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**Routinization of Prenatal Screening : Women's Perspectives on Decision Making about Screening  
Uptake**

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**Routinization of Prenatal Screening:  
Women's Perspectives on Decision Making About Screening Uptake**

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Thesis prepared in partial requirement for the degree MSc in Epidemiology

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## TABLE OF CONTENTS

|   |    |
|---|----|
| <b>ABSTRACT</b> .....   | 4  |
| <b>INTRODUCTION</b> .....   | 5  |
| <b>Technology, Risk &amp; Surveillance Medicine</b> .....                           | 5  |
| <b>The Medicalization of Pregnancy and the Creation of Prenatal Care</b> .....      | 7  |
| <b>Technology in the Prenatal Period: Prenatal Testing and Screening</b> .....      | 9  |
| <b>STUDY DESIGN &amp; METHODS</b> .....   | 12 |
| <b>Study Design</b> .....   | 12 |
| <i>Rationale for a Qualitative Approach</i> .....                                   | 12 |
| <b>Sampling and Recruitment</b> .....   | 12 |
| <i>Sampling frame, eligibility, and recruitment</i> .....                           | 13 |
| <i>Purposeful Sampling &amp; Data Saturation</i> .....                              | 14 |
| <i>Sample Size</i> .....  | 14 |
| <b>Data Collection and Analysis</b> .....   | 15 |
| <i>Interviews</i> .....   | 15 |
| <i>Methods of Analysis</i> .....  | 15 |
| <i>Analysis Tools</i> .....   | 16 |
| <b>Research Ethics</b> .....  | 18 |
| <b>Note on the Presentation of the Research</b> .....                               | 18 |
| <b>LITERATURE REVIEW</b> .....  | 19 |
| <b>The Routinization of Prenatal Screening</b> .....                                | 19 |
| <b>The Complexity of Choice</b> .....   | 20 |
| <b>The Presentation of Prenatal Screening</b> .....                                 | 24 |
| <b>The Reconceptualization of Risk</b> .....  | 28 |
| <b>The Value of Information</b> .....   | 32 |
| <b>Prenatal Screening and Responsible Parenthood</b> .....                          | 37 |
| <b>Prenatal Screening and Abortion</b> .....  | 38 |
| <b>Perceptions of Disability</b> .....  | 44 |
| <b>RESULTS</b> .....  | 48 |
| <b>Characteristics of the Sample</b> .....  | 48 |
| <b>Themes Arising from the Interviews</b> .....                                     | 48 |
| <i>Women’s Perceptions of Choice</i> .....  | 48 |
| <i>Reasons for Accepting Screening: Non-Invasiveness</i> .....                      | 54 |
| <i>Reasons for Accepting Screening: Reassurance</i> .....                           | 56 |
| <i>Thinking About the Possibility of a Positive Result</i> .....                    | 59 |
| <i>Reasons for Accepting Screening: Preparation</i> .....                           | 64 |
| <i>Reasons for Refusing Screening: The Risk of a False-Positive Result</i> .....    | 68 |
| <i>Reasons for Refusing Screening: Avoiding Decisions About Abortion</i> .....      | 72 |
| <i>Reasons for Accepting or Refusing Screening: Perceptions of Disability</i> ..... | 74 |
| <b>DISCUSSION</b> .....   | 78 |
| <b>Reflections on the Methods</b> .....   | 78 |
| <i>Sample</i> .....   | 78 |
| <i>Interviews</i> .....   | 79 |
| <b>Summary of the Results and Their Implications</b> .....                          | 80 |
| <i>The Issue of Choice</i> .....  | 81 |

|  |     |
|--|-----|
| <i>Risk and Reassurance</i> .....                                | 83  |
| <i>Information About Screening: Procedure Over Purpose</i> ..... | 86  |
| <i>Ethics of Screening: Abortion &amp; Disability</i> .....      | 88  |
| <i>Implications for Healthcare</i> .....                         | 91  |
| <i>Directions for Future Research</i> .....                      | 93  |
| <b>REFERENCES</b> .....  | 94  |
| <b>APPENDIX 1: Initial Interview Schedule</b> .....              | 100 |

## ABSTRACT

**Background:** Prenatal screening programs, in which screening is routinely offered to all pregnant women, have been implemented in a number of regions in Canada and other countries. Such programs are typically marketed as having the goal of providing women with the opportunity to make an informed choice about screening. Studies have suggested, however, that structural and cultural factors related to the rise of surveillance medicine have combined to effectively routinize the offer and uptake of prenatal screening, potentially hindering the capacity to ensure true autonomy and informed choice for women.

**Purpose:** This study was conducted to explore the concept of the routinization of prenatal screening by examining women's accounts of their decision making about accepting or declining prenatal screening and what judgments they made about the value of prenatal screening for themselves and others.

**Methods:** This was a descriptive, exploratory study using qualitative research methods for data collection and analysis. Data were collected from 18 women who had delivered healthy babies using semi-structured interviews. Both data collection and analysis were conducted using methods of Grounded Theory.

**Results:** Routine uptake of prenatal screening was described by many women. Themes arising from interviews included: the recognition of choice and/or the need for deliberation; the ways in which prenatal screening is presented; the value placed on the information provided by screening; varying conceptions of risk; and the relationships between prenatal screening, abortion, disability, and responsibility.

**Conclusions:** Factors contributing to the routinization of prenatal screening operate at a variety of levels: individual, structural, and cultural. Further research is needed to clarify and quantify the effects of routine acceptance of screening on women and their families, and to determine the most effective and appropriate ways of ensuring that women's choices are truly informed and deliberated.

## INTRODUCTION

### Technology, Risk & Surveillance Medicine

Our culture holds a certain set of biases toward the roles and value of technology and its application in society. The simple existence of a technology can imply its use value. This is particularly true in the health care field, within which there seems to exist what Hofmann describes as an *imperative of possibility*, whereby “[t]hat which is possible to do has to be done” (Hofmann, 2002). Medical culture is one that espouses action, as opposed to passivity, as a virtue (Fox, 2000). Physicians are mandated by such fundamental constitutions as the Hippocratic oath to do everything possible to benefit their patients, and it has been shown that there exists a preference toward solving health problems with the use of technology (Nordin, 2001). It has also been argued that questions about the purpose or potential benefit of an intervention are often obscured by a focus on the efficacy of the technology (Callahan & Parens, 1995). Thus, rather than asking whether or not a particular intervention ought to be done at all, doctors and patients alike are more and more frequently asking, what is the best (read: most technologically advanced) way to proceed with this intervention? Moreover, as a result of this culture within which technological superiority is viewed as a sign of social progress, and ownership & mastery of the newest, most technologically advanced gadgets a status symbol, patients as consumers have come to expect the most advanced diagnostic procedures and treatment (Dworkin, 1982; Hofmann, 2002).

This frequently unquestioned acceptance of the value of medical technology has consequences at the individual and societal levels. While the increasing number of available technological solutions to particular questions of health and illness are touted as providing patients with increased choice, and therefore increased control over their care, many have suggested that the socially-created perception of a technological imperative may actually result in a reduction in patient autonomy (Anderson, 1999). Patients, it has been shown, often find it difficult to refuse tests or treatments that are offered them, due both to their trust in the expertise of their healthcare professionals, as well as to their own fear that they may later regret not having made use of every available opportunity to protect their health (Tymstra, 1989). Assumptions regarding the necessity of procedures can result in a lack of real deliberation about the potential benefit or meaning of the procedure for individual patients. As Pickstone demonstrates (2000), there has been an historical shift in the way patients are perceived and treated in the medical system; while previously patients were examined more in the context of their personal biography, they are currently increasingly being seen as entities for technological exploration and diagnosis. Such explorations are, in turn, redefining our concepts of health and disease. No longer are people looked upon simply as being either healthy or ill, rather technology is allowing us to identify disease, precursors to disease, and increasingly more risk factors for disease at earlier stages than ever before. As the 'medical gaze' has moved deeper into the human body, particularly in the context of genetic discoveries (Webster, 2002), new diseases, and new formations of the concept of health in general have emerged (Hofmann, 2001).

In particular, a culture of risk has been created (Lupton, 1999) in which people are increasingly being defined not by their current health status but by their estimated potential for future disease, as identified by complex sets of screening tools and statistical models. With this, differences (i.e. physiological, molecular, genetic) are now being unmasked of which we were previously unaware, and a new category has been created of patients without symptoms, or as Williams and Calnan (1994) have named them, the 'worried well'. Clarke and colleagues (2003), in a recent outline of the current trend in medical practice – and society as a whole – toward the 'biomedicalization' of health, expanded this concept with the following statement:

*Health cannot be assumed to be merely a base or default state.*

*Instead, health becomes something to work toward, an ongoing project composed of public and private performances, and an accomplishment in and of itself.*

Today, everyone is a potential patient, and people are expected to monitor themselves or to seek out services to monitor their risk status, in what has become known as 'surveillance medicine' (Armstrong, 1995). The responsibility for health surveillance, and, it could be argued, for health itself, has shifted away from the physician and the medical community, and become internalized by the patient. As a result, the boundaries between *healthy* and *ill*, *normal* and *abnormal* have become blurred.

### **The Medicalization of Pregnancy and the Creation of Prenatal Care**

One area where this trend has been well documented is with respect to pregnancy care. In an historical analysis of the medicalization of pregnancy, Barker (1995) demonstrated the ways in which biomedical rhetoric was used throughout the 20<sup>th</sup> century to change the perception of the uncomplicated pregnancy as a normal event to that of a potentially pathological state. This new perspective positioned pregnancy within a disease model, postulating that only physicians had the skills and technology to make an accurate ‘diagnosis’, and therefore undermining women’s own knowledge and experiences of pregnancy. Public health programs aimed at expectant mothers came to highlight the precariousness of pregnancy, and emphasized the responsibility of the woman for behavioural self-regulation and ‘proper care’ in order to ensure a ‘happy ending’ to her pregnancy (Barker, 1995). As a result, all pregnancies were assumed to require medical supervision, and the idea of prenatal care was born.

In modern Western society, prenatal care has become the norm. For example, while less than five percent of pregnant women in the United States are estimated to have had any contact with a physician prior to delivery until into the 1920s, by 1994, 96% of pregnant women received regular prenatal care (Barker, 1995). Over the second half of the 20<sup>th</sup> century, it has been shown that the population health focus on identifying indications for high-risk pregnancies and on the relationship between maternal behaviour and negative fetal outcomes, resulted in the cultural acceptance of medical surveillance in pregnancy (Terry, 1989). In a study of the authority given by women to biomedical knowledge in prenatal care, Browner and Press (1996) showed that this process is not only accepted, but highly valued by women both because they perceive the status of ‘being informed’ as

one of the most important responsibilities of pregnancy, and because they see such increased surveillance as providing reassurance about the course of their pregnancy and the health of their baby. However, despite the widespread acceptance of prenatal care *in general*, they also found that women are not indiscriminate acceptors of clinical recommendations received in the prenatal period, rather they actively interpret medical information, ‘picking and choosing’ which pieces of advice suit their own goals and prior knowledge. The authors contrasted this to the almost entirely unquestioned authority given to biomedical knowledge during childbirth and hypothesized that the distinction lies in the differing role of technology in the two stages of pregnancy. Writing in the mid 1990s, they stated that “[w]hile childbirth in America is now a primarily technological endeavor, this is not yet the case for prenatal care” (Browner & Press, 1996).

### **Technology in the Prenatal Period: Prenatal Testing and Screening**

Beginning in the late 1980s however, and continuing to this day, the use of technology has become increasingly prominent in the prenatal period in the form of prenatal diagnosis and screening for congenital anomalies. Amniocentesis – the most widely used form of prenatal diagnosis – became available to pregnant women in the 1970s. During this invasive procedure, a needle placed through the woman’s abdomen extracts a sample of amniotic fluid from which fetal cells are obtained and subjected to chromosomal analysis. Amniocentesis can accurately diagnose a number of chromosomal abnormalities, however it carries with it an associated miscarriage rate of 0.5%-1.0% (Health Canada, 2002). Prenatal screening refers to a variety of noninvasive methods

used to obtain a statistical representation of a pregnant woman's risk of carrying a child with a major congenital anomaly, most notably Down syndrome, Trisomy 18, and neural tube defects (NTDs) ([www.fetalalertnetwork.com](http://www.fetalalertnetwork.com)). In Canada, as in most other countries, prenatal screening began with maternal age-based screening programs in which women over 35 were considered high-risk (1/250 chance of giving birth to a child with Down syndrome), and routinely offered amniocentesis (Health Canada, 2002). Over the last 30 years, scientific discoveries of relationships between certain chemical markers in pregnant women's blood and risk of chromosomal anomalies led to the development of screening methods that can be applied to pregnant women of all ages. These typically combine measurements of three or four maternal serum markers into a statistical algorithm along with maternal age, and in some instances a detailed ultrasound scan. Results are presented to women as a probability, typically between 15-20 weeks gestation, and women deemed 'high-risk' (typically requiring a result of 1/250, but may vary by site) are offered further diagnostic testing ([www.fetalhealthnetwork.com](http://www.fetalhealthnetwork.com)).

