Perfect Babies – Perfect Parents – Perfect Pregnancies:

The Routinization of Prenatal Testing

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A thesis submitted to
The Faculty of Graduate Studies and Research
In partial fulfillment of the requirements for the degree of:

Master of Arts

Department of Sociology and Anthropology
Carleton University
Ottawa, Ontario
August 17, 2009

Your file Votre référence
ISBN: 978-0-494-58425-5
Our file Notre référence
ISBN: 978-0-494-58425-5

Abstract

Advancements in women's reproductive technology have resulted in women having to face the decision whether to undergo prenatal testing. This study explores the factors involved in women's decisions around prenatal testing and assesses the extent to which the decision making process differs between women who choose to only have limited prenatal testing and those who choose to have various forms of prenatal testing, including genetic screening. The research assesses women's role in the routinization of prenatal testing and the medicalization of pregnancy. Twenty women who have recently given birth participated in in-depth interviews in Ottawa, Ontario. Foucault's theory on biopolitics is used as the theoretical framework.

Acknowledgements

I would like to thank my supervisor, Dr. Andrea Doucet, and committee member, Dr. Janet Siltanen, for their constant support and invaluable guidance over the past two years. It was a great privilege to be able to learn from such excellent scholars. I am also very grateful to the women who generously agreed to participate in this study and who shared their experiences with me. I further would like to acknowledge the help of my parents, who gave me the strength and confidence to follow my goals. Finally, my husband, Mark, and our daughter, Aleah, have endured me during this whole process. Without their love, encouragement and patience, I would not have been able to write this thesis.

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Introduction

> The web of our life is of mingled yar, good and ill together; our virtues would be proud if our faults whipp'd them not, and our crimes would despair if they were not cherish'd by our virtue. (Shakespeare, 2004)

In his play *All's well that ends well*, Shakespeare reminds us that human life is characterized by both good and ill and that people have to learn to live with these aspects of themselves and of those around them. This passage claims that both human strengths and weaknesses are essential and interdependent elements of a good life. Thus, the 'best' life is not necessarily one in which all goes according to plan, nor is it one which can only be lived by individuals without flaw of character or of genetics.

Prenatal screening programs, in which screening is offered routinely to all pregnant women, have been implemented in a number of industrialized countries, such as Canada, the United States, Britain and Australia (Health Canada, 2002; Williams *et al.*, 2005). Testing programs tend to be marketed as having the goal to provide parents-to-be with information about the health status of their fetus so that they can make an informed decision about the progression of their pregnancy. Currently, therapeutic interventions are not available to treat most anomalies that are detectable through prenatal testing. Thus, the only options available to women who receive a non-reassuring test result (an indication that the fetus is affected with a congenital disability) are to terminate the pregnancy or to prepare themselves for a life with a child with disability (Brajenovic-Milic *et al.*, 2008: 79-80; Rothenberg and Thompson, 1994).

Prenatal testing may occur through either screening or diagnostic procedures. Screening tests indicate whether a fetus is at increased risk for congenital abnormalities, while diagnostic tests indicate whether a fetus is affected with a congenital abnormality.

Women who receive a non-reassuring result on a screening test may then be offered a prenatal diagnostic test if the chances of having an affected pregnancy are higher than the miscarriage risk associated with the testing procedure (Health Canada, 2002).

The simple existence of a technology often implies its use value, which holds particularly true in the health care field. Hofmann (2002) describes this phenomenon as an imperative of possibility whereby "that which is possible to do has to be done" (Hofmann, 2002). Action, not passivity is considered a virtue in medical culture (Fox, 2000). Physicians feel mandated, potentially due to the Hippocratic Oath, to do everything possible to make their patients healthy, and studies have shown that a preference exists to solve health problems with the use of technology (Nordin, 2001). This preference goes so far that physicians and patients alike are more likely to ask what the most technologically advanced way to proceed with an intervention is, rather than asking whether a particular intervention should be done at all. Clearly, questions about the purpose or potential benefit of an intervention are often obscured by a focus on the efficacy of the technology (Callahan and Parens, 1995). The often unquestioned acceptance of the high value of medical technologies has consequences at both the individual and societal level. Biomedical knowledge consistently outpaces the understanding of social, political, and ethical meanings and consequences of diagnostic technology to society (Gregg, 1993; Tudiver, 1993; Lippman, 1991). Even though the increasing number of available technological care and screening procedures appear to provide patients with increased choices and thereby increased control over their own care, many have suggested that the perception of a technological imperative might actually result in a reduction of patient autonomy (Anderson, 1999).

In this study, I explored the concepts of routinization of prenatal testing and of medicalization of pregnancy by examining women's accounts of their decision making about accepting or declining testing and their attitudes regarding the value of prenatal tests. I argue that most pregnant women accept prenatal testing without making a truly informed decision, thereby allowing the medicalization of their pregnancies to take place without questioning the status quo. I argue that adequate knowledge about the possibilities and limitations of prenatal testing is lacking. Furthermore, I believe that many women do not perceive their pregnancy to be at risk, but that they nevertheless accept the care and surveillance of the medical profession.

I was able to analyze how the perspectives of women who decided against some forms of routine prenatal testing differ from those of women who participated in most forms of prenatal testing. The Foucauldian concepts of biopolitics / biopower and medical gaze informed my analysis. This study adds a lacking Sociological perspective to the academic and public discourse surrounding prenatal screening and testing. Rather than focusing on the moral or the clinical implications of prenatal diagnostics, this study explored women's perspectives in the larger phenomenon of the medicalization of pregnancy. Also, the research includes both the voices of mothers of non-disabled and of disabled infants, thereby allowing for a greater understanding of women's pregnancy experiences than was possible in previous studies which tended to exclude one of those groups of mothers.

In the following chapter, I discuss the relevant issues raised in previous scholarly work. I provide a description of the relevant prenatal medical tests and of their historical development. Also, I outline the notions of risk, morality and life worth living as they

apply to prenatal testing practices. In chapter 2, called "Medicalization of Pregnancy," I discuss what it means to be normal, healthy and perfect, as it pertains to babies, parents, and pregnancies. Furthermore, I provide a secondary analysis of the routinization of prenatal testing using the routine ultrasound as an example. Also, I summarize the results of previous studies regarding informed consent and decision making in prenatal testing. In chapter 3, entitled "Methodology," I illustrate my location in the research. In addition, I explain my sampling strategy, the method of the unstructured interview, and the analytic approaches I used for the study. I also describe Foucault's concepts of biopolitics / biopower and the medical gaze, which are used in the analysis of the data. In chapter 4, I outline the characteristics of the women I interviewed. In addition, I present the relevant data from the unstructured interviews, which is categorized into the following themes: routine, risk, influence of others, guilt, I happen to love my genetic anomaly, and advice. Chapter 5 discusses the dominant themes: risk, routine, and knowledge, which stand out when viewed through a Foucauldian lens and provide a link to existing scholarly literature. I explain the conclusions of this study, its strengths and limitations as well as future research possibilities in chapter 6. The appendices include: Demographics of Interviewees, Letter of Initial Contact, Interview Guide, Letter of Information, Informed Consent, Resource Sheet, and Request for Poster Distribution.

Chapter 1: Prenatal Medical Testing

Introduction

In this chapter, I describe the most commonly used prenatal testing technologies; ultrasound, integrated prenatal screening (IPS), amniocentesis, and chorionic villus sampling. I also outline the historical development of prenatal care and the employment of prenatal testing. Furthermore, I discuss the topics of risk in the clinical care setting, morality and life worth living.

Prenatal testing includes a cluster of technologies which are primarily used to assess the genetic normalcy of a fetus in utero (Rapp, 1998: 45). More than 3,000 diseases have already been identified as having some genetic component (Kinderlehrer and Longley, 1998: 609); therefore, I will only list the most prominent conditions which are being screened for in prenatal genetic testing. Trisomy 21, or Down syndrome, is the genetic abnormality which is being tested for most frequently. In this condition, the fetal cells contain three copies of chromosome 21 instead of two. The severity of the condition varies across individuals, with some form of mental disability being always involved (Browner *et al.*, 2003: 1935). The next most frequently tested condition is failure of embryonic neural tube closure. It is often thought to be related to a lack of folic acid in the maternal diet, but it can also be of genetic origin. Embryos whose neural tube fails to close properly will develop either anencephaly, open ventral wall defects or open spina bifida. In anencephaly the brain fails to develop almost entirely and the condition is usually fatal shortly after birth. Open ventral wall defects are openings in the abdominal wall, which might be repaired after birth (sometimes even during pregnancy) and the outcome can be complete recovery or include varying degrees of disability.

Spina bifida includes opening in the vertebral (spinal) column which can also lead to varying degrees of disability, ranging from urinary incontinence to partial paralysis (Ennever and Lester, 1995: 8; Laurensen, 1983).

The most commonly employed prenatal screening tests are ultrasound and triple-blood test which is also referred to as integrated prenatal screening (IPS). If screening tests are positive or if the fetus is thought to be at risk due to maternal age or a family history of genetic disorders, diagnostic tests, such as amniocentesis, and chorionic villus sampling are used to detect conditions in the developing fetus.

Ultrasound

The use of ultrasound scanning is deeply embedded in prenatal maternity care around the world. Many obstetricians in developed and, increasingly, in developing countries already practice routine ultrasound during pregnancy (Villar *et al.*, 1999). Generally, it is used to provide information about fetal anatomy, gestational age, placental position, multiple pregnancies, and the sex of the fetus (Bashour *et al.*, 2005: 148). Ultrasound pictures are made from directing high-frequency sound waves at the uterus (SOGC, 2008: 1). The Society of Obstetricians and Gynaecologists of Canada (SOGC) recommends an ultrasound for all pregnant women at 18 to 22 weeks gestation when the fetus is easily visualized. It is sufficiently early in the pregnancy to give an accurate estimation of gestational age, and the fetus is sufficiently large for all the major organs and body parts to be examined for any defects (Alexander, Levy and Roch, 1993: 105).

Ultrasounds are considered to be non-invasive because it is generally assumed that no harm is done to the mother and the unborn child. Nevertheless, ultrasounds involve targeted energy exposure to the fetus, and some studies have found subtle effects on fetal development, including low birth weight, increased chance of postnatal death and delayed language development (Proppe, 2007; Testart *et al.*, 1982; Davis *et al.*, 1992; Kieler *et al.,* 2001). Oakley (1993) compares the routine use of ultrasound technology as a prenatal screen with the use of X-ray technology in the 1950's. At that time, X-rays had no known adverse effects on the patients. Oakley stipulates that the fetal screening ultrasound does not have a history of sufficient duration to enable a full assessment of long term use.

When ultrasounds were first used as diagnostic tools during pregnancy in the 1950s, they became quickly popular because of their apparent non-invasive nature. Also, the possibility to see the baby before it was born made the ultrasound examination an exciting and social event. However, in 1984 the media brought to public attention the possibility of some possible hazard in the use of ultrasound, especially to pregnant women (Alexander, Levy and Roch, 1993: 112). That same year, a working party was set up by the Diagnostic Methods Committee of the British Institute of Radiology to consider all evidence presently available for and against the use of diagnostic ultrasound. It was concluded that even though there is no full evidence to suggest that ultrasounds are harmful, they should only be performed for valid clinical reasons rather than just to see the baby (Alexander, Levy and Roch, 1993: 114). This way of thinking is in line with the current opinion of the SOGC, which recommend prudent use of the technology and a

limitation of energy exposure to the minimum that is medically necessary, even though the medical risks of ultrasound are only theoretical (SOGC, 2007: 364).

Integrated Prenatal Screening (IPS)

In Canada, the triple blood test is always employed first to determine the probability of any genetic abnormality in the fetus, including Down syndrome and failure of embryonic neural tube closure. It is a non-invasive test which combines nuchal translucency screening with maternal serum screening. The nuchal translucency test is done using an early ultrasound, usually between 11 and 14 weeks gestation (Kaiser *et al.*, 2004). It is used to screen for fluid collection in the fetal neck and to measure maternal serum biochemical markers (Spencer, 2002). Maternal serum screening is a blood test that basically measures if the maternal serum alpha-fetoprotein level (MSAFP) is elevated at about six to nine weeks gestation. No universal cut-off exists; it ranges from 2 to 2.5 depending on the testing centre (Milunsky, 1998). A study by Ennever and Lester (1995) has found that "with these MSAFP cutoffs, 97-99% of positive women will be false-positives" (8).

For women who undergo IPS, approximately ten to twenty percent will have results indicating an increased risk of Down syndrome or Trisomy 18. Of these women only one percent to two percent will have a pregnancy actually affected with Down syndrome, Trisomy 18, or neural tube defects (Health Canada, 2002). Due to the high number of false-positives, fetal screening using the triple-blood test is not considered diagnostic. Women whose test results are positive are offered further tests to establish a more valid diagnosis (Modra, 2006: 256; Browner *et al.*, 2003: 1935). However, women

have to wait on average two months to be able to have further testing done, which creates a lot of psychological distress in an unnecessarily high number of pregnant women and their families. In Canada, IPS is completely covered by the health care system of all provinces and territories regardless of the women's overall risk-status. In California and in parts of Europe, this test is mandatory, while in Germany individuals have to pay for it themselves unless they are members of a high-risk group (Erikson, 2003).

Amniocentesis

Amniocentesis is usually employed in cases where the IPS indicated potential genetic abnormalities. It is an invasive prenatal diagnostic test that is used to diagnose fetal chromosomal abnormalities. This procedure involves the insertion of a long needle through the woman's abdomen into her uterus in order to withdraw a small amount of amniotic fluid. The amniotic fluid is cultured and the genetic karyotype of the fetus is produced, which is then analyzed to determine if any genetic abnormalities are present (Gregg, 1995). The procedure is best performed between 16 and 20 weeks of gestation (Laurensen, 1983: 20). The predictive properties of amniocentesis are quite good with 99.4 percent accuracy in diagnosing chromosomal abnormalities. However, the test's potential iatrogenic effects[1] can be very severe, including fetal bleeding, spontaneous abortion and fetal death as the result of needle puncture or other indirect mechanisms (Laurensen, 1983: 21). In Canada, miscarriages are triggered for about one percent of all cases (Shaffer *et al.*, 2002: 86; Health Canada 2002).

[1] An iatrogenic effect refers to illnesses or injuries which result from medical interventions (Bolaria and Dickinson, 2002: 31).

Besides amniocentesis potentially posing a risk to the health of the fetus, its findings can also have severe consequences on the well-being of the mother. While women have to wait for two weeks to receive the results of their test, they are likely to have already felt fetal movement. This increases the psychological pressures and moral dilemma a woman faces if she is told that her fetus has some genetic defect. Also, a pregnancy termination at this stage of gestation can pose a health risk for the mother and for subsequent pregnancies (Rowley, 1984: 140).

Chorionic Villus Sampling

Chorionic villus sampling (CVS) is an alternative method to amniocentesis. It is an ultrasound-guided technique which obtains chorionic tissue from the developing placenta (SOGC, 2005: 1051). The advantages of CVS over amniocentesis are that it can be conducted directly after the results of the IPS are in; at eight to nine weeks of gestation, and that the results are available within 24 hours (Kuller *et al.*, 1996; Rowley, 1984). However, physicians only recommend CVS to women who have a very high chance of carrying an abnormal fetus, because the probability of having a miscarriage as a result of the procedure is double as high as it is for amniocentesis; about one in 50. Also, in some cases tested infants have been born with limb deformities (Shaffer, 2002; Kuller *et al.*, 1996).

History of Prenatal Testing

The intense care and application of diagnostic procedures during pregnancies is a relatively new phenomenon. A number of historical events, including wars,

developments in medical, genetic and statistical research and social and cultural phenomena shaped the type of risk assessment strategies which are employed today. These events also help to understand the modern significance of prenatal diagnostic tests.

Profound changes took place regarding medical theory, practice, culture and institutions during the early nineteenth century. McGee (2000) claims that the medicine of 1790 would have been recognizable to Hippocrates and Galen while the medicine of 1900 would be recognizable to us today (92). In the early 1800s, first and most prominently in France, the use of tests and instruments began to replace the testimony of the patient in the encounter between patient and care provider. Physicians began to control medical examinations through the introduction of a variety of medical testing devices. In modern times, it has become hard to imagine a physician who does not carry a stethoscope. This drastic change in medicine was the first important step towards routine prenatal testing.

Until the beginning the twentieth century, only a few very wealthy women consulted physicians for pregnancy care, and most of the focus on risk reduction was placed on the birthing process (Oakley, 1984: 28-32). The rising medical interest in pregnancy during the early twentieth century corresponds with the formation of the fetal welfare movement. About three decades after childbirth was routinely managed and controlled in clinical settings, pregnancies also became problematized (Skocpol, 1992). In Canada, public education training programs were starting to be offered during the time of the First World War to educate women about healthy pregnancies and motherhood. The aim of these programs was to build a stronger nation, since it was held that "nations are built of babies" (Arnup. 1994; Davin, 1978) and because only healthy babies make

strong soldiers. During the interwar period, routine prenatal care became standard practice with the dual goal of reducing fetal mortality and preserving maternal health (Mitchinson, 2002: 158).

The shift of the management of health on an individual level to the management of health at the level of populations was also relevant in shaping the development of prenatal diagnostic techniques. Vital statistics had become popular during the time of the World Wars, and prenatal mortality was added to the list of official mortalities in Canada by the end of the 1940s. "Official vital statistics do more than count deaths; they represent targets for national and subnational health systems to reduce" (Weir, 2006: 28). Therefore, the governance of pregnancies and the introduction of risk assessment strategies became important, and widespread prenatal risk assessment had already entered clinical practice by the late 1960s (Weir, 2006: 27).

In addition, the developing new science of genetics had important contributions to the development and application of prenatal diagnostics. Watson and Crick first analyzed the structure of deoxyribonucleic acid (DNA) in 1953, and by the middle of the 1960s, researchers were already able to perform karyotyping. They could extract fetal chromosomes through amniocentesis and photograph and systematically order them on the basis of physical characteristics (Singer *et al.*, 1998: 633; Hilton, 1972: 8). The race began to identify markers for an increasing number of genetic abnormalities.

A real revolution of prenatal medical care happened with the introduction of the diagnostic ultrasound in the mid 1950s. Physicians started to use ultrasound to scan for abdominal tumors, many of which turned out to be pregnancies (Neilson and Grant, 1989). The technology was developed further and in the 1970s, sonographers were able

to produce a real-time picture with a dynamic image of the fetal structures in utero (Milne and Rich, 1981). Ian Donald of Scotland, who pioneered the use of ultrasounds to examine fetal growth, made a speech in the mid 1970s, that 'The day may come shortly when routine ultrasound examination will be offered to every pregnant patient' (Alexander, Levy and Roch, 1993: 112). Donald was right; ultrasound technology developed quickly and it is currently the most common form of fetal prenatal testing.

Two forces were pushing the social impact of the new genetic screening techniques into opposing directions. Prior to the 1980s, the legal restrictions against abortion were still almost universally in force, which reduced the usefulness of prenatal genetic tests. Hilton (1972), for example, describes that a book on genetic counseling published in 1970 had only half a page of information on amniocentesis (8). However, the 1960s also saw an increased public fear in infant disability. Thousands of infants were born with deformation due to the impact of thalidomide, and people began to demand in increasing numbers the legalization of abortion (Landsman, 1998: 79). The second movement eventually won, and medically indicated abortions became legal in most of the Western world.

Risk in Clinical Care Settings

> Nothing is a risk in itself; there is no risk in reality. But on the other hand, anything can be a risk; it all depends on how one analyses the danger, considers the event (Ewald, 1991: 199).

In order to fully understand why risk factors are treated the way they are in clinical care settings it is important to review what it means to 'be at risk' and how this concept was shaped in medical discourse. In the 17th century, the theory of probability

was developed by Pascal and de Fermat; however, it was only applied to gambling theory. These probability theories were further elaborated and led to the introduction of statistical thinking in the 19th century, which was soon applied to medical events and to the epidemiological studies of risk (Finkler, 2003: 53). Statistical methods rely on the production of normal probability curves which contributes to a division of various human aspects into normal or pathological, backed up by science.

Prior to the Renaissance, individuals in the Western world believed strongly in the religious notion of predestination and that any risks were solely in control of God. It was assumed that "God simply chooses those he will save without regard to his foreknowledge of their lives... God knows the world by knowing himself" (Sanders, 2007:153). Through the emergence of science within all aspects of social life, religious predestination was replaced by probability, thereby making human life much more random than it had previously seemed. Before, people could assume that their life would take a meaningful path as determined by God and that any diseases or disabilities they would encounter along the way came to them for a reason. During the Renaissance, people learned that they could influence their own life through specific actions; "Man creates the world" (Heller, 1984). However, individuals also realized that diseases would often occur unexplained.

The advent of genetics and of genetic inheritance in the 20th century reintroduced a sense of determinism into medical discourses, giving the notion of risk a whole new meaning. Now, every individual who has a family history of a disability is considered to be at risk, but the person's future can potentially be controlled as long as the risk factors are managed and reduced (Finkler, 2003: 55). Nevertheless, one of the biggest problems

in medicine is that "our inheritance is neither determined nor controllable at present" (Finkler, 2003: 63). Inheritance of specific traits is only avoidable through a pre-selection of embryos during in vitro fertilization and through medically indicated abortion, a notion I will discuss further.

