
Meredith G. Vanstone, The University of Western Ontario

Supervisor: Elizabeth Anne Kinsella, The University of Western Ontario
Joint Supervisor: Jeff Nisker, The University of Western Ontario

A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Health and Rehabilitation Sciences
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by

Meredith Vanstone

Graduate Program in Health & Rehabilitation Sciences

A thesis submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy

The School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario, Canada

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Co-Supervisor

Dr. Elizabeth Anne Kinsella

Co-Supervisor

Dr. Jeff Nisker

Supervisory Committee

Dr. Pamela McKenzie

Examiners

Dr. Louis Charland

Dr. Marilyn Evans

Dr. Carol Herbert

Dr. Lisa Schwartz

The thesis by

Meredith Grace Vanstone

entitled:


is accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy

Date

Chair of the Thesis Examination Board
Abstract

This thesis examines the process of informed decision-making for low-risk women in their first pregnancies as they consider whether or not to participate in non-invasive, non-diagnostic prenatal screening.

Using a social constructionist approach with a theoretical lens of feminist bioethics, data from three sources were used to consider different aspects of the process of informed decision-making about prenatal screening. Data obtained from patient education materials, Society of Obstetricians and Gynecologists of Canada policy documents, and interviews with pregnant women were examined using the principles of constructivist grounded theory.

Findings are presented in the form of four integrated articles, addressing the issues of: I) the potential for metaphors and figurative language in prenatal patient education materials to be implicitly or explicitly directive; II) different counseling strategies and decision-making models for health care providers to consider when striving to offer prenatal screening in a way which supports autonomous informed choices; III) the type and content of information that women have identified as necessary to consider themselves informed when preparing to make a decision about participation in prenatal screening; IV) a proposed model for the ways in which information from different sources is sought, received, and interpreted by women engaged in the process of making a decision about prenatal screening.

Informed decision-making about prenatal screening is a complex issue, requiring significant efforts on the part of the health care professional offering screening, and necessitating careful consideration by the woman making the choice. Given an understanding of the complex social context within which these screening tests are offered and chosen, the process of informed decision-making may be more challenging than suggested by current policy and public education documents.

Keywords

Prenatal screening, informed decision-making, informed choice
Co-Authorship Statement

I, Meredith Vanstone, acknowledge that this thesis includes four integrated manuscripts that evolved as a result of collaborative endeavors. In the four manuscripts, the primary intellectual contributions were made by the first author who: researched the methodology, designed the research, developed the ethics application, conducted the literature reviews, undertook the data collection, transcribed and coded the data, led the data analysis and led the writing of the manuscripts. The contribution of the co-authors, Dr. Elizabeth Anne Kinsella and Dr. Jeff Nisker, was primarily through the supervision of the research, theoretical and methodological guidance, intellectual and editorial support in crafting the work for publication.
Dedication

This work is dedicated to my parents, for always making me believe that I can do anything I set my mind to, and to my husband, for helping and supporting me the whole way- on this and absolutely everything else.
Acknowledgments

Attending graduate school is a privilege. Thanks to all who enabled me not just to attend graduate school, but to really, truly enjoy it. I could not have done this without the support of family, friends, colleagues and mentors; I am especially indebted to those who have blurred the lines between these categories. To describe my gratitude in a few short lines here would diminish your contributions, I hope I can thank you more adequately the next time we meet.

Elizabeth Anne Kinsella, Jeff Nisker, and Pamela McKenzie have had a significant impact both on this research and on my identity as a scholar. I discuss some of their many contributions in Chapter 9, with the intention of acknowledging the privilege of working with these scholars and the ways in which they facilitated my experience of the doctorate as not just a process of coming-to-know, but also of coming-to-be (Green & Lee, 1995).

This research could not have been completed without the willingness and enthusiasm of the participants, the generosity of the examining committee, the co-operation of the London-Middlesex Health Unit, and the financial support of the Social Sciences and Humanities Research Council; Canadian Institutes for Health Research (CIHR) Training Program in Reproductive, Early Development and In-Utero Health (REDIH); CIHR Institute of Human Development, Child and Youth Health; Faculty of Health Sciences, University of Western Ontario; Department of Obstetrics and Gynecology, Schulich School of Medicine and Dentistry, University of Western Ontario; Genome Canada.
# Table of Contents

**CERTIFICATE OF EXAMINATION** ......................................................................................... ii

**Abstract** ................................................................................................................................ iii

**Dedication** ............................................................................................................................. v

**Acknowledgments** ................................................................................................................ vi

**Table of Contents** ................................................................................................................... vii

**List of Tables** ........................................................................................................................... xv

**List of Figures** .......................................................................................................................... xvi

**List of Appendices** ................................................................................................................... xvii

1 **Introduction** .......................................................................................................................... 1

1.1 **Interdisciplinary Bricolage** ............................................................................................ 2

1.2 **Situated Research** ........................................................................................................... 4

1.2.1 **Standpoint of the researcher** .................................................................................... 4

1.3 **Story of the Research** ..................................................................................................... 7

1.4 **Definitions of Terms** .................................................................................................... 10

1.5 **The Study of Prenatal Screening as Conceptualized in this Dissertation** ............. 13

1.6 **Methodology** ................................................................................................................ 13

1.7 **Plan of Presentation** ..................................................................................................... 14

1.8 **Conclusion** ................................................................................................................... 16

1.9 **References** ..................................................................................................................... 18

2 **Literature Review** ................................................................................................................ 23

2.1 **Background Terms and Concepts** .............................................................................. 23

2.1.1 **Types of prenatal and diagnostic screening** ............................................................ 23

2.1.2 **Risk status** ............................................................................................................... 26

2.1.3 **Physical risk** ............................................................................................................. 27
2.1.4 Social-psychological risk.......................................................................................... 27

2.2 The 2007 SOGC Clinical Practice Guideline on Screening for Fetal Aneuploidies: Implications for prenatal care................................................................. 28

2.2.1 Genetic screening and primary care providers.................................................. 30

2.3 Prenatal Screening and Disability.......................................................................... 31

2.3.1 Social construction of disability.................................................................... 34

2.4 The Ethos of Non-directive Genetic Counseling............................................... 35

2.5 Autonomy: Preconceived and Re-conceived....................................................... 41

2.5.1 Relational autonomy. ................................................................................ 43

2.6 Re-examining Risk................................................................................................ 46

2.7 Influential Prenatal Screening Literature.............................................................. 47

2.7.1 Abby Lippman (Canada, Epidemiologist, Bioethicist)................................. 49

2.7.2 Barbara Katz Rothman (USA, Sociology)................................................... 51

2.7.3 Rayna Rapp (USA, Anthropology)............................................................... 52

2.7.4 Carole Browner and Nancy Press (USA, Anthropology)............................ 53

2.7.5 Theresa Marteau (United Kingdom, Health Psychology)............................ 54

2.7.6 Recent contributions to the literature............................................................ 56

2.8 Conclusion............................................................................................................ 57

2.9 References............................................................................................................. 58

3 Epistemological and Theoretical Perspectives............................................................. 85

3.1 Introduction........................................................................................................... 85

3.2 Epistemological Underpinnings: Constructionist and Critical Perspectives ...... 85

3.2.1 Constructionist.............................................................................................. 85

3.3 Critical Social Theoretical Perspective.................................................................... 91

3.3.1 Medicalization.............................................................................................. 91

3.3.2 Normalization.............................................................................................. 95
3.3.3 Foucault's governmentality & bio-power. .................................................... 97
3.3.4 Risk. ........................................................................................................ 100
3.3.5 Congruencies between critical and constructionist perspectives. ............ 102
3.4 Theoretical Lens .......................................................................................... 103
  3.4.1 Feminist bioethics. .................................................................................. 103
3.5 Conclusion ..................................................................................................... 107
3.6 References ................................................................................................... 108
4 Methodology and Methods ............................................................................. 114
  4.1 Introduction .................................................................................................. 114
  4.2 Part 1: Methodology .................................................................................. 114
    4.2.1 Reflexive research .............................................................................. 114
    4.2.2 Constructivist grounded theory .......................................................... 119
    4.2.3 Constructionist approach to grounded theory ..................................... 120
    4.2.4 Why grounded theory? ....................................................................... 125
    4.2.5 Social construction, grounded theory, metaphor, and reflexivity ......... 125
  4.3 Part 2: Methods .......................................................................................... 127
    4.3.1 Study design ....................................................................................... 127
    4.3.2 Research question ............................................................................... 128
    4.3.3 Study #1: How do prenatal screening patient education materials portray concepts related to prenatal screening? .................................................. 129
    4.3.4 Study #2: How do policies and guidelines shape the offer of prenatal screening? .................................................................................. 133
    4.3.5 Study #3: How do women use information when making a decision about whether or not to participate in prenatal screening? ......................... 135
    4.3.6 Memo writing ...................................................................................... 142
    4.3.7 Methodological decisions .................................................................... 143
  4.4 From research questions to manuscripts: the evolution of the research ....... 146
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.5 Conclusion</td>
<td>150</td>
</tr>
<tr>
<td>4.6 References</td>
<td>151</td>
</tr>
<tr>
<td>5 Critical Reflection and Prenatal Screening Public Education Materials</td>
<td>157</td>
</tr>
<tr>
<td>5.1 Introduction</td>
<td>157</td>
</tr>
<tr>
<td>5.2 Background</td>
<td>158</td>
</tr>
<tr>
<td>5.3 Prenatal Screening Educational Materials</td>
<td>159</td>
</tr>
<tr>
<td>5.3.1 Prenatal screening in Canada</td>
<td>159</td>
</tr>
<tr>
<td>5.3.2 Prenatal public education pamphlets</td>
<td>160</td>
</tr>
<tr>
<td>5.3.3 Prenatal screening educational materials and non-directive language</td>
<td>161</td>
</tr>
<tr>
<td>5.4 Metaphoric Textual Analysis</td>
<td>162</td>
</tr>
<tr>
<td>5.4.1 Assumptions about metaphor</td>
<td>163</td>
</tr>
<tr>
<td>5.5 Critical Reflection</td>
<td>164</td>
</tr>
<tr>
<td>5.6 Texts: Inclusion Criteria</td>
<td>165</td>
</tr>
<tr>
<td>5.7 Analysis</td>
<td>168</td>
</tr>
<tr>
<td>5.7.1 Metaphors of prenatal screening</td>
<td>168</td>
</tr>
<tr>
<td>5.7.2 Figurative language</td>
<td>169</td>
</tr>
<tr>
<td>5.7.3 Neutral versus suggestive terminology</td>
<td>169</td>
</tr>
<tr>
<td>5.7.4 Non-directive versus directive language</td>
<td>170</td>
</tr>
<tr>
<td>5.7.5 Clear versus indirect language</td>
<td>171</td>
</tr>
<tr>
<td>5.7.6 Able-ist versus disability rights language</td>
<td>171</td>
</tr>
<tr>
<td>5.7.7 Metaphors</td>
<td>172</td>
</tr>
<tr>
<td>5.8 Discussion</td>
<td>174</td>
</tr>
<tr>
<td>5.9 Conclusion</td>
<td>177</td>
</tr>
<tr>
<td>5.10 References</td>
<td>179</td>
</tr>
<tr>
<td>6 Information-Sharing to Promote Informed Choice in Prenatal Screening in the Spirit of the SOGC Clinical Practice Guideline: A Proposal for a Alternative Model</td>
<td>185</td>
</tr>
</tbody>
</table>
6.1 Introduction......................................................................................................... 185
6.2 Prenatal Screening for Fetal Aneuploidy............................................................ 186
6.3 Informed Choice and Autonomy ....................................................................... 186
6.4 Non-Directive Counseling.................................................................................. 187
  6.4.1 Is non-directive counseling possible?..................................................... 187
  6.4.2 Is non-directive counseling desirable?.................................................... 188
6.5 Proposed Alternative Model of Informative Decision-Making and Shared Decision-Making................................................................................................. 190
  6.5.1 Information sharing phase...................................................................... 192
  6.5.2 Deliberation phase. ................................................................................. 193
  6.5.3 Decision-making phase. .......................................................................... 194
6.6 Conclusion .......................................................................................................... 195
6.7 References........................................................................................................... 196

7 Pregnant Women’s Self-Identified Information Requirements When Deciding to Participate in Non-Invasive Prenatal Screening ........................................................ 204
7.1 Introduction......................................................................................................... 204
7.2 Methods............................................................................................................... 207
  7.2.1 Recruitment................................................................................................ 207
  7.2.2 Eligibility. .................................................................................................. 208
  7.2.3 Data collection. ....................................................................................... 209
  7.2.4 Data analysis. .......................................................................................... 209
7.3 Findings............................................................................................................... 210
  7.3.1 Category I: What is prenatal screening?.................................................. 210
  7.3.2 Category II: What conditions are being screened for?............................ 212
  7.3.3 Category III: How will the results of prenatal screening be communicated? ................................................................................................................. 212
  7.3.4 Category IV: How will the results of the screening be interpreted?...... 213
<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.3.5</td>
<td>Category V: What are the options after receiving the screening results?</td>
<td>215</td>
</tr>
<tr>
<td>7.3.6</td>
<td>Category VI: What does it mean to live with a child with a condition or disability?</td>
<td>216</td>
</tr>
<tr>
<td>7.3.7</td>
<td>Category VII: How can an informed decision about participating in prenatal screening be made?</td>
<td>217</td>
</tr>
<tr>
<td>7.4</td>
<td>Discussion</td>
<td>218</td>
</tr>
<tr>
<td>7.5</td>
<td>Conclusion</td>
<td>220</td>
</tr>
<tr>
<td>7.6</td>
<td>References</td>
<td>221</td>
</tr>
<tr>
<td>8</td>
<td>Women's decision-making about participation in prenatal screening: Beyond the clinical encounter</td>
<td>232</td>
</tr>
<tr>
<td>8.1</td>
<td>Introduction</td>
<td>232</td>
</tr>
<tr>
<td>8.2</td>
<td>Existing Models of Medical Decision-Making</td>
<td>233</td>
</tr>
<tr>
<td>8.3</td>
<td>Methods</td>
<td>235</td>
</tr>
<tr>
<td>8.3.1</td>
<td>Study design</td>
<td>235</td>
</tr>
<tr>
<td>8.3.2</td>
<td>Recruitment</td>
<td>235</td>
</tr>
<tr>
<td>8.3.3</td>
<td>Eligibility</td>
<td>236</td>
</tr>
<tr>
<td>8.3.4</td>
<td>Data collection</td>
<td>237</td>
</tr>
<tr>
<td>8.3.5</td>
<td>Data analysis</td>
<td>237</td>
</tr>
<tr>
<td>8.4</td>
<td>Findings</td>
<td>237</td>
</tr>
<tr>
<td>8.4.1</td>
<td>Category 1: Receiving information about prenatal screening</td>
<td>239</td>
</tr>
<tr>
<td>8.4.2</td>
<td>Category 2: Seeking information about prenatal screening</td>
<td>242</td>
</tr>
<tr>
<td>8.4.3</td>
<td>Category 3: Working towards understanding prenatal screening</td>
<td>245</td>
</tr>
<tr>
<td>8.4.4</td>
<td>Category 4: Making a decision about prenatal screening</td>
<td>248</td>
</tr>
<tr>
<td>8.5</td>
<td>Discussion</td>
<td>253</td>
</tr>
<tr>
<td>8.5.1</td>
<td>Models of information seeking to inform health decision-making from information science</td>
<td>255</td>
</tr>
<tr>
<td>8.5.2</td>
<td>Discrepant cases: Avoiding information to manage uncertainty</td>
<td>257</td>
</tr>
<tr>
<td>8.6</td>
<td>Conclusion</td>
<td>259</td>
</tr>
</tbody>
</table>
8.7 References .......................................................................................................................... 260

9 Conclusion ........................................................................................................................... 272

9.1 Introduction .................................................................................................................. 272


9.3 My understanding of reflexivity. ................................................................................ 277

9.3.1 Engaging in reflexive thought to understand standpoint. .............................. 278

9.3.2 Engaging in reflexive thought to make explicit research decisions. ......... 280

9.4 Insights and Reflections on the Relationships Among the Manuscripts .......... 281

9.4.1 Informed decision-making. ................................................................................. 282

9.4.2 Discursive tensions in prenatal screening. ...................................................... 285

9.4.3 Discursive tensions and participation in narratives of medical discourse and everyday understanding: Illustration of broader critical themes..... 290

9.5 Quality criteria .......................................................................................................... 295

9.5.1 Quality criteria for interdisciplinary work. ...................................................... 296

9.5.2 Quality criteria for grounded theory work. ...................................................... 301

9.6 Contributions of this work ...................................................................................... 303

9.6.1 Implications for patient education materials. ................................................. 303

9.6.2 Implications for clinicians providing prenatal care. ...................................... 304

9.6.3 Implications for policy. ..................................................................................... 305

9.6.4 Implications for informed decision-making. ................................................. 306

9.7 Directions for future research. ............................................................................... 307

9.8 Strengths and Limitations ....................................................................................... 308

9.8.1 Communicating with different disciplinary audiences .................................. 308

9.8.2 Re-committing to a focused inquiry ................................................................. 309

9.8.3 Process vs. product ......................................................................................... 310

9.9 Conclusion .................................................................................................................. 310
9.10 References ........................................................................................................... 312
List of Tables

Table 1: Reasons why non-directive counseling may not be possible ........................................ 37

Table 2: Reasons why non-directive counseling may not be desirable .................................... 39

Table 3: Search strategy ........................................................................................................ 133

Table 4: Prenatal screening patient education pamphlets ..................................................... 166

Table 5: Search terms (each +Canada, +Ontario) ................................................................. 168

Table 6: Proposed hybrid model for informed and autonomous decision-making in prenatal screening ............................................................................................................................... 190

Table 7: Participant demographics ........................................................................................ 207

Table 8: Self-identified information requirements of women considering prenatal screening ............................................................................................................................................... 212

Table 9: Participant demographics ........................................................................................ 236

Table 10: Self-reported choices regarding participation in prenatal screening ................. 249
List of Figures

Figure 1: Eligible types of prenatal screening according to SOGC guideline ....................... 127

Figure 2: Optimal timing for screening and diagnostic tests ............................................. 137

Figure 3: Example of iterative evolution of coding ......................................................... 142

Figure 4: The process of decision-making about prenatal screening .................................. 238
List of Appendices

Appendix 1: Example of reflective memos for participant "Lucy" ........................................ 325
Appendix 2: Research ethics approval .................................................................................. 327
Appendix 3: Recruitment poster ........................................................................................... 328
Appendix 4: Interview guide ................................................................................................. 329
Appendix 5: Letter of information and consent ................................................................. 331
Appendix 6: Example of initial analytical diagram created for each participant .............. 335
Appendix 7: Publisher permission to republish Chapter 5 ................................................ 336
Appendix 8: Publisher permission to republish Chapter 6 ................................................ 337
Appendix 9: Curriculum Vitae .............................................................................................. 338
1 Introduction

This dissertation presents a grounded theory study of the process of prenatal screening, considering professional policy, public education materials, and the perspectives of women pregnant with their first child. In 2007, the Society of Obstetricians and Gynecologists of Canada (SOGC), in conjunction with the Canadian Council of Medical Geneticists (CCMG) released a clinical practice guideline instructing that all women should be offered non-invasive prenatal screening to detect fetal aneuploidy and incomplete neural tube closures (Summers, Langlois, Wyatt, & Wilson, 2007). This guideline was re-affirmed in 2011 (Chitayat, Langlois, & Wilson, 2011), with increased emphasis on the variety of conditions that can be detected through the first trimester ultrasound and blood work.

Prenatal screening, as will be explained in more detail in Chapter 2, is a non-invasive, non-diagnostic test performed by ultrasound measurements and a series of blood tests. The results of these tests are combined with the mother's age at the expected date of delivery to produce a probability that the fetus has a chromosomal anomaly or incomplete neural tube closure. The pregnant woman can then choose to have an additional invasive, diagnostic test, such as amniocentesis or chorionic villus sampling, to confirm the findings (Wilson et al., 2005). There are few in-utero treatments for the conditions detected; for most women, prenatal screening provides information to consider when choosing to continue or terminate the pregnancy.

The guiding question for this research is: From the perspective of women under the age of 35 in their first pregnancies, seeking prenatal care from a family physician, how is the process of choosing to participate in prenatal screening enacted in light of the new SOGC guidelines? This guiding question informed the data collection and analysis of data from three different sources: policies and guidelines, patient education materials, and pregnant women. The data from these three different sources were examined to respond to different elements of the process of choosing whether or not to participate in prenatal screening:
1) How do prenatal screening patient education materials portray concepts related to prenatal screening?
2) How do policies and guidelines shape the offer of prenatal screening?
3) How do women use information when making a decision about whether or not to participate in prenatal screening?

This dissertation reviews and analyzes the medical and social scientific literature on prenatal screening; investigates the ways in which it takes place in Canada by analyzing Canadian professional policy and patient information materials; gathers information from pregnant women who have been offered and made a decision about participation in this screening test; and composes an argument for changes that may increase the potential for women to make informed choices about participation in prenatal screening.

1.1 Interdisciplinary Bricolage

The process of prenatal screening is at the juncture of many disciplines, such that this dissertation is necessarily interdisciplinary, engaging with literature from medicine, genetic counseling, bioethics, women's studies, sociology, anthropology, library and information science, and disability studies. As this research has evolved, I have recognized that the most compelling aspects of the topic are at the intersection of multiple types of disciplinary knowledge: doctor-patient communication, reproductive rights, and social justice in terms of available choices and resources for women, families, and people with disabilities.

In this interdisciplinary endeavour, I have taken the approach of a researcher as bricoleur (Levi-Strauss, 1962), a term which has no exact translation in English, but which Claude Levi-Strauss describes as a person who works with a heterogeneous repertoire, using whatever she has at her disposal (Levi-Strauss, 1962). The bricoleur does not have a set repertoire of tools and materials to use for every job, but uses whatever is available to complete the task, collecting and making use of an enlarging stock of tools which is the "contingent result of all the occasions there have been to renew or enrich the stock or to maintain it with the remains of previous constructions or deconstructions" (Levi-Strauss, 1962, p. 11). In this quotation I see acknowledgement that bricolage approaches are a
those which fit, work, illuminate, and aid, regardless of disciplinary affiliation and b) often a result of techniques, ideas, and approaches that have fit, worked, illuminated and aided in the past. With that said, coherency between approaches is important; while hammers and screws are both tools with a myriad of effective uses, applying a hammer to a screw will have poor results.

With bricolage, I attempt to fashion a theoretical and methodological approach through which multiple perspectives are used, shaped by the topic of inquiry and internal congruence rather than disciplinary knowledges or expectations. This approach recognizes the socially constructed nature of knowledge and the tendency of objectivism to "avoid contextual specificities that subvert the stability of its [objectivist] structures, its fragmenting impulse that moves it to fold its methodologies and the knowledge they produce neatly into disciplinary drawers" (Kincheloe, 2001, p. 681). The metaphor of the researcher as bricoleur also acknowledges the iterative nature of qualitative research; choices of analytical practices are not always made in advance, but are made in response to the evolving context and questions of the research (Denzin & Lincoln, 2000). This iterative strategy is encouraged in grounded theory as a way of being responsive to the evolving nature of qualitative inquiry (Charmaz, 2006).

The evolving, iterative approach of research as bricolage requires a new form of rigor that accounts for a new ontological context, where the object of inquiry is inseparable from its socio-cultural and historically situated context (Kincheloe, 2001). In Chapter 9, I propose guidelines for quality criteria to assess the rigor of this interdisciplinary work, drawing on a shift in the humanities and social sciences to standards of reflexivity, situation/standpoint, and means of production and re-presentation (Hodge, 1995). Emerging work on quality criteria for interdisciplinary research concerns an emphasis on contributions to different knowledge domains, coherent theoretical perspectives and effective communication (Manathunga, Lant, & Mellick, 2006; Mitchell & Willetts, 2009; Mitrany & Stokols, 2005; Wickson, Carew, & Russell, 2006).
1.2 Situated Research

The knowledge I have produced in this dissertation sits at the junction of several situated standpoints: mine, yours, and the research participants’. My standpoint has been influenced not just by my experiences and situation, but also by supervisory committee collaborators and the literature. Dorothy Smith (Smith, 1987; Smith, 1990) describes standpoint as the way we each make knowledge that draws upon our individual experiences and subjectivity. For Smith (1987), it is important to begin research inquiry from a standpoint rooted in every day experiences with recognition that one's own particular subjectivity is located in a constantly shifting matrix of social locations (Hesse-Biber, 2007). It’s not only important to recognize the impact of the standpoint of the researcher; in Chapter 9 I explore the possibilities for understanding the standpoint of the research participants and as you are reading, I ask you to consider your own standpoint. The meaning of the text you hold in your hands is not mine, but remains to be completed by you, from your particularly situated perspective (Smith, 1987). Smith (1983) states that readers make sense of texts in a social way, using the interpretive schemas they have learned as individual members located in particular positions of particular societies. In Chapter 9 I discuss some of the reflexive decisions that I made while working on this research to assist you to travel between my perspective, the perspectives of the participants, and your own perspective (Koch & Harrington, 1998).

1.2.1 Standpoint of the researcher.

It is common for qualitative research dissertations to include a short sketch of the author, so that readers may understand the particular standpoint or situated location of the person who created that work. I will describe my social standpoint and then briefly outline the major way in which my intellectual standpoint has changed throughout this research, a conversation that will be continued in Chapter 9.

My social standpoint is one of privilege. I am young, white, able-bodied, educated and wealthy. I am married to a man who supports my intellectual and other endeavours both financially and emotionally. I have not yet been pregnant, although I plan to be a mother...
one day. I have not grown up in close contact with someone who has a disability, but I have known people with disabilities as friends and classmates.

My intellectual standpoint cannot be named so easily. I have an undergraduate degree in Philosophy and Health Studies. I have always liked to read and talk, to argue and debate. I chose not to become a lawyer because I hated the idea of precedent- that the decision in one case should be applied to other cases if they could be argued to be sufficiently similar. I have always been interested in the idea of exceptions, and grey areas. I entered the M.Sc program at Western looking to do a medical ethics project about a topic related to reproduction. I decided at that time that I should pick a topic that I was interested in, but about which I had no strong personal viewpoint, so that I could think of it from different angles, and look at different perspectives. I didn't realize it at that time, but I see now that topics which have a personal meaning forced me out of the comfort of the grey area and made "intellectualizing" difficult. I think this is why I chose to study prenatal screening- it was at the juncture of many topics I find interesting, but I don't have a personal experience or connection that keeps me in one corner. It's less challenging for me to be open minded about different perspectives than it might be if I had a disability, a religious affiliation, or the experience of being pregnant. My challenge has become to recognize the ways in which this is a personal topic, and to see how my past experiences and situation make me gravitate to particular ideas or points of view.

In the endeavour to identify the ways in which my personal standpoint has shaped and changed the questions I ask, the data I collect, and the claims I make, I am attempting to engage in a process of scholarship with 'strong objectivity' (Harding, 1987). Strong objectivity describes a socially situated view of the researcher, research participants and the research process that examines the data created and claims made at the junction of these perspectives. "The notion of strong objectivity conceptualizes the value of putting the subject or agent of knowledge in the same critical, causal plane as the object of her or his inquiry" (Harding, 1986, p. 161). When considering the extent to which I engaged in reflexive examination of my standpoint and positioning, it is important to consider the limitations of the structure of the integrated article style. Each article was written within the genre and word limit of a particular journal, with a specific audience in mind. In most
cases, it was not possible to expound upon the ways in which I tried to work reflexively throughout the research process. In Chapter 9 I address these ideas more fully, drawing together the choices made necessary by the integrated article style and outlining some of the considerations of standpoint and perspective in which I engaged, but which were not included in the published manuscripts.

A final note about my motivation throughout this project: when I explain my thesis topic to non-academics, I am often asked the same question: "So..... are you for or against prenatal screening?" I think academic contacts are interested in this question, too, but tend to ask it in a more subtle way. The short answer is that I am neither for nor against prenatal screening and abortion, nor is taking a stance on that question the aim of my research. Professionally, I think that any choice a woman decides to make is the right choice, as long as it is informed to a degree she judges sufficient. I am interested in doing this research to examine and develop ways in which informed choices can be supported. Prenatal screening is an important opportunity for some women. For some, it's a source of anxiety. Prenatal screening may be an essential part of the choice to become a parent for some women while for others, it's unnecessary and may even be offensive. My interest in this project is to try and help women obtain the information they need to make their own decision about the screening tests.

In the interest of transparency to the reader and reflexive awareness of myself, I have thought about what I might choose when offered prenatal screening. I would probably choose to participate in the tests, since I consider myself, in the words of one participant, "the type of person who likes to know as much as possible". Knowing what I do now, I would request my first trimester results when available, so that if a high risk result was returned, I could access earlier diagnostic testing (chorionic villus sampling). I'm not sure what I would do with a definitive positive finding. Thinking reflexively, I recognize my reluctance to include this information in my dissertation, but I think it is important for the reader to understand the way I approach the research. My decision whether or not to terminate an affected pregnancy would depend on many factors, including what condition was found, how I felt at the time about pregnancy, motherhood, social and financial resources, my career, and my partner's feelings about the same. I think it's hard to know
what you would do in a difficult situation before you are faced with that choice, and have access to all the information available to you at that time. This difficulty in forecasting decisions was illustrated in my interview data. I asked each research participant what options she would be considering if she received a high risk result from the screening test. Some women stated they would consider invasive, diagnostic testing, some women stated that they wouldn't consider this testing. Only two of the sixteen women told me that they would consider abortion for Down syndrome, a percentage which is very different from epidemiological statistics, which show that about 90% of pregnancies with confirmed cases of Down syndrome will be terminated (Biggio, Morris, Owen, & Stringer, 2004; Gekas et al., 2009; Joan & Alberman, 2009; Korenromp, Page-Christiaens, van, Mulder, & Visser, 2007). Considering the discrepancy between these figures emphasizes the importance of participant standpoint: did the volunteer participants have particular views on the topic that made them more likely to volunteer? How did the social situation, experiences and resources of the volunteer participants differ from the epidemiological research populations? Were research participants less likely to express their intention to terminate in the event of a condition? Is it harder to predict how you might make a difficult choice before you are in that situation?

1.3 Story of the Research

The germ of this research idea started in September 2006, the last year of my undergraduate degree, during a class on qualitative research methods. For the final project of this class, we created a research project and completed a literature review, chose a methodology, and outlined a study design. I chose prenatal screening for this project, and developed a research project that is (rightfully) quite different from the one contained in this thesis. As I look back to my initial literature review, I am struck by some of the enduring issues of interest. In my first "statement of the problem", written in October 2006, I wrote: "what is lacking, however, is literature on best practices for introducing and explaining prenatal screening". I problematized the consequences of this gap in a much different way than I do now, but my enduring interest has been in the ways the presentation of prenatal screening shapes and constrains the choices available to women.
I enrolled in the M.Sc program at Western in September 2007, and developed a proposal for a project that involved audio-taping prenatal visits and analyzing the ways prenatal screening was discussed. I was interested in the context and structure of information provided, assessment of comprehension, and indicators of directiveness towards a particular course of action. During my first year of graduate studies, I started to become interested in metaphors and figurative language and the impact that words have on directiveness. I also started reading about different types of genetic testing throughout the life span and was thinking critically about the ways in which prenatal screening is different from preconception genetic screening, newborn genetic screening and pediatric and adult genetic screening. These developed into two separate projects which I presented for various audiences including medical students at Western, the Western Graduate Research Forum, the Society of Obstetricians and Gynecologists of Canada annual clinical meeting, and the University of Western Ontario's Department of Obstetrics and Gynecology annual research day.

When meeting with my supervisors about my M.Sc proposal in the summer of 2008, we discussed the challenge that the research I was proposing was too large for the scope of an M.Sc degree, and was really quite related to my side projects about metaphors and genetic testing policy. The three of us made the decision to re-work the project to include some of the ideas I found the most compelling from the other projects and to complete it as a PhD project. I enrolled in the PhD program in September 2008.

As I re-worked the thesis proposal and thought about what was most interesting and most compelling from the other projects, I realized (or perhaps re-realized, looking back at my 2006 statement of the problem) that I was most interested in the issue of informed choice. I structured the project as an examination of the process of prenatal screening, to examine the ways that patient information materials and policy guidelines relate to the ways in which prenatal screening was presented to women. I decided at this point that instead of audio-taping the first prenatal visit between family doctors and pregnant women, I would talk to pregnant women directly. I was interested in more than what was said inside the doctor's office, including the ways that women might inform themselves and work towards making a choice by engaging with other material, or talking with their
partners, friends, and families. I also realized that I wasn't really interested in what the doctors *said* so much as in what the women *heard*—what they understood and remembered—and how they contextualized this information with that from other sources.

I continued to refine the research project while I wrote my comprehensive papers and created and defended a new proposal. I started to re-read the policy documents and patient education materials with a new eye for their influence on informed-decision making. The patient education materials were rich with metaphor and figurative language, inspiring a "struck by" moment (Cunliffe, 1999; Cunliffe, 2002) about the relation between this language and non-directiveness, an idea which informed the first manuscript. The sensation of being "struck by" something may inspire us to re-think or re-consider previous ideas, or open us up to new ideas. Through this, we may "be making new connections between tacit knowing and explicit knowledge" (Cunliffe, 1999, p. 9). This realization, described further in the first manuscript, re-directed my thinking about the process of prenatal screening to focus explicitly on the idea of informed decision-making and informed choice. This refinement in the direction of inquiry changed the focus of my interview guide and probes, shaping the data I collected. After interviewing the first few participants about their experiences, what I identified as most interesting in the policy documents started to shift. Instead of comparing prenatal screening policy to other genetic policy, I thought about the particular context of prenatal screening and the counseling requirements mentioned as necessary in the SOGC guideline. I started writing the second manuscript after collecting most of the participant data, during the process of analysis. Manuscript number two does not contain any participant quotes, but was formed directly in response to what participants were telling me about the conversations they had with the doctors and those which they had with their friends. Manuscript three was written at approximately the same time, and attempted to respond to the articulations of what information was important to consider when making a decision about whether or not to participate in prenatal screening. Manuscript four was the last paper written, a grounded theory of the interview data about the process of decision-making about participation in prenatal screening, including discussion of the ways women worked with information received from their doctors and other sources, sought out additional
information, and then worked on interpreting that information to come to an understanding about the screening test in order to make a decision.

In the summer of 2011, I was working on the second manuscript, a critique of the idea of non-directive counseling, an approach described as an imperative for the presentation of prenatal screening by the SOGC policy. This manuscript was written for submission to the *Journal of Obstetrics and Gynecology Canada*. The day after we submitted the manuscript, the next issue of JOGC was released, with a new prenatal screening policy (Chitayat et al, 2011). We revoked the submission so that it wouldn't go out to reviewers while we were reading the new policy. Fortunately or unfortunately, the instructions for counseling in the 2011 policy were identical to those in the 2007 policy, and so we re-submitted the manuscript without changes. Interestingly, there weren't many changes between the 2007 and 2011 policies. Chitayat et al (2011) specified that the information concerned singleton pregnancy and gave more information for physicians choosing different types of prenatal screening tests, specifications that the ultrasound should be performed by sonographers with specific training, a list of patient factors which may potentially affect screening performance, and information on additional conditions that prenatal screening can detect. In my reading of the two policies, the reason for the updated guideline seems to be the provision of practical advice for primary care physicians offering screening tests. Unfortunately, neither guideline offers practical advice on *how* to offer the screening tests.

### 1.4 Definitions of Terms

Related to the interdisciplinary and sensitive nature of the topic, there are controversies and inconsistencies around several of the key terms that I will use. In an acknowledgement that discourse and word choices can shape and construct the way we think about the world (Foucault, 1972; Lakoff & Johnson, 1980), I have made several particular choices about the language I use to describe my research topic and participants:

- To reflect my feminist theoretical perspective and in acknowledgement of the literature about the medicalization and institutionalization of birth, I refer to
pregnant women or women rather than patients in an effort to avoid historical and emotional overtones of illness (Herxheimer & Goodare, 1999).

- **Informed consent** is a legal term, and refers to an educated acquiescence to the suggestion or recommendation of a health care professional. Prenatal screening should not happen through a process of informed consent, but rather through one of informed choice or informed decision-making (Sherwin, 1998). I alternate between informed decision-making and informed choice, using the former to refer to the process and the later to refer to the product of that process in an effort to be consistent with the literature with which I am engaging.

- Dixon-Woods (2001) discusses the difference between patient information materials and patient education materials, reasoning that the former aims to provide information and the latter aims to indoctrinate to a particular way of understanding (Dixon-Woods, 2001). In this dissertation I have chosen to refer to the written materials on prenatal screening as patient education materials, reflecting the way they are commonly known and the discursive purpose that many serve. In my analysis of these materials I have found some which provide information I judged as carefully considered, balanced, and expressed in neutral language. These pamphlets might more accurately be termed information materials, but as a genre, I believe this material reflects the patient education definition suggested by Dixon-Woods (2001). Also, while I don't use the word patient to describe pregnant women, I retain that word to describe the educational materials, to nod to the embedded assumptions informing most of the examples of this genre.

- Consistent with person-first discourse advocated by disabilities scholars and advocated by the American Psychological Association (American Psychological Association, 2010), I refer to person with a disability rather than disabled person; person without a disability, and typical or average rather than normal or healthy.

- Along this same line of thinking, when making reference to the conditions detected by the prenatal screening test, I choose to use the words of condition,
aneuploidy, anomaly, incomplete neural tube closure, or the specific name of the condition rather than potentially alienating terms such as disorder, disease, birth defect, abnormality or neural tube defect (Grant & Flint, 2007; Hodgson, Hughes, & Lambert, 2005). Aneuploidy is a term which refers to the possession of an unusual number of chromosomes and is often used to refer to trisomy conditions (ex. Down syndrome) detected by prenatal screening. Trisomy conditions manifest when three chromosomes exist (triploid) where two are typical (diploid).

- I use risk to refer to the genre of risk status (i.e. low risk result), but am aware of the negative overtones this word may have (Hodgson, Hughes & Lambert, 2005). I use chance and probability when referring to the likelihood that a pregnant woman may be carrying a fetus with aneuploidy (e.g. a 20 year old woman has a 1 in 1600 chance of carrying a fetus with a chromosomal anomaly. Based on her age, she is likely to receive a low risk result from prenatal screening).

- The terminology used to describe the "product" of a pregnancy is particularly difficult and a very personal matter for pregnant women. During interviews, I adopted the terminology that the participant used, sometimes fetus or baby or pregnancy. In my written work, I use fetus or embryo before birth, depending on the stage of pregnancy, although the distinction between the two is arbitrary (Nisker, Baylis, Karpin, McLeod & Mykitiuk, 2010). Following the dictionary definition and to reflect my belief that personhood begins at birth, I use baby, infant and child only after the child is born. I use pregnancy to describe the process, and fetus to describe the creation of that process.

- Terms for abortion are often misused, sometimes for intentional effect (Grimes & Stuart, 2010). For instance, pregnancy termination, commonly used in medical literature, may be ambiguous- all pregnancies terminate, but not all abort (Grimes & Stuart, 2010). I alternate between termination and abortion depending on the disciplinary audience. I do not use the term therapeutic abortion, since all abortions can be therapeutic, for instance, therapeutic for the mother's mental health and wellbeing. I do not use elective
or genetic as an adjective for abortion to avoid inferring a moral hierarchy of types of abortion.

1.5 The Study of Prenatal Screening as Conceptualized in this Dissertation

In Chapter 2, I review the basic medical and social scientific concepts that inform my understanding of prenatal screening. In Chapter 3, I detail the particular way in which I understand prenatal screening to fit in a broader context of medicalization of pregnancy, risk, normalization, united by Foucault's notion of governmentality. I then let these threads lie loose while I respond directly to the data and the literature suggested by my research findings, engaging with ideas of information-seeking practices, informed decision-making, and non-directiveness. In Chapter 9, I pick up the literature that has been left to lie fallow from the literature review (Charmaz, 2006) and conclude by weaving together these different threads.

1.6 Methodology

Constructivist Grounded Theory (Charmaz, 2006) is the methodology used for this study, due to its: congruence with a constructionist epistemology (which I discuss at length in Chapter 3); flexibility and range of acceptable methods (Charmaz, 2006); recognition of the importance of language (Charmaz, 2005); inductive approach to examining the data without imposing particular theories (Charmaz, 2006); and congruence with an interdisciplinary approach.

As necessitated by my doctoral program and institutional research ethics requirements, I began the study with a literature review (Chapter 2), through which I identified particular areas of analytical sensitivity. When designing the study, I was aware of my interest in exploring issues of language, directive counseling, social justice, and disability. While the initial literature review was necessary for pragmatic reasons, and informed the study design, it was put aside, as per Charmaz's (2006) recommendations. As data collection and analysis simultaneously evolved, new areas of theoretical interest were identified and
explored, including information-seeking and informed choice. After data collection and analysis was completed, further literature was reviewed in response to categories identified through data collection, demonstrating a refinement of the topic, from a consideration of the broad "process" of prenatal screening to a focused examination of informed decision-making in prenatal screening. Each piece of data (patient education pamphlets, policy documents, women's perspectives) was collected and considered separately, and as part of a whole. Each manuscript speaks to one piece of data collection, but is informed by the previous data, literature, and insights that came before. Chapter 9 details insights from the inter-connection of these pieces.

1.7 Plan of Presentation

In Chapter 1, I set the stage for the research by discussing my philosophy of interdisciplinary scholarship, situating myself as a researcher, outlining the story of how this research came to take the shape it has taken, clarifying terms, and introducing methodological and theoretical choices, which will be elaborated on in chapters 4 and 9.

Chapter 2 situates the context and background of the study in an interdisciplinary collection of literature on the topic. Chapter 2 also gives some explanation of the medical and scientific aspects of prenatal screening for readers who are not familiar with the test. Emergent tensions and key issues informing the shape and importance of the study will be discussed prior to an introduction of the purpose and questions of this research.

Chapter 3 discusses the philosophical foundations of the particular iteration of constructionism I have used throughout this work. Chapter 3 also reviews the feminist bioethics and medicalization literature, which inform my theoretical framework.

Chapter 4 gives a methodological grounding of the study, including an explanation of the ways in which Constructivist Grounded Theory is congruent with a constructionist approach. Chapter 4 also includes an outline of the study design and methods and concludes with an explanation of some of the methodological decisions I made throughout the process.
Chapter 5 is my first manuscript, "Critical reflection and prenatal screening public education materials: a metaphoric textual analysis", published in 2010 in the journal Reflective Practice. This manuscript includes data from a textual analysis of Canadian prenatal screening patient education materials and engages with the idea of non-directive counseling from the SOGC guideline, querying whether or not existing written material support this counseling directive through critical reflection on the metaphors and figurative language used. The findings conclude that written material on prenatal screening is rife with directive elements encouraging women to participate in screening tests for the purpose of detecting and terminating affected pregnancies.

Chapter 6 is the policy manuscript, "Information sharing to promote informed choice in prenatal screening in the spirit of the SOGC clinical practice guideline: a proposal for an alternative model", published in March 2012 in the Journal of Obstetrics and Gynecology Canada. Chapter 6, like Chapter 5, addresses the idea of non-directive counseling in the SOGC guideline, reviewing the literature critiquing this approach and offering an alternative way of counseling, based on a particular combination of Shared Decision-Making and Informative Decision-Making. This article concludes that while the aims of non-directive counseling (autonomous informed decisions) are admirable, the method is problematic, and may be neither a desirable nor possible way of counseling. The article proposes a particular way of approaching Shared Decision-Making that supports a shared information and deliberation process culminating in the woman making her own decision, without recommendation or suggestion from the health care provider.

Chapter 7 is entitled "Pregnant women's self-identified information requirements when deciding to participate in non-invasive prenatal screening" and is currently under review at the journal Health Expectations. Drawing on data from participant interviews, this manuscript draws on women's discussions of what information they found important for making their decisions about participating, including information they came across after making their decision, but wished they had known earlier. The findings are structured in a way that may be of use to clinicians offering the prenatal screening test, as seven topics that could be used to guide a conversation. This manuscript draws a distinction between information about the test and information to make a decision about participation, a
distinction made by women but usually absent from the literature. This manuscript acknowledges the time commitment required by clinicians to provide thorough information about prenatal screening and discusses alternative ways of providing this information after the initial consultation.

Chapter 8, "Women's decision-making about participation in prenatal screening: Beyond the clinical encounter", is the synthesis of the participant information in an over-arching grounded theory. This manuscript inductively generates a model of the ways in which pregnant women seek and receive information, how they work with that information, and how this process informs decision-making. The findings contrast three different types of theories on this topic: a) the grounded theory developed from my thesis data, b) consumerist and shared theories of decision-making in health care, c) theories of information seeking practices for decision-making in the library and information sciences literature. The health care literature tends to assume a more linear process of knowledge acquisition for decision-making which places the health care provider as a central figure in the process. My iterative theory is closer to theories found within library and information sciences literature, which tend to take a non-linear view of the ways in which people seek, receive, and use information in everyday life.

Chapter 9 discusses my understanding of reflexivity and reflexive research, offers emerging insights and reflections on the relations between these four manuscripts and the research process as a whole. I propose quality criteria drawn from literature on interdisciplinary scholarship and constructivist grounded theory as a guideline for assessing the quality of this work. Finally, I address the contributions of this work and implications for prenatal screening patient education materials, policy, and counseling.

1.8 Conclusion

Prenatal screening is a process which is at the juncture of issues of interest to many disciplines, and as such, requires an interdisciplinary approach. Drawing on literature, theories, and methodologies from several disciplines, I construct a bricolage approach to this study, aiming for internal congruency rather than disciplinary consistency (Kincheloe, 2001). The shape and focus of this research has been continually refined
throughout the process, to reflect an iterative inductive approach where initial data collection and analysis provide insights to further structure the process (Charmaz, 2006). The story of this research is one of examining the process of making an informed decision about prenatal screening; the contribution is generative insights into barriers and facilitators of this process, with suggestions for how it might be improved.
1.9 References


2 Literature Review

In this chapter, I first define and explain common terms and concepts that surround the topic of prenatal screening. Second, I summarize key aspects of the 2007 SOGC Clinical Practice Guidelines, which inspired my interest in this area of research and discuss the differences between this guideline and the new 2011 guideline. Third, I examine some of the philosophical values that inform discussions of prenatal screening such as notions of risk, non-directiveness, and autonomy. Fourth, I survey the literature concerning the effect of prenatal screening on the disabled community. Fifth, I discuss the existing literature on prenatal screening by examining the work of key scholars in the field.

2.1 Background Terms and Concepts

2.1.1 Types of prenatal and diagnostic screening.

First, it is important to note that in many popular works and media publications the terms prenatal screening, prenatal testing, prenatal genetic diagnosis, and prenatal diagnostic screening are conflated. There are important distinctions among these terms: a screening program is not diagnostic, or even technological. For example, one of the most common forms of screening is maternal age, as obstetric and perinatal risks increase with maternal age (Johnson & Tough, 2012). As with other types of screening, in this example a particular criterion is used to identify individuals who may face higher levels of risk than the average person; this criterion is not sufficient to identify whether or not these individuals are actually at risk, only that they are more likely to be at risk than others who do not share this characteristic. Prenatal screening looks at a number of different markers (biochemical markers in the mother's blood, physiological markers visible in an ultrasound) to suggest whether or not the fetus is at higher risk for fetal aneuploidy or incomplete neural tube closures. Testing and Diagnosis are terms with connotations of a definitive result and are correctly used to refer to diagnostic testing such as amniocentesis or chorionic villus sampling. This study concerns the non-diagnostic prenatal screening presented during the first prenatal visit; the terms prenatal testing or prenatal diagnosis will be used to refer only to diagnostic prenatal tests. A high risk result after a screen will, in most cases, result in the offer of diagnostic testing.
There are many types of prenatal screening and an explanation of the procedural, historical, and medical information surrounding them is beyond the scope of this paper. The most commonly used and studied procedures are as follows:

**Integrated Pregnancy Screening:** Integrated Pregnancy Screening (IPS) is one type of non-invasive screening referred to by the SOGC guideline. IPS combines an ultrasound with two different blood tests. The ultrasound and first blood test (first trimester screen) take place between 11 and 14 weeks gestation. The second blood test (maternal serum screen) is done between 15 and 18 weeks gestation (Goel et al, 1998). For details about ultrasound and maternal serum screening, please see the sections below. The first trimester screen measures Pregnancy-Associated Plasma Protein A (PAPP-A) and free beta Human Chorionic Gonadotrophin (hCG) which can indicate a risk status for aneuploidy and incomplete neural tube closures. Unusual levels of this pregnancy related protein (PAPP-A) and hormone (β-hCG) can indicate (but do not always mean) a higher likelihood of aneuploidy (Breathnach & Malone, 2007). IPS has a sensitivity rate of about 85% with a false positive rate of 2% (Malone et al., 2005).

**Serum Screening:** Maternal serum screening (MSS) is a three part analysis of women’s blood performed at 15-18 weeks gestation (Goel, Glazier, Zummers, & Holzapfel, 1998). Maternal serum screening used to be the norm for prenatal screening in Ontario (Carroll & Reid, 1997), and as such is the type of screening addressed in many social scientific studies. MSS no longer meets the minimum standard for detection rate and false positive rate (Summers, Langlois, Wyatt, & Wilson, 2007). Serum IPS is a blood-work only type of screening which meets the minimum standards suggested by Summers and colleagues (2007). Serum IPS includes a first trimester PAPP-A test as well as a second trimester test of the panel of biochemicals included in the Quad Screen. The quadruple screen is a second trimester blood test which includes the original three biochemicals from MSS: Human Chorionic Gonadotrophin (hCG), Alpha fetoprotein (AFP) and Estriol (E3) and adds one additional biochemical marker, inhibin-A (Chitayat, Langlois, & Wilson, 2011). The quadruple screen takes place in the second trimester, and so may be the only prenatal screening option available for women who are late seeking prenatal care.
Ultrasound: Ultrasound, or ultrasonography, is a medical imaging technology which uses high frequency sound waves and echoes to create an image of the fetus. Sonographic "markers" visible on the ultrasound may detect physical characteristics such as nuchal translucency, which may suggest the presence of conditions such as Down Syndrome (Unterscheider & Malone, 2011). Ultrasound technology is one of the most common tools for prenatal screening because it can detect markers early in pregnancy (Unterscheider & Malone 2011) and is generally accepted to be safe, although some authors disagree (Gudex, Nielsen, & Madsen, 2006). Ultrasound for nuchal translucency is included in several types of prenatal screening approved by the 2007 SOGC Guideline (Summers et al, 2007), although there are endorsed methods of prenatal screening (Quad Screen, Serum IPS) that do not include ultrasound.

Amniocentesis: Amniocentesis is the most commonly used form of prenatal diagnosis for chromosomal and single gene disorders (Wilson, Langlois, Johnson, & Society of Obstetricians and Gynaecologists of Canada, 2007). Amniocentesis involves the extraction of amniotic fluid (which surrounds the fetus) with a needle. Current techniques allow the use of ultrasound imaging to accurately guide the needle, thus reducing negative effects of the procedure (Seeds, 2004). Amniocentesis enables the culture of fetal cells contained in the amniotic fluid to perform genetic analysis (including chromosome karyotyping) (Borrell et al., 1999). Amniocentesis was first used in the 1950s to determine the sex of the fetus so that sex-linked genetic conditions could be detected (Rothschild, 2005). The risk of fetal loss after amniocentesis is not agreed upon (see the “Physical Risk” section below), but the procedure is generally performed only to verify the results of a less invasive test when an anomaly is detected. Amniocentesis can be performed prior to 15 weeks gestation (early amniocentesis) but is more commonly performed between 15 and 20 weeks gestation (mid trimester amniocentesis) (Seeds, 2004).

Chorionic Villus Sampling: CVS is the only accepted method for first trimester diagnosis (Brambati & Tului, 2005). Evidence shows it may be as safe and as reliable as amniocentesis (Borrell et al, 1999). CVS can be performed two ways; a needle can be
inserted into the placenta through the maternal abdomen (known as transabdominal CVS) or a catheter or biopsy forceps can be inserted through the cervical canal (known as transcervical CVS) (Brambati & Tului, 2005). CVS can be done at 7-12 weeks gestation, compared to more than 15 weeks gestation for amniocentesis. CVS can detect most conditions that amniocentesis can detect. It is appropriate for DNA analysis and has the advantage over amniocentesis of quicker test results and efficacy at an earlier gestational age. It is considered to be reasonably safe, although there are risks of fetal loss, and low risks of bleeding and amniotic fluid aspiration (Brambati & Tului, 2005).

