health insurance in the Western world than it was prior to AFP testing (Lauersen, 1995). (In the United States, women without health insurance have less access to prenatal testing.)

Amniocentesis is also an invasive test not without risks. About 1% of fetuses are miscarried as a direct result of the procedure, while puncture of the placenta, the baby, the mother's bladder, infection or amniotic fluid leakage have been reported (Lauersen, 1995). The test involves inserting a needle through the abdomen into the amniotic sac to
remove a small sample of fluid surrounding the fetus, which contains fetal cells that can diagnose chromosomal and/or developmental abnormalities (Lippman, 1993).

Chorionic villus sampling (CVS) involves inserting a catheter through the vagina and cervix, and obtaining a small amount of tissue from the placenta for examination. The perceived advantage of this test is that it can be done at 10 weeks. But since this test is not very accurate, it is unlikely that someone would to decide to terminate her pregnancy without confirmation via amniocentesis anyway (Lauersen, 1995).

A central concern for critics of prenatal testing is that in spite of the long list of defects amniocentesis, AFP and CVS may detect, more common problems affecting maternal and fetal health are ignored. This creates the impression that there is an apparent hunt for fetal defects yet disinterest in the health and wellbeing of the pregnant woman.

For example, low birth weight is a greater problem than Down’s Syndrome or neural tube defects (Lippman, 1993). Given this fact, it seems reasonable to ensure good early prenatal care and proper nutrition takes precedence over universal triple screening (Lippman, 1993.) Sociologist Troy Duster asks why a national program of “material health care with prenatal services to reduce low-birthweight rates” (Duster, 1990:119) has not yet been established.

Prenatal testing, to women enjoying a high standard of living in the Western world, is seen as something desirable which can improve quality of life and healthcare. A U.S. study assessing pregnant women’s attitudes about prenatal testing found that 79 per cent of the pregnant women surveyed thought AFP testing should be offered to all pregnant women; 70 per cent felt that an ultrasound scan for fetal malformations should be offered to all pregnant women, while 26 per cent thought that that amniocentesis or
CVS should be offered to all pregnant women (Jorgensen, 1995). Fifty-nine per cent were in favour of continued research into prenatal testing.

But when socioeconomic status is considered, there are clear differences in attitudes about testing. For example, another study found that women who did not finish high school were more in favour of prenatal screening than women with high school diplomas (Kupperman et al, 1996). Other studies have found that the there are more Down’s Syndrome children born to Latinas and African-American women over 35 than White and Asian women in the same age group. This raises an issue of distributive justice: women with more money have more choices about their reproductive health than women without money. Yet, it is, ironically, the women with no money who are burdened with the costs of caring for a Down’s Syndrome child (Jorgensen, 1995; Kuppermann et al, 1996). In this population, access to testing might improve quality of life.

There are wider social implications of such testing. One controversial position presently in debate by the Canadian Disability Rights Council is that the hunt for fetal anomalies is “misleading, suspect and dangerous” (Goundry, 1993:154). For example, the Council maintains that eugenics is being practiced when women with disabilities are discouraged from having children. It also notes that approximately 90% of amniocentesis tests showing some defect result in the termination of once wanted pregnancies (Goundry, 1993). Thus, it is in women’s best interests to be made aware of these claims.

Presently many women do not seem to be questioning the eugenic aspect of detecting fetal anomalies. One can presume that many women do not “understand and appreciate” (Veatch, 1995) the eugenics aspect, because this aspect of testing is withheld,
if not, concealed, from public information on prenatal testing. However, women seeking information on this aspect of testing can certainly find it in feminist literature. Meanwhile the information on prenatal testing is couched in terminology that suggests “medical indication” for termination.

The rise in pregnancy terminations indicates that women are primarily concerned about protecting their quality of life, and their right not to be burdened with a disabled child. For example, a report from the Australian Institute of Health and Welfare (Middleton, 1997) found that a large number of Australian women are aborting their fetuses up to the 27th week, after discovering serious problems with limbs or vital organs, spina bifida or Down’s Syndrome. In 1991, 421 pregnancy terminations were recorded in Australia; by 1994, the figure had risen to 718. While Down’s Syndrome, heart problems and cranial abnormalities were the three most common birth defects that led to these pregnancy terminations, older mothers were 12 times more likely to give birth to an infant with a chromosomal abnormality than younger mothers, and 60 times more likely than younger mothers to terminate their pregnancies before 20 weeks. The actual number of pregnancy terminations in Australia is much higher, since this report was based on South Australia only. The authors of the Report further attribute this high termination rate to the fact that 100% of all expectant mothers receiving prenatal care in Australia have an ultrasound test done at the 18th week. One in seven fetuses with birth defects is being aborted.

Purdy argues this is not necessarily a bad thing; she points out that disability is often a disaster, and can destroy the quality of life for the parent caring for the child while introducing a harmed life into the world (Purdy, 1996). The problem with devoting more
resources to detect disability than to ensure normal birth weights, for example, is that most disability occurs after birth, through random accidents and incidents. In other words, most disabled people were born healthy and able – until they had an accident, which rendered them disabled. [Christopher Reeve is a good example of this, and has some compelling perspectives on this topic in his popular trade book, *Still Me* (1998, Random House).] Disability is also caused by aging and chronic diseases, such as diabetes. This is not to say that we should abandon screening for disability prenatally, but it ought to be done with more attention paid to the social context of disablism.

In the present climate, screening for disability prenatally creates a false impression that disability can be prevented and even eradicated. While some disability can be prevented through prenatal screening, much of it cannot. Thus, there ought to be room for a disabled person in society, and hence room for more people to feel less guilt, shame or remorse over their disability – whatever the cause. The social construction of what a "healthy body" looks like is also disabling. When western society values only those with perfect bodies, those without perfect function suffer discrimination (Holmes, 1992). There is also the problem of expanding definitions of disability. The more society values and idealizes perfect bodies, the more discrimination exists for people who are obese, unattractive, or visually unappealing (though perfectly able-bodied). Burn victims, for instance, are good examples of able-bodied people who are socially disabled by virtue of appearance. Distorted body image and eating disorders are another consequence of idealizing perfect bodies.

Authors who write about disability (Schatzki, 1996; Davis, 1997; Davis, 1995; Linton, 1998) point out that disability is largely a social construct, meaning that the
barriers that distinguish able-bodied persons from disabled persons are societal rather than biological. One aspect, for example, is urban planning: The way roads are built, buildings are constructed, and so on, creates many real barriers. In an urban setting where there is full access to transportation, buildings, jobs, entertainment, and so forth for people with all levels of ability, many people now labelled disabled would be transformed into productive, able-bodied persons. As more people with disabilities begin to lobby for greater access and mobility, the barriers that exist now are slowly changing.

Another aspect is prejudiced attitudes towards people with disabilities. The stigma of disability creates false assumptions about capacity and capabilities, preventing people with disabilities from obtaining good jobs, and/or the quality of life able-bodied persons enjoy.

The issue of community care, as a sexist institution (Morris, 1991) must also be looked at. There is an unequal division of labour in community care as women traditionally take on the roles of caregiving, which has made community care a much lower priority in social policy (Morris, 1991). As a result, community care remains an industry that demands hard work for low pay, which means that community care facilities are often understaffed, or dependent on volunteers, who are often untrained.

Now that it is often possible to prevent the birth of a disabled human, women may face the possibility of being sued for continuing their pregnancy – by their own child. In the U.S. case, Smith v. Brennan (1960), the claim that a child has a legal right to begin life with a sound mind and body was made (Callahan and Knight, 1992). “Such reasoning can be used to argue for recovery for both nonfatal prenatal injury and wrongful life (recovery where the plaintiff’s claim is that, given his or her predictable afflictions,
having been born constitutes an injury” (Callahan and Knight, 1992: 228-9). The notion of “wrongful life" suits is troubling since biological fathers have no legal right to prevent the mother from seeking or not seeking an abortion, it is the woman who becomes liable (Callahan and Knight, 1992).

The goal of preventing defective babies, or, producing perfect babies, often leads to the state policing of pregnancy, as evidenced by the 1997 Winnipeg case, involving a pregnant Aboriginal woman who was a substance-abuser (Somerville, 1997). The individual woman therefore becomes an agent of the state (Lippman, 1993) who must do her “duty” to prevent having a disabled child.

Fetal anomaly hunting has shifted ownership of the fetus from mother to society to the point where it has become acceptable for the state to police pregnant behaviour: “Child abuse laws which were never intended to apply to a woman’s prenatal behaviour have been used by [social service] agencies to justify their attempts to control the acts of pregnant women” (Bessner, 1994:171). Bessner maintains that turning what should be a moral responsibility into a legal obligation violates a woman’s right to autonomy and self-determination (Bessner, 1994).

With the advent of wrongful life suits, policing pregnancy can be used under the auspices of protecting the woman from a future lawsuit from her unborn fetus (Callahan and Knight, 1992). The state can also bring forth a murder charge based on prenatal behaviour. In California, Pamela Stewart (Callahan and Knight, 1992), who failed to follow certain medical instructions during pregnancy, was alleged to have caused severe brain damage to her fetus. She was charged with murder (Callahan and Knight, 1992).
When pregnancy becomes policed, more women may want to protect themselves from liability, and hence, choose not to be a gestational carrier. In the near future, some women may be able to opt for ectogenesis, or in vitro gestation (see Section 1.2). In fact, if IVG, in the future, is shown to provide more ideal conditions for fetal development, opting for carrying a child in her own womb could be viewed as risky.

This leads to the unanswerable and ultimately, unknowable, question: (when) is the fetus a person, and hence, entitled to rights? For the purposes of this thesis, it is important to note the legal definition: English common law dictates that the moment of live birth is the point at which a legal person comes into existence (Warren, 1992). The 1973 Roe v. Wade (U.S.) decision “presumed viability of third-trimester fetuses as a basis for permitting states to restrict abortion rights in order to protect fetal life in the third trimester, but not earlier” (Warren, 1992: 202).

Many feminists argue that to treat fetuses in utero as persons would make the woman less than a person. Extending legal rights to fetuses would therefore violate a woman’s basic right to personal autonomy and making decisions about her own welfare and body. However, this does not allow for the possibility that the fetus may have rights, even though it is not a person. Animals are not persons either, but yet many would argue they are entitled to rights. The problem with championing a fetus’ rights over its mother’s is that it could create a scenario in which the only time abortion would be allowed is if it were “self defence,” that is, when the mother’s life was endangered by the continuing pregnancy (Warren, 1992).

The Catholic position is also of interest: “From the time that the ovum is fertilized, a new life is begun which is neither that of the father nor of the mother; it is
rather the life of a new human being with his own growth. It would never be made human if it were not human already” (Vatican, 1987: 13).

The question of personhood and fetal rights is important from a clinical perspective. If fetuses are persons, then they are patients, which means that in the future women may be required to submit to complex prenatal surgeries against their will as fetal patients are granted pediatric status (Callahan and Knight, 1992). In some instances, this has already occurred (Pollitt, 1998; Dickens, 1989).

The notion that pregnant women are “mere maternal environments” (Callahan and Knight, 1992) or “fetal containers that may be opened and shut or otherwise forcibly manipulated for the protection of future persons” (Callahan and Knight, 1992:233) is deeply troubling.

What Is Meant By “Eugenics”?

It is important to elaborate on the social implications of screening out bad genes or defects. The term “eugenics” literally means “good genes” (Duster, 1990:112). Yet the prefix “eu” has a distinctly clinical meaning; its current usage describes “normal” readings rather than “good” readings. For example, a person with normal blood sugar levels would be described as “euglycemic”; a person with normal thyroid levels would be described as “euthyroid”. But when we turn to prenatal “readings” clearly the terms “normal” and “good” blur.

FINRRAGE, the Feminist International Network of Resistance to Reproductive and Genetic Engineering, is a group that “demands a radical reorientation of [reproductive] research that aims at enabling people – particularly women – to exert a
greater control over their fertility without sacrificing their integrity, health and well-being” (FINNRAGE Website, 1998). The organization stated the following in its 1989 Conference Report:

The combination of IVF, sex determination, genetic screening and other methods is a new form of a seemingly scientific eugenic selection which is used to discriminate and eliminate oppressed groups—women, people with disabilities, people of certain colours, races, religions, class or caste. Rather than this perverted form of prevention of disease, the women present demanded the elimination of hazardous drugs, radiation, hazardous chemicals at the workplace and in the environment and preventable infectious diseases. (Williams, 1989:83)

Duster argues that none of this is “new eugenics” and that it is inevitable that biological norms turn into social harms. He asks us to imagine Tay-Sachs screening in 1930s Germany or sickle-cell screening in the Southern U.S. during the 1950s to illustrate how easy these screens can be used to harm social groups (Duster, 1990).

While the Jewish population, for example, would not have been better off with more Tay-Sachs babies, in a climate of anti-semitism, Tay-Sachs disease could be used to further claims that Jews, as a group, are impure.

Duster’s work is a clarion call to the future of genetic research: “[W]hen eugenics reincarnates this time, it will not come through the front door, as with Hitler’s Lebensborn project. Instead, it will come by the back door of screens, treatments, and therapies” (Duster, 1990:x).

Screening ethnic groups for diseases is nothing new, and dates back to the Inquisition (Duster, 1990). Limpieza decrees (limpieza refers to purity of blood) were used to prevent people from different races or faiths from intermarrying (Duster, 1990). While it can be argued that there are good reasons for creating disease-free populations,
such as eliminating unnecessary suffering, or freeing up more resources, the problem lies in the potential for these screens to be abused by racists. Screening therefore, ought be done in a climate that is sensitive to this potential abuse.

In April 1986, California legislated the first mass screening program for prenatal testing. (Duster, 1990). Today, it is California law that all pregnant women have an alpha-fetoprotein test (Duster, 1990). This is a test that detects neural tube defects, first developed in 1972. This test is infamous for false positives and negatives, and is therefore a questionable screening tool.

With the completion of the Human Genome Project, there is no limit to what may be labelled a “defect”. Screening may eliminate serious diseases, such as Tay-Sachs in 1998; by 2020, the “gay gene” may be on the list of defective disorders. Who decides what is defect, difference, or the norm? This is obviously an old question that is the essence of Duster’s worries. The problem with old questions is that there are no simple answers. As of this writing, we can reframe the question: how is defect, difference or the norm socially constructed? For example, disability rights activists point out that the disabled body, by virtue of the very terminology “dis/abled,” (Davis, 1997) is constructed as a distortion of the norm or able-bodied, even if that disabled body is functional, able and productive.

What about the benefits of certain screens? For example, In 1970, 22 of the 30 infants born with Tay-Sachs were Ashkenazi Jews – where the disease is roughly hundred times more frequent than in the general population (Duster, 1990). It seems difficult to argue against preventing such a terrible fate for the child and parent.
Ashkenazi Jews in North American and elsewhere have the option of Tay-Sachs disease screening, but it is not mandatory. For African-Americans, the situation is different (Duster, 1990). Even though Tay-Sachs disease incidence is far more prevalent among Jews, and always fatal for the child, it remains a voluntary screen. Yet sickle-cell disease (sickle cell anemia), which is not as prevalent among Blacks as Tay-Sachs is among Jews, is not fatal, and frequently has no adverse symptoms, is nonetheless a mandatory screen in several parts of North America (Roberts, 1997; Duster, 1990). This demonstrates the potential for screening to become an instrument for racism, and shows the need for greater sensitivity to this aspect of screening. Of the sickle-cell screening program, Dorothy Roberts points out:

What began as a strategy to improve the health of Blacks soon turned into an instrument of medical abuse. Because screening programs often provided no counseling, there was rampant confusion between carriers of the [sickle cell] trait and those who had the disease...Hysteria over the sickle-cell trait led to widespread discrimination. (Roberts, 1997:257)

Children, for example, do not benefit from the knowledge that they carry the sickle-cell trait; the screening is designed to help two carriers of the trait make reproductive choices. Thus, screening all Black children for the sickle-cell trait, which is entirely different than sickle-cell disease, was an inappropriate use of the screen (Roberts, 1997).