The concept of risk can take on a variety of meanings. Originally, risk is derived from the Italian word 'risco,' meaning danger. And similar to danger, risk represents an uncertain event (Errington and Chruch, 2005: 32). Ruhl (1999) explains that risk could either be perceived as danger or as probability. However, since danger incorporates a sense of uncertainty, I do not agree with this distinction. In the context of prenatal testing, both risk as danger and risk as probability are applicable because any given risk factor implies the probability of threat or danger. This type of thinking helps to understand why all pregnancies are considered to be at risk; "threat is everywhere; no one is entirely safe, merely more or less statistically vulnerable" (Ruhl, 1999: 101). During the first prenatal visit, all women are screened for a variety of risk factors, such as age, weight, physical fitness and family history of disability. Depending on the outcome of this assessment, the pregnancy is placed into one of two possible categories; low-risk or high-risk. A no-risk pregnancy does not exist in this context. The same holds true for any other life event, it just becomes more obvious during the course of a pregnancy. For any individual it is impossible not to be at risk, "instead, individuals and populations are judged for degrees of risk – low, moderate, or high – vis-à-vis different conditions and diseases, and this then determines what is prescribed to manage or reduce that risk" (Clarke et al., 2003: 172).

The concept of prenatal care, during which a pregnant woman's risk status is determined, developed during the 20th century. Before that, pregnancy was an entirely private and female matter that did not require medical supervision or intervention. It has become the type of care we know today predominantly because pregnancy itself became pathologized and because the focus shifted from the health of the pregnant woman to that of the fetus.

As I had explained previously, the perception of an uncomplicated pregnancy as a normal event changed to that of a potentially pathological state (Barker, 1998). This new perspective positioned pregnancy within a disease model, postulating that only physicians had the skills and technology necessary for accurate diagnosis. Women's own knowledge and experiences of pregnancy were discarded. Public health programs aimed specifically at expectant mothers came to highlight the precariousness of pregnancy, and emphasized the responsibility of the women for self-regulation and proper care to ensure the birth of a healthy infant at the end of her pregnancy (Barker, 1998). Thus, all pregnancies were assumed to require medical supervision and medical prenatal care became the norm in modern Western society.

At the same time, with the introduction of prenatal care for the masses, a shift took place from an emphasis of the mother's health to an emphasis of the fetal health. Now, medical interventions are deemed necessary because of the concern to produce healthy adults thereby perfecting society in the long run. Prenatal care has shifted from being a private concern to becoming a social concern because of the fetus's role as a future family member and as a productive citizen of a nation (Findlay, Miller, 2002: 192). Weir (1996), who wrote extensively on the governance of the fetus, points out that the

fetal body has become the primary object for the problematization of risk within a society in which prenatal care is characterized increasingly by population-based risk techniques. She explains that in Canada, risk is attached to the pregnant women in clinical practice through three separate processes:

> Standardized risk assessment authorized by each provincial and territorial ministry of health for all women undergoing antenatal care; routine prenatal screening tests for all pregnant women; prenatal diagnostic testing where authorized by indications of 'increased risk', either as a result of positive results from screening tests or due to clinical indication (Weir, 1996: 379).

Thus, just as the fetus becomes an object within biomedicine, the "pregnant body has become the subject" of a variety of medical interventions (Weir, 1996: 379). I speculate that Foucault would describe the fetus as an object of knowledge, and the pregnant woman as a subject of power.

This increasing concern of health in our Western culture, as well as the medical profession's need to maximize their societal status and to extent their fields of jurisdictions "have encouraged an ever-widening conception of the conditions that require medical management and treatment (Schur, 1983: 93). This hold of power over life is what Foucault considered to be one of the basic phenomena of the nineteenth century (Foucault, 1997: 239). It is best understood in reading Foucault's *The Birth of the Clinic* that only through the growth of modern medicine around the seventeenth and eighteenth century, it became possible to regulate populations in order to maximize life itself. Also, in order to link medicalized pregnancy to the regulatory powers of biopolitics, we have to remember that "it was the taking charge of life, more than the threat of death, that gave power its access to the body" (Foucault, 1989: 143).

Weir (2006) uses the term 'clinical risk' for the specific type of medically defined risk as it applies to the developing fetus. It includes the judgment of risk using an epidemiological knowledge of risk in populations as well as the judgment of normal and pathological in the clinical care setting of a single individual. These two judgments of risk are not as easily compatible as it appears in clinical practice. While epidemiologists calculate risk through the study of a population, thereby allowing for the production of probability statistics, risk in the clinical setting only applies to single individuals, and is therefore not calculable. "Technically speaking, risk in clinical care is uncertain; the outcome from an exposure may be positive or negative, and this can only be known in the future, not at the time of care" (Weir, 2006: 65). Thus, common risk factors which are determined through epidemiological studies and principles become equated with clinical signs, making it appear as though a disease is already present.

It is further problematic to use population risk statistics in clinical diagnostic settings because most individuals have difficulty with the concept of probability. While individuals are expected to base their decision for or against a specific test on statistical information provided by their clinician, it is likely that the information will be misinterpreted (NCCWCH, 2008). Rowley (1984) has found that people tend to convert any risk statement, for example, a 1 percent chance of having a child with Down syndrome, into a binary statement; thus, it will either happen or not. "They then may visualize the worst outcome and judge whether or not they could cope with it" (Rowley, 1984: 143). The actual risk of the occurrence is being ignored.

In addition, research has shown that the way in which this risk information is presented can affect the choices women make regarding testing. For example, women

understand risk figures differently if they are given as percentages or as proportions (Gates, 2004). Also, risk may be perceived differently if it is presented in a positive rather than a negative light. Williams and colleagues (2002) interviewed an obstetrician who describes this variation in women's reaction to the same risk figure, depending on the difference in presentation; "If you scan people and you say, 'You have a 1 in 200 risk of Downs', they say, 'Is that good or bad?' And then you say, 'I'll put it another way. This baby is 99.5% likely not to have Downs', and they say, 'Oh well, I wish you had said that first'" (Williams *et al.*, 2002: 344-345). Other studies have shown that women often fail to entirely understand the idea that a low-risk result does not guarantee a healthy infant, and that a high-risk result does not necessarily mean that the fetus is affected (Pilnick *et al.*, 2004). Further, it has been argued that the simple offer of a prenatal screening test alters women's perceptions of their own risk in that it arouses the idea, which might have been previously not thought of, that something could be wrong with the fetus (Lobel *et al.*, 2005).

After the initial prenatal risk assessment, every pregnant woman is advised to follow measures of both risk management and risk avoidance or risk reduction. Pregnant women are predominantly taught by their healthcare providers, their friends and family, and mothering books and magazines. Women quickly learn that anything they do which potentially increases the risk for the infant, no matter how negligibly, "is irresponsible and un-maternal" (Kukla, 2007: 17). The available prenatal screening and diagnostic techniques are employed over the course of the pregnancy to mediate the woman's risk and to avoid any further risk, specifically that of delivering a child with disabilities (Erikson, 2003: 1993).

Even though this thesis focuses specifically on the use of prenatal medical tests, it is important to outline that the notion of risk plays a role in all aspects of a pregnant woman's life. Pregnant women are expected to live as healthy as possible in terms of diet, exercise, and life-style habits to increase the possibility of having the best fetus possible. Beaulieu and Lippman (1995) conducted a content and discourse analysis of articles in ten major North American women's magazines and they found that pregnant women are told that they may be dangerous to their fetus. The authors state that the dominant message of the articles is that women must be scientifically informed and must be "knowledgeable about the risks they may face, about how these risks can be recognized or diagnosed and about how they can neutralize them" (Beaulieu and Lippman, 1995: 65). It is relevant that only scientific knowledge coming from expert-gynecologists, obstetricians or geneticists can be considered valid knowledge since the greatest risk to the welfare of the fetus stems from medical problems. Apparently, the information in the magazines is framed to present a clear choice to the women, which is either the birth of a normal and healthy infant or the preventable birth of a somehow 'defective' infant, whose condition could have been found using prenatal testing had this option been chosen (Beaulieu and Lippman, 1995: 71-72).

All of the diagnostic technologies used to test for fetal abnormalities can potentially pose a risk to the health of both mother and fetus itself and, in some rare cases, the tests have found abnormalities where there actually were none. These negative effects of prenatal testing have been found to be ignored in popular women's magazines. Articles dealing with the benefits of getting tested neither outlined the potential iatrogenic effects of the tests, nor did they include a discussion of how women and their families

make decisions after receiving testing information which reveals problems with the fetus (Beaulieu and Lippman, 1995). Also, in the clinical setting women are counseled to weigh the risk of missing a fetal abnormality against the risk of miscarriage due to testing. Both potential outcomes are assumed to be equally undesirable by clinicians (Ennever and Lester, 1995: 8-9). This type of thinking ignores both the possibility of labeling a normal fetus defective due to wrong test results and the woman's preference of outcomes as she might not regard a fetal loss and a fetal abnormality in equal terms. In addition, this counseling strategy makes it appear as though every time no abnormalities are found the fetus will be born normal. Of course this is not correct, damage can occur during the birthing process and at any time later in the child's life, an aspect dismissed in prenatal care counseling.

In a variety of studies (see Garcia *et al.,* 2008; Jaques *et al.,* 2004; Root and Browner, 2001; Santalahti *et al.,* 1998), women explained that they feel a general push by society to accept testing. In the Western world, "those who choose not to use testing or choose to continue affected pregnancies are increasingly regarded as irresponsible" (Modra, 2006: 260). Accepting prenatal testing was presented as patient compliance rather than as individual choice in popular women's magazines. Especially for women over the age of 35, declining testing was presented as challenging mainstream biomedical assumptions about how pregnant women that age should behave (Beaulieu and Lippman, 1995: 59). Garcia and colleagues (2008) found that women who declined prenatal testing felt that society would hold them accountable for any negative consequences of their decision, "even when they felt confident that they could deal with an affected child"

(117). On the same note, individuals who accepted to be tested mentioned that the social assumption that disabled children should be aborted influenced their decision.

Pregnant women who are not over the age of 35 and who do not have a family history of disability cannot choose to have either amniocentesis or CVS without being found to be at risk through the use of the triple-blood test. Only those women who are determined to be at an increased risk of having an infant with some form of disability are offered further and more reliable testing (ACOG, 2007). Of course, this can be considered to be a form of pressure to have the triple-blood test done even though it is highly unreliable.

A woman's age is the most important individual factor which can place her into a high risk category, regardless of her health status and her family's medical history. A distinction is made between women 35 years old or older and other pregnant women. Their age implies a risk to the developing fetus; the women are therefore considered to be at high-risk, which must be managed as closely as possible (Beaulieu and Lippman, 1995: 60). In 1990, advanced maternal age was the sole indication for testing for almost 80 percent of women who participated in prenatal diagnosis (Hamerton *et al.*, 1993). For decades, medical scientists have known that the chance of giving birth to an infant with almost any genetic disorder increases with maternal age (Laurensen, 1983). Therefore, women over the age of 35 are advised to undergo varies forms of prenatal testing. Beaulieu and Lippman (1995) found in their systematic review of women's magazines that the "articles recommend amniocentesis for the 'older' woman, including those who plan to have a baby no matter what the tests reveal." (69) Thus, risk assessment is presented as uttermost importance. Medical scientists have long argued that the age of 35

is rather arbitrary, because the possibility of a genetic abnormality increases steadily with age, even among younger women (Laurensen, 1983: 25). Therefore, last year, the American College of Obstetricians and Gynecologists revised its earlier statement to only offer amniocentesis or chorionic villus sampling to women over the age of 35 or those with known risk factors. Now, "all pregnant women, regardless of their age should be offered screening for Down syndrome" (ACOB, 2007).

Morality

Life in Western societies is strongly influenced by a capitalist and neo-liberal ideology and the current state of reproductive medicine is not spared by this ideology. Capitalism is most broadly defined by production and consumption. Priority is placed on the smooth running of the ever expanding economy, which is only possible through productive hard-working labourers and a steadily consuming public. It becomes apparent that capitalist societies are in need of healthy bodies, since these tend to be the most productive and independent ones. This explains why health is considered such an extremely important possession (Clarke et al., 2003). Health is considered a commodity in capitalist societies, meaning it is both an individual goal and it needs to be maintained through the routine consumption of health care products, medical interventions and risk assessment strategies (Nichter, 2003). Since it is the individual's responsibility to be healthy, just as it is a mother's responsibility to bear a healthy child (Parker, 2007: 280), health is turned into an individual moral responsibility. Clarke and colleagues (2003) explain that it is "the individual moral responsibility to be and remain healthy" (171).

Therefore, giving birth to a normal and healthy child can be considered a social and moral responsibility in capitalist society.

Furthermore, reproduction itself is understood as a form of production within capitalist culture. In this line of reasoning, children who are born with disabilities are not only 'defective' in the medical sense, but are also 'defective products' of birth. These children do not meet any standards of commodity uniformity or normalcy and are therefore classified as disabled, defective or damaged (Landsman, 1998: 77; Phillips, 1990: 850; Martin, 1987). Mothers who make the choice to bear children with disabilities, either by not undergoing prenatal genetic diagnostics or by choosing to keep the child which society deems defective, weaken the economic structures of capitalist societies since neither them nor their children can be considered fully productive members (Scheper-Huges and Lock, 1987).

To ensure that all members of society can function and be productive at their full potential, harm reduction becomes an important measure. Harm reduction as envisioned on a continuum can be as simple as taking a daily vitamin pill (Nichter, 2003), which all pregnant women are expected to do, or it can be as severe as abortion to avoid an infant with disabilities at all costs. It is important to remember that no treatment options of monogenetic disorders exist as of today. Very little research money is spent on trying to develop some cure because research effort is not considered to be economically viable (Kinderlehrer and Longley, 1998: 615-616). Ruhl (1999) even considers the more cost-effective practice of medically indicated abortions as a form of eugenics, when she says "The interiorization of eugenics suggests that eugenic norms have been internalized so that no outward discussion of the terms of prenatal diagnosis is required. It is simply

assumed that a positive result will end in abortion, since this is seen as more responsible than giving birth to a child with known birth defects" (112). I do not completely agree with Ruhl's remark, since the decisions parents make to abort or not after receiving the results of prenatal testing are very private and include a number of other considerations. However, I do believe that the consequences of these decisions in their collective may not be as different at the societal level as social policies which are intended to alter a population's genetics.

Traditionally, medical diagnostic procedures are designed, implemented and evaluated based on the goal of reducing or eliminating the burden of disease in a population. Similarly, prenatal testing techniques tend to be evaluated by taking into account participation rates and disabled births prevented. This approach has been widely criticized because of its underlying eugenic aims, which is something that both governments and the medical community try to disassociate themselves from since the discreditation of the eugenics movement following World War II. Thus, prenatal testing is being promoted as increasing pregnant women's informed choice rather than having the termination of affected pregnancies as its goal. This may, at least partly, explain the discomfort of healthcare providers to discuss the possibility of abortion during consultations (Kerr *et al.*, 1998). Nevertheless, women are offered to have their fetus screened for specific traits and to make subsequent decisions about the course of their pregnancy. This offer itself implies that whatever the test screens for is considered problematic and can be either eliminated or at least requires special consideration before being allowed to be born.

One of the most widely reported observations in the literature is that discussions about prenatal testing tend to focus almost exclusively on the technicalities of the procedures, rather than on questions such as why the testing is done in the first place (Williams *et al.*, 2002; Press and Browner, 1997). Particularly the ethical issues of screening are avoided (Press and Browner, 1995). Care providers rarely talk about the possibility that one might have to make a decision about abortion. The same holds true for information pamphlets, which are handed to all pregnant women as an educational tool to address the lack of time care providers have to discuss screening with women. Press and Browner (1995) found that most of the space on the pamphlets is taken up with procedural details and explanations of the many benign reasons why women may receive a false positive test result. However, only limited information was provided about the conditions tested for, and a discussion of the available options should an abnormality be found was relegated to a small paragraph on the last page. Given that the only possible treatment option for most of the potentially diagnosed abnormalities is a termination of the pregnancy, the authors were particularly critical of the fact that abortion was never directly mentioned (Press and Browner, 1995). Other studies have come to similar conclusions and have confirmed the bias of the information pamphlets towards inclusion of technical details and omission of information about the potential disabilities, or of the emotional and moral consequences of a positive test result (Michie *et al.*, 2003; Bryant *et al.*, 2001).

Research has found that the medical profession views it as the moral responsibility of pregnant women to learn all that is possible about the unborn child. The knowledge is valued highly because it is medical knowledge (i.e. the knowledge has high

intrinsic value because it was obtained using complicated technology), and because it is thought to reduce threats to the fetus, who tends to be represented as extremely fragile and vulnerable in expert discourses (Weir, 1996: 373). Williams and colleagues (2002), who interviewed healthcare professionals on the capacity of truly informed consent for prenatal testing, explain that to obtain all possible knowledge that is available from healthcare technology is often described as a moral imperative in itself. "Being screened is a duty; evasion is tagged as irresponsible behaviour, a moral dereliction" (Williams *et al.*, 2002). Again, women are told to get tested but they are not told about the consequences that the test might have for them, their pregnancy and their family.

Most women whose fetuses are diagnosed with major birth defects during testing make the decision to terminate their pregnancy, regardless of their intentions prior to testing (Green, 1994), and often they feel pressure to do so. Marteau and Drake (1995) distributed questionnaires to healthcare providers, pregnant women and the general public and found that mothers who declined prenatal testing were perceived as having had more control over the outcome of their pregnancy, and that they were partly blamed if they gave birth to a baby with Down syndrome, as opposed to mothers who were not offered testing. This blame was observed in geneticists, obstetricians, pregnant women, and the general sample of men and women. Similarly, Santalahti and colleagues (1998) describe how many women feel pressured by their physicians to abort in the case of an affected child. This pressure tends to be indirect without directly recommending abortion, but that abortion was assumed to be the natural response to a positive test result.

Additionally, research has shown that a perceived lack of social support systems for people with disabilities can influence women's decisions about prenatal testing

because it affects the women's perception of their capacity to cope with and care for a disabled child (Williams *et al.*, 2002; Rice and Naksook, 1999). It has been recognized that the increase in participation in prenatal testing has further contributed to a lack of understanding and acceptance of people with disabilities. Proportionally, fewer infants are being born who have a disability that is screened for by prenatal testing; thus, parents-to-be have less exposure to disabled individuals and their families (Williams *et al.*, 2002).

Life Worth Living

It becomes apparent that every pregnant woman is placed into the role of a moral philosopher when deciding for or against prenatal testing procedures and how she will deal with the results of the testing. The context of the new technologies forces women to make judgments as to what constitutes a life worth living (Rapp, 1998: 46). Courts refuse to answer this question (see *Becker v. Schwartz*, 1978)[2], while ethicists have written extensively on the topic without coming to any conclusion. The question of what is a life worth living includes a variety of other questions, such as what is a normal infant and who makes that decision? Is it possible to rank possible lives as better or worse? And can medically indicated abortions be considered eugenics?

Davis (1997) provides a possible explanation. He claims that giving birth to a child with a previously known disability does not imply that the mother intended to harm

[2] Mrs. Becker (age 37) gave birth to an infant with Down syndrome. She sued her physician arguing that he had not advised her of her increased risk to bear a child with Down syndrome, which she would have aborted if she had known. The Beckers sued the physician for "physical injuries, for psychiatric and emotional distress to themselves, for medical costs, and for institutional expenses in caring for the child born with a genetic defect. They also sought damages on behalf of the child for wrongful life" (Fox, 1980: 36). While the court agreed with all of the first points, it did not make a decision as to whether or not the child's life is life worth living. The court stated: "Whether it is better never to have been born at all than to have been born with even gross deficiencies is a mystery more properly left to the philosophers and the theologians" (Fox, 1980: 36). The court ruled that the physician has to pay for the care of the infant (Laurensen, 1983).

the child. In this regard, a woman cannot possibly harm a child by giving birth to it regardless of its condition because otherwise it would not have been born at all (11). Steinbock and McClamrock (1994) have an opposing view on the topic. They believe that good and responsible parents would not bring a child into the world when they cannot be sure that the child will have a decent chance of a good life (12). The problem with both of these philosophical explanations is that they cannot help a woman determine how much harm a child might actually suffer due to some genetic condition and what a good life consists of. When women make decisions about prenatal testing and whether their 'defect' fetus would be harmed by being born, they have to struggle with an assessment about a past which has not yet occurred.

The issue of a life worth living becomes even more complicated when taking into account the expanding technological care and climbing survival rates of pre-term infants. The treatment of infants with birth weights of at least 500 g and/or those born at a minimum of 24 weeks gestation has been accepted and regular practices since the 1980s. Children born with such an extremely low birth weight have been shown to be at a very high risk for pulmonary and central nervous system injuries, which leads to conditions including mental retardation and cerebral palsy (Landsman, 1998: 71). It is obvious that these children represent a life worth living within the medical system, even though they are already at a very high risk to become 'abnormal' at the time labour starts. One may argue that these infants are kept alive under all circumstances because they are already persons due to the fact that they have been born. Nevertheless, it is interesting that the medical system treats two risk factors in such opposing manners; a genetic abnormality

and an extreme low birth weight, even though both are likely to lead to the same outcome.

Conclusion

This chapter explained the methods of prenatal screening and diagnostics that are most commonly employed in Canadian health care. I reviewed the risks and benefits of each procedure and the historical forces that shaped their development for medical use. Furthermore, I explored how the notions of risk in the clinical care setting and morality influence women's uptake of, and their resistance towards, prenatal testing. The chapter ends with a discussion about the question of what constitutes a life worth living. In the following chapter I summarize previous scholarly work on the medicalization of pregnancy in relation to prenatal testing.

