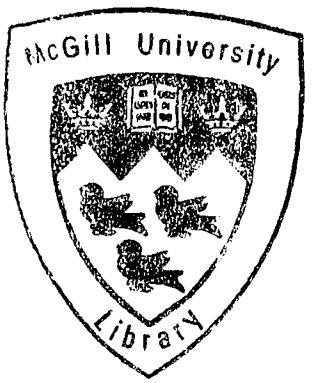

Prenatal Testing and Informed Choice: The Need for Improved Communication and Understanding Between Health Care Professionals and Pregnant Women

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ABSTRACT

This research examines the many different ethical issues that emerge in the health care setting with regards to prenatal diagnostic testing. Identifying the areas of clinical practice and religious counselling in need of improvements, particularly physician-client communication, is important to ensure that competent pregnant women make informed, considered choices about prenatal testing. This paper investigates the many factors that contribute to pregnant women's decision-making processes surrounding the acceptance or refusal of the maternal serum alpha-fetoprotein screen, ultrasonography, amniocentesis, chorionic villus sampling, and preimplantation diagnosis. Integrating scholarship in bioethics, religious studies, and the anthropological and sociological study of medicine, this dissertation offers a comparative analysis of religious attitudes toward prenatal diagnostic testing, describes the complexities of practical decision-making by pregnant women faced with genuine ethical dilemmas, and provides an analysis of ethical issues related to prenatal testing. This research will be of interest to scholars in religious studies and bioethics, prenatal genetic counsellors and obstetricians involved in the provision of prenatal diagnostic testing services, and specialists in women's health and reproductive decision-making.

RESUME

Ce projet de recherche examine les multiples problèmes moraux liés au diagnostic prénatal et identifie les domaines de pratique clinique, telle la communication entre le médecin et le patient, et de conseil religieux qui pourraient être améliorés, afin que toute femme enceinte puisse accepter ou refuser un diagnostic prénatal en toute connaissance de cause. Cette dissertation explore les nombreux facteurs qui influencent les décisions des femmes enceintes quant à l'utilisation des marqueurs sériques maternels, de l'échographie, de l'amniocentèse, du prélèvement de villosités choriales (PVC) et du diagnostic génétique préimplantatoire. Ce projet est une synthèse de différentes études académiques en bioéthique, religion, anthropologie et sociologie de la médicine. Il offre une analyse comparée des préceptes religieux en matière de diagnostic prénatal, décrit les complexités de prise de décision de femmes enceintes qui doivent faire face à de véritables dilemnes éthiques, et analyse les questions morales liées au diagnostic prénatal. Cette recherche devrait être utile à toute personne intéressée par les philosophies religieuses, aux conseillers en génétique prénatale et obstétriciens offrant des services de diagnostic prénatal, ainsi qu'à toute personne concernée par la santé des femmes et leurs choix reproductifs.

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INTRODUCTION

Pregnant women face a number of challenges as technology continues to pervade the reproductive realm. In particular, the routine use of prenatal diagnostic tests, such as maternal alpha-fetoprotein (MSAFP) screening, ultrasonography, and even amniocentesis or chorionic villus sampling (CVS) for women over 35, raises various ethical issues. Prenatal testing was initially reserved for women deemed at "high risk" for complications or fetal abnormality (Boyle 258; Thompson 308-09). Today, however, most women in North America undergo the maternal alpha-fetoprotein screen, at least one, if not two, ultrasounds, and, if over the age of 35, an amniocentesis during the course of their pregnancies (Lippman, "Prenatal Genetic Testing" 21; Institute of Medicine 78). These prenatal tests are presented to many pregnant women as routine procedures intended to benefit the health of their foetus even though these pregnancy "rituals" have not significantly improved maternal or neonatal health.[1] A number of factors have contributed to this routine administering of prenatal testing, among them the financial incentives in private, insurance-based health care systems, a growing dependency on technology in reproductive medicine, an increased fear of "wrongful birth" law suits, and the simple fact that women continue to request and actively seek these procedures.

Prenatal tests successfully identify genuine complications in some women, thereby giving obstetricians an opportunity to gauge the pregnancy and labour accordingly to decrease maternal and perinatal morbidity.[2] However, acknowledging that some women benefit from prenatal testing does not necessarily justify the uninformed routine screening of virtually all pregnant women (Oakley 285). Although the benefits of these prenatal

diagnostic tests are usually discussed at length with women, the various disadvantages and risks are often not disclosed (Mcfadyen, "First"; Mitchell 148, 150; Wolf 39-40). Among the testing disadvantages are: there is no treatment for most of the conditions detected;[3] the tests increase maternal anxiety which can lead to adverse physiological repercussions for both the woman and her foetus;[4] there is a high frequency of false-positive and false-negative diagnoses;[5] and some scholars would argue that the tests create a false sense of reassurance.[6]

Unfortunately the complexity of decision-making related to prenatal testing is often overlooked. Although a woman's decision to accept or refuse prenatal testing is complex and incorporates numerous factors (Barclay 55), health care providers sometimes reduce this decision to whether a woman wishes to "avoid birthing (and subsequently parenting and caring for) a child with a genetic condition" (Brookes 134). Regardless of a woman's religious beliefs, social class, socio-economic status, culture or ethnicity, few women base their decision to undergo prenatal testing on one factor. Differences in gender, age, race, class, religion, culture, family history and personal experiences contribute to decision-making processes and inevitably influence reproductive decisions (Donchin 238). Yet, how these issues are assessed and weighed will vary for each woman and will even vary from one pregnancy to another.

This project integrates research in bioethics, religious studies, and the critical study of new reproductive technologies. This dissertation identifies and analyzes the ethical issues embedded in the practice of routine prenatal testing and proposes that an increase in information sharing is needed amongst health care professionals, religious leaders, and

women. The analysis considers ethical issues that emerge both in the "micro" settings of individual patient-physician/parishioner-religious leader encounters as well as at the "macro" level of institutional and social structures. At both the "micro" and "macro" levels, many factors threaten to undermine and usurp women's capacity to make genuinely informed and autonomous choices pertaining to their reproductive health care. Given the unquestioned faith placed in biomedical techniques to improve health outcomes, the routine use of prenatal testing will undoubtedly continue to expand exponentially. Therefore, the ethical issues that arise as a result of such seeming indiscriminate testing must be acknowledged and appropriate institutional and professional changes must be considered to improve women's pregnancy and prenatal testing experiences.

Health care practitioners, religious communities, and society at large must understand that the decision to undergo prenatal diagnostic testing, and the subsequent decision to terminate a pregnancy in the event of a positive diagnosis, is not always as straightforward as a woman's stated position on abortion. In addition to reflecting on their own personal values and psychosocial influences, pregnant women rely heavily on obstetricians, genetic counsellors, and sometimes religious leaders for advice, guidance, and support throughout their pregnancy. Therefore, health care institutions, religious communities, and various social institutions have an ethical duty to create an environment conducive for pregnant women not only to make choices but to make informed choices.

This dissertation is comprised of three core chapters. The first chapter, an exercise in description and interpretation rather than normative criticism, provides a detailed portrait of a number of mainline religious positions regarding prenatal testing, selective abortion,

and preimplantation diagnosis.[7] This section is intended to increase health care professionals' awareness of the information disseminated to women who may rely on religious leaders and religious communities for information, advice, and counselling regarding how to handle prenatal testing and subsequent selective abortion decisions. Some health care professionals rely on religious and cultural stereotypes when treating or counselling patients (Lewis 193-94; Mitchell and Georges 390; Taylor "Of Sonograms"). The research in this area, though limited, difficult to find, and scattered throughout the medical, bioethics, health law, and theological literature, underscores the importance of not attempting to predict a woman's testing decision based on general assumptions and stereotypes surrounding her religious affiliation. This chapter constitutes, to the best of my knowledge, the first sustained effort to provide a detailed, comparative analysis of various religious interpretations of prenatal diagnostic testing. Moreover, this section highlights the serious lack of attention paid to prenatal diagnostic testing by religious leaders and scholars over the last decade despite both the increased acceptance of prenatal testing and subsequent selective abortions by pregnant women and the continued advances in reproductive technology.

Patient profiling, however, is not only based on religion. Women's cultural and ethnic background, socio-economic status, level of education, and position on abortion are other characteristics that may lead some health care providers to jump to unfounded conclusions with respect to how a particular woman will proceed with prenatal care and prenatal testing. The second chapter of this project addresses a number of studies that sought to determine whether a woman's ethnic/cultural background, socio-economic status, level of education, position on abortion, and attitudes towards disability could accurately

predict whether she would undergo prenatal testing. However, many of these qualitative and quantitative studies offer contradictory conclusions. After analyzing these studies, one can conclude that although culture, financial situation, position on abortion and attitudes towards disability inevitably influence women's decisions, women's "real world" decision-making models regarding prenatal diagnostic testing often cannot be reduced to merely one characteristic. This chapter reveals the remarkable complexity of women's decision-making strategies with regards to prenatal testing and the danger of relying on generalizations rather than the specifics of each individual pregnant patient. Stereotypes and assumptions threaten the process of informed decision-making.

The final chapter of this dissertation focuses on the lived health care experiences of pregnant women (as obtained from other scholars' qualitative and quantitative research) and their reasons for accepting and refusing various prenatal screens and diagnostic tests. For many women, their motivations for testing might extend beyond their religious affiliation, cultural/ethnic background, or socio-economic status. Women's experiences are instrumental in illuminating the communication breakdown that often occurs within the health care setting. Among the issues discussed in this section are: how testing information is presented to pregnant women; women's motivations for accepting or refusing various prenatal tests; the psychological risks that accompany these procedures as a result of false-positive and false-negative diagnoses; structural obstacles that affect access and availability of prenatal testing services; the importance of obtaining women's informed consent or informed refusal prior to testing; and the issue of autonomous decision-making, focusing specifically on whether women have genuine choices when deciding whether to accept or

decline particular tests. In brief, this chapter provides a comprehensive review of the "ethical topography" of prenatal testing.

Prenatal screening and diagnostic testing is extremely common in North America and has been offered to women for decades. However, despite the popularity of prenatal tests many women are unaware of the diagnostic capabilities of these procedures. Often, health care professionals do not ensure that women are adequately informed of the disadvantages of testing. Many individuals may dismiss concerns surrounding prenatal tests, particularly MSAFP and ultrasound, as "no big deal" or "what's all the fuss" without truly appreciating the ethical issues that emerge. Pregnant women who accept tests, whether they were adequately informed or not, and receive negative diagnoses might view efforts devoted to improving the counselling process as ridiculous and unnecessary. However, pregnant women who accept testing without being properly informed and receive positive results will inevitably be shocked and distressed both upon receiving the positive diagnosis and being thrown into a process of whirlwind, not to mention unforeseen, decision-making. That they were not adequately informed will be, for many of these women and their partners, of considerable significance. Of course not all women will want to be bombarded with complicated information addressing hypothetical situations surrounding the health of their foetus. However, women should at least have the option to receive accurate and honest information from health care providers before embarking on the prenatal testing journey. Competent pregnant women cannot make informed, autonomous choices regarding their prenatal care, particularly concerning prenatal diagnosis, if they are not in possession of all relevant information, both medical and, if desired, religious, that might influence their reproductive decisions. Recognizing the problem of inadequate communication and the

persistent underestimation of health risks in prenatal diagnostic testing, this research project develops an argument in support of better communication amongst women, health care providers, and religious leaders as a prelude to more informed reproductive decision-making.

CHAPTER ONE: RELIGIOUS POSITIONS ON PRENATAL TESTING

Pregnant women openly adhering to a particular religious faith might unfortunately find themselves without options with respect to prenatal testing. Some clinicians, perhaps to expedite the prenatal care process or to conserve their time, inadvertently filter information disseminated to pregnant women based on commonly held, yet unfounded, assumptions and misconceptions surrounding the woman's religion, her interpretation of that religion, or both. Anecdotal evidence suggests that some genetic counsellors reserve briefer counselling sessions for non-English speaking, Catholic women (Lewis 193-94). The counsellors assume abortion will not be a consideration and therefore lengthy counselling sessions addressing the various prenatal tests are prematurely considered unnecessary (Lewis 193-93).

Educating health care professionals about the numerous variations and exceptions within different religions could help both improve communication within the counsellor-client relationship and increase understanding of the complexity of prenatal testing decision-making. The following chapter outlines Christian, Jewish, Muslim, Hindu, and Buddhist positions on prenatal testing. Also addressed are some women's personal responses to the official religious teachings and how official religious positions are factored into individual decisions. The available research in the area of religion and prenatal testing supports the argument that health care professionals ought not attempt to predict women's testing decisions based on general assumptions and stereotypes surrounding religious affiliation. Within each religious tradition different understandings of childbirth, abortion, and new reproductive technologies exist. Consequently, health care providers cannot draw

straightforward connections between a pregnant woman's religious affiliation and her attitudes towards particular tests. The paucity of recent information addressing religious positions on prenatal testing should also serve as an awakening for theologians and religious leaders. As reproductive technologies advance, women must make increasingly difficult decisions pertaining to their pregnancies. Women must feel confident that in the event they turn to their religious leaders for advice and guidance, their informants are not only aware of the latest religious teachings on the new reproductive technologies available, but also have a general understanding of the various genetic and congenital foetal anomalies for which prenatal tests screen.

CHRISTIANITY AND PRENATAL TESTING

Much of the Christian-based literature situates prenatal testing within the context of eugenics and an interference with God's role as creator. Prenatal testing is perceived by many Christians as the "new eugenics" (Meilaender, "Designing" 26)—a eugenics rooted in private choice rather than governmental dictate since the only "treatment" for most positive diagnoses is abortion (Meilaender, "Designing" 26). Meilaender maintains that "[s]elective abortion means selective acceptance. The unconditional character of parental love is replaced by choice, quality control, and an only conditional acceptance" ("Designing" 27). Christian parents are encouraged to love their future children unconditionally (Meilaender, "Designing" 27). According to Meilaender's interpretation of Christian doctrine, children are gifts from God and prenatal testing, perceived as attempts to control and alter these gifts, threatens to reduce children to mere products (Meilaender, "Between" 25). The Christian faith, Meilaender states,

> requires that we live without trying to secure our own future, [faith] needs to be joined with the virtue of hope. We must hope and expect that God can complete what is incomplete in our own strivings, especially when, in order to live justly, we refrain from achieving good that can be gotten only by evil means. (Meilaender, "Designing" 28)

Christians are invited to accept "the meaning of mortal life, the limits that must be endured—not because we are unable to transcend them, but because we ought not" (Meilaender, "Between" 26). Some Christians insist that prenatal testing places an added burden on parents—an inevitable burden as long as humans continue to view themselves as independent lifebearers as opposed to "human begetters" (Meilaender, "Mastering" 875):

> If [Christians] are not simply cooperators in and with a power greater than our own, we are the lifegivers, who bear responsibility for the quality of the life we give. If we merely cooperate with a power greater than our own, our task is to benefit as best we can the life this child has. When we become the lifegivers, we may be asked to decide whether it is a benefit to have such a life. (Meilaender, "Between" 28)

Meilaender shares Oliver O'Donovans "distinction between one who is *begotten* and one who is *made*. One whom we beget shares in our being, is equal in dignity to us. One whom we make has been distanced from us, become the product of our will, and we know how limitless that will can be" (Meilaender, "Mastering" 875). Other Christian theologians maintain that prenatal testing encourages abortion and should therefore be opposed (Press and Browner, "Characteristics" 434). Some Christian denominations, however, provide alternative understandings of the relevant issues and permit abortion and selective abortion as a last resort (Peters 1996: 1037). Regardless of the Christian denomination to which a woman subscribes, her reproductive decisions may contradict the teachings of her church.

Catholic Positions

The Catholic Church teaches that prenatal diagnosis is "morally licit" (Paul II 114) provided the tests are low risk both to the unborn child and the mother (Paul II 114). The sole purpose for undergoing testing must be to provide early intervention therapy, whether fetal surgery or emergency surgery/treatment at birth, in the event that a fetal anomaly is detected (Paul II 25, 114). Although the physical risks involved with amniocentesis have decreased, the available treatments for *in utero* and neonate therapy for genetic diseases remain quite limited.[8] Therefore, Catholicism prohibits amniocentesis unless the foetus in question stands to benefit from the procedure or if the foetus is at high risk for a genetic disorder (Ashley and O'Rourke 250). Pope John Paul II states, "When they [prenatal diagnostic techniques] do not involve disproportionate risks for the child and the mother, and are meant to make possible early therapy or even to favour a serene and informed acceptance of the child not yet born, these techniques are morally licit" (Paul II 114). Prenatal diagnostic testing for "eugenic" purposes, namely undergoing testing with the intention of aborting for fetal anomalies, is strictly prohibited (Paul II 114; Ashley and O'Rourke 249): "Such an attitude is shameful and utterly reprehensible, since it presumes to measure the value of a human life only within the parameters of "normality" and physical well-being" (Paul II 114). According to official Roman Catholic doctrine, Catholicism is "unconditionally pro-life" (Paul II 50) and induced abortions are considered "crimes against life" (Paul II 7), regardless of the circumstances (Brown 76).

Protestant Positions

Among the various Protestant denominations, differing opinions on the issue of prenatal testing emerge. Many of these views appear inextricably linked to the discussion of abortion, particularly selective abortion. The permissibility of prenatal testing for Protestant Christians often depends on whether the woman is testing with the intention of aborting positively diagnosed foetuses. Although some Protestant denominations allow for abortion in certain circumstances, foetal anomaly is rarely considered among the accepted exceptions for abortion. Religious responses to questions addressing prenatal testing and selective abortion will vary depending on the minister consulted. One must also note that a number of Protestant denominations have not clearly documented their positions on prenatal testing and selective abortion specifically. However, The Presbyterian Church (U.S.A.) and The Evangelical Lutheran Church in America offer some insight with respect to their positions on prenatal testing.

The Presbyterian Position

As with many other Christian denominations, Presbyterians are divided on the issue of abortion (Eisenberg and Schenker 42; The Presbyterian Church (U.S.A.)). As documented by the Presbyterian Church (U.S.A), although abortion is not the desired response to unwanted or problem pregnancies, the Church states that a woman's decision to undergo an abortion "can be a morally acceptable, though certainly not the only or required, decision" (The Presbyterian Church (U.S.A.)). Terminating pregnancies resulting from rape or incest are considered legitimate exceptions (The Presbyterian Church (U.S.A.)). Abortion is also justified if the pregnancy threatens the physical and/or mental health of the woman

(The Presbyterian Church (U.S.A.)). With respect to prenatal diagnostic testing, abortions might be justified if the tests report a positive diagnosis of "severe physical or mental deformity" (The Presbyterian Church (U.S.A.)). Based on the Presbyterian Church's position on abortion with respect to severely affected foetuses, one can deduce that prenatal testing, including amniocentesis and CVS, would be permissible. However, the Church holds that using prenatal testing techniques to engage in sex selection procedures is immoral and abhorrent (The Presbyterian Church (U.S.A.)).