For example, despite a prevalence study in California that found no differences in sickle cell trait frequency among Blacks (Roberts, 1997; Duster, 1990), Black airline employees carrying the sickle-cell trait in the 1970s were either grounded (high altitudes are considered to be risky for people with sickle cell disease, but do not affect carriers) or fired (Roberts, 1997; Duster, 1990). In 1979, a Black man was forced to resign from the
Air Force Academy when he tested positive for the sickle-cell gene, even though he did not have the disease, and in fact, was a mountain climber (Duster, 1990). By the mid-1970s, seven U.S. states mandated sickle-cell gene testing in school children (Roberts, 1997; Duster, 1990). By disabling such instruments for racism, there could be more benefits enjoyed by society. In this case, weighing the benefits of such screening over the social harms that arise from screening abuses, would help to decide the issue.

Nobel-Prize Winner Linus Pauling, actually suggested that:

[T]here should be tattooed on the forehead of every young person a symbol showing possession of the sickle-cell gene or whatever other similar gene, such as the gene for phenylketonuria, that has been found to possess in a single dose. It this were done, two young people carrying the same seriously defective gene in single dose would recognize this situation at first sight, and would refrain from falling in love with one another. It is my opinion that legislation along this line, compulsory testing for defective genes before marriage, and some form of semi-public display of this possession, should be adopted.” (Duster, 1990:46)

Herein lie the social harms that come from constructing biological norms. When it is established that certain genetic diseases are distributed unevenly among certain ethnic groups, there is the possibility of preventing certain groups of people from reproducing through carrier screening, and certain people from being born through prenatal testing.

The trouble with identifying genes with a specific ethnic group is that many disorders are based on environmental factors ranging from industrial pollutants to diet and lifestyle. For instance, the highest incidence of spina bifida (open spine), a neural tube defect (NTD), is among residents of a small industrial town in southern Wales (Duster, 1990). Epidemiologists may attribute this to some industrial contaminant, but it is more cost-effective for governmental bodies to maintain that spina bifida is a “genetic” disorder (Duster, 1990); otherwise, environmental clean-up and remediation would be
necessary. Ironically, the most recent research on spina bifida finds that it is a preventable disorder when the mother ingests adequate servings of folic acid during the first six weeks of her pregnancy (Brown, 1997). This research points to the fact that one disorder still labelled “genetic” is actually preventable by adjusting one’s diet. (Certainly, most disorders are multifactorial in that environmental triggers trip the “genes”.)

Unfortunately, diet is very much a social issue: “We have long known that babies with neural tube defects are more likely to be born to women of lower socioeconomic status and poor diets. In the United States, there was a rash of such births during the Great Depression, with a steady decline since” (Duster, 1990:54).

In 1992, the United States Public Health Service announced that all fertile women in their childbearing years should consume 0.4 milligrams (400 micrograms) of folic acid per day. Other specialists advise that this amount is too low; they recommended that 0.6 mg (600 micrograms) of folic acid per day in the first 10-12 weeks of pregnancy will prevent 70% of all NTDs (Brown, 1997). The U.S. Food and Drug Administration (FDA) began to fortify all refined grains and cereals with folate, a salt of folic acid by January 1, 1998. This translates into 140 micrograms of folic acid per 100 grams (Brown, 1997).

Regardless of their overall value, widespread prenatal screening will widen the gap between the rich and poor unless it is available to all. Unless they are universally available, the problem of access issues surfaces. The issue of access is somewhat more complicated by expensive screening tests and equipment, however. What happens when only rich women have access to prenatal screening? More “undesirable humans” will be born to poor women. Eventually, defective humans will only appear in lower socioeconomic classes, while the rich will have larger numbers of normal children. For
example, in California “the earliest consumers of amniocentesis were primarily white middle-class females in their middle thirties... Women who show up for amniocentesis tend to be much more likely to come from the higher social and economic strata” (Duster, 1990:62-66).

If neural tube defects can be prevented through diet, how many other disorders, currently blamed on genetics, can probably be prevented by adjusting diet and/or lifestyle? The future of prenatal screening points to more emphasis on screening for adult-onset disorders ranging from heart disease and diabetes to various cancers (Duster, 1990). Mental illness (Duster, 1990; Chesler, 1972) is also being blamed on genetics, even when there are clear social forces causing women’s depression (Chesler, 1972).

The majority of lung cancer is caused by smoking (other causes include pollution and second-hand smoke). Therefore, looking at who smokes – and why -- could be a better way to calculate who will get lung cancer than screening for a “lung cancer gene” at birth. For example, when 40% of Black males now smoke, compared to 31 percent of white males, the top twenty biotechnology firms are still devoting their resources to finding genetic markers of diseases linked to smoking (Duster, 1990).

In 1971, a Harvard psychologist “speculated that someday ‘the tendency to be unemployed may run in the genes’” (Duster, 1990:97). Duster also notes that between 1976 and 1988, articles on the genetic causes of crime, mental illness, intelligence and alcoholism in the popular print media increased fourfold (Duster, 1990). This suggests a public acceptance of the genetic causes for social problems, which is not surprising given the role the media plays in supporting these claims.
Ultrasound

First used in Scotland in 1957 (Mitchell, 1994), ultrasound is so routine in Western prenatal care, it is often not considered a true “prenatal test” (Lippman, 1993). Ultrasound provides a detailed visual picture of the pregnancy, and can detect fetal size, position, sex, defects or anomalies (Lauersen, 1995).

Medical arguments for the routine use of ultrasound are grounded in the rationale of preventive medicine, economics and individual choice. Routine ultrasound, it is argued, means fewer pre- or post-term babies, fewer ‘costly’ low-birth weight babies, fewer unanticipated complications in childbirth (e.g. placenta previa or breech birth), and the early detection of fetal anomalies so that parents have the ‘choice’ of terminating the pregnancy or preparing for the birth of a child with disabilities. (Mitchell, 1994:147)

If women were given the opportunity to refuse an ultrasound, then choices regarding terminating the pregnancy would have more meaning for women who do decide to undergo an ultrasound scan. But studies to date on routine ultrasound screening have concluded that for low-risk pregnancies, ultrasounds do not change the odds of having a healthy baby (Mitchell, 1994; Ewigman, 1993). “Medical critics of the routinization of this technology argue that there is still no clear and consistent evidence that ultrasound is safe or that its use in all pregnancies improves maternal or neonatal health or is cost effective” (Mitchell, 1994:147).

One problem with routine scans is that not enough time is provided for the ultrasound “scanner” to truly detect an anomaly; only half of all fetal anomalies can actually be seen through ultrasound (Mitchell, 1994) because of the imperfect image an ultrasound produces, which leads to false positives or false negatives.
Mitchell also points out that ultrasound has shifted the informant on fetal status from mother to doctor, which means that the experience of the pregnant woman is devalued as she becomes a container for the fetus. The fetus becomes seen as a separate entity from the mother through ultrasound (Mitchell, 1994).

One study that looked at informed consent and ultrasound showed that physicians offer very little or no information about ultrasound (Mitchell, 1994), suggesting that this test is considered so "normal" and routine, it is equated with something as harmless as being examined with a stethoscope. The women in this study learned about ultrasound not through their physicians, but through conversations with other women who had undergone the procedure. The most disturbing revelation was that none of the women interviewed were asked to consent to the procedure, although consent must be obtained for fetal genetic screening, thus making ultrasound a non-voluntary prenatal test. This study also found that even when women were concerned about potential risks of ultrasound (such as hearing loss, ear infections, etc.), "the risk of harm from the ultrasound was perceived as 'small,' but paradoxically, one that had to be taken in order to reduce the risks of fetal anomaly" (Mitchell, 1994: 149).

Yet when one examines the bioethical literature surrounding informed consent, there is nothing to suggest that physicians should not obtain consent for ultrasound. Especially since an abnormal finding on an ultrasound may lead to further genetic tests, or even termination of a pregnancy (Capen, 1994).

Why, then, has ultrasound become so accepted as a standard in prenatal care? Mitchell concludes:

[W]ithin current obstetrical thinking, women and fetuses are either at 'low risk' or 'high risk' for developing problems; there is not state of 'no risk'.
Risk is what justifies the routine widespread use of ultrasound to ‘catch’ fetal anomalies. ‘Ideology of risk’ situates responsibility for the outcome of pregnancy primarily on women. Unspoken, but assumed, is the belief that ‘good’ mothers do not ‘take risks’ and therefore avail themselves of this technology. (Mitchell, 1994:149)

There is also the issue of investment: when health care providers invest in expensive ultrasound equipment, there is a desire to cash in on that investment.

**Sex Selection**

Because ultrasound provides a visual image of the fetus, it frequently determines the sex of the fetus. In the medical literature, sex selection is considered acceptable to prevent the transmission of sex-linked genetic conditions; for “family completion” to provide different sex than a couple’s previous offspring (Thobani, 1993).

But because of women’s position in the world, and the fact that in many cultures, girls are not valued, sex selection is often the only way for women to control their economic destinies. Ultrasound clinics in India, for example, are being used as a tool to design offspring that will improve the lot of the mothers, lest they be doomed to a life of suffering for producing female offspring. All over India, women line up to have ultrasound testing for the express purpose of knowing the sex of their child. If it’s a girl, they abort; if it’s a boy, they cry with glee (Duster, 1990). Female children are considered economic burdens in India, while male children are economic assets. The male-to-female population is now so unbalanced in favor of boys, many Indian authorities and activists are worried (Duster, 1990). In the early 1900s, there were 97 females born in India for every 100 males. By 1970 the ratio dropped to 93:100, which authorities linked to infanticide. By 1990, a study looking at abortions in Bombay found that out of 8,000
abortions, 7,997 were female fetuses (Duster, 1990). Another report estimated that 78,000 fetuses were aborted in India between 1978 and 1982 (Duster, 1990).

Although the 1971 *Medical Termination of Pregnancy Act* in India was passed to prevent aborting for reasons of gender, since amniocentesis began in India in 1974, the medical establishment reported that it was being misused for sex selection (Duster, 1990). Since so many physicians in India simply ignored the law, by 1988, the State of Maharastra introduced legislation to ban technologies that could detect sex.

Some feminists wonder if sex selection could actually help a woman’s social position in India, by preventing the cruel practices of infanticide, child neglect for female children, and bride-burning. The problem with this rationale is that continuing sex selection practices continue to lower the status of women in general (Wertz and Fletcher, 1992).

In Canada, Bill C-47 would make it illegal, after an ultrasound, for a doctor to reveal the sex of a child to its parents, except if the reasons are health-related. Health related reasons would involve sex-linked diseases, such as hemophilia (The House of Commons of Canada, 1996).

But in the absence of any firm legislation on this issue, sex selection is still common. Studies that looked at sex preferences in the United States over a 50 year time span show that parents still prefer a male child as the only or first child (Jones, 1996), while other studies show a willingness on behalf of parents to preselect the sex of the child (Jones, 1996). In Canada, Koala Labs is an example of a disturbing sex selection clinic in Vancouver that targeted East Asian parents (Thobani, 1994). Sex selection must be understood as “part of a eugenic dynamic in a society that facilitates selective
breeding; preferences almost universally favour boys...For practical purposes, therefore, sex selection works to facilitate male selection” (Thobani, 1994:140).

Sex selection is not limited to “in vivo” (in the body) testing (Jones, 1996) via ultrasound imaging or amniocentesis. There is now such as thing as “postconceptive in vitro techniques” (Jones, 1996) whereby the sex of the embryo is preselected in a laboratory and implanted in a woman (Jones, 1996). In addition, more than 70 clinics in the U.S. now offer sperm separation for the purposes of sex preselection (Jones, 1996).

In countries where abortion is legal, women have the right to an abortion without having to provide good moral reasons for doing so. Therefore, banning sex selection could damage hard-won legal battles for a woman’s right to control her body or the quality and size of her family (Wertz and Fletcher, 1992).

Sex selection can also leave a pregnant woman vulnerable to abandonment. Wertz and Fletcher report the case of a mother of three sons, pregnant with her fourth child, whose husband threatened to leave her unless she agreed to abort a male fetus. He wanted a girl for balance, even though she didn’t care about the gender (Wertz and Fletcher, 1992).

Preimplantation Screening

Another issue concerns trait selection technology (TST) (Jones, 1996), also known as preimplantation genetic screening (PGS). Important genetic information about the embryo can now be detected when the embryo is only eight cells old (Jones, 1996).

PGS combines in vitro fertilization (IVF) techniques with genetic screening techniques to enable parents to determine their child’s genetic traits (Norton, 1996). This
technology makes it possible for parents to selectively breed offspring, choosing specific, “non-therapeutic, performance” traits such as hair color (Norton, 1996). The science of trait selection is not yet developed, but given the advances in genetic technology, it would not be surprising if companies began to market trait selection to women as a service, even though it may be nothing more than snake oil.

There are serious philosophical questions we, as a society, ought to be asking about PGS. Ought scientists (and parents) be held to the same moral standards for non-therapeutic PGS as they are for non-therapeutic research on children? Ought an embryo be at risk for disposal when there is no medical indication (i.e. when the health of the mother or fetus is not affected by PGS) to “diagnose” its genetic traits (Norton, 1996)? And ought parents be selecting traits in their children that may benefit the economic lifestyle of the parents (Norton, 1996)? Unless women are encouraged to ask themselves these questions, and are made aware of the fact that they are participating in a social experiment when they opt for non-therapeutic PGS (preselecting sex or other cosmetic traits), making an “informed” decision about whether to avail themselves to PGS does not seem possible.

Problems With Consent

“Informed consent, and even the validity of any tacit consent, is, in the social context [of prenatal care], and under the current definitions and guidelines, a medical and legal fiction” (Capen, 1994:167).

Ethicists agree that informed consent is a “transition concept” (Veatch, 1995) laden with problems ranging from determining what is the “good” or in the best interests
of a particular patient to the question of whose will is being suppressed or enabled through this process (Veatch, 1995). Some refer to informed consent as a “misleading and dysfunctional” (Dickens, 1985) term with respect to the physician-patient relationship, implying that: if a patient declines treatment, s/he is not informed; information is provided solely to obtain consent; and that refusing treatment does not have to be as informed as consenting to treatment (Abella and Rothman, 1985:243-263).

For the purposes of this thesis, consent will be discussed in the context outlined by Etchells, Sharpe, et al (July 15, 1996): “The autonomous authorization of a medical intervention by individual patients.” Here, it is said that informed consent implies acceptance of treatment as well as refusal of treatment. Treating someone without his consent constitutes battery, while treating someone without adequate informed consent, constitutes negligence (Etchells et al, 1996:178). There are also three components of consent:

- **Disclosure**: Has a woman been provided with relevant and comprehensive information by her clinicians? According to Canadian statutory and common law, disclosure means that “a description of the treatment; its expected effects (e.g. duration of hospital stay, expected time to recovery, restrictions on daily activities, scars); information about relevant alternative options and their expected benefits and relevant risks; and an explanation of the consequences of declining or delaying treatment must be provided. A woman should also be given an opportunity to ask questions, while her doctors should be available to answer them (Etchells et al, 1996:388).
- **Capacity and competency**: Does the woman understand information relevant to a treatment decision and appreciate the reasonably foreseeable consequences of a decision or lack of decision? Does she “understand information and appreciate its implications” (Etchells et al, 1996:657). Does she understand what’s being disclosed and can she decide on her treatment based on this information? What is problematic about this aspect of informed consent and prenatal care is that the level of information disseminated to the pregnant patient need not be tailored to her, specifically, but to what a “reasonable woman” (Capen, 1994) might want to hear, even though many bioethicists agree that disclosure must include facts relevant to the particular person.