Chapter 2: Medicalization of Pregnancy

Introduction

The medicalization of women's lives is real and apparent in Canadian society and the increasing use of prenatal medical testing represents one important aspect of that phenomenon. Most of the contemporary literature defines medicalization as the increased medical control over all aspects of women's lives and bodies, legitimized by regarding a normal bodily state as a medical condition (Freund *et al.,* 2003: 207; Bolaria and Dickinson, 2002: 185; Warren, 2000: 181; Zola, 1972, 1991). In the following sections, I explore how the issue of medicalization in the context of prenatal testing has been discussed in the literature. Specifically, I provide an overview of the scholarly work in relation to what constitutes a perfect baby, a perfect parent and a perfect pregnancy. I summarize the findings of previous research on the routinization of prenatal testing, and I discuss the routine ultrasound in greater detail as a specific case. Finally, I illustrate the importance of informed consent and decision making in prenatal testing.

Perfect Baby

A widespread belief in contemporary society is that every woman in our society wishes for her child to be born healthy. It is not unusual to hear a pregnant woman or her family members say that they do not care about the gender of the child as long as it will be healthy. However, what does it mean to be healthy? Commonly, health is understood as the absence of disease. When health care providers refer to the healthy baby, they are making a kind of reverse diagnosis; the infant born without any symptoms of illness is considered healthy (McGee, 2000: 116). However, Herzlich (1973) illustrates that the

difference between health and illness is not as clear-cut as it may appear. Both are considered to be complex experiences which are not reducible to one single explanatory factor.

In the context of pregnancies, health tends to be equated with being normal; however, the definition of normalcy is just as subjective as the definition of health. While one person might consider a normal infant to be one who is free of any physical and mental disability in the strict medical sense, another individual might think of a range of classified disabilities to be normal. For example, research has shown that some deaf parents regard their child's potential deafness as a benefit, rather than a risk or abnormality (Davis, 1997: 7). It becomes apparent that the distinction between healthy and disabled as well as between normal and pathological is much more fluid than it is presented in the medical discourse.

Nevertheless, the pressure in our society is high for women to produce children that are normal, meaning free from physical and mental disability (Dixon, 2008: 8), and prenatal medical testing is employed to ensure the fetus' state of normalcy. The technological testing requires the use of a classificatory system that defines normalcy and abnormality. During testing, every fetus is judged against this standard model; thus, normalcy is determined by the tests' cut-off scores (Lauritzen and Hyden, 2007: 1; Clarke *et al.*, 2003: 172; Ewald, 1990).

According to Foucault, the norm always circulates between the disciplinary and regulatory, where disciplinary power relates to control over individual bodies operating through institutions, and the regulatory power relates to control over life itself at the level of populations. "The norm is something that can be applied to both a body one wished to

discipline and a population one wishes to regularize" (Foucault, 1997: 253). Thus, the norm of disciplinary power and the norm of regulatory power intersect in the normalizing society. Both disciplinary and regulatory powers come together in pregnancy through biopolitics and the medical gaze. This gaze represents the surveillance onto which disciplinary power is based. These Foucauldian concepts, biopolitics and medical gaze, are further elaborated in chapter three.

Perfect Parent

The fact that most pregnant women undergo prenatal genetic testing is also related to the definitions of children and parenthood within Western ideology. In modern times, becoming a parent is assumed to be a choice rather than an obligation. It is usually perceived that women choose to have children instead of having an extensive education or career, for example, or that they choose to have children later in life to complete their education first. Therefore, "each child must be born 'worth it' in relation to other options available" (Landsman, 1998: 73), and technological testing is the only insurance to have this perfect child. Parents might be attracted to genetic screening and diagnostics because they feel it enables them to participate scientifically and systematically in the construction of their perfect baby (Lupton, 1999: 69; Lippman, 1991).

Prenatal diagnosis makes it appear as though it is possible for every woman to have a perfect and normal child; infants born 'less-than-perfect' are considered to be the result of parents' less-than-perfect choices. Normalcy is connected to moral identity in Western society. Both the disabled infant and its parents are labeled as non-normal, which is associated with badness and deviance. The stigmatizing effects of this label are

very negative and they are especially strong because the label is deemed to have been avoidable.

Parents of 'defective' children are not only stigmatized because they are thought to have failed to reduce their risks by not having done prenatal testing. Mothers are also often blamed for any of their children's conditions; they must have done something wrong during pregnancy. The mother is held responsible for the outcome of her pregnancy regardless if she could have done anything to prevent the child's condition (Ruhl, 1999:110). A study by Lawson has found that women who chose to either not have prenatal testing or to give birth to a child with disability following a prenatal testing diagnosis are perceived by both the general society and physicians as less deserving of sympathy and social aid to help them raise their child (Lawson, 2003). It is evident that in our society good parents participate in prenatal testing. Testing increases levels of knowledge and information over the course of the pregnancy and it involves technology, all of which are valued highly in the Western world (Suter, 2002). It is likely that pregnant women are aware of these perceptions and values and that women feel pressured to undergo prenatal testing, thereby limiting their reproductive autonomy.

The responsibility for a good and successful pregnancy lies predominately with the parents-to-be, specifically with the pregnant woman. This responsibility is stressed in contemporary handbooks for pregnant women, which tend to highlight the most extreme views in medical discourses on the risks that could potentially affect the unborn child. Women are taught a long list of both expected and unacceptable behaviours which relate to every aspect of their lives. For example, The North-American bestselling book "What to Expect When You're Expecting" by Murkoff, Eisenberg and Hathaway (2002) outlines

that pregnant women should avoid any consumption of alcohol and tobacco, avoid sugar substitutes, not take spa baths, ensure that their microwave ovens do not leak potentially harmful microwaves, not use electric blankets, avoid having diagnostics x-rays, be careful in using household cleaning products and insecticides and not take prescription or over-the-counter therapeutic drugs (even headache pills) if possible. Readers are further advised to embark on a careful diet that maximizes vitamins, protein and minerals and avoid all sugary and fatty foods. Pregnant women are expected to attend regular pregnancy check-ups, and undergo a series of urine and blood tests and internal examinations. Their weight and blood pressure should be regularly checked by their caretaker and the book explains when to participate in other medical tests, such as ultrasounds and IPS.

It becomes evident that pregnant women are deemed responsible for the wellbeing of their pregnancy; thus, their own health and that of their fetus. This focus on self-responsibility for one's health first began to emerge as a governmental strategy in the eighteenth century, which helped to ensure that pregnant women would participate in this medicalization of pregnancies. Health became "at once the duty of each and the objective of all" (Foucault, 1984: 277). Foucault claims that from the middle of the eighteenth century, the family unit became a particularly important element for governmental surveillance and disciplinary purposes, developing into "the most constant agent of medicalization" (280). The problem of the child was constructed through discourses on the regulation of the family, with parents, especially mothers, being charged with the responsibility of monitoring and facilitating their children's development and health. Since then, women have been constructed as active citizens

predominantly through their responsibilities in caring for the health and wellbeing of others, which they are expected to do as wives and mothers. Women's efforts in "fulfilling these responsibilities are aligned with those of the state through risk and public health discourses." (Lupton, 1999: 62)

Parental autonomy is held higher during prenatal doctor visits and genetic counseling than in any other area of medicine, specifically because clinicians try to avoid the label of abortionist, because no treatment is available for genetic conditions, and because reproductive issues are considered to be a very private matter (Davis, 1997: 7-8). However, autonomy is a double-edged sword. While autonomy allows parents to choose to have testing done and to decide on how to handle the results without coercion from the medical practitioners, it assumes that the complete responsibility of all actions taken lay with the decision maker (Garcia *et al.*, 2008: 115; Fineman and Walton, 2000: 41-42). This explains why the parents and even more so the mothers of disabled children are blamed for their children's conditions.

In our society, not only the mothers of disabled children are stigmatized for their choices. Prenatal diagnostics carry a risk of miscarriage, and when a pregnancy is spontaneously aborted because of the effects of a test, the woman likely feels regret and guilt because she would be deemed responsible for the loss of a healthy child. Similarly, a woman who terminates a pregnancy because her fetus is found to have some genetic predisposition will have to live with the label of being a woman who has had an abortion (Garcia *et al.*, 2008: 118; Scully *et al.*, 2007: 211).

Perfect Pregnancy

To regard pregnancy as non-normal and therefore as a pathology relates to the historical practice of medicine to regard anything deviating from the functioning of a healthy male body as disease. Prior to the middle of the twenty-first century, all medical research was conducted on adult men, thereby taking the male body as the norm for all other members of society; women, children, and the elderly (Martin, 1987). As a result, many of the basic bodily functions of women, specifically those relating to the reproductive system, were regarded as problems which required medical interventions (Findlay & Miller, 2002: 187).

In addition, the philosophy of Rene Descartes was very popular during the time of the Enlightenment, and it has influenced the path of modern medicine. According to Descartes, the human body represents a machine; disease occurs when this machine breaks down. Thus, it is the physician's task to repair the bodily machine (Straub, 2002: 14-15). Multiple machines of the same type and function are identical to each other, which makes it possible to standardize procedures of maintenance and repair. However, human bodies do not usually resemble each other in the same way machines do, and their functions vary widely across ages and the sexes, as well as within age groups and the sexes. Nevertheless, physicians have tried throughout history to normalize the discourse of medicine through the creation of categories and standardized procedures, and I agree with Conrad (2007) when he states that "it is the very process of medical categorization that creates medicalization" (13).

With the creation of the clinic and thus the establishment of teaching hospitals, the importance of measuring and classifying individuals and their ailments became

emphasized. These classifications made it possible to invent instruments and technologies that were designed for very specific maladies or procedures, and to create standardized norms which would allow physicians to recognize when medical intervention is necessary. Furthermore, medical students are predominantly socialized to become competent, rather than caring physicians. They have to memorize the etiology and biomedical forms of treatment for all possible diseases and they learn human anatomy through dissection. However, this strong emphasis of competence over caring results in an objectification of the human body, and specifically of the patient. Thus, it is evident that obstetricians seem to focus stronger on technical than on human concerns, and that pregnant women and their unborn children are often treated as standardized cases.

Medical professionals might not regard pregnancy directly as a disease, but they view it as having the potential to result in problems that would require medical interventions or treatments. Viewing pregnancy from such an angle has been filled with contradictions for women. Some women do experience problems during their pregnancy, and the advances made by science and technology have improved the chances of a positive outcome. The problem for other women, however, is that while the label 'high risk' might allow them to receive additional medical services, it also invalidates the women's perceptions, thoughts and feelings by reducing them to only one factor, such as age. The age in which Canadian women are becoming first time mothers is increasing, with more women having babies over the age of 35 than ever before in history (Eggertson, 2004:1656). Women over 35 are automatically classified and labeled as

'high-risk' during their pregnancy which goes along with an increase in obstetrical screening during pregnancy and during birth.

The medicalization of pregnancy was not only driven by the power of obstetricians and gynecologists. Women themselves demanded and still demand technological screening and diagnostic procedures to ensure the health of their fetus and the normalcy of their pregnancy (Bolaria and Dickinson, 2002: 191).

> Women collaborate in the medicalization process because of their own needs and motives, which in turn grow out of the class-specific nature of their subordination. In addition, other groups bring economic interests to which both physicians are women are responsive. Thus a consensus develops that a particular human problem will be understood in clinical terms. This consensus is tenuous because it is fraught with contradictions for women, since, ... they stand both to gain and lose from this redefinition (Riessman, 1983: 4).

I believe Zola (1978) was correct when he claimed that "the medicalization of society is as much a result of medicine's potential as it is of society's wish for medicine to use that potential" (95).

Routinization of Prenatal Screening

The College of Obstetricians and Gynecologists recommends that all pregnant women are offered prenatal first-trimester screening. It is important to note that all medical tests available to pregnant women are voluntary in Canada. However, a number of studies have found that prenatal screening tests are often presented as routine care which do not require the participation of the pregnant women in the decision-making process (Case, 2007: 655; Van den Berg *et al.*, 2005: 85; Al-Jader *et al.*, 2000: 23; Marteau *et al.*, 1992;).

In cases where women are aware that it is their personal decision to get tested, their choices are often not well informed because many women lack the necessary knowledge about the procedures involved. A review by Green and colleagues (2004) on the psycho-social aspects of prenatal screening, which included 106 publications from 12 different countries, found that women's understanding of screening tests is poor. In addition, accepting prenatal testing tends to be presented as reflecting good parenting (Dixon, 2008: 54) which makes it feel compulsory to choose the socially acceptable option of getting tested (Press and Browner, 1997).

Today, prenatal tests are offered on a routine basis, even though the techniques involved are not considered to be part of the medical routine assessment. In the 1990s, most women who chose to undergo prenatal genetic testing had sought out the services themselves. Now, all women are offered the procedure, and most women are found to have limited or no prior knowledge of these tests (Browner *et al.*, 2003: 1933-34). Many individuals also do not fully understand the concept of probability statistics and the medical jargon which are used by physicians, and they often do not know that no treatment options are yet available to treat genetic defects. Therefore, it is not easy to evaluate if the decision for or against testing made by many pregnant women can be considered to be fully informed (Modra, 2006). Furthermore, physicians often make no distinction between tests which are medically recommended and those which are merely offered during a prenatal consultation. A study by Anderson (2002) found that when patients were offered prenatal testing, their "initial reaction was to assume it is a medically necessary procedure" (251).

The routine Ultrasound

The ultrasound is a prime example for a routinely offered prenatal medical test. It has become standard procedure and is firmly embedded in prenatal care in most places in the world (Bashour *et al.*, 2005: 147). Many healthcare providers and pregnant women alike cannot imagine a pregnancy in which no ultrasound is performed, and most parents-to-be would feel deprived if it would not be offered to them (Alexander, Levy and Roch, 1993: 105). In Canada, obstetricians routinely scan pregnant women between 18 and 20 weeks gestation as recommended by the Society of Obstetricians and Gynaecologists. At that time, the fetus is easily visualized because it is sufficiently large for all major systems to be examined for any defects and sufficiently small to fit completely onto the screen.

Previous research of parents' experiences with ultrasounds has shown that the scan is usually understood to be a routine test that is used to confirm the normality of the fetus. However, there is a clear difference between selective medically indicated and routine use of ultrasound. The timing of the scan, its length, the details inspected, the level of sophistication of the equipments used and the experience of the ultrasonographer all vary with the reason of why a scan is being performed (Enkin, Keirse and Neilson, 2000). While the value of the medically indicated use of ultrasound screening for specific indications, "such as possible fetal malformation, placental position and multiple pregnancy, has been clearly shown. Evidence that supports the routine use of ultrasound for antenatal screening of normal pregnancy has not yet been firmly established in spite of its widespread use" (Bashour *et al.*, 2005: 147).

Compared to other prenatal tests, ultrasounds are very popular because they provide the parents with a picture of their infant, rather than just with a list of numbers that require medical knowledge for interpretation. Ultrasounds are increasingly understood as a social and not as a medical event. They mark the first opportunity for parents to see their baby. The ultrasound image does not represent a medical document for most parents, but the first photo of their baby (Lauritzen and Hyden, 2007: 94). For many future parents, the ultrasound has such an important confirmatory role that they do not announce the pregnancy until after the scan (Marteau, 1995; Al-Jader *et al.*, 2000; Garcia *et al.*, 2002). Parents might not always be fully aware of the medical purpose of the ultrasound and most regard it predominantly as a means of 'meeting' their baby and making the pregnancy experience more realistic.

A degree of parent-child bonding takes place as a result of the ultrasound scan. Campbell and colleagues (1982) examined the psychological impact of ultrasound on two groups of pregnant women, where one group was allowed to watch the screen during the scan and the other group was not. Afterwards, all women filled out a questionnaire which assessed their parental attitudes to their pregnancy. It was found that the group who was allowed to watch the screen was feeling stronger emotional ties to the fetus than the group who was not allowed to watch (Campbell *et al.*, 1982). Bashour and colleagues (2005) also found that ultrasounds can aid in the bonding between mother and infant when women are able to view the fetal image. He stipulates that it is related to an increased maternal awareness of the pregnancy. In addition, ultrasounds allow fathers to be involved in the pregnancy experience, which is another feature appreciated by many parents (Bashour *et al.*, 2005: 149).

Ultrasounds can be a fascinating and happy experience for pregnant women and their partners, and research confirms that where a choice is made, women consent to being screened with an expectation of having a positive experience. However, an ultrasound is a medical diagnostic tool and not a machine to produce photos for baby announcements. It is possible that the results of a scan are not at all what the pregnant woman had expected, which could be that some physical anomaly is found, or the unexpected presence of a twin, or that the sex of the fetus is different from what the woman had wanted. All of these examples could have adverse effects on the psychological wellbeing of the woman (Clement *et al.*, 1998).

Since ultrasounds produce visual images of the fetus, a conception of the fetus as separate and autonomous in relation to the pregnant woman has emerged (Lauritzen and Hyden, 2007: 93). This representation disrupts the notion of pregnancy being an interior experience. The fetus is no longer in the context of a private pregnancy experience, whose existence is only confirmed by the sensations and emotions felt by the pregnant woman. Rather, the ultrasound pushes the fetus into the public sphere and it becomes "the object of externalized mechanisms of surveillance and regulation" (Lupton, 1999: 62). Even though ultrasounds produce pictures of the fetus and of parts of the pregnant woman's body, these images do not speak for themselves. A medically trained professional is needed to interpret, explain and communicate the fetal representation to the parents-to-be. It becomes evident that with the routine use of ultrasound scans, the importance of pregnancy as a woman's interior experience is replaced by a necessity for medical technology and knowledge. The pregnant woman is no longer the expert of her own pregnancy.

Informed Consent and Decision Making in Testing

Lidz and colleagues (1988) argue that informed consent can be regarded either as a distinct event or as a process. The latter is a more dynamic ideal which acknowledges periods of changing emotions and informational input and the patients' reflections thereof in the context of their personal lives. Informed consent as a process requires a relationship between clinician and patient which allows for the exploration of all issues relevant to informed decision making. Even though this type of relationship would be the ideal in prenatal care, in practice, informed consent tends to be approached as a distinct event. It is a rational choice which follows the provision of information and it tends to be associated with legal liability. Information is provided unidirectional, the clinician provides the patient with technical information about testing, and no real discussion of the broader ethical issues of testing and how they align with the patient's value system is included (Press and Browner, 1995).

"Structural and cultural factors related to the rise of surveillance medicine have combined to effectively routinize the offer and uptake of prenatal screening and diagnostics, thus hindering the capacity to ensure true autonomy and informed choice for women" (Press and Browner, 1997). To understand if women are able to make informed decisions when it comes to prenatal testing it is important to ask whether women perceive prenatal tests offered to them as a choice at all. When surveying women after they were offered testing, a number of studies found that while the tests may not have been presented as mandatory, many women felt that it was just as often presented as something that was good to do, that most other women do, or as just one of many routine tests that

do not require a special decision (Tsianakas and Liamputting, 2002; Al-Jader *et al.*, 2000; Santalahti *et al.*, 1998; Marteau *et al.*, 1993). Other studies, which directly observed interactions between healthcare providers and pregnant women showed similar results. For example, Press and Browner (1995; 1997) found that while women may be told that participation in testing is voluntary, in most instances this is not made explicit. In cases where women are told that the testing is voluntary, practitioners were likely to add that it is recommended. The authors suggest that it is an interaction of institutional and individual clinician support that shapes the process through which women come to understand and decide about screening.

In some instances, women are not even aware that they are being tested because they might not understand the information that is given to them (Green and Statham, 1996: 143), which makes the possibility for informed consent impossible. Especially complicated genetic information using risk ratios and probabilities are frequently misunderstood (Rothman, 1986). Although the stated goal of providing women with information about prenatal testing is to enhance their reproductive autonomy by enabling them to make informed decisions, this goal is frequently not achieved. For example, Marteau and colleagues (1993) observed that physicians present incidence information, which represents the frequency with which fetal abnormalities occur, to women in a manner that emphasizes the increased risk of giving birth to a disabled infant, while deemphasizing the risk of having any complication from the testing procedure itself. The actual probability for each of these events to occur is very similar, each being approximately one in one hundred[3]. Also, the chance of the infant being disabled is

[3] Average population based risk of Down syndrome = 1:112; average population based risk of miscarriage due to amniocentesis = 1:100 (Marteau, Plenicar and Kidd, 1993).

overemphasized even though most children are born healthy. Healthcare providers do not encourage informed and conscious decision making merely by communicating medical risks and benefits (Kukla, 2007: 18).

Clinicians have to be aware of their responsibility to prepare pregnant women to make an informed decision for or against testing. Women might accept a test by default because they do not want to lose the option as their pregnancy progresses without allowing for time to think about how they might react to testing results (Brajenovic-Milic *et al.*, 2008: 83).

> Fostering conscientious autonomy in the health care domain might include guiding and encouraging patients' attempts at medical self-education, displaying respect for their capacities for judgment and responsibility and holding them accountable for exercising them, and also using expertise to help them make a contextually appropriate rational decision (Kukla, 2007: 17).

With regards to prenatal testing, it is necessary that the pregnant woman recognizes her personal values about testing and abortion, and that the couple discusses the possible implications that come with a positive test result.