Transabdominal CVS is considered safer than transcervical CVS because the needle does not pierce the membrane therefore the antibacterial barrier properties of the maternal tissues remain intact (Brambati & Tului, 2005). In the mid 1990’s there were reports of a few clusters of children born with limb anomalies after CVS (Kuliev et al., 1992) however, later research reported that the rates of limb anomalies were similar to the general population and that the clusters may have been coincidental (Brambati & Tului 2005; Philip et al., 2004).

2.1.2 Risk status.

It should be noted that some authors find the word risk to be value laden (Grant & Flint, 2007; J. Hodgson, Hughes, & Lambert, 2005; Skotko, 2005; Skotko, 2006). They suggest a term such as “chance” would be more congruent with a non-directive approach. For a more theoretical discussion of risk, please see section 2.6, "Re-examining Risk".

Prenatal screening is not diagnostic, but rather gives the patient an idea of her risk status of having a child with an anomaly. Furthermore, as prenatal screening is only targeted towards certain anomalies, it is possible that a woman could receive a low risk result, but still have a child with an anomaly (Fanos, Spangner, & Musci, 2006). The opposite of this can also occur- a woman can receive a high risk result that is found to be a false positive on amniocentesis or after birth (Fanos, Spangner & Musci, 2006). Risks are provided statistically (i.e. 1 in 200, 1 in 37), with the high/low/medium risk lines drawn idiosyncratically. Patients and physicians might not agree on what constitutes a high or low risk.
Rayna Rapp (1999) conducted a 9 year ethnographic study of genetic counselors and their patients. She concluded that risk status is a significant stress to pregnant women and that many do not initially understand that prenatal screening tests will not provide a definitive answer (Rapp, 1999). This theme is echoed throughout both the social science and medical literature (Carroll, Brown, Reid, & Pugh, 2001; Heyman et al., 2006; Kleinveld, Timmermans, de Smit, & Ader, 2006). Rapp also includes an interesting discussion of how risk status interpretation varies across ethnic and socioeconomic lines:

How do we convey a chromosome risk when a low income pregnant Afro-Puerto Rican woman experiences a 100 percent chance of running out of food stamps this month, a 25 percent risk of having one son or brother die in street violence, and an 80 percent chance of getting evicted by the end of the year? A one-in-180 chance of having a child with a chromosome abnormality at age 35 is probably the best odds she’s facing. (New York genetic counselor in Rapp, 1999, p.69)

2.1.3 Physical risk.

Prenatal screening tests have low physical risk, although diagnostic prenatal tests, such as amniocentesis or CVS, do carry physical risks (Farrell et al., 1999). As discussed earlier, amniocentesis carries a risk of miscarriage, as well as the rare risk of malformation (Farrell et al, 1999), and so is only performed when other, less invasive procedures indicate that there is a higher risk of anomaly. It is difficult to establish an exact rate of miscarriage for amniocentesis. The commonly accepted rate by SOGC is 0.6-1% or (Wilson et al., 2007) but a recent, and much criticized, study (Kuehn, 2006) suggests that the rate is actually closer to 0.06% or 1 in 1600 (Eddleman et al., 2006). The rate has also been reported as high as 1.53% (Wilson et al, 2007). It should be noted that even procedures seen as low risk (for example, ultrasound) are not proven safe (Gudex et al, 2006) and may require additional testing to determine whether or not there are long term effects.

2.1.4 Social-psychological risk.

The social and psychological risks of prenatal screening are often overlooked in the medical literature. Some authors contend these risks are also often neglected in
discussions of prenatal screening between physicians and patients (Browner, Preloran, Casado, Bass, & Walker, 2003; Marteau et al., 1992; Pilnick, Fraser, & James, 2004; Pilnick, 2004; Press & Browner, 1995; Press & Browner, 1997; Smith, Slack, Shaw, & Marteau, 1994; Smith, Shaw, & Marteau, 1994).

Social and psychological risks are the greatest risks that many pregnant women and couples face during prenatal screening and are the concern of many excellent social scientific and bioethical works (Franklin & Ragone, 1998; Gastmans, 2002; Rapp, 1999; Rothenberg & Thomson, 1994; Rothschild, 2005). There are several authors who have dedicated much of their careers towards exploring these issues (see all listed sources: Abby Lippman, Carole H. Browner, Nancy Press, Rayna Rapp, Barbara Katz Rothman) and there have been many national and international conferences convened to work on these issues. Issues commonly addressed in this literature include the emotional strife of selective termination, aborting a much wanted but potentially anomalous fetus, anxiety around testing, carrying an “abnormal” fetus, struggling with issues of abortion, not being able to acknowledge a pregnancy until the fetus is “confirmed healthy”, worrying about the impact of a disabled child on other children, a marriage, mental resources, and finances.

2.2 The 2007 SOGC Clinical Practice Guideline on Screening for Fetal Aneuploidies: Implications for prenatal care

Prior to the 2007 clinical practice guideline, Canadian women were offered prenatal screening based on advanced age or family history, although some provinces had screening programs offered to a wider population of pregnant women (Carroll & Reid, 1997). The definition of advanced maternal age has changed as scientific knowledge and the field of biostatistics has progressed, but in Canada it is generally considered to be 35 years (Johnson & Tough, 2012). Rothschild (2005) notes that 35 years is a generally accepted marker of advanced maternal age in many countries, but it is an arbitrary threshold based more on economics than medicine. It is also often cited that 35 years of age is the threshold because at that age the physical risks of amniocentesis are equal to the risk of receiving a test result positive for anomalies (Wilson et al, 2007). The new
SOGC guidelines are, in effect, recognizing the arbitrary nature of screening after age 35. After all, although older women have a much higher probability of bearing a child with Down Syndrome (for example), most children with Down Syndrome are born to women below 35, due to the higher numbers of women under 35 having children (Rapp, 1999). The 2007 SOGC guidelines state that all pregnant women, regardless of age, must be offered non-invasive screening for “the most common clinically significant fetal aneuploidies in addition to a second trimester ultrasound for dating, growth, and anomalies” (Summers et al 2007, p. 149).

There are several implications to the SOGC guideline: first of all, it implies that all pregnancies have the potential to be high risk pregnancies. Secondly, it forces consequences of testing such as iatrogenic anxiety or the experience of a “tentative pregnancy” (Rothman, 1989) on to a larger number of women. Third, this recommendation expands the scope of practice of many family physicians who care for pregnant women. Previously, if a woman desired prenatal screening or was over the age of 35, her physician might refer her to a genetic counselor or obstetrician. With the new guidelines, physicians must discuss prenatal screening with all their pregnant patients. Some family physicians may lack the knowledge necessary to provide all the necessary information (Tyzack & Wallace, 2003), or be unprepared to provide counseling in a non-directive way (Summers et al, 2007), considering that in other circumstances (e.g. regulating blood sugar, controlling hypertension) non-directiveness may be seen as a problematic way of practice (Caplan, 1993; Williams, Alderson, & Farsides, 2002b). Fourth, it normalizes the experience of prenatal screening in the eyes of the health care provider, which may affect both the standard of care and the discourse used by the physician (Press & Browner, 1995; Press & Browner, 1997; Seavilleklein, 2009). Fifth, Asch (2000) has argued that the expansion of prenatal screening will continue to eliminate people with disabilities from our society, which could increase marginalization and reduce many forms of social and financial support, this idea is further elaborated in section 2.3, “Prenatal Screening and Disability”.
2.2.1 Genetic screening and primary care providers.

It is predicted that genetic screening services will increasingly become the domain of primary care providers (Biesecker & Peters, 2001; Greendale & Pyeritz, 2001). This raises questions concerning the implications of this transfer of counseling from specialist genetic counselors to family physicians, including whether family doctors have sufficient time, training, knowledge, and resources to provide this service.

Genetics has an ever expanding role in medicine and is poised to change family medicine in a number of different ways. By generating new screening and diagnostic tests, the Human Genome Project will introduce new ethical challenges with regard to informed consent, patient autonomy, confidentiality, malpractice, and psychological complications (Fetters, Doukas, & Phan, 1999). As genetic services expand into the domain of family medicine, there are many benefits, but also many potential challenges.

The SOGC Clinical Practice Guideline (Summers et al, 2007) expands the scope of prenatal care in family medicine to include genetics. Prenatal screening has been performed by family physicians in the UK (Qureshi, Armstrong, & Modell, 2006) and California (Browner & Press, 1996) for some time. Ontario family physicians have been counseling patients about Maternal Serum Screening (MSS) since 1993 (Carroll & Reid, 1997). Park and Mathews (Park & Mathews, 2009a) found that 68% of pregnant women in Newfoundland and Labrador discussed Maternal Serum Screening with their family physician. There have been several investigations into the strengths and weaknesses of genetics in family medicine, the findings of which will be summarized in the following section. The conclusion of most of these studies and systematic reviews is that good quality counseling about genetic and prenatal testing requires knowledge, training, time, and commitment on the part of the health care provider, however the question is raised as to whether the majority of family physicians possess all of these necessary components.

Greendale and Pyeritz (2001) have produced an important commentary on the current state and future direction of genetic screening in primary care. For various reasons, the number of specialist geneticists (both PhD and MD medical geneticists as well as master’s level genetic counselors) has not kept pace with the need for these professionals.
The result of this is that non-genetic specialists and primary care providers take on an increasing amount of this workload. Greendale and Pyeritz (2001) suggest that non-specialists providing this service “may not be able to provide accurate risk assessment, choose appropriate tests based on clinical and family histories, or interpret DNA results” (p. 226). Furthermore, there is a shortage of family physicians in general (CFPC-CMA PCWTP, 2009), and adding another service to their already full roster is problematic.

There are some significant advantages to moving genetic services into the domain of the primary care provider. First, it is unlikely that there will ever be enough specialist geneticists and genetics counselors to provide these services. The nature of family medicine (long term care, ability to develop relationships, knowledge of family members and family dynamics) has many possibilities for excellent genetic care (Greendale & Pyeritz 2001). Unfortunately, the nature of family medicine also discourages excellent genetic care because of issues such as time constraints (Carroll, Blaine, & Ashbury, 2006; Watson, Shickle, Qureshi, Emery, & Austoker, 1999; Young & Ward, 1999), financial considerations (Carroll et al, 1999), and lack of current knowledge about developments in genetics (Watson et al, 1999).

### 2.3 Prenatal Screening and Disability

One of the most compelling arguments against a cavalier attitude to prenatal screening comes from the disabled community. Known in bioethical circles as the expressivist argument, it is argued that by identifying certain genetic conditions as undesirable and aborting fetuses with these conditions, negative judgments are made about the status and value of the lives of people with these particular conditions. This argument is taken up widely by feminist philosophers and by the disabled community (Edwards, 2004; Gedge, 2010; Kaplan, 1994; Klein, 2011; Lippman, 1991; Lippman, 1999b; McMahan, 2005; Patterson & Satz, 2002; Press, Browner, & Tran, 1998; Scott, 2005) who argue that a systematic bias against people with disabilities is embedded within the structure and practice of prenatal screening.

Another related argument is the quality of life argument. Terms such as *suffering* and *low quality of life* are subjective and many people with disabilities do not rate their subjective
life experience as poor (Albrecht & Devlieger, 1999; Asch, 2000). Disability scholars are concerned with the way that quality of life is perceived by the general public and interpreted in the prenatal screening debate. Disability advocates frequently argue that their quality of life is affected more by societal barriers than their disability. For instance, Deborah Kaplan (1994) compares a wheelchair to a pair of eyeglasses; it is a tool for people with mobility limitations. A wheelchair only impacts on quality of life when architecture, technology, and attitudes get in the way. Scholars participating in this debate question the use of selective abortion as a response “to social problems that could be resolved through other policy initiatives” (Kaplan, 1994). It should be noted that most “birth defects” are the result of prematurity, low birth weight, and environmental exposure. Many of these conditions could be ameliorated with social, environmental and economic programs (Wertz & Fletcher, 1995).

Because caring for a disabled child, as any other child, requires patience, time, and resources, advocates of the expressivist argument do not support a ban on prenatal screening (Gedge, 2007; McMahan, 2005; Patterson & Satz, 2002). Instead, they advocate for increased awareness about living with a disability, increased social support for persons with disabilities and their caregivers, and non-directive counseling that does not include subconscious prejudice against disability (Kaplan, 1994; Parens & Asch, 2000; Wertz & Fletcher, 1995).

Within these ideas, feminist standpoint theory \(^1\) (Harding, 1987; Harding, 2004) contributes to an understanding of the phenomenon. Harding’s standpoint theory argues that “knowledge claims are always socially situated and that failure by dominant groups to interrogate beliefs arising from their social situation leaves them in an epistemologically disadvantaged position, that is, one that distorts” (Patterson & Satz, 2002, p.121). For example, if health care providers who counsel about prenatal screening fail to make themselves aware of the reality of living with a disability, they may impart

\(^1\) While both Harding (1986, 2004) and Smith (1987, 1992) name their work "standpoint theory", the theories are quite disparate (Smith, 1993). This section uses Harding’s conception of standpoint theory; Smith’s standpoint theory is discussed in Chapter 3 and 9.
incorrect knowledge to their clients, who then make decisions based on this distorted knowledge (Grant & Flint, 2007). It is necessary for genetic counselors (and other health care professionals who provide prenatal screening counseling) to acquire knowledge about the lived experiences of the conditions identified with prenatal screening so that they can provide appropriately “non-directive” counseling to patients. Some writers wonder if truly informed choice and completely non-directive counseling is possible, noting that the words used to describe the process of prenatal screening create anything anomalous as inherently pathological (Grant & Flint, 2007; Skotko, 2006; Hodgson et al, 2005). Press et al (1998), Grant and Flint (2007), and Skotko (2005, 2006) argue that when health care professionals speak about prenatal screening, they should be prepared to provide patients with contact information for parent groups and social groups that advocate and care for people with the conditions being discussed. A number of scholars have suggested that this is not happening, that many women receive no information whatsoever about what it is like to live with or raise a child with the different conditions being tested for by prenatal screening (Browner & Press, 1996; Marteau, Slack, Kidd, & Shaw, 1992; Marteau, 1995; Pilnick et al., 2004; Pilnick, 2004; Press & Browner, 1995; Press & Browner, 1997; Skotko, 2005; Skotko, 2006).

During informal communication during the International Conference on the “Healthy” Embryo (University of Western Ontario, November 16 2007), legal and disability scholar Jackie Leach Scully made the valuable point that it is important to differentiate between terms such as disability, disease, condition, illness, impairment. There is significant difference between the participatory abilities of people with deafness, cystic fibrosis, Down syndrome, or hydrocephaly. Different conditions should be given different considerations (Leach Scully, personal communication, November 16, 2007). Various conditions are often conflated in prenatal screening debates, created as the “other” in opposition to “normal” (Rothschild, 2005). Wertz and Fletcher have also noted that the academic literature tends to consider “disability” rather than speak about certain conditions and they identify this trend as harmful and counterproductive (Wertz & Fletcher, 1995).
2.3.1 Social construction of disability.

There is a wide range of literature on the ways in which disability is socially constructed. Scholars tend to take what I term a strong constructionist (e.g. Wendell, 1996) or a weak constructionist (e.g. Asch, 2000) viewpoint. The strong constructionist view of the social construction of disability, exemplified by the work of Susan Wendell, holds that impairments in functioning are only disabling because of the way in which society is constructed- they are not inherently disabling. Weak constructionists differ in stating that although disability is largely socially constructed, there are some attributes of impairments which are inherently disabling, such as the experience of living with chronic pain (Asch, 2000).

Wendell (1996) outlines a number of ways in which society disables people who do not live up to the idealized vision of a citizen, that is the white, male, young, fit, able-bodied, wealthy citizen. First, she describes ways in which social conditions affect people’s bodies. Then she names a number of societal norms which can be disabling. In one illuminating example, Wendell identifies the pace of life as a societal factor which disables people who may be able to be productive and contributing members of society, but because of the pace they are expected to keep, are unable to make contributions. For example, we could consider a worker who would be able to work a half time job based on the productivity expectations for this amount of work. If those productivity expectations were to increase, the worker may not be able to keep up and be forced to leave employment. In this way, the social construction of the expected level of individual productivity “can eclipse the actual contributions of people who cannot meet them, making people unemployable when they can in fact do valuable work” (Wendell, 1996, p. 39).

Wendell points out that disability is also constructed by the inability to give individuals the assistance they need to live productively. For example, the inefficiency of public transit disables people who cannot drive for reasons such as poverty, epilepsy, blindness, paralysis etc. Wendell points out that society gives a lot of assistance to non-disabled people such as education grants and training, public communication, public transportation, recreation, social support etc. When these services are geared towards
non-disabled people they are considered an entitlement of being a citizen. If these services are adapted so that people with impairments can use them, they are considered charity.

Such discussions about the social construction of disability raise a number of questions related to prenatal screening. How is disability constructed by health care professionals when they talk about prenatal screening? How do societal constructions of disability and the lives of disabled people affect the decisions that pregnant women make about prenatal screening? How can health care professionals circumvent these societal norms and constructions to assist the woman in making her own decision about her own family? The SOGC guidelines (Summers et al., 2007; Chitayat et al., 2011) do not explicitly address the issue of how disability is constructed in society, however they do address the issue that prenatal screening, diagnostic testing, and the decision to continue or terminate the pregnancy should be the woman’s own decision. They suggest this can happen through non-directive counseling.

2.4 The Ethos of Non-directive Genetic Counseling

Non-directiveness is one of the original and principal tenets of genetic counseling (Fine, 1993; Weil, 2003; Wertz & Fletcher, 1989) and has long been considered the “norm” in genetic counseling practice (Burke & Kolker, 1994; Kolker & Burke, 1998). Non-directiveness originated from Carl Roger’s (1951) psychosocial counseling model of Client Centered therapy, adopted by the first graduate program in genetic counseling, at Sarah Lawrence College (Weil, 2003). Non-directiveness is thought to be important because it aims to promote and support autonomous decision making by clients. Emphasizing individual choice and decisions separates the field of genetic testing and diagnosis from its undesirable cousin, eugenics (Duster, 2003). Bartels et al (1997) report that 96% of American genetic counselors surveyed thought non-directiveness is very important to genetic counseling practice (Bartels, LeRoy, McCarthy, & Caplan, 1997). It is regularly included as an imperative in literature from other medical professions, including the SOGC Clinical Practice Guideline (Summers et al, 2007).
There is a core group of scholars in genetics and bioethics who question whether non-directive counseling is possible or desirable. These discussions center around definitions of non-directiveness, the values that it may hide or silence, the opportunities that may be lost for active engagement with counselees, and the moral and ethical discussions that it prevents. Within this argument, there are four different camps:

<table>
<thead>
<tr>
<th>N-D is possible, desirable</th>
<th>N-D is not possible, but it is desirable</th>
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<tr>
<td>N-D is possible, but not desirable</td>
<td>N-D is neither possible nor desirable.</td>
</tr>
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</table>

Of these four options, the accepted view in the medical mainstream is that non-directive counseling is both desirable and possible, but the tide has shifted in the genetic counseling and midwifery communities (Burkell & McKenzie, 2005). Many authors present compelling arguments to support the need for an acknowledgement of the impossibility of non-directive counseling. I situate myself in the place which sees the spirit of non-directiveness as desirable and on a continuum of possibility, however I view a purist practice of non-directive counseling as neither desirable nor possible. By the spirit of non-directiveness, I mean the aim of providing complete and balanced information provided without intent to persuade the woman to pick a particular outcome. I propose that providing information in the spirit of non-directive counseling becomes more possible when we acknowledge the effect our personal standpoint has on the information we provide and the way we provide it. An ideal approach towards non-directive counseling appreciates the standpoint of the counselor and counselee (Smith, 1987), and encourages counselors to provide information in a way that the counselee can apply to her particular situation. I describe this idea further in the second manuscript, Chapter 6.
Table 1: Reasons why non-directive counseling may not be possible

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Reasoning</th>
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<tr>
<td>(Anderson, 1999)</td>
<td>There are moral imperatives embedded within counseling that make non-directiveness impossible.</td>
</tr>
<tr>
<td>(Bartels et al., 1997; Williams et al., 2002a; 2002b)</td>
<td>Difficulty ensuring that verbal and non-verbal cues are non-directive. By choosing what information to present and how to present it, you cannot be non-directive.</td>
</tr>
<tr>
<td>(Cunningham-Burley &amp; Kerr, 1999)</td>
<td>Practitioners and clients may hold different perspectives about genetic risk and disease, making neutrality on the part of practitioners impossible.</td>
</tr>
<tr>
<td>(Bhogal &amp; Brunger, 2010)</td>
<td>Health professionals cannot help weaving their own values into the information they impart.</td>
</tr>
<tr>
<td>(Greendale &amp; Pyeritz, 2001; Smith et al., 1994)</td>
<td>There is often a lack of time for proper counseling, especially when this counseling is provided by primary care providers.</td>
</tr>
<tr>
<td>(Stacey, 1996)</td>
<td>There is a power differential between patient and physician which prevents neutrality in their communication.</td>
</tr>
<tr>
<td>(Weil, 2003)</td>
<td>Directiveness can be inadvertent (counselor’s values show despite attempts to be neutral), inevitable (there are inevitable choices to be made re: choosing information to present and how it should be presented), or institutional (the message and setting can imply one course of action is preferable or desirable).</td>
</tr>
</tbody>
</table>
| (Williams et al., 2002b)          | Attempting to give information in a value neutral way can undermine the possibility of encouraging open communication.  
|                                  | Denial of advice/opinion may be interpreted as a lack of care.  
<p>|                                  | There is influence to follow particular screening pathways. This can be overt or covert, such as the state sanctioning a screening program.  |
| (Greendale &amp; Pyeritz, 2001; Williams et al., 2002a; Williams et al., 2002b) | Genetic counseling has now expanded to be the jurisdiction of practitioners who may not normally practice in a non-directive way.  |</p>
<table>
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<tr>
<th>Author (year)</th>
<th>Reasoning</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Anderson, 1999)</td>
<td>The moral imperatives hidden in counseling make it difficult for couples to make a decision that these imperatives do not support. They make the offer of genetic testing a medical directive rather than a choice.</td>
</tr>
<tr>
<td>(Benkendorf, Prince, Rose, De Fina, &amp; Hamilton, 2001)</td>
<td>Practitioners often practice non-directively by using indirect speech, which leads to confusion on the part of the patients. Indirect speech does not invite the patient to state his or her values.</td>
</tr>
<tr>
<td>(Caplan, 1993)</td>
<td>Non-directiveness ignores many difficult issues and isolates itself from the moral, ethical, and political issues inherent in genetic screening.</td>
</tr>
<tr>
<td>(Clarke, 1997)</td>
<td>Non-directiveness fails to address the social and economic context in which the decision is being made.</td>
</tr>
<tr>
<td>(Clarke, 1994)</td>
<td>Unacknowledged directiveness is much more dangerous than acknowledged directiveness. Using a norm of non-directiveness may hide directive elements.</td>
</tr>
<tr>
<td>(Gervais, 1993)</td>
<td>Non-directive counseling may hide the value of autonomy from examination and reevaluation.</td>
</tr>
<tr>
<td>(Caplan, 1993; Stacey, 1996)</td>
<td>The ethos of neutrality silences public discussion of difficult issues related to “improving the population”. It also prevents discussion within medical genetics about these issues.</td>
</tr>
<tr>
<td>(Vanstone, Kinsella, &amp; Nisker, 2012)</td>
<td>A non-directive approach may hide excuses for directiveness, such as Bartels et al (1997) informants who admitted using directive counseling when their clients could not comprehend information because of low socioeconomic status, low education, different cultures.</td>
</tr>
</tbody>
</table>
| (Weil, 2003) | Non-directiveness impedes the future progress and evolution of the profession by inhibiting creative responses to the challenges posed by advances in genomic medicine.

It may constrain counselors, many of whom feel they cannot counsel both actively and non-directively. |

Bartels et al (1997) found that while 96% of American genetic counselors thought of non-directiveness as a very important value, 72% of them admitted to being sometimes directive. They acted in a directive fashion for several reasons. Many admitted that it was difficult to be non-directive because the language they use, the information they present and the way they present it are all directive, even if the counselor strives to take a neutral stance. Others admitted consciously pursuing a directive counseling strategy when the client didn’t understand the information, a better choice was clear, there was a perceived need for further medical care or counseling, or the client couldn’t make a decision. Bartels et al (1997) did not examine the assumptions behind some of these reasons, for instance, that 15% of their respondents took a directive stance when clients were unable to understand the information for reasons of low mental function, low socioeconomic class, low education, client immaturity, cultural practice, and comprehension. I wonder if there would be a more effective way of presenting the information so that the client could understand it in order to articulate his or her values and preferences, rather than the counselor deciding that a directive approach was necessary due to the socially disadvantaged status of the client.

Williams, Alderson, and Farsides (2002b) examine what is happening with genetic counseling now that it is increasingly being carried out by health care providers who do not normally practice in a non-directive way, such as obstetricians and family physicians. Anderson (1999) and Greendale and Pyeritz (2001) share this concern about the provision of genetic counseling by other care providers. Park and Matthews (2009) report that 37% of women in Canada who participated in prenatal screening did so because their physicians instructed them to participate. Williams et al (2002b) state that attempting to give facts in a value neutral way is not possible or desirable and ask instead, what aspects
of directiveness are acceptable and what aspects are problematic? They support an attempt to understand the difficulties of non-directiveness and the possible uses of alternative counseling strategies through professional and public debate.

Anderson (1999) interviewed 24 couples who received prenatal genetic counseling. She found that there are moral imperatives embedded in the process of genetic counseling which are not explicitly articulated and therefore not questioned. These moral imperatives empower professionals and make it possible for them to portray genetics as a social good. With this in mind, it is not correct to equate non-directiveness with the protection or fostering of autonomous decision making. The informants Anderson interviewed who accepted genetic testing did not see it as an autonomous choice, but rather as a medical directive that a person could follow or not follow. They were “swept away” (p. 132) by the moral imperatives embedded in the testing and unable to articulate a counter argument to justify not pursuing the testing.

2.5 Autonomy

One of the most commonly cited advantages for striving towards non-directive counseling is that it promotes patient autonomy. Literature on directive vs. non-directive counseling often assumes the inherent value in supporting autonomy and concerns itself with the achievement of this value, without questioning whether it is something we should strive to achieve. This approach is well grounded in traditional bioethics, but traditional conceptions of autonomy in relation to prenatal screening have recently been challenged by a number of scholars (Ho, 2008; Langston, 2009; McLeod, 2002; Seavilleklein, 2009). Victoria Seavilleklein (2009) has written an interesting synthesis of the ways in which autonomy is used to justify the widespread offer of prenatal screening. She contends that prenatal screening does not promote autonomy and a more patient-centered approach necessitates the use of a relational conception of autonomy, as articulated by Susan Sherwin (1998).

Autonomy is one of Beauchamp and Childress’ (Beauchamp & Childress, 2009) four guiding principles of bioethics. While many bioethicists have critiqued the theory of principlism (Clouser & Gert, 1990) and traditional conceptions of the principle of
autonomy (Mackenzie & Stoljar, 2000; Sherwin, 1998; Wolpe, 1998), it is still one of the most popular decision making guides in medicine and the values espoused by Beauchamp and Childress have been adopted by other disciplines to guide ethical decision making. Autonomy is the central value espoused by most of the leading approaches in health care ethics (Sherwin, 1998).

Despite its wide popularity, autonomy has been challenged as a worthy principle on several fronts and these arguments will be explored briefly. But first, where does the value of autonomy come from? Whose value is it? Is it really a universal good that should be used to guide clinical decisions as Beauchamp and Childress (2009) suggest? Catherine Myser (2003) suggests that autonomy is part of the normativity of whiteness of bioethics, a term she uses to describe the invisible cultural norms that are behind so-called universal values. Myser challenges the universality of autonomy by contending that it is a cultural value. Fox (1990) identifies self determination/autonomy as the 'highest moral good' in American bioethics. She discusses the “American-ness” of bioethics as an important indicator of its WASP ethos and whiteness. Myser (2003) calls for the problematization, displacement, and relocation of the dominant white center of bioethics. This would involve the adjustment or revision of dominant bioethics values and concepts, such as autonomy. Myser (2003) asks us to examine the dominant values in bioethics and ask what ideas and concepts these values suppress. For instance, the focus on self determination, individualism, and autonomy may subjugate values of community, relationships, altruism, sacrifice, and love. What ideas do our values hide and what do they show? Whose values are they and where do they come from?

The principle of autonomy guides many approaches in prenatal screening: the norm of non-directiveness in genetic counseling, the idea that an individual has the right to determine her own future without consideration of the community, and the idea that suffering hardship (e.g. financial difficulties that may be encountered when raising a child with special needs) is an experience one must deal with alone. Discussions of choice and the right to choose are considered in isolation from and without acknowledgement of the influence of the social and political structures in which they are deeply embedded (Ho, 2008; Lippman, 1999a) Considering the social construction of the
value of autonomy and the implications this value has in relation to the offer of prenatal screening, I introduce a different conception of autonomy, Sherwin's (1998) relational autonomy. Relational autonomy fits well with a feminist approach to prenatal screening, and allows consideration of the ways in which decisions about prenatal screening are linked to family, community, societal, and socio-economic considerations.

2.5.1 Relational autonomy.

Feminist scholars are particularly concerned with the value of autonomy. As Sherwin (1998) points out, feminists are often unsure whether or not to support the principle of autonomy. On one hand, it affords protection to people who are vulnerable to coercion and other influences. Without strong respect for the principle of autonomy, patients and other vulnerable populations may be abused and exploited. On the other hand, is autonomous decision-making really possible? When one considers the power differential between physician and patient (Bhogal & Brunger, 2010; Summers, 1994), social and political structures which oppress women (Lippman, 1999) and possibly coercive or constraining contextual factors specific to prenatal screening (García, Timmermans, & van Leeuwen, 2008; Hunt & deVoogd, 2003), it is unclear if wholly autonomous decisions are possible. Sherwin makes a distinction between autonomy and agency. A woman presented with choices about prenatal screening may exercise agency by choosing the option which she prefers, yet due to constraining factors outside of her control, that decision may not be autonomous (Lippman, 1999a; Sherwin, 1992; Sherwin, 1998). For instance, societal factors may constrain autonomous choice in prenatal screening;

The societal treatment and professional viewpoints of disability continue to shape the meaning of pregnancy and the role of screening programs, pre-determining people's decision-making framework and feasible options while giving the illusion of autonomy. ... the ableist socio-cultural framework is full of negative messages about impairments. It constructs the meanings of a good life according to the able-bodied and able-minded ideals, underlying the social and professional structures within which discussions and decisions regarding various impairments are held.(Ho, 2008, p.197)
McLeod and Sherwin (McLeod & Sherwin, 2000) declare that oppression is unrecognized as an inhibitor of autonomy equal to coercion, internal compulsion, and ignorance. Sherwin (1998) makes the assertion that the value of autonomy serves to “hide the workings of privilege and to mask the barriers of oppression” (Sherwin, 1998, p. 25) by letting those indoctrinated into the North American culture of individualism and autonomy think of their successes as self created and deserved. Sherwin infers that this type of thinking creates an obliviousness to the barriers that oppression and disadvantage pose to self determination. As a result, privileged people may be inclined to blame less privileged people for not achieving similar levels of success, without acknowledging the costs of oppression.

Oppression problematizes the conditions for autonomy. Sherwin (1998) writes that patient decisions are thought to be autonomous if 1) the patient is deemed to be sufficiently competent (rational) to make the decision at issues, 2) the patient makes a reasonable choice from a set of available options, 3) the patient has adequate information and understanding about the available options and 4) is free from explicit coercion toward or away from one of those options. Sherwin (1998) states that each criterion is more problematic than it initially appears. The call for patient competency can exclude people who are not equated with being rational - traditionally the rationality of women and other members of oppressed groups have been questioned. The requirement of a patient to make a reasonable choice from a set of available options is problematic because the set of options and the “reasonableness” of the decision is constructed by someone other than the patient herself. The call for adequate information and understanding is problematic because the information that is made available to patients is that which has been deemed: worthy of funding by policy-makers, worthy of study by researchers, and relevant by health care providers. Decisions made at policy, research, and management levels affect the relevance of the available information and the list of available options. Regarding the third criterion, access to relevant information, power, knowledge and experience differences between the health care provider and patient can make the provision of comprehensible and relevant information difficult. Patients may feel too intimidated to ask questions and so may not receive the information they need in a way they can understand. The fourth condition, a demand for freedom from coercion
when making decisions is difficult to evaluate when the decision-maker is oppressed. Sherwin (1998) gives the example of a woman who chooses prenatal diagnosis and abortion because she cannot afford to care for a disabled child in the society in which she lives, even if she would value that child herself.

When a woman’s sense of herself and her range of opportunities have been oppressively constructed [so that]… having a(nother) child will impose unjust and intolerable costs on her, it does not seem sufficient to restrict our analysis to the degree of autonomy associated with her immediate decision about a particular treatment offered. We need a way of acknowledging how oppressive circumstances can interfere with autonomy. (Sherwin, 1998, p. 28)

Sherwin proposes the concept of relational autonomy as an essential element of a feminist health care ethic (Sherwin 1992, 1998; McLeod & Sherwin, 2000) that will both serve as an alternative to and address some of the shortcomings of a traditional conception of autonomy. Relational autonomy could be called situational or contextual autonomy, because it focuses on considering the individual as part of a web of relations, both personal and public. It is best understood to be “a capacity or skill that is developed (and constrained) by social circumstances. It is exercised “within relationships and social structures that jointly help to shape the individual while also affecting others’ responses to her efforts at autonomy” (Sherwin, 1998, p. 37).

Sherwin supports this theory with Marilyn Friedman’s call for contextualized thinking as a way of highlighting the limitations of minimalist moral theory by paying attention to contextual details in issues of justice, care, and relationships (Friedman, 1987 as cited in Sherwin, 1992). Relational autonomy recognizes that individuals define and pursue autonomy within their own specific context and that particular context shapes the way that autonomy can be achieved (McLeod & Sherwin, 2000). Relational autonomy also calls for attention to dimensions beyond the individual patient, focusing on the broader social context of the individual patient rather than his or her cognitive decision-making capacity. McLeod and Sherwin (2000) argue that a focus solely on the individual ignores key elements at the source of problems and fails to acknowledge the interconnected
nature of a person in her society. A focus on the individual encourages patients to see their decisions in isolation from the decisions of others, which can increase their sense of vulnerability and dependence on medical authority (Sherwin, 1998).

2.6 Re-examining Risk

Risk is a concept that is often discussed in relation to prenatal screening. In an earlier section I discussed the idea of physical risk and the expression of statistical risk. Risk is a word with an unclear meaning and status, both in the context of prenatal screening and social science inquiry in general (Heyman, Alaszewski, & Brown, 2010; Roth, 2010). Risk is used in many different ways in prenatal screening, for instance, risk may be used to refer to physical risk and statistical expressions of risk, as discussed earlier in this chapter. There is literature describing risk in many contexts: minimizing risks of prenatal screening (Ekberg, 2007); the risk of invasive procedures (Wilson et al, 2007); the experience of having a pregnancy labeled high risk (Heyman et al., 2006); negative connotations associated with the word risk and the transfer of those negative connotations to the conditions one may be at risk for (Hodgson et al, 2005; Grant &Flint, 2007); congruency between pregnant women's perceptions of risk and the risk statistic derived from prenatal screening (Georgsson Öhman, Grunewald, & Waldenström, 2009) and the challenges of interpreting risk statistics (Burkell & Campbell, 2005; Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz, & Woloshin, 2007; Gigerenzer & Gray, 2011; Miron-Shatz, Hanoch, Graef, & Sagi, 2009; Press and Browner, 1995; Rapp, 1999).

Receiving a label of high-risk has been shown to produce several negative psychological sequelae in pregnant women, including perceptions of a loss of control (Saxell, 2006), fewer positive expectations about the pregnancy (Heaman, Gupton, & Gregory, 2004), increased stress and increased negative emotions (Jordan & Murphy, 2009).

But what is risk? There is a large body of literature on risk theory, but in this thesis I engage with a few particular conceptions of risk. Abby Lippman examined the socially constructed nature of risk in regards to prenatal screening (Brunger & Lippman, 1995; Lippman, 1991; Lippman & Wilfond, 1992) and the ways in which it may be used to exert social control over women. Bob Heyman (Heyman, Henriksen, & Maughan, 1998; Heyman et al., 2006; Heyman et al., 2010) has considered the increasing societal
sensitivity to risk as providing a particular historically and socially situated approach to visualizing alternative futures (Heyman et al., 2010); preoccupation with a risk oriented way of looking at the world shapes health care delivery and practice. This perspective was explored in relation to midwifery practice, where medical conceptions of risk were found to create tensions between midwives' wishes to empower and protect their clients (Scamell, 2011). Deborah Lupton is a sociologist who has examined the social construction of risk (Lupton, 1999a) in the context of public health (Petersen & Lupton, 1996), everyday life (Tulloch & Lupton, 1997; Tulloch & Lupton, 2003), AIDS and HIV (Lupton, McCarthy, & Chapman, 1995; Tulloch & Lupton, 1997) and pregnancy (Lupton, 2011; Lupton, 1999b). Her work is discussed at length in Chapter 3 for its relevance to prenatal screening. Lupton’s book traces the evolution of different concepts of risk, based on the idea that the identification of risks takes place in specific socio-cultural and historical concepts. Lupton believes that Western culture’s fascination with control over one’s life has resulted in the popularization of the concept of risk to explain deviations from the norm, misfortune, and frightening events. This concept assumes human responsibility for these events and behooves us to recognize that “something must be done” to prevent misfortunes. Risk is culturally significant because the “concepts we identify as risky are ontologically important- they have significant implications in the way we understand the world, and social and material orders” (Lupton, 1999a) (p. 14).

2.7 Influential Prenatal Screening Literature

There is an enormous amount of literature about prenatal screening available in the fields of medicine, nursing, midwifery, and philosophy, but most of the literature I have engaged with addresses prenatal screening from a social scientific perspective. A significant amount of critical literature on prenatal screening was published in the 1990's; foundational work was published by Canadian scholar Abby Lippman (Basen, Eichler, & Lippman, 1993; Beaulieu & Lippman, 1995; Brunger & Lippman, 1995; Lippman, 1991; Lippman, 1993; Lippman & Wilfond, 1992; Lippman, 1993; Lippman, 1994; Lippman, 1999a; Lippman, 1999b); American anthropologists Carole Browner and Nancy Press (Browner et al., 2003; Browner et al., 2003; Browner & Press, 1996; Browner et al., 1996; Browner, Preloran, & Press, 1996; Markens, Browner, & Press, 1999a; Markens,
Browner, & Press, 1999b; Markens et al., 2010; Markens, Browner, & Mabel Preloran, 2010; Press et al., 1998; Press & Browner, 1995; Press & Browner, 1997; Root & Browner, 2001); American medical anthropologist Rayna Rapp (Rapp, 1984; Rapp, 1988; Rapp, 1998; Rapp, 1999); American sociologist Barbara Katz Rothman (Rothman, 1993) and British health psychologist Theresa Marteau (Dormandy, Hankins, & Marteau, 2006; Loeben, Marteau, & Wilfond, 1998; Marteau et al., 1992; Marteau et al., 1992; Marteau, Plenicar, & Kidd, 1993; Marteau, 1995; Marteau et al., 2000; Marteau & Dormandy, 2001; Marteau, Dormandy, & Michie, 2001; Marteau & Kinmonth, 2002; Marteau & Richards, 1996; Michie, Bron, Bobrow, & Marteau, 1997; Michie, Dormandy, & Marteau, 2003; Michie, Lester, Pinto, & Marteau, 2005; Sapp et al., 2010; Smith et al., 1994; Smith et al., 1994; Van den Heuvel et al., 2008; Van den Heuvel et al., 2009). Several significant interdisciplinary collections of work on prenatal screening were also published during this time period (Asch, 2000; Franklin & Ragone, 1998; Rothenberg & Thomson, 1994). Much of this work addresses the diagnostic prenatal test amniocentesis and precursors to contemporary prenatal screening, such as the maternal serum screen or the alphafetoprotein screen. These differences notwithstanding, this literature articulates an array of foundational questions about nondiagnostic prenatal screening.

Browner, Lippman, Marteau, Rapp, Rothman and Press have greatly influenced contemporary social scientific scholarship of prenatal screening, and more recent literature has built on their scholarship by examining prenatal screening in the national contexts of Canada (Bhogal & Brunger, 2010; Burkell & McKenzie, 2005; Gagnon et al., 2010; Legare et al., 2011; Park & Mathews, 2009a; Park & Mathews, 2009b; Seavilleklein, 2009; Spoel, 2006; St-Jacques et al., 2008); Australia and New Zealand (Hodgson et al., 2005; Hodgson, Gillam, Sahhar, & Metcalfe, 2010; Jaques, Halliday, & Bell, 2004; Jaques, Bell, Watson, & Halliday, 2004; Jaques, Sheffield, & Halliday, 2005; Jaques et al., 2010; Milligan, 2004; Milligan, 2008; Mulvey & Wallace, 2000; Mulvey & Wallace, 2001; Rostant, Steed, & O'Leary, 2003; Rowe, Fisher, & Quinlivan, 2006; Tyzack & Wallace, 2003) and Europe (Dahl, Hvidman, Jørgensen, & Kesmodel, 2011; Dahl, Kesmodel, Hvidman, & Olesen, 2006; Ekelund, Jørgensen, Petersen, Sundberg, & Tabor, 2008; Gottfredsdóttir & Árnason, 2011; Gourounti & Sandall, 2008; Gudex et al.,
In this section, I will review some of the contributions of the foundational social scientific work on prenatal screening mentioned above and describe some of the emerging themes in contemporary work.

2.7.1 Abby Lippman (Canada, Epidemiologist, Bioethicist).

Abby Lippman is a Canadian scholar who works with issues of genetics, feminism, and ethics. She uses a critical feminist/social justice and constructionist lens to examine prenatal screening. In three similar articles, Lippman (1991, 1992, 1995) examines the ways in which prenatal screening has been socially constructed and the impact that this construction has had on the status of women, children, and people with disabilities. Her argument is relevant to my motivation for undertaking a critical and constructionist examination of prenatal screening.

Lippman (1995, pg. 375) identifies a number of contradictory constructions of prenatal screening:

- “public health”, or a way of reducing the frequency of selected birth defects.
- “reproductive autonomy”, or a way of giving women information to expand their reproductive choices.
- “assembly line”, a way of separating out those products we wish to develop from those we wish to discontinue.
- “autonomous control”, a way of respecting (increasing) women’s autonomy to choose the kinds of children they will bear.
- “reassurance”, a means of reassuring women to enhance their experience of pregnancy.
- “disaster avoidance”, a way of avoiding an undesirable future.

Lippman recognizes that these constructions are in tension with each other, but often occur together, particularly the themes of reassurance, control, and choice.
decries this discourse as marketing strategy, one which hides other facets of prenatal screening by not asking questions such as why reassurance is sought, how risk groups are generated, and how eligibility for obtaining this kind of reassurance is determined. The discourse on prenatal screening further constructs the project by constructing a “need” for prenatal diagnosis and the promotion of “choice”. These concepts are further analyzed in Lippman (1991) and (1992).

Despite its insistence of objectivity and neutrality, the Western biomedical system is grounded in particular social and cultural assumptions. These assumptions shape the way that disease, malady, and disorder are constructed by biomedicine, as there is no essentialist or universal biological basis for these conditions. There is no value-free view of disease, rather, scientists give biological processes different forms in different people, thereby creating disorders and disabilities as social products. Technology used by biomedicine reinforces and reflects social norms and standards that exist within power relationships in our society. Just as disease cannot be value-free, neither can technology.

As a development in a world stratified by hierarchies of gender, class, and race, prenatal screening cannot escape being used in a stratified way, and therefore reinforcing unequal distribution of health. Prenatal screening takes place in a particular historical and cultural context where risk dominates pregnancy. Lippman notes that when pregnant, women are immediately labeled high-risk or low-risk, but never no-risk (Lippman, 1992). The risk identified by authorities is never external, never the effect that a woman’s occupational or social environment might have on the baby. Risk is always internal, and sets up the pregnant woman as the party worthy of blame regarding behavior she may have engaged in during pregnancy, food or vitamins she may not have ingested, and substances she may have smoked, eaten, or drunk. After attaching a risk label, medicine reconstructs a normal experience – one that requires their supervision. Lippman (1991, 1992) predicts that eventually the “high-risk” age category of 35 years and older will be removed, thereby making all pregnancies high risk and encouraging physician surveillance and control over all pregnant women.
Lippman (1991, 1992, 1995) asks what choice really means when the pregnant woman is forced to choose from options constructed by others. The discourse of reassurance that surrounds prenatal screening hides the fact that reassurance could be offered in other ways. Many more babies have health problems after being born premature or underweight than with a genetic anomaly. Would it not be more reassuring to provide women who live below the poverty line with adequate nutrition? Why is genetic testing more reassuring than allocating funds for home care, respite care, and domestic alterations that would let women manage their special needs if their child is born or later develops a health problem? Is bearing a child with Down Syndrome really a choice when society does not truly accept children with disabilities or provide assistance for their care?

2.7.2 Barbara Katz Rothman (USA, Sociology).

Any discussion of prenatal screening would be remiss not to include Barbara Katz Rothman’s groundbreaking work *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood* (1989). Katz-Rothman interviewed 120 women, men, physicians, and genetic counselors in the early and mid eighties, when the prevalence of amniocentesis and genetic abortion was growing and the issues with which this literature review is concerned were first being articulated. Reading this work more than two decades later, I am struck by the prescience of many of the questions and issues that Rothman raised. When she completed her book in 1989, chorionic villus sampling was just starting to be used in mainstream clinics, and it was expected to solve many of the difficult “late abortion” issues of amniocentesis. Serum screening was not available in the form that we know it today, but the potential of an early blood test for abnormalities was seen as a magic cure for many problems of existing technology. Rothman raises potential issues about both CVS and serum screening that are relevant today- does the possibility of an early (and less traumatic) abortion mean that the tests might be used with less gravitas? Could they become a vehicle for sex selection?

While our technological capabilities have increased greatly since 1989, the questions Rothman raised at that time are still relevant today. For instance, Rothman describes the decline in Tay Sachs research with increased use of amniocentesis. Before amniocentesis,
there was a lively research community dedicated to finding treatments and cures for this disease. Rothman describes the great public pressure to find therapies and cures for this disease. After the gene for Tay Sachs was isolated and it became possible to screen for the disease and selectively abort affected fetuses, this research stopped and the focus shifted to screening and prevention programs. Rothman discusses how technology and change comes from social pressure and asks “where is the social pressure when a room of fifty Tay Sachs babies is replaced by fifty individually grieving women” (Rothman, 1989, p. 231)? In 2012, we take a “screening and prevention” approach to many more conditions, many of which are significantly less severe than Tay Sachs. Rothman makes reference to a cure for the painful condition of Tay-Sachs, but we could consider this warning also applicable to other types of support for people with disabilities. From where will the social pressure for increased support and acceptance for people with disabilities arise when these people are less visible in society?

2.7.3 Rayna Rapp (USA, Anthropology).

Rayna Rapp undertook a nine year ethnography of genetic counseling in New York City which resulted in her 1999 book *Testing Women, Testing the Fetus*. One of the most important ideas she discusses concerns the effect of a patient’s race, language, age, socioeconomic status, and religion on the prenatal counseling session. Rapp found that counselors consciously or unconsciously alter their discourse, explanations, and information to match their perception of the patient in front of them. Counselors are forced to make quick judgments about the scientific literacy and education level of a patient that sometimes result in explanations that are too simple or complex for the patient to understand. Rapp also discusses the use of metaphor as an important tool for tailoring scientific explanations to a particular patient. She found that genetic counselors used several stock metaphors to describe things such as genes, DNA, and testing. The metaphor they used for each individual patient appeared to depend on the initial judgment made about the patient’s education and scientific literacy level. Patients were never asked explicitly about their level of education which at times resulted in misjudgments and substandard patient care. Rapp notes that metaphors don’t always translate through language and culture and that when genetic counselors used metaphor they sometimes gave false
ideas to patients. For instance, she found that a disproportionate number of Spanish speaking women understood amniocentesis as a needle through a woman’s belly button into the baby’s umbilical cord (Rapp, 1999, p. 83). She explained this misunderstanding as a result of an inappropriate metaphor for Spanish speakers and a cultural disconnect. It is interesting to note that most other research about genetic counseling and the presentation of prenatal screening from this time period do not mention cultural or socioeconomic variables relevant to the experience. This thread has been picked up in later work: (Bhogal & Brunger, 2010; Browner et al., 2003; Hunt & de Voogd, 2003; Hunt & de Voogd, 2005; Hunt, de Voogd, & Castañeda, 2005; Teman, Ivry, & Bernhardt, 2011).

### 2.7.4 Carole Browner and Nancy Press (USA, Anthropology).

Carole Browner and Nancy Press have produced a wide range of work about prenatal screening together and separately (Browner et al., 2003; Browner et al., 2003; Browner & Press, 1996; Browner et al., 1996; Browner et al., 1996; Markens, Browner, & Press, 1999; Markens et al., 2010; Markens et al., 2010; Press et al., 1998; Press & Browner, 1995; Press & Browner, 1997; Root & Browner, 2001). Much of this work focuses on the experience of Latinas in the southwestern United States, although a few of their articles concern American women generally. In their 1997 article about the acceptance of prenatal screening, Press and Browner (1997) found that the attitude of the health care practitioner was of great importance when predicting whether or not women would accept prenatal screening. In clinics that had great support and pressure towards patient acceptance of prenatal screening, acceptance rates were double the national average. Genetic counselors, nurses, and doctors were observed as tending to downplay the risk of prenatal screening and concentrate on the physical test rather than the emotional and ethical implications. They directed patient attention to the fact that the Maternal Serum Alpha Fetoprotein (MSAFP) test was a blood test and often grouped this screening test with other routine prenatal blood tests for anemia or diabetes. In many cases, pregnant women did not understand what they were being tested for, much less ideas of risk status and the consequences of receiving a high risk result. Browner and Press (1995) suggest that there is pressure on health care professionals to ensure a high uptake of prenatal
screening tests among their patients, due to a climate of medical malpractice suits. Physicians may wish to protect themselves from “wrongful birth” and “wrongful life” suits (Cowan, 1993) by providing all the information possible, even if it is not wanted. In another study, Browner and Press found that women’s stated opinions about disabled people were often in direct opposition to their decisions about whether or not to abort a fetus with a genetic condition that would cause disability (Press et al, 1998). In their study of serum screening in California, Browner and Press found that HMO-employed health professionals went out of their way to secure “compliance” with the test, often assuming consent unless a patient indicated explicitly that she did not wish to have the test done (Press & Browner, 1994). These health care providers used language that was very persuasive as well as conversational tactics to direct patient attention to the logistics of the test rather than other issues. Women were informed that MSAFP screened for vague conditions such as “birth defects in the baby” or that prenatal screening “shows us how your baby is developing” without information about specific conditions or the physical or emotional implications of raising a child with those conditions (Press & Browner, 1991). Press and Browner are very critical of this stance and have written a number of articles in opposition to the techniques used by the counselors they studied (Press & Browner 1992, 1994, 1995, 1997, 1998, Browner & Press 1995).

2.7.5 Theresa Marteau (United Kingdom, Health Psychology).

Theresa Marteau is a health psychologist who has conducted a prolific amount of quantitative and qualitative research on prenatal screening, focusing on the topic of informed decision-making. Marteau's early work describes a dire state of decision-making in the United Kingdom. For instance, Marteau and her colleagues (1992) taped 102 consultations between patients and obstetricians or midwives. They found that most consultations focused on the procedural information about the test and that little specific information was given about the conditions the test screened for, the meaning of negative and positive results, or the limitations of the test (false positives, false negatives, conditions not tested for). On only two occasions (of 102 interviews) were women informed that a negative test result does not mean that the fetus would be unaffected. In over half of the consultations, women were not asked to make a decision to choose the
test, but were told it was a routine test. Marteau attributes the hospital’s 90% uptake rate to the fact that women were provided with incorrect and misleading information, or that important information was often omitted. This uptake rate is astounding, considering Rapp (1999) found hospitals with an uptake rate as low as 30%. Another Marteau publication (Smith, Slack, Shaw & Marteau, 1994) suggested that incorrect and misleading information provided to women may be a result of a lack of knowledge about prenatal screening and testing by the health professionals counseling about these tests. Inadequate knowledge to counsel about prenatal screening and testing has also been found amongst British and Australian physicians. (Sadler, 1997; Tyzack & Wallace, 2003).