- **Voluntariness**: Is the woman being allowed to make her health care choice free of any undue influences? To answer the question, we need to take into consideration internal factors, such as pain, as well as external factors, such as manipulation (Etchells et al, 1996:1083) which involves “the deliberate distortion or omission of information” in an attempt to induce her to accept testing (Etchells et al, 1996:1084). The issue of force should also be considered, in that it can involve the use of sedation. This is a particularly relevant issue with respect to labour and childbirth. If a woman is on any pain medication one can question whether she can voluntarily consent to anything in this state. On the other hand, pain is considered an internal factor that can also interfere with voluntariness, and it’s reasonable for a health care team to defer decisions until the pain has been treated (Etchells et al, 1996:1085).
According to Capen (1994), most women are given limited choices when a fetal anomaly is found instead of enough information to truly make an informed decision: they can have other "confirmatory" tests, continue the pregnancy or terminate it (Capen, 1994). The amount of information provided to the pregnant patient also depends on the model of "doctoring" her physician adopts (Emanuel, 1992). The most familiar is the paternalistic model (not practised, or legal in Ontario), where the physician makes the decision for the pregnant woman. The informative model is one where the physician presents enough information to the woman for her to make her own choice: "But even though [the informative model] is more patient-based...it is still an unrealistic one given the generally acknowledged power discrepancy between the physician and the pregnant woman patient" (Capen, 1994:163).

Since so many prenatal tests are considered "non-therapeutic" procedures, meaning that they do not offer any clear therapeutic benefit, more, rather than less, information should be provided to the patient by law (Capen, 1994). However, since the medical nature of prenatal tests have been fused together with a perceived social responsibility for mothers to identify defects, it is difficult for women to truly determine whether the care needed is therapeutic or non-therapeutic in nature (Capen, 1994).

The social burden of "fetal anomaly hunting" rests upon the shoulders of the woman, who still is responsible for family health care (Lippman, 1993), and is "expected to do all that is recommended or available for the sake of her children" (Lippman, 1993:47). Therefore, a woman who wants to have a healthy child, but would accept a less healthy child, may not really be agreeing to be tested, but socially coerced (Lippman,
1993) into it lest she appear to be a bad mother, or have her competency be called into question when she refuses a procedure (Lippman, 1993).

It is also important not to dismiss the argument that a mother’s desire to be tested could be a good choice, based on good information, and good moral decision-making; her desire not to bring a sick child into the world must be respected, as this is what informed decision-making represents.

Since pregnant women are vulnerable by virtue of the fact that they are carrying another life, there is often a reluctance to refuse a procedure because of the fear of compromised care -- particularly when prenatal visits revolve around timing for various tests (Capen, 1994). “There is considerable social pressure on the pregnant woman to consent to the procedures her physician suggests because she fears that the relationship will be damaged if she does not. A test represents attention at a time when many women equate such attention with care” (Capen, 1994:165).

There is peer pressure to have prenatal tests, as demonstrated from this excerpted interview:

It seemed that all my friends wanted to make sure I knew about amniocentesis. Everywhere I went, acquaintances of only a few months would “inform” me of this device for detecting if my pregnancy were “normal.” At first, I just politely responded that I knew about it, but didn’t want it. Then I started getting angry, because I began to realize what they were implying…that any sane woman over 35 with an ounce of brains would have amniocentesis. “Do you have religious objections?” they’d ask. As if being crazy or stupid or religious were my only options. (Duster, 1990:79)
The issue of defensive medicine is present as well. To avoid a possible malpractice suit, physicians may be offering unnecessary tests as routine. Women are also more likely to accept testing when it is explained as routine (Capen, 1994).

A problem with the way information is disseminated to women has to do with the paternalistic model of medicine (See Section 1.2). Information is often presented to women only when it is deemed safe to do so. Doctors will often withhold information if they believe the facts will distress or depress the patient (Warren, 1992).

The consent form also appears to be an “advance directive, giving permission ahead for procedures, and as a general consent, covering a wide range of contingencies” (Ekman Ladd, 1992:217).

*Social Harms And Prenatal Testing*

Some of the following dilemmas regarding prenatal testing present themselves:

1. *Who owns this information?* It is currently unclear whether a woman who tests positive for carrying a “defective” fetus can keep the information confidential.

   “In principle, confidentiality bars physicians from making disclosures to a patient’s relatives of health risks to them that become apparent in the course of the patient’s diagnosis and treatment” (Dickens, 1996). There is no duty to warn, but doctors may still have the power to warn. And that power could be misused.

2. *How will this information be used?* The film Gattaca dramatizes the results of a genetically-obsessed culture. In this film, one’s genetic makeup determines one’s
eligibility for education, employment, and social status, even though the film’s protagonist makes it clear that “genoism” (discrimination against people with genetic “defects” or mutations) is against the law. Gattaca shows a world where every strand of hair or eyelash serves as one’s genetic resume.

A demonstration of how the focus on genetics can lead to genetic discrimination lies in the treatment of African Americans in the 1970s; those who were carriers for sickle cell anemia “suffered discrimination which included denial of admission into the Air Force Academy, relegation to ground jobs by major airlines, and increased insurance costs” (Norton, 1996:117-118). (See Eugenics section for a more detailed discussion.)

Insurance companies have also exerted pressure on women to abort fetuses. In one case, an insurer would only cover genetic testing for cystic fibrosis if the woman agreed to abort if the fetus tested positive for the disease (Norton, 1996). “In light of the history of the excesses of eugenic programs and discrimination based on genetic makeup, there is a need to pass legislation which would prevent abuses of genetic screening” (Norton, 1996:118).

“Carrier” discrimination can occur as well. People who are carriers of disorders, but who do not have the disease themselves have lost their medical insurance in the United States (Kennen, 1996). The problem with genetic tests is that they are usually interpreted in terms of the worst possible outcome (Kennen, 1996). For example, some people with cystic fibrosis have much better outcomes than others (Kennen, 1996). Nevertheless, one HMO limited the coverage of a pregnant woman because she refused to abort a fetus identified with cystic fibrosis (Kennen, 1996).

Any given genetic defect could become a lifelong social disability in the sense
that it could brand people unemployable or undesirable. Could insurers in the near future require, for example, "genetically-defective" people to undergo unreasonable testing or procedures as a condition of coverage? Or would health insurance premiums simply become unaffordable for genetically-defective children? "The possibility of genetic discrimination may complicate epidemiological research unless the public, employers, insurers, physicians, and researchers reach a consensus on the meaning of, and need for, genetic information" (Bondy et al., 1997).

3. Sons and Daughters. At what point does a mother tell her child about a genetic defect found prenatally if she elects to give birth to that child? The emotional impact of a son or daughter knowing that s/he may carry a "defect" may be an unfair burden unless there is better education. How will this information affect other decisions this child makes, ranging from career choices to contraception methods, to childbearing? Secondly, would adult tests such as BRCA-screening become available prenatally? "As resources shrink, pressure to cut costs will increase -- even, perhaps, if that entails inhibiting the reproductive decision making of some individuals...Some commentators have suggested that the public health model be applied to genetics, ...with even mandatory abortion of affected fetuses" (Parens, 1996:409). Given this possibility, our culture may be closer to a "Gattican" society than we think.

Section 1.2: A Feminist Bioethics Perspective

A discussion of prenatal testing must include a feminist perspective of bioethics. Are women's interests being considered in the debate? As of this writing, feminist work in bioethics hasn't had much impact on medical practice: women’s interests continue to be
ignored in the face of reproductive technologies and policies that affect them (Purdy, 1996). Therefore, this section will explore how the current patriarchal system of medicine affects reproductive choices.

The Medical System As Oppressive

It's not possible to discuss feminist bioethics without discussing the current medical system in the Western world -- and its ethics. Many feminists have demonstrated how Western medicine is oppressive to women. This should come as no surprise, considering that, like the rest of the industrialized world, Western medicine, too, is a male construct.

It hardly needs saying that despite considerable progress for women in recent years, men—mostly white, middle-class, heterosexual men—still in charge, both in society generally and in the medical profession, and, consciously or subconsciously, choose social arrangements that reflect their perceived interests. Worse still, individual practitioners may still be gripped by common sexist—even misogynist—attitudes for which medical education currently provides no antidote... [For example,] how could we have been so oblivious to the gender differences in physician-patient relationships, differences that lead doctors to suppose that women need tranquilizers when the same symptoms in a man suggest a heart workup. (Purdy, 1996:2-3)

Although “[c]hecking for gender problems should become as integral to bioethics as is checking for spelling errors” (Purdy, 1996:19) clearly this is not happening. The fact that medical ethics discussions do not include critiques of patriarchal practices in medicine (Sherwin, 1992) illustrates that bioethics as it stands, does not constitute a feminist approach.
The world in which we live and work is not structured to accommodate women who must breastfeed, look after a sick child or menstruate (Wendell, 1992). The public world is the world of "health" in which the healthy, male (i.e. non-menstruating, non-pregnant, non breastfeeding body) has been the public standard of productivity, and performance. "...women (and children) have been relegated to the private, and so have the disabled, the sick and the old (and mostly women take care of them)" (Wendell, 1992: 69).

The structure of our current medical system is not questioned by mainstream writers; ethical debates surround an accepted institution of medicine (Bequaert Holmes, 1992; Sherwin, 1992) even though women use the medical system more often than men (B.C. Women’s Hospital and Health Centre Society, 1995). With women’s reproductive health at the forefront of research, “the expanding dependence of women on male skills and authority should be a crucial concern” (Bequaert Holmes, 1992: 4).

Susan Sherwin states that present medical practices have contributed to the oppression of women (Sherwin, 1992). In fact, the institution is so instrumental in furthering oppression of women and other second-class citizens, it should really be viewed, according to Sherwin, as a political institution (Sherwin, 1992).

The traditional role of male physician and female nurse are still played out (Warren, 1992), despite the fact that many nurses are now male and many physicians are now female. The physician’s tasks are masculine (where s/he is granted decision-making authority) and powerful, while the nurse’s tasks are submissive and powerless (Warren, 1992). For example, the physician’s training is much more theoretical and technical (Warren, 1992) than the nurse’s training; as a result, the physician has final decision-
making authority for a patient’s treatment (Warren, 1992), even though there may be moral disagreement between the physician and nurse with respect to treatment.

“...nurses’ decision-making authority is subordinated to ‘doctor’s orders’” (Warren, 1992: 36). When it comes to patient education, since teaching is considered a traditionally more “female” role, that education is often expected to come through nurses rather than physicians (Warren, 1992).

What Phyllis Chesler proclaimed in her 1972 book, *Women and Madness*, Sherwin reiterates: “by medicating socially induced depression and anxiety, medicine helps to perpetuate unjust social arrangements” (Sherwin, 1992: 22). Similarly, medicating socially induced infertility (Khatamee, 1988), and the natural process of pregnancy and childbirth, perpetuates unjust social arrangements and undoes some of the social wrongs that legalized abortion was supposed to have corrected. A review of the writings of feminist ethicists on the subject of reproductive health shows that medicalizing and pathologizing pregnancy does not serve the interests of women at all, but rather, the interests of government and a male-dominated social structure. Laws that were passed to serve the interests of women are being used to oppress them. A woman’s personal decision to abort an unwanted child, which is an expression of her autonomy and self-determination, is being eroded into a “duty” to abort an undesirable human to serve the interests of society at large. As soon as a right becomes a legal duty, it is no longer a “choice”. This is why understanding and appreciating (Veatch, 1995) the social agenda behind the “termination question” is necessary for informed consent to take place.

The body of work that exposed the abusive, if not, criminal, treatment of women at the hands of psychiatrists (Chesler, 1972; Caplan, 1994), can also be used to look more
closely at the treatment of women at the hands of gynecologists, obstetricians and geneticists. “With its authority to define what is normal and what is pathological and to coerce compliance to its norms, medicine tends to strengthen patterns of stereotyping and reinforce existing power inequalities” (Sherwin, 1992: 22).

It is crucial to look at how obstetrical issues impact other relationships affecting women, since women tend to try and preserve relationships (Gilligan, 1982). For example, Warren points out that in the philosophical literature, abortion is discussed in the context of autonomy and personhood (i.e. whether the fetus is a person and has rights; or whether the mother’s right to self-determination is more important). What Warren argues is missing from the debate is “a network of issues surrounding the parent-(especially mother-) child relationship” (Warren, 1992: 39). Warren also points out that philosophers have ignored the issue of adoption as a moral issue: “…when is it morally permissible for [a mother] to give up the newborn for adoption?…Is it permissible for a woman to conceive in order that the child be adopted—if everyone, including the child and the adoptive parents, benefit? If it is, then surrogate motherhood (money issues aside) would have a more solid moral foundation” (Warren, 1992: 39). Warren uses adoption as an example of what’s missing from the abortion debate – relationships amongst other family members, such as parents and children, siblings, grandparents and grandchildren.

“The tendency in medical ethics to see abortion decisions as isolated from other aspects of women’s lives misses the most important feature of the feminist campaign for reproductive freedom for women” (Sherwin, 1992: 26). Again, the decision to terminate a pregnancy cannot be informed unless a woman truly understands whose social agenda
she is serving. I suggest that even when she terminates for purely financial reasons, someone other than herself profits more from her decision. Even though she may enjoy a higher standard of living, and be relieved of the burden of an unwanted child, society will be relieved of the costs involved in caring for that child (in the form of welfare or social services, for example).

Feminist versus Sexist Ethics

Warren introduces the term "sexist ethics" to describe moral questions that involve power struggles or control. In other words, when questions revolve around patient autonomy, those with the "the moral authority to make the final decision" (Warren, 1992:33) are perceived to be in the masculine role, whether they are patient or physician.

Carol Gilligan points out that women have a tendency to preserve relationships, and thus approach moral problems from a different angle than men. Carol Gilligan’s body of work has helped to reframe a new ethic, sometimes known as the "ethic of care," which some define as a truly feminist ethic, and others as a female ethic. Gilligan found that the male ethic was one concerned with justice and "rules" while the female ethic was more concerned with preserving relationships through communication, cooperation, and seeking more information (Gilligan, 1982). This difference has sociological roots in that women have been traditionally preserving relationships in their roles as mothers and caregivers for centuries. In other words, while men are more concerned with human rights, women are concerned with human dynamics.
Women’s moral decisions are more likely to be based on contextual and narrative frameworks rather than formal and abstract frameworks. As Gilligan herself is careful to point out, questions remain as to whether this is a finding related to gender or to social roles. “[W]omen’s moral differences … may be a function of their subordinate or tentative social position” (Tronto, 1987:649). In other words, “a different voice” may be a product of social status, not gender. For example, males who are in a minority group in North America are much more likely to follow an ethic of care (Tronto, 1987). Thus, if white men were in subordinate roles, in which they were primarily the caregivers in society, would they follow an ethic of care (Tronto, 1987) that rested on “the social conditions of secondary status” (Tronto, 1987:649)?

With an ethic of care comes a reluctance on behalf of women to judge because they are uncertain about their own moral principles and they feel excluded from participating directly in society at large (Gilligan, 1982). Moral problems arise from “conflicting responsibilities rather than competing rights” (Gilligan, 1982:19) and can hinge on the capacity to assume a caring role (Tronto, 1987).

An ethic of care could become a defense of caring only for one’s own family, friends, group, nation. If the preservation of a web of relationships is the starting premise of an ethic of care, there is little basis for critical reflection on whether those relationships are good, healthy, or worthy of preservation. (Tronto, 1987:660)

This leads to the problem of women using “soft relativism” (Tronto, 1987:660) to decide complex moral dilemmas, demonstrated by one of the subjects in Gilligan’s research, who continuously answers “it depends” (Gilligan, 1993:xxi) to moral problems.