Conclusion

In the previous pages, I have illustrated the complexity of defining what is healthy and normal in the context of infancy, parenthood and pregnancy. Striving for normalcy has had immense implications on the routinization of prenatal screening in Canada. The chapter reviewed the ultrasound, which is embraced both by healthcare providers and by pregnant women, as an important example of a routine prenatal screen. In addition, I have explained the importance of informed consent and decision making in prenatal testing as it has been discussed in previous scholarly work. In the following chapter, I

reflect on my personal standpoint regarding prenatal testing, and I present the methods which I have employed for data collection and analysis. I also discuss the theoretical concepts of biopolitics / biopower and medical gaze that guided my data analysis.

Chapter 3: Theory and Methodology

Introduction

For the purpose of this study, I interviewed young mothers about their decision making processes during their pregnancies and analyzed the results using Foucault's theory on biopolitics and biopower. The study received approval from the Carleton University Research Ethics Committee on October 2nd, 2008. In the following sections, I describe my position regarding the research topic. Additionally, I explain the unstructured interview which I chose to employ for data collection, how I sampled participants, and the kind of questions I asked. Furthermore, I discuss the ways in which I analyzed the data, and I explain Foucault's concepts biopolitics / biopower and medical gaze.

My Location in the Research

Reflexivity is an important issue when conducting research; it is especially relevant during the analysis of qualitative data. Who I am as a researcher, and the scientific and personal values I hold, have influenced all of the choices I had to make during the various stages of this project, and there is a need to reflect on these values. It was necessary for me, and beneficial to the reader, to understand my epistemological assumptions and experiences. This understanding has enabled me to effectively collect and analyze the data, and provides the reader with the necessary background information to comprehend how my conclusions were derived.

I am very aware that I hold strong values about my research topic. I oppose unnecessary medical interventions, the standardization of "normal" pregnancy and

childbirth, and the treatment of pregnant women by the health care system as though they are under-age and lacking agency. Because my own position towards, and experience with, prenatal testing is such an integral part of my research, I am not striving for value-neutrality. Qualitative methods are in line with my own standpoint, and are most applicable for my project, since they regard values as important throughout the research process (Bryman, 2006: 112; Schulenberg, 2007: 100).

I first became interested in prenatal testing when I encountered it during my own pregnancy. During my initial prenatal visit, in March, 2008, my physician filled out a long yellow form asking me a lot of personal questions regarding my level of education and that of my partner, our medical history and our family's medical history. Also, my height, weight, blood pressure and age were recorded. She asked me to reflect on whether any of my own or my partner's family members have congenital heart defects, Down syndrome, fragile X syndrome, diabetes, spina bifida, or any other form of mental or physical disorders. She then determined that my pregnancy was in the low risk category; there were no genetic disorders present in our families and I was healthy, of average weight, and most importantly younger than 35 years old. Before rushing out of the room, she mentioned that we would do the genetic test as part of the blood work during the next prenatal visit. I was shocked. From this time until the next scheduled exam two weeks later, I pondered what exactly this genetic test was and why I would have to do it. I found it especially odd that I would still have to undergo genetic tests, despite being reassured that my pregnancy was not at high risk for any reason. Since this was my first pregnancy, I was not aware of the rules and regulations surrounding

Canadian prenatal care, and therefore I did not know if I had the right to decline participation in this blood test.

I read everything I could find on the internet about the genetic screen and had long discussions with my partner about the test and our position towards it. The more I thought about the test, the more issues I found with it. For example, I did not trust the test's validity because the results are based solely on the analysis of *my* blood; my husband's blood would not be analyzed. I was also alarmed by its high rate of false-positives, which would require a woman to undergo more invasive testing to obtain stronger results. Although my partner and I did not have a clear standpoint on the issue of abortion in the event that something is found to be wrong with the fetus, we knew that we did not want to participate in any invasive testing that could impose a risk on the pregnancy. Thus, the early genetic blood test felt like an unnecessary and potentially harmful procedure in our situation; it had a higher chance of producing worry and doubt than reassurance. During my next prenatal visit, I told my physician that I did not want to get tested. She agreed with neither my choice nor my reasoning. In her opinion, the test was highly valuable because it would provide us with information that we could not obtain otherwise that early in the pregnancy. Also, she said that because it is just a blood test, no harm would be done. Nevertheless, she accepted my decision and did not screen for chromosomal abnormalities.

Two months later, I switched my prenatal care provider to a midwife in Ottawa. I quickly learned that pregnant women have a lot more choices regarding all of the medical tests. For example, prior to any blood test, the midwife would go through a checklist explaining everything that was being tested for, and would ask me if I understand the

information and consent to it. I even had a choice between using the doppler or a stethoscope to measure fetal heart rate, and every procedure she did was explained. My previous physician had never specified to me what the tests were looking for. It became quickly apparent that prenatal tests were presented differently to women depending on their care provider, that women's possibility to give informed consent was not always present and that "routine" tests might not have to be so routine after all.

Evidently, my pregnancy experience made me aware of prenatal testing and shaped my thesis topic. I also believe that being pregnant during the study had an influence on my ability to find participants and on the answers I received. Some of my participants mentioned when they saw that I was pregnant that they would gladly help me with my research project because I belonged to the circle; mothers have to help one-another. I also felt that being a pregnant female researcher allowed the women to speak more openly about their private experiences. The women I interviewed were often curious about my own testing and care provider decisions, and about my interest in the topic. Openness is important during research so that the participant feels more comfortable with the interviewer (Grills, 1998). However, it was difficult to decide how to answer women's questions regarding my personal testing decisions because I did not want to impose my values onto them. If the question arose during the interview I told the woman that I would gladly share that information with her after the interview was over because I wanted to focus my full attention on her experience. I tended to share less information with participants who had undergone a lot of prenatal testing, because I did not want the interviewees to feel as though they had to defend the choices they had made.

Although I would like the analysis of my research to be neutral and value-free, I have to acknowledge that I have personally made decisions which are more in line with some of my participants than with others. My pregnancy experience is an integral part of all aspects of my thesis research. I have tried to be aware and reflexive of my position on prenatal testing throughout this research process in order to provide an unbiased account of the individual experiences of the interviewed mothers.

Sampling

One problem faced by the qualitative researcher is that the unit of analysis cannot be designated before entering the field. Thus, the number of research participants that is necessary to obtain complete results has to emerge during the process of conducting the study (Sandelowski, 1995). During the design of the study I estimated a sample size of 15 mothers of non-disabled children and 5 mothers of disabled children to be feasible and sufficient. However, these numbers had to be modified after the data collection had started. Within the given time-frame it was not possible for me to obtain more than two interviews with women who have disabled children. However, since their answers were more similar to either the limited testing or the extensive testing group than with each other, and since my original focus was to compare the attitudes and experiences of women who have decided to participate in a number of prenatal tests to those who only had a limited amount of testing done, my research did not suffer from having so few interviews with disabled children's mothers. Also, the number of interviews conducted with mothers of non-disabled children was slightly increased to 18. At a total of 20

interviews, I concluded the data collection phase because the information provided had reached a level of saturation in which common themes and patterns had emerged.

I used strategic sampling for the recruitment of interviewees. Because I was limited in the number of interviews I could conduct, it was necessary to employ an information oriented selection of participants. Flyvberg (2002) explains that strategic sampling is done "to maximize the utility of information from small samples and single cases. Cases are selected on the basis of expectations about their information content" (230). I was strategic in my sampling because I distributed requests for participation in both mainstream and more alternative as well as in an online forum for parents with Down syndrome children. Therefore, I consider the women I interviewed to be maximum variation cases. The women's experiences vary across four dimensions, which are age[4], type of health care provider, being the parent of a disabled or a non-disabled infant, and having undergone limited or extensive prenatal testing[5]. These types of cases will allow me to explore the significance of various circumstances on the attitudes and experiences of women in relation to medicalized pregnancies.

I chose to interview only women who resided in Ontario at the time of their pregnancy, because the health care system varies with respect to maternal care among the various Canadian provinces. In Ontario, women are able to choose to have a midwife as their care provider, rather than physicians or obstetricians. A pregnant woman's care provider is likely to influence her decisions regarding prenatal testing because of the type of tests offered, the way they are offered, and the information that is provided about the

[4] Having given birth to their last child before or after the age of 35.
[5] I define limited prenatal testing as precluding all forms of genetic testing (i.e. maternal serum screen, amniocentesis, chorionic villus sampling). Women belonging to either category might have participated in ultrasound scans.

tests. It is possible that I would have derived different conclusions in a different research location, such as a province in which the health care system does not support the care of midwives[6].

To find women for the interviews, I distributed flyers and posters in public libraries, coffee-shops, and children's clothing, toys and consignment stores in Ottawa, and I posted the flyer on the website of the Down Syndrome Association of the National Capital Region. A few women responded to this letter of initial contact. In addition, I employed information-oriented sampling, in which information is maximized because all cases are chosen based on the expectations of their informational content (Flyvberg, 2002). After each interview, I handed recruitment materials to the women, asking them to distribute them among their acquaintances. Through this purposive sampling technique, I was able to conduct a sufficient number of interviews, while ensuring that confidentiality was maintained, since the women did not know if her friends contacted me to be interviewed.

Qualitative Interviews

Qualitative inquiry operates from the participant's perspective, which allows the researcher to investigate underlying assumptions, attitudes, and the rationale for these. Based on my review of the literature, I formed questions to explore women's experiences of decision making during prenatal testing and to find out which factors influenced their decisions and how they evaluated prenatal screening and diagnostic programs. The

[6] Midwifery is recognized as a legal and regulated profession in the following Canadian provinces and territories; Ontario (since 1991), Alberta (since 1994), British Columbia (since 1996), Quebec (since 1999), Manitoba (since 2000), the Northwest Territories (since 2003), and Saskatchewan (since 2008) (Canadian Midwifery Regulators Consortium, 2009).

method of data collection I used was the unstructured interview. It "is a guided conversation whose goal is to elicit from the interviewee rich, detailed material that can be used in qualitative analysis" (Lofland, and Lofland, 1995: 18). This method enabled me to gather very detailed data on women's experiences and attitudes in relation to prenatal testing. It gave me the opportunity to understand women's experiences from their subjective viewpoint.

Between October, 2008 and January, 2009, I conducted 20 individual unstructured interviews with women who have given birth in Ontario within the last five years[7]. In Ontario, it is legally mandated to offer prenatal screening to all pregnant women; thus, I could assume that all women had been offered some form of prenatal testing by their physician or midwife.

A number of interviews were done in various coffee shops in Ottawa. However, some interviews took place in the women's home, which was sometimes the most convenient for the mothers of young children. I found it important that the women could choose not only a suitable time for the interview but also the location in which they would feel most comfortable. Prior to the start of each interview, I explained to each participant the purpose of my research, as well as issues dealing with confidentiality and informed consent. I ensured that the women knew that all their answers were given voluntarily and that I would treat their answers with full confidentiality. This information was written up in the letter of information for participants[8] which I signed and left with the participants for them to keep. I then had each participant read and sign a consent

[7] Chapter 4 outlines more fully the particular characteristics of the women (see pages 68-71).
[8] The letter of information for participants can be found in Appendix D.

form[9]. Both the letter of information and the consent form had been approved by the research ethics board at Carleton University.

The length of the conversations varied and they lasted between 45 and 90 minutes. I audio-taped each conversation using a digital audio recorder. Recording the interviews was useful because it provided me with a full account of each participant answers without having to interrupt their line of thought to write down their answers (Maykut and Morehouse, 1994). I was able to re-listen to parts of individual interviews during the data analysis and I could provide full quotes with confidence. However, it is possible that the women's way of talking was influenced by the presence of the recorder (Rapley, 2001). All participants were given the choice of whether to be tape-recorded, and none of them declined.

I began the actual interviews with a general outline of my questions. I told the women that I was interested in their experiences with prenatal testing; the decisions they had to make and the information they received. I then asked each participant about her age, and the age of her children. I did not specifically ask for family status, or occupational background; however, all women provided this information throughout the conversation.

I asked each woman to tell me about her recent experience(s) of being pregnant. In two cases, this was the only question I asked, because often women would tell their story, thereby answering most of my other questions. Other times I used probing questions, either to find out more about a specific point a woman had made, or to guide

[9] The consent form can be found in Appendix E.

the interview back to the topic of prenatal testing. The kind of probing questions I asked included, but were not limited to, the following:[10]

1. Was your pregnancy considered to be at risk for any reason?
2. What medical tests did you have to assess your fetus during your pregnancy? When did you have the test done? Where were you tested? How long did you have to wait for the results? What were the results?
3. How did you make the decision to get (not to get) tested? What role did your care provider play? What role did your partner play?
4. What information did you receive from you care provider regarding prenatal testing? Do you feel that this information you received was enough?
5. Do you have family members or do you know individuals with Down syndrome or some other form of disability that was present at birth?
6. What would you have considered to be a negative or bad test result? How did you prepare for dealing with such a result? Were you told about the options you have if test results indicated that something was not right?
7. What advice would you give to an expecting woman?

Analytic Approach

This section explains the analytic approaches which were used to analyze the data from the interviews. Analysis of the data started after all interviews were completed and transcribed. I used ATLAS/ti for the organization and the analysis of my interview data. Reflexivity was particularly important during my data analysis because I was very closely

[10] The complete interview guide can be found in Appendix C.

connected to the topic through my own pregnancy experience. Therefore, I used the Listening Guide by Mauthner and Doucet (1998) to make myself fully aware of my social and emotional situation in relation to my participants. The Listening Guide involves a five step process during which the researcher engages with the interview transcripts in different ways, thereby ensuring that he or she is aware of the different lenses through which the data can be analyzed. During the first reading, I focused on the actual story which the woman told me. Quite broadly, I considered what happened, where it happened, and who was involved. During the second reading, I emphasized my own reaction to the story. I took note of specific emotions the story evoked, and how my own assumptions influenced how I read and understand the narrative. During the third reading, I shifted the focus to the woman who is telling her story. I tried to decipher what her emotions were during specific events, and which type of language she uses to describe her own role and the experience. In the fourth reading, I placed the emphasis on how each woman describes her relationship with her caregiver, as well as with family members who were important for her during the pregnancy. Finally, during the last reading, I formed connections between the individual experiences and broader social structures.

Using the Listening Guide, the first two readings of the transcripts allowed me to systematically familiarize myself with the data. At the same time, using the Listening Guide enabled me to separate my personal experience and values from those of my participants. During the next three transcript readings, I also used coding and diagramming to organize and interpret the interview data. "Codes are labels that classify items of information as pertinent to a topic, question, answer, or whatever" (Lofland and

Lofland, 1995: 186). Diagramming is a "visual presentation of the relationships among parts of something" (Lofland and Lofland, 1995: 197). Coding enabled me to recognize patterns and individual differences in the interview data. From statements in the interviews, I formed descriptive codes for each participant. Afterward, I formed analytic codes by reviewing the descriptive codes. I merged those that belonged to one category, and omitted those that were not important in relation to the topic. In the next step, I reevaluated the appropriateness of the analytic codes, and the final labels I used for the analysis were the focus codes. I then indicated which statements in the data belonged to which label. Later on, those statements served as examples in the discussion of the data. The Listening Guide informed the coding process. During the third reading, I coded predominantly for the use of the word "I" in the women's stories. This allowed me to find connections between the issues most pertinent to all participants. In the fourth reading, I coded for relationships, which illustrated the influences of others on the women's testing decisions and the women's perceived judgments from others. During the fifth reading, I incorporated Foucault's theory on biopolitics into the coding process. After the focus codes were finalized, I used diagramming to indicate the connections between the labels. Those relationships are explained in the discussion in chapter 5.

Theoretical Perspective

Biopolitics / Biopower

For Foucault (1989), the terms biopolitics and biopower meant that life became the center of contemporary politics. It is the maximization of life through a number of regulatory technologies which monitor and control the processes of life. Biopolitics is

where life and politics meet. In the biopolitical framework, the technologies of biopower are exerted to maximize life. The individual is the subject of power, because the individual is the subject of the diffused and immanent networks of power relations. "The old power of death that symbolized sovereign power was now carefully supplanted by the administration of bodies and the calculated management of life" (Foucault, 1989: 139-140). Pregnancy and birth are important aspects of the calculated management of life because life must be ensured, sustained and multiplied. Pregnancy specifically is central to the production of life, thereby becoming the predominant focus of biopower. Today, mothers are not only responsible for their children's health, but at the same time they are responsible for the health of the population. Therefore, pregnant and labouring women are being kept under constant surveillance by strong networks of power and knowledge. Foucault (1989) explains that "the hysterization of women, which involved a thorough medicalization of their bodies and their sex, was carried out in the name of the responsibility they owed to the health of their children, the solidity of the family institution, and the safeguarding of society" (146-147). This means that the mother has to guarantee for the life of her fetus, and to guarantee for the continued existence of society, which Foucault (1989) referred to as her "biologico-moral responsibility" (104).

To fully comprehend the relevance of biopower for the medicalization of pregnancy, it is necessary to discuss how Foucault theorized about the concept of power. For Foucault, power is neither centralized, nor can it be possessed. Rather, it is a diffused and immanent relation.

> Power is not something that is divided between those who have it and hold it exclusively, and those who do not have it and are subjected to it. Power must, I think, be analyzed as something that circulates, or rather as something that functions only when it is part of a chain. It is never

> localized here or there, it is never in the hands of some, and it is never appropriated in the way that wealth or a commodity can be appropriated; ... power passes through individuals. It is not applied to them. (Foucault, 1997: 29)

Thus, Foucault sets the current meaning of power apart from the way in which it was conceptualized prior to the French Revolution. Power is no longer held by some sovereignty; it is no longer possible to point out one person in society who is powerful at all times. Also, power is no longer simply domination, because it is limiting and repressive at the same time as it is enabling and productive. In addition, Foucault states that "the individual which power has constituted is at the same time its vehicle" (Foucault, 1980: 98). This point is important, because it explains how, historically, women participated in the medicalization of pregnancy, even though it meant handing over their control to the physicians. It also outlines the relational property of power, because the person who is exercising power and the person on whom it is exercised are both subjected to the same technologies of power.

Furthermore, Foucault differentiates between two technologies of power, which are disciplinary and regulatory (Foucault, 1997). While disciplinary technology usually operates through institutions at the level of the individual bodies, regulatory technology operates at the level of populations and on life itself. Thus, regulatory technology is what Foucault refers to as biopower, or biopolitics. These terms describe the governing of life itself, which has been replaced by the historically earlier sovereign power over death.

> So after a first seizure of power over the body in an individualizing mode, we have a second seizure of power that is not individualizing but, if you like, massifying, that is directed not at man-as-body but as man-as-species. After the anatomo-politics of the human body established in the course of the eighteenth century, we have, at the end of that century, the emergence of something that is no longer an anatomo-politics of the human body, but

> what I would call as "biopolitics" of the human race. (Foucault, 1997: 243)

Currently, governments in most Western countries increasingly organize the welfare and health of populations because they are interested in increasing their force and productivity, which cannot be achieved with sick individuals. Thus, with the political focus on life, the concern is to maximize life and to minimize risk in terms of hygiene, health, and many other regulatory controls over the population. Managing and monitoring populations becomes central. Prior to the Enlightenment, power was quite visible and tangible because it took the form of the sovereign king or queen. However, now we have disciplinary societies where power is much more invisible. Nevertheless, its effects are felt by everyone. Disciplinary power is strongly based on surveillance, which will be elaborated on further in the section on the medical gaze.

With the emergence of biopolitics and the subsequent biomedical definition of the fetal body, the fetus "is projected onto the bodies of pregnant women on a population basis" (Weir, 1996: 377). Biopower and the construction of normalcy are ultimately linked together. Biopolitics is based on the historically specific institutional and technical developments within medicine and within general society itself, and these developments have shaped "our very ideas of what it is to be a normal human being" (Rose, 2001: 19).

Nevertheless, I think that biopolitics and biopower alone cannot explain the extensive use of statistics in modern medicine. Through its probabilistic properties, statistics allow medical personnel to make judgments about the most likely course of a specific condition or disease. Throughout medical school, medical students learn

repeatedly that they will be facing a number of uncertainties once they are working in the field, because "despite unprecedented scientific advances, the life of modern physician is still full of uncertainty" (Fox, 1988: 20). Fox distinguishes between three types of uncertainties. First, physicians are aware of their own professional ignorance because they know that it is impossible for a single individual to completely master all available medical knowledge. Second, physicians are continually reminded that medicine itself is not all-knowing because medicine is not able to cure everything. Finally, physicians have to deal with uncertainty because they are often unable to distinguish between personal and medical ignorance (Fox, 1988: 20). Therefore, physicians introduce structure and normalcy into as many medical procedures as possible to limit the amount of uncertainty they are facing. Similarly, as soon as power had taken hold over life through the emergence of biopolitics, demographers began to measure medical conditions, such as pregnancy, in statistical terms (Foucault, 1997: 243).

The technicalization and normalization within the hospitals also ensures the power of the medical profession in relation to the average person. Patients accept that physicians come to determine what is normal and what is not, thereby giving physicians the capacity to impact on and to regulate their behaviours. Foucault points out that this exercise of power is only influencing rather than determining, because our discussion would otherwise be no longer about power but about obedience.