Smith, Shaw and Marteau (1994) found that counseling usually focuses on the procedural nature of the test and neglects counseling components. They attribute the high uptake of screening tests to the inadequate provision of information. In their study of 353 pregnant women offered serum screening for Down Syndrome, it was found that after counseling, most women did not understand that: most positive test results are false and women will often have unaffected babies, negative test results do not guarantee a unaffected baby, about 5% of women are recalled for further, more invasive testing. Only 38% of women understood that the test being offered was for Down syndrome (Smith et al, 1994). Supported by both her own empirical research and a review of existing literature, Marteau (1995) found that prenatal screening/testing programs are rife with issues of poor understanding, anxiety, and with false reassurance. Marteau’s career has focused on improving the state of informed decision-making in prenatal screening and testing (Marteau & Dormandy, 2011). To this end, Marteau has examined ways of promoting and measuring informed decisions.

Marteau has examined the efficacy of different ways of presenting information (Loeben, Marteau & Wilfond, 1998; Marteau et al, 2000; Michie, Lester, Pinto & Marteau, 2005) including an empirical study of non-directiveness. She found that directive statements were prevalent in the genetic counseling visits observed, particularly when counselees were of lower socioeconomic status or judged by counselors to be highly concerned.
Neither counselors, counselees nor the standardized rating scale concluded that these sessions were conducted in a non-directive way (Michie et al, 2005).

Marteau, with colleagues Susan Michie and Elizabeth Dormandy, have offered an influential definition of informed choice as one which is "based on relevant knowledge, consistent with the decision-maker’s values and behaviourally implemented" (Marteau, Dormandy & Michie, 2001 p.99). They developed a multi-dimensional validated measure to determine how often decisions about prenatal screening can be characterized as informed (Michie, Dormandy & Marteau, 2003; Marteau & Dormandy, 2001; Marteau, Dormandy & Michie 2001). This measure has been cited over 200 times, and used in screening contexts such as breast cancer (Sepucha, Ozanne, Silvia, Partridge, & Mulley, 2007), colorectal cancer (McCaffery, Wardle, & Waller, 2003), cardiovascular risk (Marteau & Kinmonth, 2002). Marteau is still actively publishing in this area; her recent work has examined the role of ambivalence to making a decision about prenatal screening (Dormandy et al., 2006; Sapp et al., 2010).

### 2.7.6 Recent contributions to the literature.

The scholarly legacy left by Lippman, Browner & Press, Rapp, Rothman and Marteau continues to inform current work about prenatal screening. This literature is reviewed in each of the four manuscripts (Chapter 5-8), so in the interests of avoiding repetition, an additional review is not included here. Prevailing themes in this literature include an emphasis on promoting autonomous choice (Seavilleklein, 2009; Williams et al., 2002b; Williams, 2006) by examining the ways information is provided by clinicians (Bhogal & Brunger, 2010; McKenzie, 2004; Pilnick et al., 2004; Pilnick, 2008); patient education materials (Dahl et al., 2006; Fox, 2006; Sanderson, Wardle, & Michie, 2005; Stapleton, Kirkham, & Thomas, 2002); decision-making processes (Dahl et al., 2011; Gagnon et al., 2010; Legare et al., 2011; Schwennesen et al., 2010; St-Jacques et al., 2008); and the experiences of women deciding about prenatal screening in particular social contexts (Cavanagh, Mathews, & Crane, 2007; Ekelund et al., 2008; Gottfreðsdóttir & Árnason, 2011; Gourounti & Sandall, 2008; Hodgson et al., 2010; Hunt & deVoogd, 2003; Park & Mathews, 2009a; Park & Mathews, 2009b; Teman et al., 2011; van Berkel & van der Weele, 1999).
2.8 Conclusion

The context of prenatal screening in Canada has changed significantly since 2007 with the introduction of the SOGC guidelines (Summers, 2007), with prenatal screening now being offered to all pregnant women, rather than just those over the age of 35. This guideline assured consistency across Canada. The literature indicates there are some significant problems with the values that predicate prenatal screening, the process in which it is introduced, and the choices that are offered. There are significant implications to the lives of women, children, and people with disabilities. By investigating the way in which prenatal screening is currently taking place, the aim of this research is to gain insight into current practices, and to explore avenues for improving women’s experience, as well as the education and future practices of health care practitioners in this important area.
2.9 References


Retrieved from


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3 Epistemological and Theoretical Perspectives

3.1 Introduction

Continuing with the metaphor of the bricoleur (Levi-Strauss, 1962) introduced in Chapter 1, in this chapter I set the stage for my bricolage, describing the foundational knowledge that informs my approach and my choice of tools for this project. In this research, I have engaged with two epistemological perspectives, constructionism and critical social theory, and the theoretical lens of feminist bioethics. I begin by describing the way I understand constructionism, the critical social theories I engage with, and the points of congruency between the two. I then outline the work of several scholars who have influenced my approach to feminist bioethics, and contributed to the way I think about prenatal screening.

Switching metaphors, I conceptualize my epistemological and theoretical approach as combining different lenses to see something unique, something which was perhaps visible, but out of focus in each individual lens. Bateson (1979) describes binocular vision as the confluence of two different but compatible perspectives which, when used together, have the ability to create new understandings. To expand upon the metaphor, each lens of a pair of binoculars has a particular scope, or field of focus, which shows the object of the looker’s gaze in a particular way. An individual lens may bring particular objects into focus while obscuring others. When both lenses are combined, a different scene comes into view, a scene which is more than the sum of what was seen through each individual lens. I use the metaphor of “lens” here to describe the influence that a collection of theoretical perspectives has on the way I see the world.

3.2 Epistemological Underpinnings: Constructionist and Critical Perspectives

3.2.1 Constructionist.

There is significant confusion and conflation surrounding constructivist and constructionist perspectives. Within both the *ivist* and the *ionist* categories there are many different iterations. Briefly, the distinction between *ivist* and *ionist* theories can be
summarized as follows: *constructivism* most accurately describes "epistemological considerations focusing exclusively on the ‘meaning-making activity of the individual mind’"; *constructionism* "is used when the focus includes ‘the collective generation [and transmission] of meaning’" (Crotty, 1998, p.58). These perspectives do not exist in isolation, but can be conceptualized as existing upon a continuum, with those focused on subject-centered meaning making (meaning making activity of the individual mind) at one end, and socially centered meaning making (social generation of meaning) at the other (Crotty, 1998).

Constructionism is not defined by clear cut boundaries, especially since it has been adopted by several different disciplines and has evolved in several directions at once (Gubrium & Holstein, 2008). Weinberg (2008) defines social constructionism as an attempt to demonstrate “how certain states of affairs that others have taken to be eternal and/or beyond the reach of social influence are actually products of specific sociohistorical and/or social interactional processes” (pg. 14). The way that these 'states of affairs' are produced by sociohistorical and social interactional processes, to a large extent in the absence of the intent or consciousness of the individual, is the one of the main epistemological claims of social constructionism. Constructionism focuses on discourse and interaction as some of the methods through which meaning is produced in society. Discourse is a key term in constructionist theory and one which has many meanings; I understand discourse in the Foucauldian sense. Mills (2003) emphasizes the multiple and sometimes contradictory ways that Foucault uses the word “discourse”. One of the most widely cited definitions is found in *The Archaeology of Knowledge* (Foucault, 1972), and that is the definition I choose to work with. Foucault (1972) defines discourse as a group of institutionalized statements (including any type of utterance) about a particular topic (or object) that function socially by forming that topic. A discourse is a regulated group of statements that can combine with other discourses in predictable ways. There are rules which lead to the distribution and circulation of certain utterances and statements … but rather than seeing discourse as simply a set of statements which have some coherence, we should think of a discourse as existing because of a
complex set of practices which try to keep them in circulation and other practices which try to keep other statements out of circulation. (Mills 2003, pg. 54)

According to Blood (2005), discourse, or group of statements is the manifestation of thought into language and can both transmit and produce power, defining the ways we can talk or think about a topic (or object), and therefore defining the truth of that topic (or object). Discourse shapes and constrains our ways of understanding the world, by acting as a system that structures our perceptions of reality. By understanding Foucault’s conception of the way that discourse operates, we can see that social construction (as it uses the methods of discourse and interaction- or the social process of discourse) can be used as a way to effect social change, especially by challenging authoritative accounts of the way the world is in order to foster participation in effecting change (Gergen, 1999).

One of the seminal texts on social construction, The Social Construction of Reality, by Berger and Luckmann (1966), declares that “language used in everyday life continuously provides me with the necessary objectifications and posits the order within which these make sense and within which everyday life has meaning for me” (pg. 22). Social construction also holds that discourse affects and is affected by social relationships, structures, and organization (Gergen, 1999). Through this statement, Gergen emphasizes the collective nature of meaning generation, through language and other social processes. The emphasis on the importance of discourse is particularly strong in psychological accounts of constructionism (Gergen, 1999; Hibberd, 2005), and postmodern (Saussure, 1983), and poststructuralist (Foucault, 1977) uses of constructionism. Sociological accounts of constructionism focus more on social interactions and processes (Gubrium & Holstein, 2008).

“Social processes” can be a vague and confusing term, perhaps best explained by Fish (1990). Crotty (1998) quotes Fish (1990) declaring that all objects are made through society and convention, rather than simply found. There are social institutions and conventions in which we are already embedded and through which we make meaning (constructivist) and meaning is made through us (constructionist): “these institutions are the source of the interpretive strategies whereby we construct meaning” (Crotty 1998, pg. 53).
From a social constructionist perspective, humans are understood to use meaning made by the social world and to interact with the world as it makes meaning through them, therefore the historical and social context of the world is revealed as important in this meaning-making activity (Crotty, 1998). From a social constructionist perspective, people do not make meaning by interacting with each and every phenomenon, they are born into a world full of cultural meaning and people come to make their own meaning through meanings and discourses that already exist (Crotty, 1998). Crotty (1998) offers a summary of this perspective:

We enter a social milieu in which a ‘system of intelligibility’ prevails. We inherit a ‘system of significant symbols’. For each of us, when we first see the world in meaningful fashion, we are inevitably viewing it through lenses bestowed upon us by our culture. Our culture brings things into view for us and endows them with meaning and, by the same token, leads us to ignore other things. (p.54)

Crotty warns against the misconception that the social in social constructionism refers to the type of object that has meaning (for example, that a rock cannot be socially constructed). He clarifies that it refers to the way meaning is made (perhaps the rock itself was not made through social construction, but the way we understand what that rock is, what it can do, and how it can be used is socially constructed). For example, objects in the natural world have meaning that is made socially, and it is the social aspect which leads us to a particular interpretation of these objects, guiding our interpretation to emphasize and ignore certain other aspects.

### 3.2.1.1 Hacking’s (1999) constructionism.

Canadian philosopher Ian Hacking (1999) has written a persuasive text that asks the following critical questions of constructionist theory: What is socially constructed? How far does social construction stretch? Are there different types of social construction?

Hacking identifies that most constructionist scholars start with the meaning, or definition, of social construction but do not ask what the point of social construction is. By interrogating the purpose of social construction, Hacking has created a version of social
constructionism that is readily applicable to critical research. Hacking states that most social constructionist statements are based on local claims. A local claim is a claim about the constructed nature of a specific thing (X). Local claims may be influenced by overarching claims, but their point is to raise consciousness about something specific (X). They are (in principle) independent of each other. For instance, an individual could support the local claim that workplace gender roles are socially constructed, but refute the claim that starvation, or the boy scouts, or gravity is socially constructed. Hacking points out that it is a very different kind of social construction that sees danger as socially constructed than that which sees reality or women refugees as socially constructed. He thinks it is possible to see concepts as socially constructed, but objects as not constructed. That is not to say that the meaning, use, connotation, feeling etc. of the object is not constructed, just that the object itself is not constructed. Hacking cautions that most constructionists conflate the object with its meaning.

Hacking makes the astute observation that most people who use social construction want to show the arbitrary nature of a specific thing (X) as a starting point to criticize, change, or destroy. They might employ a social constructionist approach to recognize that X is taken for granted or established by the order of things, and then further use a constructionist approach to uproot this opinion of X as inevitable, hoping to change the way that people think about X or the way in which X operates in the world. Within this observation, Hacking also notices that people seem to have grades of commitment to social construction, but there is little room in traditional constructionist theory to identify different levels of commitment. Commitment to social construction may be assessed by asking “what are we saying when we say X is socially constructed?” Hacking suggests that depending on our level of commitment to constructionism, we may be stating one or more of the following: X is taken for granted; X appears inevitable; X is not determined by the nature of things; X is not inevitable; X is quite bad as it currently is; X would be better if it was done away with or radically transformed. Hacking then expands this theory to include several different types of social construction.

Hacking's vision of social construction describes a perspective filled with infinite small differences, with the universalist notion of social construction on one end of the
continuum and what I will term “partial construction” on the other. Within this continuum he identifies 6 stances: Historical, Ironic, Unmasking, Reformist, Rebellious, and Revolutionary (Hacking, 1999, p. 19).

3.2.1.2 How I understand constructionist theory.

Within Hacking’s work I am able to find an increasingly sure foothold for my own constructionist stance. I identify with the “Unmasking” type of social constructionism. Within this type of constructionism, I do not seek to refute ideas (necessarily) but to unmask them by exposing the function they serve, to strip them of their false appeal or false authority. Hacking identifies that some “Unmasking” constructionists may also (although not necessarily) be “Reformist” constructionists. Reformist constructionism believes that X is quite bad. They have no idea how to live without X but by understanding that X is not inevitable, they can modify some aspects of it to make it less objectionable. While I identify mainly with the Unmasking stance, I also appreciate aspects of Reformist stance, particularly the hope to modify aspects of X.

I situate myself in a constructionism that recognizes the power of discourse and social institutions to shape the meanings that people live within. In order to recognize that discourse and institutions can have a real effect, one must embrace a certain amount of what I have termed “partial world construction” after the writings of Hacking (1999) and Harris (2008). From Harris’ (2008) objective sociological constructionism (OSC), I take the aspect which emphasizes that an individual’s understanding of her life, her self, and her world is influenced by the power exercised through social institutions, formal or informal. I draw from social constructionism an emphasis on the importance of discourse as the vehicle through which one articulates the parameters of her world and herself. I believe, like OSC thinkers, that these constructions have the power to effect real change; that family relationships are real, not just the “putative interpretations of relationships” and that many people experience the forces of racism, classism, ageism, and sexism as changing their realities, and not just their perception or interpretation of what is real.
3.3 Critical Social Theoretical Perspective

My critical social theory perspective is at the nexus of several inter-related topics: the ways in which medicalization, normalization and risk function as forms of social control which are intrinsically related to Foucault’s ideas of power/knowledge and governmentality. It is important to note that Foucault’s conceptual ideas overlapped considerably with one another, and continued to evolve throughout his life, as did the interpretations and applications of his work. Most of the writers I draw upon to understand the topics of medicalization and risk are indebted to Foucault. I begin by introducing the topic of medicalization before providing an outline of the main Foucauldian concepts that inform this work. This ordering was chosen to provide context for my explanation and interpretations of Foucault. I will then move on to discuss various ideas of risk. Throughout this section I provide explicit links between prenatal screening and the ideas I am engaging with. While headings have been added throughout as an aid to the reader, it should be noted that the ideas are inter-linked and the divisions made by the headings are somewhat artificial.

3.3.1 Medicalization.

Following a review of the literature, Morgan’s (1998) definition of medicalization remains my favourite, for its simplicity and impact. Morgan starts with a standard definition by one of the seminal thinkers on the topic, Peter Conrad. Conrad and Schneider (1980) see medicalization as the unintentional or intentional expansion of the domain of medical jurisdiction. Morgan politicizes the term, declaring that successful medicalization involves a culture that supports “the legitimacy of using medical concepts, theories, and discourses to describe medicalized life phenomena and the acceptance of the use of medical interventions to 'treat' them" (pg. 85). This may not seem overtly political, however the ensuing explanation of the dialectic nature of the process of medicalization completes this definition. Morgan sees medicalization as necessitating a dialectical relationship between micro-institutionalizations (through self management and doctor-patient relations), macro-institutionalizations, and societal conceptualizations. In short, medicalization is not something that is simply imposed on people by the institution of medicine. Medicine does not expand its jurisdiction through a creeping invasion of
territory as conceptualized by Zola (1972). Morgan makes the point that people must accept or acquiesce to the new jurisdiction that medicine proposes for itself, thereby becoming implicit in the process of medicalization. As an example of this implicitness, sometimes people request increased medical surveillance, or medical definitions of formerly non-medical problems. Conrad and Schneider (1980) discuss several examples of this, such as the lobby for alcoholism to be classified as a disease. I view Morgan’s definition as political because I read Foucault’s conception of bio-power, governmentality, and normalization into the idea that people must accept, acquiesce, and even request participation in this new jurisdiction of medicine. I see her definition as related to social construction because of her emphasis on the dialectical nature of the relationship between the individual and the institutions, and between institutions. Morgan’s definition of medicalization also emphasizes the way that social forces can create new needs, opinions, and discourses at the level of the individual. Morgan also recognizes that not all people, indeed, not all women, are medicalized to the same extent—other social forces shape the relationship between an individual and the institutions of medicalization.

Morgan posits that there are three contextual conditions that successful medicalization requires: First, the domain (e.g. sexual satisfaction) / process (e.g. menopause) / topic (e.g. alcoholism) currently becoming a medicalized problem must be defined in medical terms through assimilation into medical paradigms or theories. This problem must be describable through medical discourse. Second, medical authorities must be seen as the only legitimate authorities in terms of having knowledge and control over the problem. They must have the means to apply this knowledge to the medically defined problem. Third, there must be widespread acceptance of the dominant medical conceptualization of this problem. This process of successful medicalization has the effect of transferring “the locus of pathology from society to the individual” (Figlio, 1983, p. 232 as cited in Wilkerson, 1998). As medicalization becomes more politicized (by transferring responsibility from society to the individual), social roots of problems are obscured. Prenatal screening provides an example of this. As screening technology advances, the responsibility for the support of individuals with disabilities moves from society (in terms of supportive housing, health care, recreation) to the individual (responsibility of mother
to prevent individual with disability from being born). The onus placed on women to
detect and abort fetuses with disabilities may obscure the responsibility of society to help
all people live to their full potential.

By discussing the context, process, and interactions which necessitate successful
medicalization of a domain, process, or topic, Morgan demonstrates the many levels upon
which medicine’s social control may operate. This is in contrast to definitions offered by
Zola (1972), and Conrad and Schneider (1980) who view medicalization as a
contextually opportunistic colonization or Wilkerson (1998) who describes
medicalization as a conscious affront against women in an effort to exert control. More
nuanced discussions of medicalization involve descriptions of why women pursue
medicalization. Again, there are multiple layers to this question. Some theorists describe
the benefits of medicalization— it offers legitimacy to a perceived problem, efforts and
resources to solve the problem, and social acknowledgement of the problem (Conrad &
Schneider 1992). Conrad and Schneider (1992) see medicine’s capacity for social control
as a way to “secure adherence to social norms using medical terms to minimize,
eliminate, or normalize” (p. 242). Others discuss the way social control operates twice:
once to convince a person she has a problem and then again to convince her that medicine
is the answer (Lock, 2001). Kathryn Pauly Morgan conceptualizes an even more
complicated approach. The processes of medicalization do not just operate on people,
but are also put into motion by people. Her idea of how micro (i.e. medicalized
subjectivity, the gaze) and macro (i.e. social, economic, political, symbolic forms)
institutional factors interact with medicine echoes the social constructionist tenet that
society shapes and is shaped by its members (socially constructed knowledges) and the
Foucauldian idea that power is exercised by enabling people to act in order to constrain
them (Foucault, 1978). Morgan (1998) sees the “ordinary life world” (p.87) as shaping
and as shaped by conceptualizations of medicine, macro-institutional effects, micro-
institutional effects (through self management and through doctor-patient relations). All
of these institutions shape each-other as well as the “ordinary life world”.

In The Birth of the Clinic, Foucault (1973) discusses how social control was at one time
exerted through the church, upon the soul. Foucault suggests that as the social power of
church began to decline, medicine filled the void of power by exerting control over the body. Foucault contends that medicine exerts control over the body through disciplinary tactics: by regulating its forces and operations, as well as the economy and efficiency of bodily movements. Conrad (2007) describes several contextual forces that promote medicalization: a decline of religious influence; a rise in scientific authority; a rise in trends toward individualism, technological solutions, and humanitarian concern. As the authority of scientific knowledge increased, knowledge was re-defined as that which is measurable, objective, irrefutable, and neutral. Medical authority increased concurrently due to claims based on a similar epistemic base. Instrumentation was a large part of the authority of this knowledge. After all, the scientific paradigm holds that instruments cannot lie. Instruments also appeal to the desire for observable and measurable knowledge popularized by science (Wilkerson 1998). Foucault (1973) states that medicine’s normative moral authority is located in its epistemology, and that knowledge about the body is both the effect and a condition of the exercise of power (Foucault, 2003).

But what is the relationship between medicalization and prenatal screening? As medicalization has normalized and promoted prenatal screening, the implications, purposes, and practices of pregnancy have changed. As prenatal screening becomes more normalized and therefore more frequent, social support and acceptance for people with disabilities has become increasingly rare. Taylor (2008) notes that an increasing amount of money, time, technology, and effort has been spent incorporating technology into finding (and aborting) fetuses with disabilities. Comparably, very little time, effort, and money has been spent ameliorating social inequalities that demonstrably produce similar health problems.

Medicalization has a curious affect on issues such as the ones mentioned above. When problems become subsumed into the institution of medicine, they are removed from discussion amongst ordinary citizens in the public realm, and become part of the medical realm, where only people with medical authority may discuss or critique them (Conrad & Schneider, 1992). I think this has two potential effects. First, there are few ways for citizens to express opinions about what they think is acceptable medical practice or
behaviour. Would citizens choose widespread prenatal screening? We don’t know since there has never been public debate because the topic is in the realm of medical authority. Second, are individual women able to choose what they want to do? Some might say yes, since prenatal screening is an optional procedure that incorporates an informed decision-making process.

### 3.3.2 Normalization

I appeal to the notion of normalization when considering these questions. Normalization can be understood here in two ways: normalization of the screening test and normalization of ways of being. Considering normalization of the screening test, Susan Sherwin (2001) states that women are well conditioned to comply with medical advice and direction about their pregnancies. This ideology of compliance is hard to resist because it is built upon the discourse of protecting the unborn child. Women who may not wish to have prenatal screening, or other types of medical intervention, may feel obligated to participate. Sherwin (2001) questions the autonomy\(^2\) available to a woman considering ultrasound. She finds that the normalization of the technology places an enormous burden of proof on those who do not want to participate. Each use of the technology consolidates its “necessity” and the power and control of those who provide it. Seavilleklein (2009) makes a similar point about normalization: “the very offer of screening, however it is framed, may create a perceived need for testing, especially when screens have been selected and implemented by the medical system; this decision establishes screening as a legitimate use of scarce medical resources and thereby surreptitiously underlines its importance” (p. 75). Sherwin (2001) also argues that the technology medicine uses to examine the fetus distances the mother from her pregnancy. The constant testing may create anxiety. This distance and anxiety has the effect of making the mother more reliant on her physician, increasing the sense of dependence and minimizing reproductive autonomy.

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\(^2\) See the literature review for a lengthy discussion of different conceptions of autonomy in prenatal screening
Concerning normalization of ways of being, medicine’s inclination to measure and compare people has created a body of numerical information that defines normal as average. This allows medicine to compare people based on whether or not their traits fall in or outside of the norm. If they are outside, they are encouraged (or coerced) to engage in treatment or practices which bring them closer to the norm (Lupton, 1999a). The Human Genome Project has intensified this idea of “normal”. By mapping the human genome, scientists have produced a definition of “genetically normal”. Unfortunately, no one individual meets that baseline norm- individual genomes show infinite variations. In other words, we are all deviants (Lock, 2001). If one questions whether any of us are genetically “normal”, a challenging question is raised: What gives any institution the authority to declare particular genetic compositions as better or worse than others?

The notion of risk is intrinsically linked to normalization- for example, genetics does not always explicitly refer to “normality” or “deviation”, but uses the idea of risk to express this concept (Waldschmidt, 2005). “High-risk” people are those singled out as requiring expert knowledge and surveillance in order to become normal. Lupton (1999a) sees two kinds of medical risk: clinical risk (deviation from characteristics observed in case studies) and epidemiological risk (deviation from observations of patterns identified with associated risk factors). These two types of observable risk serve to make risk calculable and governable, therefore making them problems that require action. This is the way that normality as risk is seen to govern women- by inciting them to take action to prevent risk. Any deviation from the statistical norm means that woman is high-risk, abnormal, and in need of medical surveillance. In prenatal screening, risk distribution is continuous, with no sharp definition of what is normal and what is high-risk (Waldschmidt, 2005). Notably, in pregnancy there is no “no-risk” category - all pregnant women are seen as at some level of risk and in need of expert surveillance. The more prenatal screening tests are introduced, the more intensified discourses of risk become and the more choices a woman must make (Lupton, 1999a). These new tests exert a subtle (and sometimes, not-so-subtle) pressure on women to conform by participating in the tests.
3.3.3 Foucault's governmentality & bio-power.

It is impossible to discuss medicalization, normalization, and risk without talking about the ideas of Michel Foucault. I will introduce Foucault by talking about his idea of risk as a component of governmentality and then move on to provide a brief synopsis of how Foucault’s idea of governmentality informs his notions of risk, normalization and bio-power. Finally, I discuss the ways in which these concepts are related to prenatal screening.

Governmentality is a concept developed most fully during Foucault’s lectures at the College de France (Burchell et al, 1991). Governmentality is the basis of the technologies through which we become subjects, through which we police others and are policed ourselves. In this way, governmentality is an attitude associated with governance of self in order to allow the governance of others- it creates subjects in order to control them. The word “police” is very important- Foucault gave this word more meanings than we typically associate it with in English, and defines it relative to the sublimation of the individual into the social entity (see Barker, 1998 for a full explanation).

Foucault’s construction of risk as a method of governmentality, as discussed in his 1978-79 lectures at the College de France, is particularly relevant to risk in prenatal screening (Foucault, 2008). He contends that risk is formed by expert knowledges that provide guidelines and advice by which populations are governed. They do this by comparing things against norms and training people to conform with these norms (and thus be rendered productive). Central to this theory is the idea of normalization (Foucault, 1978). Foucault’s normalization is a form of social control whereby norms are constructed and those who adhere to those norms are rewarded while those who deviate are punished. Normalization and governmentality are enacted by technologies of mass surveillance, monitoring, observation, and measurement. They help maintain disciplinary power, by ensuring that people discipline themselves and each other, creating productive and docile bodies (Foucault, 1977). Normalization and governmentality are also seen to construct understandings of bodies in space and time and use these understandings as a disciplinary tool. From this Foucauldian perspective, risk is understood as a disciplinary strategy of
regulatory power by which populations and individuals are monitored and managed (Lupton, 1999b).

Foucault’s concept of normalization can be used to understand the appeal of prenatal screening. Foucault sees two possible ways for power to act: negatively (juridico-discursive) through repression or positively (bio-power), through enablement and self-surveillance. Foucault has used the term “juridical” to describe negative power in a way that draws attention to its relation with the law and law enforcement. This type of power forbids, prevents, and restrains. It “is poor in its resources, sparing of its methods and monotonous in the tactics it utilizes, incapable of invention, and seemingly doomed always to repeat itself … the power to say no” (Foucault, 1978, p.85). Foucault sees the second type of power (bio-power) as more interesting and more effective because it can overcome the paradox that paralyzes juridical power. Juridical power is paralyzed because of a paradox in its function: it is incapable of doing anything except rendering its target also incapable of doing anything. Bio-power is an agent of transformation in human life, bringing life and bodily mechanisms into the realm of knowable, calculable things (Foucault 1978). This causes life, the body, and bodily mechanisms to be subject to power (Dreyfus & Rabinow, 1982). The knowledge and measurability of life is central to the idea of normalization through medicalization. As human science developed, bodily mechanisms began to come under the control of the institution of medicine. Medicine measured, counted, calculated, and then formed ideas of “normal” which allowed it to appraise, hierarchize, judge, and draw a line between acceptable and unacceptable ways of being, beginning the process of normalization. Foucault saw normalization as the “outcome of a technology of power centered on life” (Foucault, 1978, p. 144). According to Foucault (2003), normalization can only function through knowledge; knowledge is both an effect and a condition of the exercise of normalizing power. In a series of lectures given a year after the publication of The History of Sexuality (Vol 1), Foucault expanded on his ideas of normalization as an exercise of power that is linked to intervention and transformation (Foucault, 2003). He makes clear that, in his view, what is normal is not linked to any kind of natural law or principle of intelligibility, but is entirely socially constructed. Normalization does not make a clear distinction between those who are normal or abnormal, instead it works by making a series of fine and
constantly observed differences between individuals who are normal and those who are not.

Foucault (1978) stated that the success of power “is proportional to its ability to hide its own mechanisms” (p. 86) and by this measure, bio-power succeeds admirably. By engaging with the process of normalization, bio-power works through enablement and coercion and through self-surveillance. Bio-power enables citizens to act in order to constrain them (Tremain, 2005). In contrast to the operation of negative juridical power (excluding, banishing, marginalizing, repressing), normalization fashions, observes, knows, includes, forms knowledge, functions through production, distributes according to individual capacities and is linked to a series of mechanisms that secure formation, investment, accumulation and growth of knowledge (Foucault, 2003). Normalization does repress, but only as a secondary effect (Foucault, 2003).

Governance through normalization (bio-power) is an important idea to feminists. Although Foucault is widely criticized by the feminist community for failing to differentiate between the way that bio-power and normalization have operated differently on male and female bodies, his ideas have been taken up and furthered by feminist scholars. In many cases, ideas which are credited to Foucault were published in different forms in feminist literature prior to his work (Bordo, 1994). Bordo (1994) believes that the reason why bio-power produces and normalizes bodies is to serve prevailing relations of dominance and subordination. While Foucault (1977) denies the centralization of a power that is used to subordinate certain subjects more than others, stating that power is not held by any one group or person, but acts on and through all people - it is not authoritarian, conspiratorial, or orchestrated, Bordo emphasizes the idea that people and groups are positioned differently within fields of power, stating that “no one may control the rules of the game, but not all players on the field are equal” (Bordo, 1994, p. 232).

Tremain (2005) sees practices of bio-power as central to the emergence of the disabled subject. Normalization and medicalization of human life have “created, classified, coded, and controlled social anomalies by which some people are divided from others and objectivized” (Tremain, 2005, p. 6). As measurement of human function gave way to
statistics, people became individualized through practices of division, classification, and ordering around a norm. Individuals came to identify themselves in relation to this norm, thereby making themselves subjects to this bio-political form of government.

Following this idea, prenatal screening might be conceptualized by some as a method of governmentality that may encourage subjects to normalize themselves (and their unborn children). Prenatal screening may create resistance to difference and encourages subjects to do what is necessary to engage in societal normalization. The practice of prenatal screening may be cloaked in the rhetoric of “choice”, autonomy, and reassurance (Lippman, 1991; Seavilleklein, 2009). Dreyfus and Rabinow (1982) point out that belief that one is resisting repression (by acting autonomously and making choices) actually supports domination and normalization by hiding the real workings of power. This rhetoric of choice is a strong example of the way that citizens may be governed through enabling action in order to constrain (Tremain, 2005). In this way, the “choice” presented by prenatal screening may also be seen as a risk to the health of women, children, and people with disabilities (Lippman, 1991). Prenatal screening may also be viewed as related to Foucault’s idea that statistical normality is a form of government. The whole idea of risk status is based on statistical normality, stratified by age. Value judgments of standard deviation and definitions of the mean (Waldschmidt, 2005) have become the basis for decisions of risk, further diagnostic testing, and pregnancy termination.

3.3.4 Risk.

Lupton (1999a) sees pregnant women as surrounded by a “complex network of discourses and practices directed at the surveillance and regulation of the body” (p. 59) that intensify as they become more noticeably pregnant. Lupton links this risk discourse to Foucault’s (1978, 1991) conceptions of apparatuses of bio-politics in neo-liberal societies and efforts on the part of the state and other agencies to discipline and normalize citizens, to render them docile and productive bodies. Lupton (1999b) develops this argument further, to compare realist, weak, and strong constructionist conceptions of risk. Neo-liberalism is a modern political philosophy which aims to transfer control from the state to the private sector, ostensibly for an improved (free market) economy. Concerning health policy, neo-liberalism proposes a sort of constructivist governance-
proposing to make health directly accessible, through strategic (as opposed to naturalistic) policies and defining “health” not as an absolute concept but a series of measurable targets (Osborne, 1997).

Strong constructionist conceptions of risk stem from Foucault. This viewpoint sees risk as socially and culturally created. Nothing in itself is a risk, but according to risk discourse, everything has the possibility to be risky. Risk is not embedded in an individual; it is a combination of a number of factors that produce the likelihood of an action being deemed unacceptable by social norms. Risk does not exist in reality, only in the culture that created it. Risk discourse is a central component to ensure social order.

Lupton discusses the way in which pregnant women are positioned in a network of surveillance, monitoring, measurement, and expert advice. This surveillance is enacted by authorities, members of the public, and women themselves as they self-monitor and self-regulate in order to achieve norms created by knowledges of risk. The web of surveillance becomes clear when the regulation of pregnant behaviours is considered in terms of rules about diet, smoking, alcohol consumption and exercise. Lupton sees pregnant women as vulnerable to these governing surveillance strategies because to resist is to declare that one does not care about her own health and welfare or that of her fetus. In fact, many women demand more access to medical surveillance, including an increased number of ultrasounds to “alleviate anxieties and fears that the fetus is healthy” (Lupton, 1999b, p. 90). This is an illustration of how medicalization requires the participation of its subjects. To refine Conrad and Schneider's (1980) colonization metaphor, medicalization does not conquer new territory with weapons, or when the native inhabitants are sick or sleeping, but rather tempts the inhabitants with new ideas and technologies, encouraging them to invite these items into their homes, extol their virtues to their friends and families, and thereby create a niche and re-shape the daily lives of the inhabitants to the point that they no longer recognize the ideas and technologies as new or foreign.

Lupton’s ideas of risk contribute to an understanding of why women engage in prenatal screening, why society supports prenatal screening without question, and the difficulty
women may have resisting societal norms by questioning medical methods of surveillance, monitoring and measurement.

O’Byrne and Holmes (2007) take Lupton’s idea of risk even further by examining the way that risk operates in Plato’s *The Good Citizen*. O’Byrne and Holmes understand risk to be constructed through, among other ways, discourses, with definitions continually in flux to allow mechanisms of control to be synchronized with activities that are ‘risky’ to the society. This is applicable to prenatal screening, where words such as “birth defect” create a discourse of what types of children are acceptable to society and what types are unacceptable and ‘risky’.

One major criticism that feminist scholars raise with respect to Foucault is that by treating male and female bodies as the same, he does not problematize the gendered nature of power and does not recognize that they have different relationships to institutions. Although Conrad (2007) sees medicalization as only marginally more active on female bodies, most authors in this area view medicalization as much more controlling to female bodies (ex. Bordo, 1994). Bartzky (1998) states that each woman lives her body as seen by another, an anonymous patriarchal other (p. 34) and that medicalization has more impact on women’s bodies as a result of this. Foucault is also criticized for the lack of agency he attributes to individuals. Many medicalization scholars see individuals as *operating with* the institution rather than being *operated on*, congruent with Foucault’s bio-power, but as in the discussion at the beginning of this section, it is often unclear if “operating with” is through acquiescence or agency (ex. Conrad & Schneider, 1992; Morgan, 1998; Reissman, 1998). Regardless of these criticisms, Foucault is a main contributor to theories of how medicalization acts as social control.

**3.3.5 Congruencies between critical and constructionist perspectives.**

If we accept the constructionist assumption that what we understand about our world is not arbitrary and that we can fashion our own future by the ways we describe, explain, and represent the world (Gergen, 1999), we can see that constructionism invites us to re-think our reality, to question the current traditions, practices, and “ways of doing”.
Critical constructionism asks us to pay special attention to the claims of those who purport to be objective and neutral. Gergen invites us to ask ourselves the following questions: What are the repercussions of these ways of talking? Who gains? Who is hurt? Who is silenced? What traditions are sustained? Which are undermined? How do I judge the future we are creating? (Gergen, 1999, p. 62). These questions have informed my standpoint and my thinking on prenatal screening and the ways in which prenatal screening is discussed in various venues.

Hosking (2008) sees critical questioning and constructionism to be congruent, reasoning that they can work together because constructionist theories “implicitly embrace metatheoretical assumptions that center a singular real-world reality (the assumption of ontology) and sharply distinguish this real-world reality from knowledge about it (the assumption of epistemology)” (p. 671). This may be part of the confusion Hacking (1999) identifies in constructionist authors. What is the ontological belief and what is the epistemological belief? I believe the existence of an empirical, real-world ontology and a constructionist epistemology is possible and that this combination can produce the possibility of critical constructionist questioning. When I use my binocular critical-constructionist lens, I must recognize the way that I am constructing what I see and acknowledge that the process of research is intrinsically linked with the product- there is no separation between the two.

3.4 Theoretical Lens

3.4.1 Feminist bioethics.

It is well understood that feminism is not a singular or unitary theory, but rather a large and amorphous collection of ideas. The feminist work that I engage with to inform my theoretical lens is that of Abby Lippman, Susan Sherwin and Dorothy Smith. The work of these women is not necessarily fully congruent, but neither is it contradictory. The commonalities that I draw together to compose my theoretical lens include a focus on everyday experience and the value of social justice for women and other marginalized groups.
The work of Abby Lippman has been described at length in Chapter 2, so is only briefly revisited here, to highlight the aspects which inform my theoretical lens. Lippman does not explicitly claim to be a theorist, but her body of work on prenatal screening suggests that she adopts a theoretical lens which equates ethics with social justice in everyday life. Lippman works within the constructionist paradigm to examine the way that dominant cultural constructions of concepts such as motherhood, gender, disease, disability affect the everyday lives of women, children, and people with disabilities. While she does not name her particular constructionist influences, she defines how and what she sees as constructed. In the following passage, she explores the construction of biological disease:

Despite their biological reality, human diseases, disorders, and disabilities – the objects of prenatal screening- are not just physical or physiological states with fixed contours. Rather than being merely “out there” awaiting our discovery, they are social products with variable shapes and distributions that we fashion, interpret, and give meaning to via our beliefs, attitudes, values, and interests. Western biomedicine is our ethnomedicine, and it does not describe a pre-existing biological reality. Particular social and cultural assumptions (Wright & Treacher, 1982) influence the scientific researchers who give the biological processes of observed diseases particular forms through their diagnostic labels and causal attributions. Those forms vary across different human groups and at different periods of time. How the processes are counted, defined, and studied, and how people are assigned to the categories created is necessarily context-specific, reflecting how those with power at any particular historical time construct a particular physiological or physical condition as a problem. (Lippman, 1994, p.12)

When assumptions, discourse, and values are predicated on dominant knowledge, how can members of oppressed groups navigate institutional structures in a way that allows them to make their own choices and live in the way they want? For instance, would prenatal screening be needed for “reassurance” if dominant knowledge had not already “decided that certain women were at risk and that the condition for which the risk existed warranted diagnosis before the baby with it was born” (Lippman, 1994, p.16)? Phrased
another way, where is individual choice when all the given options are constructed by someone or some institution that does not share the conditions that predicate the lives of the individuals being offered the choice? “Continuing a pregnancy when the fetus has been found to have Down syndrome cannot be considered a real option when society does not truly accept children with disabilities or provide assistance for their nurturance” (Lippman, 1994, p.19). Lippman sees the social world as stratified along lines of gender, race, class, and (dis) ability. When using this lens to study prenatal screening, a critical examination of the potential for reinforcing inequities and inequalities in health is important, as these inequities affect the way that choice can occur.

Many choices are just not open to many women, in particular to those women who are kept poor, those with disabilities, racialized women, lesbians and so on (see Roberts, 1997). Seeing choice as gender (class, race, or otherwise) neutral hides the operations of power that construct choices, reaffirms existing privileges in society and, in general, glosses over the many differences between women that matter (Wolf, 1999). It ignores how access to economic and social resources is essential to freedom of choice and how freedom of choice cannot exist without secure social justice, what Petchesky (1993) calls the “conditions without which rights cannot be realised in practice”. It renders invisible the persisting absence of social justice for women. (Lippman, 1999b, p.282)

Canadian philosopher Susan Sherwin (1992, 1998; McLeod & Sherwin 2000) has influenced my thinking through her conception of relational autonomy as an essential element of feminist bioethics. I have discussed relational autonomy at length in Chapter 2. Elements of Sherwin’s theory which are useful for my theoretical lens include an acknowledgement of the way that power differentials between physicians (medical institution) and women may influence the decision making processes of women engaging with the medical system. The individual context and circumstances of a person greatly affect the options available to her- with this recognition, we can see that for some women, choosing to engage in prenatal screening and abortion may never be a truly free or autonomous choice. For others, who have more power and resources in the form of wealth, social status, and education, the choices presented by prenatal screening and
abortion may be closer to her own choices. For Sherwin, individual and societal context is essential to conceptions of autonomy. On a macro level, historical and political contexts influence bureaucratic decision makers which affect scientific and governmental funding agendas, therefore affecting the information and options women are required to use to make decisions about prenatal screening. For example, on a macro level context, our cultural emphasis on individualism can disguise elements at the source of decisions and problems, and fail to acknowledge the interconnected nature of power in society.

Canadian sociologist Dorothy E. Smith informs my theoretical lens through her standpoint theory, which demands attention to contextual factors in order to promote social justice. Smith explicitly states that her theory is not a theoretical construct, but a place to begin inquiry (Smith, 1993). Smith’s work is useful not just as a place to begin inquiry but also as a lens through which every day practices can be considered and examined.

Smith (1987) has, on occasion, been subsumed into the category of feminist standpoint theory (e.g. Naples, 2003), however Smith (1993) protests that her notion of standpoint is very different from Harding (1986) and contemporaries. For Smith, standpoint is an idea that aids in building a sociology of women’s lived experience. She uses it to explore how power dynamics are organized and experienced in the context of women’s everyday lives, paying specific attention to how social relations are embedded in this context. Smith provides a framework for conceptualizing community (women or other oppressed groups), starting with an active knower who is connected to others in particular, identifiable ways (Smith, 1992; Naples, 2003). However, this method does not privilege the knower, but rather shifts the ground of knowing to the social field. Smith (1992) sees knowledge as socially organized, therefore “never an act or an attribute of individual consciousness” (p. 91). Smith’s (1987) method of inquiry is concerned with the examination of “abstractions” and the ways in which these are combined with concepts and knowledge to become socially organized practices. Making these practices visible also makes visible the ways in which we participate in these practices and incorporate them into our own knowledges (Smith, 1993).
Smith (1990b, 1990a) has written about ways in which texts can act to organize social action, and can function to reveal the ways in which bureaucrats and institutions seek to organize social action. Using the metaphor of the text as a “crystal which bends the light as it passes through” (Smith, 1990b, p. 121), Smith suggests that the text can be seen as aiding social organization. “The operative part of a social relation is activated, of course, by the reader but its structuring effect is its [the text’s] own” (p. 121). By examining texts we can gain access to the “ontological ground of institutional processes which organize, govern, and regulate” (p. 122) society- although we may not normally acknowledge this, due to our habituation to texts. Through a close examination of texts we can also examine the ways in which facts are constructed to serve the purposes of particular groups, usually to the detriment of another group. “A fact is constructed in a definite institutional context, and its organization reflects that context. An inner coherence is established between the actuality thus represented and the statements that can be made about it” (Smith, 1990a, p. 78).

3.5 Conclusion

Through a bricolage of critical and constructionist theories, my research questions the taken for granted notions of prenatal screening in an attempt to critically question the meanings and understandings of this test, and the ways in which they reflect the meanings and understandings of our broader society. With a focus on the individual situated location of women being offered and making a decision about whether or not to participate in prenatal screening, I seek to contribute to knowledge which explains and informs some of the opportunities and challenges they may face.
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4 Methodology and Methods

4.1 Introduction

In the first part of this chapter, I outline the reflexive approach I use with Kathy Charmaz's Constructivist Grounded Theory, discuss the congruency between constructivist and constructionist visions of grounded theory, and address the issue of why I chose a grounded theory approach to the research. In the second part, I provide a detailed account of the methods I used for the three linked studies.

4.2 Part 1: Methodology

4.2.1 Reflexive research.

Instead of treating reflexivity as a component of the methods section of this project, I consider it to be part of the methodology, necessary at each stage of the research process. The move towards reflexive methodologies is popular within feminist research, as it recognizes the “shifting positionalities of the researcher and participants ... [and] offers the opportunity for raising new questions, engaging in new kinds of dialogue, and organizing different kinds of social relations” (Hesse-Biber & Piatelli, 2007). Considering feminist research to be reflexive research allows many different kinds of methodologies, both quantitative and qualitative, to find a home in feminist scholarship—a famously broad and variable field.

Reflexivity is an evolving topic, used and defined in many different ways. Since the purpose here is not to conduct a literature review on reflexivity, I outline the way I use the term and set aside other possible ways of considering it, not because they are without merit, but rather because this is outside the scope of this project. Loosely, I use reflexivity to mean positional reflexivity (Koch & Harrington, 1998; Macbeth, 2001), or an examination of the social and individual contexts of researcher and participant as a means to deconstruct “dualities of power and anti-power, hegemony and resistance, and insider and outsider to reveal and describe how our representations of the world and those who live there are indeed positionally organized” (Macbeth, 2001, p. 38). The purpose of this kind of reflexivity is to seek “a critical understanding of ordinary worlds by reference to
larger but unnoticed arrangements and conditions” (Macbeth, 2001, p. 40). I think
reflexivity is also important in considering the ways in which an individual’s position
affects the way knowledge is constructed, and how the everyday world is interpreted,
related to, and moved within.

Sharlene Nagy Hesse-Biber and Deborah Piatelli (2007) outline the purpose of reflexive
research:

The purpose of research is not to validate a Truth, but to enable different forms of
knowledge to challenge power. Multiple truths and diverse knowledges become
the actual product of research when the subjectivity, location, and humanness of
the knower are included. (Hesse-Biber & Piatelli, 2007, p. 498)

Koch and Harrington (1998) discuss academic reflexivity as providing the opportunity to
consciously consider how, why, and when research decisions are made, and how these
decisions affect the research process and product. They encourage researchers to “sign-
post” their writing with reflexive decisions, allowing readers to engage with the
viewpoints of both the researcher and participants to decide if the research is plausible.
Feminist reflexivity goes farther than this, interrogating not just personal and cultural
views the researcher holds, but also how and why these viewpoints came to be, and the
broader significance of this for how knowledge is generated. Taylor and White (2000)
ask researchers to broaden this conscious consideration of how research decisions are
made to consider how knowledge is generated; they call for researchers and practitioners
to explicitly acknowledge the particular types of knowledge they use to make sense of
situations and events, and to consider how various types of knowledge may be culturally
constructed (Taylor & White, 2000).

Dorothy E. Smith (Smith, 1974;1987) invites feminist researchers to take a step farther
back, to acknowledge our particular standpoint as individuals, and to consider how that
standpoint affects the way we interact with the world (and the way the world interacts
with us). She says that it behooves researchers to think about the individual standpoints
of the participants in the research, and to engage with these individuals rather than
observe them from an outside position. According to Smith (1987), this consideration of
standpoint is important because nothing (no academic discipline) and no one (no researcher) can avoid being situated, so Smith (1990b) calls for research that acknowledges that situatedness and builds it into our methodological and theoretical strategies. Smith (1987) highlights the ways in which the researcher affects her data: she “is and must be an active participant in constructing the events she treats as data” (Smith, 1990b, p. 13). The ways in which the researcher constructs the data is one of the focuses of reflexive thought. This echoes Bourdieu’s instruction that critical theorists must examine their own relation to the research object, reflecting the scientific gaze back on themselves (Bourdieu 1993 in Hesse-Biber & Piatelli, 2007).

Smith’s methodology, like all reflexive research, challenges the unquestioning production of “objective” knowledge (Hesse-Biber and Piatelli, 2007). Smith’s goal (1987; 1990a; 1990b; 1993; 1997) is to elucidate a method of social research that is reflexive about the everyday experiences of people’s lives, and that asks what are the facts, how did they become facts, and how does factual knowing occur. This situated line of questioning requires a “dizzying change in perspective” (Campbell, 2003, p. 11) in pursuit of the goal of interrogating how people make sense of the world, and how particular meanings are constructed. Smith (1974; 1987) proposes to change the relationships between the researcher and the object of knowledge, creating a new relationship based on direct experience of the everyday world; she asks how else do individuals interpret information and events, if not through their direct experience? Reflexive research begins with the researcher’s original and immediate knowledge of everyday life (what Smith terms an ‘insider’s’ approach), and moves to an exploration of what passes beyond everyday life and how that particular way of understanding is deeply implicated in how everyday life is represented (Smith 1974, pg. 12).

An insider’s strategy takes concepts, ideas, ideology, and schemata as dimensions and organizers of the ongoing social process that we can grasp only as insiders, only by considering our own practices ... Taking up critique-as-inquiry or inquiry-as-critique as an insider adds a further dimension [to inquiries of knowledge of the relations and apparatuses of ruling]. Inquiry becomes an essentially reflexive critique. For the relations explored here can be grasped only as we are insiders
participating in them. At the same time, in exploring them we bring into view not just our actual practices of thinking, reasoning, reading, making sense of accounts, and so forth, but the actual social relations we participate in by doing so. In this way, as insiders, relations that our own practices are embedded in can be made explicit and examinable through inquiry. (Smith, 1990a, p.202-204)

By approaching research from this angle, it is possible to link everyday subjectivities with underlying institutional structures (Doran, 1993). When approaching research in a way that inquires into the “way things work”, the actualities of our everyday social practices become visible and research becomes a necessarily reflexive activity: “critique is investigation and investigation is a reflexive critique, disclosing practices we know and use ... disclosing how our practices contribute to and are articulated with the relations that overpower our lives” (Smith 1990a p.204).

In light of these perspectives, the challenge becomes how to incorporate reflexivity into research in a concrete way. Hesse-Biber & Piatelli (2007) have created a unique method to increase researcher reflexivity adapted from Conner & Bliss-Moreau’s (2006) experience sampling, of which I have adopted in an adapted form to increase my own reflexivity as a researcher. Experience sampling is a technique to document subjective experience in the moment, and over time. Participants are reminded through various technological means to stop and record their subjective experience based on questions offered by the researchers. Conner & Bliss-Moreau (2006) maintain that this resolves temporal issues such as lapses in memory or the loss of emotion when experiences are measured at a later date, or when a participant is asked to recall how they felt at a certain time. Hesse-Biber & Piatelli (2007) call this technique reflexive sampling. Reflexive sampling involves periodic reminders throughout the project for the researcher to “check-in” with herself about how things are going. By using a reflexive diary, tape recorder, or notes on a portable data device, key questions can be answered at pre-determined times. These reflections can be used for reflexive thought later. Hesse-Biber & Piatelli (2007) suggest some of the key questions one might answer, including questions about researcher and participant standpoint and positionality, relationship with participants, attentiveness to difference, and reflexive interrogation of data. Since I am not doing field
research, but collecting interview data in discrete chunks, I chose to use several events as markers to engage in reflexivity. I wrote a reflexive journal entry after conducting each interview, during or after transcribing each interview, when insights occurred to me during coding, and after each round of coding. I recorded my reflexive journal entries in the form of emails in to special research memo e-mail account and through handwritten entries in a research notebook. I have included an example of a typical journal entry as Appendix 1.

This technique was helpful because I have a hard time remembering to interrogate myself and my data without what Brookfield (1998) calls a critical incident, or what Smith (1987) terms a “point of rupture” (p.49) between my personal experience and social forms of consciousness. When I am working away and things are going well, it is hard to remember to stop and analyze. Sometimes writing these entries was difficult, and felt forced. This was especially the case later in data collection, when I felt like I was repeating some of the same ideas again and again. At other times, I was compelled to write and wrote freely. In practice, I found that my reflexive journal and analytical memos blended together, with many areas of overlap. I found these journal entries helpful in tracing analytical ideas through their progression and identifying possible topics for manuscripts. For instance, after transcribing Carrie's interview, I wrote a journal entry about the possible theme of information-seeking:

Transcribing this interview made me think that there's a real possibility for a paper about what information women would want in order to make a decision about prenatal screening, what they would find helpful in the pamphlet, when they want the pamphlet etc. For instance, there have been a number of women mention they would want to get the pamphlet before talking to the doctor so they understand a little bit about what they're going to be offered and they can ask questions at that time, rather than getting all the information at once and having to make a decision without a chance to think about, it ask questions and then think about it again. ... A lot of the women are asking the why questions: why would I want to get this test? Why would I not want to get this test? what can I do with the information? Structuring the pamphlet to answer these questions might be
helpful... What is the test, why would I want to get it, why would I not want to get it, what will the test tell me, what can I do with that information. I think that these questions would be helpful.