Soft relativism has implications for women making decisions about terminating a pregnancy, who cannot rely on a set moral principle of “right or wrong” to make this
choice. Gilligan’s research showed that many women make decisions based on who will be more hurt by the choice. According to one of Gilligan’s subjects: “I think what confuses me is it is a choice of either hurting myself or hurting other people around me” (Gilligan, 1982:80). This sentiment echoed throughout Gilligan’s abortion decision study. For example, in several cases, the decision to abort or not to abort was made to preserve the relationship with the father. In some cases, aborting would threaten the relationship, while in other cases, continuing the pregnancy would threaten the relationship. If other children were involved, similar considerations were often made; if continuing the pregnancy would interfere with the well-being of existing children, for example, the decision to terminate could be made. The “voice” of women in this sense is a voice that cares about continuing and preserving social connections at the cost of self determination and autonomy. “It was partly because of the link between voice and choice that the Roe v. Wade decision initiated or legitimized a process of psychological and political growth for many women” (Gilligan, 1993:xvii). This may explain why, in countless situations, women conceive a child the father does not want, in the belief that the baby will save the relationship.

A minor point worth exploring is whether Gilligan’s work sheds light on the relationship between women and physicians, and the seeking of information on prenatal health. Gilligan’s research suggests that women may hesitate to ask important questions, for example, in order to preserve their relationships with the physicians, which in turn, protects the baby in the form of uncompromised health care.

Women’s discovery of the problems that ensue from rendering oneself selfless in order to have ‘relationships’ was momentous in releasing
women’s voices and making it possible to hear what women know….Women’s choices not to speak or rather dissociate themselves from what they themselves are saying can be deliberate or unwitting…Choices not to speak are often well-intentioned and psychologically protective, motivated by concerns for people’s feelings… (Gilligan, 1993:xii)

Purdy suggests that moral philosophers have had a working model of feminist ethics for centuries – in the form of utilitarianism. She argues that feminism “has a great deal in common with an intelligent utilitarianism.” Because utilitarian principles judge the “moral worth of an action based on its consequences,” and because it “demands that the interests of every party affected by an action be taken into equal account” she maintains that this approach serves the interest of all disadvantaged groups – including women (Purdy, 1996). She also points out that utilitarianism strives to offer alternatives to given actions, and “builds in consideration of longer-term possible consequences of the chosen action and its alternatives; such consideration is essential in safeguarding the interests of women and members of other disadvantaged groups” (Purdy, 1996:26). But more simply put, utilitarianism is concerned with “finding happiness and avoiding unnecessary misery” (Purdy, 1996:26). What could be more appealing, Purdy asks, to women than that? By looking at everyone’s interests, Purdy hopes to avoid falling into the trap of creating “special interest” ethics (Purdy, 1996:24). “What I hope for in the long run is that feminism will permeate all ethics, leaving ‘feminist ethics’ to wither away. Only this outcome safeguards us from ‘respectable’ theories that ignore women’s interests” (Purdy, 1996:24).

Historically, utilitarian approaches to public health have been quite positive. For example, in the 1840s, England’s Edwin Chadwick argued on utilitarian grounds, in his
report on the Sanitary Condition, that spending more money in the short term on public health and sanitation, would pay off in the long term (people would be healthier, and more productive). He proposed a sophisticated sewage system that became part of the Public Health Act of 1848. (Duster, 1990).

Sherwin is not an advocate of utilitarianism, however:

Utilitarianism requires that we calculate the relevant utility values for all persons (or beings) affected by an action or practice and proceed according to a calculation of the relevant balances. In contrast, those engaged in doing feminist or medical ethics often reflect a desire to take account of the details of specific relationships and to give added weight to some particular utility related qualities like caring and responsibility. Many of those engaged in feminist ethics diverge even further from standard utilitarianism, for they argue that the preferences of the oppressed ought to be counted differently from those of the dominant group. (Feminist objections to pornography, for instance, do not rely merely on the weighing of harms done against pleasure produced but reflect concern about the dehumanizing effect of the message of pornography whatever the utilities involved turn out to be.) (Sherwin, 1992: 20-21)

There is debate about whether feminist ethics requires a completely new ethic or whether it can build on an existing ethic, such as utilitarianism, which “is intended to convey its concern with everyone’s welfare” (Purdy, 1996:29).

Dispensing With The Womb

There are some feminists who suggest that the only way to build a level social and moral playing field is through ectogenesis, which refers to the creation of human life outside the womb, also known as in vitro gestation, or IVG (Murphy, 1992). Other feminists reject this idea because it diminishes what is remarkable about women – the capacity to give life. “Is the best way to abolish sexism a method that downgrades a
female capacity — pregnancy? This suggests that the way to deal with difference is to annihilate it” (Murphy, 1992:190-1).

Murphy reminds readers of compelling arguments made more than 30 years ago that pregnancy should not have to be woman’s work (Murphy, 1992). For example, Shulamith Firestone’s argument at that time was referring to pregnancy as barbaric, because it deformed the female body (Murphy, 1992). She questioned whether it was fair that women sacrifice their bodies for the sake of the species. Ironically, the main problem with today’s new reproductive and genetic technologies is that rather than freeing women from their biology (as some feminists envisioned) they are enslaving their biology to the values and beliefs of mostly male infertility specialists. Thankfully, those arguing for ectogenesis also warned us that within the current social structure, ectogenesis may not be freeing. (Murphy, 1992).

Assuming that IVG is possible, and even imminent, what would happen to the pro-choice movement? Murphy warns that once the fetus is removed from the woman’s body, all efforts to protect fetal rights will be made, which will mean that elective abortions for fetuses growing in the natural womb will be much more difficult to obtain (Murphy, 1992), especially since, given IVG’s availability, the fetus can be transferred into an artificial womb.

Once IVG is introduced, however, the question of the fetus’ viability must be reframed (Murphy, 1992). If it can survive outside the mother’s womb from day one of the pregnancy, the definition of viability Roe v. Wade changes, and this could deeply impact women’s rights to choose abortion (Murphy, 1992). Once parents of an IVG baby begin to pay large sums of money to reproduce in this manner, how will they react to
women who want to terminate a natural pregnancy? (There are currently tensions between infertile women, who pay large sums of money for assisted reproduction, and the prochoice movement.) Furthermore, what about the issue of terminating an IVG pregnancy? Once the fetus is disconnected from the woman's body, does she still have a right to end the pregnancy (Murphy, 1992)?

There may also be conflict over continuing an IVG pregnancy. What if it were discovered that the IVG baby had Down's Syndrome, and the facility "housing" the fetus wanted to terminate life support against the parents wishes? Conflict between the state and the woman's right to bear a child with a defect could arise (Duster, 1990).

Terminating the fetus in such a case would not conflict with a woman's right to control her body; it would involve, however, the issue of continuing to "grow" genetic material from two gamete donors (Murphy, 1992). "While this right might justify termination of IVG fetuses, it could also be used by men to demand abortion on the part of their female partners" (Murphy, 1992:192).

The moment the fetus is removed from the woman's body, it becomes a product that can be perfected, leading to fetal "quality control" (Murphy, 1992). This would be a direct route to the "eugenics backdoor" (Duster, 1990). IVG would inevitably lead to sex selection, trait selection, and of course, disease prevention -- even when the disease is a treatable (though not necessarily curable) adult-onset disorder (Murphy, 1992), such as Type 2 diabetes.

Clearly, dispensing with the womb creates new problems for women. But there is still the matter of dealing with the fact that the woman, for now, is a "fetal container" (Purdy, 1996). Upon reading about a case concerning a baby with a brain defect, Purdy
remarks: “I kept waiting for the author to notice the fetus’ location inside a woman and to recognize that she has interests and perhaps even rights. He never did” (Purdy, 1996:1).

Sometimes the interests of women and their fetuses are different. But so are the interests of our “younger selves” and “older selves” (Purdy, 1996). “Can I in my old age come to sue myself for behaviour I engaged in when younger” (Purdy, 1996:91)? In other words, if one views fetuses as part of a woman’s body, and not separate, it stands to reason, as it is the case with conjoined twins, perhaps, that there may be diverse interests sharing the same body (Purdy, 1996). There are often conflicting interests between the father and mother, even when the father may not be involved with the woman at all (as is the case with donor sperm).

Section 1.3: Summary of Literature Review

Making a decision to undergo prenatal testing necessarily entails making a decision about whether to terminate a pregnancy. Some women may make this decision based on their own interests; many will make this decision based on the interests of the social connections surrounding them (Gilligan, 1982); some will need to weigh their own interests against those of a fetus; still others may consider some of the wider implications their personal decision has on society at large.

In the utilitarian view, having early information early about the health of a fetus is a benefit: it can prevent bringing a potentially harmed life into the world; it can also protect the mother’s quality of life. But when the tests results are ambiguous, and it is not clear whether the fetus is healthy or harmed, women ought not be morally or legally required to make a termination decision unless all the information is available. Otherwise,
healthy fetuses that are wanted could be aborted, and this would have far-reaching implications on the individual woman suffering the loss and society at large. On the other hand, fetuses that were guaranteed to be healthy, could be born harmed, and this would also have devastating consequences for the mother, and implications for society as well.

This thesis is not concerned with the right answer to the question "ought we perform prenatal tests?" It is concerned with the quality and quantity of information provided to the women who must answer that question for themselves. If, as a society, it is agreed that the benefits of prenatal testing outweigh the potential harms, information ought to be available to the mother on what, exactly, the potential harms are. Without full information made available to women on the debate over prenatal testing, their choices remain limited. Furthermore, if there is agreement that the benefits of testing outweigh potential harms, access to testing should be made available to all women, and this is currently not the case.
Focus and Purpose of the Study

As discussed in the Introduction, the focus of this study was to analyze patient and trade literature surrounding prenatal tests. The purpose of this study was to find out whether the quantity and quality of this literature—on its own—is enough to facilitate informed consent. However, this study does not measure the impact this literature has when accompanied by verbal counselling.

Since I first began researching and writing extensively about women’s health issues in 1993, several women (some, readers of my books who wrote to me; some, personal friends and acquaintances) told me about negative and disturbing prenatal testing experiences, which were hauntingly familiar. The test that caused the most duress was the maternal serum alphafetoprotein screening test, which is designed as a test that only identifies possible “red flag” conditions in the fetus, rather than definitive problems. The universal experience was this: the woman was told that she “needed” the test, and was not given a choice to decline it. Then, she was told that the results indicated that her baby had a “high risk” of being a Down’s Syndrome baby, and that to confirm the diagnosis, she would require an amniocentesis. The woman would become very stressed in the weeks that followed, until she had progressed in her pregnancy to the point where an amniocentesis procedure could be performed. A waiting period of between four to six weeks would ensue, during which the woman would become further agitated and anxious, and would begin to make her termination decision prior to receiving the test
results. The results of the amniocentesis showed that the baby was healthy and normal in every sense, and while this obviously relieved the woman, she nevertheless felt robbed of the experience of enjoying her pregnancy.

These “ordinary” pregnancy experiences were not considered extraordinary enough by the medical system to warrant any pre-test counselling. Even had they been, there are not enough counselors (Parens, 1996; Hospital For Sick Children, 1998). As of this writing, only 12 new genetic counsellors graduate in Canada each year (Hospital for Sick Children, 1998). One study done in the late 1980s also found that 99% of all practising genetic counselors were women; 95% were white. This sends a message to the non-white client about who sets the norms, even if the “task of the genetic counselor is to lay out the options for clients, but not to cajole, press, advise, or ‘counsel’ in one direction or another about whether to have a child with a high potential for (or even a fetus diagnostically determined to have) a genetic disorder” (Duster, 1990:78).

The fact that a screen for a given disorder even exists acts as an external social pressure on the client, even when a counsellor is indeed non-directive: Interviews with women who refused to undergo prenatal screening by amniocentesis revealed “that the mere existence of the new technology, and the social distribution of knowledge about its availability act together as twin pressures on a potential client” (Duster, 1990:79). The absence of a test could also be damaging, if that test were available to some women but not to others.

I do not need to rely on personal anecdotes to relay what is becoming the modern-day prenatal parable. All I have to do is pick up a copy of the Canadian magazine, Chatelaine from my local grocery store:
When Sharon, 33, was pregnant with her second child last year, a routine ultrasound suggested her child might have Down's Syndrome. A follow-up amniocentesis, a more accurate test for Down, showed that the fetus was healthy. But Sharon... [is clear about one thing: had the test confirmed a Down diagnosis, “I would have terminated for sure.” (Jones, 1998:41-3)

Reporter Deborah Jones then relays the experiences of “Dione” who tested positive for the cystic fibrosis (CF) carrier gene (she only went for the test because she was “following the advice” of her family doctor).

For Dione and Wayne, the next step was to get Wayne tested. If he were a CF carrier, giving their child a one in four chance of having the disease, they’d agreed to adopt... As it turns out, having cystic fibrosis is not as bleak a diagnosis as it was even 20 years ago. At the cystic fibrosis clinic at St. Paul’s Hospital in Vancouver, there are adult CF patients whose disability is so mild that some run marathons, others have thriving careers and many contemplate having children of their own... [T]he expected life span of a person with CF has jumped from the early 20s to the early 30s. (Jones, 1998:39-41)

In the same issue of Chatelaine, another story appeared by Pamela Clarke, entitled “One Mother’s Story”:

My abortion was scheduled at 7:30 the following morning. I was six months pregnant and terrified we were making the wrong decision. We would never know for sure if our baby was as profoundly retarded as the geneticists said he might be. But we did know that we couldn’t bring a child into the world who we believed would suffer for the rest of his life...

The insanity started with an experimental blood test that thousands of expectant mothers took last year. Tom and I were shocked to learn our baby had a marginally increased risk of Down’s Syndrome...

Then, a friend’s acquaintance who’d had similar experiences with prenatal testing insisted we meet the medical geneticist who had handled her case. He reviewed our files. We were stunned when he called to say he felt we had every good chance of having a perfectly normal child... Three long months later, our [healthy] son was born... The pain of what we went through will never completely go away. (Clarke, 1998:39-41)
Parens argues that “the potential for genetic counselors to do harm ‘merely’ by providing unwanted or misunderstood genetic information is enormous” (Parens, 1996:408). What happens, in the absence of counselling (or in the absence of good or competent or ethical counselling) when literature is what women turn to for information?

Indeed, the ability to make an informed decision is directly related to one’s literacy skills. Literacy and privilege (Breen, 1994) have become tangled up with informed consent to the extent that the latter has become just one more “privilege” to the educated minority instead of a patient’s right. For example, anyone with a grade eight reading level is considered literate; anyone with a lower reading level is considered to have low literacy skills. Non-English speaking immigrants to Canada are also more likely to have a lower level of literacy in English. Statistics Canada estimates of the two million women with low literacy, half a million cannot read at all (Breen, 1994), while the remaining 1.5 million are considered “functionally illiterate” (Breen, 1994). “This means that although they have some reading skills, they find reading and understanding printed materials so difficult that they are often unable to use community programs and service [or fill out] complicated forms. They can’t read a consent form in a hospital and they can’t read or benefit from ... most of the material produced by the women’s health movement” (Breen, 1987:28).

At least 2 million women in Canada, as of 1987, lacked the literacy skills to read patient and trade literature on prenatal testing. Given immigration trends in Canada over the last decade, this statistic has likely increased, rather than decreased as of this writing. In order to understand the kind of literature in this study, a woman must be able to
understand “sentences containing as many as 45 words, including verbs and embedded clauses” (Breen, 1987:30) as well as punctuation. Breen concludes: “The reader with limited skills, who is often poor and at much greater health risk, has very little access to this information. Unless more easy-to-read materials are produced, lack of information will continue to jeopardize the health of these women and their children” (Breen, 1987:33).

What I hope this research can do is emphasize that health care providers have a moral obligation to provide clear, and accessible literature on prenatal testing so that women are not coerced into verbal prenatal counselling, which entails other ethical problems.