The Lutheran Position

The Lutheran faith believes in the sanctity of life and insists that abortion only be considered as a last resort (Stuck, Faine, and Boldt 258; Evangelical Lutheran Church in America). Many Lutheran pastors favourably view the progress made in genetics as "advantageous to those involved" (Stuck, Faine, and Boldt 260). Although the Lutheran Church strives to protect the lives of the unborn, certain circumstances allow for induced abortion (Evangelical Lutheran Church in America). For instance, according to the Evangelical Lutheran Church in America's (ELCA) Social Statement on Abortion, abortion is considered "morally responsible in those cases in which continuation of a pregnancy presents a clear threat to the physical life of the woman" (Evangelical Lutheran Church in America). Also, abortion is permissible for pregnancies resulting from incest and rape (Evangelical Lutheran Church in America). When prenatal diagnostic tests reveal severe foetal abnormalities that will result in tremendous suffering and the premature death of the neonate, the Church states that parents, after consulting with medical professionals, can "responsibly choose to terminate the pregnancy" upon receiving positive diagnoses (Evangelical Lutheran Church in America).

Stuck, Faine, and Boldt's study examined Lutheran pastors' views of therapeutic abortion for genetic anomalies (Stuck, Faine, and Boldt 252). According to the ELCA abortion statement, the church is "committed to supporting those who face problematic pregnancies in ways that effectively address their immediate as well as long-term needs" (Stuck, Faine, and Boldt 252). Stuck, Faine, and Boldt's research found that pastors were more inclined to support a termination decision as the severity of a foetus' disease or condition increased (Stuck, Faine, and Boldt 255, 260). Lutherans are opposed to terminating a pregnancy if the future child has a possibility of living with the help of "reasonable and necessary" technology (Stuck, Faine, and Boldt 258). However, in the event that a woman decides to terminate an affected pregnancy the majority of ELCA pastors felt they should support the woman in her decision (Stuck, Faine, and Boldt 256-57).

ELCA pastors recognize the benefits of genetic counselling and are, themselves, eager to serve as an additional source of support for those pregnant women undergoing reproductive decisions (Stuck, Faine, and Boldt 260). However, despite their positive affirmation of genetic advances, their beliefs surrounding pregnancy termination vary tremendously (Stuck, Faine, and Boldt 260). Stuck, Faine, and Boldt's research further reinforces the observation that gross generalizations should not be made about religious understandings of prenatal testing and abortion.

Christianity and Preimplantation Diagnosis

Many Christian denominations seem to support preimplantation genetic diagnosis and gene therapy more than prenatal testing and selective abortion (Peters 1037). Although

a number of Christians prefer preimplantation diagnosis to prenatal testing, certain motivations for undergoing this process are not condoned. Specifically, using preimplantation diagnosis to ensure that the embryo's DNA matches the DNA of an existing child whose life needs saving violates the Christian tradition that ideally treats each person as an end in themselves rather than a means to an end (Veenker 18). However, the Catholic Church disapproves of *in vitro* fertilization (IVF) and deems this method of bearing children unethical based in part on the fact that IVF techniques separate the "procreative from the unitive purpose of marital act" (Ashley and O'Rourke 244, 246-47; Mackler 283). Therefore, one might infer that because preimplantation diagnosis requires IVF, the Roman Catholic Church would not condone this procedure. However, some Roman Catholic theologians permit IVF in certain situations provided the gametes used belong to the married couple seeking IVF (Mackler 283).

In a study conducted by Dorothy Wertz, out of the 476 working-class, predominantly Catholic women surveyed, 35% stated that preconception sex selection, ascertained through preimplantation diagnosis, should be available to everyone without restrictions (Wertz 36). 13% of the women felt that such procedures should be limited to families with three or more children of the same sex (Wertz 36). In a similar survey polling 988 women, 40% felt that pre-conception sex selection should be available to all women without any restrictions (Wertz 36). The varying positions on some of these issues, even amongst practicing Catholics, underscores the importance of discussing reproductive options with all pregnant women, regardless of their professed faith.

JUDAISM AND PRENATAL TESTING

Any attempt to develop a Jewish ethic in the area of reproduction is "at best an extrapolation from more fundamental Biblical teachings or norms bearing on human life" (Green 250). The essence of any proclaimed "Jewish" position stems from the *halakhic*, or legal, tradition (Green 251). Although an orthodox tradition, conservative and reform scholars also turn to the *halakhic* tradition for "moral guidance and inspiration" (Green 251). Jewish law does not offer one specific teaching on reproductive issues (Green 251). Rabbis will often offer different rulings on prenatal testing, selective abortion, and pre-implantation diagnosis, even if they are within the same Jewish denomination (Brown 75; Green 250). According to Green, the *Halakha* offers two orthodox positions on the subject of prenatal testing and selective abortion, one "stringent" (Green 251) and one "lenient" (Green 251). Green argues that although the majority of Jews adhere to the stringent interpretation, the lenient position more accurately represents the Biblical and Talmudic traditions (Green 252).

According to the Jewish Orthodox view on genetic testing, Jewish people have an obligation to procreate (Green 253; Mackler 277). Economic, emotional, and/or genetic conditions should not interfere with performing this religious responsibility (Green 253; Mackler 277). The stringent orthodox position holds that a couple's genetic constitution is not considered a valid reason to abstain from procreating (Green 253, 257). However, infertile couples are exempt from the latter mandate even though IVF is morally permissible within the Jewish tradition (Mackler 279, 286). Although traditional Jewish law does not grant the foetus full personhood status, the foetus is a "divine creation" and deserving of

societal protection (Mackler 287; Brown 76; Eisenberg and Schenker 42). Moreover, the orthodox view believes in the sanctity of all human life from the moment of conception (Green 258-60) and the *Halakha* does not condone abortion for fetal anomalies (Brown 78). Therefore, the stringent orthodox position adamantly opposes a liberal abortion policy even though abortion is not regarded as homicide.[9]

However, the health of the pregnant woman takes precedence over the health of the foetus (Brown 76; Eisenberg and Schenker 42). If the woman's health and overall well-being is threatened, an abortion is permitted provided both medical and rabbinical experts are consulted.[10] Stringent orthodox scholars believe that selective abortion of foetuses positively diagnosed with genetic conditions should be prohibited (Green 257). However, since a pregnant woman's physical, emotional, and mental health is considered, if the birth of a disabled child will cause the woman tremendous suffering, then selective abortion is permitted (Mackler 287; Green 257; Brown 76): "With certain notable exceptions, most *halakhic* authorities do consider psychiatric morbidity as a danger to life and may therefore permit termination of pregnancy should the mother's mental health be threatened" (Brown 76). Conversely, J.D. Bleich, an orthodox rabbi and *halakhic* authority, insists "The fear that a child may be born physically malformed or mentally deficient does not in itself justify recourse to abortion (qtd. in Brown 78).

Since prenatal testing often serves as a precursor to selective abortion, orthodox rabbis typically do not condone the use of such technological interventions (Steiner-Grossman and David 1360; Green 258). Moreover, Rabbi Immanuel Jakobovits insists that pregnant women should not terminate their pregnancies solely for genetic reasons given the

uncertainty of the prenatal tests and diagnoses (Green 257). Given the risk of false-positives and the inability of prenatal tests to diagnose the severity of the condition, women could conceivably abort unaffected or "minimally" affected foetuses (Green 257). Yet, even if prenatal tests could always yield 100% certain positive diagnoses, Rabbi Jakobovits maintains that abortion should be prohibited (Green 258).

Jewish law also interprets the belief in the sanctity of life from the perspective of therapeutic intervention geared towards restoring health (Green 255). Jews view technology as one of God's gifts and embrace medical technology and intervention without abandoning faith in God and divine providence (Rapp, Testing 155; Green 255). The *Halakha* permits the implementation of some therapeutic technologies to:

> prevent or cure genetic disease, whether these efforts are undertaken prior to conception, during uterine development or following birth. Efforts to use chemical or biological agents to alter genetic material in the germinal cells or embryo, efforts to provide replacement therapy in utero or beyond, and surgical correction of congenital anomalies are all permitted as being in conformity with the general talmudic encouragement to medical healing. (Green 256)

Prenatal testing is permitted, according to Jewish law, provided selective abortion for fetal anomalies does not occur (Brown 76). However, other orthodox scholars are opposed to amniocentesis unless the mother is unequivocally at risk (Green 258).

Once the dominant view within the Jewish community, the more lenient orthodox tradition is now the minority position (Green 260). Given this tradition's "reduced legal valuation of prenatal life" (Green 260), pregnancy termination is permitted for reasons other than maternal physical or psychiatric morbidity (Green 260). Eighteenth century Rabbi

Jacob Emden ruled, "in view of the reduced valuation of the fetus in Jewish law, abortion is permissible in any case of 'great need' on the mother's part. Her life, he argued, did not have to be in danger" (Green 265). This lenient orthodox view also allows for the abortion of full term foetuses if the mother's life is threatened (Green 261). Jewish proponents of the more lenient orthodox position maintain that the strict orthodox position on medical ethics has more to do with

> determining moral standards than with a strict legal analysis ... many conservative *halakhic* writers have actually justified rulings in ambiguous cases, by lamenting a decline in Jewish observance and by expressing the hope that Jewish morals will not be found wanting in any comparison with strict Protestant or Roman Catholic teaching. (Green 267)

Selective Abortion Permitted Prior to 40 days Gestation

Although different rabbis within the orthodox Jewish tradition have contrasting opinions with respect to selective abortion for genetic conditions, abortion is often permitted up to 40 days post conception (Wapner et al. 1133; Brown 77). Pregnancy termination is permitted after 40 days if the thought of bearing and raising a disabled child is causing the pregnant woman great emotional distress (Brown 77; Green 266). Rabbi Moshe Feinstein, however, maintains that abortion should never be permitted, even if the procedure takes place before 40 days gestation (Brown 77). Similarly, Rabbi Unterman, appointed Israel's Chief Rabbi in 1956, a position which he held until his death in 1976, stated that "the prohibition against taking life is not suspended to enable parents to have an easier life than they would otherwise have done had a severely disabled child been born" (Brown 77).

Conversely, Rabbi Waldenberg, a Judge of the Jerusalem Rabbinical Court, ruled that abortion for a serious disability was permitted provided that quickening (the moment when the foetus "announces itself to its mother" (Duden 80) and the woman becomes conscious of her pregnancy (Duden 80)) has not yet occurred and the procedure is enacted before the second trimester (Brown 77; Eisenberg and Schenker 42). Scholars who adhere to the more lenient orthodox position insist, "since the severely deformed fetus is not a viable life, aborting it in late pregnancy is not culpable under Jewish law" (Green 266). In instances where the foetus is diagnosed with Tay-Sachs, Waldenberg permits abortion up to 7 months gestation (Brown 78; Green 266). However, Rabbi Waldenberg also advises couples against undergoing amniocentesis unless the pregnant woman is older or has previously given birth to a child with an anomaly (Brown 77). Waldenberg cautions against selective abortion and insists that couples seek rabbinical advice prior to acting on positive diagnoses (Brown 77). A clear Jewish opinion regarding the MSAFP screen does not exist (Brown 78). Anencephalic foetuses are not considered "being[s] with a soul" (Brown 78) and, therefore, "[do] not have claim to our protection" (Brown 78). However, MSAFP also detects spina bifida foetuses, a condition not viewed as dire as anencephaly and the severity of the condition often remains unknown until birth (Brown 78).

Although many rabbinical authorities allow selective abortions prior to 40 days gestation, most prenatal tests occur after 40 days, leaving observant orthodox Jewish couples without reproductive options. Therefore, researchers have studied the effects of chorionic villus sampling (CVS) at less than 40 days gestation to provide Jewish couples with an opportunity to terminate affected pregnancies (Wapner et al. 1133). In the United States, CVS is usually performed after 10 weeks (70 days) gestation (Wapner et al. 1135). Wapner

et al.'s study concluded that experienced CVS technicians could "safely and reliably" (Wapner et al. 1133) execute the test at less than 8 weeks gestation (Wapner et al. 1133). However, CVS is two times more risky if performed before 10 weeks gestation (Wapner et al. 1133; Powell 45). Pregnancy loss increases two-fold and the risk of foetal limb reduction and facial malformations if the pregnancy is carried to term increases between 1%-2% (Wapner et al. 1133-1135; Powell 45; ACOG 6). Despite the aforementioned increased risk of early CVS testing, couples adhering to the orthodox Jewish faith often accept those risks in exchange for additional reproductive options (Wapner et al. 1133). Given the increased risk of early CVS testing, pregnant women who do not object to CVS testing after 70 days gestation, which provides the option of a first trimester abortion, are advised to undergo testing at the later date to reduce the possibility of foetal loss or foetal injury (Wapner et al. 1136). Since the difference between CVS at 7 weeks compared with 12 weeks is theologically critical for orthodox Jews, Wapner et al. maintain that pregnant women can ethically choose the riskier procedure of early prenatal testing for religious reasons provided informed consent is obtained (Wapner et al. 1136).

Judaism and Preimplantation Diagnosis

Judaism does not consider preimplantation diagnosis and selective embryo transfer more problematic than prenatal testing and selective abortion (Mackler 287). Since embryonic diagnoses occur by day three post-fertilization, embryos are discarded well before the 40-day demarcation line, a process preferred by many women as it avoids the abortion of a more developed foetus *in utero* (Mackler 287). Judaism considers the use of IVF, subsequent preimplantation diagnosis, and selective embryo transfer ethically

permissible for couples who wish to bear children without debilitating disorders (Mackler 288, 298). Corroborating the latter position, orthodox Rabbi Y. Zilberstein states:

> one cannot close the door in the face of despondent people who suffer mental anguish in fear of giving birth to sick children, pressure which can drive the mother mad. Therefore, in the case of a serious genetic disease that affects the couple, it is difficult to forbid the suggestion [for genetic testing through IVF]. (qtd. in Mackler 287-88)

Judaism also permits preimplantation diagnosis for sex linked genetic diseases (Mackler 288).

ISLAM AND PRENATAL TESTING

To arrive at a position on prenatal diagnostic testing, Islamic scholars and theologians, much like authorities within other religious traditions, first examine their theological texts. Muslims do not condone abortion given their respect for and commitment to protecting human life throughout all phases of human development (Alkuraya and Kilani 450). In 1990 the Islamic Jurisprudence Council declared a *Fatwa*, a religious ruling, legally permitting abortion before 120 days (17 weeks) gestation (Alkuraya and Kilani 450; Greeson, Veach, and LeRoy 361). However, the genetic tests must prove "beyond doubt" (Alkuraya and Kilani 450) that a given foetus is definitely affected with a severe and incurable anomaly that will compromise the lives of both the affected neonate and his or her family.[11] Once the 120th day has passed abortion is strictly prohibited, even if the foetus is affected with a genetic disorder (Ahmed et al. 378, 382). The Council based this ruling on the belief that Prophet Mohammed said ensoulment occurs at 120-days post-conception (Alkuraya and Kilani 450). After 120-days, "God sends an angel to [the embryo] with four

instructions. The angel is ordered to write the Sustenance, life span, deeds and whether eventually his lot is happiness or misery, then to blow the Spirit into him" (Alkuraya and Kilani 450). However, despite the Juriconsult and Islamic scholars' rulings permitting selective abortion before 120 days gestation, views on abortion prior to ensoulment still range greatly among the Islamic religious leaders (Ahmed et al. 382).

Although the Muslim Juriconsultants, both Sunni and Shiite, deemed abortion permissible prior to 120 days gestation, the general public in many Muslim countries are often uneducated, illiterate, and unaware of the Juriconsultant *Fatwa* rulings (Greeson, Veach, and LeRoy 361; Salihu 1036). Consequently, the Muslim masses follow the teachings of their Imams (religious leaders), many of whom, Hamisu Mohammed Salihu suggests, do not teach according to Islamic Juriconsultants' rulings (1036). Alkuraya and Kilani discovered in their research that most couples were unnaware of the *Fatwa* issued on abortion (449). Such ignorance is not surprising since many Imams are strictly opposed to pregnancy termination, including preimplantation diagnosis (Salihu 1036). Alkuraya and Kilani found, in their study of Saudi Arabian families, that an increase in *Fatwa* education lead to an increase in abortion acceptance but did not affect the prenatal diagnostic testing acceptance rates (Alkuraya and Kilani 449). However, some Muslims, despite having learned about the *Fatwa,* still oppose pregnancy termination (Alkuraya and Kilani 449). Religious convictions definitely shape some Muslims' decisions regarding prenatal testing and selective abortion (Alkuraya and Kilani 450; Zahed et al. 1110; Zahed and Bou-Dames 426). However, in Lebanon, a country comprised of Muslims and Christians, therapeutic abortions are prohibited under Lebanese law unless the pregnant woman's health is threatened (Zahed et al. 1109; Zahed and Bou-Dames 424). Yet, both social and therapeutic

abortions are privately performed on a regular basis (Zahed et al. 1109; Zahed and Bou-Dames 424).

Islam and Preimplantation Diagnosis

Preimplantation genetic diagnosis creates a welcome alternative to prenatal testing for some Muslims, as this procedure occurs months before ensoulment (El-Hashemite 223). Islam permits IVF provided that the gametes are from the husband and wife seeking the treatment (Greeson, Veach, and LeRoy 361; El-Hashemite 223). Preimplantation diagnosis is deemed permissible by the Muslim Juriconsultants since this technique is considered a form of treatment and not an attempt to interfere with or modify Allah's creations (El-Hashemite 223). However, not all couples qualify for preimplantation diagnosis (Salihu 1036). The expense of this technique also acts as a barrier for many families.

HINDUISM AND PRENATAL TESTING

Hindus perceive procreation as the primary, though not sole, purpose of marriage ("Insight"). Conception, considered a Divine act, is the moment when a soul from the next world connects to this world (Coward and Sidhu 1168; "Insight"). The foetus is considered a person from the moment of conception (Coward and Sidhu 1168). Hindus' belief in rebirth means that "conception is the rebirth of a fully developed person who has many previous lives" (Coward and Sidhu 1168). Children are viewed as gifts from God and all stages of growth and development from conception to birth are considered "*sacred events, honoured by a ceremony, or samskara, marking these rites of passage*" ("Insight").

Abortion is strictly prohibited according to Hindu Scripture and tradition (Coward and Sidhu 1169; "Insight"). According to classical Hindu teachings, the "transmigration of consciousness occurs at conception" (Hughes and Keown 109). Therefore, all abortions, regardless of the stage of foetal development, incur "the karmic burden of killing" (Hughes and Keown 109). However, exceptions are made when the pregnant woman's life is at risk (Coward and Sidhu 1169; "Insight"). Hinduism does not condone selective abortions for actual or potential genetic anomalies, whether physical or mental, "for each birth, normal or not, is revered as having a divine purpose to be understood, not manipulated" ("Insight"). Therefore, one might legitimately infer that prenatal genetic testing is not condoned if the intention is to abort positively diagnosed foetuses. However, many Hindus, particularly in rural communities, prefer sons to daughters (Coward and Sidhu 1170). Consequently, "the religious prohibition of abortion is sometimes at odds with the cultural preference for sons" (Coward and Sidhu 1170).

Hinduism and Preimplantation Diagnosis

Many Hindus consider preimplantation diagnosis a more acceptable means of determining foetal sex (Malpani, Malpani, and Modi 12). Preimplantation diagnosis bypasses the prenatal testing and sex selection abortion procedures deemed "unethical," not to mention illegal, in some countries (Malpani, Malpani, and Modi 12).