This idea catalysed a focused code for "information" and that coding produced the findings for manuscript 3, Chapter 7. More information about this analytical process is described in Figure 3, section 4.3.5.8.

4.2.2 Constructivist grounded theory.

The methodology of grounded theory was developed in the 1960’s by Glaser and Strauss (1967) in an attempt to support and systematize the field of qualitative research. Grounded theory is a research approach that is used to inductively develop theory based on qualitative data, with all theoretical concepts extracted directly from the data and not imported from other theories or analyses (Walliman, 2005). Glaser and Strauss’s 1967 work was revolutionary because it blurred the line between theory/research and data collection/analysis, and challenged the prevailing view of qualitative research as without rigor (Charmaz, 2000). Glaser and Strauss (1967) provided some of the first written guidelines for conducting qualitative research, which had previously been taught through a mentoring system (Charmaz, 2000).

Since its origin in the work of Glaser and Strauss, grounded theory has moved through many theoretical orientations as different scholars have taken it up and made it their own. The theoretical framework used in this study is constructivist grounded theory as formulated by Kathy Charmaz (Charmaz, 2000; 2004a; 2004b; 2005; 2006; 2008).

Charmaz’s constructivist grounded theory differs from the more traditional objectivist formulations of grounded theory in a few key ways. Constructivist grounded theory (CGT) recognizes that both the researcher and the research participants create data through their interactions. CGT researchers claim that what is discovered “arises from the interactive process and its temporal, cultural, and structural contexts” (Charmaz, 2000, p. 524). This is different from objectivist grounded theory (OGT), which builds on the assumptions that what is observed is independent from the observer. OGT attempts to
achieve reliability and validity through description, analysis, and prediction. CGT does not attempt to develop generalizable truth, but recognizes the importance of the subjective interpretation of the individual and how that subjective interpretation is always evolving and always influencing interpretation of the data. Charmaz urges a move away from the didactic and prescriptive guidelines for grounded theory as espoused by Strauss and Corbin (Strauss & Corbin, 1998) towards a methodology that is flexible, with emergent and interactive guidelines (Charmaz, 2000).

Grounded theory is, above all, inductive. It starts with the data, with individual cases, stories, observations- the more variety in the data, the better! These data are analyzed systematically using a series of categories and codes. These codes emerge from the data, they are not taken from pre-existing hypotheses or prior studies. Charmaz recommends line by line coding, encouraging the examination of each minute piece of data as the best way to find potential significant pieces of information. After some initial coding, themes and categories can be identified. It is then time to go back and re-code, with these new insights. Slowly but surely, theory starts to arise from the data, which leads back to more data collection. As the next data are analyzed, new insights will emerge, making it is necessary to go back to the first bit of data with these new insights in mind. Grounded theory is an iterative process, new data reveal more to be studied and more things to examine (Charmaz, 2004a). Throughout this process, the researcher engages in memo writing, or taking notes about thoughts that occur during the analysis. Charmaz describes memo writing as helping to “elaborate processes, assumptions, and actions that are subsumed under your code” (Charmaz, 2004a, p. 511).

4.2.3 Constructionist approach to grounded theory.

I am working with the constructivist positioning of grounded theory as formulated by Charmaz (2000; 2004a; 2004b; 2006; 2008). In the following section, I make the case that Charmaz’ constructivist grounded theory is congruent with a constructionist stance. To understand the similarities and differences between constructivism and constructionism, it is useful to conceptualize the two concepts as existing upon a continuum of perspectives (Crotty, 1998). Constructivism focuses on the ways in which individuals construct meaning, and constructionism focuses on the ways in which
meaning is shaped by social, political, and discursive factors beyond the individual (Crotty, 1998).

Holton (Holton, 2007) sees the search for a paradigm as futile, and counterproductive, believing that grounded theory can “transcend specific boundaries of established paradigms to accommodate any type of data sourced and expressed through any epistemological lens” (pg. 268). I do agree that grounded theory fits into multiple paradigms, but I think it is necessary for each researcher who uses GT to explicitly state the paradigm s/he is working within, and his or her epistemological viewpoint, as this will strongly shape the questions that researcher asks, the way s/he approaches participants, the way in which data analysis is undertaken and carried out, and the themes that “emerge” from the data. In short, the researcher’s epistemological and ontological assumptions shape the research process, the interpretation of the data collected, and the themes or theory that may be the outcome of a grounded theory project.

Charmaz almost always titles her work “constructivist” grounded theory (Charmaz 2000; 2004b; 2005; 2006; 2008), but her methodology is also congruent with a constructionist stance. In this section I will examine direct and indirect epistemological statements Charmaz has made and argue that her work is congruent with Hacking’s (Hacking, 1999) vision of social constructionism.

Constructionism and constructivism are often confused and conflated, but there is also room for congruence between the ideas. Charmaz’s iteration of grounded theory has not escaped this tendency. For example, in his criticism of Charmaz’s constructivist grounded theory, Glaser (2002) consistently conflates the terms “constructionist” and “constructivist”, sometimes in the same sentence. A quick search of the research database Google Scholar retrieves 300 more hits for “Charmaz AND constructionist” than for “Charmaz AND constructivist”- this may indicate that Charmaz’s grounded theory is being used for constructionist research, that the two terms are commonly conflated, or that the terms may legitimately represent an area of overlap. It may also represent a general trend in the social sciences towards constructionist rather than constructivist research.
On occasion, Charmaz does use the constructionist label. For instance, Charmaz (2005) describes her work developing grounded theory “as a social constructionist method” (p. 509), and as imbuing “grounded theory with social constructionism” (Charmaz, 2008, p. 401). She explicitly renames her previous work (Charmaz 2000; 2004a; 2006) as “distinguishing between a social constructionist and an objectivist grounded theory” (2008, p. 398). Despite this, in most of her work she maintains the “constructivist” label.

4.2.3.1 Charmaz’s explicit definitions.

Charmaz (2006; 2008) explicitly defines her personal version of constructivism, in two very different contexts. Charmaz (2006) is a glossary entry in a methodological manual, and Charmaz (2008) is a footnote explanation about why a chapter on CGT is a relevant inclusion to *The Handbook of Constructionist Research*. In the first, Charmaz defines constructivism as:

> A social scientific perspective that addresses how realities are made. This perspective assumes that people, including researchers, construct the realities in which they participate. Constructivist inquiry starts with the experience and asks how members construct it. To the best of their ability, constructivists enter the phenomenon, gain multiple views of it, and locate it in its web of connections and constraints. Constructivists acknowledge that their interpretation of the studied phenomenon is itself a construction. (Charmaz, 2006, p. 187)

In a footnote to a chapter for the *Handbook of Constructionist Research*, Charmaz (2008) explains her reasons for equivocating between constructionism and constructivism. She states she is framing her work using “the more general rubric of social constructionism” (p. 409) to find a better fit with the theme of the book. Charmaz states that her version of constructivism holds that “people make their worlds but do not make them as they please, rather, worlds are constructed under particular historical and social conditions that shape our views, actions, and collective practices” (p. 409), which I see as useful to scholars working from a constructionist stance. Charmaz then cites other constructivist/constructionist grounded theory authors (including herself, Adele Clarke and Anthony Bryant) who locate their epistemological roots in sociological social
constructionism. Later in this article, in the main text of the chapter, Charmaz (2008)
gives an important reason for sticking with constructivism: incongruent to her vision for
grounded theory, she notes that “20th century constructionism treated research worlds as
social constructions, but not research practices” (p. 398).

These definitions give me room to work with Charmaz’s methodology within a
constructionist paradigm congruent with Hacking (1999)’s vision of constructionism,
which I suggest is congruent with the way Charmaz defines her vision of constructivism—
it realizes the constructed nature of research practices and research worlds, it holds that
there is a real world which is interpreted in different ways depending on the ways in
which the interpreter has been shaped by her social, historical, and cultural context while
still granting the interpreter agency to shape her own view of the world within that
context, making explicit the situated location of the interpreter’s context/standpoint.

### 4.2.3.2 Charmaz’s implicit definitions.

In addition to explicit definitions, Charmaz implicitly describes the constructivist
epistemology that informs Constructivist Grounded Theory in many publications. Some
of these epistemological statements may be seen as consistent with a constructionist
approach. For example, Charmaz (2006) sees texts as both individually and socially
constructed: “people construct texts for specific purposes and they do so within social,
economic, historical, cultural, and situational contexts. Texts draw on discourses....” (p.
15). This is congruent with constructionism if emphasis is placed on the way that the
individual constructs texts and is shaped unknowingly by discourse, as opposed to
focusing solely on the individual’s conscious construction within that context. Charmaz
(2006) states that a “CGT approach means learning how, when, and to what extent the
studied experience is embedded in larger and often, hidden positions, networks,
situations, and relationships.” (p. 131). This statement is quite congruent with
constructionism, although Charmaz brings it back to constructivism in the next sentence,
focusing on the individual knower: “Subsequently, differences and distinctions between
people become visible as well as the hierarchies of power, communication, and
opportunity that maintain and perpetuate such differences and distinctions. A
constructivist approach means *being alert* to conditions under which such differences and distinctions arise and are maintained” (p. 131).

Implicit statements show that the epistemological tenets of grounded theory can be interpreted through a constructivist or constructionist lens. Examining these statements shows that there is room to do constructionist work with Charmaz’ constructivist grounded theory. Constructivist grounded theory is, in many ways, consistent with Hacking’s (1999) vision of social construction.

**4.2.3.3 Epistemological congruence between Charmaz and Hacking (1999).**

I propose that Hacking’s “unmasking” and “reformist” types of social construction identified earlier are in many ways congruent with Charmaz’ constructivist grounded theory. In Charmaz (2005), a paper advocating CGT as a research method of social justice research, Charmaz details questions in critical social justice inquiry that CGT is well suited to answer (pg. 513-514); many of these questions are central to the “Unmasking” type of social construction, exposing ideas to examine what function they serve, thereby stripping them of false appeal and authority (Hacking, 1999). For example, Charmaz (2005) lists some questions relevant to social policies and practices that are directly applicable to my examination of the policies and practices of prenatal screening.

What are the rules, both tacit and explicit? Who writes or enforces them? How? Whose interests do the rules reflect? From whose standpoint? Do the rules and routine practices negatively affect certain groups or categories of individuals? If so, are they aware of them? What are the implications of their relative awareness or lack of it? To what extent and when do various participants support the rules and the policies and practices that flow from them? When are they contested? When do they meet resistance? Who resists and which risks might resistance pose? (Charmaz, 2005, p. 514)

With these questions in mind, I use Charmaz’s Constructivist Grounded Theory within the constructionist perspective identified by Hacking (1999).
4.2.4 Why grounded theory?

Charmaz (2005) inspired me to think about the ways in which CGT inspires critical questioning about social justice issues, considering the standpoint of the researcher and participants. This congruence of purpose suggested an effective method for investigating my research questions. When reading the work on metaphor analysis, I also noted an echo of grounded theory. Both Rigney (2001) and Schmitt (2005) think of metaphor analysis as revealing insights that can be categorized conceptually to reveal an underlying theory. By examining the metaphors used in a particular culture, it is possible to develop a theory about the way an issue is understood by members of that cultural group.

This insight led me to work towards developing a grounded theory project with a theoretical sensitivity to metaphor. I believe Charmaz would support the theoretical focus on metaphor, because she encourages researchers to “pay careful attention to respondents’ language” (Charmaz, 2004a, p.505) including metaphor (Charmaz, 2006). Charmaz also encourages the adoption and creation of new methods, provided they are used to support a transparent analytic process (Charmaz, 2008). I am encouraged by Charmaz’s invitation to stretch grounded theory to adapt it to my own needs and goals (Charmaz, 2006). Concerning metaphor, I am indebted to the work of Lakoff & Johnson (1980), who consider metaphors to be a socially contained way of structuring reality which function by organizing and shaping the way the world is understood.

4.2.5 Social construction, grounded theory, metaphor, and reflexivity.

The choice of Charmaz’s constructivist grounded theory was carefully considered. I was intuitively drawn to it because of my own constructionist leanings, but I was wary of the relativism that constructivism can carry (Boghossian, 2006). I find relativism inappropriate as an ethical framework and my ethical tendencies made me feel uneasy about adopting what may be perceived as a relativistic methodology. I draw on a critical feminist lens and Hacking’s form of social constructionism to overcome the problems relativism may pose.
Lakoff and Johnson’s (1980) ideas of metaphor seemed congruent with social constructionism to me, and there is support in the literature for this link. Gurney (1999) has outlined a number of ways in which metaphor is a crucial component to the social construction of reality. First, metaphor both constrains and enables social creativity. It implies a way of thinking and seeing that affects an individual’s relation with the world. Second, the metaphors used in a particular group define and hold that social group together, by building and maintaining a shared culture. Sometimes these cultural metaphors become so familiar that their original meaning is lost− they become a sort of “shorthand for common-sense social relationships” (Gurney, 1999, p. 1716). Third, metaphors can be inherently political. The selection of metaphors a person makes is very significant in the way that they exercise forms of power and resistance. In this way, metaphors do ideological work (Cresswell, 1997). Fourth, metaphors are conceptualised within a framework of rhetoric. Appeal to metaphors, aphorisms, and social maxims add a moral quality to speech, by implicitly expressing values. They associate common sense (as socially constructed, of course) with morality and prejudice (Gurney, 1999).

I also noted echoes of Foucault in Gurney’s third point, which is expanded upon in Cresswell’s 1997 work. The focus on the ways in which power and resistance are exercised to shape reality supports both my critical feminist and constructionist leanings. Gurney’s fourth point reminded me of the ancient pre-Socratic Greek philosophers (such as Gorgias) and the importance they placed on influential power of carefully chosen language to make a rhetorical point. To these scholars, the content of a message could be less influential than the way the message was communicated.

Constructionist grounded theory is congruent with an analytical sensitivity to metaphor. Charmaz has explicitly addressed the use of metaphor as a unit of exploration (Charmaz, 2000) and as a powerful tool for analysis and writing of grounded theory work (Charmaz 2006; 2008). Charmaz (2008) asks us to “interrogate taken-for-granted metaphors” and invokes Martin (1999)’s instruction for feminist researchers to find the sleeping metaphors in science and “awaken them”.

Sleeping metaphors wield power precisely because they remain tacit: They shape the text and, moreover, our conceptions of the realities it addresses. Such metaphors shape what we see and how we see it and contain hidden reasons that explain, justify, and perpetuate why we see it that way. (Charmaz, 2008, pg. 450)

The relationship between my theoretical perspectives (feminist bioethics, social constructionism) and methodological perspectives (reflexivity, grounded theory, metaphor) is exemplified in this quote.

4.3 Part 2: Methods

4.3.1 Study design.

In this research project my purpose was to investigate the process of prenatal screening in light of the 2007 Society of Obstetricians and Gynecologists of Canada (SOGC) Clinical Practice Guideline (Summers, Langlois, Wyatt, & Wilson, 2007), which mandated that non-invasive prenatal screening must be offered to all Canadian women. As stated in the SOGC guideline, non-invasive prenatal screening can take several different forms, and due to geographical differences and resource disparities, SOGC has refrained from endorsing one particular type. Eligible types of prenatal screening are those which meet the SOGC’s minimum standard for detection rate (> 75%) and false positive rate (< 3% in the first trimester, < 5% in the second trimester) (Chitayat et al, 2011). According to Chitayat et al (2011), eligible tests (see Figure 1) are First Trimester Screening (FTS), Quadruple Serum Screening (Quad), Integrated Prenatal Screening (IPS), IPS without inhibin A, and Serum IPS. In this project, the term "prenatal screening" refers to any or all of these different options.

<table>
<thead>
<tr>
<th>Test</th>
<th>Markers</th>
<th>Trimester</th>
</tr>
</thead>
<tbody>
<tr>
<td>FTS</td>
<td>NT, β-hCG, PAPP-A, MA</td>
<td>1</td>
</tr>
<tr>
<td>Quad</td>
<td>AFP, uE3, β-hCG, inhibin A, MA</td>
<td>2</td>
</tr>
<tr>
<td>IPS</td>
<td>NT, PAPP-A, AFP, uE3, β-hCG, inhibin A, MA</td>
<td>1&amp;2</td>
</tr>
<tr>
<td>IPS -inhibin A</td>
<td>NT, PAPP-A, AFP, uE3, β-hCG, MA</td>
<td>1&amp;2</td>
</tr>
<tr>
<td>Serum IPS</td>
<td>PAPP-A, AFP, uE3, β-hCG, inhibin A</td>
<td>1 &amp; 2</td>
</tr>
</tbody>
</table>
4.3.2 Research question.

The primary research question of this thesis is: “From the perspective of women under the age of 35 in their first pregnancies, seeking prenatal care from a family physician, how is the process of choosing to participate in prenatal screening enacted in light of the new SOGC guidelines?”. This guiding question informed my choice to collect data from three different sources: policies and guidelines, patient education materials, and pregnant women. The three types of data were chosen to respond to different elements of the process of choosing whether or not to participate in prenatal screening:

1) How do prenatal screening patient education materials portray concepts related to prenatal screening?
2) How do policies and guidelines shape the offer of prenatal screening?
3) How do women use information when making a decision about whether or not to participate in prenatal screening?

With these three sub-questions in mind, I undertook three mini studies, all of which are united by their relation to the main research question about choosing whether or not to participate in prenatal screening. First, regarding patient education materials, written information about prenatal screening may be used by some women to inform themselves prior to making a decision. These materials may be provided by a physician or found through a different venue, for instance, passed along by a friend or relative or searched out on the internet. A close examination of publicly available prenatal screening public education pamphlets was important to examine some of the types of information women receive in the process of making a decision. Second, since processes of prenatal screening in the context of family medicine are shaped by policy, I searched for and analysed policies that are relevant to the presentation and process of prenatal screening. Finally, I interviewed women about their thoughts and experiences navigating the process of prenatal screening. I asked women currently going through the process of prenatal screening about their experiences so far, including how they came to make a decision about whether or not to participate.
4.3.3 Study #1: How do prenatal screening patient education materials portray concepts related to prenatal screening?

The first study involved a metaphoric textual analysis of publicly available prenatal screening patient education material (see manuscript one, Chapter 5). The methods of this study are briefly described in the published manuscript, and elaborated in more detail in this section.

4.3.3.1 Inclusion/exclusion criteria.

Written material included in the study met the following inclusion criteria:

1) Publicly available through health care providers, public health agencies, or online.
2) Available in English.
3) Aimed at an audience of women considering prenatal screening.
4) Produced by an organization that might be considered authoritative by women.
5) Addresses prenatal screening.
6) Available free of charge.
7) Any English language material which does not meet these criteria but is provided by a family physician or other health care provider to a participant.
8) Any English language material mentioned by a participant, authored by an authoritative source, and relevant to the Canadian context, even if not produced in Canada.

Materials which are aimed at professionals, written by a non-Canadian organization, or those which address only prenatal testing were excluded. Peer-written sources or materials which did not readily identify their author were omitted.

I was hoping to broaden my sample of patient education materials during the interview process, by explicitly asking interview participants if their health care providers had given them any written materials and then collecting and analyzing these materials. I was also prepared to include written material that was not given by a health care provider, if a woman found and used a source that was of a type that might be given by a health care
provider (i.e. not a peer-written source). I was more flexible with the inclusion criterion (#8) for the sources participants mentioned, anticipating that women might, for instance, find an American pamphlet online.

I intentionally structured the inclusion and exclusion criteria so the publication date of a pamphlet was irrelevant, reasoning that if the pamphlet is currently available or is being circulated at the time of data collection, it should be eligible for inclusion. This inclusion criterion proved relevant, as one interview participant was given an out-of-circulation pamphlet by her doctor. This pamphlet, entitled "Prenatal Screening: It's your choice", was produced by the Ontario Maternal Serum Screening Committee. I had collected it before it was removed from circulation for another project, and included it in the sample when the participant mentioned it by name.

Interview participants mentioned accessing many sources of information that I do not consider formal patient education materials. For example, many women talked about reading popular books, participating in online pregnancy forums, and engaging with peer-written sources (e.g. blogs). While these are interesting sources of information, close analysis of this type of written material is outside of the scope of this project. I noted the information sources mentioned by women and considered the variety of these sources in analysis, but did not seek to closely examine these sources.

4.3.3.2 Data collection.

I collected Canadian prenatal patient education written materials as a means to investigate how prenatal screening is explained and portrayed to women. Before conducting interviews, I collected an initial sample of patient education materials as a way to gain an understanding of the variety of materials available to women in Ontario. During interviews, I asked each participant if they had received any written material from their prenatal health care provider, and if they could remember the title or other identifying information about the material. I intended to add new written materials to the sample as they were mentioned by interview participants. While I predicted that my sample of written material would grow during the interview process, this was not the case. Participants mentioned finding information online and being given many pamphlets, but
most had discarded the pamphlets by the time of the interview and few were able to recall identifying details about those pamphlets. Thus, collection of written patient education materials was limited to the initial sample I gathered through an online search.

The sample of public education materials included materials developed by professional colleges related to obstetrical care in family medicine (e.g. SOGC), local health care institutions (e.g. Northwestern Ontario Regional Genetics Program), academics working on this topic (e.g. June Carroll et al’s (2007) Genetics Education Project), advocacy organizations for people with disabilities (e.g. Canadian Down Syndrome Society), and industry sources that profit from selling the materials for prenatal screening tests (e.g. Warnex Laboratories).

**4.3.3.3 Data analysis.**

When analysing patient education materials, I was guided by the inductive principles of grounded theory (Charmaz, 2006). After a quick code and a focused code (Charmaz, 2006 see further explanation in the section addressing analytical techniques used for participant data), I identified metaphors and figurative language as an important aspect of the information provided by these materials, and chose to focus further analysis on this aspect of the data. Analysis of metaphor and figurative language evolved into an approach we called Metaphoric Textual Analysis (Vanstone & Kinsella, 2010), informed by the work of Lakoff and Johnson (Lakoff & Johnson, 1980a; 1980b), Schmitt (2000; 2005) and Charteris-Black (Charteris-Black, 2004). Metaphoric Textual Analysis (MTA) is an approach which combines the inductive strategies of grounded theory (Charmaz 2006) to critically reflect on the various interpretive messages and ideological strains that may be present in the text, based on the explanations offered by Lakoff and Johnson (1980a, 1980b) as to the ways in which metaphors are fundamental to the ways in which a person in a particular historical social location understands the world.

I began analysing metaphors and figurative language using a word by word coding strategy (Charmaz, 2006) to identify key concepts. Schmitt (2000; 2005)suggests a word for word analysis of metaphors to establish a lexicon of metaphoric concepts. This is congruent with Charmaz’s focus on creating codes as the data are studied (Charmaz,
2004a), and her instruction to “interrogate taken-for-granted metaphors” (Charmaz, 2008, p. 444) as a way to strengthen analysis and writing. I then segmented texts into metaphoric parts “by means of anchoring examples and an operationalisation of the concept of metaphor” (Schmitt, 2000). These units of analysis, the metaphoric parts, were examined for fit into larger conceptual categories (Schmitt 2000, 2005; Lakoff & Johnson, 1980a). In order to give analytic consideration to the informational impact of the metaphor, including implicit messages and ideological stances that may be embedded in particular metaphors, I engaged with the process of critical reflection as ideology critique (Brookfield, 1998; 2009). I used this particular approach to critical reflection as a way to alert myself to potential ways in which ideologies might be operating in patient education materials. This recognition was the first step in gaining insight into the ways in which patient education materials might help produce what Joe Kincheloe has called “a meta-awareness of the way consciousness is constructed” (Kincheloe, 2008, p. 218).

While engaging in this analytic process, which was iterative, messy, and at times overwhelming, I came to recognize that the process of critically reflecting on potential ideologies at work through metaphor was similar to what Strauss and Corbin (1998) describe as the "flip-flop" technique for comparison of theoretical categories in their explanation of Comparative Analysis. Strauss and Corbin (1998) describe Comparative Analysis in two ways: the first involves comparison of object/object or incident/incident, and the second is a comparison of theoretical category. For the first, comparison can help differentiate features and define one object from another. For the second, comparison can “bring out possible properties and dimensions when these are not evident to the analyst” (Strauss & Corbin, 1998, p.94). Theoretical comparison can be done via the “flip-flop” technique, or through the use of systematic comparison. The “flip-flop” technique involves turning a concept inside out, asking how it might be different, or what might change if it was different in a certain way. This description mirrors the process I engaged in to think critically about possible implications of metaphor and figurative language.
4.3.4 Study # 2: How do policies and guidelines shape the offer of prenatal screening?

In the second study, I examined the existing policy and guidelines on prenatal screening, two Clinical Practice Guidelines published jointly by the Society of Obstetricians and Gynecologists of Canada and the Canadian Council of Medical Geneticists. These guidelines were considered with regards to their relevance to the offer and presentation of prenatal screening, in order to suggest an alternative approach to the proposed counseling model (manuscript two, Chapter 6).

4.3.4.1 Inclusion/exclusion criteria.

The inclusion criteria for this study were broad, encompassing any policy document that affects the way that prenatal screening takes place in Canada. Excluded documents include private policies (for instance, clinic-specific policies) and policies from other countries not officially adopted by a Canadian agency. I also excluded policy statements, suggestions, and reports that originate from a source that does not have direct influence over how services are provided (e.g. academic articles). Also, documents that were not available to me as a member of the public were necessarily excluded.

4.3.4.2 Data collection.

The purpose of collecting policy documents was to examine the ways in which they shape the implementation of prenatal screening. I used various tools to find relevant policy documents, including policy databases and search engines (both academic and non academic). When this search failed to yield many results, I contacted relevant organizations by telephone and e-mail, to ask if they had any relevant policy documents. The following resources were searched:

Table 3: Search strategy

<table>
<thead>
<tr>
<th>Databases:</th>
<th>National Guideline Clearinghouse</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMA Infobase</td>
<td></td>
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</table>
Few relevant policies and guidelines were found. The Society of Obstetricians and Gynecologists of Canada, in conjunction with the Canadian College of Medical Geneticists had produced a clinical practice guideline governing prenatal screening (Summers et al, 2007). These groups released another clinical practice guideline concerning prenatal screening in July 2011 (Chitayat, Langlois, & Wilson, 2011). I did not find any other policies or guidelines, despite inquiries to each professional college. I did find several policies that were peripherally relevant, such as policies relevant to abortion produced by the Canadian Medical Association (CMA, 1988) and Society of Obstetricians and Gynecologists of Canada (Davis, 2006) or the Ontario Health Insurance Plan schedule of benefits for physician services.

4.3.4.3 Data analysis.

Due to the lack of policy documents retrieved, I decided not to undertake an inductive grounded theory analysis. Instead, I approached the analysis conceptually, examining the
ways in which the literature on the process of prenatal screening was congruent with or in conflict with the ideas suggested by Summers et al (2007) and Chitayat et al (2011). Using the counseling instructions in these policy documents, I conducted a literature review and examined the implication of these instructions in light of literature on relational autonomy, informed decision-making, non-directive counseling, and shared decision-making.

**4.3.5 Study #3: How do women use information when making a decision about whether or not to participate in prenatal screening?**

The third study involved interviews with women who had recently been offered prenatal screening, but had not yet received results (if they chose to participate). When interviewing these women, I asked about their thoughts, opinions, and experiences of the offer and presentation of prenatal screening and their considerations and decision-making processes when making a choice about whether or not to participate. The results of this third study are addressed in manuscripts 3 and 4, Chapters 7 and 8.

**4.3.5.1 Inclusion/exclusion criteria.**

To be included in the study, participants met the following criteria:

1) Fluent English speaker.
2) First pregnancy.
3) Under the age of 35 at expected date of delivery.
4) Receiving initial prenatal care from a family physician.
5) Had not yet received results from prenatal screening (if participating).

Exclusion criteria include:

1) Women who had previously been pregnant.
2) High risk pregnancy that may affect the way prenatal screening is offered or understood (self-defined).
3) First discussion of prenatal screening with a health care provider that is not a family physician (unless the provider worked under the direction of a family physician, for instance, a nurse working in the office of a family physician).
Most women seeking prenatal care from a family physician will have low risk pregnancies, as high risk pregnancies are usually referred to an obstetrician or maternal fetal medicine specialist. I chose not to include women with high risk pregnancies in this project because they may be offered prenatal screening in a different way, or have different considerations when considering the offer.

When I corresponded with a women to schedule an interview, I mentioned eligibility criteria, including "low-risk" pregnancy, letting each women self-identify her personal level of risk. I decided to let women self-identify rather than imposing additional exclusion criteria because there is no clear medical definition of “low risk”. In a seminal paper on the topic of defining risk in pregnancy, Wilson and Schifrin (1980) define low risk as “a patient not considered high risk”, or a patient not carrying a “pregnancy with an increased risk of a poor outcome” (p. 653). Inconsistent definitions and assessment of risk continue to be a problem. Stahl and Hundley (Stahl & Hundley, 2003) categorized women as high or low risk using several different assessments from Germany, Scotland, and the Netherlands. There was little consistency between the assessment tools and many women were classified differently between measures. Jordan and Murphy (2009) remind us that “the validity of most scoring tools is undetermined and the benefit of prenatal risk scoring systems remains undocumented” (p. 192).

### 4.3.5.2 Participant sampling & recruitment.

I arranged to interview women after they discussed prenatal screening with their family physician, but before they received results (if they decided to participate) or before they reached 21 completed weeks gestation (if they decided not to participate). The timing of the reception of results may vary from woman to woman, and is partially dependent on the type of test chosen. The 2007 and 2011 SOGC Clinical Practice Guidelines (Summers et al, 2007; Chitayat et al, 2011) present several different options for prenatal screening, on the understanding that geographic limitations and resource differences throughout Canada make the endorsement of one type of screening impossible. Practitioners are invited to use any test that meets the minimum diagnostic standards and screens for the “most common clinically significant fetal aneuploidies” (Summers et al, 2007, p. 147).
Each component of screening can take place over a range of gestational dates, making it difficult to establish concrete gestational dates for recruitment.

Figure 2: Optimal Timing of Screening and Diagnostic Tests

Source: Chitayat et al, 2011; Evans et al, 2007; Wald et al, 2003; Wilson et al, 2005;

Most women who participate in prenatal screening will receive their results in the second trimester, after the serum screen is analyzed. The blood and urine for the serum screen should be collected between 15-21 completed\(^{3}\) weeks (Wald et al., 2003), but the earlier in this time period the samples are collected, the more chance a woman will have to make a decision about pursuing diagnostic testing and/or pregnancy termination. Allowing time for collection, analysis, and scheduling of a follow up appointment,

\(^{3}\) “completed” week means the 6\(^{th}\) day of that week. Weeks are counted from the date of the woman’s last menstrual period.
women who participate in a form of IPS will most likely receive their results sometime after 16 completed weeks. Some women may participate in first trimester screening only, or contingent screening and receive their results much earlier (Chitayat et al, 2011).

4.3.5.3 Participant sampling.

The sample began purposefully, with three participants recruited online and through word of mouth. These initial interviews and data analysis informed purposive sampling completed at the first London-Middlesex Health Unit Prenatal Fair, where an additional seven participants were recruited. Simultaneously, an additional participant was recruited from an online advertisement and another through word of mouth from a personal contact. After these twelve participants were interviewed and the data was analysed, theoretical saturation was near, but additional women were sought to shed light on the theoretical properties of declining screening or having a lower level of education. One additional participant was recruited online and three additional participants were recruited from the London-Middlesex Health Unit Prenatal Fair for a total sample of 16 participants. Recruitment ceased at this time, as theoretical saturation had been met. Charmaz (2006) describes theoretical saturation as the time when “gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical properties” (p. 113), and advises researchers who believe they may have reached theoretical saturation to go back and recode earlier data to try and define new leads in order not to foreclose analytic possibilities and end up with a final analysis that is superficial.

4.3.5.4 Purposeful sampling.

I used purposeful sampling to identify participants who had recently received the offer of prenatal screening but had not yet received results (or chosen not to participate). Purposeful sampling is often confused with theoretical sampling (Coyne, 1997). Indeed the use of theoretical sampling necessitates a purposeful sample to begin (Glaser, 1978), as it is impossible to sample theoretically before categories have been formed through analysis (Charmaz, 2006). Patton (1990 as cited in Coyne, 2003) describes purposeful sampling as a way of selecting “information-rich cases for study in-depth … those from
which one can learn a great deal about issues of central importance to the research” (pg. 169). Glaser (1978) further describes the initial sample as taken from groups which the researcher believes will “maximize the possibilities of obtaining data and leads for more data” (pg. 45). Women were purposefully sampled through

- Word of mouth referrals from personal contacts and former participants who pass flyers (Appendix 3) to their contacts. (2 women)
- Recruitment posters (Appendix 3) at places young women frequent- fitness centres, grocery stores, drug stores, community gathering places. (0 respondents)
- Online pregnancy forums. (4 women)
- Attendance at the prenatal fairs run by the Middlesex-London public health unit. These fairs occur monthly and are aimed at women in the first 16 weeks of pregnancy. (10 women)

Since participants self-selected participation in this study, I predicted that the sample would likely be composed of women who had thought deeply about prenatal screening, those with strong interests in related topics (i.e. disability rights, anti-abortion), or those seeking more information. I reasoned that women who are happy with the process and have no questions about it might be less likely to volunteer to be part of the study, although they are an important group to include. This prediction was true for the women recruited online, but some women recruited at the Prenatal Fair seemed to be satisfied with their experience and not have particularly strong thoughts or opinions about the topic.

4.3.5.5 Theoretical sampling.

In addition to purposeful sampling, I also used theoretical sampling. Theoretical sampling shaped the recruitment of new informants in order to elaborate and refine the developing categories (Charmaz, 2006). This was achieved by focusing recruitment on the emerging categories and my evolving understanding of the developing theory (Glaser, 1978). Through theoretical sampling I aimed to recruit women who chose not to participate in prenatal screening. As analysis evolved, women with lower levels of education and those
who were considering pregnancy termination in the event of a high-risk result were sampled theoretically through the use of screening conversations with potential participants. This methodological decision is discussed further in Chapter 9.

### 4.3.5.6 Data collection.

I conducted semi-structured interviews with sixteen pregnant women. Each woman was interviewed once. While Charmaz (2006) thinks it may be important to return to participants during analysis, if emerging categories require more questioning, in this project a second interview was not possible. The interview focuses on the presentation of prenatal screening and intentionally omits discussion of actual results; by the time the interview data was analyzed, participants would have likely received the results of their test, which may affect the way they remember or consider the initial presentation of the test.

### 4.3.5.7 Design of the interview guide.

Charmaz (2006) emphasizes the importance of a well constructed interview guide in order to produce rich data for analysis by guiding the participant to reflect on their experiences. The questions of the interview guide should be constructed to fit the participant’s experience, while at the same time exploring the interviewer’s topic of interest. By keeping the interview guide short and open-ended, the interview can become more conversational and the interviewer can respond to the information the participant is giving, probing some points for more information (Charmaz, 2006).

While the structure of the interview guide remained consistent between interviews, sub-questions changed throughout data collection to reflect my evolving understanding of the developing theory at the time of the interview. New sub-questions were oriented towards expanding or elaborating existing categories (Appendix 4).

### 4.3.5.8 Data analysis.

I inductively analyzed data with the aim of developing theory about the process of making a decision about participating prenatal screening from the perspective of pregnant women. Charmaz (2006) sees coding strategies as flexible, provided the research includes
an initial code which eventually progresses to a focused code. The purpose of the initial code is to develop a coding plan; the focused code will identify core categories. I refined these ideas further into theoretical categories, with multiple, iterative rounds of coding wherein emerging insights fueled additional analysis and data collection.

**Quick Code:** A “quick code” necessitates textual data. For the interview data, analysis began with transcription in order to perform a “quick code” (Glaser, 1978; Charmaz, 2006), a fast open code used to keep the researcher’s mind open to the possibilities of the data by using codes which are “provisional, comparative, and grounded in the data” (Charmaz, 2006, p. 48). Charmaz (2006) thinks an initial quick code helps the researcher remain receptive, and sparks new ideas.

**Line by Line Coding:** After the initial “quick code”, line by line coding of each transcript (Charmaz, 2000; 2004a; 2006) was completed using literal, theoretical, and metaphorical codes that are active. Glaser (1978) suggests that coding with gerunds (a noun derived from a verb, usually ending in –ing) is helpful because these active words allow the researcher to identify processes.

**Focused Coding:** Focused coding is used to make relationships and connections through some of the commonly occurring or significant codes identified in the initial process. This stage of coding requires decision making about what initial codes are analytically significant, or what codes may contribute to the formation of categories.

**Theoretical Coding:** Theoretical coding took place after the completion of focused coding (Glaser, 1978), to examine the relationship between focused codes. This can help with formulating an initial theory. Glaser (1978) has identified possibilities for theoretical coding families (ex. causes, context, identity-self, means-goals). Charmaz (2006) cautions that although theoretical coding can assist with precision and clarity, theoretical codes must fit your data and substantive analysis- they should be suggested from earlier coding. Researchers cannot simply choose one of Glaser’s theoretical coding families and apply it to the data.
As an example of how coding categories were formed, Figure 3 is a diagram detailing the way in which coding evolved for the third manuscript, Chapter 7. This diagram includes different levels of coding and analytical questions which inspired the next round of coding.

Figure 3: Example of Iterative Evolution of Coding

### 4.3.6 Memo writing.

I engaged in memo-writing throughout the entire research process to address reflexive and methodological considerations. Memo-writing is often seen as the intermediate step between coding and writing about the theory for presentation or publication (Glaser, 1978), but Charmaz (2008) thinks this conception of memo-writing understates the importance of the process. Charmaz (2006; 2008) sees memo writing as an integral part of grounded theory, allowing the researcher to trace ideas and categories as they develop, and providing a framework for exploring, checking and developing ideas. Memos were recorded in two ways- as loose notes when needed around specific pieces of data, and as
a journal to record my feelings and progress about the project, data, and discoveries. Charmaz (2008) recommends the following strategies for using memos effectively:

1) Title the memos for easy sorting and storage
2) Write memos throughout the process
3) Use memos to define, delineate, and compare codes
4) Include the relevant data right in the memo
5) Outline the consequences of the code/category
6) Note gaps in the data and conjectures about these gaps

I managed the research memos throughout the project by opening a research-specific e-mail account, where I could e-mail myself memos (written or dictated). This format allowed me to search the memos and, if needed, to circulate them to my advisory committee and record their responses. I also uploaded these memos into my data management software (N-Vivo), so I could link them directly to the data. I wrote memos after conducting each interview, transcribing each interview, coding each interview, and during each round of coding. I also wrote memos about the process of the research.

4.3.7 Methodological decisions.

As I have discussed earlier in this chapter, I have been committed to a reflexive approach to the research process, and to thinking carefully about possible implications of the methodological decisions I have made throughout the project.

1) I chose to collect and analyze the textual data before the interview data. In part, this decision was theoretical, as a way of informing myself about the context in which prenatal screening takes place in Canada and familiarize myself with some of the material and terminology that my interview participants might encounter. Since it is easier to go back and re-examine texts, or change search criteria for texts than it is to re-interview participants, I wanted to go into the participant interviews with as much understanding as possible. There was also a logistical part of this decision: the use of textual data did not require research ethics permission or involve a long phase of recruitment.

2) I chose to recruit participants in multiple ways, by posting online ads through classified ad sites (kijiji.ca, craigslist.ca) and online pregnancy forums; posting ads in
local businesses and community gathering sites; using social networks to recruit via word of mouth; attending the London-Middlesex Health Unit Prenatal Fair. I didn't receive any responses from the classified ad sites or from physical posters. I received a handful of responses from online pregnancy forums. I received several word of mouth referrals, but only two resulted in interviews. Others were excluded before an interview because they miscarried or because they were not receiving prenatal care from a family physician. I recruited most participants through the Prenatal Fair, where I had set up a table with recruitment posters and letters of information. I spoke to all participants directly and if they agreed to be contacted, I collected their contact information and e-mailed or phoned at a later date to arrange an interview.

I chose to use multiple recruitment methods because I wanted to reach women who weren't "information-seekers", but those who might see the poster or ad while living their day to day lives, rather than looking for information on pregnancy. I had ads out for about a month before I attended a prenatal fair, and had received little response. The word of mouth referrals meant that I was referred to women who shared news of their pregnancy very early on; these women may have been more likely to decline prenatal screening or not be considering pregnancy termination in the event that a condition was found (Rothman, 1989). Of my final participant pool, 14 of the 16 women were recruited through ads on a pregnancy related site or at the Prenatal Fair. These women may be more active in seeking information about pregnancy than others. With that said, as discussed in manuscript four, there was one woman (Lucy) who chose not to seek information about prenatal screening and two women (Farah and Nadia) who chose to stop seeking information. All of these women were recruited through the Prenatal Fair, suggesting that perhaps attendance at the Prenatal Fair did not necessarily correlate with an interest in actively seeking information about prenatal screening.

All participants were self-selected volunteers and so perhaps were more interested than average in research, or in the topic of prenatal screening. No honorarium was offered for participating. Participants were offered the choice to be interviewed in person or over the phone; most preferred to be interviewed over the phone (nine of 16 women), even those who were recruited in person (seven out of ten women), perhaps reflecting convenience.
For those who were interviewed in person, I offered the option of a public place of their choosing, the public library, their home or my office (in London or Hamilton). Two chose to be interviewed in their home, one in my office, one in a public library, and one in a coffee shop. Four of these interviews were longer than average, perhaps because we established better rapport, perhaps because there were few distractions, or perhaps because agreeing to meet somewhere indicated higher interest and a higher commitment of time to the interview. The women with the shortest interviews were all interviewed over the phone, all recruited at the Prenatal Fair, and all participating in prenatal screening. Compared to the other participants they had average level of education, were average age, had some but not extensive knowledge of people with disabilities. These women may reflect participants that don't have particularly strong thoughts or feelings about prenatal screening who may not have responded to an online ad, but agreed to do an interview when personally recruited.

3) I chose not to do a second interview or any form of member-checking because I was interested in capturing thoughts and opinions about prenatal screening before the woman had received any of her results (if participating). I reasoned that the results a woman received might colour her thoughts about the prenatal screening test, such as creating reassurance from anxiety in the event of a low-risk result. At the time of the interview, women who were participating in prenatal screening were on average 15.6 weeks gestation (range: 11-20 weeks). It is possible to receive results as early as 16 weeks along, which gave a very small window for transcribing and analyzing data in time for member-checking. At the time of the interview, some women had the results appointment scheduled within days, making member-checking impossible for this group. I did not want to collect member-checking data from some but not all women, or to self-impose a timeline which would place pressure to conduct the analysis very quickly, meaning I might miss something important, or not be able to engage deeply with the analytical process. Instead of member-checking with the participant who provided the data, I decided to query future participants about emerging themes, and incorporate participant response to the evolving analysis in this way. There was also an ethical element to the decision not to return to the participants for member-checking: with the possibility that some women may receive high-risk results, I did not want to re-open the conversation
about making a decision to participate in prenatal screening, which may potentially cause emotional stress, or heighten existing emotional stress.

4) For the patient education material collection, I chose to restrict my data collection to Ontario or Canadian sources, in order to reflect the material that my participants were most likely to encounter. This means that I would include material published by a national organization (such as the SOGC) but not a provincial organization from outside of the province (for example an Alberta based public health unit). I left flexibility in the inclusion criteria to include any pamphlet or material mentioned by a research participant. I chose to exclude books and websites, in order to keep the data collection focused and to remain within one genre of information. These inclusion criteria decisions were made to reflect the information that would be most likely be available to the interview participants in the study, but allow flexibility to account for the broad availability of information online. Many health organizations make their patient information publications available online, where they can be accessed by a broader population. Presumably any patient information materials I could find online can be accessed by my research participants. During data collection, about half of the women revealed that they were given patient information materials from their physicians. Only one could provide the title of the pamphlet, the others had discarded, forgotten, or misplaced their pamphlets.

4.4 From research questions to manuscripts: the evolution of the research

Grounded theory is a methodology which is useful when not much is known about a topic, as it aims to start by collecting broad data which will be continually refined through ongoing analysis throughout data collection (Charmaz, 2006). I started with one overarching research question and three sub-questions, aimed to address the three types of data I planned to collect. In the process of data collection and analysis, the questions were refined, to respond to the type of data available (in the case of the policy documents) and the evolving categories being identified through data analysis (all three types of data). An additional round of refining the research questions took place while
drafting each manuscript; in order to respond to what the data was saying and the particular story emerging from each data set.

Manuscript one (Chapter 5) responds to the first research sub-question, "How do prenatal screening patient education materials portray concepts related to prenatal screening?". I began this study by reading through patient education materials in order to gain an understanding of the type of information women may receive when choosing whether or not to participate in prenatal screening. As I was reading, particular terms and words started to jump out at me. The experience of reading the patient education materials was transformative, and may be considered a critical incident (Brookfield, 1998) or a "struck-by" moment (Cunliffe, 1999). At the time I was reading this material, I was deep in the literature, as necessitated by the requirements of my program. I was aware of some literature about potentially prejudicial terms about disability, such as "handicap", but what I noticed when I read was that the tone of some documents was persuasive, rather than informative. These two thoughts, about the potential of language to be prejudicial and persuasive, inspired me to think more deeply about word choices and the impact that they may have on women. I started to read more about theories of metaphor and the constructive power of language to shape and constrain understandings of the world, and of possibilities (Lakoff & Johnson, 1980). At the same time, I was examining policy documents, and I became aware of the imperative for "non-directive" counseling in the SOGC clinical practice guideline (Summers et al, 2007). The story I chose to tell about these data addressed the ways in which theories of metaphor disrupt the notion that communication can be non-directive. I closely examined the language and metaphors in the patient education materials to reflect upon ways in which they might be suggestive, persuasive, or otherwise directive of a particular way of thinking about pregnancy, disability and motherhood.

Manuscript two (Chapter 6), began with sub-question two, "How do policies and guidelines shape the offer of prenatal screening?". When I wrote this research question, before I had conducted an in-depth search for policy documents, I imagined that I would find many different types of policy documents from different health
professions involved in prenatal screening (family physicians, obstetricians-gynecologists, midwives, genetic counselors), different levels of government (provincial health insurance agencies, local health integration networks, funding formulas) and potentially some policy in the grey literature, from advocacy groups concerned with pregnancy, public health, or disability. When I started to search, I found that this was not the case. Beyond the SOGC guideline which catalyzed my interest in this project (Summers et al, 2007), there was very little publicly available policy on prenatal screening. However, the policy that did exist was extremely important, precisely because there wasn't a lot of other guidance for health care professionals counseling about prenatal screening. From my initial literature search, one aspect of the SOGC guideline stood out as particularly important: non-directive counseling. This was interesting to me, because it indicated that the SOGC stood firmly behind the notion that screening should be the choice of the individual woman, and that they did not conceptualize it as some sort of population "health" issue. I was also interested to note that the mention of non-directive counseling and informed decision-making merited only a brief mention, suggesting that physicians were assumed to be well acquainted with the pragmatic aspects of facilitating informed decision-making through a process of non-directive counseling. Yet, from my prior literature review I was familiar with a large body of evidence suggesting that this was not the case. At this point, I started to consider how to represent my findings in a manner that would be appealing and helpful to clinicians. From regularly reading the *Journal of Obstetrics and Gynecology Canada*, I knew that if I wanted to address this clinical audience, I had to write a policy or literature review piece, rather than a qualitative research piece (see section 9.8.1 for more information), but this fit well, as they were the only group producing policy about prenatal screening. With this understanding, and having identified non-directive counseling as a particular element of interest, I focused my study on this topic. This study examined SOGC policy directives, in light of the literature on non-directive counseling and other models of counseling for informed choice, to suggest an alternative to non-directive counseling, and to provide some detailed ideas for clinicians to consider regarding the ways in
which counseling to support informed decisions might take place in the specific context of prenatal screening.

Manuscripts three and four (Chapters 7 and 8) both evolved from the third research sub-question, "How do women use information when making a decision about whether or not to participate in prenatal screening?". The data that I collected from women about their experiences of being offered and making a decision about whether or not to participate in prenatal screening were so rich that it would be impossible to tell all of the stories that I saw within these data. During the iterative process of data collection and analysis, I quickly identified the concept of "information" as an important analytical construct, and pulled all mentions of "information" from the rest of the data, in order to consider the different ways in which women talked about this idea. This became manuscript three, through the iterative process of coding described in Figure 3, in the Data Analysis section (4.3.5.8). I observed that the literature on informed decision making constructed the idea of what it was to be "informed" in a very particular way, relying heavily on statistical and biomedical understandings. From Sherwin (1998), I understood that the social construction of rationality and being informed may contribute to problematic aspects of traditional conceptions of autonomy (for more detail see section 2.5). With this in mind, I approached the data with the question of what information the women reported as important for their decision-making process about participation in prenatal screening. I wrote the first draft of the manuscript to portray these findings, however later then refined the categories to tell the story of what information women require in a manner which could be beneficial to clinicians, who are a significant source of information for women.

In the fourth manuscript (Chapter 8), I examined the interview data as a whole, to consider the broader processes described by women as they talked about how they came to make a decision about participating in prenatal screening. In this manuscript I propose a grounded theory model which describes the whole process, portraying how women indicated that information was sought, received, and interpreted as they worked towards making a decision.
4.5 Conclusion

This research examined the question of how the process of prenatal screening is enacted in Ontario in light of the 2007 SOGC guidelines, from the perspective of young women in their first pregnancy. This question was examined using an inductive grounded theory approach, and drew on data from three different sources: patient education materials, policy and guidelines, and pregnant women. In this chapter, I described the methodological approach (constructionist grounded theory) and the particular methods adopted for this study. In Chapter 9, I explore some of the connections between the different types of data and discuss the ways in which these three data sets enable a fuller understanding of the process of prenatal screening.
4.6 References


5 Critical Reflection and Prenatal Screening Public Education Materials: A Metaphoric Textual Analysis

“In most cases, what is at issue is not the truth or falsity of a metaphor, but the perceptions and inferences that follow from it and the actions that are sanctioned by it. In all aspects of life, not just in politics or in love, we define our reality in terms of metaphors and then proceed to act on the basis of the metaphors. We draw inferences, set goals, make commitments, and execute plans ... by means of metaphor”

(Lakoff & Johnson, 1980a p.158)

5.1 Introduction

This paper presents a study of prenatal screening educational materials that uses metaphoric textual analysis as a means of critical reflection to examine implicit messages in educational resources. An assumption of the study is that metaphoric language is important because it shapes our understanding of the world. Lakoff and Johnson (1980a, 1980b) suggest that metaphors are used every time an abstract idea is discussed; they allow abstract ideas to be understood by comparing them to concrete ideas. This comparison highlights certain similarities, and disguises or de-emphasizes differences. Metaphors may also have the effect of creating similarities where none exist. The acceptance of metaphoric language without examination means an acceptance of the similarities with the comparative object which shapes the way an object/idea is conceptualized, discussed, and used.

In 2007, the offer of prenatal screening was expanded. Previously, maternal age (>35 years) was the main criterion when offering testing; after Society of Obstetricians and

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Gynecologists of Canada Clinical Practice Guideline (Summers, Langlois, Wyatt & Wilson, 2007), prenatal screening will be offered to all pregnant women in Canada. When instructing physicians to offer prenatal screening to all women, Summers et al (2007) explicitly state that counseling about this issue should be non-directive, promote choice, and be respectful of the needs and quality of life of people with disabilities. This study draws on metaphoric textual analysis to examine whether the written public education materials available to Canadian women are consistent with these aims.

This paper begins with a brief examination of prenatal educational materials in the context of prenatal screening in Canada. This is followed by an explanation of the methodology and analytical approaches of the study. Findings from the prenatal screening public education pamphlets are presented, and highlight the figurative and metaphoric language identified in the educational resources.

The discussion considers the ways in which prenatal screening education pamphlets may communicate subtle directives to women, and offers suggestions for the design of non-directive prenatal screening educational materials. In addition the discussion considers the ways in which metaphoric analysis can foster critical reflection and reveal insights important for the design of educational materials in health care.

It is important to note that discussions of prenatal screening can be morally charged due to their inherent relation to politicized and ethically contested ideas about disability and abortion. When educational materials are cast as “non-directive” or neutral, it may be difficult for patients, practitioners and educators to recognize the ideological assumptions embedded within. The authors of this paper do not wish to make moral or ethical judgments with respect to the findings, but rather to illuminate the issue so that those who design health education materials and those who use them may be better informed.