Gathering The Data

In order to get a good concentration of information rather than widely scattered pieces of data, I initially focused on collecting distributed prenatal literature (i.e. patient literature) from three urban hospitals in the downtown core of Toronto, known for high quality obstetrical care: The Toronto Hospital, Mount Sinai Hospital, and Women’s College Hospital. These hospitals which reflect a wide mosaic of patients in an urban setting. In addition to these hospitals, the following Toronto clinics were contacted:

- Access Alliance (a multicultural community health centre)
- African Community Health Services
- The Bay Centre For Birth Control
- Central T.O. Community Health Centers
- East End Community Health Center
- Women’s Health in Women’s Hands
- Planned Parenthood of Toronto
- Riverdale Community Midwives
- Mother Risk Program
- The House (Community Health Centre)
- Immigrant Women’s Health Centre
- Midwives Collective of Toronto
- Common Ground Women’s Health Centre

This list of clinics was collected from YMCA of Metropolitan Toronto Guide to Women’s Groups and Resources, published in 1993, its last year of publication. The list of clinics was then cross-referenced with a newer booklet, published by the YMCA, entitled The Women’s Survival Handbook For Metropolitan Toronto, published in 1996.

I made some initial phone calls to eliminate clinics that were clearly not appropriate sources for prenatal testing information, such as abortion clinics, family counselling centres, shelters, AIDS clinics, or organizations designed to help victims of violence. In the 1993 booklet, women’s organizations were being mixed with women’s health clinics. Meanwhile, clinics tailored to meet the needs of specific cultural groups, such as the Anishwabe Health clinic, designed for Aboriginal clients, were not clearly identified. However, the 1996 booklet better identified the services of the organizations listed, although some clinics listed in the 1993 booklet, still in operation now, were not found in the 1996 booklet. Women’s Health in Women’s Hands is an example.
The Riverdale Community Midwives kindly referred me to The Hospital For Sick Children’s Fetal Diagnosis and Treatment Centre (although none of the hospitals in this study did). Therefore, I included The Hospital For Sick Children in this study. The *YMCA of Metropolitan Toronto Guide to Women’s Groups and Resources* listed two Women’s Health Care Centres at St. Joseph’s Hospital and St. Michael’s Hospital; I included these hospitals in this study as well. I also called The Ontario College of Midwives.

Trade literature on prenatal testing was collected from four downtown bookstores, known for wide selections on pregnancy/parenting books: Parentbooks, The Toronto Women’s Bookstore (both on Harbord Street in Toronto), Chapters (on Bloor Street in Toronto), and The World’s Biggest Bookstore (Bay and Dundas in Toronto).

In order to yield meaningful results, I decided to go through ordinary rather than extraordinary means to collect this information. If one purpose of this study was to see how accessible printed literature on prenatal testing is to the average woman seeking information, I needed to measure ordinary access routes to such information, rather than using my status or experience in the health field to track down less accessible material.

I phoned each hospital and clinic listed above, and I said (often to an answering machine): “I need some information on prenatal testing and I’m looking for any printed literature or information you have on prenatal tests. My name is X (I used a pseudonym – the name of a friend in case my own name as an author was familiar) and I can be reached at Y (I used that friend’s phone number).”
Mount Sinai Hospital’s response to this request was curt, if not, rude. The “front line” receptionist who answered my call simply said: “All prenatal testing now goes through The Toronto Hospital. You’ll have to call there.”

When I called the Toronto Hospital’s “Patient Information” line, I got an answering machine. In order to get a live person, I called four times. Finally, I was referred to the “genetic testing” department at The Toronto Hospital, whereupon, the voicemail message said: “This is X. I’m in the office between 1:00 pm and 4:30 pm. Please leave a message and someone will return your call.” I left a message, but no one returned my call. When I called back within the time interval “X” was in the office, the line was continually busy, and so I left another message. But that call was not returned either. Finally, I called the next day and was connected to “X”. I repeated my simple request. She told me that not very much information was “put out” on that topic, and that the one item she had was from 1993, although the “government was working on a newer version.” I picked up the material, which consisted of three items. (See Chapter 3.) I also went to the patient waiting area of The Toronto Hospital’s obstetrics department. No information on prenatal testing was distributed on the coffee tables. Current affairs magazines (Time, Newsweek, etc.) were there as well as one copy of the magazine, Great Expectations (out of date). Great Expectations did not have any articles on prenatal testing; its editorial was limited to articles on nutrition, exercise, and postpartum issues (mostly emotional issues with respect to dealing with newborns, etc.) It contained formula company advertisements, which go against the WHO code on the marketing of
breastmilk substitutes.) There were many brochures and pamphlets in this area on contraception and breast self exam.

When I called the Women’s College Hospital switchboard and asked my question, I reached a helpful woman when I was transferred to the right department. She admitted that there “wasn’t much,” would “dig up” what she could and would leave an envelope for me at their reception desk. Inside the envelope were four items. (See Chapter 3).

I could not gain access to Mount Sinai’s obstetrics waiting area unless I was a patient. Women’s College Hospital’s waiting area had a “gatekeeper” whom I could not get past.

St. Joseph’s Hospital referred me to its Childbirth and Parenting Services department, which had no literature on prenatal testing; St. Michael’s Hospital referred me to its family practice unit, which also had no literature on prenatal testing.

I called the Fetal Diagnosis and Treatment Centre at The Hospital For Sick Children and got an answering machine. To date, I have left four messages and my call has not been returned.

The Clinics

An average of three phone calls per clinic were made before I actually reached someone live; in a number of cases, five phone calls were made to reach a live human. In most circumstances (98% of the time) my call was not returned; I reached real people because I kept calling. No clinic had any prenatal testing literature available with the exception of The Bay Centre for Birth Control, although I was welcome in many instances to set up a counselling session and “talk to someone,” however, since I was measuring printed matter only, I did not set up an appointment. The following represents
my literature collection experience from the women's clinics, followed by a discourse analysis:

- Access Alliance: I was told they had no prenatal testing literature.
- African Community Health Services: I was told they had no prenatal testing literature.
- The Bay Centre For Birth Control: This was actually The Women's Health Resource Center at 790 Bay Street in Toronto. There was quite a bit of material here. (See Chapter 3.)
- East End Community Health Center: I was told that the nurses “might have literature” but to collect it, I would have to be a client.
- Women's Health in Women's Hands: My call has not been returned.
- Planned Parenthood of Toronto: I was told they had no prenatal testing literature.
- Riverdale Community Midwives: I was referred to The Hospital for Sick Children for information.
- Mother Risk Program: I was told they had no prenatal testing literature.
- The House (Community Health Centre): I was told to call a hospital for such information.
- Immigrant Women’s Health Centre: I was told “we only have literature on family planning.”
- Midwives Collective of Toronto: I was told they had no prenatal testing literature.
- Common Ground Women’s Health Centre: My call has not been returned.
Given the volatile nature of funding for the women’s health clinics called in this study, it is unfair to target these clinics as providing a disservice to women simply because they do not have prenatal testing literature. Most of these clinics are community-based, and therefore rely on government grants, volunteers, and private donations to stay open. None of these clinics are funded by public health dollars. The situation is different for the large hospitals contacted in this study, which derive funding from a much larger pool of resources: corporate donations, research grants from pharmaceutical companies, tax dollars and provincial funding. However, cuts in nursing and support staff will also have implications for the fielding of phone calls and requests for information.

When printed materials on prenatal testing are scarce within hospitals, it is not surprising that a similar scarcity will be felt at the community or grass-roots level. The situation as of this writing, is particularly dire, given the serious cuts the Ontario government has delivered to social services.

There is also a need to situate prenatal testing literature within the climate of public health priorities. For example, materials on HIV prevention, safe sex and contraception, breast self-exam, or Pap smears are given more weight when it comes to educational grants because of the prevalence and gravity of the issues they address. Much of the educational materials on women’s health are provided by non-government organizations, which provide advocacy and education on specific issues, such as breast cancer, breastfeeding or infertility. There are no prenatal testing organizations at present, dedicated to providing education materials exclusively on prenatal testing.
However, a feminist and transformative approach to education materials (see Conclusions) may offer a solution to the absence of printed information on prenatal testing at the community and grass-roots level.

As for the failure of many women's health clinics to return my call, there is a real problem with adequate staffing and telephone relief. Typically, these clinics tend to be overwhelmed with phone calls and people dropping in without appointments. When no prenatal testing literature exists, and there are several people with more serious problems who can be helped, callers or voicemail messages requesting non-existent printed materials, are understandably, and necessarily, prioritized.

Midwives

When I called the Ontario Midwives Association, I was told that they had no prenatal testing literature, and was referred to either The Toronto Hospital or Women's College Hospital for this information.

The Trade Literature

I had no problem gaining access to trade literature on prenatal testing. All I had to do was walk into a bookstore and survey what was on the bookshelf. I chose bookstores known for wide selections on pregnancy and childbirth, which were within the urban geographic corridor studied. The bookstores I chose were Chapters on Bloor Street in Toronto; The Toronto Women's Bookstore; Parentbooks; and The World's Biggest Bookstore. (See Chapter 3 for a discussion of the these consumer books.)
Coding The Data

Patient Literature

Again, "patient literature" refers to any literature collected from hospitals and clinics. The first step in my coding process was to list absent information as one of my main codes. I did this by creating a checklist (See Table 2.1) of essential information I felt should be present. Because I am dealing with consent issues, I went to clinical ethics literature for guidance, looking at Etchells et al (1996); Etchells and Sharpe (1997), and Veatch (1995) to construct the checklist. Because I collected so little material from hospitals and clinics, it was crucial to note what information could not be found in the collection. This is one study in which the absent information revealed more than what was actually collected. Then, as I read through the material, I noted what details were omitted from the literature I did have.

Step two was to evaluate whether the literature was accessible. When one considers that a woman once asked a prenatal counsellor if a fetus was the "same thing" as a baby (Duster, 1990), plain language is obviously necessary in order to communicate technical material.

To assess accessibility and readability, plain language guidelines (Coe, 1992) were used. Plain language involves more than replacing jargon and complex language with shorter sentences and familiar words. The goal of plain language is to reach people who cannot read well or who do not have time to read well; to avoid misunderstandings and errors; and to save the reader time (Coe, 1992). Simplifying words (such as "use" instead of "utilize"); cutting out unnecessary words (for example, replacing "in the event of" with "if"); avoiding jargon; explaining technical terms; avoiding "noun chains" such
as “world food production,” which are harder for readers to understand; and using active voice, and short, simple sentences, are all tools used to create plain language documents (Coe, 1992).

First, I considered whether the materials were accessible to the intended audience, and whether it was clear that the author took the following reader characteristics into account:

- age range
- gender
- first language
- education level
- cultural traditions
- math abilities
- potential biases
- sensitivities

I then looked at whether the written materials incorporated the following:

- Personal pronouns, such as you, we, and I;
- Clear links between ideas;
- Titles and subtitles that were informative or summarized the text;
- Most important information at the beginning;
- Use of graphics, charts, and pictures to reinforce the crucial facts and points;
- One idea per sentence;
- Sentences under 35 words;
- Use of verbs instead of nouns for action;
- Use of active voice;
- Familiarity versus formality; and
• Simplified words instead of jargon and acronyms

    I also looked at more subtle problems, such as use of "double negatives." For example, "He is not absent" is less clear than "He is present." Unnecessary preamble, such as "it is important to add that..." wastes time and detracts from the document's clarity. There are also organizational problems that detract from a document's clarity. Some common pitfalls include using bullets instead of numbers when describing step-by-step procedures; using simpler punctuation, such as commas instead of semicolons or colons.

    The typography of the document was also considered. I looked at the following:

    • Spacing between paragraphs;
    • "White space" (i.e. was there text on every inch of the page?);
    • Use of left justified and right ragged margins;
    • Highlighting of text (how much text was shaded, for example, or boxed?);
    • Typeface (Fonts with a serif are easier to read); and
    • Use of ink and colour (was there a large amount of light text on a dark background?)

    Step three was to read the literature from a feminist perspective: did the literature take a woman's perspective, fetus's perspective, patriarchal perspective or societal perspective?

    Step four was to examine the level of paternalism in the brochures. For example, were terms such as "the patient" used instead of simply "you" or "women" or "couples"?
Step five was to examine whether the literature was heterosexist. Was the literature targeting heterosexual couples only? Was it allowing room for a “partner” to be of the same gender as the mother? Was the information focused on the father at all, or completely assuming that the mother (who may lesbian or heterosexual) was the decision-maker?

Step six was to simply note the author of the material and the date it was written. All “for more information” numbers cited in the literature were called as well.

Steps two through five required a different kind of reading each time. I was looking for key words (even root words) and phrases demonstrating the perspectives and themes for which I was screening. Within each reading, I found other sub-trends such as value-laden terminology; intimidating language; improper use of acronyms; assumptions of negative outcome; signs of coercion; genetic discrimination; and so on. “Qualitative researchers gauge when they are finished by what they term data saturation, the point of data collection where the information you get becomes redundant” (Bogdan and Knopp Biklen, 1992:70).

When I reached saturation, roughly 15 themes were recorded. Once recorded, the themes were input onto my computer, and I began to re-pack what I had unpacked into a two-tiered socio-ethical framework. The first tier dealt with the surface message of the literature; the second tier dealt with the hidden message of the literature. I then formed two organizing questions: What is of ethical interest in this piece of literature? What is of sociological interest in this piece of this literature. Finally, what is of socio-ethical interest (see Chapter 3)?
Consumer Literature

I used a similar process for coding the consumer literature, except in this case, it was important to code the author information. I noted whether the author was a lay writer or medical doctor, the author's credentials, and whether a foreword or afterword by a recognized specialist was included. The latter is important because when such a foreword or afterword exists, it suggests that the text, perspective, and tone of the book has been vetted through that medical specialist, who may have heavily edited the book, perhaps editing out important lay perspectives. Forewords and afterwords are often requirements of publishing contracts signed by lay authors, who, without medical credentials, are considered to have no authority to write about medical topics without the approval of a medical specialist, who acts in the role of supervisor. Given the fact that many feminists are critical of medical "experts" in that they tend to espouse perspectives that do not support women's interests, this was an important feature to code.

I also looked at visuals in the books (most had none) to determine whether the visuals could be deconstructed in such a way as to reveal further codes, sub-trends or themes.

Limitations Of The Study

This study is not looking at newspaper or consumer magazine articles on prenatal testing, or medical journal articles, which many women may be reading, too. This material is vast, and a separate study focusing on consumer magazine articles would need to be done. Although I have reviewed quite a few of these articles for my thesis research, and in fact, reference some, I am not collecting them as data for analysis.

This study did not contact individual family doctors to see what, if any, literature they are distributing to their patients. Often, family doctors are supplied information or
patient literature by pharmaceutical companies, or companies that supply genetic tests or imaging equipment to hospitals. A separate study looking at these materials may have yielded some interesting results.

This study does not look at the patient literature from infertility clinics. This would require a different study. I did conduct extensive research in 1997 to coincide with a thorough revision of my book, *The Fertility Sourcebook* (2d edition, 1998, Lowell House). At that time, the only patient literature I could find concerned fertility drugs and the embryo transfer process; there was no literature on preimplantation screening or prenatal testing.
TABLE 2.1

Does the printed material provide...

1. Text in accessible, plain language?
2. Relevant and comprehensive information about what the test detects and does not detect?
3. A description of the test, risks, and side-effects?
4. Information about what negative and positive test results mean?
5. Information about relevant alternative options, their expected benefits and relevant risks?
6. An explanation of the consequences of declining or delaying the test?
7. White space so the reader can write down questions for her health care provider?
8. Suggested questions to ask the health care provider?
9. Information about the foreseeable consequences of a decision or lack of decision to have the test?
10. A phone number to call for more information?
CHAPTER 3
ANALYSIS OF PATIENT AND TRADE LITERATURE

The most important fact my analysis reveals is that there is a distressing dearth of accessible literature on prenatal testing. So much so, that a study into why this dearth exists is warranted, and may even become the focus of my own doctoral research. The best way to articulate the absence of information is to reveal what, indeed, I did manage to collect.