BUDDHISM AND PRENATAL TESTING

Although abortion is perceived as a "violation of the First Precept against taking life" (Barnhart, sect. 2) and the Buddhist tradition is predominantly opposed to abortion,

Buddhists are divided on the issue (Barnhart, sect. 1; Hughes 185). Western and Japanese Buddhists permit abortion in certain circumstances while other, perhaps more traditional, Buddhists prohibit the practice, perceiving abortion as murder (Hughes 183; Barnhart, sect. 1). The ancient Theravada texts are most frequently cited to support the anti-abortion position (Barnhart, sect. 1 and 2). The more lenient Buddhist views surrounding the abortion controversy stem from Mahāyāna traditions (Barnhart, sect. 1). However, James Hughes writes that the "classical Buddhist texts, from the Pali canon through the Mahāyāna *sūtras*, offer no specific guidance" on the issue of abortion (Hughes 183). Amidst the various Buddhist positions, Barnhart maintains that one can decide to have an abortion without violating fundamental Buddhist principles (Barnhart, sect. 1). Although the early Buddhist scriptures emphasize the value of life, they do not expressly espouse the position that "'individual life begins at conception'" (Barnhart, sect. 2). According to Hughes, however, Buddhism "adopted classical Hindu teachings that the transmigration of consciousness occurs at conception, and therefore that all abortion incurs the karmic burden of killing" (185).

Buddhism's emphasis on compassionate action is often appealed to in arguments supporting abortion: "if one's intention is not so much to end a life as to rescue others, then we are not dealing with a simple case of intentional killing. In other words, compassionate action will always involve weighing up the full range of circumstances that bear on a situation or action" (Barnhart, sect. 3). Keown also states that Buddhism would accept aborting a foetus to save the life of the mother as an exception to the general anti-abortion sentiment (Barnhart, sect. 2).

Buddhist ethics is often divided into three categories, absolutist, utilitarian, and virtue-oriented, each of which generates a different response to whether abortion is ever justified (Hughes and Keown 109; Hughes 186). Buddhist absolutists maintain that abortion is never justified and bad karma will ensue if one chooses to undergo an abortion (Hughes and Keown 109). Utilitarian Buddhist ethics, an ethic adopted primarily by Western Buddhists, states that "the Buddhist should seek the greatest happiness for the greatest number" (Hughes 186). Consequently, abortion can be considered a compassionate action with good karmic consequences in some circumstance if the suffering of all parties involved is mitigated as a result (Hughes and Keown 109-110; Hughes 186). Among conditions evaluated are the sufferings of mothers who give birth to unwanted children versus the alternative suffering of undergoing an abortion (Hughes 186). Also weighed are the sufferings of children knowing they are unwanted versus the alternative "suffering" incurred as a foetus being aborted (Hughes 186). Even the societal state and general population is taken into account (Hughes and Keown 110). If the mother's life is threatened and/or the foetus is having an adverse effect on her health, an abortion would be permitted (Hughes 186). According to a utilitarian Buddhist ethic, abortions are considered ethical if children will be born with disabilities (Hughes 186). Though not expressly stated, one might infer that Buddhists adhering to a utilitarian ethic would most likely support prenatal testing to assess the physical status of the pregnant women and their foetuses to enable couples to assess the potential sufferings for all involved.

Finally, Buddhist virtue-oriented ethics assesses the "intentions and psychological state of the actor as determining the morality and karmic consequences of an act. In this case the mental attitude and motivations of the pregnant women and her collaborators would

determine the ethics of abortion" (Hughes 188). The mindset of the women both at the time of conception and during her decision-making process regarding abortion is crucial (Hughes 188). For instance, "aborting a fetus conceived without an effort at contraception or without serious moral reflection would be more karmically significant ... than an abortion necessitated in spite of contraception" (Hughes 189).

PREGNANT WOMEN AND THE INFLUENCE OF RELIGION ON THEIR REPRODUCTIVE DECISIONS

Various studies have attempted to ascertain the extent of religious influence on the reproductive decision-making processes of pregnant women. Press and Browner concluded that religion was not an accurate predictor of prenatal testing ("Characteristics" 438). Even though women who claim to adhere to a particular religious faith might be more inclined to refuse testing (Press and Browner, "Characteristics" 438-39), there are other pregnant women who, despite their devout faith and personal vow never to abort, undergo prenatal testing and do not put, as one woman stated, "all [their] trust in God" (Browner and Preloran, "Latinas" 361-62, 364).

Given the gross assumptions made about Catholic women, one might note that Catholic women are just as likely to avail themselves of prenatal testing and abortion services as non-Catholic women (Wapner et al. 1133; Rapp, Testing 252): "Indeed, national and regional surveys suggest that Catholic women obtain about 32% of all abortions in the U.S., a figure somewhat higher than their representation in the population at large" (Rapp, Testing 252). Also, Catholics and Protestants were just as likely to refuse testing (Press and

Browner, "Characteristics" 438). Jewish women often maintain that if a woman has an amniocentesis then she is automatically going to abort if a positive diagnosis is reported (Rapp, Testing 223). According to Jewish mothers, the Jewish position is, as apprehended by Rapp through interviews with women from a variety of religious traditions, "Why not use the miracles of modern technology to make life better?" (qtd. in Rapp, Testing 157).

Although each religion has its own doctrine with respect to prenatal testing and selective abortion, "there is no definitive 'Catholic,' 'Jewish,' or 'Protestant' position on reproductive technology, when viewed from the pregnant women's point of view" (Rapp, Testing 159). Moreover, many women maintain that their position on prenatal testing reflects their own unique interpretation of religious doctrine rather than the Church's official stance on the issue (Rapp, Testing 159, 253). Similarly, that religious doctrine and cultural practices tend to diverge reinforces the position that a woman's religion is not always an accurate predictor of prenatal testing decisions.

CHAPTER TWO: SEARCHING FOR PATTERNS IN PREGNANT WOMEN'S DECISION-MAKING

Health care professionals do not always limit their patient profiling to a woman's religious affiliation. Race, class, ethnicity, socio-economic status, position on abortion, and even body weight, are among the criteria sometimes used to pigeonhole women. In a study conducted by Mitchell, sonographers were found to make a number of cultural assumptions. Women from certain ethnic backgrounds tended to respond to ultrasonography differently and consequently were depicted as either "impassive, unemotional, or overly interested in the 'wrong thing'" (Mitchell and Georges 390). Perceived maternal behaviour, as observed subjectively by the sonographer immediately prior to the ultrasound procedure, forecast the tone of the prenatal appointment. How much information pregnant women received from the ultrasound often depended on how the sonographer "felt" about the woman (Mitchell 151; Mitchell and Georges 390; Taylor "Of Sonograms"). Mitchell and Taylor noted that if the sonographer perceived the pregnant woman as one who cared for the health of her baby and was eating and behaving appropriately, she would receive a detailed account of the status of her foetus, possibly an ultrasound picture, and/or the foetal sex (Mitchell 151; Taylor "Of Sonograms"). In contrast, women who did not appear to make efforts to preserve their health, and by extension their foetuses' health, or seemed primarily interested with knowing the foetus' sex, would receive a terse, abridged account of the foetus' status from their sonographer (Mitchell 151; Taylor "Of Sonograms"). Women who confessed to having smoked during their pregnancy would be told, incorrectly, that smoke was visible within the placenta (Mitchell 151). Overweight women were often "reminded that their bodies hinder[ed] a thorough examination of the foetus" (Mitchell 151). Women "overly"

(Mitchell and Georges 390) eager to learn the sex of the foetus, especially East Asian and South Asian women, were frequently told that "Finding out the sex isn't important. The most important thing is that the baby is healthy" (qtd. in Mitchell 151). The assumption, particularly with Asian women, is that they only wanted male babies given the Asian culture's preference for sons (Mitchell and Georges 390). Black women and First Nations women also received little information during their ultrasound, as these women were sometimes assumed to be "unexcited, or unmoved, by the prospect of having a baby" (Mitchell and Georges 390). If sonographers' primary concern is to protect foetuses, they should give all of the women—whether or not they are regarded as "good mothers"—detailed feedback. Studies show that women who get comprehensive information from their sonographer throughout the ultrasound experience react more positively to the exam and suffer little, if any, emotional turmoil (Oakley 185).

Unfortunately, as demonstrated above, caregivers sometimes view pregnant women as representative of particular stereotypes rather than unique individuals with concerns and needs specific to their life situation independent from specific group memberships. Qualitative studies have also documented incidences of overt discrimination during ultrasound screens and genetic counselling appointments. Of course not all health care providers participate in such reductionistic behaviour. However, all health care professionals must realize that women's "real world" decision-making models regarding prenatal testing extend for many beyond both religious beliefs and rational actor models that posit straightforward calculations of risks and benefits.

Various research projects have attempted to determine which factors will most likely influence women's testing decisions. A pregnant woman's class, socio-economic status, culture and ethnicity, and/or position on abortion are among the characteristics explored. However, the research findings are generally inconclusive and contradictory. They emphasize the importance of not making assumptions based on stereotypes. Moreover, one must consider the predictive limits of such studies, particularly sample size, the limited number of studies conducted, geographical location, accessibility and availability of prenatal tests, and the regional politics surrounding particular reproductive issues. This chapter outlines various studies designed to ascertain decision-making patterns among certain "types" of women and questions whether such endeavours are beneficial in terms of improving the health care and counselling of pregnant women.

THE DICHOTOMY BETWEEN RELIGIOUS TEACHINGS AND CULTURAL PRACTICES

Although some health care professionals might adopt certain religious stereotypes into their thinking, cultural assumptions are equally common. However, in many cases pregnant women profess religious beliefs that do not coincide with their cultural practices. Religious teachings and the cultural practices of women adhering to such teachings are often incongruous, particularly in countries where sons are highly coveted. A number of countries have adopted modern sex-selection technologies to replace their more traditional methods, which include evaluations of the time of conception, physiological and emotional characteristics, and food preferences (Khanna 174, 178; Malpani, Malpani, and Modi 11). However, article 14 of the Council of Europe's convention on Human Rights and

Biomedicine states, "The use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided" (qtd. in Dickens 335).

Despite the strict opposition to abortion outlined by Hindu scriptures and teachings and the specific conditions that must exist for abortion to be permissible within the Islamic faith, prenatal testing and selective abortions are highly sought after throughout India. Prenatal testing became available in India in the 1970s and was initially portrayed as a means through which a woman could reduce the likelihood of genetic anomalies (Rajan, "Will India's"). However, the sexing capabilities of these tests were soon realized and consequently prenatal testing became used primarily for discovering foetal sex (Rajan, "Will India's"). As a result of prenatal testing and sex selection abortion, female feticide grew rampant in India, the impetus for the Indian government's ban on the utilization of prenatal tests for sex selection purposes in 1994.[12] The *Prenatal Diagnostic Techniques (Regulation and Prevention of Misuse) Act* designed in 1994 was enacted officially in 1996.[13]

The law banning prenatal testing to ascertain foetal sex also made advertising these tests as sex selection tools illegal (Khanna 179; Rajan, "Will India's"). In the event that prenatal testing is used, foetal sex must not be revealed to the pregnant woman or her family (Khanna 179). Doctors who perform the tests for sexing purposes, relatives who encourage the tests, and women who undergo the tests, all risk fines and/or imprisonment and physicians also risk having their license suspended (Khanna 179; Rajan, "Will India's"). Nevertheless, these tests continue to be advertised (Rajan, "Will India's"). Women continue to seek prenatal tests and selective abortions and physicians continue to provide testing and

sex selection abortions for substantial sums of money (Singh 32; Khanna 179; Rajan, "Will India's"). Criminalizing prenatal diagnosis has not succeeded in decreasing the use of these tests. Rather, the ban has simply pushed the once hygienic clinics underground and out of urban areas (Khanna 179; Rajan, "Will India's"). Testing costs have also increased dramatically given the added risks to all involved (Khanna 179; Rajan, "Will India's"). Women maintain that the ban has only increased the difficulty of acquiring testing but will not succeed in obliterating the practice (Khanna 179), for "if people are convinced that the law is not for their welfare they are going to find ways of disobeying it" (qtd. in Rajan, "Will India's"). Enforcing this ban is difficult given the overwhelming support for sex selection testing and selective abortion (Rajan, "Will India's"; Akkara, "Churches"). Rendering sex selection testing and selective abortion illegal is argued by many to be a useless endeavour, as the problem of female feticide is embedded deep within the patriarchal social structure of India's Hindi and Muslim communities (Rajan, "Will India's").

Since testing for sex selection purposes is illegal, obtaining accurate statistics regarding the prevalence of these prenatal testing practices is difficult given that all involved operate in secrecy, records are not kept, and occurrence is underreported (Khanna 172, 177, 179). In the past, jeopardizing the health and safety of the pregnant woman by subjecting her to an abortion for a suspected female foetus was considered socially reprehensible in some communities and stigmatization would inevitably ensue (Khanna 174, 178). Today, however, the risks of late-term and repeated abortions for women, including haemorrhaging, reproductive tract infections, anaemia, and the inability to carry future pregnancies to term, are often outweighed by the prospect of bearing a son (Khanna 178; Rajan, "Will India's"). Although women are supposed to be informed of the potential risks and side effects that

accompany prenatal diagnostic testing, most women remain uninformed (Khanna 178-79). Moreover, women generally have little, if any, control over reproductive decisions (Khanna 178).

Female foeticide is also extremely common in Asia, and statistics approximate that several million female foetuses have been aborted over the past two decades (Miller 1083). New reproductive technologies are well received in China given their culture's general preference for sons (Chan et al. 426; Wong and Ho 393). The One Child Policy mandate in China has inevitably had an impact upon sex selection technologies (Chan et al. 426; Wong and Ho 395). This policy, coupled with the desire to bear sons, drives many Chinese women to seek sex selection for their first pregnancy (Wong and Ho 395). Japan is also familiar with sex selection technologies and abortion is relatively common.

Women in a number of patriarchal countries are expected to obey dutifully the reproductive decisions made by their husbands and family members (Khanna 178). Although seemingly subservient, some women do resist and contest their family's orders and refuse both prenatal diagnostic testing and sex selection abortions (Khanna 178). Therefore, health care professionals caring for and counselling pregnant immigrant women, should never pre-judge or assume that these women intend to uphold either their homeland's cultural or religious norms.

CULTURAL AND ETHNIC VIEWS OF DISABILITY INFLUENCES PRENATAL TESTING DECISIONS

How communities view both disability and mothers who give birth to disabled children influences some pregnant women's decisions regarding prenatal testing, especially if that community is not accepting of disabled children (Rapp, Testing 285). Different cultures vary in their acceptance of disabled people. Therefore, some women might make their prenatal testing decisions according to how they feel their community will respond both to them and their future handicapped child in the event they refuse prenatal testing. Although people with physical or mental disabilities are sometimes stigmatized in many cultures, not all people within these cultures share the views of the perceived majority.

Marriage connections are extremely important in many countries and communities. A family's connection to disability can potentially ruin marriage prospects for family members, as disabilities and genetic conditions are often assumed to be hereditary (Mitchell and Georges 397; Durosinmi et al. 434). For example, in Greece and Nigeria individuals with physical disabilities are often highly stigmatized and marriage contracts, particularly in Nigeria, are terminated if background checks into family histories yield undesirable medical information (Mitchell and Georges 397; Durosinmi et al. 434). Consequently, Greece has a very high abortion rate surpassing that of North America (Mitchell and Georges 400). In Nigeria, although prenatal diagnostic testing is accepted (despite the lack of access to the services), the risks associated with abortion coupled with women's religious convictions often outweigh the cultural alienation that might accompany the birth of a child with a disability (Durosinmi et al. 434-35). Also, Nigerian women's social status is typically defined by their fertility (Durosinmi et al. 434). Therefore, despite the cultural emphasis

placed on perfection, some Nigerian women refuse to abort affected foetuses out of fear they will not be able to conceive in the future (Durosinmi et al. 435). Nigerian women who give birth to children with disabilities might find themselves ostracized not only by their community but also by their husbands (Durosinmi et al. 434): "in a society where polygyny is rife...a man can abandon the woman who bears him 'problem' children" (Durosinmi et al. 435).

Similarly, in some orthodox Jewish communities where marriages are often prearranged, families with handicapped members are stigmatized, especially families suffering from a history of mental handicaps (Rapp, Testing 284). Judaism places great emphasis on religious literacy and the reading of the Torah is considered a "survival strategy" (Rapp, Testing 284). Consequently, some Jewish families perceive children with mental handicaps as a threat to their family's survival (Rapp, Testing 284). As one Jewish mother commented to Rapp, "Jewish people don't accept mental retardation" (qtd. in Testing 275). Consequently, some Orthodox families living in the United States have been known to send their Down syndrome babies to Canada and Israel to evade this social scrutiny (Rapp, Testing 284). Other Jewish families, however, keep all their children together, as they perceive mentally handicapped children as "gifts" bearing possibilities for enlightenment (Rapp, Testing 284).

Several studies suggest that Chinese and Latino families also commonly focus on survival mechanisms and therefore have difficulty accepting children with handicaps. Chinese culture tends to emphasize academic achievement among their primary survival tactics, rendering children born with cognitive disabilities difficult to accept (Rapp, Testing

284). Some recent Latino immigrants also report that disabled children are "an impediment to survival in a new homeland" (Rapp, Testing 308). Jewish and Chinese families tend either to abort or put up for adoption foetuses and neonates diagnosed with Down syndrome (Rapp, Testing 284). Latina women on the other hand, despite their view of disability, were two times more likely than European-American women to refuse amniocentesis (Browner and Preloran, "*Para*" 379; Press and Browner, "Characteristics" 427). However, Browner and Preloran confess they are not certain whether similar results could be replicated in a larger study ("Para" 379).

Somalians, in contrast, tend to have a different view of disability. Somalians allegedly possess a welcoming attitude towards people with disabilities. Family is of the utmost importance to many Somalians and the threat of disability does not influence their reproductive decisions (Greeson, Veach, and LeRoy 359). Greeson, Veach and LeRoy conducted a study involving Somali immigrants to ascertain whether traditional genetic counselling sessions would benefit them or if modifications to the North American counselling approach would need to be made to serve Somali immigrants (Greeson, Veach, and LeRoy 361). Somali culture greatly values fertility and most women rely on Allah for their reproductive fate (Greeson, Veach, and LeRoy 369). In this study, some Somali women maintained that preventing disabilities was not within their control (Greeson, Veach, and LeRoy 370). They believed Allah gave women disabled children as a test of their appreciation of God's gifts (Greeson, Veach, and LeRoy 370).

In theory, Somali culture offers tremendous emotional support to those people within their community afflicted with disabilities (Greeson, Veach, and LeRoy 372). Institutions

for the handicapped are considered deplorable and are, therefore, nonexistent in Somalia (Greeson, Veach, and LeRoy 366, 372). Family members care for disabled loved ones (Greeson, Veach, and LeRoy 371). Disabled people are allegedly not stigmatized (Greeson, Veach, and LeRoy 371). However, as with most cultures, one might notice a large discrepancy between theory and practice with regards to caring for and socially accepting people with disabilities (Greeson, Veach, and LeRoy 372). In fact, many people with disabilities are, in fact, ill-treated and neglected in Somalia (Greeson, Veach, and LeRoy 372). Also, given the added stress that disabled children place on their families, some Somali husbands and fathers abandon their wives and handicapped children (Greeson, Veach, and LeRoy 367).