5.2 Background

This study began with a feeling of dissonance experienced while reading prenatal screening educational pamphlets. The power of the language within the pamphlets was striking: specificities about “problems”, “diseases”, “defects” that could be detected
through “simple”, “quick”, blood and ultrasound tests, “allowing” women to “make decisions” about “ending the pregnancy”, or “providing reassurance” about a “healthy baby”. Reading these pamphlets was a critical incident (Brookfield, 1998) or a critical vibration (Holloway, 2002) that prompted reflection about the implicit messages about pregnancy and disability communicated in prenatal screening educational materials. Holloway (2002) describes a critical vibration, or feeling of dissonance/frustration, as “The Scream”, which acts as a call to theoretical reflection\(^5\) from the opposition and struggle of everyday life. The Scream may take different forms: an inarticulate mumble of discontent, tears of frustration, a scream of rage, a feeling of unease, of confusion or of longing. Whether the dissonance we feel arises from direct or indirect experience, Holloway states that this is the starting point of reflective thought- not reason, not rational philosophizing, but dissonance and opposition. Holloway’s critical vibration encapsulates the feeling and process of critical reflection that led to the study.

One of the tenets of prenatal screening/testing discussions in Canada is non-directive counseling (Summers et al, 2007). Despite this clear guideline, the pamphlets appeared to use directive language cloaked in the guise of “choice” (Lippman, 1991). Intensive reading revealed common metaphors and conceptual systems of metaphor that promoted prenatal tests as a way to “reassure” women about “healthy” babies and find “defective” fetuses in time for “termination of the pregnancy”. The prevalence of this directive message was unsettling and fostered critical reflection on the ways that certain common metaphors promote particular ideological messages.

### 5.3 Prenatal Screening Educational Materials

#### 5.3.1 Prenatal screening in Canada.

Prenatal screening is a probability calculation based on a number of factors. The calculation shows the chance that a fetus has some sort of aneuploidy, including an open

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\(^5\) Holloway does not connect this term with traditional Reflective Practice scholarship and related terms, although there is an echo of critical reflection in his description of the purpose and operation of theoretical reflection.
neural tube defect (e.g. spina bifida), chromosomal anomaly (e.g. Down syndrome), or physiological anomaly. There are many accepted variations of prenatal screening tests, depending on the resources of the geographical area in which the test is performed, and the time at which the woman presents for prenatal care (Summers et al, 2007). Generally, prenatal screening involves an ultrasound and maternal blood test. The results of these tests are used with the woman’s age to calculate a probability of fetal aneuploidy. Prenatal screening tests are not definitive, but are a non-invasive way of determining a probability. If the probability of aneuploidy is judged to be high, the woman can choose to engage in an invasive testing technique (such as chorionic villus sampling, or amniocentesis) that will provide a definitive result. The invasive tests have risks of miscarriage, bleeding, malformation, and amniotic fluid aspiration (Brambati & Tului, 2005; Farrell et al, 1999) so they are not used unless a non-invasive test establishes a probability of aneuploidy that is worrisome for the woman. There is no cure or treatment for most of the aneuploidies detected by prenatal screening, and women who receive a positive screen for aneuploidy have the options of abortion, adoption, or increased time to prepare to raise a child with this condition.

In 2007, prenatal screening policy in Canada changed significantly. A 2007 Clinical Practice Guideline issued by the Society of Obstetricians and Gynecologists of Canada (Summers et al, 2007) mandated that prenatal screening must be offered to all pregnant women, in a non-directive way that promotes informed consent and choice (p. 147). Summers et al (2007) also specify that prenatal screening should be offered in a way that “shows respect for the needs and quality of life of persons with disabilities” (p. 147). The opportunity to access prenatal screening can be an important choice for Canadian women. However, the offer of prenatal screening and ensuing decisions require careful consideration.

5.3.2 Prenatal public education pamphlets.

Public education pamphlets are used widely in medical screening programs (Fox, 2006) and are highly valued by women considering prenatal screening as a preferred way of obtaining information, second only to discussions with their physician (Dahl, Kesmodel, Hvidman & Olesen, 2006). However, the tone of information, word choice, and balance
of content provided can effect the way that patients make decisions about whether or not to engage in prenatal screening (Bryant et al, 2001; Dahl et al, 2006; Loeben, Marteau & Wilfond, 1998).

Dixon-Woods (2001) discusses the discourse embedded in patient information pamphlets. She finds that most pamphlets are written from a “patient education” perspective, a discourse which characterizes patients as incompetent, passive, and forgetful. These pamphlets seek to educate patients in order to “bring patients’ knowledge into line with what is medically ‘correct’” (pg. 1419) and to ensure compliance with biomedical priorities. Raffle (2001) discusses the way screening pamphlets are used to encourage uptake of screening, rather than provide information to encourage choice. A recent review of the literature about patient education pamphlets reveals that they are used to save time in a medical consultation, achieve cost-benefits for the health care system, and as a substitute for expensive professional time (Dixon-Woods, 2001). Dixon-Woods (2001) theorizes that a contrasting discourse to “patient education” pamphlets is “patient empowerment” pamphlets. Patient empowerment pamphlets aim to provide information as a means of empowering patients to make informed choices, rather than correcting them or persuading them to acquiesce to biomedical priorities.

5.3.3 Prenatal screening educational materials and non-directive language

The process of decision making around prenatal screening has been well studied in Britain, the USA, and Australia. Current public education materials about prenatal screening and testing in these countries have been critiqued for: requiring literacy levels above that of a general audience (Freda, Damus & Merkatz, 1999); insufficient information to make decisions about testing (Shepperd et al, 2006); negative tone (Bryant et al, 2001; Loeben et al, 1998); omission of information (Van den Heuvel et al 2008); and language that may be viewed as prejudicial (Hodgson, Hughes & Lambert, 2005). Public education materials with these issues are problematic with respect to the goal of facilitating non-directive counseling and informed choice as necessitated by the Clinical Practice Guideline governing this procedure (Summers et al, 2007).
Many studies address the explicit information included in the pamphlet, such as the balance of information (Bryant et al, 2001), number of positive and negative descriptive statements about conditions tested for (Loeben et al, 1998), or content of information provided (Dahl et al, 2006). Previous studies often mention the affect that word choice can have on the perception of particular conditions and decision making, however such studies do not investigate particular words and their implicit messages.

Non-directive counseling, which involves providing sufficient and comprehensive information in a neutral fashion in order to encourage the client to make an informed choice, is one of the original tenets of genetic counseling (Fine, 1993; Weil, 2003). Although long considered the “norm” in genetic counseling practice (Burke & Kolker, 1994) some authors argue that non-directive counseling may be impossible to fully achieve (Anderson, 1999; Bartels, LeRoy, McCarthy & Caplan, 1997; Cunningham-Barley & Kerr, 1999; Williams et al, 2002). Others wonder if it is even desirable (Anderson, 1999; Benkendorf, Prince, Rose, Fina & Hamilton, 2001; Caplan, 1993; Clarke, 1994; Gervais, 1993; Weil, 2003) as it may prevent the client from accessing the full value of the counselor’s professional knowledge and expertise. Nonetheless, the current guidelines (Summers et al, 2007) advocate non-directive counseling as an imperative to prenatal screening counseling; the central concern of this study is to analyze the pamphlets with attention to implicit messages that may be directive.

In light of this review, the questions of the current study are: What are the primary metaphors and figurative expressions embedded within PNS educational pamphlets available to pregnant women in Canada? What does critical reflection on these metaphors reveal about implicit messages embedded within the educational materials? What are the implications for the design of future prenatal screening health education pamphlets?

5.4 Metaphoric Textual Analysis

This study, one component of a larger grounded theory study about the process of prenatal screening, used a textual analysis technique we have called Metaphoric Textual Analysis, informed by the work of Lakoff and Johnson (1980a, 1980b), Charteris-Black (2004), and Schmitt (2000, 2005). A metaphor is a linguistic device that describes one
(abstract) idea by comparing it to another (concrete) idea (Lakoff & Johnson 1980a). For example, when an ultrasound image is described as a “picture”, the abstract idea is the interpretation of sonic data to create a visual image. This is described in terms of a concrete idea (a picture is a visual image that is not the interpretation of sonic data). This visual metaphor is extended when we speak of an ultrasound letting the mother “see” the baby; the word “see” is a metaphor because no visual information is used, a literal description would be that an ultrasound lets the mother see a visual image compiled from a mechanical interpretation of sonic/aural data. This level of literal detail can be cumbersome; the metaphor facilitates understanding by comparing the abstract idea to a concrete one. However, when a comparison is made certain similarities are highlighted while differences are de-emphasized. This emphasis/de-emphasis may direct a particular understanding of the abstract idea.

Metaphoric textual analysis is an approach that analyzes metaphors within textual material in order to critically reflect on various interpretive messages, and ideological strains within the text. Such an approach is based on the assumption that metaphors are fundamental to how humans understand the world (Lakoff & Johnson, 1980a), and that different levels of reflection may be engaged through metaphoric thought (Charteris-Black, 2004). An examination of metaphoric systems can help to reveal particular ideologies which may inform that system (Charteris-Black, 2004; Lakoff 2002).

Metaphor can also be used to prompt reflection (Kinsella, 2000), examine unstated opinions and assumptions (Charmaz, 2006), uncover bias created by provision of unintentional information (Kitzinger, 1999), and to foster insight into the way an individual or society systematically organizes the world (Lakoff & Johnson, 1980a). Metaphor has been used in critical textual analysis to reveal ideologies (Fraser, 2006; Lule, 2004; Martin, 1984, 1987, 1991; Sontag, 1978; Taylor, 1998, 2008) and has been developed into an analytical technique (Schmitt 2000, 2005).

5.4.1 Assumptions about metaphor.

More than just a linguistic flourish, metaphor is a way of thinking and persuading (Charteris-Black, 2004). Metaphor acts as an interpretive bridge between abstract and
concrete ideas, thus structuring the way we conceptualize the world (Lakoff & Johnson, 1980a). Metaphor creates particular boundaries around the way we can think about and interact with a particular topic. Lakoff and Johnson (1980a, 1980b) explain how the way we conceptualize a concept systematically influences the way that concept takes place, the way we think about that concept, the way we interact with that concept. Metaphors also act to fill gaps in a lexicon; this may be semantic, accommodating changes in a conceptual system, or pragmatic, conveying specific intentions of the speaker (Charteris-Black, 2004). Many metaphors are conceptually related. Lakoff and Johnson (1980a) use the example of Argument Is War; there are multiple metaphors about arguing that compare it to battling (e.g. attack a position, indefensible, strategy, new line of attack, win, gain ground etc.) These expressions form a systematic way of talking (and thinking) about arguing; they also shape the way we enact arguing, as an adversarial process where there is a winner and loser, attacks, counter attacks, defences etc. How might our interpretations be different if we thought and spoke about argument in terms of metaphors of dancing? Dancing metaphors may encourage consideration of the cooperative and artful aspects of arguing, ideas which are hidden or de-emphasized when describing argument with the metaphors of war.

Metaphor influences understanding in a way that may give false impressions of physiological systems that may lead to incorrect notions of the body, anatomy, and medicine (Banks & Thompson, 1996), change treatment decisions (Martin, 1984), affect the understanding of cellular processes (Brown, 2003; Martin, 1991), and even change the path of investigation and conceptualization of DNA and genetics (Kay, 2000).

### 5.5 Critical Reflection

Metaphoric textual analysis invokes a process of critical reflection on the implicit messages and ideological stances that may be embedded within the metaphors used in the text. It questions the taken-for-granted meanings of the language used, encouraging these meanings to be challenged and reconsidered. Critical reflection is a term with multiple meanings that has been used across several disciplines. In this project we engaged with the idea of critical reflection as ideology critique (Brookfield, 1998, 2000, 2005). This approach to critical reflection focuses on becoming aware of the ways in which an
ideology affects social relations by imposing particular assumptions and belief systems (ideologies) which encourage, support, and maintain particular ways of viewing the world (Brookfield, 2000, 2005). Critical reflection is the first step to ideology critique, encouraging recognition of the ways ideology operates in the world. Critical reflection helps produce what Joe Kincheloe calls “a meta-awareness of the way consciousness is constructed” (2008, p. 218), in this instance through language. Such a recognition aids in the identification and analysis of the way we work in the world and the way the world works in us (Kincheloe, 2008).

Critical reflection is based on the idea that decisions and actions originate from a consideration of the broader moral, ethical, political and historical context (Yost, Sentner & Forlenza-Bailey, 2000) with a focus on ends as well as means (Zeichner, 1981). Critical reflection is focused on “helping people come to an awareness of how an [ideological system] shapes social relations and imposes - often without our knowledge - belief systems and assumptions” (Brookfield, 2000, p.36). Ideology critique aims to reveal hidden insights about the nature of the “taken for granted” world (Brookfield, 2000). In short, critical reflection informs the methodology of the current study in a number of ways. First, critical reflection allows taken-for-granted meanings in the public education pamphlets to be questioned and different possible interpretive understandings to be explored. Second, critical reflection draws attention to implicit ideological messages in the public education materials, and the actions these messages propose.

5.6 Texts: Inclusion Criteria

Thirteen prenatal screening public education pamphlets were included in the study (Table 4). The following inclusion criteria were used to identify texts in the study: publicly available; available in English; aimed at women considering prenatal screening; written for an Ontario or Canadian audience; major focus is prenatal screening (although texts which also discuss prenatal testing were eligible); available free of charge; available online. Pamphlets aimed at professionals, written by a non-Canadian organization, or that address only prenatal testing were excluded. Inclusion and exclusion criteria did not
address the date of publication of the pamphlet; if the pamphlet was available at the time of the search, it was eligible for inclusion.

Table 4: Prenatal screening patient education pamphlets

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>URL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Prenatal Risk Assessment Program</td>
<td>First Trimester Combined Screening (FTS)</td>
<td><a href="http://www.earlyriskassessment.com/Portals/0/FTS%20Information%20Brochure_v2.pdf">http://www.earlyriskassessment.com/Portals/0/FTS%20Information%20Brochure_v2.pdf</a></td>
</tr>
<tr>
<td>Genetics Education Project</td>
<td>For Women and Their Families .... A guide to understanding prenatal screening tests</td>
<td><a href="http://www.barriemidwives.com/info/Prenatal-Screening_A_Guide_to_Understanding.pdf">http://www.barriemidwives.com/info/Prenatal-Screening_A_Guide_to_Understanding.pdf</a></td>
</tr>
<tr>
<td>Mt. Sinai Hospital</td>
<td>Integrated Pregnancy Screening (IPS)</td>
<td><a href="http://www.mountsinai.on.ca/care/pdmg/tests/ips">http://www.mountsinai.on.ca/care/pdmg/tests/ips</a></td>
</tr>
<tr>
<td>Ontario Multiple Marker Screening Program</td>
<td>Ontario Multiple Marker Screening Program</td>
<td><a href="http://tbh.net/programs_&amp;_services/maternity_centre/ontario_multiple_marker_screening.pdf">http://tbh.net/programs_&amp;_services/maternity_centre/ontario_multiple_marker_screening.pdf</a></td>
</tr>
<tr>
<td>Ontario Maternal Serum Screening Committee</td>
<td>Maternal Serum Screening: it’s your choice</td>
<td><a href="http://www.lhsc.on.ca/programs/rmgs/mss/pamphlet.htm">http://www.lhsc.on.ca/programs/rmgs/mss/pamphlet.htm</a></td>
</tr>
<tr>
<td>Ontario Maternal</td>
<td>Integrated Prenatal</td>
<td><a href="http://www.lhsc.on.ca/programs/rmgs/mss">http://www.lhsc.on.ca/programs/rmgs/mss</a></td>
</tr>
<tr>
<td>Serum Screening Committee</td>
<td>Screening (IPS): it's your choice</td>
<td>/pamphlet.htm</td>
</tr>
<tr>
<td>---------------------------</td>
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</tr>
<tr>
<td>Northwestern Ontario Regional Genetics Program</td>
<td>Prenatal Screening and Testing Options</td>
<td><a href="http://www.tbdhu.com/clinics/genetics/genetics+pamphlets.htm">http://www.tbdhu.com/clinics/genetics/genetics+pamphlets.htm</a></td>
</tr>
</tbody>
</table>

The educational pamphlets were obtained through an online search of health care agencies, professional colleges, advocacy groups, industry groups, and government programs operating in Ontario, Canada. Search strategies were limited to public search engines in order to locate educational material that is accessible to the public. A list of search terms is included in Table 5.
Table 5: Search terms (each +Canada, +Ontario)

<table>
<thead>
<tr>
<th>Prenatal screening pamphlet</th>
<th>Screen positive, down syndrome</th>
<th>Maternal serum screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integrated pregnancy screening</td>
<td>Integrated prenatal screening</td>
<td>Prenatal screening, brochure</td>
</tr>
<tr>
<td>Should I get prenatal screening?</td>
<td>Prenatal screening test</td>
<td>Prenatal screening, patient education</td>
</tr>
<tr>
<td>Prenatal screening, patient information</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5.7 Analysis

Schmitt’s (2000, 2005) Systematic Metaphor Analysis, based on Lakoff and Johnson’s Conceptual Metaphor Theory, was adopted to guide the analysis of this study. The analysis began with an initial review of each pamphlet; metaphors, figurative, and questionable language were circled. The metaphors and figurative language were then identified using a word by word coding strategy (Schmitt, 2000, 2005), and grouped both across and within individual pamphlets. This grouping facilitated the identification of key conceptual metaphors that established a lexicon of metaphoric concepts. Each conceptual metaphor system, or series of conceptually related metaphors, was used for interpretive and reconstructive analysis. Various possible interpretations of each conceptual metaphor system were then considered using critical reflection.

5.7.1 Metaphors of prenatal screening.

The metaphoric textual analysis of the pamphlets identified many examples of metaphors reflected both in figurative language and in particular discrete metaphors. Some of the most salient examples are included below as illustrative examples. The quotes are drawn
from the prenatal screening educational resources identified earlier, and identified by resource number.

5.7.2 Figurative language.

Figurative language is a term that refers to a word, or group of words, which do not have a literal definition (denotation), or which has a connotation that may add layers of meaning. For example the word “embryo” does not have a concrete definition- the progression between a blastocyst/embryo/ fetus is defined idiosyncratically (Nisker, Baylis, Karpin, McLeod & Mykitiuk 2009). Figurative language in this study was found to be: neutral or suggestive, non-directive or directive, clear or indirect, and able-ist or oriented toward disability rights.

5.7.3 Neutral versus suggestive terminology.

Neutral terminology is difficult to achieve in prenatal education materials, as seemingly neutral words such as baby and fetus carry implicit assumptions. One pamphlet used neutral terminology by adopting the word “pregnancy” throughout. Six pamphlets consistently used the word “baby”, and two pamphlets differentiated between fetus/baby at the point of birth. Other pamphlets used the term “fetus” or “embryo” to refer to an affected pregnancy or decision to abort, and “baby” or “infant” when promoting reassurance provided by the test, or the desire to have an unaffected child. This terminology can be suggestive in various ways. As an example, one can readily see that the phrase “your choice to abort your infant” has a different interpretive and emotional meaning than “your choice to abort the fetus”. Suggestive terminology was more evident in some pamphlets than others. For instance one pamphlet declared that a serum screen performed in the second trimester can “pick up approximately 60% of infants with Down Syndrome” (#2). The use of suggestive terminology such as baby/fetus can disrupt the goal of non-directive or neutral counseling, but it can also function ideologically. The ethically and morally charged nature of these words can communicate an ideological directive to the reader. A full discussion of the implications of the use of such morally charged words is beyond the scope of the current paper.
5.7.4 Non-directive versus directive language

The language in the pamphlets could be seen to be directive to different degrees within the pamphlet. For instance, the meaning of the screening results can be quite directive of what should be done after receiving results. A less directive way of describing results is to describe what they mean without a value judgment. For example, “screen negative means a lower chance of Down syndrome” (#8) is less directive than using a negative result to create a dichotomy between health in opposition to disability. This dichotomy is created when a negative result is said to lead to “the birth of a healthy baby” (#7), “perfect baby” (#3), or “normal baby” (#9). Conversely, a result is less directive when described in terms of information currently available, without judgment about future possibilities. For example, describing a positive result as a higher chance of a “birth anomaly” (#1) is less directive than describing a positive test result in terms of a “severely affected baby” (#2).

The way some of the pamphlets portray what the test offers to a woman (or couple) can be directive, for instance when the pamphlet implies how the woman will feel about her result. Promising feelings of reassurance, choice, and control in the event of a negative screening result can direct women to participate in testing, i.e. “normal results of prenatal screening are reassuring” (#7). This language omits possible feelings of anxiety or worry the woman may experience if she receives a positive result from the screen. Many pamphlets omitted discussion of possible feelings and decisions to be made if a positive result is received, although one discussed this issue in great detail (#11). Less directive language would include specific information about decisions and plans that can be made in the event of a positive result, i.e. “prepare for the birth of a baby who may require additional care, opportunities for prenatal preparation and education of family members, choice to terminate the pregnancy” (#3).

Another example of directive language was found in the word “risk” which was frequently used in the materials examined. When pamphlets describe the results as conveying a “risk”, this may be seen as implicitly directive because the word risk has a negative connotation. For instance, we don’t talk about someone having a risk of winning the lottery. A less directive word is one which conveys the likelihood of the results
without a value judgment, for example incidence (#8), chance (#11, 12), or probability (#8).

### 5.7.5 Clear versus indirect language.

Abortion is an integral concept to prenatal screening, since most of the conditions tested for do not have treatments, or cures. Prenatal screening is usually offered under the assumption that women can choose to have an abortion if they do not wish to give birth to a child with an aneuploidy. Many pamphlets fail to state this fact clearly, using vague phrases such as “make a decision about this pregnancy” (#5) or euphemisms like “choose whether or not to continue with pregnancy” (#2). Often the word “termination” is used, although Grimes and Stuart (2010) find this to be vague and confusing, since all pregnancies terminate eventually- in birth, miscarriage, or abortion. Only one pamphlet used the word “abortion” (#11).

A number of pamphlets do not address the issue of what to do with test results, or what choices are available beyond the opportunity to engage in further testing. When this issue is addressed, it is often set as a dichotomy: abortion or no abortion. For instance, pamphlet #2 states that women should make the decision to participate in testing “after considering what they would do if the results suggested there was a problem”, although the pamphlet does not discuss any option beyond “make a decision regarding continuing the pregnancy”. Pamphlets 3 and 11 give some alternative options after receiving a positive screening result, including adoption, preparation for the birth of a baby with special needs, and education of self, friends, and family members.

### 5.7.6 Able-ist versus disability rights language.

Many of the pamphlets analyzed for this project contained distinctly able-ist assumptions. Words such as “healthy”, “normal”, and “perfect” were placed in opposition to “difference” and “genetic condition”. Genetic conditions and physiological differences are described as “birth defects”, “problems”, and “abnormalities”. The screening tests are constructed as providing “reassurance”, and offering “choice”, allowing the mother/couple to “make decisions about how to proceed”. Prenatal screening tests rarely detect conditions that can be ameliorated through therapy; most times the “choice”
offered is about whether to abort a wanted child based on a numerical “risk” that fetus may have a genetic condition or physiological difference. Disability rights advocates point out that prenatal screening frequently makes assumptions about “who” ie. able-bodied, “normal”, “perfect” people, are of value to the world (Parens & Asch 2000).

5.7.7 Metaphors

The pamphlets were filled with metaphors, including metaphors that described biological and technological processes (e.g. test is performed, blood is collected, cross the barrier, rearrangement of pieces of chromosomes, genetic material, carry a baby), and administrative issues (the cost is covered, the test is provided for). Sometimes metaphors were used as euphemisms (losing the pregnancy, assuming the costs of a test that is not covered). Some words that we use as nouns are also metaphors (labour, delivery, miscarriage). A number of metaphors reflected strong “able-ist” ideological assumptions. Many of these metaphors occurred in multiple pamphlets. Three metaphors that dominate the field are presented below: birth defect, prenatal screening, and prenatal testing.

5.7.7.1 Birth defect.

Birth Defect is a commonly used metaphor that was frequently seen in the educational pamphlets. Such a metaphor may be seen as implicitly comparing a fetus to a defective product. This metaphor may be interpreted as commodifying the fetus by emphasizing that something is wrong, useless, abnormal, flawed, or not functioning, that it is less valuable than similar “products” without a defect. “Birth Defect” may also be seen as comparing birth to production, reinforcing the idea of fetuses as products and mothers as producers. According to Rothman (1989), the commodification of conception implicitly places the blame for a birth defect on the mother- the “inept worker” (p.6).

5.7.7.2 Prenatal screening.

The metaphor prenatal screening, adopted as the dominant phrase by the medical community, may also be interpreted as participating in the Birth as Production conceptual system. Prenatal screening acts as “quality control”, separating wanted fetuses from unwanted. Screening is the process of examining a number of objects and sorting
them based on pre-determined criteria; keeping the good, and discarding the bad. Prenatal screening may be viewed as a metaphor for the process of sifting, of running material through a sieve (or screen), which catches some pieces of material and lets others fall through. Kress (2006) observes that in the “screen” metaphor “the sense of partitioning is strongly present; ... there is stuff on the one side that does not reach the other- and is not supposed to- the stuff on the one side is actively sorted so as to make it suitable for whatever uses there may be on the other” (pg 201). When a baker screens, or sifts, flour, she places the raw material on the sieve and lets most fall through (fetuses without aneuploidy), but the size of the hole in the sieve (diagnostic criteria) catches the undesirable material (fetuses with aneuploidy), allowing it to be subject to further scrutiny and then discarded (aborted) if it is not up to a pre-determined standard. This metaphor disguises the fact that the diagnostic criteria are arbitrary. While some people may consider Down syndrome to be a problem, others would not agree; the inclusion of a condition in a list of unspecified “birth defects” or “problems” does not allow individual women to think about particularities. The discourse has already decided particular conditions are a defective way of living, expressed by naming that condition a “defect”.

5.7.7.3 Prenatal testing.

Prenatal testing is also a metaphor, that may be seen as describing the procedure not as information seeking, but as information validating. A test is something that can be influenced: diligent test takers will pass, proving their knowledge, worth, or utility; negligent test takers will fail, proving their laziness, ignorance, or uselessness. A test is evaluated as pass/fail, and these are valued accordingly. By describing prenatal screening as a test, the true nature of the procedure may be seen to be disguised. A prenatal screening test seeks information, it does not validate the information provided by a woman. The woman being tested cannot do anything to influence the outcome, and her past actions have not affected the outcome in any way. By using the word test, responsibility for the outcome is placed on the mother. Although results from prenatal tests are described as positive/negative, ideological messages (as outlined in the rest of this paper) may implicitly communicate what the desired result should be; women may
internalize this and interpret the reception of desired result (negative for aneuploidy) as “passing the test”.

5.8 Discussion

Prenatal screening is now a routine part of prenatal care for pregnant women of all ages in the Canadian context (Summers et al, 2007). Education about this process and the consequent choices available to women is an important complement to clinical practice. Yet, critical reflection through metaphor analysis reveals that the language used within such educational material has not achieved the level of neutrality necessitated by the requirements of non-directive counseling. Indeed subtle ideological messages may be seen to be conveyed through metaphoric and figurative language, and these messages may implicitly guide women in the choices they make about their pregnancies.

Metaphor is an inextricable component of language, and so the presence of metaphor within the educational pamphlets is not in itself problematic. Rather, the analysis reveals that metaphors may contain ideological messages that appear so natural and self-evident that they may not be questioned, even though they may guide or influence women’s understandings, actions and choices. It is this dimension which is of concern. This implicit directive to conform to biomedical objectives is what Dixon-Woods (2001) refers to as “patient education” discourse and is prevalent in most of the pamphlets in this study. Some pamphlets, notably (#8 and 11), participate in a “patient empowerment” discourse, presenting comprehensive information without directives, so women can evaluate the information and decide how they wish to proceed.

Lakoff and Johnson (1980a) contend that we are not aware of the ways that metaphors construct our conceptual system, because we react to that conceptual system automatically. The subversive potential of metaphor rests on the assertion that they are “so natural and so pervasive in our thought that they are usually taken as self evident” (Lakoff & Johnson 1980a p.29). Recognition of the subversive power of metaphor calls to mind Foucault’s conceptualization of discourse. Foucault (1972) views discourse as a group of institutionalized statements (including any type of utterance) about a particular topic (or object) that functions to form that topic. A discourse is a regulated group of
statements which can combine with other discourses in predictable ways—there are “rules which lead to the distribution and circulation of certain utterances and statements … but rather than seeing discourse as simply a set of statements which have some coherence, we should think of a discourse as existing because of a complex set of practices which try to keep them in circulation and other practices which try to keep other statements out of circulation” (Mills, 2003, p. 54). Discourse is the manifestation of thought into language and defines the ways we can talk or think about that topic (or object), therefore defining the truth of that topic (or object) (Blood, 2005). By defining the truth of an object, discourse shapes and constrains our ways of understanding the world. Unreflective acceptance of a particular discourse shapes the way we perceive reality. This study has used metaphoric textual analysis as a means to engage in critical reflection, and to question some of the taken-for-granted messages conveyed in prenatal screening educational material.

Many of the pamphlets analyzed contained distinctly able-ist assumptions. This discourse promotes a particular conclusion or choice of action before any other information is established (i.e. information such as what is the condition, what is it like to live with that condition, what is it like to raise a child with that condition, what resources are available etc.). Conclusions are promoted through rhetorical features such as construction of the oppositions of normal/abnormal, health/disability, reassurance/worry, which create an idea of what type of person is valued, and construct the way that pregnant women can think about their future child. Discourses of choice and reassurance, and problems, decisions, solutions compose an internal logic of seek-detect-destroy. When a physician offers a test to “reassure” a new mother that her baby is “healthy”, how can she dispute the definition of healthy, or contest that reassurance may not be provided?

One of the strongest assumptions present in the prenatal screening pamphlets is that people with disabilities are “defective”, and would be better off if they had never been born. An alternative idea, one mentioned in only one pamphlet by the Canadian Down Syndrome Society, is that people are differently abled. Just as society provides resources and support to average people in the form of public transportation, public education etc.,
people with disabilities are entitled to similar support in order to promote healthy, productive lives (Wendell, 1996).

One prevalent metaphor system revealed in the analysis was the notion of *Birth as Production*. Martin (1987), Katz Rothman (1989) and Taylor (2008) have described this metaphor as conceptualizing the fetus as product, mother as labourer, and doctor as manager. Taylor (2008) has extended this metaphor to show how prenatal diagnostic testing via ultrasound “represents a way in which doctor/managers try to make sure that fetuses, whose production they oversee, are of consistently high quality” (Taylor 2008 p.119). Katz Rothman has named this “‘quality control’ on the assembly line of the products of conception, separating out those products we wish to develop from those we wish to discontinue” (Katz Rothman 1989, p.8).

The metaphor of Birth as Production provides an example of the way metaphor can implicitly shape our perception of reality and our understanding of concepts. For example, when women are asked if they want to have a prenatal test on the basis of the information that “2-3% of babies born have some type of major birth defect” (#2), they may consider the test differently than if asked if they want to participate in a screening test to tell “the CHANCE [original emphasis] of having a baby with Down syndrome, trisomy 18, or an open neural tube defect” (#11). The metaphor of “defect” is scary. It participates in the Birth as Production metaphor system by comparing a fetus to a manufactured product that doesn’t work, is faulty, mis-formed, should be sent back. This metaphor is misleading; persons living with Down syndrome or spina bifida may not think of themselves as defective. However, by using metaphors that analogize a fetus to a defective manufactured product, the test becomes more desirable- the conceptual metaphor implies that prenatal screening is a “quality control” test, to find and eliminate products that are not made to a certain standard. This metaphor is subversive because it judges the value of people living with certain conditions, without naming those conditions so the reader can investigate and decide for herself.

Implications for future prenatal screening public education pamphlets are simple to state, but may be difficult to achieve. Critical reflection on the figurative language and
metaphors used in this literature is essential. Educational writers are advised to critically interrogate the metaphors and figurative language used and the implicit messages that such language conveys. What messages are being conveyed to women, both implicitly and explicitly? What assumptions about disability may be implicitly present? What are the beliefs, values and opinions of the writer and how are these portrayed through word choices? What ideological messages permeate the dominant discourses surrounding this procedure? How might information be conveyed that supports the aim of informed choice and non-directive counseling?

5.9 Conclusion

This project does not aim to abolish metaphors from public education literature, nor does it aim to demonize prenatal screening. Access to prenatal screening is an important resource for Canadian women. However, it is important that each woman receive thorough information in a sensitive manner, so she can carefully consider her feelings, opinions, and options. While many of the pamphlets analysed in this study include problematic language, some provide comprehensive information stated in simple, neutral terms. As non-directive educational materials that promote informed choice, the pamphlets published by Mt. Sinai Hospital and the Genetics Education Project were exemplary. They included comprehensive information and avoided many of the subtle ideological directives present in other materials.

The universalization of prenatal screening in Canada (Summers et al, 2007) brings access to this procedure to a wider demographic of patients, but also provides instructions about how prenatal screening should be presented. Many of the metaphors currently used in prenatal screening patient literature do not support the counseling goals of non-directiveness, informed choice, and respect for the needs and quality of life of persons with disabilities as mandated by the Clinical Practice Guideline governing this practice (Summers et al, 2007). A critical examination of the language in these pamphlets reveals a need for more careful attention to the language used in patient education materials with the aim to empower women to make an informed choice. This study shows how metaphoric textual analysis can be used as a means of critical reflection that reveals ideological assumptions in supposed neutral educational materials. The findings have
implications for the design of accurate and sensitive prenatal screening educational materials, aimed at empowering women to make informed choices.
5.10 References


6 Information-Sharing to Promote Informed Choice in Prenatal Screening in the Spirit of the SOGC Clinical Practice Guideline: A Proposal for an Alternative Model

6.1 Introduction

The 2011 Society of Obstetricians and Gynaecologists of Canada’s Clinical Practice Guideline “Prenatal Screening for Fetal Aneuploidy in Singleton Pregnancies” (Chitayat, Langlois, & Wilson, 2011) recommends that clinicians, most frequently physicians, nurses, and midwives, offer non-invasive prenatal screening for chromosomal anomalies and incomplete neural tube closures to every pregnant woman. The Guideline recommends that clinicians provide “understandable” information about the screening tests in a “non-directive” manner in order to “ensure informed decision-making” (Chitayat et al., 2011). This recommendation is consistent with the 2007 SOGC Guideline on prenatal screening for fetal aneuploidy (Summers, Langlois, Wyatt, & Wilson, 2007), encouraging each woman to evaluate her options and consider her preferred course of action in relation to her particular situation, experiences, and personal values (Chitayat et al., 2011; Summers et al., 2007). However, recent research in genetic counseling has raised concerns that non-directive counseling is neither possible (Kirklin, 2007) nor desirable (Weil, 2003; Williams, Alderson, & Farsides, 2002) and may not be the best way to facilitate informed choice (Elwyn, Gray, & Clarke, 2000; Kirklin, 2007; Weil, 2003). We consider here whether non-directive counseling may unintentionally create obstacles to the SOGC Guideline’s goal of an informed counseling process leading to autonomous decision-making, and propose an alternative approach specific to the context of prenatal screening that combines aspects of informative (Emanuel & Emanuel, 1992) and shared models of decision-making (Charles, Gafni, & Whelan, 1997; Charles, Gafni, & Whelan, 1999; Charles, Whelan, & Gafni, 1999).

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6.2 Prenatal Screening for Fetal Aneuploidy

The process of prenatal screening requires pregnant women to make a decision that is qualitatively different from most other patient decisions because of the necessity to understand and integrate complex and value-sensitive concepts in a context where there is no single “right” decision. When deciding whether or not to participate in prenatal screening, a woman must consider the potential for additional decisions about diagnostic testing and pregnancy termination (Wilson et al., 2005), as well as psychosocial risks to herself (Paren & Asch, 2000; Press, Browner, & Tran, 1998; Rapp, 1999; Rothman, 1993) that may arise. These concepts are considered in conjunction with the woman’s personal values and circumstances (Durand, Stiel, Boivin, & Elwyn, 2010; Markens, Browner, & Preloran, 2010). As prenatal screening requires women to make a type of decision that is different from most other medical procedures, it requires a type of decision-making process that is different from that suggested by traditional models of informed consent (Whitney, McGuire, & McCullough, 2004; Whitney et al., 2008) or the models of informative (Emanuel & Emanuel, 1992) or shared decision-making (Charles et al., 1997; Charles et al., 1999; Charles, Whelan et al., 1999; Emery, 2001).

6.3 Informed Choice and Autonomy

A narrow conception of autonomy may be problematic in light of the social and cultural contexts within which women make decisions about prenatal screening (Thachuk, 2007). Code (1991) and Sherwin (McLeod & Sherwin, 2000; Sherwin, 1992; Sherwin, 1998) posit that the way autonomous informed choice is enacted can be problematic for patients who do not fit the ideal of the autonomous decision-maker; the model of autonomous decision-making assumes patients to be self-sufficient, independent, articulate, accustomed to making decisions, and possessed of the resources necessary to allow a range of choices. In addition, physicians are assumed to have the time, knowledge, and communication skills to provide the patient with complex information, evaluate the patient’s comprehension of the information, and encourage the patient to make a decision based on her values and preferences, without regard for health care costs or legal liability (Sherwin, 1998). In many instances, these traits and circumstances of the ideal autonomous decision-maker and the ideal decision-facilitator may not co-exist. Thus,
pregnant women may not be in an ideal position regarding informed choice in considering prenatal screening.

6.4 Non-Directive Counseling

The SOGC Guideline’s recommendation for non-directive counseling when offering prenatal screening (Chitayat et al., 2011) is intended to encourage informed choice that reflects each woman’s individual values and circumstances. Non-directive counseling is one of the principal tenets of genetic counseling (Fine, 1993; Kolker & Burke, 1998; Weil, 2003; Wertz & Fletcher, 1989), and is important because it aims to promote autonomous informed decision-making (Weil, 2003). However, others have argued that for reasons of impossibility and undesirability, non-directive counseling may not be the best way to achieve autonomous decision-making (Elwyn et al., 2000; Fine, 1993; Kirklin, 2007; Petersen, 1999; Weil, 2003; Williams et al., 2002). There are many descriptions of non-directive counseling, each with their own particular nuances (Smets, van Zwieten, & Michie, 2007), and the SOGC Guideline does not identify a particular model of non-directive counseling or describe how this strategy should be used in the context of prenatal screening (Chitayat et al., 2011). The following sections will examine some of the arguments against the strategy of non-directive counseling, and propose an alternative approach to encouraging autonomous decision-making about prenatal screening.

6.4.1 Is non-directive counseling possible?

The capacity for non-directive counseling is constrained by the broader context in which prenatal screening is presented (García, Timmermans, & van Leeuwen, 2008; Smets et al., 2007). It has been argued that non-directive counseling may not be possible, given the barriers to dissolving the persuasive authority embodied in the offer of a medical procedure by a health care provider in an institutional setting (Weil, 2003), funded through a universal health care program (Hunt & deVoogd, 2003). In these circumstances, the offer of prenatal screening may imply a recommendation to accept prenatal screening, thus rendering the goal of non-directive counseling unachievable (Clarke, 1991).
The possibility of non-directive counseling may also be constrained by whether or not the counselor is able to identify and avoid directive elements (Kolker & Burke, 1998). For example, in a study of genetic counselors, it was difficult for the counselors to determine what verbal and non-verbal cues could be considered directive (Bartels, LeRoy, McCarthy, & Caplan, 1997). Further, directive cues may include commonly used terminology such as “abnormalities” or “risks” (Grant & Flint, 2007; Hodgson, Hughes, & Lambert, 2005; Parens & Asch, 2000). In addition, making the necessary choices of what information to present and how to present it can itself be directive (Brunger & Lippman, 1995; Kirklin, 2007; Rantanen et al., 2008; Weil, 2003; Williams et al., 2002). Further, clinicians may hold perspectives and opinions about prenatal screening that are different from their patients’, making neutrality difficult to achieve. This may be problematic (Cunningham-Burley & Kerr, 1999), because of the power and knowledge differential between patients and clinicians (Stacey, 1996; Summers, 1994).

Seventy-two percent of genetic counselors (who have received training in non-directive counseling and are allotted longer periods of time to counsel patients than physicians) acknowledge that they sometimes counsel directly (Bartels et al., 1997). For example, clinicians have reported choosing to counsel directly when they perceived that their patients could not comprehend the information because of low education level, cultural or language differences, or low socioeconomic status (Bartels et al., 1997; Michie, Bron, Bobrow, & Marteau, 1997), when the clinician thought there was a “better choice” for the woman (Bartels et al., 1997), or when the woman was having trouble making a decision (Bartels et al., 1997).

### 6.4.2 Is non-directive counseling desirable?

Observational research on non-directive counseling sessions has found that practitioners counseling non-directively often do so by using indirect speech, such as “some people may want to…” when outlining various choices or considerations (Benkendorf, Prince, Rose, De Fina, & Hamilton, 2001). This strategy may lead to confusion on the part of women about whether or the information applies to them, and it does not invite women to state their values (Benkendorf et al., 2001). Genetic counselors have reported that non-directive counseling constrains their ability to counsel actively and impedes their wish to
share the information that is most relevant to a particular woman (Weil, 2003). For example, a clinician who sees an incompatibility between a woman’s decision and her expressed values may wonder about incomplete or incorrect understanding and may wish to counsel more actively (Suter, 1998; Weil, 2003). Non-directive counseling may be even more challenging for practitioners who do not normally practise in a non-directive way, especially considering that in other circumstances (such as regulating blood sugar or controlling hypertension) non-directiveness may be seen as a problematic way of practice (Caplan, 1993; Williams et al., 2002). Time constraints in primary care medicine may be an additional obstacle to non-directive counseling (Greendale & Pyeritz, 2001).

It has been argued that non-directive counseling may not be desirable because counseling in this way may omit discussion of controversial issues related to prenatal screening (Caplan, 1993), such as issues of disability or pregnancy termination (Caplan, 1993; Stacey, 1996). If a woman feels a sense of discomfort or moral distress, she may not be able to identify what issue is causing discomfort, which may prevent her from considering the source of that discomfort when making a decision (Anderson, 1999). In addition, counseling in a non-directive way may make it difficult for a woman to identify directive elements that may creep unintended into the counseling (Clarke, 1997). In this way, non-directive counseling may harbour unacknowledged directive elements and therefore may be more disempowering than a counseling model where directive elements are explicitly acknowledged so they can be considered by the woman (Clarke, 1994; Kessler, 1992; Kessler, 1997). Women may also perceive the option of prenatal screening as a medical directive, rather than a choice (Anderson, 1999), even if the information is presented in a non-directive manner. For example, 37.4% of Canadian women surveyed about their reasons for participating in maternal serum screening reported that they participated because my "doctor told me I should have the test” (Park & Mathews, 2009 p.150).

We propose an alternative model to non-directive counseling that retains the spirit of the SOGC Guideline’s emphasis on the imperative of informed decision-making by encouraging providers to counsel actively in a way that supports women to make their own informed choice about prenatal screening.
6.5 Proposed Alternative Model of Informative Decision-Making and Shared Decision-Making

To accommodate the specific circumstances of prenatal screening, we propose an alternative model of decision-making that combines aspects of informative decision-making (Charles et al., 1999; Emanuel & Emanuel, 1992) and shared decision-making (Charles et al., 1997; Charles et al., 1999; Charles, Whelan et al., 1999) (Table 6).

Table 6: Proposed hybrid model for informed and autonomous decision-making in prenatal screening

<table>
<thead>
<tr>
<th>Information-sharing</th>
<th>Non-Directive Counseling</th>
<th>Informative Decision-Making</th>
<th>Shared Decision-Making</th>
<th>Proposed Hybrid Model</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinician</strong></td>
<td>Clinician imparts objective, clinical, value-free information</td>
<td>Clinician imparts objective, value-free information</td>
<td>Clinician and woman “exchange” clinical information and values</td>
<td>Clinician and woman share clinical information, personal values (woman), and professional values (clinician).</td>
</tr>
<tr>
<td><strong>Deliberation</strong></td>
<td>Woman only; clinician cannot express opinion to avoid being directive</td>
<td>Woman only; deliberation is simplified to “selection” in this model.</td>
<td>Clinician and woman engage in interactive deliberation, suggesting and discussing treatment options and preferences</td>
<td>Clinician counsels actively in a way that supports the woman to fully understand the information and its implications</td>
</tr>
<tr>
<td><strong>Decision-Making</strong></td>
<td>Woman only</td>
<td>Woman only</td>
<td>Clinician and woman together</td>
<td>Woman only</td>
</tr>
</tbody>
</table>

* “Woman” may also include partner or anyone else the pregnant woman decides to
include in decision-making

In informative models of decision-making (Charles et al., 1999; Emanuel & Emanuel, 1992), the health care provider gives the patient scientific and clinical information and the patient deliberates and makes a decision on her own. In contrast, shared decision-making (Charles et al., 1997; Charles et al., 1999; Charles, Whelan et al., 1999) promotes an exchange of clinical information and personal values from both patient and provider, leading to a shared deliberative and decision-making process.

Shared decision-making was developed in the context of decision-making about life-threatening illness (Charles et al., 1997), and while it has much to offer clinicians who counsel about prenatal screening (Elwyn et al., 2000; L. M. Hunt, de Voogd, & Castañeda, 2005; Legare et al., 2011), the value-sensitive context of prenatal screening requires careful consideration. Charles and colleagues (1997) conceptualize the process of SDM as comprising three stages: information exchange, deliberation, and decision-making. Charles and colleagues also recognize the value of flexibility between SDM and an informative approach, stating that in practical use, clinicians may need to change frameworks midstream (Charles et al., 1999). We propose a particular hybrid model for the context of prenatal screening, recognizing that each stage depends on the one before and the end goal of counseling (encouraging the patient to make an autonomous, informed decision) must guide the clinician’s approach through all stages of the counseling session.

Légaré and colleagues, who found that both pregnant women and family physicians are willing to participate in SDM when considering prenatal screening, call for more “theorization and development of strategies” to facilitate this process (Legare et al., 2011 p.320). Our proposed hybrid model of decision-making in prenatal screening begins with the information-sharing phase of SDM, uses a particular hybrid of SDM and IDM in the deliberative phase, and ends with the decision-making phase of IDM (Table 6). Our model modifies “information exchange” from the model of Charles and colleagues (Charles et al., 1997) to “information sharing,” in order to explicitly acknowledge that information can be, but is not always, provided by both parties, and to reflect a collaborative approach.
6.5.1 Information sharing phase.

The information-sharing phase of the hybrid approach follows the model of SDM in that information is shared between the pregnant woman and her obstetrical care provider, with each sharing both medical knowledge and values. Echoing Freire’s writing on education (Freire, 1993), Charles and colleagues (Charles et al., 1999) emphasize that patients are not ‘empty vessels’ waiting to be filled up with technical knowledge. Rather, patients come to the clinician’s office with their own beliefs, values, fears, experience, and, often, medical knowledge from friends, family, or other sources. A woman’s individual perspectives on prenatal screening, parenthood, disability, and abortion will affect the way that she will interpret the information received from her clinicians, and so it is important that clinicians initiate conversations about values and perspectives, so that the information shared is more relevant to their patients. Bhogal and Brunger (Bhogal & Brunger, 2010) have written that it is important for clinicians to make an effort to be aware of their own perspective and to recognize the influence their personal and professional values may have on the ways they think and speak about prenatal screening and testing (Bhogal & Brunger, 2010). In SDM, health care providers attempt to be explicit about their values with patients (Charles et al., 1997; Charles et al., 1999; Charles, Whelan et al., 1999), and to recognize that their patients’ values may differ; clinicians using our proposed hybrid approach will be aware that they will later ask each woman to make her own decision and that providing extensive information about the clinician’s own values may unduly influence the woman’s decision. Nonetheless, clinicians using our proposed hybrid approach will keep their personal values in mind, and might wish to share values related to their clinical expertise and experience, especially when this perspective would assist in exploring the values or opinions expressed by the woman during counseling. For example, clinicians might acknowledge that, in their experience, prenatal screening can provoke anxiety, especially for those who are not sure what they would do in the event of a high risk result. This can be an opportunity to explore issues of anxiety, the time frame for receiving results, and feelings about interpreting uncertain results. Genetic counselors have acknowledged the utility of sharing their own values, calling for support and guidance about ways in which to do this productively (Bower, McCarthy Veach, Bartels & LeRoy 2002; McCarthy Veach, Bartels
& LeRoy, 2002; Weil, 2003) and arguing that patients can make use of the attitudes and opinions of their counselor without being unduly influenced (Kessler, 1997).

### 6.5.2 Deliberation phase.

In the IDM model (Emanuel & Emanuel, 1992), the patient has full control over deliberation and decision-making, and the clinician’s role is limited to providing additional information, if needed, or correcting misunderstandings. In SDM, the clinician is an active partner in deliberation, suggesting ideas and making recommendations.

As in SDM, our proposed hybrid model envisions the clinician participating actively in the deliberation process. In contrast to SDM, clinicians using the proposed hybrid model will counsel actively without expressing any preference for a particular course of action. For example, the clinician may encourage a woman to think critically about the implications of particular courses of action and the ways in which her personal values may come to bear on these different choices (Jansen, 2001). In this way, the provider is a valuable participant in the deliberative phase, as a caring, informed individual who has some understanding of the patient’s values and a strong understanding of the possible implications of different courses of action.

To illustrate the contrast, there is no deliberation phase in IDM; a clinician provides the information needed to make the choice, assesses the woman’s comprehension, and then asks her to deliberate without clinician participation (Emanuel & Emanuel, 1992). In SDM, the deliberation process involves interaction between the thoughts, opinions, and recommendations of the clinician and the patient (Charles et al., 1997; Charles et al., 1999; Charles, Whelan et al., 1999). The SDM clinician may offer a recommendation and a rationale, while encouraging the patient to express and discuss reasons for her proposed course of action. The proposed hybrid model is distinct from SDM in that the clinician does not make recommendations but assists the woman in considering the available options and their possible implications, including how these options may fit or conflict with the patient’s values.
Of course, some women may prefer that their clinicians take a more or less active role in deliberation. For women who are clear about their values and desires, a prolonged deliberation process may not be necessary or desirable. Open communication about expectations of each other’s roles is necessary to engage in a process that is acceptable to all parties (Charles et al., 1997). Deliberation may also include other people the pregnant woman chooses to involve in her decision-making; Charles and colleagues (Charles et al., 1999) recognize that a patient’s decision-making process often includes consultation with family, friends, or other health care professionals.

6.5.3 Decision-making phase.

At the time of decision-making, our proposed hybrid model follows the IDM model (Emanuel & Emanuel, 1992), which encourages a patient to make an autonomous decision about participation in prenatal screening that reflects her particular situation and values; it proposes that the patient makes the decision on her own, or in consultation with her partner or family (as she prefers), based on the information provided by the clinician. There is no role for the clinician in the decision-making process other than to support and facilitate the course of action chosen by the patient.

Our proposed model further follows the IDM model, because this approach is more suitable than SDM for decision-making about prenatal screening given the uncertain nature of the results and the morally sensitive nature of the decision. In this type of situation, it is necessary that the provider not have an investment in the decision a woman makes. Prenatal screening is an example of a decision where clinician investment would “go beyond the boundaries of an appropriate clinical role because the provider might harm the patient by inadvertently steering her in a certain direction.” (Charles et al., 1999 p.657) While the application of a clinician’s experience and knowledge to treatment decision-making may be appropriate in other situations, particularly those for which evidence-based guidelines suggest there is a “best” treatment (Charles, Whelan et al., 1999) to achieve patient well-being (Charles et al., 1999), decisions about prenatal screening do not have one best answer or right way forward. They “are too personal and too devastating to be made by anyone other than the woman or the couple involved” (Summers, 1994 p.1690).
6.6 Conclusion

The SOGC Clinical Practice Guideline on Prenatal Screening for Fetal Aneuploidy encourages each woman to make her own decision, informed by comprehensive information about the screening tests and reflective of her personal situation and values. Rather than non-directive counseling as the best model to serve this goal, we propose a hybrid approach that combines informative decision-making and shared decision-making in a strategy to encourage pregnant women and clinicians to discuss prenatal screening in a way that promotes informed choice based on a woman’s particular circumstances and values. We recognize that the hybrid approach may impose additional requirements on clinician time, but we believe it will assist clinicians in supporting women to make informed choices regarding prenatal screening.
6.7 References


120.