The Toronto Hospital

The first item was a cheaply produced printed booklet (Document A) entitled: "University of Toronto Prenatal Diagnosis Program: Information for Patients" (revised 1994). The quality of the document suggests that there was little funding available for patient literature. The next booklet was of higher quality print and paper (dated July 1993) developed by the Ad Hoc Implementation Committee for Maternal Serum Screening. It was entitled: "Maternal Serum Screening" with the following subheads: (a) "what can maternal serum screening tell me?"; and (b) "how do I get maternal serum screening done?" This was a fairly detailed brochure that folded into several sections, and included what appeared to be a consent form, as well as a list of genetic testing centres for all of Ontario. (Hereafter, called Document B.)

A separate form accompanied both booklets entitled "Genetic Family/Pregnancy History Questionnaire," (Document C) which required a signature of the patient and a genetic counsellor. What the patient was agreeing to with her signature was not spelled out. Table 3.1 is a detailed summary of my technical content analysis for The Toronto
Hospital (TTH) Literature. The following summarizes what I refer to as the socio-ethical problems this collection of materials presents. Often, social and ethical issues are represented as separate or distinct, but it is clear from this research that the social issues raised by this material are what, in fact, create the ethical or moral problems.

Document A

Because this document was so technical, it is likely that it intimidates rather than informs women. The booklet begins with an attempt to explain “Chromosomes and Birth Defects” presenting an actual visual of Trisomy 21. A small arrow points to what we presume is a problem but there is no text accompanying the arrow at all. The booklet then presents an Age/Risk chart on the following page, which is followed by information on the amniocentesis procedure (how it is done, what it detects, and the risks of the procedure). Following that, information to the reader on chorionic villus sampling (CVS) is presented (how it is done, “conditions” it detects, and “abnormalities” it does not detect; risks of the procedure, and accuracy). Then, a complex chart that compares the accuracy and risks of amniocentesis to CVS follow, followed by a series of sections on: RH-Negative information (3 lines) and Ultrasound (3 short paragraphs). The lack of detail on these short sections suggest that they were added on later.

On the last page of this booklet the subhead: “Possible Problems In Interpretation of Results” appears with extremely complicated terms, such as: “mosaicism”; “chromosomal variations”; and “maternal cells”. In my view, the most important sentence of the entire booklet – “In rare cases, the interpretation of the result will be inconclusive” – is hidden on the last page. Following this, the subhead: “Abnormal results” appears, which then tells parents that they will have to decide whether to continue or terminate the pregnancy. Termination after 24 weeks is
referred to as a “mini-labour,” a most inappropriate euphemism for what is an extremely unpleasant procedure. The booklet also tells us that in the case of an abnormality or difficult interpretation, the “referring physician will be informed and an appointment will be arranged for the patient to discuss the findings with a geneticist or genetic counsellor.” There is no mention of how the woman will be informed. This paternalistic sentence suggests that the doctor has more right to the information than the woman herself.

The core socio-ethical problem is obvious: women who are not well-versed in scientific terminology or medical language; women who do not speak English as a first language; and women whose reading level in English is below grade 12; may not be able to understand or appreciate anything in this booklet because it is so technical. Even if it does disclose the risks of various procedures, it is moot. A woman who cannot understand what is being disclosed cannot make an informed decision, much less give informed consent to any of the tests discussed.

While this booklet cannot be faulted from a legal perspective, in that it is clearly providing information to the reader, it is not providing the information in language that women from all educational backgrounds and cultures can understand. For example, the booklet contained a complex charts on Trisomy 21; age/risk ratios; amniocentesis procedures, laden with medical terminology; and complex statistics and numbers. Terminology such as “chromosomal mosaic,” “structural abnormality,” “fetal viability,” “transabdominal,” “transcervical,” and “blood grouping,” were all used without any lay explanation. The booklet, in short, contained no plain language, was written in passive voice throughout, while paternalistic terms such as “the patient,” “the fetus,” and “the placenta” isolated the reader from the material.
The booklet was also heterosexist, assuming that the baby is a product of two heterosexuals, rather than two women who have used donor sperm or a single woman using donor sperm. All illustrations in the booklet show a white baby and white mother as well.

Subtler problems surface, too. Value judgments are being made throughout about what is “normal” and what is “abnormal”. Who is setting these standards? Who decides what is abnormal? Which social group is being harmed by these norms?

The technical nature of the information immediately excludes women with low literacy skills, creating a scenario where these women do not have the same opportunity for informed consent as women with high literacy skills. Yet, justice demands that all women have access to information about their health, and access to the same standard of care. Therefore, this type of literature may serve to widen the gap between the classes as less educated women become more at risk for giving birth to “defective” children than more educated women, and must therefore bear the expense of caring for a child with health problems. The result is that the group who can least afford “defective” babies is being forced to bear them.

In short, the booklet is paternalistic, pro-fetus, and heterosexist, assuming that the mother is a heterosexual woman; and assuming that her only interests must be in preventing the birth of a defective fetus. There is no mention of a father’s interests, nor is the woman given information on the possible deeper social implications of testing for defects or anomalies. The reader is not referred to any organization or association that can provide further details on Down’s Syndrome or spina bifida, or other anomalies, a serious omission.
**Document B**

This document presents the same problems as Document A, for it, too, is technical, paternalistic, and fetalistic. Medical terms without sufficient explanation included “hydrocephalus,” “anencephaly,” “estriol,” “chorionic gonadotropin,” and “positive/negative result” (which is confusing rather than technical). A troublesome line of text included: “If you decide not to have [this screen] this decision will not affect your medical care in any way.” By assuring the reader that her care will not be compromised, there is a suggestion that it could be. Reassurance would be better communicated through a paragraph that frames the decision as a personal choice that is based on many factors.

The special problem presented here is the attached consent form. In large type is written: “Please sign this form and return it to your doctor or midwife. It will be kept in your file.” In small type is written: “I have read this pamphlet about Maternal Serum Screening. I have been able to ask questions and I have received the information I need to make a decision.” Many women reading this pamphlet may not read the small type (it is easy to miss) and sign the form, thus giving “uninformed consent” because they may not realize what they are signing. Women who do read the small print may be anxious about what they have read, and may just sign it in order to be screened within the time frame the booklet suggests.

**Document C**

This is a disturbing questionnaire that looks more like a market research tool for genetic testing companies than something that could possibly benefit the woman whose signature it bears. The form lists several diseases that may not be understood, as well many technical
medical terms, without explanation, such as "autism," "neural tube defects," "premature menopause," and "chromosome abnormalities".

Once the parents disclose their ethnic origins, the mother’s complete medical history (disguised as pregnancy history), and their combined family history (including information on first cousins), it is unclear who owns this information. Furthermore, it is not clear where this form is going. Some of the information parents are asked to disclose is not necessarily about genetic disorders, such as premature menopause, cancer, various mental illnesses, or learning disabilities. Unless this information is kept strictly confidential, it could be damaging. For example, employers, the future child’s school, or even a future divorce lawyer could potentially access this information if it is not confidential. The document asks for the woman’s signature (not the man’s) as well as the signature of the genetic counselor, suggesting the woman understands exactly what she is signing, when, in fact, she may not. The potential for social harm is enormous with this particular document. The fact that it accompanies prenatal testing booklets also suggests that genetic counseling, if not mandatory, is at least, inevitable.

**Women’s College Hospital**

The first item was a brochure entitled “Facts you should know about Tay-Sachs Disease” (hereafter referred to as Document D) authored by The Hospital for Sick Children Tay-Sachs Testing Program. On the back of the brochure was an outdated phone number.

The second piece of literature was a yellow flyer entitled “Group B Streptococcal Infection in Newborns: Information for Parents” (Document E). This is about how an infected woman could prevent passing on Group B strep to her newborn by
having a vaginal culture done around the 35th week of pregnancy, followed by antibiotics during labour. This is not prenatal testing information per se. The third piece of literature was a poorly photocopied section from the Toronto Hospital’s brochure on Maternal Serum Screening—without the title and consent form (Document F). The fourth piece of literature was an odd insertion: “Cord Blood: Biological Insurance for your child and family” (Document G) authored by the Toronto Cord Blood Programme, “an initiative of The University of Toronto Department of Obstetrics and Gynaecology” located at The Toronto Hospital. For further information, the brochure tells us to contact the Human Tissue Cryopreservation Laboratories. This brochure discusses how parents could store stem cells from the umbilical cord of their newborn, which could be used in the event that the child, or a relative of that child, required bone marrow transplants in the future. That is, one surmises, in the event of cancer. This is clearly not prenatal testing literature at all. The following summarizes the socio-ethical problems this collection of material presents.

Document D

At least Tay-Sachs Disease is a condition most will agree, is a cruel affliction that seems reasonable to prevent. This brochure uses scare tactics in an attempt to pressure any parent at risk into screening, and it could be argued that there is moral justification for doing so. The most obvious, and glaring, problem this document presents is that it targets only Jews, and completely omits the other population at high risk for Tay-Sachs Disease: French Canadians from Quebec. Since the 1980s, it has been known that Ashkenazi Jews (Jews of Eastern European origin) and French Canadians are at identical risk for this disease: 100 times the risk of the general population (Lauerson, 1995;
Hechtman et al, 1990). Singling out one risk group, while omitting the other, is deeply disturbing. Either this document presumes there are no French Canadians from Quebec living in Ontario who are planning to reproduce; or it presumes that French Canadians are not entitled to the same opportunities as Jews to prevent this disorder, creating a scenario where more French Canadian babies will die of Tay-Sachs Disease than Jewish babies. Even were this document to mention that French Canadians are at risk for this disease, the document appears in English only.

Jews are also harmed by the omission of French Canadians; they are singled out as a “risk group” and branded genetically damaged, which in another climate, could be used to persecute or ostracize them (Duster, 1990). (See Chapter 1 for information on the social harms Tay-Sachs Disease screening may create.) Similar harms have been noted with sickle cell disease screening. Blacks were considered more at risk than Greeks, for example, even though Greeks (and other Mediterranean groups) are at the same risk of sickle cell disease (Duster, 1990).

Another problem with this document is the wrong number at the back readers can call “for more information”. The brochure also includes a section: “Will There Be a Charge For this Service?” In that section, appears the sentence: “The program is not funded. We ask for a tax deductible voluntary contribution of $10.00.” I find this section distasteful and inappropriate. I cannot help but wonder whether the request for money has something to do with the fact that Jews are stereotyped as “rich”. Would a brochure targeting only French Canadians ask for such a donation?

Another problem is the fact that this document is technical, and this presents the same socio-ethical dilemmas discussed under Document A. It contains many technical
terms, including "storage disease," "ganglioside," "hexosaminidase," and "sphingolipidoses".

**Document E**

This document has to do with general maternal health, and why it was chosen by Women's College Hospital staff as a prenatal testing document is a mystery. The fact that it was included is what presents the problem. This information is accurate, and not as difficult to understand as some of the other documents discussed in this thesis. But a woman receiving this information in lieu of much more relevant information, would not be served adequately. It may also serve to confuse a woman, creating the impression that Group B Strep screening is of chief importance, when it is not. The one saving grace, perhaps, is that the literature was fairly recent; it was revised in May, 1997.

**Document F**

Because this is a badly photocopied portion of Document B (which had several fold out sections that were difficult to follow), the obvious problem is this: important information is being omitted, which certainly impedes informed consent.

**Document G**

The inclusion of this pamphlet in a package to a woman requesting "information on prenatal testing" is problematic. A handwritten note was stapled onto this brochure which said: "Not exactly testing but info available." The note suggests that the available literature is so limited, this staff member was trying to compensate for the absence of information by supplying, at least, information that was distantly related. But that sends a
more disturbing message: we have no information. No information cannot facilitate informed consent.

The Bay Centre For Birth Control

In the past, I have told women that The Bay Centre For Birth Control is Toronto’s “best kept secret.” The fact that no staff member at Women’s College Hospital suggested I go to The Bay Centre for Birth Control for information, or even The Women’s Health Resource Centre (which is part of the Bay Centre for Birth Control), suggests that many women are not told about it. No other hospital or women’s clinic I contacted suggested it, either. Although this centre was listed in the YMCA directory (see Chapter 2), this directory is not readily available.

The Bay Centre for Birth Control had an impressive Health Reference Centre and database, which a staff member showed me how to operate. A woman using this database would need some basic computer literacy skills and the reading literacy skills and research ability to scroll through dozens of complicated articles from medical journals and a few consumer articles. Much of the material was related to HIV testing, however, which is not the kind of information that is germane to this particular thesis, as discussed in the Introduction. (See Table 3.3 for a complete list of material available through this database.)

The socio-ethical dilemmas this list presents are two-fold: (1) The articles are too complicated for women with low literacy skills or women whose first language is not English, to understand, and this impedes informed consent, and presents many of the same problems discussed under Document A; (2) The Bay Centre for Birth Control, by virtue of its name, is not an obvious place women would go for such information when
they are already pregnant because it suggests contraceptive or abortion information only, rather than information on pregnancy and childbirth.

**Trade Literature**

Table 3.2 outlines the prenatal testing content of the trade books analyzed from the trade data “collection sites”. Since there is so little patient literature available on prenatal testing, women who need this literature are virtually forced into the trade books. That means they will either have to purchase at least one pregnancy book, or go to a library, library collection at a women’s clinic or centre, or the Internet to search out the information. Purchasing pregnancy books costs money. The average pregnancy book retails for approximately $25.00. Therefore, the public library, or other library collections, become the only place a woman of lower income can go for information. There, the selection of pregnancy books is limited, however, because of limited copies and outdated editions as newer tests become available. This creates a problem. For the most up-to-date material, a woman must either purchase a new book or conduct an Internet search, which means she must have access to a computer. Moreover, finding the time to go to a library or finding access to a computer, may be challenging for women who work long hours.

I had initially expected to find much more material on prenatal testing in the trade literature, and had planned this section as a separate chapter. However, what I found was simply more of the same patterns identified in the patient literature: paternalistic, technical prose with a heterosexist slant. (I have excluded my own book, *The Pregnancy Sourcebook*, from the analysis of trade literature, which was on the shelves at the bookstores I used as collection sites.)
With the exception of the books I have marked in Table 3.2, none of the books presented prenatal testing as a choice to the reader. Instead, they were explained as a necessary step in the prenatal experience that should be “discussed with your doctor” (Kitzinger, 1996; Hotchner, 1997). Phrases such as “discuss whether you are a candidate for this test” were common (e.g. Kitzinger, 1996). In short, no woman could escape “consulting her physician” (Kitzinger, 1996) after reading the trade information. The typical prenatal testing section discussed what the test entailed, who should seek out testing (the list was long, and therefore, encompassed most of the readership), and what the tests could detect. The only test where risks were mentioned concerned amniocentesis, but the text was always careful to present the risks as minimal and “rare” occurrences (Kitzinger, 1996; Hotchner, 1997). With the noted exceptions in Table 3.2, no book mentioned any unknown risks associated with ultrasound, for example. No book presented positive or alternative perspectives on Down’s Syndrome, or other conditions typically screened out through prenatal testing, but a few of them offered phone numbers to organizations that could offer more perspectives or information.

The books that raised socio-ethical issues surrounding testing were not written by doctors (Sussman and Levitt, 1989; Rothman, 1993; Greg, 1995). Unfortunately, although there may have been quality information, they required higher literacy skills. In one instance (Sussman and Levitt, 1989), the authors carefully outlined every possible genetic disorder to which various ethnic groups are vulnerable. Some of the disorders were so obscure, that this information may serve to intimidate the average reader.

It is also important to note that many women living in Toronto may not be aware of Parentbooks or The Toronto Woman’s Bookstore, and may be going to bookstores in
shopping malls, such as Coles or Smithbooks, which have far more limited selections of pregnancy books.