Family and friends generally serve as tremendous support systems (Greeson, Veach, and LeRoy 361). However, Somali immigrants often must separate from one another during the immigration process and consequently they may not have family or friends nearby once they have resettled (Greeson, Veach, and LeRoy 362). Such a loss of familial support may make the care of disabled Somali immigrants more difficult, as communal ties are stretched or broken (Greeson, Veach, and LeRoy 372). Many Somali immigrants try to maintain their homeland values and cultural practices with regards to caring for the disabled (Greeson, Veach, and LeRoy 369-72). However, some Somali women expressed the belief that over time Somali immigrants' future reproductive practices and choices might reflect more Western views, including an openness to selective abortion for foetal anomaly (Greeson, Veach, and LeRoy 369-72).

IMMIGRANT WOMEN'S RESPONSES TO NORTH AMERICAN PRENATAL CARE PRACTICES

Immigrants to North America tend to bring with them their own ethnocultural views of medicine, medical procedures, and disability. Consequently immigrants are sometimes unwilling to adopt North American medical and cultural practices (Rapp, Testing 174). Amniocentesis is a procedure that many immigrants have a hard time accepting, especially at 35 years of age, for many countries usually only offer amniocentesis to women over 40 years old (Rapp, Testing 174). Studies focusing on Latina immigrants found that most pregnant women did not feel the need to know everything there is to know about the status of their foetus, at least not to the same extent as European-American women (Browner and Preloran, "*Para*" 377). Some Latina women refuse prenatal testing because they are confident in their ability to give birth to healthy children (Browner and Preloran, "*Para*" 369). Others do not see modern reproductive technologies as essential interventions (Browner and Preloran, "*Para*" 369). Some women declare that they "know" their foetus is developing normally based on the absence of pain, awareness of foetal activity, feelings similar to previous pregnancies, and an intuitive sense that they are carrying a healthy foetus (Browner and Preloran, "*Para*" 375). Also, some pregnant women appeal to their existing healthy children as evidence of their ability to bear healthy children (Browner and Preloran, "*Para*" 376). They consider healthy offspring sufficient justification for refusing prenatal tests (Browner and Preloran, "*Para*" 376). Some women decline further testing after receiving a positive MSAFP test result, not necessarily because they are aware of the high false-positive rate associated with MSAFP screens, but rather because "they saw nothing in their reproductive histories or current reproductive experiences to warrant the concern raised by providers" (Browner and Preloran, "*Para*" 376). Women confident in their ability to

bear healthy children are not worried about positive test results (Browner and Preloran, "*Para*" 376-77). They view test information as secondary in importance to their body signals and intuition (Browner and Preloran, "*Para*" 376-77). In continuing with the argument that managing prenatal care and prenatal testing according to stereotypes and general behaviour is dangerous, some Latina women in Browner and Preloran's study wanted to know the health of their foetus and agreed to prenatal testing, particularly if they had previously suffered reproductive health problems ("*Para*" 378).

However, misunderstandings also contribute to Mexican immigrants' refusals. Many women confuse MSAFP and amniocentesis or are convinced that MSAFP automatically leads to amniocentesis (Press and Browner, "Characteristics" 438). Others decline amniocentesis thinking, incorrectly, that the "[amniocentesis] needle is inserted through the navel" (Browner and Preloran, "*Para*" 375). However, existing confusion surrounding MSAFP and amniocentesis in addition to having skewed understandings of the procedures seemingly has more to do with a lack of, or at least poor, communication than cultural differences. Improved communication between obstetricians, genetic counsellors, and immigrant women coupled with efforts to ensure that pregnant immigrant women truly understand that which is explained to them (especially if English is not their first language) would inevitably decrease the number of prenatal test refusals based on misunderstandings, correlatively increasing reproductive options for many women.

Many immigrant women, including those from Mexico and Greece, accept prenatal tests because of their unquestioned faith in United States medicine (Browner and Preloran, "*Para*" 378; Mitchell and Georges 395). Greek women are similar to many North American

women in that they seek prenatal tests to feel reassured and to relieve the uncertainty of pregnancy (Mitchell and Georges 395). In fact, many pregnant Greek women no longer trust manual exams and prefer gaining access to what they perceive as the best technology has to offer: "The doctor needs to show that he's modern too. That is, some [doctors] will do an exam with a machine just because a woman will trust him more if he does" (Mitchell and Georges 395).

THE PREDICTIVE VALUE OF CLASS AND SOCIO-ECONOMIC STATUS

As with most studies seeking to determine predictors of prenatal testing decisions, the assessment of women's class and socio-economic status as influencing factors, measured through income and education levels (Press and Browner, "Characteristics" 435), reveals contradictory findings. Genetic counselling and prenatal diagnostic testing services were initially sought by middle- and upper-class Caucasian women (Greeson, Veach, and LeRoy 360). Today, women from cultural minorities and lower income brackets are now seeking genetic counselling and availing themselves of prenatal technologies at an increasingly rapid rate (Greeson, Veach, and LeRoy 360). However, Rapp and Hollander insist that such services remain a luxury of the privileged and women with higher socio-economic status are more likely to accept testing (Rapp, Testing 218; Hollander 2). Browner and Preloran found that poor ethnic minority and immigrant women are less likely to use new technological interventions to ascertain the status of their foetuses ("*Para*" 369). Yet, other studies indicate that household income is not an indication of test acceptance or refusal (Browner and Preloran, "*Para*" 372; Browner and Preloran, "Latinas" 358). Browner and Preloran propose that the limited use of new reproductive technologies by impoverished minority and

immigrant women can be explained simply: either these women are not offered the tests or they do not have access to the tests ("*Para*" 369).

Unfortunately some women are "forced" to refuse prenatal testing given certain social obstacles. Not all women have access to prenatal clinics and, therefore, many women, especially low-income women, are structurally rejected from making the decision to undergo testing (Rapp, "Refusing" 54). Seeking prenatal care too late in the pregnancy explains why many women do not get prenatal testing (Rapp, Testing 170; Rapp, "Refusing" 53; Greeson, Veach, and LeRoy 375). Some women only become aware that they are pregnant after the window of opportunity for the various prenatal tests has closed (Rapp, Testing 170; Rapp, "Refusing" 53; Greeson, Veach, and LeRoy 375). Language barriers, limited financial resources, and an overall lack of information, particularly for recent immigrants, also explains the low uptake of testing by minority and immigrant women (Rapp, Testing 172; Rapp, "Refusing" 54). A woman's inability to find and/or afford baby-sitters and transportation, bad weather, household commitments, and other daily stresses are among the obstacles that prevent some women from keeping their genetic counselling and prenatal testing appointments (Rapp, Testing 172; Rapp, "Refusing" 54). Also, many women cannot afford to take time off work to meet with their genetic counsellors prior to the diagnostic test and few can take an entire day off work following the test (Rapp, Testing 105, 172). Women are strongly urged to rest after amniocentesis or CVS, as most procedure related miscarriages occur within the first 24-48 hours following the procedure (Rapp, Testing 105). Institutional barriers also serve as obstacles to obtaining access to counselling services (Rapp, Testing 169-70; Rapp, "Refusing" 53; Press and Browner, "Why" 981). Press and Browner maintain "it is the characteristics of the different medical settings in

which the test is offered, and not differences among individual women or groups of women, which best explain this variation [of whether women accept or refuse testing]" ("Why" 981). Braving busy prenatal clinics and dismal-looking waiting rooms, conversing with intake nurses, often in the woman's second language, and being bombarded with complicated paperwork is often intimidating and frustrating for many pregnant women (Rapp, Testing 170-71; Rapp, "Refusing" 53).

Studies were also performed at the international level to ascertain the extent to which prenatal testing is used and whether such services are sought predominantly by the more affluent. In Lebanon, low socio-economic and education levels leads to low acceptance rates of prenatal testing (Zahed et al. 1109, 1112; Zahed and Bou-Dames 427). The cost and availability of the tests also influence test acceptance. In Lebanon, the cost of the prenatal tests exceeds the income of most Lebanese at risk for haemoglobinopathy (Zahed and Bou-Dames 427). In Nigeria, most women who could afford to travel overseas to benefit from prenatal diagnosis and selective abortion would do so; however, the current economic situation in Nigeria renders overseas travel in search of prenatal diagnosis impossible (Durosinmi et al. 434). Conversely, in some communities in India, prenatal testing is considered affordable as ultrasound and abortion services amount to less than one third of a family's monthly income (Khanna 178).

Given both the cost and time involved in undergoing prenatal testing, one might assume that a woman's socio-economic status would play a significant role in the decision to undergo prenatal diagnostic testing. According to studies performed by Press and Browner, no correlation between social class and test acceptance or test refusal was detected

(Press and Browner, "Characteristics" 437; Browner and Press, "The Normalization" 313). Rapp found that although working-class and working-poor Hispanic and African-American women agree to undergo amniocentesis, poorer pregnant women from ethnic minority backgrounds are generally more likely to refuse the testing (Testing 168-69; "Refusing" 51-52). In a study involving Latina women, Browner and Preloran found that low and working class Latina immigrant women make similar choices regarding prenatal testing as middle class European American women (Browner and Preloran, "Latinas" 354, 367). However, the researchers suggest that they make the same choices for different reasons (Browner and Preloran, "Latinas" 354, 367). For instance, the Latina women in the study considered their loyalty to their family, family experiences, and even supernatural phenomena such as curses when making reproduction decisions (Browner and Press, "Latinas" 355, 366). However, notwithstanding the role of cultural models and frameworks of understanding, women of all cultures usually consider a number of different issues prior to making testing decisions, including family and life history, though perhaps not necessarily supernatural phenomena. Recognizing that studies are small and often interview women of all classes who have access to testing, one must not forget that these studies do not and cannot represent all women of a certain class status.

One discovery related to class has to do with women consulting self-help books, internet sites, hotlines, and family members in an attempt to acquire as much knowledge as possible on pregnancy, prenatal care, and prenatal testing.[14] Middle class European-American women were found to be most likely to consult the aforementioned sources, including private physicians, while Latinas rely predominantly on the experiences of family, friends, neighbours, and even strangers (Browner and Preloran, "Latinas" 366-67; Rapp,

Testing 168). However, one might question whether such findings can wholly be related to class, as Latina women were found not to share the "must know everything" mentality assumed by North Americans.

Different levels of education will inevitably influence testing decisions if genetic counselling sessions are not tailored specifically to the information and language level needs of each client. Each pregnant woman enters the counselling relationship both with varying levels of knowledge surrounding prenatal testing issues and comprehension abilities. Adopting a uniform method of prenatal counselling that treats all pregnant women as intellectual equals is detrimental to all pregnant women. Although women's levels of education may theoretically serve as a relatively sound predictor of whether a woman accepts or refuses prenatal testing, health care professionals should never accept education as a definitive predictor in practice. Given the counselling services available and the alleged commitment by health care institutions to improve informed consent, a pregnant woman's lack of education and/or her failure to understand testing issues indicates an urgent need for improved counselling.

A PREGNANT WOMAN'S VIEW OF SELECTIVE ABORTION

A woman's "current age, age at first pregnancy, number of previous pregnancies, number of miscarriages, or number of live births" (Press and Browner, "Characteristics" 437) was not found to influence a woman's decision to undergo MSAFP testing (Press and Browner, "Characteristics" 437). Even a woman's previous experiences with people with genetic and/or congenital conditions did not accurately forecast test uptake (Brookes 149).

However, women who had never had an abortion were more likely to refuse prenatal testing (Press and Browner, "Characteristics" 437-38; Hollander 2). Press and Browner found that women's abortion history was one of the best predictors for amniocentesis acceptance ("Characteristics" 437-38). Although a woman's history of abortion may serve as a predictor of test acceptance, a woman's stated position on abortion is less revealing.

Several studies suggest that a woman's stated position on abortion will not yield accurate test acceptance/refusal predictions.[15] Although a woman's opposition to abortion might partially or entirely account for her refusal to undergo testing, automatically assuming that women who agree to prenatal testing will terminate affected pregnancies is a false and widespread assumption (Press and Browner, "Characteristics" 437, 441; Browner and Preloran, "*Para*" 375). A number of research studies found that over half of the women who consented to amniocentesis had no intention of terminating their pregnancy, regardless of the diagnosis.[16] Many women reported difficulties getting diagnostic tests once they informed their health care provider that abortion would not be an option if the results returned positive: "I couldn't get this done, the amniocentesis, because it wasn't worth their while to do it" (qtd. in Brookes 39). Conversely, in Press and Browner's 1998 study, 60% of the women who refused the MSAFP test noted they could foresee certain circumstances that might lead them to terminate a pregnancy ("Characteristics" 440).

These studies reinforce the complexity of prenatal testing decision-making as few, if any, accurate predictors for prenatal testing exist. Brookes mentions that although culture, ethnicity, socio-economic status, view of disability, and stated position on abortion have proven inconclusive in terms of forecasting testing uptake, there are a number of other

potential prenatal testing predictors that have yet to be explored (Brookes 149). However, exploring them might not constitute the most productive research agenda. Many variables contribute to the decision-making process of all types of women and the variables often change with each pregnancy. Furthermore, identifying "standard" patterns in prenatal testing behaviour could actually compromise pregnant women's prenatal care experiences. One might think that understanding how women make decisions would be incredibly beneficial. Such knowledge could offer tremendous insight for health care professionals who may make unfounded assumptions about particular women given their religious affiliation, cultural background, or economic status, and in some cases might treat and/or counsel according to those assumptions. Dispelling existing misconceptions, assumptions, and stereotypes held by some health care professionals in North America would aid in the prenatal care received by a number of pregnant women. However, studies designed to ascertain prenatal testing predictors could conceivably continue the profiling of pregnant women by simply getting rid of old generalizations and substituting them with new ones.

Efforts to understand women according to various "categories" fails to view them as complex characters who cannot simply be reduced to one particular aspect of their lives. Realizing the complexity of prenatal decision-making should encourage health care professionals to adopt a person-centred approach to prenatal care and genetic counselling—an approach that appreciates individual differences and recognizes that information regarding prenatal testing should not be withheld simply because of alleged trends identified in prenatal decision-making. Women's actions with respect to prenatal testing and selective abortion may contradict their professed values and beliefs and may challenge family and community teachings. Generalized decision-making models and assumptions about culture,

ethnicity or social status should not serve as a substitute for understanding which external and internal factors affect each individual pregnant woman. Although certain trends in prenatal testing acceptance and refusal may exist, the health care of women who do not conform to these trends should not be compromised. Specifically, the inability to establish concrete predictors of prenatal testing reinforces the importance of implementing an approach to prenatal testing that recognizes the individuality of decision-making experiences. Decision-making unfolds over time, often involves considerable uncertainty, and typically takes many different and unpredictable factors into account. Understanding that each pregnant woman will have her own personal reasons for accepting or refusing prenatal testing is crucial to ensuring that health care institutions, health care practitioners, and religious leaders meet the health care and counselling needs of each pregnant woman.

CHAPTER THREE: THE HEALTH CARE EXPERIENCES OF PREGNANT WOMEN REVEAL COMMUNICATION WEAKNESSES IN THE PRENATAL COUNSELLING PROCESS

Pregnant women typically want to do everything in their power to ensure that they bear healthy children. Seeking prenatal care in a timely fashion, abstaining from caffeine, alcohol, nicotine, and other drugs, and monitoring eating and exercise habits are among the responsibilities both imposed on and assumed by pregnant women. Prenatal screening and diagnostic testing are also commonly included on this list. Over the last ten years, prenatal screening and diagnostic testing have acquired the status of medical interventions that responsible expecting mothers must not refuse. Focusing this research on some of the most common prenatal tests, few women refuse MSAFP and ultrasound screens and increasing numbers of women request amniocentesis and CVS.[17] As noted in the previous chapter, efforts to establish which "types" of women opt for prenatal testing and which "types" of women resist the technological invasion of pregnancy are arguably futile. Each pregnant woman, regardless of her ethnicity, religious beliefs, or affiliations with larger communities and organizations, endeavours to make decisions with each pregnancy that best suit her unique life situation. For some women decision-making involves embracing their cultural and community norms and values. Other women are much less influenced by religious and cultural conventions. Although patterns of decision-making among pregnant women from specific religious, ethnic and social backgrounds are difficult to identify, the reasons why women accept or reject prenatal tests have been carefully documented and appear to be cross-cultural and widespread. This chapter addresses various motivations behind women's prenatal testing decisions and demonstrates how pregnant women's rationales indicate a

need for improvement in the way genetic and prenatal testing information is communicated to pregnant women to ensure that they make informed decisions.

WHY PREGNANT WOMEN ACCEPT PRENATAL TESTS

Pregnant women actively seek prenatal testing, especially amniocentesis, if they have a family history of genetic conditions and/or are from an ethnic group predisposed to certain genetic conditions (Tercyak et al. 74; ACOG 1, 5; Browner and Preloran, "*Para*" 373). Some pregnant women accept prenatal tests because they want to follow the recommendations of their physicians and comply with the standard prenatal care regimen (Browner and Press, "The Normalization" 319; Browner and Preloran, "*Para*" 377). MSAFP and ultrasonography are screens recommended by many obstetricians and gynaecologists and presented to pregnant women as a routine, necessary part of prenatal care, rather than a voluntary, optional screen.[18] If MSAFP is presented to women as a voluntary option it is usually strongly "recommended" (Press and Browner, "Why" 983; Press and Browner, "Risks"). Due to the way in which both MSAFP and ultrasonography are presented to many pregnant women, many are oblivious that they can refuse such procedures (Kohut, Dewey, and Love 270; Parens and Asch, "The disability"). One might argue that pregnant women accept MSAFP and ultrasound more readily than amniocentesis or CVS because these screens do not pose any known physiological risk to either the women or their foetuses. MSAFP and ultrasonography are considered safe, non-invasive, virtually risk-free procedures (Browner and Press, "The Normalization" 309, 312; Press and Browner, "Why" 980, 987; Markens, Browner, and Press 360). To many women, MSAFP

and ultrasound are ideal prenatal screens capable of reducing their risk of bearing children with genetic or congenital abnormalities.[19]

Most pregnant women want to satisfy their desire to know everything there is to know about the status and health of their developing foetus.[20] Equipped with information about the health of their foetuses, women feel empowered and in control of their reproductive options.[21] Prenatal testing enables women to explore their existing options in the event of a positive foetal diagnosis. Depending on the diagnosis, a woman can investigate intrauterine therapy or foetal surgery, arrange to have medical specialists on hand during the birth, prepare emotionally and financially for the birth of a special needs child, make arrangements for adoption, or opt for pregnancy termination.[22] Viewing prenatal testing as an opportunity to prepare practically and emotionally for the birth of a disabled child is quite common (Brookes 138). Some women tend to view prenatal diagnosis as an opportunity to ensure that they will be able to fulfil the needs of all individuals with whom they have intimate, caring, relationships (Brookes 138; Rapp, Testing 131). For instance, when faced with a positive diagnosis many women consider "the ethical impact of a positive diagnosis on themselves, other family members, and the fetus, while describing the limits of how they want to live" (Rapp, Testing 131). Such a relational response to prenatal testing adheres to Joan Tronto and Bernice Fisher's definition of caring. They write,

> On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web. (Tronto 103)

Women will frequently assess the strength of their relationships with others and determine whether pre-existing relationships will aid in their personal ability to care for a child with a disability (Brookes 138; Kvande 324). Women facing the reality that they might give birth to a disabled child consider their ability to care for themselves and their existing children (Brookes 143, 147-48). Some women, however, refuse testing because regardless of the disability they are confident that their future child will be loved and cared for within the family unit.