Prenatal screening programs, in which screening is routinely offered to all pregnant women, have been implemented in a number of regions in Canada, the United States, Britain, and Australia, among others (Health Canada, 2002; Press & Browner, 1997; Williams et al, 2005; Rostant et al). Such programs are typically marketed as having the goal of providing women and their families with information about the health status of their fetus so that they may make an informed decisions about the progression of their pregnancy. Evaluations of prenatal screening programs, however, have traditionally taken the form of economic analyses based on estimations of the cost savings to society

from the prevention of the birth of affected fetuses (Taplin et al, 1988), which would seem to imply that a high uptake is the driving force behind the benefit of such programs. The ethical implications of such an approach, however, with its eugenic undertones, are unacceptable to many in society (Anderson, 1999). As a result there has been a movement in recent years to change the way prenatal screening programs are designed and evaluated in order to ensure proper attention is paid to its psychosocial effects and that women's autonomy is maintained in decisions about screening uptake (Green, 2004; Marteau et al, 2001).

Studies have suggested, however, that structural and cultural factors related to the rise of surveillance medicine have combined to effectively routinize the offer and uptake of prenatal screening, thus hindering the capacity to ensure true autonomy and informed choice for women (Press & Browner, 1997). The goal of this study was therefore to explore this concept of the routinization of prenatal screening by examining women's accounts of their decision making about accepting or declining prenatal screening and what judgments they made about the value of prenatal screening.

## **STUDY DESIGN & METHODS**

### **Study Design**

This was a descriptive, exploratory study using qualitative research methods for data collection and analysis. Data were collected using semi-structured interviews, and both data collection and were conducted using methods of Grounded Theory described by Strauss and Corbin (1998) and Morse and Field (1995).

### ***Rationale for a Qualitative Approach***

Qualitative researchers work inductively, with the purpose of generating description and/or theory about a phenomenon or event (Morse & Field, 1995). Qualitative inquiry is a process of documenting, describing, and identifying patterns, concepts, and relationships between concepts with the ultimate goal of identifying variables and creating theoretical explanations that explain reality. The research operates from the 'emic' or 'native' (i.e. patient, participant) perspective, allowing the researcher to investigate subjective phenomena while examining underlying assumptions, attitudes, and the rationale for these. This methodology is therefore ideal for our study as the focus is on exploring women's experiences of decision making during screening and their subjective evaluations of prenatal screening programs.

### **Sampling and Recruitment**

### *Sampling frame, eligibility, and recruitment*

The sampling frame was composed of all women who delivered a baby at the Ottawa Hospital between December 2003 and March 2004. Eligible participants were English-speaking women who, at the time of the study, had recently delivered healthy infants at the Ottawa Hospital. Women known to have suffered perinatal or pregnancy loss, or to have delivered an infant with a major congenital anomaly were excluded due to concerns about distress during the interview process. Participants were selected with the goal of creating two roughly equal subgroups of women who had accepted prenatal screening through serum and/or ultrasound screening (“acceptors”) and those who had declined (“decliners”). As the offer of prenatal screening to all pregnant women is legally mandated in Ontario, it was assumed that all women had been offered some form of prenatal screening or testing.

As this study population might be considered ‘vulnerable’, an arm’s length recruitment procedure was implemented – this protected privacy and helped minimize the possibility of coercion. Potential participants were first approached by research nurses who were part of the OMNI research group, a team which was independent of this study. They provided written descriptions of the research within a day of delivery to all women on the post-natal ward who met inclusion criteria and did not meet exclusion criteria. Those who agreed to be contacted were then visited by the researcher for this project, while they were still on the ward. She obtained contact information and written consent to review

their medical records to determine if they would be invited for participation based on screening status and characteristics used for purposive sampling as described below.

### ***Purposeful Sampling & Data Saturation***

In qualitative research, the composition and size of the sample are decided with the goal of inductive hypothesis-generation. This is achieved via a process known as purposeful sampling (see Glaser & Strauss, 1967, and Strauss & Corbin, 1998). During this process, participants are selected in order to maximize opportunities both to compare events and identify themes, and to identify the properties and dimensions of these. Initially, the goal is to generate as many themes as possible, therefore data is gathered from as wide a range of participants as possible, to ensure that all possible variations in experiences and relevant themes are uncovered. Once a number of themes have been identified, the sampling procedure then becomes aimed at developing these by identifying all of their sub-themes and how they relate to each other. Sampling stops once each theme is saturated, meaning that (a) no new or relevant data seem to emerge in new interviews regarding a theme, (b) the theme is well developed in terms of its properties and dimensions demonstrating variation, and (c) the relationships among themes are well established (Strauss & Corbin, 1998).

### ***Sample Size***

Because of our use of the concepts of purposeful sampling and data saturation, an exact sample size could not be planned before beginning data collection and analysis. While 6-8 participants often suffice for a homogeneous sample, 12-20 are commonly needed when looking for disconfirming evidence or trying to achieve maximum variation (Lincoln & Guba, 1985; Miller, 1991; Luborsky & Rubenstein, 1995). Our final sample size was 18 women, with 13 acceptors and 5 refusers. To ensure maximum variation and development of identified themes, we attempted to include women who belonged to a range of ethnic, educational, and socioeconomic subgroups. A full description of the sample can be found in the results section.

## **Data Collection and Analysis**

### ***Interviews***

Data collection took place during a 30-45 minute semi-structured interview with each participant. Interviews took place in the women's homes, approximately six weeks after birth, and were tape-recorded. Written consent for participation and tape-recording was obtained at the beginning of each interview. Interview tapes were transcribed verbatim and verified by an independent researcher.

### ***Methods of Analysis***

Grounded theory is defined as an inductive process of identifying analytical themes as they emerge from the data (i.e. from the ground up) (Glaser & Strauss, 1967; Pope et al., 2000). Using this methodology, data collection and analysis occur concurrently (Glaser & Strauss, 1967). Coding of transcripts therefore began after the first interview, and informed the subsequent interviews. It should, however, be noted that qualitative data analysis does not follow a rigid step-by-step procedure, but requires the researcher to be both flexible and creative in his or her approach to uncovering the meaning of the data (Morse & Field, 1995; Strauss & Corbin, 1998). With this in mind, the analysis began with a microscopic analysis (focusing on individual words, phrases, ideas, or events) of the initial interview(s) in order to identify and index all possibly relevant themes. This was then followed by sorting of the data into more overarching themes. Coding was simplified and systematized with the use of the computer software package QSR N.6. Coding was also verified by an independent researcher. Hypotheses were then developed, representing potential theoretical relationships between the variables identified during the coding. The hypotheses were constantly verified, refuted, or altered via constant comparison with new and existing data. Once the major concepts were identified, the relevant literature was reviewed. Interview transcripts, memos (see below), and the literature were reviewed in an iterative, circular fashion, using constant comparison until the content of our central argument was saturated (see Morse & Field, 1995; Strauss & Corbin, 1998).

### ***Analysis Tools***

The process of identifying and developing themes was assisted by a number of techniques including questioning, constant comparison and writing memos.

*Questioning* involves asking questions with regard to each segment of each transcript in order to stimulate the discovery of properties, dimensions, conditions and consequences of emerging concepts. Some questions include: Who? When? Why? Where? What? How? How much? With what results? (Strauss & Corbin, 1998)

*Constant Comparison* is the process by which incidents discovered in the data are compared to each other for similarities and differences, and are then placed into categories. This was done systematically; as each incident was identified, it was compared to previous incidents and themes were added to reflect as many of the nuances in the data as possible. (Pope et al., 2000) This was enhanced by *searching for negative cases*, which involves examining data for incidents that refute an emerging proposition (Morse & Field, 1995).

*Memos* are the researcher's written records of analysis, thoughts, interpretations, questions, and directions for further data collection. Memos serve the dual purpose of keeping the research grounded in empirical reality and maintaining that awareness for the researcher. (Strauss & Corbin, 1998) Memos are also necessary to maintain an audit trail of the research process, which improves the validity of the research by providing a clear account of the process of data collection and analysis (Mays & Pope, 2000). Memos were recorded as fieldnotes for each interview, as well as a series of reflective notes at all

stages of analysis. Memos were dated and recorded in numbered notebooks so that the process of conceptualization of the research could be easily tracked.

### **Research Ethics**

This project was approved by the Research Ethics Board of the Ottawa Hospital.

### **Note on the Presentation of the Research**

As mentioned previously, the data analysis and literature review were completed in a circular, iterative fashion. For clarity, these have been presented separately, with the literature review first, although it is recognized that the order could just as easily have been reversed.

## **LITERATURE REVIEW**

### **The Routinization of Prenatal Screening**

Routinization can be found on many levels, from a lack of attention given to the deliberation of screening decisions by women and their healthcare providers, to the structural and social forces that make up the context in which such decisions are made. Direct evidence of routinized decision making in prenatal screening comes from the number of studies reporting a majority of women who view participation in prenatal screening to be a 'routine', 'self-evident' or 'harmless' procedure that is less a choice as it is "a medical directive that a person follows or does not follow" (Anderson, 1999: p.131; Santalahti et al, 1998; Santalahti et al, 1998b; Al-Jader et al, 2000; Pilnick, 2004). Sandelowski and Jones (1996) described how women undergoing prenatal testing felt as though they had often 'backed into', rather than actively chosen to undergo testing. Similarly, in studies by both Santalahti and colleagues (1998) and Press and Browner (1997), only approximately 20% of women in each study were reported to have made their decisions about screening actively or with considerable deliberation. Such self-report, however, does little to explain how these routine decisions play out in practice or why they have come to be this way. Michie et al (1999), built on these previous studies by using the theoretical concept of systematic processing of information, to develop a scale to measure the extent to which people make decisions systematically as opposed to heuristically (i.e. rule-of-thumb based). When used on a sample of women who had been offered prenatal screening, it was found that women, in general, were not making

decisions systematically, and moreover, that women who accepted screening had made their decisions less systematically than those 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 behaviour, co-operating with perceived expectations of clinic staff” (Michie et al, 1999: p.746).

The question of whether or not women perceive screening tests to be offered to them as a choice at all is an important one. When interviewing or surveying women after their experiences being offered screening, a number of studies found that while screening may have been presented as not 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 don't require a special decision (Santalahti et al, 1998; Al-Jader et al, 2000; Tsianakas & Liamputtong, 2002). Other studies, in which the interactions between healthcare providers and pregnant women were directly observed at the time of the screening offer had similar results. During research in California, for example, Press and Browner (1995; 1997) observed that while women may be told that participation in screening is voluntary, in many instances this is not made explicit, and that if it is, practitioners are likely to add that it is ‘recommended’. The authors suggested that it is a combination of institutional as well as individual clinician support that shapes the processes through which women come to understand and decide about screening.

### **The Complexity of Choice**

Support for this hypothesis comes from a few different angles. After observing consultations between midwives and pregnant women, at which offers of nuchal translucency screening were made, Pilnick (2004) displayed that even when practitioners paid careful attention to presenting screening as requiring an active decision, some women still did not perceive it as such. In a previous report, it was also found that many women seemed to have made their decisions about screening participation prior to arriving at this first consultation (Pilnick et al, 2004). It seems, therefore, that in some cases, not only are women not perceiving prenatal screening as requiring special consideration, but that they may be doing so based on understandings and perceptions they have developed independently of what is presented to them when screening is offered. While the potential influence of the clinician and the way he or she frames the screening offer is not denied, these observations suggest that there are other underlying factors, aside from simply the specific clinician-patient interaction at the time of the screening offer, that may be driving routinization. Quantitative data also support this theory. In comparisons between attitudes of midwives and obstetricians at two UK hospitals where screening uptake differed (26 vs. 61%), Dormandy and Marteau (2004) found no association between attitudes and uptake at the individual level, however practitioners at the hospital with higher uptake were shown to have more positive attitudes toward screening than those at the hospital with lower uptake. Based on this, 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. Either way, it is clear from this study that the institutional culture has

as much, if not more, of an effect on screening uptake as do individual provider-patient interactions.

The mode by which institutional culture can come to impact on women's individual decisions may, in part, be explained by the 'what is must be best' theory of technology initially developed by Porter and Macintyre (1984). These authors showed that, particularly with respect to prenatal care, women tend to assume that systems of care that are being offered have been well thought out by the experts and authorities, and are therefore in turn assumed to be the best possible systems. As a result, they are less likely to actively consider the personal usefulness of such services than they would if these were provided by those whom they consider to be less trustworthy sources. Indeed, trust in healthcare professionals' beneficence and expert knowledge are cited by many women as influencing their perceptions of prenatal screening as being valuable (Tsianakas & Liamputtong, 2002; Williams et al, 2005). As has been shown, however, systems of care founded on the use of medical innovations are rarely implemented in a systematic manner, rather it is typical for the use of a technology to become standard practice long before real evaluations of its effectiveness or ethical or social acceptability have been carried out (McKinlay, 1981).