When the author of a pregnancy book was not an obstetrician or a physician of any kind, the book usually contained a foreword by a physician or obstetrician, who was presented as the "Medical Advisor" on the book. (This is to avoid liability.) The result is that the book advocated the practices of the current medical system, presented the reader's doctor as the official word, and advocated prenatal testing. A feminist perspective, meaning that the woman's interests were being served, could be found in other areas of these books, in chapters that focused on finding the right doctor or planning a labour experience that was right for the woman. In fact, there is an abundance of trade books specifically devoted to labour experiences, which truly represent a woman's interests over a doctor's interests. For example, Tracie Hotchner (1997) and Sheila Kitzinger (1996) devote considerable space to birth plans, midwives and doulas. The problem with the trade literature is the same problem as in Document A: they require high literacy skills. This creates the same class problem: less educated women have less information on prenatal testing than more educated women. Therefore, this creates the dilemma where, again, less educated women have fewer choices about their prenatal care than educated women.

Summary
The repeated problem of technical information demanding high literacy skills in English was seen across the data collection sites, in both patient information provided by hospitals, and trade literature available in libraries and/or bookstores. There are far-
reaching socio-ethical implications: whenever health information is tied to high literacy skills in English, there will be groups of people excluded from making informed health decisions, even if they are highly educated. This is a problem of distributive justice, widening the gap not only between rich and poor, but also between those with high literacy skills in English and those with low literacy skills in English. Frequently, poor women are not native speakers of English. However, it is not a foregone conclusion that there is always a link between English literacy and income levels.

The repeated problem of insufficient information or a lack of information on prenatal testing runs counter to the principles of informed consent, patient autonomy and the right to self-determination.
Table 3.1*

Material Found Through The Bay Centre for Birth Control Database Using Keywords: “Prenatal Testing”


Counseling highlighted for gene test. (prenatal testing for cystic fibrosis should require at least an hour or ore of counseling) Christine Mlot. Science News, August 16, 1997 v152 n7 p111.


Compliance with voluntary prenatal HIV testing in a large HMO. Carlole Limata et el. Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology, June 1, 1997 v15 n2 p126(5).

Health Officials call for prenatal testing. (Nebraska) AIDS Weekly Plus, Jan 6, 1997 p18 (1).


What you may not know about pregnancy tests, and they tell your doctor about your baby’s health. (As They Grow: Pregnancy) Nancy Josephson. Parents Magazine, April 1996 v71 n4 p77 (2).


The value of prenatal testing. (Point of View) Alyson Reichard. The Exceptional Parent, August 1995 v25 n8 p29 (3).


*Reproduced here as appears on database.
<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Prenatal Testing Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>American College of Obstetricians and Gynecologists</td>
<td>Planning for Pregnancy, Birth, and Beyond (1997)</td>
<td>- extensive description of all tests; no socio-ethical issues discussed</td>
</tr>
<tr>
<td>Gordon Bourne, FRCS, FRCOG</td>
<td>Pregnancy (1996)</td>
<td>- discusses “monitoring the fetus” through various tests</td>
</tr>
<tr>
<td>Ronald Caplan, M.D.</td>
<td>Your Pregnancy (1992)</td>
<td>- discusses various “routine” prenatal screening tests</td>
</tr>
<tr>
<td>Sheldon Cherry, M.D.</td>
<td>Understanding Pregnancy &amp; Childbirth (1992)</td>
<td>- has a small amount of information on genetic testing</td>
</tr>
<tr>
<td>*Lachlan de Crespigny</td>
<td>Which Tests For My Unborn Baby (1997)</td>
<td>- Detailed descriptions of tests in a Q &amp; A format</td>
</tr>
<tr>
<td>Glade B. Curtis, M.D., FACOG</td>
<td>Your Pregnancy After 30 (1996)</td>
<td>- looks at “screening for congenital abnormalities”</td>
</tr>
<tr>
<td>*Murray Enkin, Marc J.N.C. Keirne, Mary Renfrew and James Neilson</td>
<td>A Guide to Effective Care in Pregnancy and Childbirth (1996)</td>
<td>- discusses genetic counselling and ethics; less paternalist</td>
</tr>
<tr>
<td>*Robin Greg</td>
<td>Pregnancy in a High-Tech Age Paradox of Choice (1995)</td>
<td>45-page chapter called “Risky Choices” looks at medical norms, risks to woman and baby, and socio-ethical issues</td>
</tr>
<tr>
<td>*Tracie Hotchner</td>
<td>Pregnancy and Childbirth (1997)</td>
<td>- A brief look at the emotional risks</td>
</tr>
<tr>
<td>*Shiela Kitzinger</td>
<td>The Complete Book of Pregancy and Childbirth (1996)</td>
<td>- “Windows into the uterus” provides more extensive descriptions of tests, risk factors, choices.</td>
</tr>
<tr>
<td>Vivienne Parry</td>
<td>The Antenatal Testing Handbook (1993)</td>
<td>- Title may be confusing; does discuss testing dilemma &amp; discusses abnormal results</td>
</tr>
<tr>
<td>Raymond Polakin, M.D.</td>
<td>What You Didn’t Think To Ask Your Obstetrician (1992)</td>
<td>Q &amp; A format explaining various “routine” tests</td>
</tr>
<tr>
<td>Howard Shapiro, M.D.</td>
<td>The Pregnancy Book For Today’s Woman (1987)</td>
<td>“The New Obstetrical Technology” looks at the risks involved with some tests, such as who should be tested - no ethical issues discussed.</td>
</tr>
<tr>
<td>*Barbara Katz Rothman</td>
<td>The Tentative Pregnancy: How Amniocentesis Changes (1987)</td>
<td>- Looks at ethics and prenatal testing; non-directive counselling; ambiguous diagnoses; uses personal and expert testimony; opposed to the idea that prenatal testing in any way liberates women</td>
</tr>
<tr>
<td>*John Sussman and Blake Levitt</td>
<td>Before You Conceive: The Complete Pre-Pregnancy Guide (1989)</td>
<td>- Looks at eugenics and social harms</td>
</tr>
</tbody>
</table>

^What appeared on the bookshelves at time of data collection. Listed alphabetically by author.
* Books that presented thorough discussions on socio-ethical issues raised, and which presented testing as a choice to woman.
CHAPTER 4

THE PHENOMENON OF ABSENT INFORMATION

For the purposes of this thesis, “absent information” refers to the absence of prenatal testing literature that is accessible to women of varying literacy skills. Literature that targets only women who are presumed to have English as a first language, a university level education (I include women who are self-educated in this category), and enough disposable income to finance the purchase of trade literature, presents a variety of socio-ethical problems discussed in the previous chapter. (See under Document A.)

This is not the “chapter 4” I intended to write at the outset of this research. I had anticipated being bombarded with so much prenatal literature, that separate chapters on the Patient and Trade literature would be necessary. This was not my finding. Initially, I coded (see Chapter 2) absent information as a “pattern”. As I began to think more about the results of this research, and approached the codes from a more holistic perspective, what I saw was not so much a pattern, but a “phenomenon,” which the Webster’s dictionary defines as: “any extremely unusual or extraordinary thing or occurrence”. When five university teaching hospitals (and nearly every woman’s health clinic contacted) in the largest and most densely populated city in the country do not provide pregnant women with accessible literature on prenatal testing, the situation is both disturbing and unethical.

In the 1976 film All The President’s Men, Robert Redford (portraying Washington Post reporter Bob Woodward) observes: “It’s not the fact that people aren’t talking; it’s the way they’re not talking that bothers me.” This sentence characterizes my
own experience with trying to find prenatal testing literature. The way my request for literature was handled bothered me more than the fact that not much material was available. When my phonecalls are unreturned, when I am shuffled from one department to the next, and when I encounter dismissive, staff disinterested in the pregnant woman’s right to know, I worry about the experiences of pregnant women searching for the same information.

Considering how much money is being invested in the Human Genome Project, it seems there should be a moral imperative for some of that money to go into lay literature on genetic screening. Since there is not a lack of funding for genetic research, there should not be a lack of funding for the development of such literature. Unfortunately, I cannot answer why there is no patient literature on prenatal testing unless I conduct extensive interviews with the appropriate hospital personnel. I will discuss, however, the socio-ethical impact this phenomenon has on women.

To answer the specific research questions posed in my Introduction: in the absence of counselling, there can be no informed consent about the medical or social implications of prenatal testing, when there is no accessible patient or trade literature on prenatal testing. Without informed consent there are no meaningful reproductive choices for women, since to make a meaningful choice, they must have enough information. When there is no choice, a woman cannot exercise her right to self-determination and autonomy, nor can she do the moral soul-searching (Purdy, 1996) she must, to “do the right thing”. And when these rights are denied her, she has no more power to control what happens to her body than the developing fetus within her. In short, the scenario is a philosophical nightmare for libertarians, utilitarians and especially, feminist ethicists.
Coercing Counselling

The very absence of this literature coerces women into a counselling session – with someone – about prenatal testing. I use the term “coerce” because it seems that counselling ought to be an option for women, rather than something they are forced into because there are no other options available.

Unfortunately, we cannot assume that a doctor is an adequate counsellor, especially since that doctor has not been trained to be a counsellor, which certainly requires different skills. We cannot even assume that the doctor is a good, and “virtuous” (Pellegrino, 1988) physician. “In the virtuous physician, explicit fulfillment of rights and duties is an outward expression of an inner disposition to do the right and the good. One is virtuous not because one has conformed to the letter of the law or one’s moral duties but because that is what a good person does” (Pellegrino, 1988:119). Surely not all doctors are good people.

Private counselling sessions raise some familiar, yet disturbing doctor-patient (or the new term, counsellor-client) dynamics, first observed by Phyllis Chesler in 1972. Chesler was writing about psychotherapy; yet the image of a frightened woman bombarded with scientific and medical jargon, still mirrors much of the female experience in patriarchal culture (Chesler, 1972), reinforced by paternalistic medicine. In other words, a scenario where the doctors/counsellors are powerful and the patient/client is powerless is being reinforced through prenatal counselling. I have substituted the word “psychotherapy” with “counselling” in the following quote to emphasize just how little has really changed for women in the medical system:
For most women [counselling] is just one more instance of an unequal relationship, just one more opportunity to be rewarded for expressing distress and to be "helped" by being dominated. [Counselling is] based on a woman's helplessness and dependence on a stronger authority figure; [it] may, in fact, be viewed as re-enactments of a little girl's relation to her father in a patriarchal society... (Chesler, 1972: 108)

When counselling is involved, potential benefits of prenatal screening can only be delivered in the presence of good counselling, not simply counselling. In the same way that mammography demands a good pathologist on the scene to interpret the mammogram, prenatal genetic testing demands proper counselling before and after testing (Parens, 1996). Without proper counselling, Parens compares handing out test results to handing a loaded gun to a child. But that is not his worst fear. There are not enough counsellors to meet the need. In the U.S., for example, roughly 12 million people could benefit from some sort of genetic counselling, but there are only 1000 trained genetic counselors (Parens, 1996). As mentioned earlier, only 12 counsellors per year graduate in Canada.

Who is, and what makes, a "good genetic counselor"? Is this term even tenable? Wertz and Fletcher (1992) point out that it is impossible for counsellors to be nondirective or neutral when they are giving advice or withholding services. Duster (1990) shares the same concerns, adding that counsellors cannot be neutral "information givers" on one hand, and emotionally supportive on the other.

And since "people are too varied in their class, cultural, and racial heritages, too varied in their religious and secular commitments, and too varied as personalities...there are no formulas, and no list of ethical guidelines from a professional's manual which can adequately define the correct role" (Duster, 1990:79-80). In short, Duster (1990) suggests
that "the notion of unbiased, nondirective genetic counseling is a fiction (Duster, 1990:145).

Several studies (Duster, 1990) demonstrate that the interactions between genetic counsellor and client vary. For example, counsellors may not be able communicate information to Client A as well as s/he can to Client B due to the following (Duster, 1990):

- language barriers;
- “extraordinary variability” in knowledge;
- presuppositions by the counselor that clients understand and appreciate what is important, “even when the counselor and the counseled have quite different reference points for what is ‘important.’” Furthermore, “the short time period of the counseling session insures this, and the counselor literally cannot afford to spend time going through ‘the basics’ with respect to the ‘important’ genetic knowledge base” (Duster, 1990:138-9).

Data show “that in situations of uncertainty, people are likely to let a ‘hunch’ override the risk figures presented to them” (Duster, 1990:139).

Duster’s research revealed that in the typical 15-minute counselling session provided in his U.S. study (in Toronto hospitals, counselling sessions last approximately 60 minutes), the presumption of client knowledge was so unrealistic, that “[the counsellor] uses without explanation the terms ‘amniotic sac,’ ‘18 cubic centimeters,’ and ‘fluid from the fetus’” (Duster, 1990:142). As for the “non-directive” nature of this session, Duster observed that when one woman remarked to her counsellor that a 1% risk
of Down's Syndrome seemed low, the counsellor responded with: “When you were in your 20s, it was 1 in 1,200” (Duster, 1990:143).

But where is the choice for her? She cannot return to her twenties. The client then says that “it is much more likely than I would care to risk.” But what is more likely? Is it not the relief provided by the counselor that shapes the new response? The counselor then “explains” to the woman that this is why she (the pregnant woman) [can choose] to have the amniocentesis. The woman replies, “Yes, that’s why I [am doing] it.” (Duster, 1990:143)

When language barriers exist between the client and counsellor, there are also problems with interpreter ethics. Kaufert, an American, observes that the current medical literature “seems to assume that language intermediaries play a neutral role that does not influence decision making...and treats culture and language as ‘barriers’ to be overcome by training clinicians to alter their communication ‘style’...” (Kaufert, 1996:73).

It is important to note, too, that administrative rules and health policies can affect the physician-interpreter-patient relationship. The roles and powers of the interpreter vary according to these policies, and “interpreter programs may have been created to meet governmental regulations or to mediate institutional problems rather than to solve problems for patients” (Kaufert, 1996:72).

Many hospitals, for example rely on untrained hospital personnel or staff for interpretation (Kaufert, 1996), a practice which fails to take into account the confidentiality of information. Sensitive information may become common knowledge within the patient’s and/or interpreter’s community (Masi, 1989). Although Kaufert is commenting on the U.S. medical system, the same problems, exist in Canada. In fact, these problems may be even more pronounced in this country as Canada reflects a wider
mosaic of cultures and languages, considering its population size. Canada’s health care system is also suffering from lack of funding, leaving no room for paid interpreters.

"Some researchers recognize the power of an interpreter as a gatekeeper who has the power to elicit, clarify, translate, omit, or distort messages" (Kaufert, 1996:72). In the clinical setting, the interpreter may have far more influence on the patients than the doctors.

There are ethical problems inherent in interpretation such as confidentiality or accuracy. Since some interpreters may be biased, this can colour information presented to patients.

There is also the problem of revealing information when there is no way the patient or client can benefit from the information. Revealing information for the sake of knowing is often counterproductive. So, the benefit of good counselling may be little more than "enlightened impotence" (Parens, 1996:406).

Genetic counselors and scholars are also worried about the commercialization of genetic information. Companies devoted to profits will be tempted to play on the anxiety of defensive doctors and many women’s lack of information surrounding prenatal screening. Women who are not high risk will want to be tested “just to be sure” (Parens, 1996:410).