In addition, according to Foucault, the norm always circulates between the disciplinary and regulatory, where disciplinary power relates to control over individual bodies operating through institutions, and the regulatory power relates to control over life itself at the level of populations. "The norm is something that can be applied to both a

body one wished to discipline and a population one wishes to regularize" (Foucault, 1997: 253). Thus, the norm of disciplinary power and the norm of regulatory power intersect in the normalizing society. Both disciplinary and regulatory powers come together in pregnancy through biopolitics and the medical gaze. This gaze, which is the topic of the next section, represents the surveillance onto which disciplinary power is based.

Medical Gaze

With the shift of medical practice from the bed of the patient to the location of the hospital, diagnosis and treatment of diseases no longer rested on an interaction and exchange between physician and patient, but they came to be based on the physician's physical examination, and thereby his medical gaze. Foucault (1973) points out that the patient became "the rediscovered portrait of the disease". However, the patient is not only subjected to the physician's gaze during an examination. During the sixteenth century, which was a time of re-emergence of the scientific inquiry, anatomical dissections on human corpses entered the field of medicine (Straub, 2002: 14). And with the establishment of the "modern" clinic, within which medicine was practiced and taught, the pathological anatomical gaze became gradually bound to the clinical gaze. This new form of medicine stressed that the course and etiology of a disease could only become visible through examination of the body after death. Thus, through the dissection of corpses, humans could become objects of science.

The first textbook of human anatomy, which was completely based on human dissection, was published in the late 18th century by Giovanni Morgagni (Straub, 2002:

15). Shortly thereafter, Bichat published his book *Traite des membranes*, also based on human dissection, which is an analysis of bodily tissue, rather than a simple description of human anatomy as Morgagni's *De sedibus* was. Thus, Bichat introduced the clinical gaze into anatomical dissection, because "tissual analysis makes it possible to draw up general pathological categories beyond Morgagni's geographical divisions; broad groups of diseases having the same major symptoms and the same type of evolution will emerge through organic space" (Foucault, 1973: 129). At that time, the concepts of life and death were no longer perceived as far apart and oppositional to each other as they had been before. Only in studying the dead were physicians able to understand life and pathological anatomy became necessary to fully understand disease, and hence the specificity of life.

The invention of a number of technical medical instruments allowed physicians to refine their anatomo-clinical gaze. For example, the invention of the Leeuwenhoek microscope in the eighteenth century allowed physicians to observe germs, bacteria, yeast, blood cells, and all of the tiny tissue in the human body thereby making virtually all of disease visible to the medical gaze (Straub, 2002: 15). For Foucault, the convergence of these new forms of patient observation with the formulation of associations between the finding of pathological anatomy and the symptoms of patients is equivalent to the clinical revolution of the eighteenth century (Jones & Porter, 1994: 32).

A number of gazing instruments were also developed to observe the course of pregnancy, the most important ones being x-ray and ultrasound. Once these methods of observation were employed frequently in hospitals, which was not until the twentieth century, physicians no longer had to solely rely on the speech of pregnant women to

obtain both research and clinical knowledge of pregnancy and the fetal body (Weir, 1996: 376). Thus, the obstetrician or gynecologist became the one who knew about the fetal health, and the pregnant mother had to start relying on that outside knowledge to be informed about the state of her body. Weir argues that the frequent employment of these fetal diagnosing techniques resulted in an exponential increase in the number of disorders found, illustrated by the "textual elaboration of the foetus as a discursive object" (Weir, 1996: 376). The same holds true for obstetrical medicine in the twenty-first century. Currently, the vast majority of pregnant women participate in regular ultrasounds, and an increasing number of women make use of fetal chromosome screening techniques.

In all areas of medicine, not only prenatal, patients used to be examined predominately in the context of their personal biography and their self-reported level of wellbeing, while presently, they are increasingly regarded as entities for technological exploration and diagnosis. As this medical gaze has moved deeper into the human body, for example within the context of genetic discoveries, new diseases and new formations of the concept of health have emerged (Hofmann, 2001). Technology is allowing us to identify disease, precursors to disease, and increasingly more risk factors for disease at earlier stages than ever before. A culture of risk has been created (Lupton, 1999) in which people tend to be defined not by their current health status but by their estimated potential for future disease. This potential is identified by complex sets of screening tools and statistical models. Everybody becomes a potential patient, and people are expected to monitor themselves and to seek out services which monitor their risk status, a trend that has been coined as surveillance medicine.

The example of the pregnant woman illustrates that physicians come to define medical truth through the use of elaborate observing technology within medical scientific discourse.

> The eye becomes the depositary and source of clarity; it has the power to bring a truth to light that it receives only to the extent that it has brought it to light; as it opens, the eye first opens the truth: a flexion that marks the transition from the world of classical clarity – from the enlightenment – to the nineteenth century (Foucault, 1973: xiii).

Even though truth is a relative and ever changing concept, once the human body was completely visible to the scientific and clinical gaze, physicians came to define and continually re-define medical truth. Thus, truth becomes a historical category always depending on the medical knowledge available at any specific time. The medical profession exercises its power and control through the use of mechanisms of observation because the results of these observations become medically defined knowledge of social bodies. In turn, once this knowledge becomes socially accepted truth, the power of the medical profession is reproduced (Foucault, 1997: 24-25). Therefore, power and knowledge become inseparable.

The tight connection between power and knowledge means in the case of pregnancy that the opportunity of the physician to observe and study the pregnant woman and the fetus by means of complex technologies and the medical gaze provides the physician with knowledge on the pregnancy. This knowledge is then used by the physician to control the course of the pregnancy, thereby subjecting the pregnant woman to his or her power. In turn, this exercise of power can increase the physician's knowledge about pregnancies. Also, it becomes evident that the physician's gaze is

related to both the disciplinary power of the medical profession over the pregnant women and the regulatory power of biopolitics over pregnancy.

Conclusion

In this chapter, I have reflected upon my personal standpoint regarding prenatal testing, and about the choices which I had to make during the sampling stage of my research. Using a qualitative research approach was in line with my epistemological standpoint. Also, conducting unstructured interviews helped me to understand women's attitudes and experiences regarding prenatal testing from their subjective viewpoint. I used the listening guide and coding to analyze the data, which enabled me to separate my personal values from those of the interviewees, and to differentiate between the themes that were most relevant to the women in this study. Foucault's concepts of biopolitics / biopower and the medical gaze were reviewed because they provided the theoretical framework for the analysis. I highlight the relevance of using Foucault's concepts to understand the routinization of prenatal testing in chapter 5. I summarize the personal characteristics of the interview participants, and I present their perspectives on prenatal testing in chapter 4.

Chapter 4: Women's Perspectives on Prenatal Testing

Introduction

As discussed in chapter 3, my research draws on unstructured interviews with 20 women who have given birth in the province of Ontario within the last five years. The first part of this chapter, called "Interview Participants," outlines the demographics of the women who participated in the interviews[11]. The subsequent sections describe the women's responses, which are organized into related themes. The dominant themes that run through all interviews are: routine, risk, influence of others, guilt, and advice.

Interview Participants

The women I interviewed for this study were fairly similar in relation to their demographics. However, I found great variations in the accounts the women provided about their prenatal testing experiences. All women who participated were married or living in a common-law relationship, and have been living in Ontario for most of their lives. One participant is of African decent and 19 participants are Caucasian. Six of the women have one child, nine have two children, and five have three children. The age of the participants at their time of giving birth to their last child ranged from 27 years to 47 years, with a median age of 34 years and a mean age of 35 years; thus, most women gave birth in their mid-thirties[12]. Approximately half of the participants (9) where 35 years old or older at the birth of their last child, which is the age cut-off for placing pregnancies into the high-risk category. Interestingly, the time between the birth of a woman's first child and her second child never exceeded two years.

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[11] The characteristics of all interviewees are outlined in Appendix A.

[12] The ages at which women gave birth were as follows: one at 27, two at 31, three at 32, one at 33, four at 34, two at 35, one at 37, two at 38, one at 40, one at 41, one at 42, and one at 47.

The women came from very diverse professional backgrounds; however, the educational level was high in the entire sample, with most women having graduated from post-secondary education[13]. Five of the interviewed participants work in the health care sector, with two women being nurses, one a physician, one an NICU[14] nurse, and one a mental health social worker. Four women are government workers in various and unrelated positions, one woman is an actress, one a financial consultant, one a writer, one runs a home daycare, and seven women are stay-at-home mothers.

During their pregnancy, most of the interview participants (14) were in the care of an obstetrician or gynecologist, while six women had their pregnancies followed by a midwife. All women delivered healthy infants either in a hospital or their home in Ottawa, Ontario. Two women are mothers of a child with Down syndrome and all other children were born disability free. The infant of one mother was diagnosed with Down syndrome during the course of her pregnancy. Markers were found on the fetus' heart during an ultrasound, and the subsequent diagnosis was made using amniocentesis. The mother of the other child with Down syndrome found out about her child's condition at birth.

In relation to the women's experiences with prenatal testing, exactly half of the women participated in a limited amount and in an extensive amount of prenatal tests[15]. Approximately half way into their pregnancies, all women's healthcare providers started to regularly use the doppler to measure fetal heart rate. In addition, most women had a

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[13] This overrepresentation of highly educated professionals in the sample can be explained by the snowball sampling method I used to find my participants. The method is further explained in the Methodology section.

[14] Neonatal Intensive Care Unit

[15] A limited amount of fetal prenatal testing is defined as including doppler use and ultrasound. An extensive amount of fetal prenatal testing further includes genetic screening techniques, such as IPS, amniocentesis, and CVS.

number of ultrasound, with a median number of 3 and a mean of 3.5, and only one woman did not have a single ultrasound[16]. Four women also had a 3-d ultrasound, which they had to pay for privately. In this study, nine women underwent IPS in the first trimester of their pregnancy and six of these women are 35 or older. Very few women opted for more invasive fetal prenatal tests. Two women had an amniocentesis in addition to the IPS, and one woman went for amniocenteses during her previous pregnancies. During her last pregnancy, she had chorionic villus sampling without doing the IPS first.

I analyzed the women's responses based on them belonging to either the limited prenatal testing or the extensive prenatal testing group, with exactly half of the participants falling into each category. This allowed me to recognize similarities and differences in their perceptions towards routine testing, risk, disability, and ultimately the medicalization of pregnancy. As outlined in table 1, extensive testers were more likely to be 35 years or older (7) than were limited testers (2). Age is important because a pregnancy is considered high-risk within the medical system as soon as a woman is 35 years old. Women who had a limited amount of testing did only differ slightly in terms of their choices of healthcare provider. Six women were in the care of a midwife and four went with an obstetrician. However, all women in the extensive testing group were cared for by an obstetrician. This is not as evident as one might think because all women who were in the care of a midwife had also been offered the IPS. Nevertheless, they all declined. Women in both the limited and the extensive testing groups gave birth to approximately the same number of children. In total, limited testers had one disabled and

[16] In total, one woman had no ultrasound, two had 1, five had 2, six had 3, two had 4, one had 5, two had 7, and one had 13 ultrasounds.

18 non-disabled children, and extensive testers had one disabled and 19 non-disabled children. Participants who made use of fetal genetic tests during their pregnancy had ultrasounds much more frequently than participants who did not have genetic testing done. Eight of the ten women in the extensive testing group had three or more ultrasounds (one woman had up to 13), as compared to only four of the ten women in the limited testing group (the highest number of ultrasounds was four).

Table 1

The Demographics of Interview Participants Organized by Testing Choice

		Limited Prenatal Testing	Extensive Prenatal Testing
Age at birth of last child	< 35	8	3
	≥ 35	2	7
Healthcare provider	OB/Gyn	4	10
	Midwife	6	0
# of children[17]	Non-disabled	18	19
	Disabled	1	1
Ultrasound usage (excluding IPS ultrasounds)	< 3	6	2
	≥ 3	4	8

[17] In 2004, the prevalence at the time of birth of identified congenital abnormalities in Canada was 4.8%, or 479.8 per 10,000 total life births. The birth prevalence of Down syndrome, the most frequently occurring genetic disability, was less than one percent, with 13.5 per 10,000 total births (Public Health Agency Canada, 2008: 159).

Routine

All women in this study considered routine prenatal tests to be important; however, there was a divide as to which tests are conceptualized as routine procedures. When women had to make decisions during their pregnancies, they liked to follow advice which included the word routine because if something is the norm it is most likely safe. Ella (34, 3 ultrasounds)[18] explained, "We didn't do the screening test for Down syndrome, no, we didn't do that one. Is that routine? Because we did everything that is routine." And Petra (35, Down's child, 1 ultrasound) told me, "The only prenatal test that we performed was the routine ultrasound." Women used different terms to describe tests that they perceived to be routine such as "standard ultrasound" said by Julia (38, 2 ultrasounds, IPS) and "regular test" mentioned by Deidre (34, 2 ultrasounds). Nevertheless, all women talked about routine tests during the interviews, and there is no difference between the limited and the extensive testing group regarding which tests were perceived as routine.

In addition, a number of women in both groups assumed that they could not refuse to participate in routine prenatal testing. This becomes evident from an answer of Ella (34, 3 ultrasounds),

> I had an ultrasound early at about 8 weeks and then, I guess at 16 weeks. Oh, and I had a three-d ultrasound, that was like at 32 weeks, and that's about it. The obstetrician suggested me to have these, like there are just the routine ones. The 3-d one, I asked for it, and we had to pay for that one. It's a private service. I think it's like 150, and then you get a cd. And we saw her face exactly how it looks now. And my husband was with me for the ultrasounds; it was a great experience. Well, the other ones weren't a choice really; they were pretty much just routine.

[18] The first number in the bracket after a woman's name refers to her age at the time she gave birth to her last child. Thus, Ella was 34 years old when her son was born.

The issue around routine testing was especially apparent for ultrasounds. Many women seemed to assume that they are obligated to have at least one ultrasound, and most women considered the 18-20 week ultrasound scan routine. However, women could not easily differentiate between routine as an obligation and routine as a recommendation and this made it hard to understand if they felt as though they were given a choice when the testing was offered. Hannah (32, 13 ultrasounds) explained regarding ultrasound use, "They suggest 20 weeks; I think that's the only one you kind of have to do, or at least are supposed to, like strongly recommended." And Giselle (40, 7 ultrasounds, IPS) outlined regarding the IPS, "The chromosome test was offered because of my age, right, I was over 35, so again, no choice in that. I mean they said it is highly recommended that you do that, because you are 40." Perceiving the IPS as routine was the main difference between the extensive and the limited testing group. Extensive testers often listed the IPS when they outlined all of the routine tests they participated in. Women in the limited testing group only mentioned ultrasound scans as routine tests and some women told me that they think the choice of IPS is often misunderstood. For example, Anne (33, 1 ultrasound) said, "For me I already knew that I wouldn't want the screen, but I did read the flyer just to see what was in it. I mean it says here it's your choice, but I think most people don't see that. That's what one does more in the general sense."

Risk

Prenatal tests are offered to women as a mean of indicating and avoiding risks and the kinds of tests offered depend on the risk status of the individual woman. In this study, four relevant themes emerged in relation to risk; risk perception, age, reassurance,

and risk of testing. The level of self-perceived risk was indicative of the testing choices of all women. Clinicians use age is an important determinant of a pregnant woman's risk status, and often women consented to prenatal testing to reassure them that their fetus was indeed healthy.

Risk Perception

All women negated the question, "Was your pregnancy considered to be at risk?" Most limited testers did not go into details what it meant for them to be low-risk. They quickly told me that their pregnancies were risk-free and then went on to discuss other issues. For example Ella (34, 3 ultrasounds) said, "I wasn't considered to be at risk" and Deidre (34, 2 ultrasounds) outlined, "I wasn't at risk, and I was working. I worked up until my first day of maternity leave which was the day that she was born." Only Cora (34, 5 ultrasounds, IPS) went into more detail to explain where she placed herself and her family in terms of risk:

> You know, we don't have cases in the family, so of course we could do the testing and kind of know that it shouldn't be that much of an issue. Like we were low risk, but I figure being high risk, that would have pushed even more the balance of wanting testing. And I have heard of stories where you have the testing done and there are negatives and positives. And people who were told that the risk is this or that, and they end up with a perfect child. And vice versa, even when you have the test, you can still have issues. But the percentage in our case was at the lowest possible. Like of course there is always some possibility, but like, we couldn't have been lower than that. Like there is always a possibility but we were at the lowest one.

Her answer illustrates the struggle women go through to understand what it means for them to be or not to be at risk and to make subsequent testing decisions.

The concept of risk was more relevant to the women in the extensive testing group. Giselle (40, 7 ultrasounds, IPS) had become pregnant using in vitro fertilization,

which made her pregnancy more risky. She told me, "Till about the first three months, they considered me to be at risk. After about that I went to a regular Ob/Gyn. I wasn't in the high risk in any way." Giselle based her risk-status only on her fertility issues, she did not even mention her age. Madison (37, 3 ultrasounds, IPS) also had fertility problems, but she did not believe that this put her pregnancy at risk:

> I was considered high risk for miscarriage just in the first trimester, because I have had an ectopic before followed by two miscarriages, so in that sense, they did consider me high risk. But looking back, I probably hadn't needed to see a high risk doctor. Once the initial ultrasound was done and gave me the all clear, I don't feel like I was more at risk than anybody else, really.

Risky Age

Interestingly, even though most of the women in the extensive testing group were 35 years or older at the time of birth (seven out of ten), they did not perceive themselves to be at risk. In the eyes of their care providers, their pregnancies must have been categorized as high-risk because of their age, but most women did not mention it. Julia (38, 2 ultrasounds, IPS) spoke for many women over 35 when she explained, "No, I wasn't at risk. I was healthy all the way through. I had all the right numbers, and I had all the right measurements." Susan (47, 3 ultrasounds, IPS) was angry at her healthcare provider for calling her pregnancy high-risk only because of her age. She did not believe it:

> I was always healthy. I was considered at risk because I was old. I was at risk for everything. Before I even made my first prenatal appointment I was considered high risk simply because of my age. But it never made me feel. You know, when they told me that they considered me to be high risk because of my age, I didn't feel at high risk, I didn't buy into it. But because of my knowledge, I didn't buy into it. But that wore down over the course of the pregnancy, because you are bombarded constantly. And even though I had a lot of information. It wasn't like I ever gave in and did anything that I didn't want to. Like I resisted prenatal testing

> of the kinds that I didn't want. But it was very difficult and it caused me huge anxiety.

The importance of age when determining risk status was also acknowledged by women in the limited testing group. Interestingly, women in this group were more likely to agree with an increased risk at age 35, whereas women in the extensive testing group did not consider 35 to be a magical cut-off number. Hannah (32, 13 ultrasounds) illustrated the relevance of being 35 and at high-risk when she said, "Ya, if I were over 35, I would definitely do the IPS. I'm trying to get pregnant before that so, at 34." Similarly, Iris (31, 4 ultrasounds) states, "I think that if I was over 35 and the doctor felt that for whatever reason there was a risk of some sort or that we needed to know a certain piece of information and the doctor really felt like we needed to do something like the amniocentesis, then I would do it."

Feeling Reassured

Regardless which type of test was being discussed, women were very optimistic about the test results. All participants mentioned frequently that they underwent prenatal testing to confirm what they had already assumed; that their fetus is viable and healthy. Testing to find out what is already known was specifically relevant with ultrasound scans. Anne (33, 1 ultrasound) explained that she wanted to have one ultrasound done to confirm that her baby was generally healthy; "I just wanted to feel a little bit reassured." When I asked Hannah (32, 13 ultrasounds) what she would have considered to be a bad test result, she answered, "I didn't really think about that before though, I was just like, I will be fine. I was being confident that it was fine. I was just doing it as a formality." Many women claimed that they were not worried about the possible test results and that

the tests would rather increase their confidence in the health of their fetus. Robin (42, no testing) struggled with this issue. She had hoped for her pregnancy to be as natural as possible and she wanted to only consent to prenatal testing if it was medically indicated. Nevertheless, she mentioned repeatedly throughout the interview that she would have liked to have the additional confidence which a good test result could have provided her; "So I knew that I wouldn't abort. But I was really fighting with me if I should have that baby tested to have that confidence that the baby is okay." Ultimately, Robin did not schedule an ultrasound appointment.

Risk of Testing

Prenatal tests sometimes fail. They sometimes detect problems when there are none, they can miss problems, and they can cause problems. Petra (35, Down's child, 1 ultrasound) made the experience of a prenatal screen failing; "The ultrasound did not show that there were any reasons to suspect that we were carrying a child with Down's. So we did not want any further testing done. We declined testing for all three boys." Women from the limited testing group often discussed the risks posed by some tests in the interviews. They mentioned both the potential for psychological and for physical harm, and they talked about it with reference to all different types of tests. Anne (33, 1 ultrasound) decided against the IPS because she said:

> The other thing, a test can be wrong. So people go through a lot of emotional upheaval and then things can turn out fine. I mean, your health as a pregnant woman is a big, you know, you want to be healthy and to feel good about yourself. You want to feel positive. You definitely don't want that stress, like to find these things out when you are pregnant instead of just being very positive about it that would be very hard to then be positive if you know that. I'd think you would spend the rest of your pregnancy worrying about it and thinking about it

> and being really upset about it. Probably crying a lot, and I don't know how much that would help in the end.

Robin (42, no testing) made similar decisions during her pregnancy, because she was afraid that the tests' results could upset her:

> If they find something that is just going to make me worried because a very high percentage of findings are false-positives, then I'm going to have a terrible pregnancy and I might have a healthy baby at the baby in the end. Or I can have a healthy happy pregnancy and have an unhealthy baby in the end, and I'd rather pick that. If you could actually do something about these findings, like intrauterine surgery or such, then I'm on board.