The relationship of McKinlay's career model of medical innovations in relation to prenatal screening technologies was explored by Press and Browner (1997), who demonstrated how legal, structural, and political forces combined to effectively routinize the delivery and acceptance of MSAFP screening in the United States in the late 1980's

and early 1990's. In 1985, after a series of promising reports based on pilot studies in the UK and US, the American College of Obstetricians and Gynecologists issued an alert warning of the potential for malpractice suits to be brought against doctors who fail to offer MSAFP to pregnant women who then give birth to a baby with a disability that could have been detected by screening (American College of Obstetricians and Gynecologists, 1985). Despite the absence of any discussion of the ethical, legal, or social issues surrounding the implementation of this new technology, the state of California soon after, in 1986, legally mandated that Maternal Serum Screening be offered to every pregnant woman. In the following years, California displayed significantly higher rates of screening uptake compared to other areas of the United States, and while it could be argued that this was a result of different patient preferences in each region, Press and Browner's comparative analysis of uptake rates from the earliest feasibility and evaluation studies of screening programs in the US, UK, and Canada led them to hypothesize that it was largely structural forces, as opposed to individual forces, driving these differences.

In considering how structural forces impact on women's decisions at the individual level, it has been suggested that the simple offer of a screening (or any other) test suggests its usefulness by implying, as suggested above, the general approval of the medical community. While most healthcare professionals would explicitly see informed choice as central in all forms of screening, many would probably recognize that the offer of screening alone implies its endorsement and the subtle encouragement of its acceptance (Ryder, 1999; Williams et al, 2002). Most observers would therefore see non-directive

counseling as a crucial component of any screening program that is implemented with a purported aim of promoting truly informed decision making. In interviews with a variety of healthcare providers involved in the screening process (including midwives, obstetricians, radiologists, hematologists, and clinic managers, among others), one study found that this principle can be problematic in practice; practitioners described working on a continuum of nondirectiveness, ranging from “acting in partnership *with* women at their request, through to *deciding for* women, either covertly or overtly, in their ‘best interests’” (Williams et al, 2002c: p.342). Directiveness, however, need not be so purposeful or explicitly recognized. In fact, over and above the implication of endorsement described above, and even while doing one’s best to avoid directing women toward a particular decision, practitioners recognize that their choices about what information to give to women, and how they frame the offer, set the framework within which women think about screening (Ryder, 1999; Williams et al, 2002; Williams et al, 2002c).

### **The Presentation of Prenatal Screening**

Understanding the way in which information about screening is presented and framed is relevant to an understanding of how its acceptance can come to be routinized. One of the most widely reported observations in the literature is that discussions about screening tend to focus almost exclusively on the technicalities and procedure of screening, rather than questions of why screening is done (Press & Browner, 1997; Williams et al, 2002d; Pilnick, 2004). It has been found that, in particular, the ethical issues of screening –

notably, the potential to be put in a situation where one has to make a decision about abortion – are avoided (Press & Browner, 1995). Information leaflets, a universally employed source of information, introduced as much to address the lack of time providers have in which to discuss screening with women as to be an educational tool, are no more comprehensive. As part of their study in California, Press and Browner (1995) found that much of the space on the leaflets given to women was taken up with procedural details and explanations of the many benign reasons women may receive a positive test result (i.e. false positive). Only vague information was given, however, about the conditions being screened for, and a discussion of what options were available should an abnormality be found was relegated to a small paragraph on the last page. Given that the only ‘treatment’ option for most potentially diagnosed abnormalities is termination of pregnancy, the authors were particularly critical of the fact that abortion was never directly mentioned (Press & Browner, 1995). Other studies have confirmed the bias of information leaflets toward inclusion of procedural details and omission of information about the potential disabilities, or of the emotional and moral consequences of positive screens (Bryant et al, 2001; Michie et al, 2004).

This particular framing of screening decisions as a series of technical and procedural considerations (i.e. accuracy of tests, risk of false positives/negatives, procedure of blood collection, etc.) may also be traced back to institutional policies and structure. When asked about the introduction of prenatal screening programs, midwives in the UK, for example, described how initial training sessions and discussions were similarly focused on administrative and procedural details, such as how to properly fill out paperwork and

collect blood, rather than on the outcomes of screening or questions of the value of screening for individual women (Ryder, 1999). As a result, many midwives felt unprepared to deal with women's emotional reactions to positive screens, and suggested that screening had been introduced without much forethought for women's needs. Press and Browner (1995), as well, described how the avoidance of discussions about abortion at the time of offering screening tests was not simply an oversight on the part of individual healthcare workers, but a matter of institutional policy.

A recent study of information giving and knowledge uptake during offers of amniocentesis – most of which were made in response to a positive screen – helps to shed some light on the differences in information given by providers and that sought by women. Hunt et al (2005) defined a number of informational elements that ought to be included in such offers, including risk figures, procedural details, possible informational outcomes, reasons for doing testing, and alternatives to testing. In interviews with both patients and clinicians, they discovered that while clinicians' information giving was strongly focused on the meaning of the risk figure that had resulted in the positive screen, women gave very little thought to this. Instead, women tended to focus more on a generalized, binary notion that there may be something wrong with their baby, as well as on their reasons for doing an amniocentesis: to be reassured that their baby was, in fact, healthy, and to reduce the considerable anxiety that had been caused by the positive screen. In fact, no statistical correlation was found at all between the completeness of information included in consultations and women's levels of knowledge during interviews. The authors suggested two possible reasons for the discrepancy, one being

that women may experience an ‘information overload’, and the other that little technical and risk-based information is retained because it isn’t relevant to the ways in which women actually make decisions about testing. Direct observations of consultations, in which positive screen results are provided and women are offered amniocentesis, seemed to confirm this second hypothesis, with the authors noting that “the clinician and patient seem to be talking past each other, with the clinician loosely following a script of anticipated questions and answers, which did not necessarily interact with what the patient was in fact asking” (Hunt et al, 2005: p.307).

Women’s levels of knowledge as it relates to their perceived capacity to make thoroughly informed decisions about screening is criticized frequently in the literature (Mulvey & Wallace, 2000; Chilaka et al, 2001; Rostant et al, 2003; ). It must be remembered, however, that any measurement of knowledge is itself a particular construct of knowledge, and as suggested above, the types of knowledge held to be valued by and relevant to women and clinicians (not to mention researchers, policy makers, and others) may be vastly different. Lippman (1999) describes how women used their own ‘embodied knowledge’ to make sense of and decisions about offers of prenatal testing:

*As we use the term, embodied knowledge resulted from various transformative, interpretive, and integrative processes in which women engaged to refashion “received” biomedical information, taking ownership of it and weaving it together with their own experiences and understandings*

*and with “inside” information, their feelings and beliefs*

*(Lippman, 1999: p.259)*

By using this concept, Lippman was able to show how types of information about screening were interpreted and evaluated differently by different women.

### **The Reconceptualization of Risk**

The provision of risk information is central to the educational component of prenatal screening programs. It has been shown that the way in which risk information is presented to women can affect their choices about screening. It is widely accepted, for example, that risk figures given as percentages may be understood differently by women than those given as proportions (Gates, 2004). Alternatively, women may also react differently to risks presented in a positive versus negative light. An Obstetrician interviewed by Williams and colleagues describes how women often react differently to these different presentations of the same risk figure:

*This is another crucial point, 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, 2002c: p.344-5).*

The confusion surrounding risks, however, is not simply a matter of misinformation. Pilnick and colleagues (2004) observed the interaction and communication between

midwives and pregnant women during offers of nuchal translucency screening in the UK and found that even though a great deal of time and effort was put into explaining the meanings of possible outcomes of the screen, women's reactions to and questions about this information often displayed a failure to entirely grasp the ideas that a low-risk result would not guarantee a healthy baby, or that a high risk result would not necessarily mean the baby was affected. In another study, Marteau et al demonstrated that women's perceptions of their own risk of having an affected child may, in fact, be vastly different than their 'real' age-related or screening-derived risk. In a survey of women offered amniocentesis because of their age, it was found that uptake was statistically significantly associated with a higher perceived risk of having an affected baby, but not with actual age-related risk; as well, no association was found between actual and perceived risk (Marteau et al, 1991). This seems to suggest that women's understanding of, and the meanings they give to information about risk, as with their overall understanding of screening, are complex and subjective, depending on much more than biomedical 'facts'.

By returning to the idea of embodied knowledge, the possibility arises that women may instead interpret the concept of risk in different ways – ways which are more meaningful to them and the context of their life. In Lippman's (1999) study, she found exactly this; women made use of their feelings about their own health and the health of their baby, stories they had heard about other women's experiences, and personal beliefs about God or fate to derive a personalized notion of their risk of having an affected child. 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, often previously unthought-of, that something

could be wrong with their baby (Kowalcek et al, 2003; Lobel et al, 2005). In a culture where pregnancy has come to be redefined as a pathological state in need of medical surveillance and management, the offer of screening may therefore be seen as encouraging the transformation of the prenatal period into a risk-assessment exercise. Women who decline have been described as actively resisting this way of looking at pregnancy (Lippman, 1999; Rapp, 1999). As Lippman (1999) demonstrates, refusers often reconceptualize the level of risk that has been presented to them in a way that favours their own personal biography over the statistical interpretation of epidemiology, weighting more heavily such factors as their pregnancy history or healthy lifestyle. In doing so, they are able to challenge the assumption in the biomedical paradigm that they are 'at risk', and therefore that prenatal testing is relevant to their needs.

The risks that are relevant to screening decisions, however, go beyond the risk of having an affected child; there are also risks inherent in the testing process itself. The most obvious of these, the risk of miscarriage due to amniocentesis, is a deciding factor for many women offered prenatal diagnostic testing (Marini et al, 2002), who weigh this risk against the perceived benefit of the information resulting from the test (Hunt et al, 2005). The impact of this risk is so great that some women, particularly those over the traditional 'high risk' age cutoff of 35, have been observed using prenatal screening (i.e. blood or ultrasound) as a form of resistance to invasive testing (i.e. amniocentesis) in what Lippman calls "a kind of technological compromise" (Lippman, 1999). When considered along with the evidence that women tend to deliberate more about prenatal testing decisions than prenatal screening ones (Santalahti et al, 1998), this suggests that the non-

invasiveness of screening may have a large impact on the routinization of its acceptance. Indeed, acceptors of screening typically perceive it to be a 'risk-free' activity (Press & Browner, 1997; Pilnick et al, 2004). Again, where differences in risk perceptions become evident is in women who refuse, for whom screening is held to be a risky activity in itself, despite its noninvasiveness. Markens et al (1999) show that refusers of screening frequently attribute risk simply to having the type of information screening can provide. While women who accept screening often do so to relieve themselves of the anxiety of thinking that there may be something wrong with their baby, refusers believe that screening may result in anxiety, particularly if they receive a non-reassuring result. The idea that the information from screening may cause harm to some has led to the suggestion that screening tests ought to be evaluated for potential 'toxicity' before implementation in the same way as pharmaceutical interventions (Suter, 2002).

While the potential of screening results to cause unwanted anxiety have been suggested to be "a reasonable response to the inherent tensions in a test which can find, but not correct, problems" (Press & Browner, 1997), women are generally not encouraged to think in this way. Hunt et al (2005) showed that while healthcare workers tend to view decisions to accept prenatal testing as the product of a rational decision-making process, refusal is seen a product of fear, cultural beliefs and misunderstanding. As a result of these assumptions, refusers have consistently been shown to have to take a very active stance in order to exercise their right not to know the health status of their baby (Rapp, 1999; Lippman, 1999; Markens et al, 1999). That this concept of resistance has emerged independently in a number of studies, is itself strong evidence supporting the notion that

prenatal testing and screening have become routine. Combined, this evidence suggests that acceptance is embedded so strongly in the medical model of prenatal care that approaches every pregnancy as being 'at risk', that it is viewed by many as less of a decision as the standard practice of responsible clinicians and 'normal' mothers.

### **The Value of Information**

In refusing screening, women are not necessarily resisting biomedical technology itself, but a certain way of looking at pregnancy. One author described:

*[A]lmost all women in our study, regardless of whether or not they took the AFP test, conceded to biomedical authority, the differences were in acceptors' and refusers' perceptions of what was medically necessary and what posed a 'risk' ...by placing AFP outside the scope of routine prenatal care, refusers could still claim that they are doing all that was 'necessary' to ensure the birth of a healthy child by avoiding 'risk' as they conceptualized it (Markens et al, 1999).*

In contrast, there is strong evidence to suggest that a majority of women who accept screening do in fact perceive it to be a part of standard prenatal care, and do not necessarily distinguish it as giving rise to any extra or special issues or concerns. As mentioned previously, the view of prenatal screening as being a 'risk free' test perpetuates for both women and healthcare providers the belief that deliberation about screening is unnecessary. While refusers may view testing as unnecessary due to their

perception of their risk of carrying an affected child being low, it is not only women who perceive themselves as high-risk who accept screening. In their study of nuchal translucency screening, Pilnick and colleagues (2004) demonstrated that many women perceive themselves as having little risk of a positive screen and accept screening either as a formality, or to get reassurance about the health of their baby. In fact, a desire for reassurance is one of the most widely reported reasons for accepting offers of prenatal screening (Press & Browner, 1997; Rice & Naksook, 1999; Hunt et al, 2005).