Therefore, the issue of harm in connection with such counselling and subsequent testing ought to be examined. Erik Parens argues that:

[T]he potential for genetic counselors to do harm ‘merely’ by providing unwanted or misunderstood genetic information is enormous. The presence of unwanted or misunderstood genetic information can be as harmful as the absence of wanted and properly understood information....Given that genetic information is difficult for many lay people to understand, and given that informed consent to testing requires
understanding that information, I should be clear how complex a task it is to get an adult’s informed consent to be tested. (Parens, 1996:408)

Informed consent notwithstanding, Susan Sherwin advocates that medical interventions involving women that further oppression rather than correct it, are harmful:

“Women’s relatively powerless positions in society make it a matter of particular importance that we guard against the likelihood that their health is sacrificed to the financial interests of [those who stand to profit]” (Sherwin, 1984: 169). Consider how the following issues might strengthen both Parens’ and Sherwin’s position:

- Testing Negative. Testing negative is never a “true negative” since the test is not an accurate prediction of the fetus’ future health. “Among the risks associated with a negative result are that some patients may mistakenly interpret a negative result to mean that they are not at risk for any form of [complication]...” (Parens, 1996).

- Testing Positive. Testing positive is not necessarily a guarantee of a health problem with certain prenatal tests. The issue of harm should be examined, in the context of whether a still-healthy pregnant woman should sacrifice her emotional health. “Patients with a positive test are at risk for...increased feelings of anxiety, depression, and hopelessness” (Parens, 1996).

- Harmful interventions. Right now, women who test positive for early prenatal tests are recommended for more invasive tests later in the pregnancy, and may be recommended for terminating the pregnancy. All of these interventions may ask
women to sacrifice their health before showing symptoms of a disease, even when the troubling issues of informed consent have been considered.

- Rich vs. Poor. Justice demands that women should be eligible for prenatal testing regardless of ethnic background, ability to pay and so forth (Parens, 1996). History teaches us different lessons about justice and women’s health. In the U.S., poor women have lower birth weights and more complications at birth than affluent women because they have less access to screening and health care delivery (NEJM, 1993). So prenatal screening may widen the gap between the rich and poor, allowing the rich more options with respect to screening. And even if certain genetic screening tests continue to be accessible through research trials, that would mean poor women are forced into becoming research subjects if they want to be tested.

- Vulnerable populations. Is prenatal testing an uncontrolled experiment on a vulnerable population? Because of past abuses involving women’s reproductive organs, public outcry demanded stronger regulations that sought to protect them, labelling women with reproductive potential “vulnerable,” thus banning them from medical research (Mastrioanni, 1994). Unless the risks of certain procedures or treatments are well-established, and women are informed of all the potential risks, women are being abused once again. This is not to say that research on women should be eliminated, but that it must be done on true volunteers who are fully informed.
The Educated Consumer

An educated woman is best able to understand the technical patient literature, or the sophisticated prose of the trade literature, in order to make decisions about her own welfare, and the welfare of the fetus. Hence, educated women have more reproductive choices than uneducated women, which means the dearth of accessible literature on prenatal testing creates problems with distributive, economic and social justice.

Yet even educated women are not being adequately informed about prenatal testing. As raised in the Literature Review, there are numerous social implications of prenatal testing that may affect the kind of choices women make. Only three trade books actually discuss socio-ethical issues related to prenatal testing. These books are not available at mall bookstores, which many women frequent. Even when the woman is educated, and she has access to good literature and competent counseling, given the vulnerability of a pregnant woman, and the amount of medical and sociological information she will require to make an informed decision about whether to undergo various prenatal tests, it does not seem reasonable to expect that she can make the decision for testing free of coercion. Perhaps most disturbing is the fact that complex genetic information is being mixed into the already technical set of prenatal tests. Poorly understood genetic information could be more harmful than no information at all (Parens, 1996). If it is too early to tell what the outcome of the pregnancy will be, perhaps it is preferable not to disclose inconclusive information until it becomes conclusive.
Summary

Clearly, women who are offered prenatal testing require layers of information; not only must they be provided with basic information about what the test detects, its risks and potential benefits, but they ought to be provided with information on the social implications of testing. When there is no accessible reading material on these tests, the information has to be provided verbally, and this creates problems ranging from counsellor biases to interpretation for women who do not speak English well, or at all. Counselling is problematic enough when there are enough counsellors to service the number of women undergoing testing. Counselling is particularly problematic when, in addition to a dearth of prenatal testing literature, there is a dearth of prenatal counsellors.
CONCLUSIONS

This thesis showed serious gaps in printed information available to women about prenatal testing. These omissions pose serious problems for informed consent, patient autonomy and the patient’s right to self-determination.

A closer analysis of the materials that were provided shows that the medical agenda is explicit and often spelled out. I propose that the literature exposes that the intent of prenatal tests is not to guarantee the health and well being of the woman, but to prevent the birth of a child with defects. Sometimes the prevention of an unwanted child can coincide with the health, safety and well being of the woman undergoing the testing. I suggest that when this happens, it is accidental. A close examination of the prenatal literature in this content analysis reveals, in the absence of verbal counselling, the possibility of “backdoor eugenics” (Duster, 1990) that is deeply worrying.

What is more distressing is that although this agenda is explicit, it is obscured by the fact that there is no document that covers the agenda per se. (For example, a document entitled “What This Test Means To Society” could discuss at least some of the broader social implications prenatal screening.) Instead, existing documents discussed the specific test, or fetal anomaly sought out. This creates the false impression that a woman is being offered real options throughout her pregnancy, when in fact, they are at best limited choices. Women can choose or refuse:

- the test (or further testing)
- termination of the pregnancy (if positive)
• conceiving (if positive, in cases where assisted reproductive technology is involved, or genetic carrier information is received).

If the test results that led to these choices were at least clear, the problem would not be as troubling. In the majority of cases, the test results are not clear at all. As this thesis reveals, it is problematic enough to expect women to understand and appreciate the medical meaning – or meaninglessness – of the tests offered when the language is technical and demands a high reading level in English. It is virtually impossible to communicate the meaning of “probability and outcome” to women who have limited mathematical skills. Even a statistician might find it difficult to make a choice when there is an emotional attachment to the “probability and outcome”.

Unless women also understand and appreciate the social pressure to test for fetal anomalies lest society be burdened with a defective child, they are not really able to make an informed choice about prenatal testing. Furthermore, given the current components of informed consent, and the complexities involved with the new reproductive and genetic technologies, the tests a woman chooses when she is not pregnant may be completely different from her choices while pregnant, or anticipating a pregnancy. In other words, a woman in her tenth week of pregnancy may not make the same choice as she may in her sixteenth or twentieth week of pregnancy.

Recommendations

Facilities that offer prenatal testing ought to be responsible for educating women about all the potential risks and benefits of testing. This must include a social analysis of risks
and benefits so that women can understand how their personal choices are indeed political choices, and how their individual decisions impact broader social policies.

Women should also be provided with information on the negative and positive aspects of caring for a child with disabilities. Materials on some positive experiences of families with Down’s Syndrome children, for example, can offer a richer perspective to women making these choices. Conversely, a realistic portrayal of the demands and pressures children with disabilities can place on families (particularly women) should be presented, too. Presenting accurate information on raising children with disabilities could be organized through visits with families caring for these children.

The educational materials must be available in plain language, so they are accessible to women of diverse educational and cultural backgrounds. This means that funding ought to be made available to facilities offering testing from educational grants from private corporations with an interest in the stakeholder, or from government grants. Testing ought not be offered unless proper educational materials on the specific test, and the social implications of testing, be provided.

*A Feminist Approach*

Funding educational materials on prenatal testing may not serve the interests of hospitals focused on genetic research and reproductive technologies. Moreover, since the technologies change so quickly, there may be the perception that funding printed materials will become obsolete within a short span of time.

Yet the gaps identified in prenatal testing literature are not the fine, technical details of each test offered, but the wider, broader questions women must ask about the testing
they undergo. Materials need to provide women with the right questions to ask of their health care providers in order to empower them. Materials that only feed them technical facts, can have the opposite effect, and intimidate the reader.

A woman-centred approach for written materials is what is missing from the current literature collected in this study. Fortunately, there are existing models of woman-centred approaches to printed literature, which can be applied here. The feminist self-help groups (Zimmerman, 1987) which emerged in the late 1960s and early 1970s, and which produced books such as Our Bodies Ourselves (first published in 1971 by The Boston Women’s Health Collective), How to Stay Out of the Gynecologist’s Office (first published in 1974 by the Federation of Feminist Women’s Health Centers, a women’s self-help collective based in Los Angeles), and A New View of Woman’s Body (1981), demonstrate how laywomen can educate themselves about their bodies and produce comprehensive materials that educate and empower from a feminist perspective. For example, the latter publication devotes an entire chapter to the clitoris.

The Boston Women’s health collective grew out of a small group of women who met regularly to discuss aspects of women’s health. Each woman in the group took a topic, such as abortion or rape, and made that the focus of her research, and then brought back what she had learned to the larger group (Zimmerman, 1987). Prenatal testing could thus be broken down into smaller components, ranging from ultrasound and amniocentesis, to topics that focus on disability and the history of the eugenics movement. A small group of women meeting to discuss prenatal testing could produce similar results, although given the technical nature of the topic, it would be time-
consuming (Zimmerman, 1987), a major drawback of this kind of approach, and one which has led to a delay in publishing collective works on women's health.

One particular model I propose here is the breastfeeding literature model.

As late as the early 1990s (Palmer, 1993), breastfeeding materials provided by hospitals or government-funded health programs and clinics were inadequate, often non-existent, and served to provide misinformation to women in order to discourage breastfeeding and encourage bottle-feeding with artificial baby milk. Meanwhile, women in many parts of the world are still discouraged from openly breastfeeding their children in public (Palmer, 1993).

The problem with the breastfeeding literature was that formula manufacturers were producing the so-called educational materials on breastfeeding, which in reality, were sales materials. Formula manufacturers still control much of the continuing education on breastfeeding and formula, luring nurses and physicians to conferences with fringe benefits (Palmer, 1993).

As the health problems of babies fed with artificial baby milk became more widely known, and woman-centred self-help groups, such as La Leche League (which functions similarly to a women's health collective) became more widely known, women began to take back control over breastfeeding education. La Leche League, for example, provides good and accurate literature on breastfeeding, and has a "buddy system" in place, where women could call other women who had breastfed and successfully resolved common breastfeeding problems. Breastfeeding advocates continue to fight for the distribution of accurate breastfeeding literature as the tension between formula company-produced literature and woman-centred literature continues in many hospitals. What is
unique about breastfeeding educational materials is that breastfeeding organizations run by women joined forces with the World Health Organization and UNICEF to draft the existing International Code of Marketing of Breastmilk Substitutes, introduced in 1981. In brief, the code ensures that accurate information about the benefits of breastfeeding and dangers of formula be provided.

Information on prenatal testing can follow a similar model. Women who have undergone testing or refused testing, could self-organize to provide accurate information on the risks and benefits of prenatal testing, as well as providing women and their families with the larger social implications these tests pose. Clearly, women are diverse as a group, and the experiences, for example, of Aboriginal women with prenatal testing will be different from Black women, which will be different from White women. Heterosexual women may also have different experiences with prenatal testing than lesbian women. Women with disabilities will have different experiences than women who are able-bodied. Thus, a prenatal testing collective needs to be established, where women from all groups can find relevant material and literature that will help them make meaningful choices and decisions with respect to prenatal testing, preconception screening, and preimplantation screening. This avoids the historical problem of one group of women controlling health education materials (Keaner, 1985).

I propose, too, that prenatal testing literature requires a similar international code as seen in breastfeeding literature, and the assistance of WHO and UNICEF in this case would not be inappropriate, given that the goal would be to ensure the health and wellbeing of mothers and children. To protect the unborn, and the pregnant woman, such a code could ensure that all materials on prenatal testing provide information on the wider
social implications of prenatal testing, information on realistic experiences of families raising children with congenital defects or disabilities, as well as all the details of the potential risks, benefits of each tests in accessible language. In countries that provide Western-style health care, the code could ensure that no prenatal test be offered to a woman without the provision of such material, and the opportunity for the woman to discuss this material with her health care provider. (This would obviously be difficult in poor or underdeveloped countries that often have insufficient medical care, and/or no health care providers.) The code could ensure that the materials do not send subtle messages about sex selection, trait selection or other possible areas where prenatal testing can be abused. Pictures idealizing prenatal testing (e.g., a smiling white women thoroughly enjoying her ultrasound experience) and intimidating charts should be banned as well.

Such a code could also stipulate:

- No government body with suspect or eugenic agendas (Jacobson, 1991), genetic technology companies, or equipment manufacturers provide misinformation to women about prenatal tests.

- No facility of a health care system should be used for the purpose of promoting potentially abusive genetic screening or testing.
• Testing facilities must purchase their prenatal testing equipment or screening tools as they would any other equipment, without financial or material gratuities or incentives.

• Health workers must disclose whether they've received funding from genetic technology companies, or companies manufacturing prenatal tests or equipment for fellowships, study tours, research grants, attendance at professional conferences, and so on. The companies must also disclose to whom they've granted funding. To prevent conflicts of interest, professionals working in prenatal health cannot receive: money, goods or services from any of these companies.

Non-Feminist Options

If a feminist approach is not adopted, at the very least, companies specializing in writing, editing and producing technical materials for the laypublic should be contracted to develop educational materials funded by private facilities. Facilities staffed with technicians are not capable of producing accessible materials, and ought to recognize that writing and editing technical materials in plain language is a special skill that requires a different professional. While this still moves the power of authorship from one set of “experts” to another, it will at least ensure that whatever literature private facilities do produce is more accessible.

If a non-feminist approach is undertaken by a prenatal testing educator, a needs assessment must be done to investigate what women identify as information gaps in prenatal testing. Women from a cross-section of cultures, backgrounds and education levels need to be asked what their information needs are with respect to prenatal testing.
While coding my research for this thesis, I had a disturbing dream that oddly enough, serves as an appropriate summary. I arrive at the home of friends around twilight, and am told: “Be careful. It’s about to start.” Suddenly the windows were being broken, and hoards of wild, uncontrolled, angry children, ranging from toddlers to preteens, swarmed into the house. They began throwing objects at us, swearing at us, and creating utter destruction. The adults were passive, terrified, and unable to exert any discipline. I was told, in fact, that the best thing to do was nothing; that any attempt to call attention to the children’s behaviour would only antagonize the situation and make it worse. Our only choice was to wait until morning, when “calm” would return. We were, in effect, prisoners of the children.

Since I have no children myself, I was unaware, in the dream, that this “night terrorizing” of adults by wild children had been going on for quite some time. It had, in fact, become quite the problem on one hand, but routine on the other. Non-parents were not informed about this night terrorizing because it was a hidden embarrassment, not openly discussed to outsiders. When I awoke, I was profoundly disturbed by the dream. What did it mean? As the dreamer, I can only relay what it meant to me.

This dream was about my subject matter: prenatal testing. The dream suggests that while calm and discipline are present by day (symbolizing to me, the present), chaos takes over by night (symbolizing, to me, the unknown or the future). There is an illusion that by conducting these tests on the unborn, the medical establishment is controlling, or disciplining the species, thus creating the illusion that parents are able to control their
“offspring”. But the reality is quite different. Prenatal and genetic testing is wildly out of control. The children in the dream are both the unborn children of the future, as well as the children born to the anguished parents who “sweated out” their test results. These children – as a generation – are angry, and they are lashing out.

Non-parents (those of us who have not been in the position of having to test and go through the anxiety of this ordeal) are not aware of how out-of-control the situation is because no one is talking about it. Just as the parents in the dream withheld information from me about this chaos that had become routine, the medical community is withholding information from women about the chaos they are entering when undergoing routine “prenatal diagnosis” testing.

The feeling in the dream was terror. The feeling I have as a researcher is also terror. The results are in fact, more terrifying than I ever anticipated. It is not what pregnant women are reading that worries me; it is not even the fact that they are not reading that worries me. What worries me is the fact that there is nothing for them to read! The absence of printed information seems immoral, if not, illegal. The results of this thesis therefore compel me to explore this subject further. Now that I know pregnant women are not reading literature, I must find out what, in fact, they are hearing. In the absence of literature, there is only counselling. As of this writing, my doctoral research seems clear: Socio-ethical issues of prenatal counselling: What are pregnant women hearing?
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