The safety of ultrasound scans was also questioned by a number of women in the limited testing group. Deidre (34, 2 ultrasounds) summarizes this attitude as follows:

> An ultrasound is not a free thing, it costs the system money, and also it's exposing the uterus to sound waves. And so to be aware that there might be consequences that we aren't yet aware of. You know because there hasn't been enough research on it, but it could be related to ailments in childhood or difficulties, ya, who knows. So for me it's the less intervention the better.

> Extensive testers also found the risk posed by some tests an important topic.

However, they only considered the potential for harm of invasive procedures, such as amniocentesis and CVS, while so called routine procedures, ultrasound and IPS, were said to be risk-free. Karla (32, 4 ultrasounds, IPS) was very keen on prenatal testing because of her experience with infants with congenital disorders. She works as a registered nurse in a neonatal intensive care unit. She told me that she probably would have done an amniocentesis if the IPS would have detected problems, but that she would have been scared to do so; "Like the IPS, it's an ultrasound and some blood work, so it's nothing. But the amnio has a risk of miscarriage. And then if you go even to further testing, even more complication, it's hard to make that decision, because what if you do lose the baby." Other women in the extensive testing group were unsure if they would schedule an amniocentesis after being screened positive (i.e. a problem is found) on the

IPS. Since the IPS was predominately done to be reassured of the health of the fetus, most women did not believe that the amniocentesis or the CVS would be part of a logical sequence after a positive IPS result. Most of women who had done the IPS had the same opinion as Giselle (40, 7 ultrasounds, IPS), when she said:

> So there was no further need to go for the amniocentesis, which I probably wouldn't have gone for anyways, but the good thing, I didn't have to make that decision. Only because the risk of miscarriages are really high. And I struggled to have her, so I wasn't going to do anything that could potentially put her at risk. I'm glad I didn't have to go through that, because the initial blood test and ultrasound was enough to see everything was fine.

Many limited testers had an opposing opinion. They also found the risk of invasive diagnostic tests to be too high, but they believed that participating in the IPS only makes sense if one is willing to go for further tests if needed. When I asked Fay (27, 3 ultrasounds) how she had decided against the IPS, she answered:

> I was scared too you know, of like the amnio. I have heard that it could give you a miscarriage, like there is a certain percentage of miscarriage just because of that needle, you know. And that is pretty scary. And you know, you do the blood test, even though there is nothing wrong, it might tell you, and then you do the needle test, and you lose the baby without anything being wrong. You know, it's not fair I think. So why go down that road.

Influence of Others

Women generally do not make prenatal testing decisions by themselves. The choices of the participants in this study were predominately influenced by the attitudes and recommendation of their healthcare providers and partners.

Obstetrician / Gynecologist

All of the women in the extensive testing group were in the care of an obstetrician as well as four women in the limited testing group. These women were more likely to

regard testing as routine procedures and they were often unclear about whether they were given a choice when specific tests were offered. Frequently, a doctor's recommendation of a test was perceived as "doctor's order." Julia (38, 2 ultrasounds, IPS) agreed to do some prenatal tests because felt she had to;

> I thought of all those tests more as an annoyance. And like the test for diabetes, I actually asked in my second pregnancy not to do the normal way. Rather than sitting around for two hours; drinking something and then waiting for two hours, I would just fast in the morning and do it then so I wouldn't have to wait for two hours. Like I understand that they have to do the test, but I was such a low risk for diabetes. But my OB wanted me to do it anyways, so I did it, but not because I really felt like I was at risk or anything.

Similarly, Ute (35, 2 ultrasounds, IPS) said, "I made the decision to have IPS done alone with my doctor. I didn't get any written information about it, but my doctor suggested the test, so I went ahead." Limited testers who were cared for by an obstetrician also believed that it is important for follow the care taker's advice. Iris (31, 4 ultrasounds) stated, "I think that if I was over 35 and the doctor felt that for whatever reason there was a risk of some sort or that we needed to know a certain piece of information and the doctor really felt like we needed to do something like the amniocentesis, then I would do it." Also, Hannah (32, 13 ultrasounds) declined the IPS but she believes "if the doctor recommends it, I think then go for it." Thus, the doctor's opinion is of highest value for those women who saw an obstetrician for their prenatal care.

A number of women were with a midwife for their last pregnancy, but they have had previous prenatal care from an obstetrician. They tended to feel a lot of pressure to undergo specific tests from their doctors, which they did not appreciate. Deidre (34, 2 ultrasounds), for example, explained "With my first pregnancy, I was under the care of a

GP and he had mentioned that IPS screen, and when I declined it he was actually quite shocked."

Midwife

Anne (33, 1 ultrasound) was also able to compare the care of an obstetrician to that of a midwife, because she had personally experienced both. For her last pregnancy, she was with a midwife, with whom she felt able to choose more freely. "So that was really nice with the midwife to tell me each thing and tell me what each thing was. And that's why our meetings were an hour long each time. She had forms to go through and she'd tick each one and I'd sign it for what tests would be done. So there was no pressure either way." Nora (34, 2 ultrasounds) outlined in greater detail how her midwives encouraged her to make informed testing decisions:

> Always, with the routine tests, as they came up, they gave me some research on it and told me to go and get my own information to see whether I wanted to do it or not. And they always gave me the option before the time for the testing came up. So they would say something like next month, there is this test that is usually offered, let us know next month if that is something that you want to do. And that was very nice because it gave me time to think about it and talk to people and that sort of thing.

Not all women agreed that the midwives tried not to influence the women's decisions. Robin (42, no testing) was upset because one of her midwives encouraged her to have an ultrasound to make her homebirth safer. Robin told me:

> The second midwife was less keen on it and was encouraging some ultrasounds to determine the placenta position. She was saying that when they are at home at a birth, they have a range of what's acceptable in terms of blood loss and such. And if they know where the placenta is, then they can go up to the upper range of the blood loss without being worried about it. Whereas if they don't know, and there is some blood loss, they have to be a lot more cautious. So she was pushing it but I declined. And I declined with the consent of the other midwife who was more holistic. She was more like are you feeling that there is a problem? No? Then we can leave it. And we agreed that by 37 weeks, if I had bleeding, because a high

> percentage of women who have placenta previa have bleeding, then I would do the ultrasound. But if there is no reason, then I wouldn't just do it.

It appears as though women did not feel any pressure for or against testing from the midwives if the women participated at a minimum in a single ultrasound.

Partner

Fathers-to-be have their own opinions when it comes to prenatal testing; they will have an equal amount of responsibility for their child, after it is born. In this study, the women's husbands or common-law partners were either in line with the women's values, or they believed that the ultimate decision should be left up to the pregnant woman. Hannah (32, 13 ultrasounds) told me, "He mostly left any decision up to me. Like we discussed it but he said whatever you want to do. So it was my decision." And Julia (38, 2 ultrasounds, IPS) felt the same way, "My partner left it up to me. I think if there would have been, like I mean even if there would have the case where we would have to make a decision, I would have talked to him about it, but ultimately, the decision would have been mine."

The amount of pressure or guidance women felt from their partners was the same for both the limited and the extensive testing group. Susan (47, 3 ultrasounds, IPS) had decided to undergo the IPS but to refuse the amniocentesis, and she was glad that her values aligned with those of her husband: "I talked about it with my husband, and he was wonderful. He said bad things can happen to children any time, and we will cope with those things. And he made me feel free to resist any testing I didn't want to have." Similarly, Fay (27, 3 ultrasounds) who was with a midwife and had resisted IPS told me, "Well, my partner didn't really see the need either." In case decisions had to be made

regarding more invasive testing, women believed it was very important that their partners shared their attitudes. However, it was not always easy for the women to fully comprehend their partners' decisions, probably because they were often unsure of their own position. Lena (41, 7 ultrasounds, CVS) explained the struggle she had trying to understand which route her partner had hoped her to take:

> No, I think, luckily my husband and I align on most of these things, but what he said, I mean he certainly, if we would have been on opposite ends of the spectrum it would have been very difficult. But it wasn't quite equal. At one point he said, you sort of have to make, like you are the one who is carrying the baby therefore really I think we have to weigh it more towards whatever you think. But he definitely wanted to have voice in what we were going to do. I think he definitely was involved in the decisions and he went through the same amount of stress and you know guilt last year when we were trying to sort all of that stuff out. But in the end, he said, I was actually surprised that he said that, but he said that when it comes down to it, you have to listen to what you say. I think he accepted that. He said, you are the one with the baby inside and feeling the movement and that sort of thing so it has to be your decision. But he wanted to have a say in it as well.

Guilt

Feeling Judged

A number of women from both the limited and the extensive testing group felt judged by others because of the decisions they made during their pregnancies. Robin (42, no testing) told me that her brother was very upset with her when she told him that she is not doing any prenatal testing: "He said this is wrong, and if you have a child that you know is deformed or deficient in some sort, then it is your duty to abort it. Your duty to the child and to society, because we don't need more people like this in this world." Also, Beatrice (32, 2 ultrasounds) and Iris (31, 4 ultrasounds) expressed that they felt a strong push from friends and family members to do the IPS, which they found hard to resist. Petra (35, Down's child, 1 ultrasound) experienced a different kind of judgment.

Her child was already born when people started to blame her for not having participated in prenatal screening:

> I felt very judged by certain members of the hospital staff after delivering [my son] and trying to come to grips with the shock of having a child with Down syndrome. Most often we would hear "Why didn't you get the testing done?" as if that would have made him be born without Down's. It seemed like a harsh judgment of our choice to take whatever child we were meant to have.

Almost all of the women who underwent IPS did not feel judged about their decision by others. The only exception is Julia (38, 2 ultrasounds, IPS). She was in the care of an obstetrician while most of her friends, who she considers to be anti-medical, went with midwives. Julia said, "I didn't really feel judged, but I definitely felt like I wasn't doing what they thought was right."

Judging – It's what you should do

Most participants did not appreciate to be judged because of their testing decisions. However, a few women believed that depending on a woman's risk status (i.e. her age and her family history of disability), prenatal testing is the only responsible decision to make. Fay (27, 3 ultrasounds) refused the IPS herself, but she firmly believes "if you are over 35 you should do the test; if you are at risk, if it's in your family and such." Iris (31, 4 ultrasounds) had the same opinion. She said, "I mean if I was older, if I was over 35 I would probably do it, just to do the responsible thing. Like you feel that maybe when you are older you maybe have to do these things a little more." Julia (38, 2 ultrasounds, IPS) also thinks that pregnant women ought to do fetal genetic testing. She explained:

> I think the tests are there because like they are there for a reason. And so especially for your first time, you shouldn't, you know, you should just do it

> unless you have very very strong convictions of why not. You know, they are for your health and that of your baby. Maybe because I had a very easy pregnancy, I passed all the tests, so I'm not afraid. So I really think that those medical tests are fine and they give you a certain sense of security; especially when you are older. And I think the mother who knows that there is certain pre-conditions in the family, they may want to do more testing and different testing and so they should.

I happen to love my genetic anomaly – He gives great hugs.

(Petra (35, Down's child, 1 ultrasound))

The intention of all fetal prenatal tests is to diagnose an anomaly or disability in the fetus before it is born. In the following sections, I will elaborate the four themes that emerged from the interviews in relation to the intentions of prenatal tests, which are disability, experiential knowledge in relation to disability, experiential knowledge in relation to prenatal testing, and abortion.

Disability

In the interviews, disability was usually discussed with reference to Down syndrome and spina bifida, because these are the most common congenital disorders and they are most frequently screened for. As expected, the limited testing and the extensive testing group had very opposing opinions on the issue of disability. All of the women who underwent IPS and more invasive procedures stated that they would have considered Down syndrome and spina bifida a bad test result. Cora (34, 5 ultrasounds, IPS) said, "Well, I made the decision because I didn't want to have a baby with a defect. Well, like something that would have been difficult to deal with like with mobility and stuff like that." And Julia (38, 2 ultrasounds, IPS), who had been trying for a number of years to become pregnant, told me, "Raising children is hard enough and when you have all these

extra challenges. I don't know if I could have dealt with it. You know, I really wanted children, but I don't know if I wanted children that bad."

Women from the limited testing group were not as concerned about the possibility of their child being born with a disability. Anne (33, 1 ultrasound) told me that she was hoping for her infant to be healthy and not disabled, but that this was not a reason good enough for her to get screened:

> There is so much talk now about the Downs community getting smaller and smaller, cause everyone is finding these things out and seeing them as not being worthy. So that makes me pretty sad, you know, just thinking of that. Because they are fully functioning human beings who have full lives and there is so many different degrees of it, and you don't know what degree your baby has. And they are actually very warm loving good people. Of course it could change your life as a parent but that is the risk you take.

Iris (31, 4 ultrasounds) expressed a similar opinion when she said, "I just felt that we are having a baby and that it was our child and that if the child was disabled in some way, we would still love the baby." Very positive attitudes towards the Down syndrome community were also expressed from Olivia and Petra, who are mothers of boys with Down syndrome. Olivia (34, Down's child, 3 ultrasounds, IPS, amnio) said, "I don't know how we deserve to be so lucky." She feels blessed that her son never had to deal with major health problems. She knows people whose child with Down syndrome has had four open heart surgeries before the age of five while her son only has developmental deficiencies.

Experiential Knowledge – Disability

Olivia (34, Down's child, 3 ultrasounds, IPS, amnio) had known about her son's condition during her pregnancy. She and her husband decided to have the child, and she

told me that this decision was influenced by her personal experience with members from the Down syndrome community. Olivia said:

> In my family, there is a young woman who is my Aunts niece. She is now 34 years old, and having watched her grow, and change over the years gave me a fairly good idea of the worst case scenario of a life with a special needs child. Things are better for her now, than they have ever been. It was not always good though. Having known her most of my life, and it was not always bad for her family, helped me to feel that we were up for the challenge of having our son.

Other women, who had declined prenatal genetic tests, also mentioned that they either have had personal experiences with disabled individuals or have friends who told them about their experiences with disabled children. Anne (33, 1 ultrasound) explained, "My friend's sister has Downs and well, we have never met her, because they live out East, but you know, he talks about growing up with a sister who has Downs, and it's like, it's his family." Robin (42, no testing) also has a friend whose infant has Down syndrome and she believes, "They are such a wonderful family and it's so cool with them." Seeing her friend raise a child with Down syndrome made her feel confident to do the same; thus, she declined all prenatal testing. Since fathers-to-be are influential on women's testing choices, their experience with disabled individuals can impact women's attitudes as well. Beatrice (32, 2 ultrasounds) summarized it as follows:

> What was very reassuring for me was, because as I said my mother-in-law works in that field, my husband has spend a lot of time, as a child, around other children or youth with disabilities. So he was very comfortable with that. He knew they were nice people and not just kind of faulty people. You know, people who had they own gifts and deficits just like everybody else. And so he felt kind of, funny thing, more familiar and comfortable with it than me. In the sense of I was willing to go with it, but I was not as directly familiar with what that would mean in terms of interaction. He even said that he was used to that and that his mom could help us also. So he said if anything, I think we would be good parents to a disabled child because we would be willing to do that. And that made sense, and that helped me make peace with the decision to not know.

All of the women in the extensive testing group claimed not to personally know anybody who has Down syndrome. Ute (35, 2 ultrasounds, IPS), for example, said, "I don't know anybody with Down's or such. But I did read about the condition in parenting magazines, and I assume that it is quite tough and challenging." Cora (34, 5 ultrasounds, IPS) is the only extensive tester who knows somebody with personal experience with a person who has spina bifida. She said,

> Well, I do have a co-worker, whose sister has spina bifida, and it's not a life. Like, had her mother known in advance, she probably wouldn't have gone through with it. Like knowing someone who has a sibling is not the same; it is hard. So even today, as an adult, her sister has such a hard time and so many operations. So it's kind of like, they might have the ability to live, but depending on the level, they still have such a hard time.

Cora perceived her co-worker's experience as very negative and it encouraged her to participate in the IPS.

Experiential Knowledge – Testing

A number of women recalled stories they have heard from friends or family members regarding prenatal testing, and how these stories impacted on their own decisions. Interestingly, only negative stories were being told during the interview. No women claimed to have participated in prenatal testing because she has heard good things about it. Women indicated that they learned from the experiences of others that testing can cause unnecessary nervousness, that test results are not always accurate, and that tests can cause harm to the fetus.

Iris (31, 4 ultrasounds) told me that she did not want to do the IPS because of her friend's experience; "I remember that she was so nervous waiting for the results. And I just thought that I wasn't going to do that. I'm not going to sit around on pins and

needles being all worried waiting to find out. It was just not worth it to me." Similarly, Giselle (40, 7 ultrasounds, IPS) reasoned that she would do the IPS but would refuse the amniocentesis because she remembered the stress her friend went through:

> The one friend who did had to go down the amnio road, because her numbers came, I'm not sure if it's high or low, but in the range where things could potentially be a problem. So she struggled with that for a while. In the end, she decided not to do it, but another friend ended up doing the amnio, and having to wait and the stress involved in that. But, the amnio came back and the baby was fine. I clearly knew the stress level and it's horrible. You are trying to stay calm, not to increase your blood pressure, but when you have this really really heavy decision, and also the waiting part, cause you are waiting for the results, is really stressful.

None of the women in this study experienced false-positives or false-negatives; however, a few women knew of people who have received incorrect test results. Ella (34, 3 ultrasounds) had lost confidence in the IPS because one of her friends had been screened during her pregnancy, and she still gave birth to a baby with trisomy 18. Robin (42, no testing) has a friend with an opposing story: "One family, she had a lot of pressure to abort, and she ended up with a healthy baby who was born the same time as my son, and he was perfectly fine. But really, you know, they consulted with a geneticist and that was in Canada, and they were told that their baby was going to be severely retarded." Understandably, Robin's confidence in prenatal tests was also reduced. Hannah (32, 13 ultrasounds) is a registered nurse, and she did not trust the results of the IPS because of stories she has heard from her co-workers in radiology. She told me "I get stories from all the techs who do x-rays on babies after the fact kind of thing, and they are sometimes aborted healthy. They are tested positive on the IPS, then they abort and the baby is healthy."

Other women felt threatened by invasive prenatal tests because they know people whose pregnancy was put at risk by their use. Susan (47, 3 ultrasounds, IPS) felt a lot of pressure from her obstetrician to undergo amniocentesis because of her age. However, she was too afraid to agree to the testing because she knows a couple which has lost their infant as a result of the procedure. She told me:

> My husband has a friend who has had a lot of trouble getting pregnant. And finally became pregnant. And she talked about how finally she felt like she was part of this club of women who could become pregnant. And then, she went to her prenatal appointment at about 16 weeks. And she asked if she wanted the amnio. So she asked what is amnio, and they said well, it's a test. So she asked 'what do most women do?' and he said 'well, most women do it.' So she went for the amnio. And this is absolutely true. And what happened is that during the amnio she got infected. And within hours she was extremely ill and her baby. And she got septic. And not only did she lose her baby but she also lost her uterus. They had to remove it surgically because of the infection. That was horrible. So that has affected their whole life. ... If it would have been risk free for my baby, I probably would have done anything, but because I know this couple who have lost their baby and her uterus; that had a huge impact on my husband and on me.

Evidently, the experiences of others had a strong impact on the women's testing decisions in both the limited and the extensive testing group.

Abortion

It is generally assumed that women participate in prenatal testing to either feel prepared for the birth of a disabled child or to terminate the pregnancy if a disability is found. Women in the limited testing group unanimously agreed that one of their reasons to refuse genetic testing was that they would probably not have aborted an affected fetus anyways. For example, Beatrice (32, 2 ultrasounds) said, "Well, we knew that we were not going to terminate the pregnancy no matter what, which is part of why we also didn't do any of the screening for really anything." And Deidre (34, 2 ultrasounds) agrees, "I

declined because to me, had I tested positive for a Down syndrome marker, I wouldn't have terminated the pregnancy. So it didn't really matter to me in that sense."

There was greater variability in the answers of the extensive testers. A few women mentioned that they were indecisive on the issue of abortion at the time of testing. Ute (35, 2 ultrasounds, IPS) explained, "I'm not sure what I would have done. I feel like I'm not strong enough to care for a disabled child; not mentally strong enough, you know?" Otherwise, it became clear that most women had made the decision to get tested because they did not want to carry an affected fetus to term. However, women seldom spoke directly about abortion or pregnancy termination and they quickly changed the subject to more pleasant issues. It is illustrated by an answer of Karla (32, 4 ultrasounds, IPS), who said,

> We had discussed that before that we wanted prenatal testing, so at least with the big abnormalities we could make a decision if that would be the case. That was as important to my partner as it was to me. What we would have decided if it was, I think you can have an idea, but until you are faced with that situation I think it's different.

Similarly, Teya (38, 3 ultrasounds, IPS, amnio) told me " It's just so very challenging, you couldn't work and you would have to take care of that child for the rest of your life. That would be very hard. But you know. I would rather not talk about this."

Advice

I asked all women if they had any advice for parents-to-be regarding prenatal testing. The themes that were mentioned repeatedly were the importance of choice and of trust.