Press and Browner (1997) claim that this subtle shift in the approach to screening as a measure to provide reassurance about health rather than to identify problems is a major cause of women's routine acceptance of prenatal screening, and that it can be attributed directly to the encompassing of screening under the framework of traditional prenatal care. They discovered that most women they interviewed had trouble articulating exactly why they had accepted screening, confirming that little deliberation is being undertaken. When pushed to elaborate on why they believed screening is useful, the majority of respondents placed a high value on the information that screening could give them about the health of their baby, although the mechanism through which such information would be helpful generally remained unspecified. Again, in contrast to refusers of screening, the knowledge offered by screening seems to be viewed by acceptors as being without risk, with many making direct statements like, "How can it hurt to know?" (Press & Browner, 1997) or "Why would I not want to have this um really unintrusive test?" (Pilnick et al, 2004). This mostly unquestioned value of information is described by Anderson (1999) as a 'moral imperative' deriving both from the culture of medicine and

Western society in general. It is assumed both that what is capable of being known ought to be known, and that this knowledge in itself will, somehow, lead to a better outcome for the mother, her family, and the baby.

In describing the offers of nuchal translucency screening by community midwives in the UK, Pilnick (2004) demonstrated that the premium placed on the increased information available through seemingly 'risk-free' technology may be embedded in the system of care. In this study, it was found that although midwives took great care to present screening as an option and not a requirement, by framing the benefits of the newer nuchal translucency screening method in contrast to the older maternal serum screening method still offered in other local hospitals, the superiority of the newer test over the older test was implied. As stated by the author, "It might be argued then, that the choice that is being presented here is as much about a choice between 'old' and 'new' forms of screening as it is between screening and no screening" (Pilnick, 2004). In the same study, midwives were observed to explain to pregnant women how the value of screening may vary for different women. They stated that some may want the results of screening to help make a decision about the course of the pregnancy, and some may simply want the information for its own sake with the intention of continuing the pregnancy no matter what. The author pointed out that what is most significant about this is not what is said, but what is left unsaid: that some women may not want the information at all. In both scenarios, screening is presented as a choice, however the framing of this choice is clearly based on the assumption that the information from screening is inherently valuable, thus obscuring the option of choosing not to be screened.

The exact value placed on such knowledge may be different, however, for women and healthcare professionals. While healthcare providers approach prenatal screening programs from within the biomedical paradigm, as an exercise focused on identifying problems in order to respond properly (be that either by preparing for an affected birth or allowing patients to make decisions regarding termination), acceptors of screening often do not give much, if any, thought to problems at all (Hunt et al, 2005). According to acceptors, one of the most explicitly stated benefits that such information can provide, as mentioned previously, is the opportunity to be reassured about the health of one's baby. Pilnick et al (2004) show that many women who had accepted testing had not considered what they might do should they be faced with a positive, and therefore non-reassuring, screening result, citing repeated themes such as 'crossing the bridge when we come to it' or 'worrying about it at the time' in their discussions with women. This expectation of a reassuring result and lack of forethought about the potential for a positive screen is not without consequence. Women who unexpectedly receive an unfavourable result have been shown to feel unprepared for the subsequent decisions they are required to make, prompting conclusions by researchers that the potential for such decisions ought to be discussed before screening is undertaken (Santalahti et al, 1996; Suter, 2002; Pilnick et al, 2004).

This seems, however, to be rarely the case; if the value of information from screening is made explicit during consultations at all, it is most often presented as a way to prepare oneself emotionally for having a baby with an anomaly. In the following quote from a

woman who refused screening, one can see how this perspective is readily accepted by women, and how it can impact on decisions about screening:

*Just because maybe the way she presented it the second time. She was presenting it like it was practical, kind of just a normal part of prenatal...and then I ran into a couple other women that were talking about it and one said "I would like to have that test done because I'm not going to have an abortion but it is good to prepare yourself in case of anything like that." So maybe next time I will have it done (Markens et al, 1999)*

By distancing screening from the morally contested issue of abortion, and presenting it as a normal part of prenatal care that allows women to prepare themselves and their families for the birth of their child, even women who are skeptical about the value of screening may be convinced. In an earlier publication from the same study examining acceptors rather than refusers, it was also noted that "on the very rare occasions when we observed a woman questioning her health care provider about the utility of MSAFP testing, the value of "emotional preparation" was an argument in favor of test acceptance" presented by the healthcare team (Press & Browner, 1997). Thus early knowledge that one's child will not be healthy or 'normal' is presumed to make adjustment to this news easier for mothers and their families than it would be if they were to learn of this only at birth. The validity of this assumption, or the mechanism of its benefit, however, do not seem to have been examined in the literature.

## **Prenatal Screening and Responsible Parenthood**

A number of studies have concluded that whether women accept or refuse any type of prenatal test, they all justify their decisions as being made based on a desire to promote the welfare of their baby (Hunt et al, 2005; Tsianakas & Liamputtong, 2002; Markens et al, 1999; Rice & Naksook, 1999). Therefore, indirect pressure to accept screening is provided by the presentation of screening by healthcare providers or the general societal beliefs that equate prenatal screening with the routine maternity care undertaken by responsible mothers. In a study of the experiences of Muslim women in Australia, Tsianakas & Liamputtong (2002) show that women's desire to be recognized as a 'normal' mother who adheres to societal values, and the presentation of screening as something that, while an option, is something that is 'better' to do and that most other women do, both encourage screening uptake. Other studies suggest that this may be associated with trust in one's healthcare professional's expertise and beneficence (Liamputtong & Watson, 2002; Anderson, 1999). In contrast, Press and Browner (1997) showed that it is by perceiving screening as being something 'extra' that is outside of routine prenatal care, that refusers maintain their sense of responsibility toward their baby.

One study reported discussions with healthcare workers who observed the impact of this way of framing screening on the capacity to promote and obtain truly informed consent. Quoting Armstrong (1995), the authors recognized that "being screened is a duty; evasion is tagged as irresponsible behaviour, a moral dereliction" (Williams et al, 2002). This

duty to be screened was broken down by another author into a subset of ‘moral imperatives’ (something one ought to do, or that is the responsible thing to do), which were described as being “so embedded in the process of prenatal genetic services that professionals take them for granted” (Anderson, 1999). Obtaining all knowledge available from healthcare technology was described as a moral imperative in itself, something that is supported with evidence from cancer screening:

Hallowell’s (1999) study...found the freedom to choose being increasingly challenged by the obligation to know. She states that the rhetoric of the new genetics constructs individuals as having a responsibility to obtain genetic knowledge and subsequently to attempt to modify their risks, and also, to be responsible for the health of others too (Williams et al, 2002).

In addition there seem to exist the assumptions that this knowledge somehow leads to increased quality of life for the mother, her family and the baby, and that ensuring this increase is something that ought always to be done; in other words, the belief that “pain and suffering can and should be avoided” through prenatal screening (Anderson, 1999). Finally, Anderson described how the economic evaluation of prenatal screening based on cost savings to society by preventing births of disabled babies, implies the existence of a responsibility to conserve public funds by testing for, and then aborting fetuses with disabilities.

### **Prenatal Screening and Abortion**

The existence of certain widely-held assumptions about therapeutic abortion, particularly within the medical community, may operate to subtly encourage the routine uptake of prenatal screening. Marteau and Drake (1995) reported the results of a questionnaire study in which they found that mothers who refuse screening were perceived as having had more control over the outcome of their pregnancy and were partly blamed if they gave birth to a baby with Down syndrome, as compared to women who were not offered screening. This blame was observed in geneticists, obstetricians, pregnant women, and general samples of men and women, although geneticists were slightly less likely to attribute blame on the basis of screening status. In interviews with healthcare providers, Williams et al (2002) describe how women were labeled as ‘difficult’ – often written directly in their charts – if they declined prenatal screening, and how they were sometimes judged if they accepted screening but chose to carry a disabled baby to term. As one health visitor in this study described:

*I've had people phoning me up to let me know that I've got a new Down's baby and it's, "they had the test and they knew they were going to have it [baby with Down's syndrome]". It's the judgmental thing, saying any woman in their senses would terminate (Williams et al, 2002).*

Similar expectations were reported in research by Santalahti et al (1998), who described how many women felt pressured by their physician to abort in the case of an affected child; often this pressure was described as being indirect, in that abortion was not directly recommended, rather assumed to be the natural response to a positive diagnosis.

That these assumptions about the relationship between prenatal screening programs and abortion most often remain unspoken has been both recognized and criticized. In an early report of their study of the California MSAFP screening program, Press and Browner (1993) observed that the topic of abortion was actively avoided by healthcare practitioners during offers of screening as part of the institutional policy of the hospital being studied. In later interviews with women offered screening at this same hospital, it was observed that only a handful of women spontaneously mentioned abortion, and, that even among these women, their statements tended to be “indirect, contradictory, and almost never focused on pregnancy termination as the only, or even most important, purpose of the MSAFP test” (Press & Browner, 1997). While a small number of women (13%), when asked directly, indicated they would terminate a fetus shown to have a serious birth anomaly, most did not pinpoint a potential abortion as the deciding factor in their acceptance of prenatal screening, instead focusing, as discussed previously, on a vague notion of the usefulness of information for reassurance or preparation. While the authors admitted that the absence of abortion in women’s discussions could have been due in part to the discomfort many may have felt talking about such a highly personal and controversial subject, they believed that this disconnect was more structural than personal, arising from the failure, as described above, to separate prenatal screening from routine prenatal care. They explained that since routine prenatal care is designed to promote fetal health, “[o]nce MSAFP testing is placed firmly under this rubric, it appears to be deeply confusing to women to think about testing and abortion decision-making together” (Press & Browner, 1997).

The link between screening and abortion tends to be more often explicitly highlighted in accounts of decliners (Press & Browner, 1997), although it is important to note that one's stated willingness to terminate an hypothetically affected fetus does not in itself distinguish decliners from acceptors. Decliners do not necessarily hold absolute moral convictions against abortion, rather most see screening as potentially putting them in the position to be required to make a decision about the course of their pregnancy that they do not want to make (Markens et al, 1999). For many, it is primarily the stress and potential for decision regret that they recognize in themselves, rather than abortion itself, that they wish to avoid, and some have been shown to admit the possibility that they may have made a different decision about screening under different circumstances – for example if their own family context were different or if the screening procedure were more accurate, less invasive, or delivered earlier in pregnancy (Markens et al, 1999; Lippman, 1999). Conversely, acceptance of screening, as discussed above, cannot be assumed to equate to a willingness to terminate an affected fetus. The lack of discussion about abortion during consultations about screening is significant, therefore, because it allows for the propagation of assumptions about women's reasons for choosing or not choosing screening, and may prevent some women from engaging in the thorough value-clarification exercise necessary for truly informed consent.

The majority of women whose fetuses are diagnosed with a major anomaly do, however, terminate, regardless of their stated intentions prior to screening (Green, 1994; Santalahti et al, 1999). In a study of women's decision making in prenatal screening – from

decisions about screening through to those about invasive testing after a positive screen, and about abortion after a positive diagnosis – Santalahti et al (1999) questioned whether some women may have gotten pulled into the process of ‘screen-test-abortion’, potentially against their own convictions, as a result of having to make the decisions that follow a positive screen under high anxiety and time-pressure. Again, it could have been that women were simply uncomfortable voicing their willingness to consider abortion in interviews, however the authors showed that whatever the reason, some women who chose abortion displayed significant ambivalence about their decision. Interestingly, newer screening technologies have been suggested to potentially pose even greater emotional risks to women having to make decisions after a positive screen, as a result of the increased quality and resolution of ultrasound scans used for first-trimester screening. In the words of an expectant mother:

*Obviously I know they can't do these tests without showing you the scan, but it's easy to sit at home and say, 'right, if they say this, we will obviously terminate the pregnancy', but when you see that baby on the screen, you don't care what it's got wrong with it, you just see that it's there and you know it's inside of you...it must be a horrible decision once you've actually seen that this is the baby inside you, to suddenly say, 'no, I don't want to carry on with it'. I think that must be quite a heartbreaking decision to make (Williams et al, 2005).*

Women's decisions regarding therapeutic abortion are therefore complex and assumptions about one's intentions regarding abortion cannot be made based on screening uptake alone. By avoiding discussions of the potential for emotional difficulties in making such decisions during pre-screening consultations, the perception of screening as a routine, risk-free activity may be maintained.