Kessler, S. (1992). Psychological aspects of genetic counseling. VII. Thoughts on


7 Pregnant Women’s Self-Identified Information Requirements When Deciding to Participate in Non-Invasive Prenatal Screening

7.1 Introduction

The provision of information to facilitate informed decision-making is recognized by professional practice guidelines in many countries, such as Canada (Chitayat, Langlois, & Wilson, 2011), the United States (ACOG practice bulletin no. 77: Screening for fetal chromosomal abnormalities.2007), the Netherlands (Health Council of the Netherlands, 2006), the UK (UK National Screening Committee & Department of Health, 2008), Denmark (Ekelund, Jørgensen, Petersen, Sundberg, & Tabor, 2008), and Australia and New Zealand (RANZCOG, 2010), as an essential part of the offer of prenatal screening. For example, the Canadian guideline states that women should be provided “understandable information … to ensure informed decision-making” (Chitayat et al., 2011). While there is no single recognized definition of informed decision-making (Bekker et al., 1999; van den Berg, Timmermans, ten Kate, van Vugt, & van der Wal, 2006), the most common element is that a reasoned decision is made by a reasonable individual (Bekker et al., 1999); this informed decision is based on “relevant knowledge”, consistent with the “decision-maker’s values” and is “behaviorally implemented” (Marteau, Dormandy, & Michie, 2001).

There is extensive literature on informed decision-making in prenatal screening and testing. Existing literature has assessed women’s knowledge about prenatal screening (Dahl, Hvidman, Jørgensen, & Kesmodel, 2011; Gekas, Gondry, Mazur, Cesbron, &

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7 A version of this chapter has been submitted for publication: Vanstone, M., Kinsella, E.A. & Nisker, J. Pregnant women's self-identified information requirements when deciding to participate in prenatal screening.

8 “Informed decision-making” is often used interchangeably with “informed choice”, and sometimes conflated with “informed consent”. Informed consent is a legal term. “Informed decision-making” emphasizes the decision-making process, whereas “informed choice” emphasizes the decision made.
Thepot, 1999; Goel, Glazier, Holzapfel, Pugh, & Summers, 1996; Jaques, Halliday, & Bell, 2004; Mulvey & Wallace, 2001; Schoonen et al., 2011), and evaluated whether or not decisions about prenatal screening could be considered informed autonomous decisions (Gourounti & Sandall, 2008; Jaques, Sheffield, & Halliday, 2005; Markens, Browner, & Press, 1999; Rowe, Fisher, & Quinlivan, 2006; van den Berg et al., 2006; M. van den Berg, Timmermans, ten Kate, van Vugt, & van der Wal, 2005; Williams, Alderson, & Farsides, 2002). Informed decision-making has been promoted through the provision of varied information and decision-making resources (Bekker, Hewison, & Thornton, 2004; Dahl, Kesmodel, Hvidman, & Olesen, 2006; Hunter et al., 2005; Stapleton, Kirkham, & Thomas, 2002).

It is well established that when asked to make a decision about non-invasive prenatal screening, many women do not have enough information to make a decision that could be characterized as an “informed” decision (Gourounti & Sandall, 2008; A. M. Jaques et al., 2005; Kohut, Dewey, & Love, 2002; Markens et al., 1999; Reid, Sinclair, Barr, Dobbs, & Crealey, 2009; Rowe et al., 2006; van den Berg et al., 2006; van den Berg et al., 2005; Williams et al., 2002), and lack of information is one of the most significant sources of decision-making difficulty (Reid et al., 2009). An “uninformed” decision-making process has been attributed to insufficient or incorrect information given by the clinician offering the test (Green, Hewison, Bekker, Bryant, & Cuckle, 2004; Marteau, Slack, Kidd, & Shaw, 1992; Marteau, Plenicar, & Kidd, 1993; Smith, Slack, Shaw, & Marteau, 1994; Tyzack & Wallace, 2003), or as a result of either time constraints (Legare et al., 2011; Legare, Ratte, Gravel, & Graham, 2008; Williams et al., 2002), inadequate clinician knowledge (Hunt, de Voogd, & Castañeda, 2005; Marteau et al., 1993; Tyzack & Wallace, 2003) or insufficient effort to include women in the informed decision making process (Gagnon et al., 2010).

There may also be differences in the information priorities of women and clinicians when counseling about prenatal screening (Farrell et al., 2011; Freda, Andersen, Damus, & Merkatz, 1993; Hunt et al., 2005; Park & Mathews, 2009). For instance, the topics clinicians were observed to emphasize during clinical conversations (ex. risks of anomaly) were not described as important by patients, or reflected as important in their
reports of what they understood about prenatal screening (Hunt et al., 2005); clinicians'
lists of pregnancy information topics women would want to hear about during a prenatal
consultation differed significantly from the lists provided by pregnant women (Freda et
al., 1993); women report that pieces of information they deem important for decision-
making are not discussed by their clinicians (Farrell et al., 2011; Park & Mathews, 2009).
A reported discrepancy between information desired by women vs. information provided
by clinicians was also noted in women who were offered amniocentesis (Durand, Stiel,
Boivin, & Elwyn, 2010).

Further, research on the offer of prenatal screening may place more emphasis on the
information domains that are considered to produce an "informed" decision (information
to understand the test), and less emphasis on the topics that have been identified by
women as influential decision-making factors (information to make a decision about the
test). These information areas may not always overlap (Farrell et al., 2011), suggesting
that for some women, there may be a difference between possessing the knowledge to
understand the test and possessing the knowledge required to make a decision about the
test. This gap may contribute to the reason why health care providers have found it
difficult to construct a conversation to facilitate informed decision-making
(Gottfreðsdóttir & Árnason, 2011). The difference between information for
understanding and information for decision-making may help explain findings that the
level of knowledge a woman has about non-invasive prenatal screening does not
necessarily correlate to self-reports of whether the information received was sufficient for
decision-making (Dahl et al., 2006; Gourounti & Sandall, 2008; Stapleton et al., 2002),
supporting the call for individualized information tailored to each woman's needs in order
to support informed decision-making (Hunt et al., 2005; F. Legare et al., 2011; Vanstone,
Kinsella, & Nisker, 2012). The relationship between the information needed for
understanding prenatal screening and making an informed decision about prenatal
screening is unknown. This project aims to identify the self-reported information
requirements of women to make an informed choice about participation in non-invasive
prenatal screening.
7.2 Methods

Constructivist grounded theory (CGT) (Charmaz, 2000; Charmaz, 2006) uses inductive reasoning to identify thematic categories about the phenomenon under investigation. It is particularly suitable when knowledge is being sought from the ‘ground’ up, for instance in this study from the first hand accounts of pregnant women (Charmaz, 2006). Grounded theory is an iterative process, with each round of coding and categorization contributing to new insights and prompting the need to return to the data to re-analyze, or to return to the field to collect more data with these new insights in mind.

7.2.1 Recruitment.

Sixteen pregnant women were purposively recruited through the London-Middlesex Health Unit’s Prenatal Fair [10], advertisements on pregnancy and classified ad websites [4] and through snowball sampling [2]. Women were sampled to represent a diversity of perspectives about participation in prenatal screening (Table 7). Sampling was completed when theoretical saturation was thought to be achieved, that is, when no new categories were seen to emerge in further interviews. This study received research ethics approval from the University of Western Ontario (#16988E).

Table 7: Participant Demographics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Participated in Screening?</th>
<th>Age</th>
<th>Urban/Rural</th>
<th># years of education</th>
<th>Recruitment method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abby</td>
<td>No</td>
<td>27</td>
<td>Urban</td>
<td>17</td>
<td>Snowball</td>
</tr>
<tr>
<td>Bridget</td>
<td>Yes</td>
<td>30</td>
<td>Urban</td>
<td>21</td>
<td>Online</td>
</tr>
<tr>
<td>Carrie</td>
<td>No</td>
<td>29</td>
<td>Urban</td>
<td>16</td>
<td>Snowball</td>
</tr>
<tr>
<td>Danielle</td>
<td>Yes</td>
<td>31</td>
<td>Urban</td>
<td>14</td>
<td>Prenatal Fair</td>
</tr>
<tr>
<td>Name</td>
<td>Eligible</td>
<td>Age</td>
<td>Location</td>
<td>Prenatal Screening</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>----------</td>
<td>-----</td>
<td>----------</td>
<td>--------------------</td>
<td></td>
</tr>
<tr>
<td>Eva</td>
<td>Yes</td>
<td>20</td>
<td>Rural</td>
<td>Prenatal Fair</td>
<td></td>
</tr>
<tr>
<td>Farah</td>
<td>Yes</td>
<td>27</td>
<td>Rural</td>
<td>Prenatal Fair</td>
<td></td>
</tr>
<tr>
<td>Gail</td>
<td>Yes</td>
<td>24</td>
<td>Urban</td>
<td>Online</td>
<td></td>
</tr>
<tr>
<td>Holly</td>
<td>Yes</td>
<td>26</td>
<td>Urban</td>
<td>Online</td>
<td></td>
</tr>
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<td>Isobel</td>
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<td>Urban</td>
<td>Prenatal Fair</td>
<td></td>
</tr>
<tr>
<td>Jade</td>
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<td>28</td>
<td>Rural</td>
<td>Prenatal Fair</td>
<td></td>
</tr>
<tr>
<td>Kyla</td>
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<td>29</td>
<td>Urban</td>
<td>Online</td>
<td></td>
</tr>
<tr>
<td>Lucy</td>
<td>Yes</td>
<td>29</td>
<td>Urban</td>
<td>Prenatal Fair</td>
<td></td>
</tr>
<tr>
<td>Madelaine</td>
<td>No</td>
<td>30</td>
<td>Urban</td>
<td>Prenatal Fair</td>
<td></td>
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<tr>
<td>Nadia</td>
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<td>Olivia</td>
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<td></td>
</tr>
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<td>Penny</td>
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<td>28</td>
<td>Rural</td>
<td>Prenatal Fair</td>
<td></td>
</tr>
</tbody>
</table>

### 7.2.2 Eligibility.

Women were eligible for the study if they were carrying their first pregnancy, self-identified as having a “low risk” pregnancy, were under the age of 35 at expected date of delivery, fluent in English and received the offer of prenatal screening from a family physician. The criteria of young age and self-identified "low-risk" pregnancy reflect
women who may not have been offered prenatal screening prior to the introduction of the 2007 Canadian professional practice guideline (Summers, Langlois, Wyatt, & Wilson, 2007). The criterion of first pregnancy attempts to capture a sample who are formally considering prenatal screening for the first time. Women who accepted the offer of prenatal screening were eligible if they had not yet received their results. Women who declined the offer of prenatal screening were eligible if they were at 20 or fewer weeks gestation.

**7.2.3 Data collection.**

Interviews were conducted between May and November 2010; 16 participants were interviewed before theoretical saturation was achieved. Interviews were audiotaped and transcribed verbatim, and researcher field notes were recorded. Women chose to be interviewed in person [5] or over the phone [11], with interviews lasting between 25 and 69 minutes (average 41 minutes). Interview questions were open-ended, and inquired into participants’ experience of being offered prenatal screening by their family doctor and how they came to make the decision about whether or not to participate. Women were asked about their information needs and sources, including information from physicians and other health care clinicians, information from friends, family or others, and information that they specifically sought out. Women were asked what information was helpful or confusing in making a decision and what information they thought someone in their situation would require before deciding about whether or not to participate in prenatal screening.

**7.2.4 Data analysis.**

Data were hand-coded and the initial analysis guided subsequent sampling, refining of interview questions, and analysis in an iterative fashion. QSR N-Vivo 8 (QSR International 2010) was used to manage the data. Data were coded in a line-by-line fashion for mentions of information needs, and then re-coded in categories and by theme (K. Charmaz, 2006). The technique of constant comparative analysis was used to explore the connections between different codes or categories between multiple participants, and between different codes or categories from the same participant (Strauss & Corbin,
Visual diagrams were generated in this process and later used to re-code and re-categorize the data in subsequent phases of analysis. Through an iterative process eight categories were identified related to women’s perceptions of their information needs concerning the decision to participate (or not) in prenatal screening. The findings are presented as questions related to information needs during the process of prenatal screening (Table 8).

Table 8: Self-identified information requirements of women considering prenatal screening

<table>
<thead>
<tr>
<th>Category</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>What is prenatal screening?</td>
</tr>
<tr>
<td>II</td>
<td>What conditions are being screened for?</td>
</tr>
<tr>
<td>III</td>
<td>How will the results of prenatal screening be communicated?</td>
</tr>
<tr>
<td>IV</td>
<td>How will the results of screening be interpreted?</td>
</tr>
<tr>
<td>V</td>
<td>What are the options after receiving the screening results?</td>
</tr>
<tr>
<td>VI</td>
<td>What does it mean to live with a child with a condition or disability?</td>
</tr>
<tr>
<td>VII</td>
<td>How can an informed decision about participating in prenatal screening be made?</td>
</tr>
</tbody>
</table>

7.3 Findings

7.3.1 Category I: What is prenatal screening?

Each of the women in this study was interested in information about what the screening test was, and what it would entail. Most women were aware of the existence of the screening test but were unclear about the details of the test before meeting with their physician, "my friend saw the same doctor so she told me ... that there would be screening, but we didn't go into detail about it" (Carrie). At the time of the research interview, the majority of women demonstrated a good understanding of at least part of
the information about the test. Nonetheless, many demonstrated gaps in knowledge, for instance about the elements of the screening test:

*Jade:* Even just that information, explaining what it [screening] actually was. I didn't even know what the elements were when I agreed to do it. I just thought it was some extra checks they would make during your first ultrasound. I didn’t really know.

The link between the non-invasive, non-definitive prenatal screening tests and the more invasive, definitive diagnostic testing options such as amniocentesis was confusing to some women. Five women did not know about the option for definitive testing (such as amniocentesis), and several others were not sure how the screening test they were currently being asked to consider was related to definitive testing.

*Abby:* It wasn’t clear to me that if you choose to have the blood test and if that comes back positive you can choose the amniocentesis. I thought you can choose to have the bloodwork AND the amniocentesis.

Madelaine was similarly confused about the relationship between amniocentesis and prenatal screening, but a discussion with her doctor clarified this information.

*Madelaine:* When I went to my doctor's office I got more of a sense of it actually being two distinct stages .... that's part of the reason that having a discussion with your doctor is important, because it sounds like it's a package deal and in reality, maybe it isn't.

A desire for more information about the logistics of the test was a theme consistently identified by participants. Women identified important aspects of logistical information such as: what the elements of the test would be “*how the test is done*” (Olivia); how information would be obtained “*I'm interested in what the results are, but also to understand what they are measuring*” (Bridget); what information the test could provide “*what they could find*” (Gail); if there is any risk to the mother or fetus “*potential risks of the procedure*” (Madelaine); and when the screening tests take place “*at how many weeks you do certain things*” (Jade).
7.3.2 Category II: What conditions are being screened for?

The women in this study expressed interest in receiving information about the conditions included in prenatal screening. All women identified that it was important to know what conditions the screening test could detect and to understand what those conditions were. Madelaine’s family physician told her what conditions could be found, but without prior knowledge of these conditions Madelaine had difficulty interpreting this information: “there were a couple of terms that were dropped casually that I had no idea what they meant.” This information is important because:

Madelaine: If this is a prenatal screen for colour blindness, I think a lot of women would make a different decision than if it were testing for something like Down syndrome.

Several women mentioned that it would be helpful to have information about the conditions written down, so they could do more research if they wished, or so that it would be easier to remember unfamiliar terms.

Holly: I forget all of them [conditions screened for] except for Down syndrome ... I would've liked to have a little bit more information on that, maybe a pamphlet from my doctor ahead of time, so I could look it up.

7.3.3 Category III: How will the results of prenatal screening be communicated?

Information about how and when the results would be communicated was an important theme. All of the women who chose to participate in the test were interested in understanding how and when the results would be communicated, for instance, "would it be a phone call or would it be in writing?" (Olivia), and who would be relaying this information:

Farah: She’ll get the results and relay everything to me instead of having anyone else call me directly with any scary information. It definitely made me feel better that she’s in the middle of it all and relates that information back.
The element of receiving results mentioned by most women was the timing of the results:

Holly: When would I find out? Are you to call me if the results are positive? Are you just going to wait until I come back in?

Understanding when the results would be received was mentioned by Isobel as important for thinking about future options, because if a high risk result is received, "you have to make a decision about amniocentesis pretty quickly". For Danielle, the timing of the results was important in terms of weighing the options available in the event of a high risk result,

Danielle: I didn't realize how long it takes and how far along you are when you get the results. ... I think it would have been a good thing for her [family doctor] to tell me. ... I just kind of assumed it would be something you find out early on ... knowing that it's taking this long, I don't think I could get rid of the baby even if they did find something.

In retrospect, Danielle stated that if she had understood how long it would take to receive the results and "how far along you are when you actually find out anything" she "would have just said 'no thank you' and gone on and waited until the baby came".

7.3.4 Category IV: How will the results of the screening be interpreted?

Information about the results of the test was identified by women as important when making a decision to participate in prenatal screening. All of the women in the study were interested in understanding how the results would be interpreted and how reliable the results were. This information also informed discussion of Category V, the options available after receiving results from the screening test.

Understanding the results of the test was one of the most frequently mentioned information needs. In order to decide if they wished to participate in the initial prenatal screening test, women indicated that they wanted information about how and when the results would be conveyed, “how long it takes to get the results” (Olivia); the limits of
the screening results, “they should say this is what you can learn, this is what we potentially can’t tell you … give a comprehensive picture of what screening can and can’t do” (Madelaine); and the reliability of the screening results “I think it’s important, in the part about what the results tell you that they do communicate that it is not definitive” (Olivia), “the percentage that it’s a false positive or false negative is this” (Madelaine).

In addition to understanding the results of the test, each woman expressed interest in information to help her understand the reliability of the results. 15 of the 16 women recognized that the test did not provide a definitive answer, but rather suggested a range, probability, or risk statistic:

Eva: I know it's not a for certain thing, they give you a fraction or a percentage of the chance of having a child with one of these disorders or defects.

Among women who understood they would be receiving results in the form of a risk statistic, there was significant variability in how women reported interpreting that number:

Farah: I think it would probably have to be a pretty high percentage for me to be concerned with, probably over 20% risk, for me to really be worried.

Nadia: One in 1000 would be high-risk.

Understanding the potential for false negative and false positive results was stated as an important part of interpreting the risk statistic.

Nadia: People [friends] have said that there are false negatives and false positives, and it is not extremely accurate... it is just numbers and you never really know how accurate it is.

Olivia: I was surprised to hear that there are a lot of false positives... Why do all of these women do this test and then end up having it not really tell them anything?
7.3.5 Category V: What are the options after receiving the screening results?

Each woman expressed interest in understanding what options were available in the event of a high-risk result from the screening test, or a positive result from amniocentesis: Eva: “What would happen if it came back after an amniocentesis that it was positive, what would I do and where would I find out information and how do they handle that?”. At the time of the interview, each of the women in the study indicated that they understood that pregnancy termination was an option in the event of a high risk result, “you have to make that decision of what you want to do to continue on with the pregnancy or not to continue on.” (Holly), however many reported that this information was not discussed by their physician. Jade explained that her family doctor told her that “if there was a positive test for something we would talk about the options at that point.” Others reported that their physicians left this part of the conversation out entirely: "The one thing that was missing was if it was positive, what would you do, what were your choices?” (Nadia).

Several women reported that their physicians discussed the options after high risk results, especially termination, in an opaque way:

Abby: "It's [the option to terminate] something I knew from previous education. She [family doctor] did say these are defects there is no cure for, but she didn’t come out and say if you find something wrong you can abort the baby or you can keep the baby knowing it has a defect."

Madelaine: "She [family doctor] wasn’t using terms like abortion or anything like that, but she was implying that some couples would take that information and make a decision and sort of, you know, dot dot dot, expecting us to fill in the blanks of what that might mean. It wasn’t necessarily obvious, you know, that couples might make a decision about whether to proceed or terminate with the pregnancy.”

While Madelaine and Abby inferred the options of terminating or continuing the pregnancy from this discussion, a couple of other women did not understand this. Gail talked about her assumption of the opportunity for early treatment “I’m sure there is
research out there on something to help improve Down syndrome in utero”. Kyla stated she drew similar conclusions from the information received from her physician, but learned differently after doing her own research:

\[ \text{Kyla: "It was put to me as 'we are going to be testing for chromosomal abnormalities like down syndrome or spina bifida'. That's all that was said. It wasn't 'because sometimes people decide they don't want to go through with the pregnancy'. ... I kind of thought that there might be treatment. ... maybe he is bringing it up because there is something they can do about it ... and then I thought well maybe it is so you're prepared. .... I didn't think that people would terminate because of the test."} \]

7.3.6 Category VI: What does it mean to live with a child with a condition or disability?

A few women, like Holly, were interested in knowing details about the experience of parenting a child with one of the conditions. She suggested this information should be provided by clinicians before women decide to participate in the test.

\[ \text{Nadia: maybe explain a little bit more in depth... Like, down syndrome is a chromosomal abnormality, the baby will have this, this and this.} \]

Most women, however, indicated interest in learning about what it would be like to parent a child with a particular condition only if they received a high risk result. When speaking about understanding what it would be like to parent a child with one of the tested-for conditions, women used language like “educate myself” (Eva), “give me a chance to research” (Danielle) or “I would find resources” (Jade), implying they did not expect that information to be provided by their physician. The two women who stated they would terminate the pregnancy no matter what condition was found indicated that they were not interested in receiving this type of information.

A few women who were more familiar with the conditions cited the spectrum component of the conditions as an important piece of information for women to consider.
Abby: *I know that just because your child has Down syndrome, it varies drastically. It can be very very mild, or it could be more severe.*

This was not, however, a frequently occurring topic of discussion, perhaps because many women appeared not to be aware of this information.

### 7.3.7 Category VII: How can an informed decision about participating in prenatal screening be made?

Participating in an informed way in the decision making process about prenatal screening was identified by each woman in the study as an important opportunity. Even the women who had no intention of participating in testing indicated that they were glad to receive information and to have the opportunity to make their own decision about participation. While women spoke about the importance of having the chance to choose whether to participate, many women spoke with concern about making sure they had enough information to make this decision.

While this ability to make the decision for one’s self was frequently identified as desirable, a number of women discussed how this may be challenging at times:

* Nadia: *It is your choice if you want to do it or not. I don’t think she [family doctor] emphasized that enough with me. I think she made it sound like it was routine.*

Kyla, to whom prenatal screening was presented as the next step in prenatal care, stated that women need to feel informed enough to make decisions about participation:

* I was a little upset. I mean, a better description would be that I didn't feel informed enough to make the decision .... I think it's great that it's available for people who want it, but I think that everybody should be informed before they are given the option.*

Women who indicated that they did not receive sufficient information to feel informed, frequently described engaging in research and seeking information independently.
Nonetheless, the participants indicated that information or guidance about resources was best provided by the clinician offering the test. Gail stated:

If they don’t have enough time to tell you, then they should direct you to some kind of pamphlet or something.

Madelaine undertook significant independent research on the contextual and logistical details of the test. She said that it could be “overwhelming” for women and that women may require the help of their care provider in locating relevant information.

I think there is potentially a lack of knowledge and I don’t know that it should just be up to women to have to seek that information.

In summary, women spoke of the importance of participating in an informed way in the decision making process about prenatal screening; of adequate information being required to make that decision; and that it would be helpful to receive information (or information resources) from the clinician offering the test.

7.4 Discussion

The participants in this study raised many topics when discussing their information needs for making a decision about participation in non-invasive prenatal screening. Some of these topics require a sophisticated understanding of complex information. Analysis of the interview transcripts identified seven major categories of information that may assist pregnant women to make informed decisions about participation in non-invasive prenatal screening. The categories are framed as questions that may be useful for clinicians to consider during the offer of prenatal screening, and include: I) What is prenatal screening? II) What conditions are being screened for? III) How will the results of prenatal screening be communicated? IV) How will the results of the screening be interpreted? V) What are the options after receiving the screening results? VI) What does it mean to live with a child with a condition or a disability? VII) How can an informed decision about participating in prenatal screening be made?. 
Counseling about non-invasive prenatal screening may present challenges to clinicians, who may not have enough time available to counsel in a comprehensive way. For example, in Canada, the average prenatal screening counseling session has been found to last less than five minutes (Cavanagh & Mathews, 2006; Cavanagh, Mathews, & Crane, 2007). Further, 56% of Canadian physicians were neutral or in agreement that counseling for maternal serum screening was too time consuming, and only 8% agreed that this type of counseling is adequately reimbursed (Winquist, Ogle, & Muhajarne, 2008). In response to such difficulties, clinicians may also consider alternative approaches to providing information about prenatal screening such as group information sessions after the first prenatal visit where pregnant women may ask questions, which may require less clinician time and result in better knowledge outcomes for pregnant women (Baldwin, 2006; Kaiser et al., 2002). Peer support and the opportunity to learn from the questions of other women is educationally valuable to pregnant women (Freda, 2004), as is more educational time with a clinician (Baldwin, 2006), such as a physician or other member of the health care team, such as a nurse practitioner. Additionally, clinician groups may wish to advocate for appropriate reimbursement for the counseling time required for prenatal screening.

Pamphlets and other written education materials may be an additional way of conveying information, as they may be read at a time of convenience, and provide key words for women who may wish to undertake further investigation (Kenny et al., 1998). Informational pamphlets have been rated by women as a valuable resource, second only to a conversation with their physician (Dahl et al., 2006). However, careful selection of written resources is important because written materials have the potential to be directive towards a particular course of action through the terminology used, tone, and balance of content (Bryant et al., 2001; Dahl et al., 2006; Hodgson, Hughes, & Lambert, 2005; Loeben, Marteau, & Wilfond, 1998; Stapleton et al., 2002; Vanstone & Kinsella, 2010) and may not provide sufficient content for an informed decision making process due to either a high literacy level requirement (Freda, Damus, & Merkatz, 1999), or provision of insufficient information (Shepperd et al., 2006; Van den Heuvel et al., 2008). In addition, video education has been shown to enhance retention of information (Browner, Preloran, & Press, 1996), particularly in groups with lower levels of literacy (Freda, 2004).
Interactive computer education may also increase knowledge, however some have suggested it may be difficult to integrate into a clinical setting (Griffith, Sorenson, Bowling, & Jennings-Grant, 2005).

The need for adequate information to make an informed decision about participation in prenatal was identified as an important theme in this study, and making informed choice an explicit clinical goal may be helpful for clinicians. One important aspect of an informed decision is to ensure that women understand that participating in prenatal screening is optional (Marteau et al., 2001; Michie, Dormandy, & Marteau, 2003). Although this is clearly expressed in clinical practice guidelines (ACOG, 2007; Chitayat et al., 2011; Ekelund et al., 2008; Health Council of the Netherlands, 2006; UK National Screening Committee & Department of Health, 2008), a number of women in this study and other studies (Kohut et al., 2002; Ladfors et al., 2001; Santalahti, Aro, Hemminki, Helenius, & Ryynänen, 1998; van den Berg et al., 2005) indicated that they were not aware that prenatal screening was optional. Clinicians might reflect on how they can facilitate informed decision making by using the questions identified in this study as a guide (Table 8), by offering women opportunities to ask questions (Hunt et al., 2005; Legare et al., 2011; Legare et al., 2008), and by offering information through various mediums. Clinicians might also facilitate informed decisions by examining their own assumptions about ‘what is best’ for women (Bhogal & Brunger, 2010), by thinking about the language they use to discuss prenatal screening (Grant & Flint, 2007; Hodgson et al., 2005; Parens & Asch, 2000) and by considering the content and presentation of information (Brunger & Lippman, 1995; Weil, 2003; Williams et al., 2002).

7.5 Conclusion

The results of this study contribute to knowledge about women's perceptions of their information needs during the decision-making process about prenatal screening. The themes identified (Table 8) may present practical guidance that could inform the practices of clinicians who introduce the offer of prenatal screening. In addition, written information, direction to resources for further information, and unique education formats such as prenatal screening groups may help to meet the information needs identified by women and promote informed choice about prenatal screening.
7.6 References


8 Women's decision-making about participation in prenatal screening: Beyond the clinical encounter

8.1 Introduction

Prenatal screening is a testing process offered to all pregnant women in Canada (Chitayat, Langlois, & Wilson, 2011) and in many other Western countries (ACOG, 2007; Ekelund, Jørgensen, Petersen, Sundberg, & Tabor, 2008; Health Council of the Netherlands, 2006; RANZCOG, 2010; UK National Screening Committee & Department of Health, 2008) through a process of informed decision-making. Prenatal screening produces a probabilistic prediction of fetal chromosomal anomalies and incomplete neural tube closures by combining the results from blood tests and an ultrasound with the woman's age at the expected date of delivery (Chitayat et al., 2011; Lam et al., 2002).

After receiving this information, each woman may be asked to make multiple, contingent decisions about whether or not to pursue diagnostic testing such as amniocentesis, which carries a risk of miscarriage between 0.5-1.5% (Wilson, Langlois & Johnson, 2007), and pregnancy termination.

Informed decision-making about participation in prenatal screening is presented by many clinical practice guidelines as an essential part of the process (ACOG, 2007; Chitayat et al., 2011; Ekelund et al., 2008; Health Council of the Netherlands, 2006; RANZCOG, 2010; UK National Screening Committee & Department of Health, 2008). While there is no authoritative definition of informed decision-making (Bekker et al., 1999; van den Berg, Timmermans, ten Kate, van Vugt, & van der Wal, 2006), the common element of different definitions is that a reasoned decision is made by a reasonable individual (Bekker et al., 1999); an informed decision is based on “relevant knowledge”, consistent with the “decision-maker’s values” and is “behaviourally implemented” (Marteau, Dormandy, & Michie, 2001).

Several counseling models have been used to describe how clinicians might facilitate informed decision-making (Clarke, 1994; Elwyn, Gray, & Clarke, 2000; Emery, 2001; Legare et al., 2011; Marteau et al., 2001; Thornton, Hewison, Lilford, & Vail, 1995); these models primarily focus on the roles and informational content of the interactions.
between clinician and patient (Entwistle & Watt, 2006). This paper examines the perspectives of pregnant women considering participation in prenatal screening, examining their information seeking and decision-making practices within and beyond the clinical environment. The central question of the study is: *How do pregnant women at low risk of having a fetus with an anomaly make decisions about participation in prenatal screening?*

### 8.2 Existing Models of Medical Decision-Making

Several models of patient-physician communication describe the facilitation of decision-making, from different perspectives. Consumerist models of informed decision-making (Emanuel & Emanuel, 1992) envision the physician transferring relevant knowledge to the patient so that the patient can make a decision. These one-way models of information transfer for informed decision-making have been described as analogous to the "banking concept" model of education criticized by Freire (1970), where patients are passive "receptacles" for information that is transferred to them, or "deposited" by the physician (Lee & Garvin, 2003). Consumerist models of one-way information transfer have been observed to be the prevailing model of patient-physician communication used by British general practitioners (Goss, Mazzi, Piccolo, Rimondini, & Zimmermann, 2005).

The rise of patient-centered medicine may be linked to the development of models of shared decision-making, as described by many authors (Charles, Gafni, & Whelan, 1997; Charles, Gafni, & Whelan, 1999; Coulter, 1999; Elwyn, Gray et al., 2000). Shared decision-making is a two-way model which involves an interactive dialogue between patient and physician, with each sharing knowledge and values, then deliberating together to arrive at a shared decision (Charles et al., 1999). Shared decision-making aims to achieve an active partnership between patient and physician (Charles, Whelan, & Gafni, 1999; Elwyn, Edwards, & Kinnersley, 1999; Elwyn, Edwards, Kinnersley, & Grol, 2000), but has been explored by few authors in the context of prenatal screening (Legare et al., 2011).

Additional models of two-way information exchange falling somewhere between informed decision-making and shared decision-making have been described (Braddock,
Edwards, Hasenberg, Laidley, & Levinson, 1999; Towle & Godolphin, 1999; Towle, Godolphin, Grams, & LaMarre, 2006). Patient-centered communication may also be conceptualized as a two-way information exchange with some shared characteristics to shared decision-making (Wensing, Elwyn, Edwards, Vingerhoets, & Grol, 2002; Weston, 2001).

The common element between these different models is a focus on the ways in which decision-making occurs inside the clinic, as a result of or during the interaction between the patient and physician. A complementary body of literature about decision-making has developed in the discipline of library and information science. With a sensitivity to the ways in which knowledge is sought and used, there exist a number of models describing the ways in which information seeking practices and behaviours inform decision-making processes inside (McKenzie, 2004; McKenzie, 2009) and outside of the clinic (Belkin, 1980; McKenzie, 2003; Pettigrew, Fidel, & Bruce, 2001). Information sciences has long moved away from a view of the learner as an empty receptacle waiting to be filled with information (Dervin & Nilan, 1986) to explore more nuanced understandings of the ways in which information seeking affects decision-making.

Evidence that decision-making about participation in prenatal screening occurs outside of the presence and direction of a clinician is plentiful, however this topic is under-examined in the healthcare literature. National surveys in Canada (Public Health Agency of Canada, 2009) and the United States (Declercq, Sakala, Corry, & Applebaum, 2007; Sakala, Declercq, & Corry, 2002) have stated that health care providers are no longer the primary source of pregnancy information, with women reporting that they find more information about pregnancy from books, friends and relatives, and the internet (Declercq et al., 2007; Public Health Agency of Canada, 2009; Sakala et al., 2002). There is a growing body of literature describing how patients use the internet, friends and family, and other sources of information to inform their health decisions (Diaz et al., 2002; Hsieh & Brennan, 2005; Lagan, Sinclair, & George Kernohan, 2010; Lagan, Sinclair, & Kernohan, 2011; Larsson, 2009); but little theorizing about the ways in which women seek, retrieve, and use information when trying to make a decision about participation in prenatal screening.
8.3 Methods

Objective: The purpose of this study was to investigate the decision-making processes of pregnant women with respect to participation in prenatal screening.

8.3.1 Study design.

The methodology of Grounded Theory (GT) (Charmaz, 2000; Charmaz, 2006) was adopted for this study. Using a grounded theory approach, data were gathered from first-hand accounts, and analysed inductively to develop theory about a particular phenomena. Data were collected and analyzed simultaneously, in an iterative fashion where insights inform further data collection and analysis.

This study received research ethics approval from the University of Western Ontario’s Health Science Research Ethics Board (#16988E).

8.3.2 Recruitment.

Pregnant women were recruited through the London-Middlesex Health Unit’s Prenatal Fair (10), notices on pregnancy and classified ad websites (4) and through snowball sampling (2). Women were purposively sampled to represent a diversity of perspectives about participation in prenatal screening (Table 9). Sampling was completed when theoretical saturation was achieved. Charmaz (2006) describes theoretical saturation as the time when “gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical properties” (pg. 113).
Table 9: Participant demographics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Participated in Screening?</th>
<th>Offered a choice about participation?</th>
<th>Would consider terminating pregnancy if condition was found?</th>
<th>Age at time of interview</th>
<th>Urban/Rural</th>
<th># years of education</th>
<th>Recruitment method</th>
</tr>
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<tr>
<td>Abby</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>27</td>
<td>Urban</td>
<td>17</td>
<td>Snowball</td>
</tr>
<tr>
<td>Bridget</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>30</td>
<td>Urban</td>
<td>21</td>
<td>Online</td>
</tr>
<tr>
<td>Carrie</td>
<td>No</td>
<td>Directed</td>
<td>No</td>
<td>29</td>
<td>Urban</td>
<td>16</td>
<td>Snowball</td>
</tr>
<tr>
<td>Danielle</td>
<td>Yes</td>
<td>Yes</td>
<td>Unsure</td>
<td>31</td>
<td>Urban</td>
<td>14</td>
<td>Prenatal Fair</td>
</tr>
<tr>
<td>Eva</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>20</td>
<td>Rural</td>
<td>13</td>
<td>Prenatal Fair</td>
</tr>
<tr>
<td>Farah</td>
<td>Yes</td>
<td>No</td>
<td>Not unless fetus would not survive to term</td>
<td>27</td>
<td>Rural</td>
<td>16</td>
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</tr>
<tr>
<td>Gail</td>
<td>Yes</td>
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<td>Yes</td>
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<td>Urban</td>
<td>12</td>
<td>Online</td>
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<tr>
<td>Holly</td>
<td>Yes</td>
<td>Yes</td>
<td>Depending on condition</td>
<td>26</td>
<td>Urban</td>
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<td>Online</td>
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<td>Isobel</td>
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<td>No</td>
<td>No</td>
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<td>Yes</td>
<td>Yes</td>
<td>No</td>
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<td>Rural</td>
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<td>16</td>
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<tr>
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<td>No</td>
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<tr>
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<td>Yes</td>
<td>28</td>
<td>Rural</td>
<td>12</td>
<td>Prenatal Fair</td>
</tr>
</tbody>
</table>

8.3.3 Eligibility.

Eligible women were: under the age of 35 at expected date of delivery, carrying their first pregnancy, received the offer of prenatal screening from a family physician, and fluent in English. Participants were interviewed after they spoke about prenatal screening with their family physician, and before they received their results from the screen (if they
chose to participate in the screening), or before 20 weeks gestation (if they chose not to participate in the screening). Table 9 describes demographic and theoretical characteristics of the sample.

### 8.3.4 Data collection.

Semi-structured interviews (see Appendix 4 for interview guide) were conducted between May and November 2010 with 16 low risk Canadian women. Interviews were audiotaped and transcribed verbatim, and field notes were recorded. Women chose to be interviewed in person (5) or over the phone (11), with interviews lasting between 25 and 69 minutes (average 41 minutes). Interview questions were open-ended, and inquired into participants’ experience of being offered prenatal screening by their family doctor and how they came to make the decision about whether or not to participate in prenatal screening. Responses were further probed to explore ideas of where information was sought and received, opinions and feelings about the test, and areas of confusion or clarity.

### 8.3.5 Data analysis.

Data were hand-coded in a line-by-line fashion, and then re-coded in categories and by theme (Charmaz, 2006). The initial analysis guided subsequent sampling and analysis in an iterative fashion. QSR N-Vivo 8 (QSR International 2010) was used to manage the data. Visual diagrams were generated to examine the connections between different codes or categories between multiple participants, and between different codes or categories from the same participant. These diagrams were used to re-code and re-categorize the data in subsequent phases of analysis.

### 8.4 Findings

The findings inform a preliminary theoretical model depicting the processes by which participants made decisions about participation in prenatal screening. In addition participants continued to investigate and think about prenatal screening after the initial decision had been made, often in preparation for making a decision about the results. All but one woman in the study described an iterative process of receiving, seeking and
interpreting information. Women described this process beginning before prenatal screening was introduced by their physicians and continuing after the decision about participation in prenatal screening had been made. For example, Gail was directed to consent to prenatal screening at her doctor's office. She described her process of decision-making starting with the reception of the information that prenatal screening existed and proceeding with the gathering of more information to improve her understanding of what she had consented to do and what future decisions she might be asked to make about the results of the screening test.

The process of making an informed decision is conceptualized in four categories (Figure 4): 1) Receiving information; 2) Seeking information; 3) Working towards understanding; 4) Making a decision. This section provides an analytic overview of the proposed model; describing each dimension, addressing the range of responses throughout each aspect, and highlighting the different views across circumstances.

**Figure 4: The process of decision-making about prenatal screening**
8.4.1 Category 1: Receiving information about prenatal screening.

The category of receiving information was elaborated by all women in this study. In particular, three aspects were prevalent in women's accounts: the sources of information received, the content of information received and a reconciliation of prior understandings of prenatal screening, pregnancy, and parenthood with the new information received.

Receiving information about prenatal screening was described as the first step in the process towards making a decision, even if at the time information is received, a decision is not necessary. For example, many women described learning about prenatal screening through a friend's experience before becoming pregnant themselves, but stated that they drew upon the knowledge gained from their friend when it was time to think about making their own decision. Related to this type of previously gained knowledge, most women stated they were aware of the existence of prenatal screening before they were offered it, but did not know many details about the procedure:

* Bridget: I really didn’t know about the nuchal translucency long before. Only when thinking about becoming pregnant did I really read about what it was. But I was aware of amniocentesis. Obviously diagnostic, but I didn’t realize that there was something that could be measured as early as 14 weeks or 11 weeks.

A few women had more extensive knowledge from formal education, or because a close friend or family member had gone through the process:

* Lucy: A lot of my girlfriends have got it done and told me about it. That’s how I knew about it. That’s how I knew it was coming and that you had to get it done before a certain time, before 13 weeks.

For five women, the offer of prenatal screening from the physician was the first time they learned about the possibility of this test:
Jade: That [doctor's offer of prenatal screening] was the first time I'd heard about it. I knew that you went for certain checkups when you're pregnant, but nothing with any detail.

8.4.1.1 Sources of information received.

Women discussed their sources of received information about prenatal screening, mentioning health care professionals, friends and family, secretaries or administrators in the offices of health care professionals, prior education and experiences, the media, and written sources passed along from health care professionals, friends, family and the public health unit. The most commonly identified sources of received information were the family doctor, friends and family.

Most women indicated that their family doctor (or nurse working under the direction of the family doctor) was the most consistent source of information, although not necessarily the most comprehensive source. All participants received some kind of information from their physician, however, the depth and breadth of this information varied greatly. Some women reported that doctors mentioned the existence of prenatal screening and then scheduled the screening tests without much discussion:

Gail: Beforehand we had no information. Going into it we just knew that there was a certain time limit we had to follow.

One women stated that her doctor provided ample information:

Madelaine: She spoke about it in detail, to the point where I remember thinking "I know this- I read the forms". She was very thorough.

The most commonly reported experience was a short conversation with a doctor who provided written information in lieu of a longer discussion:

Abby: I honestly don't think she talked about it that much. She just said here's the information pamphlets. ... It was really short, she didn't go into great detail about anything at all.
8.4.1.2 Content of sources received

Women reported receiving a number of different types of information from their doctors, most commonly general logistical information about the test as well as information about what conditions are screened for and the non-definitive nature of the results. Detailed information about prenatal screening was usually received from doctors in written form. Ten women were offered written information by their doctor and described this form of information as important. Of the six women who did not receive written information, five spontaneously mentioned that they would have liked to receive written material about prenatal screening.

Gail: Your family doctor or whatever doctor is caring for you should be able to tell you [about the screening tests]. If they don’t have enough time to tell you, then they should direct you to some kind of pamphlet or something. I never got anything.

Friends and family were also cited as a valued source of information by thirteen women. Most of those who spoke with family or friends about prenatal screening described receiving experiential information from friends and family that informed the way they thought about their own decision to participate in the screening test.

Holly: I actually have a friend who missed her date for prenatal screening and ... her daughter ..., has Down syndrome and she wasn’t prepared for it. So she hasn’t returned to work ... It affects your life quite a bit,... she’s ecstatic that she has her and she would never want to change anything ... Probably if she did find out they would have chosen not to have the baby if it was a high probability, and she's kind of happy that she never did find out because of that.

Fourteen women described receiving information from family, friends, and from past education and experience about the lived experience of the conditions tested for through prenatal screening.

Eva: I have a friend who has a child with Down syndrome, so I also knew that if I needed information or needed support or needed help with anything like that, I
was sure that she would have tons of it. And obviously, being a parent of someone with Down syndrome she is kind of an expert about it.

Danielle: I work with kids with disabilities. So I'm probably more aware than the general population would be about the things that children can be born with and the complications that might arise.

The theme of receiving information about prenatal screening had two different components: medical information received in the context of decision-making, and information (experiential and medical) received in the course of everyday life. Women described receiving a wide variety of information from these two sources; information was received from physicians in the context of decision-making, at the time when prenatal screening was introduced. In contrast, many women discussed the information they had received in the context of their everyday lives, before they were considering participation in prenatal screening.

Showing the relationship between category 1 (Receiving Information) and category 3 (Working Towards Understanding) of the proposed model, women described the process of contextualizing information received in the context of everyday life with new information received from their physician. As will be elaborated in category 3, women discussed the ways in which information received from their physicians was contextualized and made personally relevant in relation to previous information they had received from friends and family, or past work or educational experiences.

**8.4.2 Category 2: Seeking information about prenatal screening.**

In addition to receiving information, fifteen of the sixteen women actively sought information about prenatal screening in written form, both offline (15 women) and online (12). Offline written information reportedly accessed by women included information pamphlets (10), popular books on pregnancy (5) and textbooks from previous formal education (3).
Nadia: I have my maternal textbook...and it's not in my textbook. I looked for it... I went to look for the beginning parts of pregnancy and there was nothing in there about prenatal screening...That textbook is from 2002, 2003.

Bridget: I had heard of the nuchal translucency and the reason that was used ... from a book I had bought, A Pregnancy Day by Day.

Twelve women reported accessing online information sources, including popular pregnancy sites, pregnancy forums or blogs about pregnancy (7 women); medical sites hosted by the local public health unit, hospitals and research centres (4); and general ‘reading online’ (2). Kyla visited both popular and medical websites:

Kyla: Most of the information I got was from searching on the Internet. It actually started from a message board of other pregnant women who are talking about it [prenatal screening]. ... that's where I started finding more and more, to dig deeper and deeper. I think I came across some official medical sites, but it would have been nice to have that given to me right off the bat, without having to search through. Some people might stop there at the message board. And that's not always the most reliable information.

Kyla's concern about reliable information was echoed by many other women who talked about: (a) being wary of the information they encountered: "the internet can lead you all over the wrong place and give you the wrong answers. If you don’t know what’s bogus and what isn’t, well, you will end up in a web somewhere." (Gail); (b) the ways they assessed trustworthiness of the information they encountered, "a friend just recommended 'Your Pregnancy Week by Week' because it was written by a doctor, so it seems a bit more comprehensive and useful" (Farah); and (c) the ability to verify information between sources: I went to a whole bunch of websites to see if they were around the same. I know websites can just kind of throw out information, so I went to four or five different websites. (Eva).

Not all women were interested in seeking information about prenatal screening. Although fifteen reported seeking information to some extent, the one woman who did not seek
written information stated she felt the information from her doctor and her friends was sufficient. She indicated that she wanted to think positively about her pregnancy:

Lucy: The testing can go either way. I'm thinking positive so I don't think that anything is going to be wrong. I just keep that in my mind. I'm excited to see the baby in the ultrasound. That is honestly all I think about. I don't think about the testing, and I don't think about spina bifida and I don't think about Down syndrome. I don't think about any of that. ... I'm trying to have a great pregnancy. I don't want to think anything negative about my pregnancy, or about the baby.

This sentiment about avoiding information that produces fear or anxiety was echoed by Nadia, who initially started looking online for information but later stopped:

Nadia: I typed in integrated prenatal screening, and I think I read maybe the first two or three sites. It just explained it in more detail. I read a couple blogs about it, about women and their experiences and that kind of scared me so I stopped reading it. Since then, any type of question I have had about my pregnancy or any fear or anything, I don't even bother looking it up anymore, because everyone has told me just stay off the Internet and don't read anything. ... I have stayed off the net and just tried to enjoy my pregnancy the best I can.

Farah was discouraged from seeking information by the nurse in her doctor's office in order to prevent anxiety: She’s [nurse] been very good to just.... relax me. Stop reading books! She says. Calm down! Farah agrees with this approach and followed the nurse's suggestion, avoiding seeking additional information because: I would rather have it explained to me in terms of what my actual results are than get myself all worked up about what this number means or that number means.

All but one woman stated that they sought out information about prenatal screening as a way to enhance their understanding. Some women described seeking information in preparation to make a decision. Others described seeking information to increase understanding, or to prepare for future decisions that might need to be made. A few
women described ceasing to seek information in response to confusion or anxiety aroused by information that they found. The proposed model attempts to account for the possibility that a woman might not be interested in seeking information by allowing that this category may be bypassed. For instance, a woman may receive information, judge it to be sufficient, and proceed directly to making a decision.

8.4.3 Category 3: Working towards understanding prenatal screening.

Working towards understanding the information received and sought about prenatal screening was the category with the most variety and variability, reflecting a multitude of different ways of interpreting information in preparation to make a decision. The category of working towards understanding was characterized by discussions about the ways in which different pieces of information informed one another.

Some women described a process of working to consolidate the information received from the physician. Strategies such as reading a pamphlet over again, thinking further about the information presented, talking to a spouse, friend, or family member, or seeking more information were used to better understand the information presented by the physician or encountered in other contexts:

Eva: I liked having the pamphlet at home after I had talked to the doctor and had all my questions answered, then I could go through it again. When you're in the office they're throwing one million things at you, you're just kind of like "yeah, sure, that's great". When you get home you're like "yeah, what did she say again?" You can go through it [the pamphlet] and just refresh your memory. If you have other people that you want to explain it to, you are giving them accurate information.

Almost every woman talked about the ways in which she contextualized new information by comparing it to information obtained at an earlier date. For instance, women who described previous understandings of prenatal screening frequently elaborated on the knowledge that informed their current understanding. When Danielle decided to participate in prenatal screening, she didn't understand how long it would take to receive
the results. This piece of information, obtained during the wait for results, fostered reflection on the purpose and process of screening:

*If I knew how long it took and how far along you are when you actually find out anything, I don't think that I would've taken the time to do it, or put myself through the worrying about what if I do get a positive. I would've just said "no thank you" and gone on and waited until the baby came. If they see something serious in the regular ultrasound [second trimester ultrasound] they'll do further testing and tell you about that anyhow.*

Carrie described the experience of being pregnant and her sense of responsibility for another life as contextualizing information that informed her sense of what was important to her decision making:

*I thought I'd get a screen done if it's available, why not? Why wouldn't I, for my own interest's sake? ... Being pregnant is different, and talking to my doctor, reading the pamphlet, talking to my husband, it is more like there is actually a life now that I'm responsible for. I think that that is more, instead of just doing it for the heck of it, well let's evaluate what would really happen.*

Others talked about their past life experiences and how this shaped the ways they interpreted information and understood the potential outcomes of prenatal screening.

*Farah: I spent high school working in group homes with adults with autism and down syndrome and stuff so it's something I always had in the back of my head that it might be a challenge I have in my life but if that’s the way it goes, that’s the way it goes. It’s not any kind of dealbreaker or anything.*

As women talked about their understandings of the screening test, many described a process of piecing together different parts of information obtained from a variety of sources:

*Gail: I found it was fairly easy once I understood, like you get to that beginning level, once you understand what the ultrasound does and you understand what a*
nuchal translucency is, then you work from there. As long as you get that first building block and you keep following the right steps and learning what this is and why you do this and what’s for this and that. You kind of find the ladder and figure it out at the end.

Women understood and contextualized information in individualized ways, drawing on their own perspectives to interpret the meaning of information they received. For instance, after learning about false positives, Bridget and Olivia had very different reactions:

*Bridget:* I wasn’t aware of the false positive rates, but that was described well in the pamphlet. That was probably the thing that changed [my thinking] the most, and that was reassuring, the thought of the possibility of having a positive test, but even then it's not necessarily a true positive.

*Olivia:* I was surprised to hear there are a lot of false positives. I was surprised to hear it is not a very definitive test. I was like well, then why do they do this? What is the point? Why do all of these women do this test and then end up having it not really tell them anything?

The individualized nature of interpreting information about prenatal screening was also demonstrated in the way that women described contextualizing information in relation to their own personal situation. Danielle, who works with children with disabilities, described the way this affects her thinking about raising a child with a disability:

*I think I worry more than the average person might. ... I think I have a better understanding of what the families with children with disabilities go through on a day-to-day basis.*

Some women described instances where the pieces didn't fit, or they realized that a piece of information was missing, leading to identification of a gap in understanding:

*Danielle:* I don’t even know if at the first round they can say I think your child has Down syndrome or if they have to do the amniotic fluid test to say what they think
Kyla: It was put to me as "we are going to be testing for chromosomal abnormalities like down syndrome or spina bifida". That's all that was said. It wasn't "because sometimes people decide they don't want to go through with the pregnancy". ... I didn't think that was a possibility when I was thinking about it. ... Once I went home and did more research, I realized that wow, this is why people do it.

The category of "Working Towards Understanding" identifies the ways in which women talked about integrating the information that they received and sought from a multitude of sources. This category might be seen as a "puzzle piece" approach, with women describing a process of building understanding of the situation at hand by gathering different small pieces of information, comparing these pieces of information and considering them in light of past experiences. The articulated understandings were formed from medical information but also relied on more personal information, including information gleaned from the woman's own experiences, information she had received or was familiar with from friends or family. These different pieces of information were made personally relevant in conjunction with a consideration of the woman's values and perspectives.

8.4.4 Category 4: Making a decision about prenatal screening.

All women in the study, even those who were not given the choice of participating in prenatal screening, discussed multiple decisions to be made. First, the decision of whether or not to participate in the screening (Table 10). Second, anticipation of future decisions that may have to be made. These decisions were discussed in relation to information received and sought, and ways of working to understand the information; the need for participants to make decisions about prenatal screening provided the context that bound together and made relevant the information.
As summarized in Table 10, eight women stated they made their own decision about participating in prenatal screening tests without direction from their health care provider; five women indicated they were directed towards a particular course of action; three women reported that they were not given a choice about whether or not to participate in prenatal screening. The majority of women indicated that they appreciated the opportunity to make their own decision about participation:

*Nadia:* *I like that I had a choice, that I was given that choice by my doctor.*

*Olivia:* *I really appreciated her willingness to let me make my own decision.*

Five women indicated that their health care practitioners were directive in some way, such as verbal phrasing and facial expression (Carrie), giving explicit advice about what to do (Lucy, Nadia), or through non-verbal means, such as booking the ultrasound before explaining the purpose of the screening test (Penny, Gail).