Press and Browner mention that undergoing testing to prepare oneself for the birth of a disabled child rather than testing to abort is an approach that "fits easily into an American cultural ideal that puts high value on advance preparation, [but] its utility in the case of prenatal diagnosis is assumed rather than examined" ("Why" 986). They suggest that no amount of preparation can ever truly prepare a woman, or couple, for a child with a disability ("Why" 986). The "testing to prepare" strategy is, according to these scholars, a marketing ploy adopted by health care providers ("Why" 986). However, a number of women interviewed in various studies stated that they would not consider selective abortion but wanted prenatal testing to prepare themselves (Brookes 138-39; Eisenberg and Schenker 37). Even Press and Browner's research quotes women who feel they need prenatal testing to prepare themselves for the future ("Why" 985-86). One might argue that even if women can never fully prepare themselves emotionally and psychologically for the birth of a handicapped child, they are more prepared after having undergone prenatal diagnosis than if they had declined this procedure. Undoubtedly some women do not thoroughly think through the consequences of having various prenatal tests, particularly MSAFP and ultrasound. Some health care providers might underscore all of the perceived benefits of

accepting prenatal tests, including the "testing to prepare" argument, while omitting the disadvantages. However, to make sweeping generalizations regarding the perceived futility of a woman's decision to test to prepare herself and her family arguably undermines women's decision-making processes and denies their ability to make circumstance-appropriate decisions.

The most frequently reported reason for consenting to undergo prenatal testing, especially among women considered at an elevated risk of bearing a child with a chromosomal abnormality, is the peace of mind and overall sense of reassurance that these prenatal tests provide.[23] Although many women face positive MSAFP results and inconclusive ultrasound screenings, most amniocentesis results are normal.[24] Eventually these tests reassure many expecting mothers that their foetuses are healthy. Undergoing prenatal testing also serves as a means for pregnant women to demonstrate to society that they are responsible women doing everything within their power to reduce their risk of bearing a child with a disability.[25]

What Reasons for Test Acceptance Reveal About How Information is Communicated

A number of the aforementioned reasons expressed for undergoing prenatal testing indicate certain problems in the way prenatal testing information is typically conveyed to pregnant women. For instance, that many women believe prenatal testing will reduce their risk of having a child with a disability or increase their risk of bearing a healthy child independent from abortion is problematic. Most of the disorders diagnosed prenatally can neither be treated nor cured.[26] Aborting affected foetuses is, in the vast majority of positive

diagnoses, the sole means of preventing the birth of a disabled child (Duden 76-77; Taylor "Of Sonograms"; Markens, Browner, and Press 360). Health care professionals must take care that pregnant women are not led to believe that prenatal diagnosis is the means through which foetal health is achieved and birth defects prevented.

Although MSAFP and ultrasonography are routinely practiced in North America, these screens are not mandatory procedures and should not be presented to women as such.[27] The Food and Drug Administration (FDA) approved "commercial kits" for MSAFP testing in 1983 (Madlon-Kay et al. 395). Consequently, in 1985 the American College of Obstetricians and Gynecologists' (ACOG) Department of Professional Liability issued an alert informing their members that it is "imperative that every prenatal patient be advised of the availability of this test and that your discussion about the test be documented in the patient's chart" (qtd. in Annas 17). The motivation for this warning was legally based as opposed to medically based (Annas 17). Dr. Keith C. White, Director of Fellowship Activities, responded to the 1985 MSAFP Alert stating, "The College [ACOG] has not and does not recommend routine screening of maternal serum for AFP..." (qtd. in Annas 18). In December 2002 the Emory Genetics Lab re-emphasized ACOG's position on MSAFP, namely that ACOG does not recommend MSAFP as the medical standard of care (Emory Genetics Laboratory, "Maternal Serum").

The American Academy of Pediatrics' (AAP) 1991 Policy Statement recommended a MSAFP guideline based on the model created by the American Society of Human Genetics. The Policy Statement reads:

> Prenatal MSAFP screening should be voluntary with informed consent obtained and documented. The provider should indicate its availability, educate the patient about its potential, and allow the patient to make decisions concerning participation in screening and the sequential steps in the management of pregnancies. If the patient decides not to have MSAFP screening, the decision should be recorded in some manner which may include the patient's written signature. (AAP Policy Statement, 1991)

In Canada, The College of Physicians and Surgeons of Manitoba insists that due to the complications that can accompany pregnancy, "*All pregnant women who present for early prenatal care should be offered maternal serum alpha-fetoprotein screening*" (The College of Physicians and Surgeons of Manitoba, "Alpha-Fetoprotein"). In North America health care practitioners are typically guided by their professional organizations to offer MSAFP to all of their obstetric patients, yet pregnant women are free to refuse this screen.

The concerns associated with MSAFP, as raised by anthropologists, sociologists, feminists, bioethicists, and physicians, address the risk of false-positives, increased maternal anxiety, and the lack of information presented to women prior to undergoing the screen. The MSAFP screen has a very high rate of false positives which often leads to an increase in maternal anxiety.[28] The high number of false-positives occurs because the screen is designed specifically to identify women who are actually carrying foetuses with genuine genetic or congenital conditions (ACOG 2; Holtzman 46). The predictive value of a positive MSAFP result is approximately 2% (Holtzman 46-47):

> 50 out of every 1,000 pregnant women who are *not* carrying an affected fetus will have a positive test result. If only 1 in 1,000 is carrying the affected fetus detectable by the test, then there would be 50 false positives for every true positive, giving a predictive value of a positive result of 2 percent. (Holtzman 46)

Press and Browner maintain that after all of the follow-up testing that accompanies positive MSAFP screens, only 0.1%-0.2% of pregnant women who undergo MSAFP will receive a positive diagnosis from amniocentesis (Press and Browner, "Why" 981). Given the high false-positive rate the possibility of terminating an unaffected pregnancy exists. However, if the follow-up tests are performed and interpreted correctly, the risk of aborting an unaffected foetus is less than 1 in 200 (Holtzman 47).

Despite the low predictive value of MSAFP and the various concerns related to this prenatal test, MSAFP is typically presented as a safe and "simple blood test" (Browner and Press, "The Normalization" 309, 312; Press and Browner, "Why" 981) and rarely discussed in relation to abortion (Markens, Browner, and Press 362; Press and Browner, "Why" 987). To make informed, considered, reproductive decisions, all competent, pregnant women must be educated on the diagnostic potential of MSAFP and the various anomalies for which this test screens. Women must also be informed that as a result of accepting the MSAFP screen, additional screens and diagnostic tests may be needed to confirm the diagnosis, potentially ending with the need for a decision regarding selective abortion for foetal anomaly.

Performing an ultrasound on every obstetric patient that presents for prenatal care is common practice throughout North America, yet highly controversial (Chervenak and Gabbe 124-25). Professional obstetric guidelines do not, for instance, condone routine ultrasounds in all pregnancies (Boyle 258). Rather, these guidelines recommend that ultrasounds "be performed only for specific indications because of the costs involved, potential risks, differences in the level of training among physicians and sonographers, and lack of evidence to indicate an improvement in perinatal outcome" (Boyle 258). ACOG, in

its recent Practice Pattern on routine ultrasound in low-risk pregnancies, states that despite the benefits of routine ultrasound at 18 weeks gestation, because routine ultrasounds in low risk women have neither demonstrated a decrease in perinatal morbidity or mortality nor reduced the use of "unnecessary interventions," ultrasonography should only be performed in low risk pregnancies if specific indications exist (Chervenak and Gabbe 128).

The Institute for Clinical Systems Improvement (ICSI) Technology Assessment Report, a United States "safety and efficacy" (ICSI 4) report approved in October 2002, concluded that although the ultrasound screen is safe, existing risks of false-positive and false-negative diagnoses should not escape unexamined (ICSI 4). A number of recent controlled trials involving ultrasound screening found that routine ultrasounds prior to 24 weeks gestation did not "reduce perinatal mortality" (ICSI 4) and routine ultrasounds post 24 weeks gestation neither "reduce[d] perinatal mortality [n]or morbidity" (ICSI 4). Ultrasounds before 24 weeks gestation aid physicians in monitoring foetal growth and development to prevent pre- or post-term deliveries, detecting multiple pregnancies, identifying high-risk pregnancies that might require a caesarean section, and detecting foetal anomalies.[29] Ultrasonography also facilitates and improves the safety of diagnostic testing procedures such as amniocentesis and CVS (Boyle 257).

In 1993, the Society of Obstetricians and Gynaecology of Canada recommended that women routinely receive one prenatal ultrasound in their second trimester of pregnancy (Anderson 9). The Guidelines Advisory Committee (GAC) in Canada, a committee dedicated to providing physicians with the best guidelines available on any given medical topic, adopted the ultrasound guidelines developed by the Canadian Task Force in March

1994 (GAC). As of March 2002, one ultrasound performed on healthy pregnant women with low-risk pregnancies during the second trimester is considered "fair evidence to recommend" (GAC):

> A single screen has been associated with higher birth weights in singletons, earlier detection of twins, lower rates of inductions (presumably through better estimates of gestational age), and increased rates of therapeutic abortion for fetal abnormalities. However, such screening has no statistically significant effect on live births or Apgar scores. (GAC)

Ultrasonography successfully identifies genuine complications in some women, thereby giving obstetricians an opportunity to gauge the pregnancy and labour accordingly to decrease maternal and perinatal morbidity (Oakley 285). However, acknowledging that some women truly benefit from ultrasonography does not necessarily justify the uninformed routine screening of virtually all pregnant women who are often ignorant of the implications and ramifications of their decisions (Oakley 285). For instance, not all women are aware of the diagnostic capabilities of ultrasound, especially first trimester ultrasounds.[30] Consequently, many women do not necessarily associate ultrasound with future selective abortion decision-making.[31] Regardless of the benefits ultrasonography offers, if women are not fully informed of the purpose, goals, and associated risks of ultrasound screening, and are not clear on their own motivations and objectives for undergoing screening, many women will be ill-equipped to handle positive diagnoses.

Studies indicate that health care professionals advocate prenatal screens and present the information in a manner that encourages test acceptance (Madlon-Kay et al. 399; Browner and Press, "The Normalization" 315; Press and Browner, "Why" 986). Pregnant women are usually only provided with the MSAFP and ultrasound basics.[32] The

information focuses predominantly on the technical nature of the screens rather than their diagnostic potential or the various anomalies for which they are screening.[33] Most foetal anomalies detected via ultrasound occur in pregnant women, who are often unaware of their risk of bearing a child with a birth defect and unaware of ultrasonography's diagnostic role, undergoing the screening for another indication.[34] Also, approximately 95% of babies with genetic conditions are born to parents without a family history of genetic or congenital anomalies (Holtzman 46). That some women are shocked upon learning of their risk as a result of receiving a positive diagnosis highlights the urgency of improving the quantity and/or quality of the information given to pregnant women on prenatal screening procedures. Health care providers adamantly deny accusations that pregnant women are misinformed and/or poorly informed (Browner and Press, "The Normalization" 314). Efforts directed towards unearthing the crux of the discrepancy between what physicians claim to tell pregnant women regarding the various prenatal procedures and the lived experiences of pregnant women could play an important role in improving physician-pregnant woman communication.

Since information given is not always information received, health care providers should ensure that pregnant women fully understand that false-positive results are not uncommon with MSAFP and ultrasonography.[35] Given that ultrasounds are sometimes inconclusive, invasive diagnostic procedures might be necessary to ascertain a foetal diagnosis (Chervenak and Gabbe 127). Moreover, ultrasounds can and do yield inaccurate information and can lead to unexpectedly arduous labours and/or miscalculations with regards to foetal size and health (Mitchell 155; Institute of Medicine 78; Thompson, Freake, and Worrall 312). Pregnant women should also understand the uncertainty that accompanies

prenatal testing causes adverse psychological effects in many women (Oakley 183; Institute of Medicine 78-79; Hall 336).

The psychological effects/ "risks" of MSAFP and ultrasound are often disregarded in discussions surrounding these screens, as they are non-invasive and do not pose any known physical risks. However, the psychological effects of these screens and diagnostic tests are potentially debilitating for many women. Pregnant women's anxiety and stress levels rise around the time of the prenatal test, while awaiting test results, and during the disclosure of the results.[36] Although younger women's anxieties tend to dispel once the tests, particularly amniocentesis and CVS, have been completed successfully, women over the age of 35 generally remain anxious until they receive their test results (Lerman et al. 785-86; Tercyak et al. 74). Often additional stress and worry ensues upon learning the test results given the possibility of a false-positive or false-negative diagnosis.[37] Positive results lead to additional screens and diagnostic tests (Holtzman 47; Wolf 35; Hall 336). Subsequent tests can generate more stress, anxiety, and physical risk.[38] More than MSAFP or ultrasound, women fear the risk of miscarriage, foetal injury and other complications that can accompany amniocentesis and CVS, not to mention the dreaded possibility that a decision might need to be made regarding pregnancy termination.[39] Although prenatal tests increase anxiety, studies "provide no evidence for sustained or clinically significant psychological distress" (Lerman et al. 786).

Despite the added anxiety, emotional turmoil, and various complications prenatal tests tend to inflict on some pregnant women, Rapp found that 95% of pregnant women who had undergone amniocentesis were "glad" they had the testing (Testing 116). The

disadvantages are outweighed for many women by the reassurance they feel these prenatal tests bring. Lippman insists that only the women who receive the negative test results are reassured ("Prenatal Genetic" 23). This sense of being reassured is misleading because some genetic and congenital conditions can go undetected and many only present after birth.[40] Some pregnant mothers raising children with disabilities are quite sceptical of prenatal testing. They recognize only a small percentage of diseases can be detected and, therefore, do not find the tests remotely reassuring (Rapp, Testing 173; Rapp, "Refusing" 58). Couples should be informed, and understand, that even if they undergo prenatal testing, they still have a 3% chance of delivering a child with a genetic disease or congenital disorder (ICSI 4; Eisenberg and Schenker 39).

Much of what can be detected is contingent on the quality of the ultrasound equipment, the length of time dedicated to each screen, and the skill of the sonographer performing the scan (Whittle et al., "Ultrasound"). However, other conditions are overlooked because the screen or diagnostic test is not "perfectly sensitive" (Holtzman 42). Some scholars, however, appreciate how some women find reassurance through testing. Women who undergo ultrasonography, for example, are often reassured that they actually are pregnant and that their "sacrifices," with respect to adhering to strict diets and abstaining from harmful substances, have not been in vain.[41] Also, women who do not want children with genetic or congenital anomalies might also be reassured knowing selective abortion, in the event of a positive diagnosis, is an option (Wertz and Fletcher 174; Rothman 28-29; Mitchell 146-47).

WHY PREGNANT WOMEN REFUSE PRENATAL TESTS

Some women refuse prenatal screens and diagnostic tests, even when these tests are presented as routine aspects of care (Wertz and Fletcher 76; Markens, Browner, and Press 360; Parens and Asch, "The disability rights"). Women who refuse these tests do so because they do not view the test as routine (Markens, Browner, and Press 360-365). Moreover, they are wary of the risks involved, including increased stress and anxiety, false-positive test results, invasive diagnostic tests, and subsequent decision-making (Markens, Browner, and Press 360-365).

Since few women are unaware of the direct relationship between diagnostic tests and selective abortion and the other physical risks posed by these procedures, many more women choose to refuse amniocentesis and CVS (Rapp, Testing 167). The main reason for women's refusals to undergo amniocentesis and CVS is because they fear the potential physiological ramifications of the procedure.[42] In particular, they fear the possibility of a miscarriage (Rapp, "Refusing" 50, 55; Rapp, Testing 98, 167, 172; Marteau et al. 395, 398, 400). Statistics documenting the frequency of amniocentesis-induced miscarriages vary, ranging from less than 0.5% (Rapp, Testing 29, 32; Kingston 1371) to as high as 1.7% (Eisenberg and Schenker 37): typically 1:200 result in miscarriage, although the overall estimated range is believed to be from 1:100 to 1: 500 (Lerman et al. 785; Tercyak et al. 74; Browner and Preloran, "Latinas" 368). Both the ACOG Practice Bulletin and the American Academy of Pediatrics' 1994 Policy Statement quotes the foetal loss rate secondary to amniocentesis at approximately 0.5% (ACOG 5; AAP Policy Statement, 1994).

The miscarriage rate following CVS is higher than that of amniocentesis.[43] Statistics, however, vary greatly. Estimates range from 0.5%-2% (Rapp, Testing 30; Eisenberg and Schenker 36; Himes, "Early") but can be anywhere from 2.6%-6.3% for women between the ages of 35 and 39 (Lerman et al. 785). Since CVS occurs during the first trimester of pregnancy, usually between 9-12 weeks gestation, ascertaining which pregnancy losses are procedure related and which are naturally induced is difficult to determine (ACOG 6; Himes, "Early"). However, according to Kingston the threat of miscarriage as a result of CVS is approximately 2% higher than spontaneous abortion during the first trimester (1371).

Other possible physiological complications from amniocentesis and CVS also serve as deterrents for many women. Complications from amniocentesis include amnionitis, which occurs in 0.1% of the cases, maternal mortality resulting from septic shock, which occurs 1:400 000, foetal injury, though this risk is minimized as a result of ultrasound, vaginal bleeding and amniotic fluid leakage (both of which occur in approximately 1-2% of all cases), cramping, and lower abdominal pain (Eisenberg and Schenker 37; ACOG 5; Browner and Preloran, "Latinas" 368). Additional risks surrounding CVS include foetal finger and toe malformations (Rapp, Testing 30; Himes, "Early"), foetal limb reduction, membrane ruptures, vaginal bleeding or spotting, and cramping (Eisenberg and Schenker 36; Himes, "Early"). The risk of limb reduction and facial disfigurement resulting from CVS increases substantially if performed earlier than 9 weeks gestation (ACOG 6; Powell 45). Determining causality of foetal limb defects is difficult because limb reduction and malformations can occur in children who were not exposed prenatally to CVS (Himes, "Early"). Women contemplating CVS, but concerned about the risk of foetal limb

malformations are informed that if CVS is performed after 9 menstrual weeks the risk of foetal malformations is low and "probably not higher than the general population risk" (ACOG 6). Although risks associated with amniocentesis and CVS are considered relatively low, women who have battled against infertility and suffered through previous miscarriages are often extremely fearful of amniocentesis and CVS (Rapp, Testing 172). These women sometimes refuse the test because they do not want to jeopardize the pregnancy or the safety of their foetus (Rapp, Testing 172).