The influence of values and discourses about abortion on the routinization of prenatal screening occurs also at the broader social and political levels, which may impact on both women and healthcare providers both by shaping the context in which decisions about screening are made, and by formalizing the options from which they can choose after a positive diagnosis. Perhaps most obviously, the use of cost-benefit ratios comparing the costs of screening programs to the cost-savings to society from the prevention of affected births to evaluate screening programs, as mentioned previously, suggest very strongly that affected fetuses should be terminated. Moreover, such an approach also implies that uptake, and not informed choice, is the desired outcome of the offer of screening, since the more women who accept, the more disabled fetuses are likely to be detected and aborted, and therefore the greater the cost savings to society. Societal attitudes toward abortion in general have also been suggested to affect the way people perceive screening, with some suggesting that as abortion itself has become somewhat routinized – with abortions for social reasons done effectively 'on demand' – people may increasingly be compelled to screen for and abort fetuses with progressively minor abnormalities, without considering beforehand the potential implications for themselves, their families or society (Williams et al, 2002b).

## **Perceptions of Disability**

Traditionally, screening programs are designed, implemented and evaluated based on the goal of reducing or eliminating the burden of disease in a population. Given a tendency to evaluate prenatal screening programs based on uptake rates and Down syndrome (or other anomalies) births avoided, it would seem that on the surface, or at least on one level of policy, prenatal screening follows this model. This approach, however, has been widely criticized for promoting eugenic aims – something from which governments and professional bodies have been keen to disassociate themselves after the discreditation of the eugenics movement following the second world war. This desire to separate current practices in human genetics from eugenics has been the driving force behind the shift toward viewing the goal of prenatal screening programs as being to promote informed choice rather than uptake of screening or termination of affected pregnancies, and as such, may partly explain the discomfort of clinicians with raising the topic of abortion during consultations (Kerr et al, 1998). The truth is, however, that the offer of along with the option of termination does in fact imply a judgment on the part of those offering screening (the medical community, government, society) that the traits or conditions being screened for are ‘problems’ that either are worthy of elimination or, at the very least, require special consideration before being allowed into the world.

As with the issue of abortion, questions about disability have been shown to be underemphasized during prenatal care and offers of screening. While Santalahti et al

(1998) showed that disability was an actively avoided subject in the maternity centres observed in Finland, others have shown that while not avoided altogether, education about the disabilities being screened for is often minimal, under-informed, or biased. Of the eight informational elements identified by Hunt et al (2005) as being essential to offers of prenatal testing following a high-risk screen, the 'nature of the anomaly' was the least-covered element by physicians (21% average information score), and the second-least well-understood element on the part of women (33% average patient knowledge score). Similar results were seen in a study by Jaques et al (2004) who found that although Down syndrome is the most commonly screened-for condition, nearly 40% of women did not identify the condition at all when asked what they expected prenatal testing to tell them about their pregnancy.

In the information that is covered in consultations, practitioners recognize their potential to affect women's decisions about screening as a result of whether information about a disability is provided in a positive or negative light. A pediatrician explains:

...but then sometimes I have had the feeling that people, I wouldn't say, are pressurized, but that they are not necessarily given a realistic idea of what the outlook will be for their unborn child, that too black a picture may be painted, and maybe by people who don't actually know themselves (Williams et al, 2002).

This comment raises the issue that healthcare practitioners themselves often may not have experience with or an understanding of what life is like for people with congenital

anomalies and their families, thus making it less likely that they are capable of relaying accurate or balanced information to women making screening decisions. Many non-geneticist clinicians admit to relying on medical textbooks or the same informational leaflets handed out to women for their information about Down syndrome (Williams et al, 2002d). Neither of these sources, however, can be considered complete since medical textbooks focus solely on the potential negative clinical symptoms, and informational leaflets have been shown not only to contain very little information about the disabilities being screened for, but often only negative information at that, ignoring the possibility that some may perceive children with Down syndrome, for example, to be capable of having a good quality of life (Bryant et al, 2001; Michie et al, 2004).

In addition, it has been shown that a lack of social support systems (both perceived and real) for people with disabilities can influence women's decisions about prenatal screening and testing by affecting their perception of their capacity to cope with and care for a disabled child (Rice & Naksook, 1999; Williams et al, 2002). The increase in uptake of prenatal screening has, in turn, been recognized as contributing to a general lack of understanding and acceptance of people with disabilities; since fewer babies are being born with the disabilities on which screening programs are based, women, their families, and prenatal care clinicians alike are given little exposure to disabled people and their families (Williams et al, 2002d). In a sense then, the routinization of screening uptake may be said to be a self-propagating system. As stereotypes about disabilities remain unquestioned, and fewer opportunities exist to have one's assumptions about the role of the disabled in society challenged, more people may perceive prenatal screening

decisions as unproblematic, thus preventing them from thoroughly considering the impact of screening programs on women, their families, and society as a whole.

## **RESULTS**

### **Characteristics of the Sample**

Eighteen women were interviewed in total. Participants ranged from 28 to 42 years of age, with an average age of 33.2 years. Women had from one to five children, with an average of 2.2 children. All women were college or university educated. Ten women had careers in the healthcare field: three nurses, two physiotherapists, one physician, two care providers for the developmentally disabled, one medical lab technician, and one dental assistant. One woman did not work outside the home. Three women self-identified as religious: two Catholic, and one Christian. Two women were from immigrant communities: one Asian, and one African. In total 11 women in the study underwent prenatal screening in the current pregnancy, two underwent amniocentesis without prior screening, and 5 had no prenatal screening or testing.

### **Themes Arising from the Interviews**

Note: participants' quotes are identified with their study number, followed by a Y for acceptors of screening and an N for decliners. Where included, the interviewer's questions or comments appear in italics.

#### ***Women's Perceptions of Choice***

As has been indicated, the Ontario screening program is based on the principle of informed choice. Even in our small sample, however, two women talked about screening as if there was no opportunity for choice. One of these women explains how screening was presented to her:

Um, it was presented pretty much as something you are supposed to do. You have to do it, and you know, it will look for some defects or anything like that...I'm forgetting what exactly I was tested for, but, um, yes, it wasn't a big deal.

*So, is it something that you, you know, you kind of made a decision, ok, we'll do this...or was it more kind of accepting it because it was something...?*

Yes, yes, accepting it as just what everybody does. When you're pregnant it's what you are supposed to do. [Laugh.]...It wasn't like it was optional. (019Y)

The perception of screening as part of routine prenatal care seemed to make the perceived lack of choice unproblematic for this woman, as evidenced in her statement that screening 'wasn't a big deal'. The remaining data reveal examples of routinization and its resistance that were less obvious and extreme. Nearly all women made statements that suggested they did recognize screening to be a voluntary procedure. Nonetheless, despite

this clear recognition of choice, many women did not feel they had been given, or had not felt it important to seek the opportunity to deliberate on what the value of screening might have been for them personally. For instance, some recalled screening to have been directly endorsed by their physician:

That one was offered by, the doctor basically recommended and said here you go and gave the blood work sheet...They basically explained what the procedure was. They didn't really explain the entire range of tests that they were doing, they were just saying that it's a bunch of tests. I don't really know what it included.  
(002Y)

You have, you don't have to have this done, but you should have this done. What is it? It's an ultrasound and blood work. And that was about it. (029Y)

For both women, screening was perceived as something that a woman ought to do, based on the advice of her healthcare provider. Both of quotes raise a theme that was repeated throughout many other women's stories in the current research. The presentation of screening, as women remembered it, seemed most often to be focused on the technical procedures of screening.

In the following accounts, no explicit endorsement of screening uptake was reported, but women still seemed to view the decision to be screened as self-evident:

*And what were your thoughts about deciding whether or not to have that?*

Just that I, we would do it, and then, I wasn't too concerned that there would be, you know, that something would come out of it, that there were some developmental problems or whatever...I had done it with the first two, and it was just, naturally, we weren't, we weren't concerned about whether, you know, there was going to be a problem and what we would do. (001Y)

*And how was the screening presented to you?*

As a choice to do, although I think I figured that I would do anything that would be offered to me that would tell me something about my baby...I don't think I would have thought about it if it wasn't offered to me, but seeing as it was...I didn't really discuss it with [my husband] to be honest with you...It was there, I took it. (011Y)

While the first woman clearly did not see herself to be at risk of a positive screen, and the second demonstrated complete awareness that screening was optional, both accepted automatically, seemingly with no deliberation.

For another group of women, the value of screening seemed to have been presented as being inextricably linked to the increased risk of having a child with Down syndrome after age 35. Referring to the traditional age-based screening for amniocentesis, some women may have believed that some form of testing was a necessity once one had surpassed this age:

When you're older, you know, the reason why you're having this test is to make sure the baby is not mongoloid or anything like that, which you're going to be suffering until the end of your life, you know. Those kind of things we don't want, so when the doctor said that I'm recommending you to have an amniocentesis, I was like thinking, oh my god, I think I'm on that stage of having this kind of difficulty, this problem. (005Y)

Conversely, a number of women who accepted screening said they likely would not have done so had they been younger. Two women reported not having been offered screening – one during a previous pregnancy, and one during the current pregnancy – apparently because of their age. One explained:

No, they didn't offer me that. My doctor, because for her she thinks that you're more exposed at a certain age. I was only 29 when I had her, well I just turned 30. So I think she said the risk is not high for her, and she was the one, that's my doctor I had the first child, so I have a history with her, when she said that there are certain things that they require with some people.

(022N)

On one hand, this depiction may seem to provide evidence against the routinization of screening – this woman was not screened, after all – however, the nuances in this statement suggest otherwise. While we cannot know for certain whether this woman would have been offered and undergone screening had she been older, her statement seemed to imply that such a decision would be deferred to her doctor who knew which women were at risk and what they 'required'.

The testimony of another woman, who refused screening, revealed that she too felt there were often assumptions made by medical professionals about the value women place on all reproductive technology, including screening. In comparing attitudes of medical professionals toward prenatal screening to those toward contraceptive technology, she noted:

It's the same, same sort of idea, that this scientific technology is available but why aren't you using it? And obviously you're going to use it, and this is the best one to use. (023N)

These depictions of how screening was presented revealed the assumption among healthcare providers that women, particularly those older than 35, want to be screened.

### ***Reasons for Accepting Screening: Non-Invasiveness***

The idea that prenatal screening is 'the best' technology to use was voiced by a number of women, most often in direct comparison to the older and more invasive technology of amniocentesis:

And the one thing I was told, I don't remember by who, is that in the case of older women, like in my case, I was 35, it's a better test for getting an idea about Down syndrome and avoiding the amniocentesis. (001Y)

I was pleased to know I didn't have to necessarily go straight to amnio, because a) amnio scares the crap out of me, and I think there's still too high a miscarriage rate for women when they see it, they think, oh dear, that's just too much, I'm not gonna bother. It seems like it's gonna be painful, scary, you know, like

horrible, the worst, you'd rather not do it, but I found the blood-work testing... (027Y)

These women could be considered to be displaying their own form of resistance, using screening to resist the invasiveness and risk of miscarriage associated with amniocentesis. It is possible, however, that by thinking of screening decisions as choices between old and new forms of testing, rather than between having or not having testing at all, the purpose of screening could have remained undeliberated. The account of one woman in our study indicated that this may have occurred:

When they suggested that, I said, oh, it's just a, what was it, a needle? I think it's just blood they take, it wasn't invasive. If it was something like an amniocentesis, I don't, I'm not sure, I never had to think about that either, but just blood, sure, why not do it, you know. *It wasn't that big of a decision* because it wasn't anything that could...(003Y – emphasis added)

Thus, because serum screening is non-invasive and delivers no risk of miscarriage, it was perceived to be a harmless test, causing this woman to see no reason to deliberate its usefulness. As noted, in focusing on the value of the *procedure* of screening, the need to question the value of the *outcome* of screening, namely the information it provides, may therefore be obscured.

## **Reasons for Accepting Screening: Reassurance**

In order to uncover the value they placed on the information provided by screening, women were asked what they felt to be the purpose of screening or what benefits they sought by accepting screening. Many women who accepted offered little in initial discussions regarding such benefits. The response of one woman captured this very clearly:

I didn't really think of it as a benefit, just that if, I guess just to, to make sure that the baby was healthy and developing fine. I think that's it...Just more of a reassurance that everything was on track.

(001Y)

The desire for reassurance was one of the most widely reported reasons that women gave for undergoing prenatal screening in our study. The majority of women (eight) who accepted testing mentioned reassurance as either the purpose of prenatal testing or one of its main benefits:

I took the test to be reassured that everything was fine, but I sort of knew everything would be fine...you know, you can concentrate on other stuff, you don't need to worry as much about what's going to happen. (003Y)

Like, I just had to know and I didn't want to tell people I was pregnant. That's when, because you're at sixteen weeks and you're starting to show a little bit and you don't, you know, want to tell people until you know everything's fine. (007Y)

The statements of the women above were exemplary of a number of women for whom the need for reassurance seemed to have stemmed from an underlying anxiety about the pregnancy or the health of their baby. In addition, some women, like the first woman above, sought reassurance in spite of their own feelings that 'everything would be fine'.