*Carrie:* *I know she did say that less than half of her patients choose to have the prenatal done. She actually said that twice. I thought that, based on her facial*
expression and the look that she gave me, I thought she would encourage us not to.

Gail: When they mentioned it they said you don’t have to, but we advise it.

Three women stated that they did not perceive that they were given a choice about participation in prenatal screening. Each woman recounted a different reaction to this situation. Farah talked about her relationship with her prenatal care provider and was not concerned that she was not given a choice:

Farah: She didn’t mention if it was a choice. I am sure that if I had concerns with it, then that would have come up. .... I don’t question, because I’m very comfortable with her, I don’t question. It might have been different if it was a doctor I had never met, but because it was someone I have had a relationship with for years, I’m very comfortable with what she says needs to be done.

Isobel indicated that she had decided to do the test before she entered her doctor’s office and was surprised that it was not offered as a choice. However she was not really bothered because she planned to do it anyway.

Isobel: It was just thrown in there that this is what you will do then and prenatal screening was one of the things thrown in there- at a certain time you do this. So I think it was just assumed that it was something I would want without having a discussion.

Kyla learned by searching online for information on nuchal translucency that the screening test is optional and that women who choose to do that test can later choose to have an abortion if the test comes back positive. Kyla indicated that she was disturbed by this, because she would not choose to have an abortion and therefore didn't wish to participate in testing. She was upset that her family doctor did not explain this to her.

Kyla: My doctor just presented it to me as this is what we normally do, and didn't give me any options. So I'm sure that other doctors are doing that too. For the most part, people tend to really trust what doctors are saying, they see them as
the be-all and end-all. What they say is what I should be doing. That’s not really
the case. I think it’s important for them [women] to be given all the information
that they deserve, so basically informed consent.

Whether or not she was given a choice about participation, each woman in the study
indicated that she had thought about the decisions she might be required to make in the
future. Kyla, reported anticipating how she would handle those choices:

The results, from my understanding, are not 100% unless you do an amnio. I
don’t think that I would risk the amnio, if it could be potentially harmful to the
baby anyway. I would just wait and see what happened.

Nadia talked about how she would make a different decision in her next pregnancy:

I am a first-time mom and I am kind of just going with the flow, with what my
doctor suggested to me. ... Thinking about it now, I just don’t think that I would
do it again. ... Now that I know about it, and I know as much as I know about it, I
would make a different choice next time.

Of the thirteen women who made a decision about participating, most talked about the
link between how they would approach potential decisions in the future and their decision
to participate in the first part of prenatal screening.

Bridget: Even when we had the choice of whether to book the ultrasound or not,
... at that point I wanted to be sure about having the ultrasound but not wanting to
be pressured to make a decision to go ahead with an amniocentesis. That was
something we had to consider in deciding to have the ultrasound.

Madelaine: I sort of thought of it as a package deal, you know? It was presented
as different stages, it sounded like there would be a decision made after stage one,
but you automatically think of the whole process.

Some women reported that they based their decision of whether or not to participate in
prenatal screening on their anticipation of future decisions that might have to be made.
For instance, all four women who chose to refuse screening stated that they would not have an abortion regardless of the screening results. All four women talked about their decision to refuse prenatal screening in relation to their unwillingness to terminate the pregnancy, and wish to avoid the potential anxiety that might be faced when waiting for the screening results.

Abby: I knew that I wouldn’t just all of a sudden decide to terminate the pregnancy and so that was the primary reason to not even do it. If we did it knowing that I wouldn’t make that decision, we could potentially have information that would actually weigh down on us a little bit.

Many women who participated in the test linked their decision-making to what they planned to do with the results; six participating women stated that they would not terminate the pregnancy, no matter what the results were.

Eva: Myself, I wouldn't terminate. I would just kind of educate myself on how to, like what programs there are or what information I need to know to help a baby with that specific disorder.

Four women who decided to participate were uncertain of whether or not they would choose to terminate the pregnancy if a condition was found, stating that it would depend on the particular condition detected.

Lucy: If it was Down syndrome I'd keep it, but if it had spina bifida or the other thing. Then I'd have to find out the details, but if it was a severe case, I don’t think we would keep it.

For the two women who stated they would terminate the pregnancy if a condition was found, this opportunity was the reason for participating in the test.

Gail: It [raising a child with a disability] would be too much for us to take on right now. We know it would be too much for our relationship. … It just wouldn’t be good for us. We’re both [specific occupation] and we’re both [additional occupations].
Making a decision about prenatal screening was a theme which was described in multiple contexts, from the initial decision to participate in the screening test to the anticipation of later decisions that may have to be made regarding what to do with the results of the screening test. Of the 16 participants in this study, eight stated that they made their own choice about participation, five felt directed to a particular decision by their health care provider, and three were not offered the opportunity to make a decision about participation in prenatal screening. When women talked about their decision-making process, many talked about considering multiple decisions at once, often describing their initial decision about participating in the screening tests in relation to what they would or would not consider doing with the results of the screening test.

8.5 Discussion

The findings of this research draw on women’s reports of the process of decision-making about participation in prenatal screening to depict it as an iterative process of receiving, seeking, and working to understand information to inform practical decision-making and action. In these findings, the interaction between a pregnant woman and her physician was identified as an important, although not exclusive, part of the process of making an informed decision about participation in prenatal screening. This was in contrast to existing models of informed decision-making, which focus primarily on the roles and interaction between the physician and the patient and the information shared by each person (Charles et al., 1997; Charles et al., 1999; Coulter, 1999; Elwyn et al., 2000; Emanuel & Emanuel, 1992; Michie, Dormandy, & Marteau, 2003). Interestingly, the women in this study received information from physicians, but also actively sought and worked with information obtained from non-medical sources, such as popular books, and the experiences of their friends and family members when making their decisions to participate in prenatal screening. Given the broad range of sources from which women obtain information, attention and further research into the information practices of women may be warranted, so that health care providers seeking to facilitate informed decisions can support women in obtaining relevant and credible sources of information (Coleman, 2003; Diaz et al., 2002; Diaz, Sciamanna, Evangelou, Stamp, & Ferguson, 2005; Shepperd, Charnock, & Gann, 1999).
Existing models of informed decision-making provide information about strategies that may be used within a clinic to impart or exchange information to prepare the patient to make an informed health decision. These models, however, fail to consider the sense-making and decision-making work that occurs outside the clinic, despite ample evidence that patients seek information from a variety of sources (Case, Andrews, Johnson, & Allard, 2005; Declercq et al., 2007; Larsson, 2009; Public Health Agency of Canada, 2009; Sakala et al., 2002). Given the lack of attention to this aspect of the process, physician counseling time may not be used as effectively as possible and women may not be receiving appropriate informational and decision-making support.

Recognizing and acknowledging the information work that some people choose to engage in outside the clinician's office may contribute to a different way of understanding the role of the physician in informed decision-making about prenatal screening. Existing models of informed decision-making conceptualize the physician as the main information-provider and the woman as the information-receiver and decision-maker (Emanuel & Emanuel, 1992), or both the physician and woman as information-providers, receivers and decision-makers (Charles et al., 1999). The findings of the current study question the boundaries of these roles, emphasizing the breadth of the woman's role as an information seeker, receiver, interpreter, and decision-maker in addition to the role of the physician as an information-facilitator. Existing models conceptualize the content of information relevant for informed decision-making about prenatal screening quite narrowly, as including primarily medical and logistical information about the test (Emanuel & Emanuel, 1992). Some models acknowledge the importance of information about the values and perspectives of the woman and health care provider (Charles et al., 1999). In addition, this study and others (Farrell et al., 2011; Hunt, de Voogd, & Castañeda, 2005; Vanstone, Kinsella, & Nisker, 2012) suggest that women may be interested in considering different types of information when deciding to participate in prenatal screening, such as timing of the test, options after diagnosis, possibilities of experiencing anxiety and opportunities for promoting the welfare of the baby. While the majority of women in this study expressed a strong desire to seek and use information, it is important to note that not all women have the resources,
information literacy, or desire to seek information, and women may resist the imperative to become an "informed patient" (Henwood, Wyatt, Hart, & Smith, 2003).

### 8.5.1 Models of information seeking to inform health decision-making from information science

Beyond the decision-making models considered in the medical literature (Charles et al., 1997; Charles et al., 1999; Coulter, 1999; Elwyn et al., 2000; Emanuel & Emanuel, 1992; Michie et al., 2003), scholars in the field of information science have examined patient information seeking practices to inform decision-making (Case, 2002; Lambert & Loiselle, 2007; McKenzie, 2004). The information-seeking models however have not been widely disseminated in the health care disciplines. The contributions made by such models may have implications for health fields generally, and for prenatal screening in particular, as they may assist clinicians to re-conceptualize their role as facilitators of information-seeking rather than as conductors of informed decision-making.

Health information-seeking behaviour has been conceptualized as a means for patients to obtain the information required to participate in medical decision-making involving a conscious choice to actively pursue information (Case, 2002; Lambert & Loiselle, 2007). Models which emphasize active seeking, and do not include passive receipt of information, or retrieval of information from memory, have been critiqued as potentially oversimplifying the process of information seeking as a linear, non-iterative action (Johnson, 1997; J. D. Johnson, 2003; Lazarus & Folkman, 1984; Lenz, 1984; Longo et al., 2010; Miller, 1989). This critique is consistent with the findings of the current study, in which participants emphasized the influence of information obtained through past experience when interpreting new information about prenatal screening. Iterative models of health information seeking where the seeker plays an active role have been suggested by some to be more appropriate than linear, non-iterative models (Case, 2002; Foster, 2004; Lambert & Loiselle, 2007).

Sense-making (Dervin, 1983; Dervin, 1999; Dervin, 2003) is a theory which may contribute to an understanding of the iterative nature of information-seeking for decision-making about prenatal screening. Participants in this study spoke about the ways in which
(a) information gathered through past experiences informed their current information seeking and (b) the ways in which past experiences helped them make sense of the information they found when actively seeking. According to Dervin (Dervin, 1983; Dervin, 1999; Dervin, 2003), sense-making is a person-centered approach which describes the metaphorical activity of recognizing gaps in understanding and overcoming these gaps by building bridges with different pieces of knowledge acquired from different sources (Dervin & Nilan, 1986). Sense-making holds that knowledge is not a static representation of reality (Dervin, 1999), but is constantly being shaped and re-shaped, as well as constructed, re-constructed, and de-constructed. In this way, sense-making rises beyond the "implicit assumption that there is one right way to produce knowledge or to use information" (Savolainen, 2006) (p. 1117). Women in this study spoke about the ways in which knowledge about disability, parenting, and pregnancy gathered through past conversations and experiences informed the way that they sought, interpreted, and used information about prenatal screening. This past information from history and experience was frequently used to contextualize new information, it was the situational 'bridge-building' material (Dervin & Frenette, 2003). It was used to scale the gap in the information provided by clinicians, or found elsewhere, forming a knowledge from which to make a decision about participation in the prenatal screening test.

When considering the sources of information used to make sense of information about prenatal screening, the sociocultural and individual context of the information seeker (Savolainen, 1995; Tuominen, Talja, & Savolainen, 2002) and the ways in which this particular contexts shape the information acquired through everyday life (McKenzie, 2003) are important considerations. The ways in which women seek and receive information about prenatal screening may be unique from other information-seeking tasks. Women seeking information about prenatal screening are not yet visibly pregnant, and may not have chosen to share the news of their pregnancy, which may make them invisible to others they encounter in their everyday life who may have relevant experiences or knowledge to share (McKenzie, 2003). The personal nature of the decision to participate in prenatal screening may contribute to a reluctance to discuss this topic with all but one’s closest friends or relatives. The sensitive nature of the decisions involved in prenatal screening may provide a barrier to discussion with those who do
have visibly relevant experiences. For instance, women parenting children with a
disability may find inquiries about their experiences with prenatal screening offensive
(Beck, 2000). This context of an "invisible" situation (Yeoman, 2010), may help explain
why women seeking information on prenatal screening talk more consistently about
information gleaned from past experiences, active seeking and active scanning and
mention proxy information sources only in relation to very close friends or relatives
(McKenzie, 2003).

8.5.2 Discrepant cases: Avoiding information to manage uncertainty.

While most women in this study actively sought information, one woman did not seek
any extra information and two other women chose to stop seeking information. In
addition, four women chose to avoid particular types of information, by choosing not to
participate in the screening tests. Considering these cases in light of the consumerist
imperative placed on patients to be informed and make decisions about their care
(Henwood et al., 2003) may contribute to understanding the phenomena of information
seeking for informed decision-making, especially given that the discourse around the
need to inform oneself is particularly strong for pregnant women and mothers (Lupton,
1999a; Lupton, 1999b).

Information avoidance is a strategy of information management (Brashers, Goldsmith, &
Hsieh, 2002), and refers to behaviour designed to prevent or delay the acquisition of
unwanted information (Sweeny, Melnyk, Miller, & Shepperd, 2010). It has long been
recognized that information avoidance is a technique to avoid anxiety (Maslow 1963 in
Case et al., 2005). Information avoidance has been theorized as an adaptive behaviour to
manage uncertainty (Brashers et al., 2002) by reducing, avoiding, and manipulating
potential sources of uncertainty (Sairanen & Savolainen, 2010). Uncertainty is a
fundamental characteristic of the human experience (Boholm, 2003) and has been
described as a universal feature of pregnancy (Sorenson 1990 in Teman, Ivry, &
Bernhardt, 2011), given the context of increased opportunity for decision-making and
responsibility within a context of ever-increasing choice and risk (Lupton, 1999b).
In this study, seven women discussed different ways of avoiding information. Four of these women avoided information about the disability status of their fetus by declining to participate in prenatal screening. This choice is congruent with Barbour's (Barbour, Rintamaki, Ramsey, & Brashers, 2011) findings that people tend to avoid information when they feel no action can be taken, and similar to Sweeny's (2010) theorization that information is avoided when no desirable action can be taken. All four women who declined to participate in prenatal screening rejected the option of terminating the pregnancy if information suggesting an anomalous condition was found (marking this action as undesirable) (Sweeny et al., 2010). Three women who participated in prenatal screening also discussed avoiding information. Lucy stated that she did not seek information about prenatal screening beyond what she received from her doctor or had previously heard from friends because she already had the information she needed, and did not wish to seek more information that might detract from her goal to think positively about her pregnancy. Avoiding fear and anxiety was also cited by Nadia and Farah as a reason to stop looking for information about prenatal screening, aligning with Sweeny's (2010) finding that people avoid information when it may cause unpleasant emotions, or diminish pleasant emotions, and Barbour's (2011) finding of information avoidance as a strategy to manage negative emotional reactions and avoid interference with enjoyment. Nadia and Farah's approaches may fit more closely with the strategy of selective avoidance; both were willing to seek and receive some information about prenatal screening, but stopped seeking information when that information became unpleasant and unreliable (Sairanen & Savolainen, 2010). When Nadia speaks about her experience reading about other women's experiences of prenatal screening online, she exhibits 'knowledge dismissal', choosing to avoid that information after evaluating it as potentially inaccurate and threatening (Jemmott, Ditto, & Croyle, 1986; Sweeny et al., 2010). Managing information provided by prenatal screening is a balancing act between seeking and avoiding information in order to achieve the multiple goals of reducing uncertainty, maintaining optimism (Brashers et al., 2002), and meeting the medical consumerist imperative of being an informed patient and exercising decision-making agency (Henwood et al., 2003).
8.6 Conclusion

As the women in this study described the ways in which they received, sought, and worked towards understanding information about prenatal screening in order to facilitate decision-making, they described a type of knowledge production that centered on each individual and was gathered, interpreted and used for decision-making outside of the clinician's office. Women described engaging in active and passive information-seeking activities, and making sense of that information in relation to prior knowledge and experiences. Knowledge about prenatal screening was produced through an iterative combination of knowledge from physicians, medical pamphlets, and medical websites, with social and experiential knowledge from friends, family members, and other women. This knowledge was then contextualized with each woman's own life circumstances, perceptions of risk, and understandings of motherhood, disability, and family. This complex formation of understanding was described as the basis for decision-making, with the information provided by the clinician as only one rung in the ladder of knowledge.

The findings have implications for informing a broader understanding of prenatal screening; one that extends beyond the clinic, recognizes women’s active agency in the process, and aims to support women in the process of collecting, interpreting and acting upon information about prenatal screening.
8.7 References


9 Conclusion

9.1 Introduction

The following chapter ties together the themes presented so far and contextualizes them as part of a doctoral study with information on the process of the research and suggestions of quality criteria and strengths and limitations. First, I discuss the research process, including the contributions and impact of my supervisory committee. I explicitly address reflexivity, which has been mentioned in Chapter 1 and 4, outlining my particular understanding of the term and the ways in which I engaged in reflexive thought throughout the research process. In the middle of the chapter I discuss the links between the integrated articles presented in Chapters 5-8, tracing the theme of informed decision-making through the manuscripts and exploring the underlying themes introduced in Chapters 2 and 3 through an examination of discourse. In this section, entitled "Discursive Tensions", I provide a short survey of the language found in data from the three studies: patient education materials, policy documents, and participant interviews. I use this material to argue that this language indicates participation in different discourses, and I discuss the common links between the four manuscripts (Chapters 5-8) in terms of ideas of medicalization and normalization. In this discussion, I explore the ways in which medical-institutional discourses structure the social relations and institutional processes of prenatal screening. After this discussion of the common themes between the manuscripts, I introduce two sets of quality criteria that could be used to judge this work from the literature of interdisciplinary scholarship and grounded theory. I discuss potential contributions this work may make to understandings of patient education materials, clinicians offering prenatal screening, policy documents, and informed decision making. Finally, I outline some potential directions for future research and discuss some of the strengths and limitations of this work.

It is not possible to consider the process of the doctoral research separately from that of the doctoral program, where each element (coursework, comprehensive exams, proposal, dissertation) is related, feeding into and building a foundation for the next step. I can trace particular elements of this dissertation to each component of the doctoral program and in this way, the research process started long before I began to think about the study design or collected any data. In this section I discuss the many contributions of my supervisors as a way of reflecting upon the type of scholar I am attempting to 'come to be' (Green & Lee, 1995), in order to explicitly highlight the threads of the doctoral process and the ways in which I have tried to weave them together. In a later section, "Insights and Reflections on the Research Product", I will discuss the conceptual integration of the four manuscripts.

The doctoral research process is inherently linked to the supervisory relationship, a relationship which is not well studied or understood (Grant, 2003; Grant, 2005), as it is idiosyncratic and traditionally conducted behind closed doors (Green & Lee, 1995; McWilliam & Palmer, 1995). Green and Lee (1995) contend that "supervision is not simply a matter of coming to know ... it is also a matter of coming to be" (p.41) and that it is through the student's relationship with her supervisor(s) that she begins to form her own identity as an academic. The formation of the academic identity happens through multiple social and discursive sites, but the supervisory relationship remains one of the most influential (Petersen, 2007).

I have been tremendously fortunate to have been given the opportunity to work with my supervisors and their influence and support has shaped this project, and my academic identity, enormously. Until recently, I had not questioned the convention of mentioning gratitude to one's supervisors in the acknowledgement section at the beginning of the thesis. I took for granted that most students are grateful for the time and effort of their supervisors and that the acknowledgements section was an appropriate place to mention this. My acceptance of this convention began to shift as I started to think more deeply about what it means to be a supervisee, and what is asked of the supervisor. Over the past
two years (2010-2012), I have acted as a research assistant to a project studying interdisciplinary doctoral supervisory relationships (Hibbert et al., 2012; Vanstone et al., 2012). My experiences with this project caused me to reflect more consciously on the contribution of my supervisors and conclude that their influence goes far beyond that which could be acknowledged up front and then set aside. I have written in Chapter 1 and later in this chapter about the importance of acknowledging my standpoint and thinking reflexively about the decisions I've made throughout the research process. This reflexive consideration of standpoint is not complete without consideration of the ways in which I have been influenced by my supervisors.

If we consider the dissertation as a piece of woven fabric, I may have chosen the threads and woven them together, but that is so little of the work of weaving. My supervisors guided my selection of threads, worked hard to bring new threads to my attention, pointed out congruencies and inconsistencies in the threads I had chosen, strategized with me about what threads would be most valuable, most resonant, most useful, and most realistic. They helped me pick a pattern that could showcase my abilities and overcome my weaknesses while ensuring that pattern was not overly ambitious or impossible to complete with the available time and resources. My supervisors taught me how to weave, demonstrating their preferred techniques and helping me make connections with other weavers who use different techniques I might wish to incorporate. When I made a mistake in my weaving, they helped me back up, pick out the flaw, and re-weave the hole that was left. Sometimes I recognized that I had made a mistake, or left a weak spot in my fabric; sometimes I would not be aware of this. In this instance, they would gently draw my attention to the flaw in the fabric, perhaps by suggesting why some might consider it a flaw, and what action I might take to shore up my work against these criticisms. They managed to bring my attention to these flaws without making me feel like a flaw in the fabric was reflective of a flaw in the weaver. When I brought a completed section of fabric to them, they would work with me tirelessly, helping me re-work that section until it was as strong and beautiful as I was able to make it. When I felt like tossing the weaving aside and starting over, perhaps as a potter or a glass-blower, they calmed me down, picked up the discarded weaving, pointed out the strengths and worked with me to
overcome the weaknesses, re-inspiring me to start again, and keep going. Truly, I could not ask for more.

Through my work on the interdisciplinary doctoral supervisory practices project, I came to realize that for many interdisciplinary students, supervisory committees are rife with conflict. Interdisciplinary supervisory committee members may have conflicting ideas about what the PhD is and how it is done (Pole, 1998), what the content and structure of the different components should be (Blackmore & Nesbitt, 2008), or whether the content or the act of learning is of primary importance (Franke & Arvidsson, 2011). They may have different ideas about what their role should be (Franke & Arvidsson, 2011; B. Smith, 2001). These issues may be further complicated when there are two main supervisors (Kiley, 2009). After reading about the potential for conflict on interdisciplinary committees and speaking with many students who have experienced this conflict, I am so grateful for the intellectual generosity, mutual respect, and flexibility that my supervisory committee members have demonstrated. While we encountered many differences of opinion, these differences were always expressed in a respectful and open way which invited discussion and consideration of the different ways of proceeding. As a result, I think these differences led to a strengthening of my work, encouraging me to consider and respond to different conventions, perspectives, and sets of expectations. This collegial way of working across disciplines has modeled for me an exemplary way of interdisciplinary working, acting as a strong influence on my process of "becoming and being" an interdisciplinary scholar (Green & Lee, 1995, p.41).

While it feels artificial to name specific influences and contributions that my supervisors have made, I will highlight a few specific ideas here. These specific instances are only a small part of what each person has contributed, but I discuss them in an effort to be reflexive about what has influenced me and to highlight the way I have approached this research process. My co-supervisors are Elizabeth Anne Kinsella and Jeff Nisker. My third supervisory committee member is Pamela McKenzie. One trait these three have in common is that scholarship is not just a job, but a way of life. As I have come to know each person better and understand each person's work more fully, I can see the ways in which they embody the principles espoused in their academic work. To me, this
demonstrates a consistent philosophy which informs the way they approach scholarship, teaching, supervision, and collegial relations. The message I take from this role-modeling is that you should love what you study and study what you love, and approach academic work with integrity and a comprehensive, consistent philosophical approach. Over the course of the doctoral research process, I have had the experience of encountering ideas that change the way I think about the world, a sort of falling through the rabbit-hole from which there is no waking up. I have begun to understand that the way to draw strength from this experience is to match these ideas with your personal philosophy, so that you are forged as a stronger individual rather than as a fragmented one. Academically, you might experiment with different topics or methods, but the underlying philosophy of being and knowing forms the core of a consistent and congruent approach to the work.

The idea of choice has become a central theme of my doctoral work, and I think my interest and emphasis on choice reflects the ways of working I have observed with Anne, Jeff and Pam. None of them have ever said that a particular way of doing scholarship is right or wrong, just that there are different choices. Some choices fit better with others, each choice in a project leads down a different path, and being a researcher is about making carefully considered choices. It's not simply about measures of "validity", but about thinking through the implications of each choice and forming a piece of work that fits together, speaks to other work in the area, and forms a whole project that you are proud to stand behind. I think this emphasis on choices and decisions rather than a right way or a wrong way has been an important aspect of why I have enjoyed the doctoral process so much: I have been empowered to make my own choices, and entrusted with thinking through the implications of those choices.

Some of the other lessons I will take with me throughout my own academic journey: generosity and collaboration over competitiveness and territory; academic work should not live and die in the ivory tower, but should be based in, respond to, and make a difference in some part of the world; getting out there, taking risks, trying new things is always a good idea; research can have powerful effects, so it should be based in something you strongly believe in; ensure internal congruency by keeping your research
question in mind throughout the process; the influence of the researcher's personal convictions and perspective cannot be avoided and so must be acknowledged, if not in publication at least to yourself. For these ideas and for the continued support, encouragement, and guidance, of my committee members I am grateful.

9.3 My understanding of reflexivity.

Throughout my doctoral work I have developed an appreciation and understanding for the potential impact of reflexivity in the research process. Through my reading and coursework, I have developed an understanding that reflexivity is a contested term used by many people in many different ways. Most scholars agree that it is necessary for qualitative research, but there is little agreement on what it is, or how to do it (Finlay & Gough, 2003). In the following section I detail my own understanding of reflexivity and outline the ways in which I engaged reflexively with this research.

I am working with Smith’s (1987) idea that reflexivity should not be something done at the end of research, but that a qualitative research methodology should be inherently reflexive. This idea has been embraced by feminist researchers from different disciplines, working in different methodologies (Hesse-Biber & Piatelli, 2007). When Smith (1987) describes her version of sociology from the standpoint of women, she describes it as “a sociology that will lay out for people how our everyday worlds are organized and how they are shaped and determined by relations that extend beyond them” (p. 121). This is what I think qualitative research should strive to do, and I see reflexivity as the way of doing it.

I understand reflexivity as a two-pronged activity, occurring through conscious processes of meaning making (Taylor & White, 2000) as well as through attempts to make sense of our personal experience of the world when it poses a conflict with the ways we experience what Smith (Smith, 1990b) terms the 'relations of ruling'- dominant ideological relations that organize our activities in standardized ways (Smith, 1997). Smith (1983) describes our lived experiences as existing in our memories and encoded to our memories with social meaning. Our memories of "what actually happened" (Smith, 1983, p.321) arise only at the moment of reflection, and at this moment of reflection are
encoded as accounts of experience. According to Smith, our methods of constituting "what actually happened" are not only individual but also social, influenced by ideological practices and enshrined through this process of encoding. I understand the implications of this assertion to be that our lived experiences are understood by us through a process of interpretation which relies on our social experiences and location (Smith, 1987). I conceptualize this process of experiencing and encoding experiences as iterative, with each experience reinforcing, shaping, or shedding insight on to our particular assumptions about the way the world is organized, therefore shaping the way we encode future experiences. To understand our experiences, we draw on our personal assumptions, interacting with the world around us to make knowledge, form particular decisions, and reify or challenge assumptions. This is how I understand situated knowledge to be created, and why I think it is important to recognize our individual locations, particular histories, and experiences, and the ways in which these locations, histories, and experiences shape our interpretations and are located inside a broader social context.

9.3.1 Engaging in reflexive thought to understand standpoint.

As I began to consider reflexivity as the combination of experiences and socially located ways of understanding these experiences, I tried to examine my own thought processes to understand the ways in which I was thinking about my data and my taken-for-granted assumptions about the way the world works and my corresponding place in it. Smith would call this an attempt to examine my un-interrogated ways of living within a world organized by ruling relations (Smith, 1997). While reviewing cancer genetics charts for another project (Vanstone et al., In Press), I found myself imagining the women beyond the words in the chart. I recognized in this exercise that imagination was what enabled me to understand my participants as people and that it could act as a window into their particular standpoint, as a way to 'make strange' (Greene, 1988) my assumptions about the data and to query different ways of interpreting what was there. I began to understand Smith's notion of encoding experience by thinking about the process of imagining, by monitoring what kinds of aspects of the social world I thought about when I wasn't trying to do reflexivity or be reflexive, but when I was thinking about something
uncomfortable and wondering how it might be different. I see this imaginative thought process as closely linked to narrative reasoning (Mattingly, 1998). When we engage with narrative reasoning and when we create thick narratives (Nisker, 2004), we are using our imagination to fill in details of the story that we may not know, or know completely (for how can anyone ever know completely the details of even a small part of the life of another?). Examining the ways we choose to fill in these details can be a form of reflexivity when compared with possible alternative versions of the same story, or different stories.

We create narratives from our own experiences. Smith (1987) talks about the importance of beginning from a standpoint rooted in every day experiences and a particular subjectivity located in a constantly shifting matrix of social locations (Hesse-Biber, 2007). This emphasis on experiences and subjectivity is essential to radicalizing (which Smith reminds us means “remake from the root”) power relations and ideological structures. When speaking with interview participants, reviewing interview data, reading patient education materials or policy documents, I engaged with my own every day experiences of being a daughter, a sister, a wife, a friend, an employee, and a patient. In this way, I tried to examine particular situations from the perspective of a social actor in that experience, in order to recognize how I might place my own person and values into that experience (Smith, 1983). I consciously imagined what it would be like to be a pregnant woman reading these documents, or having the experience of considering prenatal screening within a nexus of social relations. I also used this imaginative exercise to 'make strange' the experiences of the participants, to try and identify my taken-for-granted assumptions of what they were expressing. This attendance to inferred experiences or opinions was particularly important since I shared several demographic characteristics with my participants (Delamont, Atkinson, & Pugsley, 2010). Through this imaginative composition of narratives, I could begin to see the way that particular standpoints may interact, providing congruence or conflict with other standpoints.

Creating imaginative narratives about the data I read was a device I used to allow me to make visible the different facets of my own standpoint, enabling me to see the differences and similarities between my standpoint and that of my participants. Harding (1987)
emphasizes the permanent partiality of this type of feminist inquiry—every story is intrinsically multi-faceted. There is no one true story. I used short quotes as an opportunity to imagine several different stories that may inform a particular utterance, and then looked back at the data as a whole for indications of what might or might not be present. By using an imaginative narrative technique to make visible traces of standpoint, I attempted to re-ground myself in the data, in what was said, rather than what I heard or chose to not hear.

9.3.2 Engaging in reflexive thought to make explicit research decisions.

Decisions in the research process were continuous and ongoing. I was aware of the ways in which my decisions framed a particular study throughout the process, including the decisions I made as an individual and with my supervisory committee when choosing the research questions, picking a venue for recruitment, designing the recruitment poster and advertisements, writing the interview guide, engaging with women at the London-Middlesex Health Unit Prenatal Fair, interacting with potential participants in person, over e-mail or over the phone—all this before I recorded a single word of an interview. Sometimes the need to make decisions about the research felt paralyzing. Every door I walked through meant that there were now other doors I could never walk through. When collecting data, I had to balance choosing the same doors for consistency between interviews with trying different doors to see if they yielded richer data. Even decisions that seemed insignificant, like choosing what clothing to wear to an interview or recruitment opportunity, at times took on momentous and paralyzing proportions. What did the clothing say about me as a researcher? What type of participants would see me as someone they would like to engage with? Who would turn away? How did my appearance and demeanor affect the way they portrayed themselves? How did my words create a particular atmosphere where certain responses were encouraged or discouraged? I noticed that many of the women I recruited in person were white, highly educated, and displaying subtle signs of wealth (e.g. orthodontically straight teeth). This didn't reflect the population I observed attending the Prenatal Fair. Did it reflect the population of first time mothers who attended the Prenatal Fair in their first trimester? Did it reflect the
population who understood "prenatal screening" or the idea of an interview study as something they wouldn't mind participating in? Or did it just reflect me? I was really challenged to move beyond this paralyzing aspect of reflexive decision-making, in which I had a hard time making any decisions because of the possible ramifications. I have detailed some of these decisions in Chapter 4. section 4.3.7.

9.4 Insights and Reflections on the Relationships Among the Manuscripts

I began this research by engaging with literature that was critical of medicalization in pregnancy, the judgments made by prenatal screening about the quality of life of people with disabilities, and the directive effects of the routinization of the offer of prenatal screening. After collecting and analyzing data, my results centered around questions of information seeking and informed choice, with little mention of the critical literature that informed the beginning of the work. In a way, this reflects the process of constructivist grounded theory (Dunne, 2011), wherein the literature review informs the researcher but is left to "lie fallow" (Charmaz, 2006, p.166) until the formation of the grounded theory in an effort to "avoid importing preconceived ideas and imposing them on [my work]" (p. 165). The literature I presented in Chapter 2 and 3 informed the way that I designed the study and approached data collection, but when I analyzed my data, I was careful to develop the emerging propositions through induction. After analysis, when I returned to the literature, I found that the emerging theoretical propositions fit better with another body of literature, that of informed decision-making. I didn't recognize the significance of this literature at the outset of the work, as is common for many grounded theorists (Dick, 2007; Dunne, 2011; Glaser, 1998), nor did I predict that informed decision-making would be the most compelling story in the data. While I chose to locate my work within the literature of informed decision-making for publication, my thinking throughout the research process was deeply influenced by the initial literature I engaged with, presented in Chapters 2 and 3. This section presents an opportunity to unite these bodies of thought.

In this section I will discuss two different themes that unite the four manuscripts, and which engage with and respond to each other. The first theme is informed choice and decision-making. I engaged with this topic in different ways through the four
manuscripts, considering how different datasets spoke to this theme and what ideas different audiences may find most compelling. The second topic of this section is discursive tensions in prenatal screening. Using the critical literature presented in Chapters 2 and 3 I highlight and explore points of tension between the medical discourses used in policy documents and patient educational materials and those revealed in the narratives of women as they discuss prenatal screening. By contrasting dominant medical discourses with narrative discourses, I explore ideas of medicalization, normalcy, and risk. Finally, I will link these two topics together and discuss the ways in which discursive tensions may impact informed decision-making by creating obstacles to women's capacities to articulate their own perspectives and make choices congruent with their own values if these perspectives counter or resist dominant discourses.

9.4.1 Informed decision-making.

As mentioned above, informed decision-making is a theme I address in all four manuscripts. In manuscript 1, Chapter 5, I work with the concept of non-directive counseling proposed in the SOGC Clinical Practice Guidelines on prenatal screening issued in 2011 (Chitayat, Langlois, & Wilson, 2011) and 2007 (Summers, Langlois, Wyatt, & Wilson, 2007). These policy documents state that prenatal screening should be offered through a process of informed decision-making and that counseling about prenatal screening should be non-directive. I don't problematize non-directive counseling in this manuscript, instead I ask if this instruction is supported by existing patient education materials. By examining the language used in patient education materials, I suggest that the language used in the material may often be seen as implicitly directive, and direct the reader towards particular understandings and certain choices of action.

In Chapter 6, I directly problematize the idea that counseling can occur non-directively, marshalling genetic counseling literature to argue that non-directive counseling is neither realizable nor desirable. I work with the concept of shared decision-making, as outlined by Cathy Charles and colleagues (Charles, Gafni, & Whelan, 1997; Charles, Gafni, & Whelan, 1999; Charles, Whelan, & Gafni, 1999) to delineate a particular way that model can be combined with a more consumerist, informative model of decision-making, as outlined by Emanuel and Emanuel (Emanuel & Emanuel, 1992) to facilitate a counseling
process wherein the clinician and woman both share their values and information, and the clinician actively counsels the woman in decision-making, although supports whatever decision she chooses to make. The model proposed in this manuscript works with two established models of counseling to propose a way in which informed decision-making may be facilitated without relying on the tropes of neutrality and non-directiveness, where each party acknowledges their own preferences and values, and is explicit about their role in the counseling process.

Chapter 7 addresses the "informed" part of informed decision-making, relying on interview data to discuss what type of information women require in order to feel informed to make a decision. The findings are presented in a way that I hope can act as a guide for clinicians about what information they may want to consider addressing during the initial prenatal visit. Similar to findings from Hunt (Hunt, de Voogd, & Castañeda, 2005) and Farrell (Farrell et al., 2011), the women in my study were interested in pieces of information that enabled them to make decisions, rather than information that may leave them "informed". The distinction between information-for-decision-making and information to-be-informed is delicate; information-for-decision-making pertains to topics such as timelines, anxiety, and details about the conditions tested for. This type of information, described by women as important for their decision-making process, is not always included in summaries of information which should be provided to ensure a woman is informed. This article serves to highlight the individual nature of information needs, and echoes Sue Sherwin's warning that the call for adequate information and understanding for informed decision-making is problematic because the information that is available is that which has been deemed relevant by research funders, researchers, professional colleges, and health care providers (Sherwin, 1998). This however may not be the particular information that an individual woman finds relevant to her decision-making process.

Chapter 8 presents a tentative model of the process of decision-making in prenatal screening, arrived at through an inductive analysis of women’s reports of their experience. It looks at how informed decision-making happens in a broader context, conceptualizing the clinical encounter as one part of an iterative, non-linear process of
information-seeking, information-receiving, and sense-making which inform the way a woman chooses to make a decision. The model outlined in this manuscript supports the idea presented by Charles (1999) and incorporated into Chapter 6, that women arrive to the clinic with knowledge about prenatal screening and ideas relevant to prenatal screening. The women in this study talked about how their experiences with people with disabilities, conversations with friends and family members, or other information they had acquired in everyday life (McKenzie, 2003) informed the way they thought about prenatal screening before they entered their clinician's office. This process of being and becoming informed did not end after the first decision was made, but continued, subsuming information acquired over the process of the pregnancy to make sense of prenatal screening in a way which was meaningful for the individual woman. Chapter 8 also addresses the discrepant case, women who chose not to seek information about prenatal screening and women who chose to actively avoid particular pieces of information, resisting discourses which assert the imperative to become informed about health decisions (Henwood, Wyatt, Hart, & Smith, 2003).

These four manuscripts present a case for informed decision-making as a complex, iterative process which is necessary, but also deeply problematic. Informed decision-making is problematic for several reasons. First, notions that information can be provided non-directively may mask the assumptions embedded in the information provided, making it difficult for women to identify and resist messages contained in this information (Anderson, 1999). Second, informed decision-making as we know it relies on information that has been deemed authoritative and relevant by medical and academic institutions, shaping the way that we can think about and understand prenatal screening, motherhood, and disability. Finally, current conceptions of informed decision-making emphasize the role of the clinician, casting the woman as a vessel to be filled with information (relevant and comprehensive information, of course) (Freire, 1993; Lee & Garvin, 2003), from which a decision can be retrieved.

Through the four manuscripts presented in this dissertation, I have challenged this notion in distinct ways. In the remainder of this section, I will challenge this notion more broadly, engaging with critical literature on medicalization, normalization and relational
autonomy to problematize the context in which informed decision-making takes place. At the end of this chapter, in the section entitled "Implications for Informed Decision-Making" I attempt to offer a few generative suggestions for future research on this topic.

**9.4.2 Discursive tensions in prenatal screening.**

When considering whether or not to participate in prenatal screening, women are faced with the task of identifying their own preferences and values in order to make a decision. It may be challenging for women to identify and articulate values and preferences which run counter to dominant discourses of "healthy" pregnancy, "normal" bodies, and "good" mothers. This may be especially true when prenatal screening is presented without acknowledgement of the values embedded in the test (Caplan, 1993; Kolker & Burke, 1998; Weil, 2003). Medical discourses of objectivity may disguise the presence of embedded assumptions and values (Asch, 2000), giving them a subtle form of power, and making it more difficult for women to think beyond or resist these discursive assumptions (Anderson, 1999).

Discursive tensions are visible in the contrast between the ways topics central to the idea of prenatal screening are described in different venues. In this section I consider two particular areas of conflicting discourse by examining the range of language used to discuss two apparently straightforward questions. First, who does prenatal screening test? A fetus? A baby? A pregnancy? The mother herself? Second, what is the aim of prenatal screening? Does the test detect disorders, diseases, defects and abnormalities or particular conditions and other ways of being? The narratives of women in this study reveal that women may struggle against dominant cultural discourses informed by values and assumptions that may not be readily apparent. Such discourses may pose challenges or create obstacles to women’s capacities to articulate their own perspectives and make choices concordant with their own values.

**9.4.2.1 Who does prenatal screening test?**

As discussed at length in the first manuscript, Chapter 5, prenatal screening patient education pamphlets use a variety of terms to describe the subject of prenatal screening, sometimes inconsistently. Some pamphlets used consistent language throughout the
publication, such as *pregnancy* or *baby*; other pamphlets differentiated between *fetus* and *baby* at the point of birth; more problematic were the pamphlets which used the term *fetus* or *embryo* when referring to an affected pregnancy or decisions about pregnancy termination and the terms *baby* or *infant* or *child* when describing the reassurance that screening tests may provide, or the desire to have an unaffected child. At times, I found the choice of language jarring, with one pamphlet stating that a second trimester serum screen can "pick up approximately 60% of *infants* with Down syndrome" [emphasis added] (SOGC, Prenatal Diagnosis: Public Education Pamphlet).

The language in the policy documents is intended for medical audiences. The SOGC guidelines on prenatal screening (Chitayat et al, 2011; Summers et al, 2007) use very similar language, duplicating many phrases and sentences. In both documents, *baby* is used twice, once referring to a child who was born with trisomy 18 (Chitayat et al, 2011, p.742) and once ambiguously, referring to age-related risk of affected pregnancy (Chitayat et al, 2011, p.739). In both, the word *fetus* is used many times, mostly referring to affected pregnancies, as pertinent to the topic of the guidelines. This differentiation is careful, and intentional, used consciously to signal whether the subject of the sentence has been born or not: "because the woman or her partner has a history of a previous child or fetus with a chromosomal abnormality" (Chitayat et al, 2011, p. 737). This wording further reminds clinicians gathering medical history information to inquire about living children and pregnancies that were aborted or miscarried. *Pregnancy* is by far the most prevalent term in both SOGC guidelines, used sometimes in place of a more specific term such as fetus or embryo: "the chance of identifying a pregnancy with a specific chromosomal abnormality" (p.738); "the practice of using [technique] to identify at-risk pregnancies" (p.739). These terms are sometimes ambiguous. For example, the 2011 guideline refers to "pregnancies" as what is conceived (Chitayat et al, 2011, p. 737), whereas the 2007 guideline refers to "fetus" as the product of conception (Summers et al, 2007, p. 149). There was also ambiguity in the language used to describe who or what was at risk of having a condition. Sometimes the pregnant woman was at risk (Summers et al, 2007, p.152), sometimes the pregnancy. Chitayat et al (2011) use the word *woman* most frequently, but occasionally referred to her as a *patient*, a discourse that may be
seen as medicalizing pregnancy, e.g. "patients undergoing first trimester screening" (Chitayat et al, 2011, p.742).

While spoken discourse is different than written discourse, examining the words women chose may reveal tensions between discourses. For instance, the word \textit{fetus} was only used by three women, and only once each. In each case, the woman used \textit{fetus} when explaining medical information she had received, such as the probability of Down syndrome, or what the ultrasound measured. \textit{Baby} was by far the most common term used by women, usually prefaced by \textit{a} or \textit{your} when speaking hypothetically, and \textit{my} or \textit{the} when speaking personally. Women used the term baby to refer to the born and unborn, affected and unaffected. \textit{Child} was also a fairly common term, and similar to \textit{baby} was used to describe the born and unborn, affected and unaffected. \textit{Seven women used the word kid, usually to describe what life would be like after they gave birth: "I think I would love that kid no matter what" (Olivia), or as a way of ascribing personhood to the fetus, such as Holly did when describing how it would be difficult to make a decision about whether or not to terminate an affected pregnancy because "it is still your kid, right?". Pregnancy was a term that was used by every woman, mostly to describe the process of being pregnant, getting pregnant, or feeling pregnant, except, notably, when it was used to describe decisions to terminate, end, or continue the pregnancy. In contrast to the policy documents, women did not talk about the pregnancy as being at risk or tested. In women's speech, pregnancy referred to the process of being pregnant, unless they were talking about abortion, in which case they used similar terminology to the policy documents.}

There was a noticeable difference between the discourses used by women and those used within the policy documents with respect to who or what was tested. Educational pamphlets struck a middle ground between the medical discourse of the policy documents and the narrative discourse of the women. Some pamphlets used similar language as the women, including adopting the term \textit{baby}, even discussing events before birth. Others used medicalized discourse, referring to \textit{fetus} and \textit{embryo}, or using \textit{pregnancy} to describe the 'product' rather than the 'process'. There were clear discursive patterns in the interviews with pregnant women; women commonly used the words \textit{baby, kid, or child} to
refer to both the born and unborn. They rarely used the word *fetus*, except when repeating medical information. Similarly, *pregnancy* referred almost exclusively to the process of being pregnant, and was not used to talk about what or who was tested or affected.

Women's tendency to use personal terms such as *baby* may reflect their adoption of the idea of motherhood; the use of medical discourse distances this relationship, perhaps a necessary tactic to make the possible consideration of terminating the pregnancy a little bit easier.

**9.4.2.2 What is prenatal screening looking for?**

As discussed in the first manuscript, Chapter 5, pamphlets used many different terms to describe what the screening test detected, including disease, disorder, defect, abnormality, anomaly, and the names of the conditions, such as Trisomy 18, or Down syndrome. Many pamphlets placed these terms in opposition to words such as healthy, normal, or perfect, stating that a negative result will lead to the birth of a healthy, normal, or perfect baby.

The language used in the policy documents is consistent, with many phrases shared verbatim between the two SOGC guidelines (Chitayat et al, 2011; Summers et al, 2007). The language used in these clinical policy guidelines is more specific and scientific, including *aneuploidy*, which refers to the possession of an unusual number of chromosomes and refers to conditions such as trisomy conditions, (ex. Down syndrome) which manifest when three chromosomes exist (triploid) where two are typical (diploid). Both policy documents also refer to *open neural tube defects*, a class of conditions such as spina bifida, that result from incomplete neural tube closures, and *open fetal defects*, including gastrochisis and omphalocele. Neither SOGC policy document uses the word *defect* to refer generally to *birth defect*, language that was present in a few pamphlets.

The word *disorder* is prevalent in both policy documents, referring to single gene disorders, autosomal recessive disorders, and "rare disorders of cholesterol and estriol biosynthesis", "common and mild disorder, X-linked steroid sulfatase deficiency" (Summers et al, 2007, p.151). Chitayat clarifies that "screening for a disorder should be undertaken only when the disorder is considered to be serious enough to warrant
intervention" (p.738). Disability was not used frequently in Chitayat (2011) or Summers (2007), only to state that screening programs should respect the needs and quality of life of people with disabilities, and to describe that particular conditions are associated with "intellectual disability" (Chitayat et al, 2011, p.744), an improvement from the language of "mental handicap" (Summers et al, 2007, p.148) and "mental retardation" (Summers et al, 2007, p.153) used in Summers et al (2007). Summers et al (2007) and Chitayat et al (2011) both use the less charged words affected and unaffected, but define affected as "individuals who have the disorder for which the screen is being performed" (p.158; p.750). The word condition is used four times in each document, referring to "chromosome conditions" (Summers et al, 2007, p.148) and "genetic conditions" (Summers et al, 2007, p.153). Both Chitayat (2011) and Summers (2007) also use the normal/abnormal dichotomy, stating that prenatal screening has the "benefit of reducing the numbers of normal pregnancies lost because of complications of invasive procedures" (Summers et al, 2007, p. 146)

In women's speech, disorder was infrequently used, once each by three women. Defect was more common than disorder, used by six women, once or twice each. Three out of the eight total occurrences of defect referred to heart defects. Disability was a more common word, used repeatedly by four women and a few times by three others. Handicap was used by two women, once each. Condition was the word I used as an interviewer, and many women picked that term up and used it once or twice after hearing it from me. Only two women used the word condition before I introduced it. Abnormality was used by four women, and followed the word chromosomal almost every time it was used. Normal was most frequently used to describe results, habits, feelings, and was only used a few times to describe people. One woman, Jade, used sophisticated vocabulary such as "characteristics", and "disposition" to refer to the conditions tested for, but this was not common. The most common words used by women were problem or issue, describing "chromosomal abnormality or some other problem" (Bridget), "developmental issue" (Gail), "genetic issue" (Carrie) or just generally used to state that the test would provide information about whether there was a "problem with my baby's health" (Nadia) or the baby "has some kind of issue" (Abby). At times it was apparent that women were struggling to find the right word to use, and interviews are full of
attempts to find the right word, such as "I think it will tell you if there's a chance of some sort of problem with the baby, like some sort of defect, I don't even know if that's the right word, some sort of genetic issue with the baby" (Carrie) or queries such as "is Down syndrome really a disease or is it just a defect?" (Penny).

9.4.3 Discursive tensions and participation in narratives of medical discourse and everyday understanding: Illustration of broader critical themes.

By examining the words used to answer two basic questions about prenatal screening (who does prenatal screening test? what is the prenatal screen looking for?), two distinct discourses were identified: medical discourse and the everyday discourse used by women as they describe their thoughts and understandings of prenatal screening. These discourses were found to overlap in many of the prenatal screening educational pamphlets, which are intended to act as a bridge between two types of knowledge, and to "educate" pregnant women into particular way of understanding prenatal screening (Dixon-Woods, 2001). Smith (1990) describes the function of texts encountered in everyday life as offering "access to the ontological ground of institutional processes which organize, govern, and regulate the kind of society in which we live" (p.122). By thinking about the ways in which the policy and patient education pamphlets act as constituents of social relations of discourse, we may begin to see the ways in which these texts act to organize social relations (Smith, 1990b).

Drawing on the ideas of medicalization and normalization, I am interested in the ways in which medical-institutional discourses structure the social relation and institutional processes of prenatal screening. Using examples from data presented in this section and in the four manuscripts of this thesis (Chapters 5-8), I discuss such relations in the following section.

Practices of bio-power, or governance through normalization of the body (Foucault, 1990) act by encouraging women to act, to participate in the discourse of the body as a knowable, measurable, standardized object (Foucault, 1990). Such practices have the
effect of identifying and re-categorizing bodies which do not fit the medicalized ideal of normal. Through this process of identification and categorization, individuals are encouraged to exercise their power to intervene and transform these potential people into something which would be identified as normal or acceptable (Foucault, 2003). In this conception, "normal" is a social construct, aided by the ability of medicine to measure, count, and calculate, in order to appraise or judge acceptable and unacceptable ways of being. These practices of classification and codification are central to the emergence of the concept of disability, dividing some people from others and objectifying them (Tremain, 2005). The process of classifying or coding some types of people as "other" can be seen in the language of measuring, identifying, finding, detecting, reporting, so that labels of disorder, defect, disability, abnormality, can be applied. The language used by women in this study echoes the creation of the atypical person as "other" but is less quick to label, using general words such as problem or issue, that participate in a much larger category than the more heavily loaded words of disorder, defect, or abnormality. Informed decision-making participates in the process of bio-power by enabling women to choose to act; it encourages them to participate in this social normalization. Belief that one is acting autonomously and making choices however supports domination and normalization by hiding the real workings of power (Dreyfus & Rabinow, 1982); a mechanism that indicates the success of power (Foucault, 1990). By cloaking prenatal screening in language of choice and autonomy, women are encouraged to participate in the workings of this powerful apparatus, to measure and identify anomalies so they can be reported and extinguished (Lippman, 1991; Seavilkeklein, 2009). When considering the different language used to describe who is tested, it is possible to see that depersonalized language of pregnancy or fetus may function to prevent a pregnant woman from thinking of her pregnancy as a member of her family until the testing process has been complete and the fetus/pregnancy has been measured and classified as "normal". The tendency to experience a pregnancy as "tentative" (Rothman, 1989) until testing is complete has been understood as closely linked to prenatal screening and testing for some time (Rothman, 1989; Taylor, 2008). Women carrying wanted pregnancies may resist this discursive attempt to distance themselves by using
personal terms such as baby or child before birth. Women who stated they did not plan to terminate their pregnancy if a condition was found made comments that prenatal screening could not detect everything that might be "wrong" with their baby, or that they did not consider the conditions detected by prenatal screening to be reason to sever the relationship that already existed with their child. This can be understood as active resistance to medicalized understandings of normal and to the consequent discursive imperative to strive for "normal" children.