Women also refuse amniocentesis because the procedure occurs between the 16th and 20th week gestation, a time when most pregnant women have already committed to the pregnancy.[44] However, some researchers suggest that amniocentesis delays commitment to the pregnancy and consequently delays maternal-foetal bonding because many women and their partners can neither commit nor bond until they receive normal test results (Himes, "Early"). Positive diagnoses require women to make rapid decisions regarding selective abortion. Many individuals consider selective abortion "ethically different" (Rapp, Testing 131) from non-selective abortion since a healthy child would have been kept (Rapp, Testing 131). Consequently, women have to confront and evaluate their own biases and stereotypes regarding life with a disability and life caring for a child with a disability (Rapp, Testing 131, 228). Also, late-term abortions require that women undergo emotionally and physically difficult labour processes.[45] Since amniocentesis occurs during the later stages of pregnancy, CVS, which is administered in the first trimester, is more appealing to some women (Durosinmi et al. 433; Zahed and Bou-Dames 427). Women receive CVS diagnoses much earlier in their pregnancy, allowing for an earlier and safer pregnancy termination if

desired (Rapp, Testing 30; ACOG 5; Himes, "Early"). Also, some studies indicate that women who undergo CVS experience less anxiety (Lerman et al. 786).

Other reasons for refusing amniocentesis and CVS are related to women's understanding of the tests and statistical information. Women may refuse the tests because they distrust the accuracy of the statistics (Rapp, "Refusing" 50; Rapp, Testing 98, 167; Browner and Press, "The Normalization" 318). Although uneducated women are more likely not to believe the statistics or the capabilities of the various prenatal tests, highly educated professionals are sometimes quite sceptical of statistical information as well (Rapp, "Refusing" 58). Misunderstandings during the genetic counselling process also affect women's decision-making with regards to amniocentesis (Rapp, "Refusing" 49; Rapp, Testing 175). Women and their partners may misapprehend the explanations of the procedures or misinterpret the consent forms (Rapp, "Refusing" 49, 57; Rapp, Testing 175). Some clients incorrectly process the statistical information provided by genetic counsellors (Rapp, "Refusing" 49, 57; Rapp, Testing 175). Such breakdowns in communication sometimes lead women to decline prenatal diagnosis.

Religious convictions, male-partner objections, and the simple fact that the diagnostic tests cannot identify or diagnose the conditions about which the parents are concerned are also among the reasons for test refusal.[46] In addition, Brookes found that many women already raising children with genetic or congenital conditions would often refuse amniocentesis (140). Essentially, these women were confident that their previous experiences raising a special needs child prepared them for any perinatal outcome (Brookes 140).

What Reasons for Test Refusal Reveal About How Information is Communicated

That women misunderstand and misinterpret information explained to them regarding genetics, prenatal testing, and individual risk definitely speaks to the need for improved information sharing between health care providers and the pregnant women counselled. In general, patients have a hard time understanding risk information: "According to research, humans do not always think rationally about risks, but instead rely on stereotypes, overestimate the likelihood of bad outcomes, underestimate the possibility of good results and think they see patterns where none exist" (Klitzman D7). Nonetheless, how women perceive risks involved with prenatal testing will influence their decisions (Markens, Browner, and Press 366). An individual's coping strategy also affects how they respond to risk information. For example, women with "information seeking" (Lerman et al. 786), as opposed to information-avoiding, coping methods present with heightened anxiety and depression levels throughout their pregnancy (Lerman et al. 786; Tercyak et al. 74). Information-seekers are also more likely to accept prenatal screens and diagnostic tests and generally have an increased perception of their risk of bearing a child with a genetic anomaly (Tercyak et al. 74; Eisenberg and Schenker 37; Mahowald 54). Regardless of whether a pregnant woman is an information-seeker or information-avoider, "stress interferes with one's ability to process key aspects of a risk message and to weigh the advantages and disadvantages of a course of action" (Lerman et al. 792).

Pregnancy can be a very stressful time for many pregnant women for reasons that extend beyond the threat of foetal anomaly. Risk is relative and often perceived differently by health care providers and the patients/clients whom these potential risks will ultimately

affect (Klitzman D7). How counsellors convey the genetic and testing information is critical, as their presentation will greatly influence how pregnant women continue to perceive their risk (Lerman et al. 785; Klitzman D7). Furthermore, studies show that in many instances women who receive genetic counselling and undergo prenatal diagnosis are susceptible to emotional distress and inaccurate perceptions of their risk (Tercyak et al. 73). This finding suggests the need for refining or remodelling existing counselling approaches. Research documents that women demonstrated an improved comprehension both of prenatal tests and various genetic conditions for which these tests screen when emotions and feelings were addressed and explored within the counselling session (Lerman 785). Given the range of emotions that overcome women and their partners during pregnancy, prenatal testing, and positive diagnoses, clients would benefit from counselling sessions that discuss life changing issues in comprehensible terms that maximize retention.

THE "NEED" FOR PHYSICIANS TO TEST

Many physicians insist on recommending "routine" prenatal testing to protect themselves from "wrongful birth" and "wrongful life" lawsuits, which may result in increased malpractice insurance. Scenarios whereby women file wrongful birth lawsuits against their obstetricians and/or gynaecologists, alleging to have misunderstood the objective of the prenatal tests they refused throughout their pregnancies, are fairly common.[47] A wrongful birth lawsuit is an action filed against obstetricians and gynaecologists by some parents of children born with handicaps (Rapp, Testing 40). In such actions parents allege their physicians failed to inform them adequately, if at all, about the risk of bearing a child with a genetic abnormality and the various prenatal tests available to

diagnose such abnormalities early in the pregnancy (Rapp, Testing 40). Thus, the parents allege deprivation of an opportunity to terminate their unwanted, affected pregnancy (Rapp, Testing 40). Other wrongful birth actions arise when prenatal testing is not performed correctly or the possibility of testing error is not disclosed. Wrongful birth lawsuits are sometimes successful and legal settlements may include the costs required to raise a child with special needs and/or compensation for emotional distress (Rapp, Testing 40; Press and Browner, "Risks"). Wrongful life lawsuits, on the other hand, occur when children take action against the health care providers and sue for negligence because their disabilities were not diagnosed *in utero* (Rapp, Testing 40). Wrongful life lawsuits are typically less successful than wrongful birth lawsuits, as the former are usually rejected on the philosophical basis that children cannot claim non-existence would have been preferable to life (Rapp, Testing 40; Press and Browner, "Risks").

Although approximately 6 out of 10 lawsuits filed against obstetricians and gynaecologists are considered meritless, and only a very small percentage of all claims succeed, the lawyers for ACOG noted the "malpractice jeopardy of *not* offering MSAFP to pregnant patients" (Press and Browner, "Why Women" 980). Consequently, some physicians may feel pressured to offer prenatal tests to ensure their medical practice conforms to the "local standards of care for legal purposes" (Lippman, "Prenatal Diagnosis: Reproductive" 190). From a liability standpoint, once a prenatal test is legally mandated, becomes the standard of care, or "simply when reasonable people think screening should be done (and the capability to perform it is present), providers who fail to screen or offer screening will have a difficult time defending themselves from liability suits" (Holtzman 42). Due to the risk of lawsuits, the American College of Obstetricians and Gynecologists

and the American Academy of Pediatrics declared prenatal diagnosis as the legal standard of care (Rapp, Testing 169; Press and Browner, "Risks").

The fear of malpractice suits often lead many physicians to offer screening to pregnant women, even if they are unable to counsel and educate effectively given their own limited understanding of the tests (Holtzman 52). Press and Browner argue that only women who do not receive MSAFP screens are a threat to physicians ("Risks"). However, as Hall and Holtzman note, administering prenatal screens and tests can also generate litigation, as women can sue in the event they receive inaccurate test results and/or foetal information (Hall 336; Holtzman 48). If a physician makes a misdiagnosis, particularly a false-negative diagnosis, or if labour is induced prematurely due to a miscalculation regarding the foetus' gestational age, a woman might initiate a lawsuit (Hall 336): "Malpractice [can] arise out of misuse as well as nonuse of the test" (Holtzman 48).

CONFLICTING NEEDS

Physicians insist that they perform routine screenings because women demand them. Some health care professionals perceive routine ultrasonography as a direct response to the "needs" of women (Lippman, "Prenatal Genetic": 26). Omitted from this argument, however, is the fact that health care practitioners often present MSAFP and ultrasonography to pregnant women as if they were routine, standard elements of their prenatal care package.[48] Furthermore, this technology is nationally publicized as a necessity. These procedures are presented as the best of modern health care for both mother and baby (Duden 75, 77; Taylor, "Of Sonograms"). Given such a "sales pitch," that many women actively

request ultrasound exams, amniocentesis and CVS is not surprising (Eisenberg and Schenker 36; Taylor "Of Sonograms"; Thompson, Freake, and Worrall 312). Lippman insists that,

> Regardless of the driving forces for dependency on this technology, the result is the construction of a particular "need": the basic "need" to know the gestational age of the fetus; the additional "need" to demonstrate that the pregnancy is progressing "normally." And the "needs" grow. "Needs" for prenatal diagnosis are being created simultaneously with refinements and extensions of testing techniques themselves. ("Prenatal Genetic" 33)

Lippman maintains that women "only come to "need" a prenatal diagnosis after the test for some disorder has been developed" ("Prenatal Genetic" 27) or once they reach a certain age—the "high risk" age ("Prenatal Genetic" 29). However, one must question whether prenatal testing differs from other technological inventions designed and implemented allegedly to afford consumers, both men and women, additional options to simplify and facilitate their lives.

Other "needs" arguably imposed on pregnant women include the "need" to produce a healthy baby[49] and the "need" to undergo testing to reassure both themselves and society that they are doing a "good job" and adhering sufficiently to their prenatal health care regimen (Lippman, "Prenatal Genetic" 29; Browner and Press, "The Normalization" 308-309, 316; Browner and Preloran, "*Para*" 369). Women are socially conditioned to believe that they must do everything within their power to give birth to a "perfect" baby.[50] However, one might argue that intuitively most pregnant women, even those addicted to narcotics or alcohol, do not want to harm their future child, regardless of existing social influences. Unfortunately, prenatal diagnosis is falsely presented as the means through which foetal health is achieved and birth defects are prevented.[51] Many women also assume

that any anomalies detected can be treated or cured (Press and Browner, "Why" 980, 985), when in fact, as mentioned earlier, there are no treatments or cures for most conditions diagnosed. Also, regardless of class, ethnicity, religious affiliation, or nationality, societies tend to hold mothers solely responsible for the health of their foetuses and future children, even though genetic anomalies are beyond women's control (Rapp, Testing 86). In an era where pregnant women are "bombarded with behavioural directives ... It is therefore not surprising that a search for proof of competence is translated into a "need" for testing; external verification takes precedence over the pregnant woman's sense of herself" (Lippman, "Prenatal Genetic" 29).

Unfortunately, a woman who refuses to undergo prenatal diagnostic testing might be subjected to a number of criticisms (Browner and Press, "The Normalization" 316; Duden 54): "Some will see her as a 'primitive' who deprives herself and her infant of the benefits of modern medicine. Others will see in her the romantic who places good will, emotions, and irresponsible trust above the certainties of modern institutionalized reality. And others will dismiss her as utopian" (Duden 54). Refusing testing often reflects poorly on the pregnant woman and indicates a failure "to do everything within her power to assure the health and well-being of her developing fetus" (Browner and Press, "The Normalization" 320). However, one might argue that the women who make informed refusals are both considering the life of their future baby and taking control of their prenatal health care decisions. Prior to engaging in prenatal diagnosis pregnant women should consider the psychological effects of the tests, the medical risks should the "benign" MSAFP or ultrasound screen lead to amniocentesis or CVS, their position on selective abortion within

their value system, and their current life situation (Wertz and Fletcher 175-76; Markens, Browner, and Press 360-65; Wolf 38, 40).

Women who accept prenatal diagnosis but decide not to terminate affected foetuses and women who refuse prenatal diagnosis and bear children with genetic conditions are perceived as "'choosing' to bear children with genetic conditions, and therefore 'choosing' the social stigma and approbation which is associated with such births" (Brookes 141). Many women feel the need to justify their decision to give birth to a handicapped child (Brookes 143). Society, and even some physicians, often perceives women who give birth to children with genetic conditions or other developmental anomalies as having demonstrated an overt "lack of care towards their child, as well as an indication of a lack of social responsibility" (Brookes 143). Specifically, women who bear handicapped children having either refused to undergo prenatal diagnosis or refused to abort affected foetuses are sometimes considered guilty of foetal neglect (Brookes 142; Eisenberg and Schenker 39).

Framed within the context of being standard procedures that "good" mothers (those who adhere to the "rules" of pregnancy and prenatal care) undergo on behalf of their foetuses' health, few women contest MSAFP and ultrasound screens.[52] Rejecting modern reproductive technologies is tantamount to rejecting the foetus (Markens, Browner, and Press 360; Browner and Press, "The Normalization" 320). Consequently, a common question posed, particularly by feminists, is whether pregnant women truly have a choice to reject prenatal diagnostic testing, including ultrasound, once recommended in the name of the baby's best interest (Lippman, "Prenatal Diagnosis: Reproductive" 191).

DO WOMEN HAVE A CHOICE?

Wertz and Fletcher found that:

> It is extremely difficult, if not impossible, for women to choose to reject technologies approved by the obstetrical profession. Once tests are offered, to reject them is a rejection of modern faith in science and also a rejection of modern beliefs that women should do everything possible for the health of the future child. (175)

Markens, Browner, and Press conclude that many women feel they truly do not have the "choice" to reject prenatal diagnosis (362, 367). Some pregnant women even define themselves as "victims of circumstance" without choices when it comes to prenatal testing (Browner and Preloran, "Latinas" 355). Yet, many women are grateful they had the choice not to bear and raise a child with a disability:

> Women who have had amniocentesis and have aborted fetuses with Down syndrome write of their relief at being able to avoid becoming mothers of severely disabled children. Even though the decision was often difficult and psychologically stressful, these women believe that prenatal diagnosis freed them to go on with their lives, continue their careers, and to have healthy children. (Wertz and Fletcher 176)

Similarly, Rapp reports that women in her study "expressed gratitude about having had a choice [to terminate], despite the deep pain that accompanied its exercise. Knowing about a profound problem in a foetus and being able to choose to avoid bringing it to term was, in their estimate, better than living with the consequences of its birth" (226). Some women already raising children with disabilities are grateful for the prenatal diagnostic technology and make decisions to terminate subsequent affected foetuses because of their inability to cope and care effectively for their existing handicapped child (Brookes 143).

On the surface, the major "choice" that women must make regarding prenatal diagnosis seems to be whether to undergo testing. This "choice" must be made amidst established social and medical norms. These norms push some women, often unconsciously, into agreeing to undergo the diagnostic tests. Women who reject these norms are often perceived as blatantly disrespecting the health of their foetus and violating their "duties" as expecting mothers. However, some critics argue that the "choice" involved is whether women will decide to raise special needs children in a society that provides few resources for families with disabled children (Brookes 138, 141; Lippman, "Prenatal Genetic" 31-32; Wertz and Fletcher 174-75). Wertz and Fletcher note,

> If choice is the absence of legal coercion or coercion by partner or family, clearly women have a choice. There is no evidence of direct coercion by doctors, as some have alleged. If the choice is interpreted in the broader context of economic and social realities, however, many women may feel that the possible alternative to prenatal diagnosis—raising a child with a disability—is so unattractive that it does not present a real choice. (174)

The social context within which handicapped children are born and the availability of care for special needs children shapes many women's reproductive decisions (Brookes 138). Societal circumstances, such as limited access to services for people with disabilities and an overall lack of long-term care facilities for handicapped people to live once their parents are no longer capable of caring for them leads some pregnant women to abort affected foetuses, even if they are generally opposed to abortion (Brookes 137, 145-46; Lippman, "Prenatal Genetic" 32):

> The question of care is central to many women's decision-making process. How much care a child will require, how much care a woman feels confident to provide, and the level of care available for children with genetic conditions and families from their communities all impact on women's decisions to undertake prenatal diagnosis as

> well as how to use the information available from testing. (Brookes 133)

Some critics of prenatal diagnosis argue that women who undergo such testing with the intention of aborting their foetuses should they receive positive test results are not making free, unconstrained "choices": "[P]renatal diagnosis cannot really be a choice when other alternatives are not available ... Society does not truly accept children with disabilities or provide assistance for their nurturance. Thus, a woman may see no realistic alternative to diagnosing and aborting a fetus likely to be affected" (Lippman, "Prenatal Genetic" 32). Rothman would even argue that some women are essentially deluded into thinking that they are making a choice: "For those whose choices meet the social expectations, for those who want what the society wants them to want, the experience of choice is very real" (32).

However, one must also view the situation from the point of view of the working woman. Women no longer operate solely within the private sector of society as wives and homemakers. Many women in North America are geared towards obtaining scholastic degrees and pursuing careers in various fields. Wertz and Fletcher maintain that now that women are in the workforce, "the cost of a child with a disability is enormous ... [as] [m]ost of the care for children with disabilities falls on the mother. Not only must she give up much of her paid employment, but she must often adopt motherhood as her primary self-identification" (175). For career women who desire children, yet have no desire to quit their jobs, prenatal diagnosis might be perceived, rightly or wrongly, as a means through which their freedom as women and as working professionals can be preserved.

Some women who undergo prenatal testing and abort foetuses diagnosed with disabilities do so in part because of the huge financial expense of raising a handicapped child (Lippman, "Prenatal Genetic" 31). Institutionalizing special needs newborns is essentially impossible since psychological studies laud the benefits of handicapped children's development within their own family environment (Wertz and Fletcher 175; Lippman, "Prenatal Genetic" 31). Placing severely handicapped children up for adoption is not typically considered a socially acceptable alternative (Wertz and Fletcher 176). Few doctors suggest adoption to pregnant women making decisions regarding their affected foetuses (Wertz and Fletcher 176). Approximately 80% of people with handicaps live at home and are cared for by their parents, usually their mother (Wertz and Fletcher 175). Both in-home and respite care is difficult to find (Wertz and Fletcher 175). Therefore, if one's family income and/or health insurance cannot, or will not in the case of some insurance companies, cover the expenses and basic needs of the special needs child some women might truly see prenatal diagnosis and abortion as their only "choice" (Lippman, "Prenatal Genetic" 31).

Excessively Negative Information Can Rob Women of Choice

Disability rights scholars might even argue that some pregnant women are "coerced" into accepting prenatal testing and selective abortion as a result of how medical information on various disabilities is presented. Studies indicate that much of the medical and bioethical literature addressing various disabilities is based on misinformation and stereotypes and is excessively negative (Parens and Asch 6; Marteau and Dormandy 186). Parens and Asch argue that many scholars and health care professionals misrepresent the disability experience and fail to reassure women that "parenting a child who has a disability can be as gratifying

as parenting a child who does not" (Parens and Asch 8). A Master of Science thesis, entitled "Genetic Counselors' Descriptions of Down Syndrome: Promoting Informed Choice for Prenatal Testing," discovered that even genetic counsellors, health care providers whose aim is to inform and educate women to ensure they possess all the tools necessary to make informed, reasoned decisions were also guilty of overly stating the negative characteristics of life with a disability (Lardy, 2002). Critics opposed to selective abortions for foetal anomalies insist that if parents and prospective parents obtained more accurate information regarding their foetuses' conditions they might not have such a negative assessment of raising a child with a disability (Parens and Asch 8).