For some women, however, this desire for reassurance may result from real concerns, as illustrated by a woman who was particularly interested in screening for neural tube defects because of a special diet she was on due to her own illness:

I guess I was just going with what, what they thought I should do and going with the most, the most amount of testing so that I could allay my family's fears really...and mine as well. (009Y)

This view of screening as a measure to provide reassurance about the health of one's baby, rather than a tool with which to discover health *problems* may have been a major cause of the routine acceptance of screening among women in our study. In fact, only one acceptor explicitly disagreed with this perspective and questioned the value of using screening for reassurance, as did one woman who refused screening:

They just want to make sure they're going to have a healthy baby though, right? Yeah, in that respect, and what if they found out they weren't?...It's funny, eh? It's how you think about it. I assume it's healthy, the testing tells me it's not. It doesn't reassure me that it's ok. (027Y)

Plus, it was such a small thing. Like, he could have, just if he came back and the test said no, you're not showing signs of any of these things, that doesn't give me a sense of relief that my child's going to be perfect medically. There's such another gamut of things that my child could have wrong. So, it's like, I don't even know, that's not going to give me peace of mind if I go "Yeah! Everything's great!" because there's all this other stuff. (013N)

These women raised concerns about the assumptions that are made by women who think of screening primarily in terms of reassurance. The first questioned whether women who sought reassurance had given thought to the possibility that they may, in fact, have received a non-reassuring result. The second suggested that women could have been lured by a negative screen result into a false belief that their child was guaranteed to be free of health problems. As these are both possible outcomes of screening, and both have the potential to give rise to ethical and/or emotional difficulties for women, it could be

argued that the failure of women to consider these possibilities, or the failure of healthcare professionals to encourage their consideration may be signs of the routinization of screening.

### ***Thinking About the Possibility of a Positive Result***

Many women seemed not to have given consideration to the potential for a positive screening result. These women described having had no plans for what they would have done had they received a positive result:

I don't know actually. No, I guess I didn't want to think about it until I knew, pretty much. So I don't know what I would have done, honestly I don't. I've never had to make any hard decisions regarding kids. (011Y)

I hadn't really decided what I was going to do once I got that information though. It was one of those things, we were just going to wait until we got the information and make a decision. We hadn't actually, but I just wanted a bit more, I guess, more reassurance or being prepared. (007Y)

No, it's hard to say too until you're faced with it...And it might be kind of scary to think about what we're supposed to do and,

but, yeah, it was, the test was done and we got our results and it was fine. (001Y)

All three of the women above had talked about reassurance as a primary motivation for accepting screening, and the second woman's quote made evident the connection between this and the lack of forethought about a possible positive screen. In admitting that 'it might be kind of scary to think about what we're supposed to do', the third gave a vague indication that she understood that a positive screen could have resulted in emotional difficulties, however she did not expand on the particular choices she might have faced.

Other women did explicitly recognize that abortion would have been an option for them following a positive screen, but upon probing did not seem to have thought through the complexity of such a decision, focusing instead on their lack of ideological opposition to abortion:

I'm not against abortion and if my child, if we had figured out that he was, that he was going to have a serious health problem I would have considered abortion.

*Ok, so what, what would you have considered, or what would be the characteristics of something that you would have considered that serious?*

Wow, um...That's a tough call, eh. I don't think I put as much thought into it before doing the test. I took the test to be reassured everything was fine, but I sort of knew everything would be fine...Yeah, I don't think, I didn't even think about 'what if'. (003Y)

Some women, however, did seem to have very clearly decided for termination of an affected pregnancy and had recognized the difficulties this decision could bring:

So, and I, I wasn't prepared to...to continue a pregnancy with a child that was, you know, that might live for six months, or nine months, or some of the horrible, you know, problems...And when my husband and I spoke, and we were, you know, we knew that if we found out some, you know, some horrible information, we wouldn't continue the pregnancy...Well, I knew there were only certain, there were certain specific chromosomes that were being looked at and they ranged from something as very minor, Down syndrome to some, some severe chromosomal problems which could lead to being born alive but not living very long, or maybe living for a length of time, but not living with any, you know, being very ill, being in the hospital, but not being able to, you know...Now what would I have done with

finding out that I had Down's versus finding out that I had some bizarre, one of the other very terrible ones? I don't know for sure because I never had to face that, that issue. (004Y)

And if it would have been identified as, you know, a potentially lethal trisomy, I would have no, I would have had an abortion...I had my decision made up. It would have been, there was options where it would have been difficult...I already knew that I had complications...I had already stayed almost two months in bed, do I just give it up? It's a little bit harder decision than if it was just a normal easy pregnancy or unplanned. (008Y)

While many of the women above commented on the difficulty of making hypothetical decisions about pregnancy termination, one woman's experience made this clearly evident. Although, as will be shown later, she actually believed very strongly that fetuses diagnosed with developmental disabilities *should* be terminated, this woman questioned whether she would have been able to make this decision under the specific circumstances of the screening process:

Yeah, I thought I would terminate. However, like I said, once I was sort of pregnant in those many months it didn't seem like it was a viable option anymore...Like, I definitely would have terminated it in the beginning when we were talking about it, but

once that belly's growing and you've had ultrasounds and you know, then you start thinking maybe they're wrong, you know.

(027Y)

The difficulties of making such decisions hypothetically was also explicitly discussed by another acceptor. She represented the only woman in the study who reported having been asked by her physician at the time of the screening offer if she had thought about how she would react to a positive screen. Rather than being prompted to consider this possibility, however, this woman strongly questioned the assumption that women should be expected to think this through in advance:

The only thing the doctor said to me was, you know, well what if, what if something, what if something's wrong with the baby. So, you know, I said, I haven't really thought about it. She goes, well you should. No. I don't want to think about it. And now I have to because now I'm gonna have to sit there and talk about it. You know, yes, I know, I know I have to think about it and I know it's something at the back of my mind, but I'm not gonna sit there and worry about it until I have to. (029Y)

Other participants, mostly those who had refused screening, disagreed with this approach, suggesting that the consideration of all possible outcomes of the test was a prerequisite of true informed decision making:

Yeah, I think you've really got to know what you're able to deal with and be prepared for it before you even go for the testing. I think you really need to know before you get that testing done what you're going to be able to deal with or else don't get it done...because you're running out of time.

*A lot of women say, "I'll deal with that if it happens."*

Then why get the testing done? Deal with it if it happens when the child's born, you know what I mean? (006N)

Why would you ever ask a question if you hadn't considered the answer? You see, I'm just that kind of person. I don't ask, I don't ask my husband if I look fat in this dress because, unless I'm prepared for him to say yes. Not that he would, but I just wouldn't bother to ask that question unless I'm prepared. And this is a major example of that. I can't imagine going in and having a test if you had not considered what you'd do with that information. (013N)

***Reasons for Accepting Screening: Preparation***

When prompted to consider how they would have reacted to a positive screen, some women felt that there could be value to receiving such information even if one decided not to have a therapeutic abortion. This included the two women in the study who had accepted screening despite a strong intention to carry their babies to term regardless of the outcome. These women claimed that having early knowledge that their baby would not be healthy at birth could help them prepare emotionally by allowing them to adjust their expectations accordingly:

Because when you hope to have healthy children and you don't, it has a major impact on your life, so it would be kind of nice to know ahead of time. (002Y)

I think if you're, if you choose to continue your pregnancy regardless, you're in a better position on the day of the birth of that child if you know what you're in for than, than if you don't have the information. If you're expecting a healthy baby that, like all of your friends have had and you find out that your child has got some problems, then I think you're better off knowing ahead so you can be prepared for it, for sure. (004Y)

Well, I think it prepares you a little better, I mean if you have something wrong when the baby's born and you know, you can

start researching it and finding out what it means and how it, and how, you know. You might think a child is going to develop one way but if they have, I don't know, Down syndrome or something like that it's going to be different, and you can kind of prepare yourself, I think, a little better, so you know a little bit more about what to expect in this shock of 'my baby's not as healthy as I thought it was going to be' (019Y)

The comments of the last woman, above, seemed to hint that early information could be valuable for practical preparation in addition to emotional preparation. Later in the interview, she expanded on this theme, suggesting that one may be able to use early knowledge of a congenital anomaly to change the health outcome for one's baby:

I would feel terrible, feel terrible. Although I think you would have the shock of the shock of something being wrong, and then in the back of your mind, "what could I have done differently if I had gotten the test? Is there anything I could have done to prevent it or make it less severe?" (019Y)

The implication of her statement is that a responsible mother is one who accepts screening, a theme also found in the statement of another woman, below:

Don't be sorry later, you know what I mean? At least when you're like, ok, like when I go to school, ok, I knew that I was going to have an exam. Do you think I'm going to pass the exam if I won't study? Of course you won't. Well, you may, you may, you don't know...but chances are you're going to fail. Like when you're having a baby, why don't you just have the test, make sure that you're feeling, you have to know yourself that you're ready to have these kinds of consequences you know, and be ready for the future. (005Y)

Some women who refused testing, however, questioned the value of finding out of a child's health problem before birth, saying, like one woman, "I don't need to know that beforehand" (023N). One woman who refused was particularly critical of the perception that accepting screening was a mark of responsible parenthood. With respect to the possible receipt of information that would tell her of her child's disability, she stated:

Well, what do I do with that now? He might have it, so I'll read up on it, but I would be reading up on it anyway if he was born and I saw that he had it...for years people were having babies with Down syndrome and then learning about Down syndrome. I didn't think that I needed to know everything about Down syndrome the second my baby entered the world. So, and that would be the same with any illness that they could have. So it's

not that I chose, oh I'm not going to learn anything, I just didn't feel like I needed to dedicate my pregnancy to learning all about the illness. I instead learned about general new baby stuff, what I can expect for sleeping, for eating, for that general stuff.  
(013N)

### ***Reasons for Refusing Screening: The Risk of a False-Positive Result***

As described above, most women who accepted screening viewed it as being low- or no-risk activity because of its non-invasiveness. Others, however, defined risk as including more than just a physical risk, referring to the emotional risk of obtaining the results of the prenatal screen. Most women who recognized this believed this risk to be inherent in what they perceived to be an unacceptably high rate of false positives in the screening procedure; the emotional risk was described as greater for women who did not understand that a screening test does not result in definitive diagnoses. This was exemplified by one woman who had received a false positive result in a previous pregnancy:

With my first baby I was thirty-three and at the time they were doing this Maternal Serum Screening...and I didn't quite understand, because I don't think it was honestly and properly explained, um, so I did the test, and it came back positive...and I didn't have much time left to make a decision about whether I

could live with the insecurity of this testing positive or whether I needed to do the amnio to, to, um, have a definite answer.

(004Y)

It is possible that this woman's acceptance of screening in her first pregnancy was the result of routine acceptance rather than systematic deliberation. Later in the interview, she confirmed that her decision to be screened had not been well-informed, and she reflected on the emotional impact this had on her:

I wasn't happy that I, that I wasn't, that I didn't have enough information to make the decision. If I had known that, I probably wouldn't have done the test...I mean, I'm an educated woman and I didn't really understand until I sat with the genetic counselor [after the positive screen] and she explained to me what exactly the test did, which was basically nothing...Because, I had two miscarriages and then I had this stupid positive Maternal Serum Screening. I was a basket case. I was actually, I was furious by the end of it all because I didn't need that on top of everything else that I'd gone through. (004Y)

Having gained a more thorough understanding of the meaning of a positive screen and been forced to consider its emotional implications, this woman chose to forego screening for amniocentesis in her second and third pregnancies. While she valued the information

from prenatal testing, the emotional risks of a false-positive outweighed the physical risks of an amniocentesis.

A number of other women in the study, mostly those who had declined screening, also expressed concern about the potential for a false positive result. For these women, the information provided by screening was seen as a potential source of unnecessary stress:

Well I never heard that it's a bad test, it's just that because there seems to be a significant false positives that have been occurring, it gave me concern of why, why do it if it's not going to be...accurate, and if it's not going to be, you know, if it's going to stress me out and you don't want stress during your pregnancy. (012N)

First of all, the percentage of accuracy was not good enough for me...I just didn't think that I needed to add an extra element of worry to my pregnancy for the thought that I might be predisposed to something that might be, I didn't want to play that odds game when the numbers didn't match. (013N)

Especially because my sister was given a test for, now I can't, what it was, an odd shaped head. They saw it in the ultrasound...They call it a lemon-shaped head, I think...Anyway,

it was some disorder, I think it was, it's one of those disorders that has a wide-range, it can be very severe and can be very, I wish I could remember what it was. Anyway, so she spent six months of her pregnancy worrying about this and had a perfectly normal child...So I can see a very negative side right there. It was a very stressful time for her. (023N)

It was not only women who resisted the routinization of screening – either by foregoing it for amniocentesis as with the first woman, or refusing testing altogether as with the above three – who recognized the potential for a false-positive result. One woman who accepted screening was aware of the potential negative emotional impact of a positive result as a reason why women may choose to refuse screening:

You should have the choice to refuse it. So some people don't want to know, they want the baby no matter what, doesn't matter. It can cause some people anxiety. You know, I can see somebody going, oh god, what happens if they come back, if the results come back, if they do come back positive, then you have to have the amnio and stuff...you know, which in itself again causes more stress. Yeah, I think it needs to be explained a lot better, be easier on people, you know. Especially the fact that there are a lot of false-positives, and it doesn't mean anything. (029Y)

It is notable that although the potential inaccuracy of the results led this woman to claim that screening ‘doesn’t mean anything’, she accepted nonetheless. Given that she emphasized the fact that one should have a choice to refuse screening, it is possible that she might have felt that she had not really been given that choice herself. While she seemed to have a good understanding of the limitations of a screening test, when taken together, these comments raise the concern that she had routinely accepted the test offered her without understanding that it was, in fact, a screen.