When considering discursive imperatives to participate in prenatal testing and subscribe to medicalized ideas of normal, there were four women who chose to participate in prenatal screening, but stated that they would not terminate their pregnancies if a condition was found. They may be seen as participating in the medicalized discourse of measuring and classifying, however also as resisting the discourse of normalization, by stating that they would not choose to terminate their pregnancy if a condition was found. All four women explained their choice by stating that prenatal screening would give them a chance to educate themselves and prepare to raise a child with a disability. They acknowledged that they would face additional challenges as a parent and that their child would require additional support. This may represent a simultaneous acknowledgement of and resistance to the societal discourse of normalization. This discourse is acknowledged through an appreciation that a person with a disability may face many challenges, many of which are socially constructed as our society has formed itself to primarily accommodate typical people (Wendell, 1996). The women’s unwillingness to act to ensure that their child and family conforms to the normalized standard may be seen as an example of resistance.

All women in the study made comments which acknowledged that children born with the conditions detected by prenatal screening will face additional challenges in their lives. Women indicated that they understood that they had personal responsibility to mitigate these challenges, either by terminating an affected pregnancy, or by educating themselves and securing the extra resources necessary to support an affected child to his or her full potential. The individual as a locus of responsibility is a hallmark of medicalization (Wilkerson, 1998), where social roots of problems and solutions are obscured and
responsibility to act is transferred to the individual and away from society (Morgan, 1998). Prenatal screening presents a clear example of this principle: the onus is placed on women to detect and abort fetuses with disabilities, obscuring the responsibility of society to help all people live to their full potential. The participants in this study discussed ways in which they would use their personal resources to support a child with a disability.

Informed decision-making is the mechanism by which modern day genetics is separated from eugenics (Duster, 2003). Granting women the choice to participate in prenatal screening empowers them to participate in governing their own bodies and families (Foucault, 1990) and disguises the workings of medicalization and normalization. However, what does choice really mean when the choices and the context within which those choices will be enacted are constructed by others (Beaulieu & Lippman, 1995; Lippman, 1991; Lippman & Wilfond, 1992)? The choice of whether or not to terminate a pregnancy is not truly a choice unless another viable option is offered, such as the choice to raise the child within a society that will provide the necessary resources and support to ensure that child is given the opportunities of all other children. It is not a choice to choose to terminate a pregnancy after a condition is found because you cannot afford to care for that child, even if you would value that child (Sherwin, 1998). When considering questions of informed choice, we must examine the context in which those choices are constructed:

When a woman's sense of herself and her range of opportunities have been oppressively constructed [so that] ... hav[ing] a(nother) child will impose unjust and intolerable costs on her, it does not seem sufficient to restrict our analysis to the degree of autonomy associated with her immediate decision about a particular treatment offered. We need a way of acknowledging how oppressive circumstances can interfere with autonomy. (Sherwin, 1998, p. 28)

Autonomy is a concept which underpins the idea of informed decision-making, and as discussed in Chapter 2, the concept of autonomy can be problematic for feminists, who support the protection it affords for vulnerable people, but are wary of the assumptions
embedded within it. Oppression may remain an unrecognized constraint to autonomy equal to coercion, internal compulsion and ignorance (McLeod & Sherwin, 2000). Models of counseling to support informed decision-making strive to remove coercion through careful directions to the clinician to act as non-directively as possible (Charles et al., 1999; Elwyn, Gray, & Clarke, 2000; Emanuel & Emanuel, 1992; Michie, Bron, Bobrow, & Marteau, 1997). These models attempt to remove ignorance by carefully considering the information necessary to be considered informed, and investigating how this information may be most effectively exchanged. Models of informed decision-making, including the ones I present in Chapter 6 and 8, rarely address the question of oppression.

Sherwin conceptualizes the relationship of autonomy and oppression as antagonistic, with the value of autonomy serving to hide the barriers of oppression by letting those indoctrinated into the North American culture of individualism and autonomy think of their successes as self-created and deserved, therefore creating an obliviousness to the barriers that oppression and disadvantage pose to self-determination and autonomous action (Sherwin, 1998). In turn, oppression poses a barrier to the necessary conditions for autonomy, by questioning rationality, constructing the information available and the definition of ‘informed’, and creating coercion through the circumstances of everyday life (Sherwin, 1998). Sherwin (1998) calls for attention to the broader social context in which individuals make decisions, acknowledging the interconnected nature of a person in her society (McLeod & Sherwin, 2000).

These theories raise issues for further and future attention in considerations of informed-decision making in prenatal screening. They suggest that rather than focusing solely on improving the counseling processes that facilitate informed choice about prenatal screening, attention needs to be paid to the societal context within which prenatal screening happens, including the resources available to women, children, and people with disabilities. When interview participants talked about what they would do if they received a high risk result from prenatal screening, they all discussed the available choices with some relation to their own ideas of what it would be like to raise a child with a disability in this society. For some, this was a feasible idea, but one which would require them to
draw on additional resources, to educate themselves, secure appropriate health care and child care, set their living space up to accommodate a child who may have a mobility impairment. For others, who stated they would choose to terminate their pregnancy if they received a high-risk result, the reasoning was also bound to society. Penny perceived that people with disabilities have fewer choices available to them: "I wouldn't want to live that life ... I just want a healthy child that can run around and have all the choices and make those choices".

These considerations open up broader social issues of significance to prenatal screening. If we live in a society where people with disabilities don't have the same choices available to them as people without disabilities, how can we imagine that the choice of whether or not to raise a child with a disability is a free and autonomous choice? The choice to participate in prenatal screening is deeply embedded within the particular societal context in which it is made. With this understanding, promoting informed choice is re-constructed as promoting informed choice between a range of limited possibilities, where the limit of the range of available choices varies for each person, depending on her personal circumstances. While informed decision making in prenatal screening appears to be an individual autonomous choice, as my dissertation draws to a close I find myself raising questions concerning the social aspects of informed decision making. When considering informed choice against an understanding of the ways in which disability and normality have been constructed in our society, a significant tension emerges. This area warrants in-depth consideration in future work about informed choice in prenatal screening.

### 9.5 Quality criteria

As introduced in Chapter 1, I approached this interdisciplinary inquiry from a standpoint rooted in a new way of considering the quality of scholarship in the humanities and social sciences; this shift draws on the criteria of reflexivity, situation/standpoint, (re)production, (re)presentation (Hodge, 1995) rather than generalizability, validity and statistical significance (Denzin, 2009). In the ongoing debate regarding quality criteria for qualitative research, I take a quasi-foundationalist stance (Denzin, 2009; J. K. Smith & Demeer, 2000), asserting that there is no "single gold standard for qualitative work"
(Denzin, 2009, p.154) and quality criteria should respond to the particular aims and goals of the research. For this research, I propose the use of specific quality criteria related to interdisciplinary research. I also outline some quality criteria specific to evaluating grounded theory work.

**9.5.1 Quality criteria for interdisciplinary work.**

In response to the shift in social scientific inquiry identified by Hodge (1995) and in recognition of the challenges of evaluating interdisciplinary work using disciplinary quality criteria, a body of literature has emerged which considers the unique challenges and contributions of interdisciplinary work and proposes corresponding quality criteria (Boix Mansilla, 2006; Manathunga, Lant, & Mellick, 2006; Mitchell & Willetts, 2009; Mitrany & Stokols, 2005; Wickson, Carew, & Russell, 2006).

Quality criteria for interdisciplinary work have begun to emerge from a number of different scholars. Common elements of this body of literature include: assessment based on contribution to different knowledge domains; effective communication of findings to multiple audiences; flexibility when working with a wide variety of literatures; breadth vs. depth considerations; reflexive approaches to the research process and different bodies of knowledge; coherent epistemological, methodological and theoretical perspectives (Boix Mansilla, 2006; Manathunga et al., 2006; Mitchell & Willetts, 2009; Mitrany & Stokols, 2005; Wickson et al., 2006; Vanstone et al, 2012).

**9.5.1.1 Different disciplinary audiences.**

Contributing and communicating to different disciplinary audiences is a significant challenge, but one which lies at the heart of interdisciplinary work. As I continue my academic career, this measure of quality may become the most prominent and most often evaluated (Boix Mansilla, 2006). I will discuss specific contributions of this work in the next section of this chapter, so here I will address the efforts and challenges of communicating to different audiences. The integrated article format allowed me to examine different stories within my research and to write them up in a way that spoke to particular audiences. For each manuscript, I made choices about the story that would be told, the language that would be used, the findings that would be highlighted and the
conclusions that would be drawn. I thought of this exercise as employing different ways of looking, focusing on some elements while letting others fade into the background. For instance, in the first manuscript, I focused on the research process, on the ways in which critical reflection on metaphor and figurative language opened different types of insights and enabled a different way of looking at the forces which shape and construct informed decision-making in prenatal screening. The second manuscript concerns the adoption of an approach from the discipline of genetic counseling into the discipline of medicine. I attempted to address this clinical audience by focusing on the practical applications of a theoretical idea, trying to walk the line between providing sufficient theory to explain and justify my idea without getting lost in an aspect of the work which may not be interesting or useful for clinicians. In the third manuscript, I focused on the findings of the research and the ways in which those findings might benefit a clinical audience. In the fourth manuscript, I attempted to address a gap between the literature in health and library and information sciences (LIS). Both disciplines address the question of how people use information to make decisions, but the nuanced theories and models in the LIS literature have not significantly permeated the health literature. In each manuscript, I tried to avoid terminology which may be confusing or misleading to particular audiences (Mitchell & Willetts, 2009), reviewing the disciplinary literature and reading similar work in the journal to which I planned to submit in order to ensure that I was writing in the expected style and genre of that discipline, so that the work would be relevant and applicable to the specific audience.

9.5.1.2 Flexibility with the literature.

Flexibility when working with a wide variety of literatures is a measure of quality that neatly summarizes why I enjoy interdisciplinary research. When I started reviewing the literature for this project, I focused on medical literature which addressed the nature of the prenatal screening test, including who was screened, who did the screening, and how and when the screening was done. I used social scientific literature to address the questions of why prenatal screening was problematic or beneficial, what the consequences might be for different groups of people. As the work progressed, I moved into the philosophical literature, reading about ethical and critical theory. I appealed to
linguistic literature when I started thinking about the function of metaphor and figurative
language. Thinking about the argumentative powers of language led me to literature
about genetic counseling, adult and patient education, counseling psychology, and
decision-making. Collecting data and identifying a new story about the use of
information for decision-making sent me to the literature in the field of library and
information sciences. Each stage of the research revealed a door to a new body of
literature, or perhaps more accurately revealed a hallway that contained several new
doors. For me, one of the joys of doctoral work was the chance to explore a huge variety
of literature and to think about the ways in which it was constructed, supported or
challenged by other literatures and to see how the integration of bodies of literature that
didn’t usually "talk" to one another led to new ways of thinking. I approached the criteria
of flexibility by continuing to look for new ideas and by trying to relate these ideas back
to each other. While this part of the work was a joy, its corresponding challenge was the
notion of breadth vs. depth.

9.5.1.3 Breadth vs. depth.

‘Breadth vs. depth’ is often used as a shorthand to refer to the traditional requirement of
doctoral work to ‘master’ a body of knowledge, rather than command a shallow
understanding of many bodies of knowledge. Golde and Gallagher (1999) challenge this
traditional requirement by stating that the pursuit of depth over breadth has led to
increasingly specialized scholars who may fail to "acquire a sufficiently solid base of
knowledge in their own discipline, much less another field, to make significant research
contributions" (p. 283). In order to understand the ways in which our work applies to
multiple fields and to avoid re-inventing the wheel in a different discipline, we must have
a broad understanding of the knowledges, histories, and problems of multiple disciplines.
In an additional argument supporting the necessity for interdisciplinary scholars to have
broad knowledge bases, Golde and Gallagher (1999) state that "working at the interstices
of two disciplines means conceptualizing and undertaking research in the absence of
established and proven frameworks and models. Trying to integrate two disciplines often
means resolving conflicts between research paradigms and methods" (p. 283). It is in this
challenge that I see the potential for interdisciplinary depth. As will be discussed shortly,
interdisciplinary work requires congruency between multiple epistemological, theoretical and methodological approaches. Constructing a congruent bricolage of approaches requires a depth of understanding of the literature and scholars used. My approach to the question of breadth vs. depth has been to attempt to acquire and demonstrate a broad command of the literature and a deep command of the research approach.

**9.5.1.4 Reflexive approach.**

Mitchell and Willetts (2009) suggest that reflexivity is important for several reasons: showing explicit engagement with the process of research across disciplines and literatures; demonstrating awareness of contradictions and gaps between materials from different contexts; providing evidence of the researcher's capacity to articulate her theoretical positioning and the impact of this position on research choices; externalizing the internal processes of the researcher in order to acknowledge limitations, offer alternative perspectives, and question research choices. I have written about reflexivity in multiple places in this thesis, introducing the idea of standpoint and positional reflexivity in Chapter 1, discussing the use of reflexivity in the research process and reflexive decisions that have been made in Chapter 4, and outlining the standpoint of the current work, including limitations and possibilities for future work in the current chapter.

I think reflexivity is important to enable me to recognize the ways in which my personal standpoint influences the research I produce. I can point to three different ways I came to this understanding. First, my commitment to a constructionist perspective means that I am conscious of the ways in which I am, as a researcher, constructing knowledge (Charmaz, 2006), and the ways in which I am, as a person, constructed by knowledge (Foucault, 1972). Second, one of the scholars I use to inform my theoretical perspective, Dorothy E. Smith, emphasizes the importance of a reflexive stance in relation to the decisions made about research and in recognition and consideration of the ways that the particular standpoint of the researcher, the research participants, and the readers interact to produce the research (Smith, 1987). Third, the exercise of writing reflective journals throughout the research project (Hesse-Biber & Piatelli, 2007) has demonstrated to me in a concrete way the relationship of research product and the research process. After this
experience, I cannot imagine being able to step outside of myself and design or conduct a study without acknowledgement of how my personal knowledge, experience, and standpoint is implicated. I think acknowledgement of the ways in which we shape the research we do is essential to the ability to move beyond that influence and establish a 'strong objectivity' (Harding, 1987).

9.5.1.5 Coherency and congruency.

Coherent theoretical perspectives are an important element of good quality interdisciplinary work (Crotty, 1998). Good quality interdisciplinary work should have a thoughtful pairing of epistemological and methodological perspectives, with enough information about this choice that readers can understand the rationale for the pairing as well as the value and limitations of the chosen approaches (Mitrany & Stokols, 2005). Taking the view that disciplinary knowledge cannot be isolated from the ways in which it was created (epistemology, methods, theories, history) (Bauer, 1990), I agree with Wickson's (2006) proposition that interdisciplinary scholarship should use different bodies of knowledge to critically reflect upon each other. The value of interdisciplinary scholarship is the new knowledge created in through this integration. Manathunga (2006) explains that the development of a diverse yet coherent epistemological and methodological approach is an important aspect of interdisciplinary learning, and demonstrates the ways in which the student can construct and apply knowledge in a higher order way, providing evidence of meta-cognitive skills in the creation of this understanding. In Chapters 2, 3, and 4 I have provided a fairly extensive review of the literature I am engaging with and an exploration of how the epistemological paradigm, theoretical perspective and methodological choices work together. While this work informed the way I designed the project, carried out the research, and wrote the four integrated articles, the relationship between these ideas are not made explicit in the articles themselves. In an earlier part of Chapter 9, I picked these ideas back up, and discussed how they formed the structure within which my articles were researched and written.
9.5.2 Quality criteria for grounded theory work.

In addition to the interdisciplinary quality criteria outlined in the previous section, Charmaz (2006) offers guidelines for quality criteria grouped around the categories of credibility, originality, resonance and usefulness. Unfortunately, she offers few guidelines for achieving or evaluating these criteria (Flick et al., 2007). Below I detail how I worked to achieve credibility, originality, resonance and usefulness in both the process and product of my research.

**Credibility:** I understand credibility in the research process to be related to the way in which categories and themes are generated inductively from the participant data. In the research product, I understand credibility to be related to making plausible claims appropriate to the strength of the data collected, neither overstretching nor understating the findings. I understand credibility to be ensured by conducting a thorough study (Charmaz, 2004a) and by providing enough evidence in the text that the reader can follow the logic of the researcher and form an independent assessment of whether the data support the findings. To achieve credibility in my work, I made sure I was intimately familiar with the data by doing all collection and transcription myself; completing memos and field notes throughout the process of data collection and analysis; working with the data in multiple contexts, asking varied questions of it; comparing the data to itself; and searching for discrepant cases to stretch my analytical categories. I engaged in simultaneous data collection and analysis, ensuring that further data collection and theoretical sampling was driven by analytical insights. In writing my findings, I included as much textual data as the format allowed, in order to allow readers to make an independent assessments of my findings. The criterion of credibility may be achieved by providing "thick descriptions" (Geertz, 1973, p.6) of the data, illustrating conclusions with substantial extracts from the raw data. This is a commonly used strategy in the interpretivist tradition, and serves to make the analytical processes more transparent to the reader as well as to emphasize that the conclusions drawn by the researcher are informed by her interpretations and are not intended to represent one universal truth (Peck & Secker, 1999). The integrated article format often restrained the amount of raw participant data that could be included; the fourth manuscript, significantly longer,
permits the inclusion of more participant data, allowing the readers better access to the data I collected.

**Originality:** Charmaz (2006) suggests that the findings of a grounded theory study should offer new, fresh insights that are both socially and theoretically significant and which can challenge, extend, or refine current ideas, concepts, and practices. The theoretical and practical contributions of this study are original in the questions that can be considered through an interdisciplinary approach. The findings are described in relation to the practical and applicable aspects of the medical literature; the critical insights of bioethical literature; and the information-seeking and decision-making process insights of library and information sciences literature.

**Resonance:** Charmaz (2006) describes resonance as the way in which the findings of a grounded theory study portray the fullness of the studied experience, drawing links to larger groups, institutions, or individual lives. I attempted to address these links by drawing out different facets of the research findings for different audiences in each manuscript, demonstrating how the findings may be linked to clinicians, policy-makers, and women. Charmaz (2006) also explains that resonance is achieved by focusing on the insights revealed in liminal, unstable, and taken for granted meanings. I have attempted to achieve this by using metaphors and figurative language as a sensitizing concept for analysis, and by employing the technique of critical reflection to examine my analysis for tacit implications.

**Usefulness:** Interpretations offered by the researcher should have practical applications in the everyday world, spark further research into other substantive areas and contribute to knowledge (Charmaz, 2006). In the manuscripts, I have attempted to make practical links to the potential applications of this research in various contexts. At the end of this chapter I discuss the possibilities for future research and the contributions and relevance of this research to various areas.
9.6 Contributions of this work

9.6.1 Implications for patient education materials.

As established earlier in this work, written materials can be a powerful way of shaping understanding and what constitutes our perceptions of truth. Written materials participate in particular discourses, are ascribed authoritative status, and define the truth of a phenomenon (Blood, 2005) therefore shaping and constraining the way that that object can be understood (Foucault, 1972). Through participation in particular discourses, texts can act to organize social action, constructing facts to serve the purposes of particular groups (Smith, 1993; Smith, 1990b). Smith uses the metaphor of a crystal to describe the ways in which texts work, "bending the light as it passes through (Smith, 1990b, p. 121), or shaping and structuring information in a way which suggests a particular truth. Smith sees textual analysis as a way of examining the institutional context in which facts are constructed; the organization of the text reflects that context. "An inner coherence is established between the actuality thus represented and the statements that can be made about it" (Smith, 1990a, p. 78).

With this understanding of the ways in which written material functions, it is important to consider specific word choices and the power that language has to shape understandings of prenatal screening, potentially describing particular actions or choices as more desirable or more correct than other choices. As established in Chapter 5, it is impossible to avoid metaphor or figurative language in human communication. The implication of this work is not that this type of language should be avoided, but that it should be carefully considered, and queried for the conveyance of intentional and unintentional meaning.

Written information materials are strongly desired by pregnant women, as sources of information to refer to later when information is more relevant or when women feel less overwhelmed by new information; to help give information to other decision-makers (e.g. partner); to provide key terms for further information seeking; to give more detail than the healthcare provider is able to. Written information may be an important aid to informed-decision making, if the material is carefully considered in terms of
comprehensiveness, comprehensibility, and balanced tone and content. Written material may be especially helpful if received before counseling with a clinician, as it can provide a general understanding of the phenomenon at hand. In this way women may use the counseling time to ask questions and deepen their understanding about particular aspects of prenatal screening that are relevant to their decision-making process rather than using clinician counseling time to learn the basic information about screening tests.

9.6.2 Implications for clinicians providing prenatal care.

Language used in counseling can shape and constrain understandings in much the same way as the language used in written materials. It's important for health care providers to question themselves about the words and terminology they choose to use, asking what messages are being conveyed, both implicitly and explicitly to women. What assumptions are present? How are the beliefs, values, and opinions portrayed in the words they choose? How might this language support or obstruct the aim of informed choice?

This process of self-questioning requires clinicians to recognize that they carry more than medical information about prenatal screening (Charles et al, 1999), and asks them to be aware of the ways in which personal values and opinions inform their thoughts and speech about prenatal screening (Bhogal & Brunger, 2010). Conversely, women carry more than just personal information and values; they may have medical information or understanding which informs their thinking about prenatal screening. This study asks clinicians to think of the counseling process as a two-way interaction where both parties have information to contribute and personal values to consider, and to recognize that for women, this process may begin before and may continue after the clinical encounter. It may be helpful for both parties to have an explicit conversation addressing what the woman needs or wants from her clinician in order to facilitate informed decision-making about prenatal screening, and what the clinician is willing and able to provide.

This conception of the clinical counseling encounter as a two-way interaction where both parties possess information and values suggests the importance of understanding the varied ways in which individual women may make decisions on sensitive issues such as
prenatal screening, recognizing that a 'one size fits all' approach is not appropriate. Some women may choose to gather information and make sense of it outside of the clinical encounter, relying on the clinician as one information resource but not necessarily the main information resource. Others may wish the clinician to take a more primary role in information provision. Some women may have made their decision to participate in prenatal screening before they arrive at the first prenatal visit; others may require the chance to think it over, talk with their partners, friends, or family members or to ask questions of the clinician at a later date.

There are many demands on clinician time and the suggestions for facilitating informed choice in prenatal screening exacerbate these demands. With acknowledgement of the additional time resources that counseling about prenatal screening may require, clinicians may wish to consider creative approaches to imparting information, such as directing women to online or other educational resources, having electronic information available at the office, offering group information sessions before individual counseling, employing non-physician health care providers for counseling purposes, or providing written information before the counseling session, so that clinician counseling time is used for particular questions and discussion rather than informing women of the basic information.

**9.6.3 Implications for policy.**

Following the suggestion that a 'one size fits all' counseling approach does not work for prenatal screening, this work suggests that counseling about participation in prenatal screening is a nuanced endeavour which requires clinician time and energy to respond to the unique requirements of each pregnant woman. The integration of counseling about prenatal screening into the existing time allotted for the first prenatal visit, without extra remuneration or educational resources, does not support clinicians in helping women make informed choices. The original clinical practice guideline universalizing the offer of prenatal screening (Summers et al, 2007) was issued by a professional college that does not control the fee-for-service payment structure of the Canadian health care system. It is not the SOGC’s role to financially support clinicians to dedicate additional time to counseling about prenatal screening, however they may provide educational support to
clinicians in the form of counseling strategies and informational resources for both women and clinicians.

As genetic testing services become increasingly prevalent in primary care, prenatal screening will become one of a variety of tests that primary care physicians will be responsible for offering, or for identifying appropriate referrals to genetic counseling resources (Greendale & Pyeritz, 2001). Other work has shown that additional educational resources are needed to provide appropriate primary care for other types of genetic testing (Burke & Emery, 2002; Carroll et al., 2009; Carroll et al., 2011; Harvey et al., 2007; Nippert et al., 2011; Suther & Goodson, 2003). This study focused on prenatal screening, but the findings about counseling, written materials, and information-seeking and decision-making are relevant to many other types of genetic screening. Genetic testing asks people to consider complex scientific information and mathematical probabilities in turn with their personal values and beliefs. The profession of genetic counseling has been established to aid in this consideration, but genetic testing has expanded into primary care; professional and funding policy needs to respond to this evolution by providing educational and resource support for primary care providers asked to assume this additional responsibility.

9.6.4 Implications for informed decision-making.

The ideas about informed decision-making and possible solutions outlined in this work are not able to be wrapped up in a neat paragraph or two. As described earlier in this chapter, I think current conceptions of informed decision-making are deeply problematic for several reasons, but I have yet to arrive at a better alternative. Sherwin writes that feminists are often conflicted about the idea of autonomy because this concept provides protection and agency to vulnerable people, but also "hides the workings of privilege and masks the barriers of oppression" (Sherwin, 1998, p. 25). I think informed decision-making is the best option we have right now, and in my work I have tried to suggest ways in which it could be improved, including acknowledgement of embedded values and assumptions, appreciation of the individualized requirements for information, and understanding that the information-seeking and decision-making processes start before and continue after a visit with the clinician.
I think for many women, prenatal screening is an important opportunity and I agree with the premise of the policy documents, that it should be offered to every pregnant woman (Chitayat et al, 2011; Summers et al, 2007). I strongly believe that every pregnant woman should have the right to make her own choice about whether or not to participate and what to do with the information she receives from the screening test; just because a choice is constrained by societal context doesn't mean it's not an important choice. After working on this project for five years, my own take-home message is that we should afford people who have atypical needs the same support to reach their potential as we afford those who have typical needs (Wendell, 1996). If we spent as much money supporting the lives of people with disabilities as we do on research and clinical services designed to prevent those lives (Lippman, 1991), we might stand on firmer ground when espousing the importance of autonomous and informed choices.

9.7 Directions for future research.

While undertaking this research I have identified several tensions between individuals and society. The premise of expanding the offer of prenatal screening is based on individual rights; as evidenced in the Clinical Practice Guidelines (Chitayat et al, 2011; Summers et al, 2007) through the emphasis on informed decision-making and autonomous choices, women should be able to make their own choices about how much information they want to know about their pregnancy, and what to do with that information. At the same time, social forces may act in many different ways (through language, available resources for child raising, social ideas of normality, accommodations of people with different needs) to shape and constrain the choices that are available to women. Future research may explore these tensions and their implications for informed decision-making.

This thesis addresses a particular type of prenatal screening that can identify particular conditions through specific mechanisms. As medical science progresses, more conditions are able to be identified prenatally, and different therapies become available, the offer and consideration of prenatal screening will become more complex. In 2008, Fan and colleagues published an account of a technique that can be used to find and analyze fetal DNA through a maternal blood sample taken as early as the 14th week of gestation (Fan,
Blumenfeld, Chitkara, Hudgins, & Quake, 2008). This technology, known as non-invasive prenatal diagnosis, will enable women to obtain diagnostic information early in pregnancy without any physical risk to the mother or fetus. The ability to analyze DNA at an early stage in pregnancy will widen the number of conditions that can be detected through prenatal screening, opening a Pandora's box of possibility (Benn & Chapman, 2010; de Jong, Dondorp, de Die-Smulders, Frints, & de Wert, 2009; Newson, 2008).

In this work, I didn't explore the pragmatic and logistical aspects of the offer of prenatal screening. Family physicians are a famously overburdened group, who juggle challenging patients, a high workload and time limitations while also trying to participate in continuing education, improve relationships with their patients, cope with limited health resources, imposed rules and regulations, and a lack of support from specialists (Lee, Brown, & Stewart, 2009). Counseling about prenatal screening takes time, and the strategies I have proposed in this thesis increase the amount of time required by the family physician. There has been significant research into innovative ways to impart information about prenatal screening without one-on-one physician-patient interaction (Baldwin, 2006; Browner, Preloran, & Press, 1996; Griffith, Sorenson, Bowling, & Jennings-Grant, 2005; Kaiser et al., 2002), and further research may explore the ways in which this type of clinician-absent information provision impacts the process of informed decision-making. For instance, information may be provided prior to a visit with the physician, so that counseling time can be used to clarify understanding, deliberate, and discuss implications of different decisions rather than impart basic information.

9.8 Strengths and Limitations

9.8.1 Communicating with different disciplinary audiences

Contributing and communicating to different disciplinary audiences is an important aspect of high quality interdisciplinary work. There were times in which I experienced a tension between retaining the intent and integrity of the work while adapting to the specific expectations and terminology of a particular discipline. Sometimes these were small issues, such as using the word *results* when I would prefer to use *findings*. In these minor instances, I took a pragmatic approach and structured the work in a way that I
thought would be understandable and compelling to a particular audience. At other times, communicating with different audiences posed more significant challenges to the integrity of the work. As an example, I had hoped to submit one of the manuscripts to a relevant clinical journal with a short word count. One of my supervisors advocated for this piece by contacting the journal editor to ask if there was flexibility with the word count, considering that my qualitative manuscript would include the data in the body of the text, rather than in tables or figures. We received a response that stated that while this particular journal was not opposed to qualitative research, they preferred that quotations be omitted, or paraphrased and summarized. Since the exclusion of participant data would compromise the credibility of the work (Charmaz, 2006), we chose to submit that paper to another journal.

9.8.2 Re-committing to a focused inquiry

In the Quality Criteria section, I discussed the interdisciplinary imperative to engage with a wide array of literature and how this was one of the most enjoyable aspects of my doctoral program. However, engaging with a wide variety of literature has concomitant weaknesses. While a wide range of interdisciplinary literature allowed me intellectual flexibility and the ability to respond to my study data in a unique way, it was a challenge to keep a sufficiently tight focus on the research questions. Throughout the doctorate, but especially in the beginning, I was constantly reading new ideas and expanding my research proposal to encompass these new ideas. While I knew that I had to rein in this tendency so that the research did not become too diffuse, it was a constant challenge to put aside interesting, valuable, and invigorating ideas, especially when I could see the ways in which these ideas could be made relevant to the project. This task became easier after I started collecting data; I began to identify a theme of informed decision-making in the data and this became the touchstone for keeping my research focused.

Engagement with a wide variety of interdisciplinary literature also presents the challenge of choosing what definitions and theories to represent as authoritative. Working within a disciplinary frame, some of this work has already been done. Disciplinary knowledge presents a range of possibilities to choose from, and a foundation of what combinations are acceptable. Working in an interdisciplinary way, I was challenged to find and
evaluate ideas from many different sources, reconciling tensions where I could find them. I fear that I have not found all the tensions, or exhausted all the sources. While I understand that it is impossible for any scholar, disciplinary or interdisciplinary, to conduct a literature review that is absolutely exhaustive, I think this is an additional challenge for those who engage with literature from a wide variety of disciplines.

9.8.3 Process vs. product.

While some may conceptualize the purpose of doctoral research to be the production of knowledge, I firmly believe that the purpose of doctoral research is also to learn, practice, and demonstrate proficiency in the research process (Franke & Arvidsson, 2011). This tension is often echoed in the language used to describe quality criteria (Reynolds et al., 2011). The product of the research is one way of evaluating whether the student has fulfilled this criteria, but I propose several other indications of this achievement: the explanatory and narrative aspects of the thesis detailing the doctoral journey; indications of other research productivity and growth on one’s CV; a well organized and intellectually compelling public presentation; considered and thorough answers to examination questions; consistent and comprehensive theoretical underpinning to the work.

I have engaged with the idea of the doctorate as a process rather than a product throughout the entire program, choosing methods, theories, and methodologies I wanted to learn and practice; incorporating as many ideas as possible; becoming actively involved in many other research projects in order to learn new ideas, work with different scholars, practice my existing skills, and expand my list of accomplishments. As I was writing my dissertation, I have used many ideas gathered from these extra research projects, the knowledge and experience I gained throughout the whole doctoral program has influenced not just the research product that I have produced, but the way I think of research, academia, and the world.

9.9 Conclusion

This dissertation has addressed informed decision-making about participation in prenatal screening in Canada, since the advent of the 2007 SOGC Clinical Practice Guideline
(Summers et al, 2007) which universalized the offer of screening tests. An examination of data from patient education materials, policy documents, and pregnant women currently experiencing this process has generated four integrated articles which comment on various aspects of informed decision-making. An examination of the literature on autonomy, normalization, medicalization, and governmentality has revealed a tension around an individualized way of considering informed decision-making: the choice to participate in prenatal screening is deeply embedded within the particular societal context in which it is made. It becomes clear that promoting informed choice about prenatal screening is not just a matter of providing clear and comprehensive information, but includes broader considerations of how choices are constructed and the ways in which particular courses of action are enabled and constrained.
9.10 References


Denzin, N. (2009). The elephant in the living room: Or extending the conversation about the politics of evidence. *Qualitative Research, 9*(2), 139-160.


Suther, S., & Goodson, P. (2003). Barriers to the provision of genetic services by primary care physicians: A systematic review of the literature. *Genetics in Medicine, 5*(2), 70-76.


Appendices

Appendix 1: Example of Reflective Memos for participant "Lucy"

The memos I wrote after interviewing Lucy and transcribing the data are typical of most of the memos I wrote- short and focused on a couple of aspects that seemed meaningful, or gave me pause.

Post-Interview Memo for Lucy

Lucy was one of my "typical" expected responses- didn't really understand it was a choice, didn't really think about it, is doing it to see the baby, would have an abortion if it was something "severe" but not for Down's syndrome.

Interestingly, she has been the only one not to know the meaning of "positive result"/"negative result" so far..... I expected this to be a more common confusion. She's also the only one without a university or college degree, so that might have something to do with it.

She said her doctor was pushing the test and when I asked why she thought he was pushing it, she compared it to a flu shot, a precaution. this was interesting comparison, especially from someone who would keep the baby if it had Down syndrome.

She has also been the only participant to mention a nurse- the fam doc told her about it very briefly as a "everyone gets it", then she was brought to the nurse who gave her a pamphlet, but didn't really talk about the screening at all.... possible the family doc didn't really talk about it because it was expected that the nurse would??

the information that mattered most to her, and the info she suggested other women should have was details about living with the conditions tested for, before deciding whether to get the test.... she was quite focused on this. I wonder if this is also reflective of her lower education level? not knowing or caring about false positives, or probabilities? when I asked how much risk would be high risk (1%, 10%, 70%) she said "any" would be high risk.....

I think I need to search out women with lower education levels to round out some categories which I can already see emerging.

also, I have a hard time knowing how to talk when I sense there is a gap in understanding, or a lower level of education. I don't want to use words that are not known and make the person feel dumb, but I also don't want to talk down to her..... I struggled with that throughout this interview

Post-Transcription Memo for Lucy:

Transcribing this I remember how difficult this interview was, how I kept trying to pull answers out of her.... she didn't seem like she didn't want to participate, and she seemed
to have some strong opinions on the topic, but she just wasn't very eloquent. It was a
difficult interview. A lot of yes and no answers with little elaboration.....

I was also conscious of not wanting to use words she didn't understand, I could tell she
had a lower level of education and I didn't want to talk down to her but at the same time I
wanted to be accessible. This was made more difficult by the fact that she didn't have a
lot of information or knowledge about the test, but also couldn't identify this.... there was
nothing she was confused about, didn't want information from her doc on anything else,
didn't want to talk about anything else, didn't have any questions.... For all the questions
re: any more investigation or what could your doctor have done better, she would always
answer "somebody else might.... but for me it was fine"

I guess this interview was the stereotype of a low level of education and low level of
interest. You don't know what you don't know.... it also may be a clue to my recruitment
problems. Why would someone with these views agree to talk to me, to give their time?
This might be the majority viewpoint and it might be what I am missing in my
sample....... someone who doesn't know alot about the test, hasn't problematized it, doing
what their doctor tells them, has misgivings about some things but is not really
complaining or thinking about it too much.....
Appendix 2: Research Ethics Approval

Office of Research Ethics
The University of Western Ontario
Room 4140, 90 Support Services Building, London, ON, Canada N6A 6C1
Telephone: (519) 661-2076 Fax: (519) 661-8684 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. J. Nieder
Review number: 16985
Review Date: March 24, 2010
Protocol Title: The process of prenatal screening, from the perspective of women: prior to their results being released
Department and Institution: Obstetrics & Gynaecology, London Health Sciences Centre
Sponsor:
Documents Reviewed and Approved:
JMC Protocol Letter of Intent (November 23, 2010), Telephone Audit, Notice, Cover Letter

Documents Received for Information:
This letter notifies you that the University of Western Ontario Research Ethics Board for Health Sciences Research involving Human Subjects (REB) has reviewed and approved, in accordance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans and the Health Canada/REB Good Clinical Practice Guidelines, the application for ethics approval to conduct research on the use of prenatal screening services. The office of the REB has also complied with the membership requirements for REB as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted below unless invalidating, unacceptable or invalidating information is received by the REB. To ensure that the REB's ethical standards are met, the investigator shall be responsible for ensuring that the study is conducted in accordance with the research protocol and the investigator's ethics approval, and that the investigator complies with the requirements of the REB, including the submission of an annual progress report.

During the course of the research, no deviations from the protocol were noted. Any adverse events that occurred were not unexpected and did not require special measures to ensure the safety of the participants. The investigator has received and reviewed a copy of the final version of the protocol.

Investigators must promptly report to the REB:
1. any changes to the study that are necessary to protect the welfare of the participants
2. any events that may affect the safety of the participants or the conduct of the study
3. any changes in the protocol that require changes to the information letter documentation, and/or recruitment materials, that will be submitted to the REB for approval.

Members of the REB who are named as investigators in this research application, or declare an interest in the work, do not participate in discussions related to this application, unless they are present in the REB meeting.

Signature omitted from published thesis

Contact information omitted from published thesis
Appendix 3: Recruitment Poster

Are you age 18-35?
Are you pregnant for the first time?

We would like to invite you to be interviewed about your experiences with prenatal screening.

The interview will occur in the first half of your pregnancy. The interviewer will ask you about your understanding and opinions of prenatal screening, and whether or not you are thinking about having the tests.

Contact information omitted from published thesis
Appendix 4: Interview Guide

1. I wonder if as we begin if you could tell me a bit about your understanding of what prenatal screening is?

2. Were you surprised to be offered prenatal screening?

3. Can you give me some background about why you think your doctor offered prenatal screening to you?

4. How did the doctor bring up prenatal screening?
   a. What did you talk about?
   b. Did you talk about prenatal screening with anybody else?

5. What was the offer of prenatal screening like for you?
   a. Can you describe, in detail, the process of the offer and your thoughts about it?
   b. What kinds of things did you think about?
   c. What kind of things did your doctor draw to your attention?

6. Did you think about prenatal screening before you became pregnant?
   a. Do you know other women who have been through this process?

7. Please tell me what you understand about the screening process:
   a. What will the results of the screen tell you?
      i. Did you talk about statistics?
   b. If you receive a negative result from the screen, what does that mean to you?
   c. If you receive a positive result from the screen, what does that mean to you?
d. If you receive a positive result from the screen, what are your next options?
   i. What level of risk would you consider high? i.e. 1 in 10, 1 in 100, 1 in 1000?

8. Have your views about prenatal screening changed, since talking to your doctor about the option to participate in screening?

9. Was there anything you were confused about, or wished you had more time to discuss during the prenatal screening visit?

10. Did your doctor give you any written material, or direct you to other resources to learn more about prenatal screening?

11. Did you do any additional investigation into prenatal screening?
   ie. through the internet, through other educational resources, through other health care providers, through the internet, etc.?

12. What information would you want someone else in your situation to know?
   a. Would this be best coming from a doctor, or written in a pamphlet, or communicated in another way?

13. What is the next step for you?

14. Is there anything else that you want to talk about? Anything that stood out for you about the process of prenatal screening? Anything you liked? Anything you wish had been done differently?

Demographic questions:

A) How did you find out about the study?

B) How old are you?

C) What do you do for a living? What type of education do you have?

D) Do you live in a city, small town, or the country?

E) Are you raising this child with a partner?

F) How many weeks have you been pregnant for?
Title of Study: The process of prenatal screening from the perspective of low-risk pregnant women

Student Researcher:
Meredith Vanstone, PhD Candidate, Health Professional Education, Faculty of Health Sciences, University of Western Ontario

Supervising Researchers:
Dr. J. Nisker, PhD, MD, Schulich School of Medicine and Dentistry, University of Western Ontario

Dr. E.A. Kinsella, PhD, Faculty of Health Sciences, University of Western Ontario

Dr. P. McKenzie, PhD, Faculty of Information and Media Studies, University of Western Ontario

You are being invited to participate in research on prenatal screening, involving women in their first pregnancies who are receiving prenatal care from a family physician. Please take your time to make a decision and discuss this proposal with family members, friends, or your doctor, as you feel inclined.

The purpose of this letter is to provide you with the information you require to make an informed decision about participating in this research. It is important for you to understand why the study is being conducted and what it will involve. Please take the time to read this carefully and feel free to ask questions if anything is unclear. Once you have read and understand the information, you will be asked to sign this form if you wish to participate in the study.

WHY IS THIS RESEARCH BEING DONE?
This research explores the ways in which women in their first pregnancy experience the offer of prenatal screening, including consideration of this offer, and decision making about whether or not to participate in testing. The reason to study this experience at this
time is because a new medical policy has recently come into place recommending doctors offer prenatal screening to all women, rather than just women over the age of 35. This research is interested in your thoughts on prenatal screening based on discussions you have had with your doctor, friends, and family, and information you have read. This study is the main component of my PhD degree at the University of Western Ontario.

WHO IS ELIGIBLE TO PARTICIPATE?
To participate in this study, you should be under 35 years of age, less than 17 weeks into your first pregnancy, and receiving prenatal care from a family physician.

HOW MANY PEOPLE ARE IN THIS STUDY?
There will be at least 8 women interviewed, although this number might increase up to 40 if the researcher feels that she needs more participants to get a better understanding of the issues.

WHAT ARE MY RESPONSIBILITIES IF I PARTICIPATE?
This project involves an audio-taped interview with the student researcher (Meredith). This interview will occur in a place of your choosing, such as your home, the interviewer’s office, or a public place of your choice. It is also possible to be interviewed over the telephone. The interview will take place after you discuss prenatal screening with your family physician, but before you receive the results from screening (if you choose to participate in screening). For most women, this will be between 9 and 17 weeks of pregnancy. The interview will last between 30 and 60 minutes, and address topics such as your understanding and opinions about being offered prenatal screening.

There is only one planned interview, and you will not be contacted again by the researchers. If you wish to contact the researchers, you may do so using the contact information provided on this letter.

WHAT ARE THE POTENTIAL RISKS?
There will be no physical risks to you in this study. We are not studying any physical or drug therapies that you might be undergoing. We will be asking you about questions that might make you feel uncomfortable, such as what you thought about when your doctor was describing prenatal screening, or how you talked about the test with your partner.

WHAT ARE THE POTENTIAL BENEFITS?
You may or may not receive any benefits from this study. There is no compensation offered to participants. You may benefit by knowing someone is interested in your experiences, and studying how this experience might be improved for other women. You may not benefit personally from your participation.

WHAT INFORMATION WILL BE KEPT PRIVATE?
All your information will be kept confidential. Any identifying information that is recorded on the audio tape during the interview (for instance, your name, your partner’s name, your place of work etc.) will be discarded when the data is turned into a computer transcript. Information recorded on the tapes will be kept private.
The data from this research may be used in a future publication. Your words may be used, but they will not be tied to any information that may identify you.

The audiotapes of the interviews will be kept in a secure location and will only be accessible by the researcher and her supervisors. They will be kept for up to five years and then destroyed. Anonymized transcripts of the interviews will be protected by passwords and stored on a secure server or computer, accessible by the researcher from home or office. Only the research team has access to the recordings and transcripts of the interviews.

CAN PARTICIPATION IN THIS STUDY END EARLY?
Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time. If you choose to withdraw, you may choose if you would like the information you have provided so far to be destroyed, or if that information is ok to keep using in the final report.

WILL I BE PAID TO PARTICIPATE? WILL I HAVE ANY COSTS OF PARTICIPATION?
Although you will not be paid to participate, your parking and other expenses will be reimbursed.

IF I HAVE ANY QUESTIONS, WHO SHOULD I CONTACT?
If you have any questions now or in the future, you can contact the researcher, Meredith Vanstone. You can contact her by email at prenatal@uwo.ca or by telephone (519) 661-2111 x89161. You can also contact her faculty supervisors, Dr. Jeff Nisker (jeff.nisker@lhsc.ca) and Dr. Anne Kinsella (akinsel@uwo.ca).

If you have any questions about your rights as a research participant or the conduct of the study, you can contact the the Office of Research Ethics at (519) 661-3036 or by email at ethics@uwo.ca. Please note that representatives of the University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study related records to monitor the conduct of the research.
**Title of Study:** The process of prenatal screening from the perspective of low-risk women

**CONSENT STATEMENT:**
I have read the Letter of Information and I agree to participate. All questions have been answered to my satisfaction. I will receive a signed copy of this form.

________________________________________
Participant Name

________________________________________   _____________
Participant Signature   Date

Consent form administered and explained in person by:

________________________________________
Name and Title

________________________________________   _____________
Signature   Date
Appendix 6: Example of Initial Analytical Diagram Created for Each Participant
Appendix 7: Publisher Permission to Republish Chapter 5

Contact information omitted from published thesis

Dear Meredith,

The T&F company policy on this is as follows: "Taylor & Francis is pleased to offer authors of its content for a thesis or dissertation free of charge contingent on resubmission of permission request if work is published."

So you need to officially request permission if your dissertation is published commercially but otherwise it's fine.

Thanks,

Bev

----- Original Message ----- 
From: Meredith Vanstone
To: blinternational@bkinternet.com
Sent: Thursday, February 18, 2012 8:24 PM
Subject: permission to re-publish article in doctoral dissertation

Hi Julie,

I am seeking permission to include an article published in Reflective Practice in my doctoral dissertation. The citation is:


Could you please let me know who I should contact to obtain written (or email) permission?

Thanks

Meredith Vanstone
PhD Candidate
Health and Rehabilitation Sciences
University of Western Ontario

The information contained in this e-mail message may be confidential. If you are not the intended recipient, any use, disclosure or copying of this material is unauthorized and prohibited. Although this message and any attachments are believed to be free of viruses, no responsibility is accepted by
Appendix 8: Publisher Permission to Republish Chapter 6

Email - Information-Sharing to Promote Informed Choice in Perinatal Care

Contact information omitted from published thesis

Dr. Genikos has given permission for you to include this article in your dissertation and has asked that you include an acknowledgement of SOGC as copyright holder.

Please let me know if you need us to send this information to anyone else.

With kind regards,

Jane

Jane Fairbanks, Assistant Editor
Journal of Obstetrics and Gynaecology Canada

Contact information omitted from published thesis
Appendix 9: Curriculum Vitae

**EDUCATION**

2007-2012  **University of Western Ontario**  PhD Candidate Health Professional Education, Faculty of Health Sciences

Title: The Process of Informed Decision-Making about Prenatal Screening: Policy, Patient Education and Pregnant Women's Perspectives

Co-Supervisors: Dr. E. Anne Kinsella, Dr. Jeff Nisker

2003-2007  **McMaster University**  B.A. (Hons) *Summa Cum Laude*

Majors: Philosophy and Health Studies

**RESEARCH CONTRIBUTIONS**

**SUMMARY:**

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**PEER REVIEWED PUBLICATIONS:**


PUBLICATIONS IN PROCESS:

Vanstone, M., Kinsella, E. A., Nisker, J. Pregnant women’s self-identified information requirements when deciding to participate in integrated prenatal screening. (Submitted)


EDITORSHIPS:


PEER-REVIEWED PRESENTATIONS

**05-2012**  Vanstone, M., Hibbert, K., Pitman, A., Kinsella, E. A., McKenzie, P., Wilson, T., Lingard, L.
Waterloo, ON
The quest for effective interdisciplinary graduate supervision: Considerations for current students and future supervisors. [Panel Presentation] *Canadian Committee of Graduate Students in Education (CCGSE), Canadian Society for Studies in Education (CSSE)*

Stirling, UK
Interdisciplinary supervision and professional practice, education and learning
*Professional Practice, Education and Learning (ProPEL) International Conference*

**04-2012**  Hibbert, K., Lingard, L., Vanstone, M., Kinsella, E. A., McKenzie, P., Pitman, A. & Wilson, T.
London, ON
The quest for effective interdisciplinary graduate supervision: A critical narrative analysis. [Poster] *Education Research Day*

**09-2011**  Vanstone, M., Kinsella, E. A., Nisker, J.
London, ON
Facilitating informed choice in prenatal screening: a hybrid model of decision-making
*Center for Education Research and Innovation Annual Symposium*

London, ON
Interdisciplinary doctoral supervision teams: Working together within, between and outside of disciplinary boundaries
*Center for Education Research and Innovation Annual Symposium*

**09-2011**  Watling, C.; Driessen, E.; Vandervleuten, C.; Vanstone, M.; Lingard, L.
London, ON
Understanding feedback responses: The potential and limitations of Regulatory Focus Theory
*Center for Education Research and Innovation Annual Symposium*
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<td>Characteristics and Understandings of BRCA-positive Women with Preventable Breast Cancer</td>
<td>Canadian Bioethics Society</td>
</tr>
<tr>
<td>06-2010</td>
<td>Kelowna, BC</td>
<td>Vanstone, M., Kinsella, E. A., Nisker, J.</td>
<td>Prenatal screening patient education pamphlets: Metaphors, figurative language, and ethical implications</td>
<td>Canadian Bioethics Society</td>
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<td>03-2010</td>
<td>Dublin, IRE</td>
<td>Bourgeault, I.L., Declercq, E., Sandall, J., Wrede, S., Vanstone, M., van Teijlingen, E., DeVries, R., Benoit, C.</td>
<td>Comparative Perspectives on Maternal Request Caesarean Sections in Canada, the US, the UK and Finland. [Poster]</td>
<td>ESF EMRC/SCSS Exploratory Workshop: Promoting Normality in Childbirth Across Europe</td>
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<td>06-2009</td>
<td>Halifax, NS</td>
<td>Vanstone, M., Kinsella, E. A., Nisker, J.</td>
<td>Reading Between the Lines: Metaphors in Patient Education Pamphlets</td>
<td>Annual Clinical Meeting, Society of Obstetricians and Gynecologists of Canada</td>
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06-2009  Vanstone, M. & Nisker, J.
Halifax, NS  Comparison of Genetic Testing in Canada: Legal, Ethical, Policy issues
Annual Clinical Meeting, Society of Obstetricians and Gynecologists of Canada

05-2009  Vanstone, M. & Nisker, J.
London, ON  Genetic Testing in Canada: From Pre-pregnancy to Adult
Paul Harding Obstetrics and Gynecology Research Day

05-2009  Vanstone, M., Kinsella, E.A., Nisker, J.
London, ON  Metaphor as an Approach to Critical Reflection
Engaging Reflection in Health Professional Education and Practice Conference

02-2009  Vanstone, M., Kinsella, E.A., Nisker, J.
London, ON  Prenatal Screening Patient Education Pamphlets: Critical Discourse and
Metaphor Analysis [Poster]
Western Research Forum

PRIZES, AWARDS & SCHOLARSHIPS:

2010-2011  CIHR Training Award; Reproductive, Early Development and In Utero
Health (REDIH) ($17,800)

2010  “Student Abstract Award” Canadian Bioethics Society. ($900)

2009-2010  CIHR Training Award; Reproductive, Early Development and In Utero
Health (REDIH) ($17,800)

2009  “Young Scholar Award” Engaging Reflection in Health Professional
Education and Practice

2009  University of Western Ontario Research Travel Award ($500)

2009  First Prize, Poster competition (Social Sciences, Arts, Humanities)
Western Research Forum

2008-2009  University of Western Ontario Research/Thesis Award ($1500)

2008-2009  SSHRC J.A. Bombardier Canada Graduate Scholarship – Master’s Award
($17,500)

2008-2009  Ontario Graduate Scholarship (declined) ($15,000)

2003-2007  McMaster University Dean’s Honour List

2003-2004  Canadian Millenium Foundation Scholarship
**SELECTED WORK EXPERIENCE**

2011-present **Research Assistant**, Center for Education Research and Innovation  
*Schulich School of Medicine & Dentistry, University of Western Ontario*  
- Involved with data collection, analysis, interpretation, for several interdisciplinary medical education projects.

2007-2011 **Research Assistant**, various departments  
*University of Western Ontario*  
- Drs. Lorelei Lingard, Kathy Hibbert, Anne Kinsella, Jeff Nisker, Susan Ray  
- Departments of Medicine, Obstetrics and Gynecology; Faculties of Nursing, Education, Health Sciences. Interprofessional Network for Scholarship of Professions' Research Education (INSPiRE).

**ACADEMIC SERVICE**


2009 Conference selection committee, program committee (member), abstract review committee (Co-ordinator). Engaging Reflection in Health Professional Education and Practice, University of Western Ontario, May 2009

2007 Organization and hosting committee (member), International Conference on the Healthy Embryo, University of Western Ontario, November 2007