Choice

It was very relevant for most women that prenatal testing remains a woman's choice, and that pregnant women are aware that they have the right to refuse any test. Both limited testers and extensive testers agreed that women must have the option to undergo or decline prenatal tests. Giselle (40, 7 ultrasounds, IPS) believes "it's the women's choice, and also the partner's. And it's really no one else's business." And Deidre (34, 2 ultrasounds) explained, "I would say, well, every test is your choice. Gestational diabetes test, it's your choice. When you go in the doctor's office for the visit, when you pee on a stick, it's all your choice. You have to be aware of those choices and that you have a right to say yes or no." Only Julia (38, 2 ultrasounds, IPS), from the extensive testing group, believed that women over 35 should be required to participate in prenatal screening.

Trust

In discourses surrounding pregnancy, the women in this study often spoke about intuition and instincts. Most women, also those who underwent a lot of prenatal testing, believed that it is important for pregnant women to trust their feelings before making decisions regarding testing. Cora (34, 5 ultrasounds, IPS) told me that she has a friend who is currently pregnant. She advised her to trust her instincts because it would allow her to know how to proceed. Giselle (40, 7 ultrasounds, IPS) similarly stated "You know, you really have to go just with your gut and with what you really believe." Hannah (32, 13 ultrasounds) believed it is important for women to both trust their instincts and their decision making abilities, because things never go as expected. And

Beatrice (32, 2 ultrasounds) summarized the general feeling that went through the interviews when she said, "I think it's just, people really need to trust the process, trust themselves, trust their bodies, trust their babies, and develop that kind of relationship."

Conclusion

A number of relevant and interrelated themes have emerged from my analysis of the qualitative interviews. Women had different opinions on what constitutes a routine prenatal test, and whether calling a test 'routine' implies that it is a medical recommendation or an obligation. Risk was discussed in the interviews in relation to four important areas: women's perceived risk status, age related risk, using prenatal testing to feel reassured, and the risk of iatrogenic effects of testing. Healthcare providers and partners have influenced women's attitudes towards routine testing and risk perception, and they have impacted on women's testing decisions. Also, women's attitudes and experiences regarding disability, prenatal testing and abortion contributed to their subsequent testing choices, and shaped the advice they gave for mothers-to-be. In the following chapter, I form the connection between the findings of my study and those of previous scholars, using a Foucauldian lens to guide the discussion.

Chapter 5: Discussion

Introduction

In this chapter, I illustrate the link between the data I gathered through interviews and the findings from previous studies. The result of this study is the application of Foucault's theory on biopolitics / biopower, as I have discussed previously in chapter 3. The dominant themes significant in linking the findings of my study to the existing literature are risk, routine, and knowledge.

Risk

One might assume that a woman's perception of her risk-status would influence the number and the type of prenatal tests she participates in. When I asked women during the interviews if their pregnancy was considered to be at risk for any reason, they all answered no. I intentionally did not ask if their pregnancy was placed into the low or high risk category by their healthcare provider to understand their personal risk-status evaluation. Evidently, the women did not perceive their pregnancies to be as risky as their healthcare providers did. For example, Ute (35, 2 ultrasounds, IPS) told me "I wasn't at risk during my pregnancy. My pregnancy was pretty healthy, I would say average." Ute was 35 years old at the birth of her child; thus, she was a high risk patient within the prenatal care setting based on her age. Similarly, Giselle (40, 7 ultrasounds, IPS) said, "The chromosome test was offered because of my age, right; I was over 35, so again, no choice in that. I mean they said it is highly recommended that you do that because you are 40." Giselle was also in the care of a high risk specialist for the first part

of her pregnancy because she has had fertility problems; nevertheless, she considered her pregnancy low-risk.

This difference between self-perceived and actual risk status has also been observed by other researchers. Marteau and colleagues (1991) have demonstrated that a woman's perception of her own risk of having an infant affected by some congenital disease is often vastly different from her actual age-related or screening-determined risk. In a survey of women who were offered amniocentesis because of their age, it was found that screening uptake was statistically significantly associated with a higher perceived risk of having an affected infant, but not with age related risk. Also, no association was found between a woman's actual and perceived risk (Marteau *et al.*, 1991). These findings suggest that the way in which women perceive risk is very subjective and complex, and depends on much more than solely biomedical facts.

Lippman (1999) also demonstrated that prenatal test decliners often reconceptualize the level of risk that has been presented to them. They base their personal risk level on their own life history and experiences rather than on the statistical risk interpretations of epidemiology. In doing so, they are able to challenge the biomedical's assumption that they are at risk, thereby making prenatal testing irrelevant to their needs.

Even though women did not accept the label of 'high-risk patient' that was presented to them by their care provider, they did accept the idea that all pregnancies are inherently risky. In the clinical setting, pregnancy is not presented as a natural phenomenon but rather as an opportunity for things to go wrong. Regardless of the health of a pregnant woman, of her fetus and of her family, the best possible outcome of

an initial prenatal evaluation is being placed into the low-risk category. The women in this study participated in this discourse. Even Robin (42, no testing), who refused all prenatal tests, considered her pregnancy low-risk, rather than risk-free. If women generally agree that all pregnancies involve some form of risk, then they are more likely to participate in disciplinary practices and are less likely to resist regulatory surveillance mechanisms.

Age is an interesting example for the creation of risk categories that illustrates a fundamental misunderstanding between pregnant women and clinicians. Many people believe that the age of 35 reflects a sudden increase in the possibility of giving birth to an infant with a congenital disability. Hannah (32, 13 ultrasounds), for example, explained that she wants to be no older than 34 for the birth of her next child and that she would participate in IPS if she was 35 or older. Also, a number of women younger than 35 claimed that testing is the responsible thing to do for women 35 years and older. Beaulieu and Lippman (1995) found this perception echoed in women's magazines. They often attach the high-risk label to motherhood over the age of 35 and they frame prenatal testing as a need for women that age. However, 35 is only an arbitrary number that was decided as the cut-off based on statistical probability. Being 35 years old represents the point at which the probability of having a procedure-related miscarriage is equal to that of having a child with Down syndrome (Pauker and Pauker, 1994). Thus, it is correct that the possibility of giving birth to a child with a congenital disability does increase with age, but it does so gradually, and 35 was only chosen as the cut-off under the premise that miscarriage and giving birth to a child with Down syndrome are equally undesirable.

Medical experts decided on the high risk cut-off age based on epidemiological studies and based on the premise that society agrees that the birth of an infant with Down syndrome and having a procedure-related miscarriage are equally negative occurrences. One problem with this approach is that the attitude of the individual pregnant woman towards Down syndrome and miscarriage is not included into the equation, and that women are generally not aware of it. The other problem is that it is assumed that all women in a specific age category have the same possibility of having a fetus with genetic abnormalities. Epidemiological risk, which is calculated through the observation of patterns in anonymous populations and the identification of associated risk factors, is directly being translated into clinical risk, which is based on an expert's observation of the characteristics of the specific individual. "The collective results of diagnostic tests on populations establish norms against which a particular woman's health and the development and growth of her foetus may be compared" (Lupton, 1999: 63). This practice is applied to all pregnant women and it is normalizing because it locates the individual woman into a framework of comparisons with many other women.

> The locus in which knowledge is formed is no longer the pathological garden where God distributed the species, but a generalized medical consciousness, diffused in space and time, open and mobile, linked to each individual existence, as well as to the collective life of the nation, ever alert of the endless domain in which illness betrays, in its various aspects, its great, solid form (Foucault, 1973: 31).

The power of the medical expert, whose knowledge is assumed to be of highest value because it is scientific and neutral, makes the norm appear moral and right. Thus, medical discourses of risk reinforce the standardized use of prenatal testing procedures.

Routine

Routine tests are often assumed to be risk-free because if clinicians present something as the norm, it will likely be safe and responsible to do. In this study, women in both the extensive and the limited testing group called ultrasound scans 'routine procedures'. However, only the extensive testers believed the IPS is part of routine prenatal screening. Thus, women did not agree on what constitutes a routine test. In addition, women had varying opinions on what it means for a test to be routine. For example, Robin (42, no testing) told me that she did not have the routine ultrasound, while Ella (34, 3 ultrasounds) said with reference to her ultrasound, "Well, the other ones weren't a choice really; they were pretty much just routine." Both women regard at least one ultrasound as routine prenatal testing. However, Robin is aware that she has the right to refuse any test even if it is called a routine test, and Ella felt obliged to participate in routine tests. I assume that Ella did not consider whether she had a choice at the time the ultrasound was offered.

Michie and colleagues (1999) have developed a scale to measure the extent to which people make decisions systematically as opposed to heuristically. When used on a sample of women who had been offered prenatal testing, the researchers found that in general, women were not making decisions systematically, and that women who accepted prenatal screening had made their decisions less systematically than women who declined. The authors hypothesized that, "whilst not having the test is a result of a decision, undergoing the test is not the result of a decision but, rather, reflects routine behaviours, co-operating with perceived expectations of clinic staff" (Michie *et al*, 1999:

746). This finding is in line with the attitudes of the women in this study towards decision making with regards to routine procedures.

Research suggests that the simple offer of a screening test suggests its usefulness by implying the general approval of the medical community. While most healthcare providers regard informed choice as central to all forms of testing, many would probably recognize that the offer of testing alone implies its endorsement and the subtle encouragement of its acceptance (Williams *et al.*, 2002; Ryder, 1999). Thus, non-directive counseling is a crucial component of all prenatal testing to promote truly informed decision making. However, women are only counseled to guide them in making a decision in cases of invasive diagnostics. Ultrasounds and IPS are seldom presented as a choice because they are considered risk-free by the medical community.

The simple offer of a test during a prenatal visit makes the test appear important and valuable to many women. Additionally, the way testing is presented, and sometimes offered, influences women's subsequent decisions. Pilnick (2004) observed midwives who discussed the options of prenatal testing with pregnant women. He demonstrated that even though the midwives took great care to present testing as an option and not a requirement, they did so within a system of care that places high value on increased information. Midwives were, for example, observed to explain to the women how the value of screening may vary for different women. They stated that some may want the information for its own sake and with the intention of continuing the pregnancy regardless of testing outcome, while others may want the results to help them make a decision about the course of the pregnancy. Pilnick (2004) points out that what is most significant about this discussion is not what is being said, but what is left unsaid. Some

women may simply not want the information derived from testing at all. Even though prenatal testing was presented as a choice, the framing of this choice was based on the assumption that the information from testing is inherently valuable, thereby obscuring the option of choosing not to be tested.

Furthermore, Dormandy and Marteau (2004) found in their study in the UK that practitioners at hospitals with high uptake of prenatal testing had generally more positive attitudes towards testing than those at the hospitals with low uptake. Based on this finding the authors hypothesized that either healthcare professionals' attitudes influence systems of care, or that certain systems of service delivery influence the attitudes of those who work within them. Nevertheless, the study shows that not only individual patient-care provider interactions have an effect on testing uptake, but also the institutional culture. The individual healthcare provider's attitude is very influential in women's decisions to undergo prenatal testing. However, women have to be aware that systems of care founded on the use of medical innovation are rarely implemented in a systematic fashion. Rather, the use of a technology typically becomes standard practice long before real evaluations of its effectiveness or ethical or social acceptability have been carried out (McKinlay, 1981).

In this study, women believed that they are considered bad patients by the medical community of they do not follow all routine prenatal care procedures. Beatrice (32, 2 ultrasounds) resisted the IPS, and she thought that this move was consistent with her role as "nightmare patient." She gave herself this label because she asked a lot of questions during prenatal visits and did not follow all routine procedures. A study by Hunt and colleagues (2005) shows that Beatrice's assumption about how she was perceived by her

obstetrician might be correct. They found that while healthcare workers tend to view women's decisions to accept prenatal testing as the product of a rational decision-making process, women's decisions to refuse testing is regarded as a product of irrational fear, cultural beliefs and misunderstanding.

The regulatory power of the medical profession, through the presentation of prenatal tests as routine, was most visible in the accounts of the women in the limited testing group. This concept of resistance has emerged independently in a number of studies (Dhont *et al.*, 1999; Rapp, 1999; Lippman, 1999), which I regard as strong support for the idea that prenatal testing has become routinized. Nevertheless, Foucault believes that resistance to power is only a new form of power in disguise. From a Foucauldian standpoint, prenatal testing which is routinely offered to all pregnant women can be problematized as an exemplar of surveillance medicine. Pregnant women are under constant surveillance by strong networks of biopower and knowledge, and the medical gaze, in the form of technological testing, ensures the calculated and normalizing management of pregnancies (Lauritzen and Hyden, 2007: 115). Specifically interesting is the shift in the medical gaze from the actual to the possible presence of disability, and thereby a focus on early detection of deviation from normalcy. This shift as well as the increase in the clinical technological possibilities to detect disability contributes to a wider gap between the knowledge of lay people and that of the medical profession.

Knowledge

Medical practitioners decide what constitutes medical (i.e. acceptable) knowledge. Through the use of ever more sophisticated technology, they propagate the

belief that they know more about the state of a woman's pregnancy than she does herself. Trust in medical professional's expert knowledge is frequently cited by women as influencing their perception of testing as being valuable (Williams *et al.*, 2005; Liamputtong, 2002). All women in the extensive testing group placed high value on the information that genetic testing could give them regarding the health of their fetus. Similarly, all women who underwent ultrasound scans believed they were necessary to obtain valuable information. Press and Browner (1997) report similar findings. In their study on women's decision making regarding prenatal care, women tended to view the knowledge offered by testing as being without risk; making direct statements such as, "How can it hurt to know," or "Why would I not want to have this really unintrusive test?" (Press and Browner, 1997). Anderson (1999) describes this unquestioned value of information as a moral imperative which is derived both from the culture of medicine and Western society. It is assumed that what is capable of being known ought to be known, and that this knowledge in itself will lead to a better outcome for the pregnant women, her infant and her family. Foucault (1989) asserts that pregnant women are responsible for the health of the population, which he coined 'women's biologico-moral responsibility' (104). Thus, women are made to believe that they can only fulfill this responsibility when they follow the medical norm and receive all prenatal testing information possible.

Since all pregnancies contain some form of risk, pregnant women are 'accidents waiting to happen' and any action is superior to inaction or passivity from a medical standpoint. Similarly, gaining knowledge is always a virtue regardless of how one

decides to act on this knowledge. Nora (34, 2 ultrasounds) told me that she did not agree with her midwife's reasoning for doing a second ultrasound scan. She said,

> She just wanted to make sure that everything was ok. And I was like, no I don't think so. Like that was not a reason. I didn't feel the need for it. I felt good; the baby was moving, everything was fine. And I wasn't worried that the baby could be harmed by the ultrasound, but you know, if it's not needed why bother? Like if there is no reason for it, then why do it? If there is no evidence to suggest that you need to do it, then why should you?

Nora trusted her bodily knowledge. She decided that she did not require medical technology to learn that her fetus was doing well. Anne (33, 1 ultrasound) also believed that gaining knowledge is neither always necessary nor always a good thing. She explained, "As soon as you know something, then you are left with the decision. Even if you already know what the answer is for yourself." She did not want to have to decide about the course of her pregnancy; thus, she resisted the IPS.

Foucault exerts that the physician's perception is key. A good doctor is one who sees everything. It must be ensured that women participate in prenatal testing because it makes more of herself and her fetus visible to the gaze of the practitioner. Also, "privileged technological knowledge is deemed relevant to decision making while the woman's experiential, bodily knowledge is considered irrelevant" (Pylypa, 1998: 30). Nora and Anne were exceptions in this study. Most women from both the limited and the extensive testing group wanted some form of screening, predominately to confirm their own embodied knowledge. They subordinated their embodied knowledge to technical knowledge. For example, Olivia (34, Down's child, 3 ultrasounds, IPS, amnio) had learned through an ultrasound that she was likely carrying a child with Down syndrome. She told me that she knew that something was not right with the baby, and the ultrasound confirmed it. Her doctor suggested her to undergo an amniocentesis to further confirm

the ultrasound diagnosis. Olivia claimed, "His thoughts were pretty much the same as ours. If it really didn't matter about the outcome then why not be sure." Therefore, she does not only subjugate herself to the surveillance of medical technology, but she embraces it. In a study on the authority women give to biomedical knowledge in prenatal care, Browner and Press (1996) also found that medical surveillance in pregnancy is not only accepted, but highly valued by women. The researchers concluded that women perceive the status of being informed as one of the most important responsibilities of pregnancy, and they see such surveillance as providing reassurance about the course of their pregnancy and the health of their infant.

Furthermore, not only women who consider themselves to be at high-risk undergo prenatal testing. In their study on nuchal translucency screening, Pilnick and colleagues (2004) demonstrated that many perceive themselves not to be at risk for a positive screen and that they accept screening either as a formality or to get reassurance about the health of their infant. This desire for reassurance is one of the most frequently reported reasons for participating in prenatal testing (Hunt *et al.*, 2005; Rice and Naksook, 1999; Press and Browner, 1997). In this study, women generally assumed that test results will be favorable, thereby confirm what they already knew.

In addition, prenatal testing was often used by women to confirm that they are actually pregnant and to make the pregnancy experience more real. Ultrasounds allow couples to get empirical evidence of the existence of the fetus because it can be both seen and heard. Most women in this study really enjoyed the scan. Comments were made, such as "I wanted to see the baby because it makes it more, ya, it makes it more real" [Teya (38, 3 ultrasounds, IPS, amnio)], "Listening to the heart beat makes it more real as

well" [Karla (32, 4 ultrasounds, IPS)], and "My husband was there for those screens. That's the other big part of the 18 to 20 week ultrasound, well each time I had an ultrasound, actually the whole thing became more real for him, too" [Lena (41, 7 ultrasounds, CVS)]. For many future parents, the ultrasound has such an important confirmatory role that they do not announce the pregnancy until after the scan (Marteau, 1995; Al-Jader *et al.*, 2000; Garcia *et al.*, 2002). A number of women, predominantly in the extensive testing group only told people about their pregnancy after having seen the fetus on the ultrasound image. Karla (32, 4 ultrasounds, IPS) said she sent out the ultrasound picture to friends and family to announce her pregnancy.

In the medical realm, ultrasounds are considered diagnostic procedures, which are used during pregnancy to scan the fetus for potential pathology. The Society of Obstetricians and Gynecologists of Canada (2007) recommends that ultrasounds are only performed by specialized medical personnel and that they are used only for medical purposes; thus, to diagnose pathology. Doctors try to maintain the power of surveillance within medicine in an effort to keep the power to confirm pregnancy and diagnose problems with medical clinicians. Women generally decide to get scanned for non-medical reasons. In this study, a number of women claimed they wanted to have an ultrasound to see their baby and to make the pregnancy experience more real, as I have explained previously. Four women even paid privately for a 3-d ultrasound, which was not performed by medical personnel. Evidently, women are looking for health results when they participate in prenatal testing while clinicians are looking for indicators of disability. This explains why many women did not consider how they would deal with an unfortunate result prior to testing. Women's strong request for prenatal tests, specifically

ultrasounds, also illustrates the importance of their role in the medicalization of pregnancy. Foucault claimed "the individual which power has constituted is at the same time its vehicle" (Foucault, 1980: 98). Women request medical tests even outside of the medical sphere; thereby strengthening the powers of medical surveillance and regulation.

Healthcare professionals repeatedly mention that early knowledge that a child will not be fully healthy or 'normal' makes the adjustment to this news easier for mothers and their families than it would be if they were to learn of it only at birth. Olivia (34, Down's child, 3 ultrasounds, IPS, amnio) was glad that they knew of their son's condition before his birth because it allowed them to prepare their older daughter, who was six years old at the time of his birth. Petra (35, Down's child, 1 ultrasound) did not know that her son had Down syndrome. She believed that the medical personnel in the hospital might have been more understanding, had they known in advance. However, she did not think that this would have been a strong enough reason for invasive diagnostics.

Prenatal tests are also offered to allow women to decide to end their pregnancy if problems are found. The interviews showed that women did not discuss this topic with their healthcare providers, a fact that bothered some women in the limited testing group. For example, Ella (34, 3 ultrasounds) claimed she would not have aborted regardless of a test's result and that she would have liked to discuss it with her obstetrician. Women in the extensive testing group avoided the issue of abortion during my interviews. A study by Press and Browner (1993) also observed that the topic of abortion was typically avoided in their interviews with women who had decided to undergo maternal serum screening. Only a small number of women, when asked directly, indicated that they would abort a fetus with serious birth defects, most women focused on the usefulness of

the information the testing would provide to feel reassured or prepared. The authors stated that women might avoid talking about abortion because talking about such a personal and controversial topic might be too uncomfortable. However, they believe the reasons to be not only personal but also having a strong structural component, which arises from the failure of the medical system to separate prenatal testing from routine prenatal care. They stipulate that because prenatal care is designed to promote the health of the fetus, and prenatal testing is now placed firmly into the same category, it becomes very confusing for women to think about testing and pregnancy termination decision-making together (Press and Browner, 1997).

Previous research has also found that women who decline prenatal testing are more likely to explicitly make the link between testing and abortion. Decliners are not necessarily strictly against abortion, rather they regard testing as potentially putting them in a position in which they are required to make a decision about the course of their pregnancy that they do not want to make (Markens *et al.*, 1999). These women try to avoid the issue of having to make a decision about abortion, and a number of studies have shown that they might have made different testing decisions under different circumstances. For example, if the women's family history would place them at a higher risk, or if the test itself was more accurate, less invasive, or delivered earlier in the pregnancy (Lippman, 1999; Markens *et al.*, 1999). A number of women in the limited testing group stipulated that they would have consented to the IPS had they been older than 35 or had a family history of disability. Nevertheless, one cannot make the assumption that testing acceptance is equal to a willingness to abort an affected fetus (Tercyak *et al.*,2001). It is significant that there is a lack of discussion about abortion

during the consultation about testing because it may prevent some women to engage the type of thorough value clarification exercise which is necessary for truly informed decision making.