### ***Reasons for Refusing Screening: Avoiding Decisions About Abortion***

While all refusers cited an intention to carry their baby to term regardless of its health status as the main motive for refusing screening, the ‘risk’ they sought to avoid was not necessarily or solely that of abortion as a moral transgression. One refuser (023N) self-identified with the pro-life movement, however the others were accepting of abortion as a option in society:

My personality and my husband’s personality is that, you know, if we get a special needs child, we get a special needs child. I’ve got special needs children in the family so you know, I’m aware and have seen what’s to handle, where some people just can’t handle people, you know, children like that. I mean, maybe if they knew they were getting it, I mean it would be a sin if they

discontinued the pregnancy but once again I think it's their choice. I don't agree with it, but once again, you know, it gives someone the choice that, you know, why have a child that they're not going to want or be able to care for end up in the system? (012N)

Yeah, I'm not really strongly against abortion, just I know I couldn't do it. I think it's a very individual thing. I think it's very important to have in society for people who can't, who know they can't deal with the pregnancy. So, I'm not anti-abortion, I'm just anti-abortion for me [laugh]...I know I couldn't cope with it as well as I could cope with a child with a problem. (006N)

Rather than being ideologically opposed to abortion, these women saw a potential abortion as a risk to their emotional well-being:

I think the number one reason for me not to do it is that, I would never want to do the 'what if' scenario for what, should I have this child or not? What if I terminate the pregnancy, or if I terminate the pregnancy, what if I didn't terminate the pregnancy? I don't think I could live with, I think that would be very difficult for me. (013N)

We weren't interested because it didn't matter, I wasn't going to terminate the pregnancy. I wasn't going to, I wanted to carry it a full term and then deal with whatever was wrong...It wasn't going to change anything anyway. It would have just made the pregnancy more stressful... (006N)

***Reasons for Accepting or Refusing Screening: Perceptions of Disability***

Women's personal experiences with and perceptions of disability both on an individual and social level were seen to influence their decisions about screening. The statement of one acceptor echoes that of the decliner above who described her experience with disabled children as making her comfortable with the idea of having a disabled child herself:

I think that we'd be the best parents to have a kid who has special needs. I've done a lot of work with kids with special needs. I've done a lot of work with kids with special needs, my mom has two, we've got two really supportive families and our oldest child would have, give the world to anything, she's a really compassionate kid. (009Y)

Another acceptor, however, credits her experience working in a group home for mentally disabled adults with her strong belief that women who accept prenatal screening or testing ought to be encouraged to terminate affected fetuses. Her discussion, quoted at length, expanded on the concept of screening as a parental responsibility described earlier to include a social responsibility:

I think the only concern I would have is that if I was a medical professional and I was screening a woman and I found that her baby had something, I would be encouraging her more likely to terminate and I have a feeling there, I would say half the women out there probably wouldn't terminate because it's god's will to have this baby and so it might be for nothing, you know...Especially first time mothers and you know, I work with the population so I see it, as where most people don't, they don't know what's involved...but I mean, I think that it's unfair, that if you want to carry through with it, that you should care for that individual, you know. That you shouldn't burden it on society later when it becomes too much to handle...They don't have a clue about what it involves. You just think it's a little bit, oh, it has a few problems, you know, we'll love it and that will be good enough. And the thing that's scary about those kinds of disorders is that some of them can be quite high functioning and

some of them can be a little lower, some of them are just scary  
with how poor that they're doing in life, you know. (027Y)

In contrast some decliners of screening felt it was a social responsibility to consider the impact of screening programs on the meaning of disability and the social makeup. To them, the desire for selective termination based on prenatal screening represented a risk to society:

In an ideal world we would all be free of handicaps and have beautiful bodies and, but I'm not sure it's meant to be that way now. And I think that a lot of these tests are trying to get to that point and I'm not interested in being at that point, for sure.  
(023N)

I think that can be problematic if it became so simple in society to make these, if it became that cold, that black and white, that if you didn't have perfection then you didn't want it at all. That we'd be missing out on so much. (013N)

Similarly to the previous acceptor, the woman below accepted screening as part of a strong belief in preventing children from being born with diseases preventable by termination. However, this attitude appeared contingent upon her definition of disease:

If, assuming you could prevent, um, let's say to begin with, you can prevent children from being born with these diseases, um, then I think that's very important. I mean, who wants to see their child with one of those, one of those diseases? And I mean, can you say that there's anything socially redeeming in a child living with one of these diseases? No, uh, and I'm not talking about Down's now because I don't consider that a disease. (004Y)

Thus, subjective perceptions of what constitutes a 'disease' can add to the complexity of relationships between prenatal screening, disability and social responsibility.

## DISCUSSION

### Reflections on the Methods

#### *Sample*

Nearly all of the women in our study were middle-class, and college- or university-educated, and we were able to include only two women from immigrant communities. Also, because 10 of the women worked in the healthcare field, it is possible that their knowledge of the issues related to prenatal screening was different than that of most women in the general population. While qualitative research is meant to describe a range of experiences, and not necessarily be generalizable to an entire population (Morse & Field, 1995), it is possible that we have missed out on some richness in our exploration of this topic as a result of the relative homogeneity of our sample. Unfortunately, our method of recruitment turned out to be not ideal in that procedures designed to safeguard patient confidentiality hindered our capacity to carry out true purposive sampling. Because the research team was prohibited from knowing anything about a woman until after she had provided initial written consent to have her charts checked and be contacted, most new mothers in fact never entered into our pool of potential participants. The only measure available to us to increase the diversity of our sample was to extend the recruitment period as long as possible in the hope that more women with a diversity of experiences would self-select into our pool. This is what was done; during later stages of recruitment, as the homogeneity of our sample became apparent, we extended the

recruitment period a number of times and did our best to purposively sample from this pool. At these later stages, purposive sampling focused mainly on increasing the number of women who were from lower socioeconomic or educational backgrounds, or who were of ethnic origin, or who had refused screening.

We chose to include in our study only women who had received negative screen results and delivered healthy babies in their current pregnancy, and who had no recorded history of selective abortion or the birth of a child with a congenital anomaly. As records did not show previous screening history, we did end up with one woman who had received a false positive screen in a previous pregnancy, and as we have seen, her story provided valuable insight into the process and effects of the routinization of prenatal screening. We chose our sample in this way for both strategic and ethical reasons. In the population, the vast majority of women give birth to a baby with no congenital anomaly, and a vast majority of women who are screened receive true negative results. This sample therefore represents the 'normal' or usual outcome, and therefore represents a baseline group, from which further research including women with more difficult experiences can draw upon for comparison. By selecting this baseline group we also minimized the possibility of causing emotional distress to women during the interview process.

### *Interviews*

It is possible that women's reflections on their decision making process and on the value they placed on prenatal screening were biased as a result of interviews being conducted

after women who were screened had received negative results, and after all women had delivered healthy babies. Green (2004) describes such women as ‘satisfied customers’ and we agree that reflections about screening may have been different in women who were screened if they had been interviewed before they received their results. Future research should take this into consideration.

Another issue with our interviews is that they only allowed us to hear women’s own perspectives and memories about what the offer of prenatal screening was like, which could be said to limit our capacity to draw conclusions about how information about screening is presented during consultations. Direct observation of consultations where prenatal screening was offered would undoubtedly have added a useful perspective to our research, and unfortunately this was not possible with the present study due to logistical constraints. We contend however that what women told us about being offered screening is valuable in itself since in examining their subjective experiences, we have heard what women took away from consultations, and therefore gained insight into what they held to have been the most important, valuable, or relevant information for their decision making.

### **Summary of the Results and Their Implications**

It has been argued that informed consent can be seen as either a process or as a distinct event (Lidz et al, 1988). The process model acknowledges that decisions are made in dynamic periods of changing emotions and informational inputs, taking place in the

context of each patient's life. In practice then, it requires a sophisticated relationship between doctors and patients in which explorations of the issues relevant to consent are woven into the entire patient education and decision making process. In bioethics, the process model represents the ideal, however, in practice, informed consent is generally approached as an event, a discrete, rational choice that follows from the provision of information, is enacted by the consent form, and is typically associated with legal liability. Press and Browner (1995) contend that this practice fails to promote true informed choice, as the unidirectional process of providing the patient with technical information about screening occurs to the detriment of real interactive discussion of the broader ethical issues of screening and how they align with the patient's value system. Their landmark study of women's reasons for accepting screening found that while according to official policy women's autonomy in prenatal screening programs reigned supreme, in practice this choice was often illusory, and routine, passive acceptance of screening common (Press & Browner, 1997). The present study uncovered a similar pattern; routine acceptance of prenatal screening seems to have occurred among many of the interviewed women, and is being facilitated by a complex set of individual, health system, and societal factors.

### *The Issue of Choice*

In the current study, many women described passivity – apparent lack of active deliberation – in their acceptance of prenatal screening. For one this arose from the perception that screening was mandatory; as such, she did not feel she had been given a

choice at all. One other woman claimed not to have had a choice, although in her case this led her not to be screened. Her comments suggested, however, that her doctor believed screening to be unnecessary for mothers of her age and that had she been over the traditional high-risk cutoff age of 35, she would have been screened in compliance with what she perceived to be a requirement of regular prenatal care. Neither of these two women expressed concern about having not been given a choice about screening; both saw themselves as simply following their doctor's orders, and seemed to trust that their doctors knew what was best for them and their baby. Previous studies of women's decision making in prenatal screening have shown that the acceptance of screening is facilitated by women's trust in the expertise and benevolence of their healthcare providers (Anderson, 1999; Tsianakas & Liamputtong, 2002; Williams, 2005). This was evident even among other women in the current study who described screening as having been explicitly suggested or recommended by their doctor. Among these women then, the acceptance of screening can be said to have reflected not so much an active choice as "routine behaviour, cooperating with perceived expectations of clinic staff" (Michie et al, 1999: p.746).

Even when screening was apparently presented in a nondirective manner, evidence was found to suggest that it may still have been routinely accepted by a number of women. Pilnick (2004) reported that even when practitioners were observed to clearly present screening as a voluntary choice, many women still viewed screening as just one of many routine prenatal tests not requiring special consideration. This held true for a number of women in our study who despite clearly recalling being offered a choice, demonstrated in

their interviews that they had undertaken little or no deliberation while deciding to be screened. There was clear evidence of heuristic – rule-of-thumb based – rather than deliberative decision making among these women. For some, the value of screening seemed to be inferred both from its offer and, again, from the failure to see prenatal screening as being separate from regular prenatal care in general. Regular prenatal care seems to be widely accepted both in the medical community and the general public as being both a necessity and inherently protective of the health of the fetus (Barker, 1998). Some women hinted at this idea of the protectiveness of prenatal screening, arguing that such information would help them to prepare emotionally for the birth of an unhealthy child, although the value of such advance preparation was questioned by others in the current study and has also been disputed in the literature (Press & Browner, 1997). Still other women referred explicitly to screening as being the logical choice for responsible mothers who care about the health of their baby. This mirrors the findings of Press and Browner (1997), who showed that the placement of screening under the umbrella of routine prenatal care can lead women to think of screening as something that ensures the health of one's baby, therefore making uptake of screening a sign of responsible parenthood, and encouraging routine acceptance.

### ***Risk and Reassurance***

A number of women felt themselves not to be at risk of having an affected child, but accepted screening anyway, stating, like most of women who accepted screening that they were simply seeking reassurance that their baby was healthy. Such desire for

reassurance has been repeatedly shown to be the primary expected benefit from screening among most acceptors (Press & Browner, 1997; Rice & Naksook, 1999; Pilnick et al, 2004; Hunt et al, 2005). Its existence suggests these women experience underlying anxiety about the health of their babies, something recognized explicitly by a few of the participants in this study. It is also possible that the offer of screening itself may create the anxiety that prenatal screening and testing then are intended to reassure, something supported in the literature (Lobel et al, 2005). Tymstra (1991) argued that the medicalization of pregnancy has created the ‘tentative pregnancy’ in which women delay attachment to their unborn child until after they feel reassured that their baby will be born healthy.