Brookes and Rapp's studies found that pregnant women already raising a child with a disability felt that health care practitioners presented overly negative pictures of what it is like to care for a disabled child (Brookes 140; Rapp, Testing 266). These scholars suggest that disability information is framed in a manner that encourages prenatal diagnosis and selective abortion for positive diagnoses (Brookes 140; Rapp, Testing 266). Moreover, excessively negative information provided by health care practitioners might undermine some women's confidence in their ability and willingness to raise a child with a disability (Brookes 140; Rapp, Testing 266). One woman confessed that despite her position against abortion, had she not already had a child with a disability, the bleak future painted by her medical practitioner would have lead her to consider seriously an abortion (Brookes 140-41). However, other studies suggest that some physicians' depictions of life with a disabled child mirror women's lived experiences. One woman interviewed in Brookes' study depicted life with her disabled child as a "lifestyle" change and she "wouldn't wish it on anyone" (Brookes 136).

Cost-Benefit Analysis

Pregnant women who undergo prenatal diagnosis and face selective abortion decisions are continually reminded of the "negative dollar costs" (Brookes 144) assigned to children born with genetic and congenital anomalies (Brookes 144). The costs that accompany the birth of a handicapped child include "lost parental productivity, consumption impact, health service costs, capital impacts (such as housing adaptation), adoption and fostering cost, and lost individual output" (Brookes 144). The combined costs of prenatal tests and selective abortions of affected foetuses are considered less costly, both to the families and society, than the lifetime care of a child with disabilities.[53] According to Weiner and Bernhardt, "the health care costs of infants and children with genetic disorders and chronic illnesses are at least three times higher than those of other children" (719). However, despite the alleged financial incentives, selective abortion for foetuses with genetic conditions is often presented to parents as a "caring response" to the foetus rather than a "cost effective" decision—a means of avoiding the plethora of physical challenges that will inevitably accompany the disability (Brookes 136). Abortion, when framed in this manner, is characterized as an opportunity to escape a life of discrimination, limited opportunities, diminishing resources, and a community generally unsympathetic to the needs of people with disabilities (Brookes 136, 137; Lippman, "Prenatal Genetic" 32).

Are Manual Obstetric Exams Still An Option?

Technology has assumed a commanding presence in obstetric wards. Therefore, one must consider whether pregnant women will truly have a choice with respect to ultrasonography if, or when, physicians become so dependent on ultrasound methods to

monitor the health and condition of the foetus that they no longer know how to "listen" to a woman's body. Prior to the ultrasound era, physicians had to ask the pregnant women questions, use their menstrual history to ascertain gestational age, listen to women's bodies and examine their "metabolic products" (Oakley 155) to monitor the pregnancy.[54] Today, obstetricians increasingly rely on ultrasounds to confirm their pregnancy management decisions and women are rarely considered the primary informants regarding their foetuses.[55] Duden notes that there has already been a rapid decline in physicians' palpation skills (76). Hall questions whether physicians have become too technologically dependent to the point where unnecessary prenatal ultrasounds are being administered: "Has the information provided by an ultrasound report supplanted wisdom?" (335). If such a fear were to become a well-known reality, women, through no fault of their own, truly might not have a "choice" when considering the merits of ultrasonography.

Women Must Make Difficult Decisions

A "choice" demands the existence of at least two options. Women have choices when deciding whether to undergo prenatal diagnosis. Some women clearly challenge existing routines and refuse the tests for a number of different reasons. Furthermore, as Childress says, "a hard choice is not a non-choice" (290). Some pregnant women, pro-life activists, and critics of prenatal diagnosis maintain that prenatal diagnosis limits reproductive freedom and inflicts "forced choices" onto women (Eisenberg and Schenker 39, 42; Rapp, Testing 225). Positive MSAFP diagnoses, inconclusive sonograms, diagnostic testing, and selective abortion essentially define these "unwanted choices" (Markens, Browner, and Press 363; Rapp, Testing 59). Rapp discovered that many women did not want to view their actions with regards to selective abortion as their choice (Testing 225).

Rather, these women stated they "'had to have an abortion'" or "'It was a forced choice'" (Rapp, Testing 225). Other women, however, took responsibility for their decisions: "'No one is forcing me to do this. I'm making my own choice. This is awful. It's the single most awful thing that's ever happened to me. But it's my choice, and I'm making it'" (Rapp, Testing 226).

That women experience discomfort, stress, and anxiety when confronted with having to make decisions about selective abortion might suggest that the initial decision to undergo prenatal screening was not adequately considered. Undoubtedly one can argue that regardless of how intellectually prepared and informed a pregnant woman might be on the issues of prenatal screens, diagnostic tests and the possibility of a positive diagnosis, no amount of information or preparation can prepare her for the reality of the actual positive diagnosis result. Furthermore, what a pregnant woman and her family decide to do in the event of a positive diagnosis and what they decide to do when they actually receive a positive diagnosis might change. As Rapp reports, some women are relatively confident that they will abort if they receive a positive diagnosis, whereas others may need to work towards a conclusion (Testing 223). In an effort to minimize the stress surrounding upsetting decisions following a positive diagnosis from the amniocentesis or CVS test, proper informed consent should be obtained prior to the MSAFP screen. Although such consent is encouraged it is rarely achieved (AAP Policy Statement, 1991; Lippman, "Prenatal Genetic" 21; Mitchell 150; Mcfadyen, "First"). One might argue that pregnant women should carefully assess the benefits and risks of prenatal testing with their physician, genetic counsellor and/or social support system prior to undergoing the procedures and at least have considered their options given the possibility of a positive diagnosis. Such

decisions are rarely easy, but perhaps if pregnant women had a more accurate picture of what prenatal testing entailed and they really knew what they personally hoped to gain from the testing process, the prenatal testing decision-making process would be facilitated.

That prenatal screens and diagnostic tests tend to inflict unwanted decision-making on some women should neither colour the procedures themselves nor their potential benefits if used and interpreted correctly. However, women who would either prefer to let "nature take its course" rather than actively make decisions or keep their pregnancy anxiety levels to a minimum, should be able to refuse consent and not subject themselves, or be subjected to, routine screens and social criticism. Although arguments are made that society's lack of interest in providing for handicapped children prevent pregnant women from making meaningful reproductive choices, there are women across the socio-economic strata who refuse testing, who accept testing but refuse to terminate affected foetuses, and who adopt special needs children. Society has room for improvement with respect to offering services for the disabled and their caregivers. Also, the general public needs to be educated on the basics of genetics, genetic conditions, and prenatal diagnosis. People must realize that undergoing prenatal diagnosis does not assure foetal health and although some maternal behaviour, such as smoking or drinking, does account for low birth weight and some developmental problems in neonates, chromosomal abnormalities occur irrespective of maternal behaviour and irrespective of prenatal diagnostic testing (Rapp, Testing 86, 88). However, societal ignorance and inaction should not serve as pregnant women's scapegoat or be viewed as the entity responsible for victimizing women. Some women might bemoan the fact that they are responsible for pregnancy and childbirth. Similarly, the advancement of reproductive technologies may also be perceived as an unwanted interference in a natural

process. However, evading or refusing responsibility for difficult reproductive decisions should not be encouraged or facilitated.

CONCLUSION: RECOMMENDATIONS FOR THE FUTURE OF PRENATAL TESTING

MOVING BEYOND STEREOTYPES

The complexity of prenatal decision-making indicates the importance of counselling each pregnant woman as a unique individual operating within various relationships rather than merely viewing her as representative of a larger group. Health care professionals harbouring prejudicial stereotypes threaten the counselling relationship and pregnant women's decision-making processes. The quest to discover patterns of decision-making is arguably futile and counter-productive if the objective of such an undertaking is to supplant, consciously or unconsciously, "old" stereotypes with "new" ones. Although general trends may exist, a utilitarian approach to prenatal care that sacrifices the decision-making of women who do not operate according to "their" particular caricature should not be encouraged. However, an increased cultural awareness on the part of health care professionals can only improve the counselling and decision-making processes. The empirical studies mentioned throughout this text, though failing to highlight cultural-, social-, or religious-specific patterns, serve to educate health care providers on the danger of operating according to existing and often unfounded assumptions. Understanding and respecting various cultural and religious norms and values is imperative in the health care setting (Coward and Sidhu 1169). Yet, health care professionals should recognize the "diversity of beliefs and practices within these populations" (Coward and Sidhu 1169) both to prevent the propagation of potentially damaging stereotypes and to ensure that the health care needs of all patients are met.

A RELATIONAL-APPROACH TO GENETIC COUNSELLING

Communication plays a critical role in the genetic counselling and prenatal decision-making process. The complicated subject matter (genetics, statistics and risk information, procedural explanations etc.) coupled with the stress and anxiety of pregnancy may prevent some women from clearly articulating their pregnancy and childbirth objectives. For some pregnant women the genetic counselling session is the first time they have even considered the risks, benefits, and overall import of the prenatal tests (Rapp, Testing 169). The intrinsic power imbalance between health care professionals and their patients often renders patients ordinarily considered competent, inarticulate and incapable of outlining their health care goals and desires (O'Neill 38; Donchin 238). The inability to identify values and beliefs is arguably not unique to patients but rather representative of most people. Donchin maintains that health care providers have an obligation to help patients identify their values to ensure that their autonomy is respected (238). She writes,

> [R]especting such patients' autonomy typically requires attention to details of their life experience and surroundings. Often patients do not fully recognize their own beliefs and values, so reaching an autonomous decision about their care may require extended exploration of their histories and motivational structures. Then too, patients' self-understandings may be so confused with others' perceptions of them (particularly in hospitals) that no decision can be disentangled from their influence. Respecting autonomy would require recognizing patients' struggles to break free from oppressive authoritative influences and assisting them to sustain relationships essential to their self-identity and well-being. (Donchin 238)

One might extend Donchin's recommendation to genetic counsellors and encourage them to assume the responsibility of helping pregnant women clarify their expectations for pregnancy, childbirth, and childrearing within the context of each woman's value system, and if necessary help them identify their values. Such an approach could help reassure

women, genetic counsellors, and obstetricians that each pregnant woman is making reasoned prenatal testing decisions. As a result, regardless of future diagnoses and/or neonate outcomes, lawsuits will decrease and women will feel confident that they made the right decision for them. To facilitate pregnant women's decision-making processes further, genetic counsellors must endeavour to foresee potential choices within the context of prenatal testing, identify possible tools needed to make those choices, impart pertinent knowledge and/or skills, and help patients acquire the necessary tools to make informed choices in their best interest[56]: "Adjusting social and environmental conditions, such as creating opportunities for choice and providing resources for learning, can help to empower people and achieve autonomy" (Kenny and Ells 322).

Adopting such a model requires improvements in counsellor-pregnant woman communication and reciprocal information sharing. The genetic counselling profession is dedicated to helping clients come to reflective decisions with regards to pregnancy and childcare management (Parens and Asch, "The disability rights"). Some genetic counsellors allegedly already incorporate some of the aforementioned communication-building tools into their sessions, including:

> discussion[s] of how testing is performed, what it can detect (including descriptions of chromosomes and genes), and what the information may mean for an affected child. Currently, the ideal process entails an exploration of the prospective parents' views about family and children, a discussion of available economic and social resources, and an exploration of any experience prospective parents may have of people who live with the conditions being tested for. (Parens and Asch, "The disability rights")

Unfortunately, ideal theories are not always converted into practice. The few studies devoted to evaluating prenatal genetic counselling intimate that such lengthy and

comprehensive genetic counselling discussions rarely occur (Parens and Asch, "The disability rights"). Moreover, one must note that most pregnant women who undergo prenatal testing do not meet with genetic counsellors and obstetricians perform the tests with little, if any, pre-test counselling (Parens and Asch, "The disability rights"). A genetic counselling approach that strives to help women clarify their value system to figure out where prenatal testing and selective abortion fit within that structure is undeniably time consuming. However, health care institutions, having undergone the paradigm shift from a paternalistic model of health care to one that emphasizes patient autonomy and self-determination, must adhere to the guidelines of the informed consent doctrine. Furthermore, for that consent to be considered ethically valid, patients must fully understand the procedures and their implications prior to giving consent. Moreover, patients must realize that they may withdraw, modify, question or clarify their consent at any time.

INFORMED CONSENT AND INFORMED CHOICE

Some scholars argue that informed consent is different from informed choice (Kohut, Dewey, and Love 266). Kohut, Dewey, and Love claim that informed consent is "a discrete event of obtaining legal approval from a patient for a procedure" (266) whereas informed choice is perceived as "a process of decision-making, which evolves through the evaluation of information and personal values related to testing" (266). Disclosure, comprehension, and voluntary choice are all required for informed choice to occur (Kohut, Dewey, and Love 266). Conversely, Kluge insists that informed consent is not achieved merely through the patients' signing of a legally appropriate form (1321). Rather, the fiduciary relationship between physicians and their patients imposes a duty on physicians to communicate with

their patients and to ensure that patients understand the information prior to signing the form and beginning the treatment (Kluge 1321). Moreover, the existence of a legally sound informed consent form should not serve as a substitute for this critical educational process (Levine 8). Informed consent should be viewed as an ongoing, continual process that spans the duration of a patient's medical treatment (or pregnancy) and patients should continue to maintain an active level of involvement throughout their treatment and consent can be withdrawn at any time (Levine 9; Press and Browner, "Risk"; Sherwin 42). Morally valid informed consent demands not only that legal documents be signed, but also that the patients comprehend the information explained (Levine 10; Marteau and Dormandy 186). Whether patients understand the information provided is often questionable (Levine 10). Regardless of whether one perceives the decision-making process as informed consent or informed choice, both modern understandings involve open and honest communication between the health care practitioners and the individual patient or pregnant woman.

Implementing the informed consent doctrine in health care institutions so the process functions properly and achieves the established objectives, particularly patient autonomy, self-determination, and bodily integrity, has proven difficult (Levine 2; Sommerville 5). Some physicians do not like having to obtain informed consent, as they feel most patients are incapable of understanding the medical information needed to weigh the treatment alternatives appropriately (Levine 5). Furthermore, statistics show that patients remember a mere fraction of what is disclosed, a fact that only reinforces some clinicians' opinions that obtaining informed consent through lengthy discussions is futile (Levine 5).

Marteau and Dormandy maintain that "an informed choice or decision has two or more characteristics: it is based on relevant, good quality information, and reflects the decision-maker's values" (186). The Institute of Medicine suggests that health care providers disclose the following to ensure that informed consent has been obtained:

> (1) fair and balanced explanation of the procedures and their safety; (2) a description of the risks and benefits; (3) consideration of all possible outcomes, including the possibility that one option might be termination of the pregnancy; (4) knowledge of the potential need for and availability of psychosocial counselling; (5) documentation of consent; and (6) full information concerning the spectrum of severity of the genetic disorders for which prenatal diagnosis is being offered (e.g., CF, Down syndrome, fragile X) [...] All candidates being offered prenatal screening and diagnosis should be informed about all of the risks and benefits described above to ensure that participation is voluntary. (Institute of Medicine 104)

Marteau and Dormandy add that women should also be informed of their available options in the event of a positive diagnosis (187). Information addressing "the impact of living with a child with a disability, including the educational and medical support that is available, and the likely impact of such a choice upon family life" should not be omitted from the informed consent disclosure process (Marteau and Dormandy 187). Women cannot make autonomous choices regarding their prenatal care, particularly concerning prenatal diagnosis, if they are not in possession of all of the possible information that might influence their decisions—including accurate and fair information on various disabilities (Levine 67; Kohut, Dewey, and Love 266).

Research studies indicate that many women undergoing prenatal testing are ignorant of both the testing procedures and their risks and benefits, thereby making truly informed choice impossible (Kohut, Dewey, and Love 266, 272). Explaining complex statistical

information to pregnant women, most of whom lack an education in statistics or biological sciences, is without question a challenging task. Nevertheless, efforts should be made to ensure that pregnant women are as informed as possible.

Efforts directed towards improving the informed consent process do not acknowledge the fact that many of the consumers' rights and bioethical approaches to informed consent issues assume that patients want more information than their physicians and/or counsellors provide (Press and Browner, "Risks"). Many women are reportedly perfectly content with the little information they receive and retain (Press and Browner, "Risks"; Press and Browner, "Characteristics" 437; Browner and Press, "The Normalization" 318). Many do not desire detailed in-depth discussions about hypothetical fetal conditions and trust that their health care providers will inform them on a "need to know" basis (Rapp, Testing 70). Not surprisingly a conflicting position exists. In their respective studies Marteau and Dormandy and Graham et al. found that many women desire, value, and benefit from their personal physician or counsellor providing them with "high quality information" (Marteau and Dormandy 186) early in the pregnancy to allow enough time for reflection prior to rendering their prenatal testing decisions (Marteau and Dormandy 186; Graham et al. 158). Given the varying preferences amongst women, the informed consent process should also enable women to postpone elaborate information sessions until the hypothetical becomes reality. Of course, signing an informed refusal should be required.

The choice not to know is a valid choice and should be respected (Kohut, Dewey, and Love 275; Matsudo et al. "Guidelines"). Given the legal concerns that surround prenatal test refusals, consent and refusal forms should be implemented for both screens and

diagnostic tests. Although genetic counsellors and health care professionals in general bear the brunt of devising effective methods to communicate complex information to pregnant women, one might argue that pregnant women have a responsibility to admit when they do not understand the information and explanations provided. Health care providers should strive to create an environment within which women feel able to confess when they are having difficulty digesting the information. Possible solutions to ensure pregnant women's comprehension of genetic risk, genetic conditions, and prenatal diagnosis involve a role reversal whereby after the counsellor explains the various statistics, procedures and test purposes, the pregnant woman must then educate the genetic counsellors on the same material. Not only would such an approach serve as an invaluable assessment tool for the clinician, the pregnant woman might learn more as a result of teaching the information to someone else. Also, physicians and genetic counsellors should incorporate emotions, feelings, and an exploration of the psychological aspects and effects of prenatal tests into their prenatal testing discussions, as such an approach has proven to improve pregnant women's levels of both comprehension and retention with respect to prenatal testing procedures (Lerman et al. 785). Personalized informed consent forms could also assure increased understanding of prenatal diagnosis and genetics by pregnant women and decrease the threat of lawsuits to physicians. Specifically, within a legally binding document each woman who accepts or refuses prenatal testing must explain, in her own words and in her language of preference, whether and why she wants each test.

As reproductive technology continues to advance, pregnant women are faced with increasingly difficult decisions. If women want to remain in control of their reproductive decisions, they must take responsibility for the decisions they make. Pregnant women must

seriously reflect on the advantages and disadvantages of prenatal diagnosis and understand their motivations for accepting or refusing various tests. In a 1997 study performed by Press and Browner, a number of women confessed that they did not give much consideration to the MSAFP screen prior to accepting the screen (Press and Browner, "Why Women" 984). Few women could articulate why they accepted this screen (Press and Browner, "Why Women" 984). A more candid depiction of both MSAFP and ultrasound by obstetricians, gynaecologists, genetic counsellors, and other health care practitioners will definitely aid in the process of encouraging women to "own" their reproductive decisions. Once informed consent procedures are improved, if women decide to refuse a particular prenatal test, their informed refusals should be recognized in a court of law in the event that they attempt to sue for "wrongful birth." To disregard an informed refusal undermines women's decision-making abilities and essentially states that women are not capable of understanding reproductive issues or making reproductive decisions based on that information. Unless women take responsibility for their reproductive decisions and are held accountable for those decisions, encouraging and implementing an improved platform for informed decision-making in the reproductive realm is futile.