Conclusion

In this chapter I used Foucauldian concepts in the discussion of those themes which were most relevant in linking the results of my research to the existing literature. Most women in my study followed the recommendations of their healthcare providers when making testing decisions; medical knowledge was deemed superior to their personal interpretation of risk and routine. The medical gaze, which is represented by testing procedures, places women under constant surveillance of the medical profession, while it normalizes and medicalizes pregnancies. In the final chapter, I provide a summary of the contributions of my study to the social sciences. I discuss the study's strengths and limitations, as well as new research questions that have emerged from the analysis.

Chapter 6: Conclusion

Introduction

The intent of this study was to explore the meanings and values that Canadian women assign to prenatal testing as well as their role in the routinization of prenatal testing and in the medicalization of pregnancy. The data gives insight into a number of factors that influence women's attitudes towards prenatal testing. In this chapter, I highlight the contributions of this study to the social sciences. Furthermore, I review the study's strengths and limitations and discuss potential directions for future research.

Social Significance

This study provides five key contributions to our understanding of the routinization of prenatal testing and the medicalization of pregnancy. First, my research offers an understanding of women's definitions of routine testing and how these definitions relate to and differ from the way in which routine testing is conceptualized by the medical profession. The routinization of prenatal testing is real and apparent in Canadian society. Acceptance of prenatal testing is embedded strongly into the medical model of prenatal care, which approaches all pregnancies as being at risk. Declining prenatal testing requires an active decision, whereas acceptance has become the default practice of normal and responsible healthcare providers and parents. Evidence for routinization was manifested in the data in various ways. For example, a number of women did not know that test participation is a choice rather than an obligation. Specifically with regards to ultrasounds, a number of women used the terms "routine test" and "required test" interchangeably. Also, some of the women who did not want to

undergo fetal genetic screening felt so judged by their care provider and others for their decision that rather than simply declining, they actively resisted testing.

Kukla (2007) explains that women do not make testing decisions in a social vacuum. Prenatal testing is considered standard and routine practice in our culture; thus, test participation will be perceived as the normal, responsible choice. However, it is important to remember that technologies such as prenatal testing are not neutral. The possibility of obtaining prenatal genetic information inevitably creates new choices that in turn can present new problems and dilemmas. The very existence of a test for fetal abnormality can create pressures to use the technology. The ongoing development of new screening programs implies that testing and selection are a desirable outcome. In this context, creating space for pregnant women to think carefully about their options, and to exercise their right to refuse testing, becomes even more important. This study illustrates that clinicians have to acknowledge the wide range of values that women bring to decisions about prenatal care in an effort to encourage women to make decisions in the context of their personal life circumstances.

Second, the study illustrates that there are subtle but very important differences in the ways in which healthcare providers and users of prenatal testing procedures evaluate the usefulness of testing. The primary reason behind testing for the majority of women in the extensive testing group was that testing would allow them to gain the knowledge they needed to give them a sense of control and a feeling of power over their pregnancy. They would use this knowledge for reassurance that their child was healthy, to prepare for life with a child with congenital abnormalities, or to terminate. Generally, women who participated in IPS often did not give much thought to possible problems. One of the

most explicitly stated benefits of testing was that it is an opportunity to be reassured about the health of the baby. Pilnick and colleagues (2004) also demonstrated that most women who accept testing do not consider what they might do in case they are faced with a positive, or non-reassuring test result. In their study's interviews, women would repeatedly make statements such as, "Crossing the bridge when we come to it" or "Worrying about it at the time." In contrast, healthcare providers approach prenatal testing from within the biomedical paradigm. They regard it as a technique focused on identifying problems in order to respond properly; either by preparing for a difficult birth or by allowing the patient to make a decision on pregnancy termination. Women in the limited testing group were aware that healthcare providers are looking for pathology when monitoring the fetus. Their primary reason behind not testing was that they would not terminate their pregnancy regardless of the test result, making the test irrelevant. These women also believed that if they participated in IPS, they were likely to experience higher levels of stress during their pregnancy, especially if their fetus was found to have an abnormality. The extensive testers' expectation of a reassuring result without any planning for the potential of a positive test result is not without consequences. It is important to remember that women have very little time to make decisions about further, more invasive, testing and the course of their pregnancy after receiving screening results.

Third, while a number of studies have focused on the routinization of prenatal testing (see chapter 2) they tended to exclude mothers of disabled infants. My research includes the voices of two mothers of children with Down syndrome, one of whom had participated in extensive prenatal testing. Interestingly, their attitudes towards prenatal testing were less similar to each other and more in line with the other women in the

limited or extensive testing groups. Thus, introducing mothers of children with disabilities into the sample of interviewees confirms earlier scholarly work on routine prenatal testing.

Fourth, Foucault's concepts of power and knowledge as well as his biopolitical framework were very useful for analyzing the medicalization of pregnancy. After the establishment of the clinic, the medical gaze became the convention for producing knowledge, thereby eliciting medical truth, a practice which has not changed since. Knowledge in the medical field is kept in the hands of few through mechanisms of exclusion (not everybody is allowed to work in a hospital) and apparatuses of surveillance, thereby increasing the clinicians' capacity of power.

> For clinical experience to become possible as a form of knowledge, a reorganization of the hospital field, a new definition of the status of the patient in society, and the establishment of a certain relationship between public assistance and medical experience, between help and knowledge, became necessary; the patient has to be enveloped in a collective, homogenous space (Foucault, 1973: 196).

The scientific knowledge provides the possibility for the clinician to exhibit power in relation to specific individuals, and to society as a whole. This type of power is not as oppressive as it had been under the rule of the sovereign (Foucault, 1997), but patients subject themselves to the physician's power out of their own will. In my study, the majority of interview participants claimed that they would have requested an ultrasound if it would not have been offered to them and a number of women participated in additional forms of testing, which they had to pay for privately[19]. Evidently, many women subject themselves to the surveillance of the medical gaze. The concept of biopolitics is especially useful to analyze medicalized pregnancy because pregnancy is

[19] Four women went for a 3-D ultrasound. They paid between $150 and $200 for the procedure.

immediately tied to biopolitics' central issue; the continuation of life. Thus, the medicalization of pregnancy is a manifestation of the power which is exercised by biopolitics.

Fifth, the information women receive from their healthcare provider regarding prenatal testing is not sufficient. A number of women in both the limited and the extensive testing group felt that they were given enough information about the technicalities of the specific tests, but that no information was provided which would guide them in making a decision in the case of a non-reassuring test result. A few women suggested that they would have appreciated a pamphlet which outlines all prenatal testing options, including so called 'routine tests' such as ultrasounds. Also some women, especially those who were in the care of obstetricians, would have liked to have had a source where they could have received additional testing information and help making a decision.

Strengths and Limitations

In this study, I interviewed all women many months after they had made decisions about prenatal testing. This was a deliberate strategy to ensure that I would not create worries in pregnant women who might have felt as though I was questioning their choices. Nevertheless, I have to acknowledge that the women's subsequent experiences and the passing of time might have influenced my findings. For example, a number of women have been pregnant multiple times, and they were not always able to fully separate each pregnancy experience. Further, all women have given birth to healthy

infants[20], which might have influenced their answers. Green (2004) uses the term 'satisfied customer' to describe such mothers, whose answers might have been different if the interviews were conducted before they received the testing results.

The strategy of purposive sampling led to a range of perspectives being included in the interviews. Previous studies on prenatal testing have excluded mothers of disabled children from their sample. Having interviewed two mothers with children who have Down syndrome enabled me to understand that their perspectives do not differ substantially from those of mothers with non-disabled infants.

I only interviewed women who voluntarily asked to be included in the study. Therefore, only women who are interested in discussing the issue of prenatal testing have participated. The final sample could be considered middle class in that all women have finished some form of post-secondary education. It is possible that a study with a different segment of the population would obtain different results. In addition, I did not collect information on the socio-cultural background of the participants, such as religious affiliation, ethnicity, and income, and I recognize that women with different backgrounds may have different values and experiences that influence decision making.

Future Research Possibilities

It is necessary to further examine how pregnant women negotiate the notion of risk and risk factors, especially as moral imperatives, given that these notions are deeply embedded in Western prenatal medical care. This could be achieved by interviewing women during various stages of their pregnancy to receive a more complete picture of the

[20] Two women gave birth to children with Down syndrome. However, they both considered their children healthy.

decision making process involved with prenatal testing. The qualitative longitudinal research design would require a minimum of three unstructured interviews with each woman; one prior to the first prenatal test, one after receiving the results, and one after birth. It would be possible to analyze how women use the information they are provided with by their care provider, the strategies women use to make decisions, and if and how their personal risk-perceptions evolve over the course of their pregnancy.

Furthermore, the understanding of routinization of prenatal testing would be enhanced by studies that compare differences in attitudes towards prenatal testing between women who received reassuring test results, women who received non-reassuring test results and decided to carry the pregnancy to term, and women who received non-reassuring test results and decided to terminate the pregnancy. Very limited research has been conducted on the latter group. Women who terminate their pregnancy after a non-reassuring screen follow the regular biomedical model; therefore, their attitudes towards testing would provide valuable information about the role of women in the medicalization of pregnancy.

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Appendix A:

Demographics of Interviewees

Pseudonym	Age	Career	# of kids	Downs kids	Testing	Care-taker
Anne (Caucasian)	33	MA Geography Government worker	2	0	1 ultrasound (week 20); doppler	Midwife
Beatrice (Caucasian)	32	Mental Health Social Worker	2	0	2 ultrasounds (weeks 8, 20); doppler	Midwife
Cora (Caucasian)	34	Statistics Canada	1	0	IPS; 5 ultrasounds (weeks 11, 19, 32, 40, 41); doppler	Ob/Gyn
Deidre (Caucasian)	31	Actress	2	0	2 ultrasounds (weeks 10, 20); doppler	Midwife
Ella (Caucasian)	34	Government worker	1	0	2 ultrasounds (weeks 8, 16); 3-D ultrasound (week 32); doppler	Ob/Gyn
Fay (Caucasian)	27	Financial consultant	1	0	2 ultrasounds (weeks 18, 32); 3-D ultrasound (week 20); doppler	Midwife
Giselle (African-Canadian)	40	Government counselor	1	0	IPS; 6 ultrasounds; 3-D ultrasound (week 19); doppler	Ob/Gyn
Hannah (Caucasian)	32	Nurse	1	0	12 ultrasounds (weeks 9, 20, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39); 3-D ultrasound (week 20); doppler	Ob/Gyn
Iris (Caucasian)	31	Stay-at-home	2	0	4 ultrasounds (weeks 18, 19, 32, 38); doppler	Ob/Gyn
Julia (Caucasian)	38	Writer	2	0	IPS; 2 ultrasounds	Ob/Gyn

					(weeks 12, 24); doppler	
Karla (Caucasian)	32	NICU nurse	2	0	IPS; 4 ultrasounds (weeks 9, 15, 18, 32); doppler	Ob/Gyn
Lena (Caucasian)	41	Physician	3	0	IPS; Many ultrasounds (every 4-8 weeks); CVS; doppler	Ob/Gyn
Madison (Caucasian)	37	MA Legal Studies Stay-at-home	1	0	IPS; 3 ultrasounds (weeks 4, 18, 18); doppler	Ob/Gyn
Nora (Caucasian)	34	Home daycare	3	0	2 ultrasounds (weeks 8, 13); doppler	Midwife
Olivia (Caucasian)	34	Stay-at-home	3	1	IPS; 3 ultrasounds (weeks 18, 24, 32); amniocentesis; doppler	Ob/Gyn
Petra (Caucasian)	35	Stay-at-home	3	1	1 ultrasound (week 18); doppler	Ob/Gyn
Robin (Caucasian)	42	MA Politics Stay-at-home	2	0	none	Midwife
Susan (Caucasian)	47	Nurse	3	0	IPS; 3 ultrasounds (weeks 10, 12, 18); doppler	Ob/Gyn
Teya (Caucasian)	38	Stay-at-home	2	0	IPS; 3 ultrasounds (weeks 9, 18, 20); Amniocentesis; doppler	Ob/Gyn
Ute (Caucasian)	35	BA Sociology Stay-at-home	2	0	IPS; 2 ultrasounds (weeks 18, 34); doppler	Ob/Gyn

Appendix B: Letter of Initial Contact

What has your experience been with Prenatal Medical Testing?

I am a Carleton MA student in Sociology who is seeking to interview women regarding their experiences with, and attitudes towards, various prenatal medical tests.

If you are between 18 and 50 years old and the mother of a young infant (newborn to 3 years old), I would like to speak to you about your experiences during pregnancy with prenatal testing.

Please contact me, Esther Baum, or my thesis supervisor, Prof. Andrea Doucet, if you would like to volunteer to be interviewed. Your participation will be anonymous and any information provided will be confidential.

Researcher: Esther Baum;
ebaum@connect.carleton.ca

Guiding Professor: Prof. Andrea Doucet; (613) 520-2600 ext. 2663; andrea_doucet@carleton.ca

Chair of the Carleton University Research Ethics Committee: Prof. Antonio Gualtieri; (613) 520-2517, ethics@carleton.ca

Appendix C: Interview Guide

This research is an aspect of the Masters thesis at Carleton University. I am interested in women's experiences with prenatal testing. The interview can be terminated at any time and questions can be refused to be answered. Are there any questions?
Discuss the Letter of Information and Release of Information Form (Consent Form), and after asking for further questions have the participant sign the form.

I would like to start the interview with a few demographic questions and a very general question about anything you would like to share regarding your last pregnancy.
Then, I will ask you about your experience with medical tests during your pregnancy, about decisions you had to make and about the information you received.
The interview will be concluded with any additional comments you may have.

a. How old were you when you gave birth to your last child?
b. How many children do you have?
c. When exactly did you give birth to your last child?
1. Would you please tell me about your recent experience of being pregnant? Was your pregnancy considered to be at risk for any reason?
2. Could you please tell me about any medical tests you had to asses your fetus during your pregnancy? When did you have the test? Where were you tested? How long did you have to wait for the results? What were the results?
3. How did you make the decision to have (not have) this test? Would you please tell me about the circumstances? What role did you doctor/midwife play? What role did your partner play? Where there any books or magazines which suggested to be tested (not tested)?
4. What information did you receive from your doctor/midwife regarding prenatal testing? Do feel that this information you received was enough? Was there anything you did not know that you would have liked to know before you made your decision?
   I received this pamphlet from my healthcare provider during the first prenatal visit. Did you receive the same one? How did it make you feel? Did it encourage/discourage you to have any of these tests?
5. What would you have considered to be a negative or bad test result? How did you prepare for dealing with such a result? Were you told about the options you have if test results indicated that something was not right?
6. Have you ever felt judged by anybody or yourself for the decision you made? Please elaborate.
7. Do you have any advice regarding prenatal tests to give to mothers-to-be?
8. Do you have family members or do you know individuals with Down syndrome or some other form of disability that was present at birth?
9. You have shared some of your experiences with prenatal testing, is there anything you would like to add or discuss that was not covered?
   Was there anything that you thought I would ask you but didn't? Do you have any questions or comments?

Appendix D:

Letter of Information for Participants and Guarantee of Confidentiality

You are being asked to participate voluntarily in a research project entitled "Prenatal Testing" that is being conducted by Esther Baum, a Sociology student at Carleton University. The aim of this study is to research women's experiences with prenatal testing. If you agree to participate, you will be asked to talk about the experiences you had during pregnancy with any prenatal tests and about the information you received during your pregnancy that prepared you for the tests. The interview will be approximately one to two hours in length. With your permission the interview will be audio recorded.

Your participation in this project is entirely voluntary and there will be no negative consequences if you refuse to participate in it, withdraw from it, or refuse to answer certain questions. In case you find interview questions distressing, the interview will be stopped. I cannot act as a counselor but I will provide you with information regarding community resources. Should you decide to withdraw from the study you may decide at any time if Esther Baum may use the information you have provided or may request that it be destroyed.

This form guarantees that Esther Baum (the researcher) will not reveal my identity to anyone. I, Esther Baum, will not use the name of any participant in written documentation; nor will I use any information that would reveal a participant's identity to others. I will not discuss information given by participants with anyone in a way that would reveal their identity to others. I also guarantee that all names will be changed during transcription. My guiding professor, Prof. Andrea Doucet will review the transcript from the interview, but she will not have access to your name or to any information that could identify you. All data will be kept in a locked file cabinet for 5 years and will be destroyed thereafter. The research from this study will be used for Esther Baum's Masters Thesis and may be used for conference presentation and publication. In any of these cases anonymity and confidentiality will be maintained.

The research project was reviewed and received ethics clearance by the Carleton University Research Ethics Committee. If you are interested to receive progress reports and/or a digital copy of the final thesis please feel free to contact me.

If you have any questions or concerns about the project please contact
Researcher: Esther Baum; ebaum@connect.carleton.ca
Guiding Professor: Prof. Andrea Doucet; (613) 520-2600 ext. 2663, andrea_doucet@carleton.ca
Chair of the Carleton University Research Ethics Committee: Prof. Antonio Gualtieri; (613) 520-2517, ethics@carleton.ca
Researcher Name: _____

Researcher Signature: _____

Date: _____

Appendix E:

Informed Consent Form for Participants

You are being asked to participate voluntarily in a research project entitled "Prenatal Testing" that is being conducted by Esther Baum, a Sociology student at Carleton University. The aim of this study is to research women's experiences with prenatal testing. If you agree to participate, you will be asked to talk about the experiences you had during pregnancy with any prenatal tests and about the information you received during your pregnancy that prepared you for the tests. The interview will be approximately one to two hours in length. With your permission the interview will be audio recorded.

- Your participation in this project is entirely voluntary and there will be no negative consequences if you refuse to participate in it, withdraw from it, or refuse to answer certain questions. In case you find interview questions distressing, the interview will be stopped. Esther Baum cannot act as a counselor but will provide you with information regarding community resources.

- Should you decide to withdraw from the study you may decide at any time if Esther Baum may use the information you have provided or may request that it be destroyed.

- The research from this study will be used for Esther Baum's Masters Thesis and may be used for conference presentation and publication. Your anonymity will be maintained by Esther Baum and your identity will not be revealed to others. All data will be kept in a locked file cabinet for 5 years and will be destroyed thereafter. My thesis supervisor, Prof. Andrea Doucet will review the transcript from the interview, but she will not have access to your name or to any information that could identify you. Also, only Esther Baum will have access to this form.

The research project was reviewed and received ethics clearance by the Carleton University Research Ethics Committee. If you are interested to receive progress reports and/or a digital copy of the final thesis please feel free to contact me, Esther Baum.

If you have any questions or concerns about the project please contact
Researcher: Esther Baum; ebaum@connect.carleton.ca
Guiding Professor: Prof. Andrea Doucet; (613) 520-2600 ext. 2663, andrea_doucet@carleton.ca
Chair of the Carleton University Research Ethics Committee: Prof. Antonio Gualtieri; (613) 520-2517, ethics@carleton.ca

Having understood the above information and after being given an opportunity to have my questions answered, I voluntarily agree to participate in this study:

Signature of Participant	Name of Participant	Date

By signing here, I voluntarily consent to be audio recorded:

Signature of Participant	Name of Participant	Date

Appendix F:

Resource Sheet

Thank you very much for having participated in my study. I greatly appreciate that you have taken the time to speak to me.
Having talked about your experiences with prenatal medical tests and your attitudes towards these tests may have prompted you to have some additional questions about these tests. The following resources allow you to seek out information which will address any questions, worries or concerns you may have.

Distress Centre of Ottawa and Region
(613) 238-3311
Offers anonymous, confidential, 24-hr. service English language service.

Tel-Aide Outaouais
(613) 741-6433
Offers anonymous, confidential, 24-hr. service French language service.

Ottawa Public Health Information
(613) 580-6744; toll-free (1-866) 426-8885
Offers a telephone service for parents of new children.

Families Matter
(613) 733-0112
Offers access to information about resources and services for people with developmental disabilities and their families.

Women's Place
(613) 231-5144
An information-referral centre for women.

Appendix G:

Request for Poster Distribution

Carleton
UNIVERSITY
Canada's Capital University

I, Esther Baum, would like to put up posters in your facility to recruit potential participants for my Master Thesis research entitled "Prenatal Testing." I am a Sociology student at Carleton University.

The aim of this study is to research women's experiences during pregnancy with prenatal testing. Women will be asked to talk about their experiences with prenatal testing, their attitudes towards these tests and the information they received which prepared them for the tests. Participation in this project is entirely voluntary and anonymous and all data will be kept confidential.

The research project was reviewed and received ethics clearance by the Carleton University Research Ethics Committee.

If you have any questions or concerns about the project please contact
Researcher: Esther Baum; (613) 302-4987; ebaum@connect.carleton.ca
Guiding Professor: Prof. Andrea Doucet; (613) 520-2600 ext. 2663, andrea_doucet@carleton.ca
Chair of the Carleton University Research Ethics Committee: Prof. Antonio Gualtieri; (613) 520-2517, ethics@carleton.ca

Having understood the above information and after being given an opportunity to have my questions answered, I voluntarily agree to posters being put up in my facility:

_____ _____ _____

Signature Name Date