This view of screening as a measure to provide reassurance about the health of one’s baby, rather than a tool with which to discover health problems has been suggested to be a major cause of its routine acceptance (Press & Browner, 1997; Pilnick et al, 2004), and represents the major difference between the views of women and those of the medical community, for whom the purpose of prenatal screening is to allow women and their families to make informed decisions about the progression of their pregnancy. Screening programs are not necessarily designed to reassure; in fact, they may be calibrated to avoid missing affected fetuses above other possible objectives, and therefore may sacrifice some specificity for maximum sensitivity. As a result, there is a significant rate of false positive results (7.2% false positive rate for Down syndrome detection by MSS in Ontario; Summers, 2003) and many women who ought to be reassured – since their babies are, in fact, healthy – have results over the cutoff, are deemed ‘high-risk’ and

therefore do not get reassured. Previous research has shown that despite the capacity of many women to speak in terms of risk, often even being able to recall specific risk probabilities, the meaning of this for the results of screening often remains misunderstood (Gates, 2004). The implications of this can be that women – particularly those who expect to be reassured – may accept screening without considering the possibility that they could receive a positive result.

A particularly informative example of this was provided by one woman in our study who had received a false positive result after routinely accepting screening in her first pregnancy. She described the positive screen as having caused immense stress and anxiety, leading her to forego screening for amniocentesis in her second and third pregnancies because of its greater accuracy. She was especially critical of the lack of information she received about screening when it was offered, and felt that if she had properly understood the probability and meaning of receiving a false positive result, she would not have accepted. It has been shown that the additional anxiety caused by a positive screen does not always subside upon subsequent receipt of a negative diagnostic test (Kowalcek et al, 2003). The potential for these effects however was not mentioned as part of the information received by any of the women in the current study. Of all the other women in the study who seemed to have recognized the potential negative impact of receiving a positive screen as being significant to their decision making, all but one were women who had refused screening. When weighing the potential benefits and harms of screening, these women, like the woman above, included the stress of receiving a positive result as a risk.

### *Information About Screening: Procedure Over Purpose*

In contrast, when asked during interviews to reflect on the benefits and harms of screening, most acceptors discussed only physical risks of the screening procedure – specifically, the lack thereof. Many women described the benefits of screening in direct comparison to amniocentesis, with most considering screening to be risk-free because it is a noninvasive procedure. These women may have used one form of technology to resist another (Rapp, 1999), however their focus on only the procedural aspects of screening without considering potential risks from the information it provides calls the thoroughness of their valuation into question. Previous research found that nearly all women who declined amniocentesis accepted prenatal screening when offered, even when they were opposed to abortion (Halliday, 2001). Pilnick (2004) found that during the offer of screening, midwives in the UK often focused on the benefits of the newer, less invasive first-trimester ultrasound over the older maternal serum screen. She contends that the way in which discussions were framed encouraged women to make a choice between the old and new screening methods, rather than between being or not being screened. The result of this was that discussions about the purpose of screening, or the value of the information for each individual woman were hindered. As we did not directly observe consultations, it is unclear how much this focus on procedure over purpose is due to the ways in which screening was presented, and how much to women's own preconceptions. Either way, in adopting this focus in interviews, these women

evidently perceived this information to have been particularly relevant to their decision making.

As stated earlier, the purpose of prenatal screening programs is to provide information to women so that they can make informed decisions about pregnancy. Therefore, one would expect women to be aware of the decisions they may be asked to make and perhaps have a tentative idea of what they would do with the information that their fetus has a congenital anomaly, should that be the case. This was not the case, however, for most of the women in our study who accepted screening. The perception of screening as a harmless procedure that is part of routine prenatal care, along with the assumption by women that they will receive a reassuring result seemed to encourage the adoption of a 'wait & see' attitude toward the potential for a positive screen. Such an approach has the potential for serious emotional consequences in these women, who are likely to be unprepared in the event of receiving bad news. As recognized by two of our participants, one who had refused screening and the other, described earlier, who had experienced a false positive result in her first pregnancy, women have only a small window of time after receiving a positive screen result in which to decide if they can live with the uncertainty this creates or if they want to proceed with invasive diagnostic testing, which itself produces additional anxiety due to its associated risk of miscarriage. It has been suggested that rational decision making can be severely hindered at this time as time pressure and anxiety caused by the positive screen can lead women to want/accept all other technological options in a chain of tests/procedures in an attempt to gain reassurance that the baby is ok (Santalahti et al, 1998).

### *Ethics of Screening: Abortion & Disability*

In contrast to the acceptors described above, decliners all seemed to have thought through to the implications of a positive screen. Although these women all cited an unwillingness to consider abortion as their main reason for refusing screening, for most this was not due to opposition to the offer of abortion itself. Instead, many saw the possible offer of an abortion as problematic for themselves personally, as a result of the stress and potential for decision regret they believed they would experience were they to be required to make such a decision. In concert with previous research, ideological acceptance of or opposition to abortion varied among our participants and could not be predicted by acceptance or refusal of screening alone (Markens et al, 1999; Lippman, 1999). What remained consistent, however, was the absence of discussion of the ethical implications of screening, or of women's values related to these, in almost all women's descriptions of their screening consultations. As will be discussed below, only a handful of women – and most of these refusers of screening – seemed to have considered these issues of their own accord when making their decisions about screening.

In the case of a positive screen followed by a positive diagnosis, women are faced with a decision that is both morally contentious and emotionally difficult: whether to continue with the pregnancy or have an abortion. Only some acceptors specifically discussed how they might have reacted to an offer of abortion. Their responses highlighted the difficulty of making such a decision, particularly in a hypothetical situation. Many women in our

study who accepted screening seem to have given little or no thought to what they would do if told their baby had a congenital anomaly, their approach exemplified by one woman who stated, "I didn't even think about 'what if'." Only one participant described having been explicitly encouraged by her doctor to think through how she might have reacted to a positive diagnosis, however her response to this was annoyance at her doctor for forcing her to think about a possibility that she neither wanted to nor believed it necessary to acknowledge unless it became a reality. The argument in favour of requiring such consideration is two-fold. Firstly, the emotional distress and time pressure women face when deciding whether or not to have a diagnostic test following a positive screen are even greater when deciding whether or not to have an abortion following a positive diagnosis. As recognized by a couple of our participants, this generally occurs relatively late in pregnancy, when women have often already bonded with their unborn child and there is only a short period of time remaining in which to make decisions about abortion. Secondly, it has been suggested that women have a social responsibility to be actively involved in considering the ethical implications of prenatal screening as a result of their social role as a potential parent, as well as an obligation to society for the effects of screening programs on social perceptions of disability (Press & Browner, 1995).

The issue of disability, like that of abortion, remained unmentioned by most acceptors when discussing their screening decisions. This is perhaps a reflection of the focus in consultations, described earlier, on the procedures of screening while avoiding issues of the purpose of screening; previous research supports this claim (Santalahti et al, 1998; Hunt et al, 2005). Two women in our study described their experiences working with

disabled children or adults as having influenced their screening choices. One woman who accepted screening with no intention to terminate believed she and her husband would be ‘the best parents to have a kid who has special needs’, both as a result of her experience working with disabled children the support available for her and her husband’s family. As Williams (2002) pointed out, women’s choices about screening may be affected by their perceptions of the support available to them in society or within their family. Lack of exposure to people with disabilities has also been suggested to facilitate uncritical uptake of prenatal screening or testing and termination of affected fetuses (Williams, 2002b), however we found that this not necessarily to be the case. Another participant’s experience working as a counselor in a group home for adults with disabilities caused her to have a completely opposite perspective as the participant above, believing that women should be encouraged to terminate affected fetuses, and that a choice not to terminate results in the burden of care being placed unfairly on society. Attitudes such as this, that attribute blame to mothers of disabled children when prenatal testing and termination are available, are prevalent in both the medical community and the general public and may subtly encourage women to accept screening (Marteau & Drake, 1995; Rice & Naksook, 1999).

Another woman interviewed, perhaps without even realizing it, brought to light what is perhaps one of the most complex issues surrounding the norms and ethics of prenatal screening programs. After describing at length her belief that there is nothing ‘socially redeeming’ in allowing a child to be born with ‘one of these diseases’, she qualified her comments by stating that they did not include children with Down syndrome, as she did

not consider Down syndrome to be a disease. The question of what constitutes normal or abnormal, health or disease is at the centre of the process of medicalization, and thus the routinization of prenatal screening. Rapp's (1999) analysis highlighted the role of women as 'moral pioneers', who through their responsibilities as mothers and decision makers about prenatal testing and termination have become the gatekeepers of society, choosing by their actions who is worthy of entry and who is not. These broad social and ethical issues making up the relationship between prenatal screening, abortion, and disability were mentioned explicitly by only two women in our study, both of whom had declined screening and who expressed concern with what they saw as a growing desire for 'perfection' in society. Indeed, if we accept the postulate that technology, to be widely accepted, needs to be introduced into an 'ideologically fertile social field' (Arney, 1982), one might argue that such a 'field' exists in Western culture. Factors such as women's careers, consumerist culture, and the availability (or lack thereof) of social and healthcare support for the disabled all provide the context in which choices about prenatal screening are identified and evaluated (Rapp, 1993 in Rice & Naksook, 1999; Williams et al, 2002), therefore likely contributing to routine acceptance of prenatal screening.

### ***Implications for Healthcare***

The approach to informed consent as a discrete event may act as a barrier to real communication between healthcare professionals and patients, resulting in missed opportunities to assist women and their families to clarify their understanding of and values about screening and therefore make truly informed, autonomous decisions.

Because of this, the assumptions upon which screening programs are based are rarely made explicit, therefore making it difficult for women to identify and question whether or not these conform to her own desires (Anderson, 1999). In order to shift toward the process model of informed consent, what is needed is for healthcare professionals to engage women in discussion, to elicit their interpretations of the meaning of prenatal screening and to help them place this in the context of their own lives. This implies movement towards a more shared model of decision making in the doctor-patient relationship (Charles et al, 1997; Elwyn et al, 2000), which has its own implications for shifts in professional culture and training.

To combat routinization, however, others contend that the essential problem lies in the broader culture of the medicalization of pregnancy and prenatal care, and that a focus on the doctor-patient interaction alone is not enough:

*If we believe that the decision to have such tests should receive more explicit and serious deliberation than most women seem to give it...we should interrogate and perhaps reform the culture of surveillance that dominates pregnancy and provides a background against which agreeing to such a test becomes the only conscientious, responsible thing to do (despite the test's almost complete lack of possible health benefits for either mother or future child). Making sure that this decision is informed and uncoerced is unlikely to alter the structure of responsibilities that all but determine the decision in advance (Kukla, 2005).*

Practitioners and policymakers alike should therefore recognize not only that routinization exists, but that it exists on a range of levels: individual, systemic, and societal.

### ***Directions for Future Research***

Further research is needed to clarify and quantify the effects of routine acceptance of screening on women and their families, and to determine the most effective and appropriate ways of ensuring that women's choices are truly informed and deliberated. Efforts should be made to incorporate the perspectives of women with the entire spectrum of screening-related outcomes: those who received false positive or negative results, those who decided for or against termination of pregnancy, and those who gave birth to an affected child. Future studies should elicit women's valuations about screening at various time points (i.e. after screening is offered, but before results are received). Consultations in which screening is offered ought to be observed in order to derive a better understanding of what information women are receiving and how it is being framed.

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## **APPENDIX 1: Initial Interview Schedule**

### **General Understanding of Genetics**

When I say “genetics”, what, if anything, comes to mind? (examples of genetic conditions?)

How would you describe your level of understanding about genetics? How do you think this compares to other women?

Where do you get your knowledge about genetics?

Do you think there are any benefits to be gained for individuals/society from genetics?

Do you have any concerns about genetics?

Where would you like to see genetics heading in the future?

### **Decision-Making About Prenatal Screening**

Can you tell me about how this pregnancy went for you? (Birth plan?)

Can you remember what sorts of tests (of any kind) were done during your pregnancy?

Were you offered any tests that you’d characterize as genetic or ‘special’ in the sense that they tell you information about your baby?

How did your physician present the tests to you?

How did you make the decision to accept or decline these tests?

Did you discuss it with anyone? Seek advice?

Did you make the same decision with earlier pregnancies? Do you think you would make the same decision again?

### **Prenatal Screening in General**

[If you declined testing for yourself,] do you think that other women should have the choice to do these tests?

To what extent do you think that the choice about prenatal genetic testing depends on circumstances? (Seriousness of condition – i.e. Tay Sachs where kids die young or MD where live longer with limited activity, available treatments/cures, family history, socioeconomic status, first/later baby)

Do you think there are benefits to be gained from prenatal screening? (information, decision-making)

### **Health Services Issues**

How important do you think genetics is in health care?

To what extent do you feel genetic tests should be paid for as part of OHIP? (all, some, none)

Where do you think the money should come from for genetic testing? (What other parts of maternity care would you sacrifice? Would you pay extra taxes?)

Is information a sufficient outcome for a test? (i.e. no intention to use that information to make any kinds of decisions)

### **Wrap-Up**

Are there any other issues you would like to raise?

### **Demographics Etc.**

Age

Education

Household situation (family in house, career)

Number of children, planning more?