SUMMARY

This research emphasizes the importance of a person-centred approach to prenatal testing. Humans are complex beings operating within complex personal and social environments. Reducing pregnant women to their religious faith, their ethnicity, or socio-economic status denies them their individuality and strips them of their complexity. Unfortunately, as evidenced throughout this project, health care professionals are often insensitive to individual diversity and consequently limit women's reproductive options and/or compromise their decision-making.

Official religious positions on prenatal testing and selective abortion for foetal anomalies range from adamant opposition, to willingness to make concessions, to relatively undecided on the issue. Similarly, women adhering to Christian, Jewish, Muslim, Hindu, and Buddhist faiths vary in their beliefs and practices. Despite the limited scholarship in this particular area of reproductive ethics, a woman's religious affiliation is not an accurate predictor of prenatal testing decisions. Moreover, a woman's decision to undergo prenatal testing and/or selective abortion without the support of her religious leader and/or community is not indicative of her level of commitment to her faith. The decision to undergo prenatal testing is intensely personal and multi-factorial and, consequently, should never automatically be reduced to one influencing variable.

The danger of health care providers leaping to incorrect assumptions regarding how women of a particular faith will respond to offers of prenatal testing multiplies when women belong to ethnic communities whose cultural practices contradict the teachings of their

professed religions. Given the personal nature of prenatal testing and selective abortion, health care providers should refrain from applying religious and cultural stereotypes when counselling pregnant women. Also, the rapid advancement of reproductive technologies coupled with the increasingly difficult decisions pregnant women face, should incite religious leaders to improve their efforts to understand and clarify the theological challenges and dilemmas endured by many of their pregnant parishioners.

Empirical research, if performed well, can be extremely helpful and offer tremendous insight with respect to different groups and behaviour patterns within those groups. However, one must remember that although empirical research may begin with an individual, the findings are population-based and not individual-based. When counselling a pregnant woman on prenatal testing and her various reproductive options, health care professionals must recognize that they are counselling the individual and not the population. Ascertaining each woman's unique objectives, goals, and desires is critical to ensure that informed decisions are achieved.

Prenatal testing research conducted by professionals in a number of different fields, including the medical field, highlights the inadequacies of prenatal counselling, particularly the obvious lack of available information provided to pregnant women. Although the birth of children with genetic and congenital conditions is relatively rare, positive diagnoses as a result of testing are not uncommon. Women obtaining prenatal care and testing should not be sheltered from the reality that positive diagnoses are a possibility and they should be afforded an opportunity to contemplate the ramifications of their prenatal testing decisions before a positive diagnosis is disclosed. Decision-making in a crisis situation is rarely

advocated as ideal practice and, given the emphasis placed on bearing a "perfect" baby, a number of women may consider a positive diagnosis "a crisis".

Expecting mothers want to do everything within their power to ensure the delivery of a healthy baby and presumably health care professionals desire the same. Failing to provide women with appropriate and available testing information arguably hinders their ability to care for that future infant, having been robbed of the opportunity to assess thoroughly the environment within which this future infant will be born. Undeniably prenatal tests can be extremely beneficial for many women and women should not be denied the opportunity to benefit from these procedures. However, for women to benefit truly from prenatal testing they must be offered an opportunity to ascertain the various implications of these prenatal tests and to have an improved understanding of how their testing decisions will impact them, their family, and their future children. Given the premise that pregnant women want to do everything to have a healthy pregnancy, they must, for their own health purposes, be aware of their personal limitations with respect to how maternal behaviour affects foetal genetics and must recognize the risks and limitations of science as they assess the merits of prenatal testing.

Bibliographic Endnotes

[1] For information stating that prenatal tests have not been found to improve substantially maternal or neonatal mortality or morbidity, see ICSI 4; Lippman, "Prenatal Diagnosis: Reproductive" 190-91; Morgan 69-70; Mitchell 146, 148; Oakley 171, 284; Institute of Medicine 78; Boyle 258.

[2] For more on the general benefits of prenatal testing see, Boyle 257-58; Institute of Medicine 77; Thompson, Freake, and Worrall 308; Mitchell 146-47; Oakley 285.

[3] For information supporting the argument that few treatments or cures exist for the diseases and conditions for which prenatal tests screen see, Taylor, "Of Sonograms"; Press and Browner, "Why" 985-87; Markens, Browner, and Press 360; Ashley and O'Rourke 250; Duden 76-77; and Lippman, "Prenatal Genetic" 27-28, 32.

[4] For more information on the increased anxieties experienced by prenatal testing as a result of prenatal tests see, Madlon-Kay et al. 398; Mitchell and Georges 397; Wolf 35; Rapp, Testing 104; Himes, "Early"; Tercyak et al. 74; Kingston 1368; and Oakley 285.

[5] For more information citing the high false positive rates surrounding prenatal tests, particularly MSAFP and ultrasound see, ICSI 4; Institute of Medicine 78; Hall 336; Holtzman 46; Taylor, "Of Sonograms"; Wolf 35.

[6] For more literature outlining the details of the how testing reinforces a false sense of reassurance see, Lippman, "Prenatal Genetic Testing" 25; Mitchell 152; Meilaender, Bioethics 54; Eisenberg and Schenker 39.

[7] Preimplantation diagnosis is a diagnostic technique that implements *in vitro* fertilization (IVF) procedures to diagnose three-day-old embryos in their eight-cell stage of development at the moment of fertilization (El-

Hashemite 223; Veenker 18; Mackler 287). Affected embryos are discarded and the "healthy" embryos are transferred into the womb (El-Hashemite 223; Veenker 18). Preimplantation diagnosis is commonly used to avoid X-linked disorders (Malprani, Malprani, and Modi 11). This technique is also used in some countries for sex selection and family balancing purposes (Malprani, Malprani, and Modi 11). This testing procedure is performed globally in more than 40 genetic centres (Veenker 18). However, preimplantation diagnosis is a technically difficult procedure and the limited time-span available for diagnosis, the limited amount of material accessible for diagnosis, and the poor survival rate of "non-transferred embryo[s] following cryopreservation" are among the challenges of this technique (Malprani, Malprani, and Modi 11). One must also note that preimplantation diagnosis is a costly technique and consequently, an option reserved predominantly for the wealthy.

[8] For additional sources that document the absence of treatments and cures for the various diseases and conditions detected via prenatal tests see, Ashley and O'Rourke 250; Press and Browner, "Why" 985-87; Markens, Browner, and Press 360; Taylor "Of Sonograms"; Duden 76-77; and Lippman, "Prenatal Genetic" 27-28, 32.

[9] For more information on the liberal abortion policy, see Brown 76; Eisenberg and Schenker 42; Green 257-60; and Mackler 287.

[10] For more information concerning preserving the health of the mother, see Brown 76; Mackler 287; Eisenberg and Schenker 42; Steiner-Grossman and David 1360; and Green 254, 258.

[11] For more information regarding the conditions that must be met prior to undergoing an abortion for fetal anomaly, see Alkuraya and Kilani 450; El-Hashemite 223; Ahmed et al. 378; and Greeson, Veach, and LeRoy 361.

[12] For more information on the widespread practice of female feticide in India, see Khanna 171-72, 174, 179; Dickens 335-36; Rajan, "Will India's"; and Akkara, "Churches".

[13] For information on the ban the Indian government placed on the use of prenatal testing for sex selection purposes, see Dickens 335; Malpani, Malpani, and Modi 11; Akkara, "Churches"; and Rajan, "Will India's".

[14] For more information on additional sources of information women use to obtain information, see Rapp, Testing 168; Browner and Preloran, "Latinas" 366; Root and Browner 215; Rapp, "Refusing" 51; and Mitchell and Georges 402.

[15] For more information on the predictive value of abortion history in prenatal testing acceptance, see Press and Browner, "Why Women" 986; Markens, Browner, and Press 363; Browner and Preloran "*Para*" 373, 380; and Browner and Preloran "Latinas" 358-59.

[16] For more information on women who consent to amniocentesis yet will not consider abortion, see Browner and Preloran "*Para*" 373, 380; Browner and Preloran "Latinas" 358-59; Press and Browner, "Characteristics" 440; Markens, Browner, and Press et al. 363; and Brookes 138-39.

[17] For additional information surrounding women seeking amniocentesis and CVS see, Eisenberg and Schenker 36; Taylor "Of Sonograms"; Thompson, Freake, and Worrall 312; and Rapp, Testing 72.

[18] For more details regarding health care practitioners' explanations of MSAFP and ultrasounds as routine see, Press and Browner, "Characteristics of Women" 440; Markens, Browner, and Press 362, 365; Lippman, "Prenatal Diagnosis: Reproductive" 190-91; Parens and Asch 11, 34; Press and Browner, "Why" 983; Browner

and Preloran, "Latinas" 357; Kohut, Dewey, and Love 270, 274; Morgan 69-70; Mitchell 146, 148; Oakley 171, 284; and Institute of Medicine 78.

[19] For more information regarding the fact that many women perceive prenatal testing as a means of reducing their risk of bearing a handicapped child see, Madlon-Kay et al. 397; Browner and Press, "The Normalization" 309, 312; Press and Browner, "Why" 980, 987; Parens and Asch 4; and Markens, Browner, and Press 360.

[20] To learn more about pregnant women wanting to satisfy their desire to know everything there is to know about the status of their foetus see, Himes, "Early"; Rapp, Testing 116, 226, 251; Press and Browner, "Why" 984, 986-87; and Browner and Press, "The Normalization" 319.

[21] Regarding women's feelings of empowerment and control once they have their prenatal test results see, Browner and Press, "The Normalization" 319; Kohut, Dewey, and Love 274; Eisenberg and Schenker 38; Press and Browner, "Why" 985; and Mitchell and Georges 39.

[22] For more information on women's reproductive options in the event of a positive diagnosis see, AAP Policy Statement, 1994; Anderson 9; Whittle, "Ultrasound screening"; Markens, Browner, and Press 365; Browner and Press, "The Normalization" 319; Tercyak et al. 74; Brookes 138-39; Eisenberg and Schenker 37, 40; ACOG 8; Press and Browner, "Why" 986; Kingston 1368; Brown 75; Boyle 258; Institute of Medicine 83; Lippman, "Prenatal Diagnosis: Reproductive" 190; Taylor "Of Sonograms"; and Beaulieu and Lippman 69.

[23] For more information on a woman's decision to accept prenatal testing for the reassurance such procedures provide see, Press and Browner, "Why" 985-87; Browner and Press, "The Normalization" 308, 315, 318-19; Kohut, Dewey, and Love 271, 274; Himes, "Early"; Eisenberg and Schenker 38; Tercyak et al. 74; Browner and Preloran, "Latinas" 357; Browner and Preloran, "*Para*" 377; Mitchell and Georges 396; Kingston 1368;

Institute of Medicine 75, 83; Taylor "Of Sonograms"; Lippman, "Prenatal Diagnosis: Can" 4; and Lippman, "Prenatal Genetic" 25, 29.

[24] Prenatal tests are reassuring because most amniocentesis diagnoses are negative see, Tercyak et al. 74; Annas 16; Press and Browner, "Why" 985; Browner and Press, "The Normalization" 316-19; Browner and Preloran, "*Para*" 371; and Browner and Preloran, "Latinas" 357.

[25] For more information on the issue of women undergoing testing to reassure society see, Press and Browner, "Why" 984; Browner and Press, "The Normalization" 308-09, 315; Institute of Medicine 75, 83; Taylor "Of Sonograms"; Lippman, "Prenatal Diagnosis: Can" 4; Lippman, "Prenatal Genetic" 25, 29; and Browner and Preloran, "Latinas" 357.

[26] That most diagnosed disorders cannot be treated or cured see, Press and Browner, "Why" 985-87; Markens, Browner, and Press 360; Ashley and O'Rourke 250; Taylor "Of Sonograms"; Duden 76-77; and Lippman, "Prenatal Genetic" 27-28, 32.

[27] For information reiterating the view that although MSAFP and ultrasonography are routinely performed they are not mandatory procedures see, Boyle 258; Emory Genetics Laboratory, "Maternal Serum"; GAC; AAP Policy Statement 1991; AAP Policy Statement 1994; ICSI 4; Wilkins-Haug 499; Simpson 7; and Chervenak and Gabbe 125.

[28] For more information on the correlation between false-positives and increased maternal anxiety see, ACOG 2; Press and Browner, "Why" 981; Madlon-Kay et al. 398; and Holtzman 46-47.

[29] For more information on some of the benefits of ultrasonography see, Boyle 258; Mitchell 146-47; Institute of Medicine 77; Taylor "Of Sonograms"; and Thompson, Freake, and Worrall 308.

[30] That some women are unaware of the diagnostic capabilities of ultrasound see, Kohut, Dewey, and Love 266; Hyett and Thilaganathan, "First"; Mcfadyen "First"; Mitchell 148, 150; and Wolf 39-40.

[31] For information noting the fact that many women do not associate ultrasounds with selective abortion see, Kohut, Dewey, and Love 266; Hyett and Thilaganathan, "First"; Mcfadyen, "First"; Mitchell 148, 150; and Wolf 39-40.

[32] For more information on the subject of women only being educated on the basics of the screening tests see, Browner and Press, "The Normalization" 313-15; Press and Browner, "Why" 983; Mcfadyen, "First"; Mitchell 148, 150; and Wolf 39-40.

[33] For studies indicating that women are often informed predominantly about the mechanics of the test rather than the anomalies for which the test screens see, Brookes 141; Browner and Press, "The Normalization" 313-15; Press and Browner, "Why" 983-84; Mcfadyen, "First"; Mitchell 148, 150; and Wolf 39-40.

[34] For more information confirming the fact that many diagnoses are made via ultrasound in women oblivious to their risk see, ACOG 3; Kohut, Dewey, and Love 266; Hyett and Thilaganathan, "First"; Holtzman 45; and Kingston 1370.

[35] For information that discusses the false-positive rates that accompany prenatal screens see, ACOG 2; ICSI 4; Press and Browner, "Why" 981; Institute of Medicine 78; Thompson, Freake, and Worrall 312; Hall 336; Taylor "Of Sonograms"; and Wolf 35.

[36] For more information on the anxieties some women experience as a result of prenatal tests see, Madlon-Kay et al. 398; Mitchell and Georges 397; Wolf 35; Rapp, Testing 104; Himes, "Early"; Tercyak et al. 74; and Kingston 1368.

[37] For information regarding the stress that results given the possibility of false-positive or false-negative diagnoses see, Institute of Medicine 78; Hall 336; Taylor "Of Sonograms"; Wolf 35; and ICSI 4.

[38] For information attesting to the fact that with each test, women's stress builds, see Lerman et al. 785; Tercyak et al. 74; Marteau et al. 398, 400; Wolf 36; and Hall 336.

[39] Regarding women's fears surrounding amniocentesis and CVS see, Browner and Preloran, "Latinas" 353; Tercyak et al. 74; Press and Browner, "Characteristics" 438; Lerman et al. 785; and Marteau et al. 398, 400.

[40] For more information on the argument that the reassurance women claim to experience is actually misleading see, Lippman, "Prenatal Genetic" 25; Mitchell 152; Meilaender, Bioethics 54; and Eisenberg and Schenker 39.

[41] For information addressing scholars who understand how women can be reassured through testing see, Saetnan 339-40; Mitchell and Georges 396; Taylor, "Of Sonograms"; Wolf 28; and Mitchell 153.

[42] Regarding the fear of physiological complications of amniocentesis see, Rapp, "Refusing" 50, 55; Rapp, Testing 98, 167, 172; Marteau et al. 395, 398, 400; Zahed et al. 1110; and Zahed and Bou-Dames 426.

[43] Statistics addressing the increased risk of CVS see, Rapp, Testing 30; Eisenberg and Schenker 36; Himes, "Early"; and Powell 45.

[44] For more information regarding women's refusal to undergo amniocentesis due to the late stage of the test see, Rapp, "Refusing" 60; Rapp, Testing 129, 131, 179; Himes, "Early"; Press and Browner, "Why" 981; and Meilaender, "Mastering" 873.

[45] For more information on the emotional and physical trials of late term abortions see, Rapp, Testing 131; Himes, "Early"; Press and Browner, "Why" 981; and Eisenberg and Schenker 39.

[46] For more information on women's test refusals on the basis of religion, male influence, and the inability for the tests to identify conditions that concern the couple see, Zahed et al. 1109-112; Zahed and Bou-Dames 426; Durosinmi 435; Rapp, Testing 167, 177-78, 181; and Rapp, "Refusing" 50-51, 58, 61.

[47] For more information surrounding the use of prenatal testing to prevent lawsuits see, Press and Browner, "Why" 982; Markens, Browner, and Press 362; Press and Browner, "Risks"; Rapp, Testing 40; Lippman, "Prenatal Diagnosis: Reproductive" 190-91; Thompson, Freake, and Worrall 312; and Wolf 36.

[48] For more information regarding the fact that MSAFP and ultrasonography are presented to women as routine and standard practice see, Browner and Press, "The Normalization" 309, 312; Press and Browner, "Why" 987; Mitchell 148; Morgan 69-70; and Markens, Browner, and Press 362, 365.

[49] For more information on the "need" for women to bear a healthy child see, Browner and Press, "The Normalization" 309; Brookes 141; Markens, Browner, and Press 360; Lippman, "Prenatal Genetic" 27-28; Lippman, "Prenatal Diagnosis: Reproductive" 190; and Taylor "Of Sonograms".

[50] For more information on the quest for the "perfect" baby as achieved through prenatal testing see, Press and Browner, "Why" 985-87; Markens, Browner, and Press 360; Lippman, "Prenatal Genetic" 27-28, 32; Mitchell and Georges 401; and Browner and Preloran, "*Para*" 369, 378.

[51] That many women believe prenatal testing prevents birth defects see, Press and Browner, "Why" 985-87; Markens, Browner, and Press 360; Parens and Asch 34; Rapp, Testing 68; and Lippman, "Prenatal Genetic" 27-28, 32.

[52] For more information on the subject of women not refusing prenatal tests because they want to be considered "good" mothers see, Markens, Browner, and Press 360, 366; Root and Browner 218; Browner and Press, "The Normalization" 309, 315; Beaulieu and Lippman 60; Lippman, "Prenatal Diagnosis: Reproductive" 191; Morgan 69-70; Mitchell and Georges 391, 402; and Mitchell 148.

[53] For more information regarding the cost of handicapped children see, Kuppermann, et al., "Who"; Eisenberg and Schenker 39; Browner and Press, "The Normalization" 308.

[54] For more information on technology's replacement of manual obstetric care see, Rothman 24; Oakley 155, 182; Taylor "Of Sonograms"; and Duden 76.

[55] For more information on the argument that physicians rely on technology to manage pregnancies rather than the pregnant women themselves see, Thompson, Freake, and Worrall 308; Saetnan 339; Mitchell 147; Taylor "Of Sonograms"; and Oakley 155.

[56] For more information on the role of health care professionals in helping patients identify their values and then act accordingly see, O'Neill 38; Sherwin 42; Ells, "Shifting" 423; and Kenny and Ells 320, 322.

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