

PRENATAL TESTING DECISIONS:
WOMEN'S NEEDS AND WELL-BEING

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Abstract

Objectives: Advancements in women's reproductive technology have resulted in women having to face the decision whether to undergo prenatal testing (PNT). This study explored the factors involved in women's decisions around PNT and assessed the extent to which the decision making process differed between women that chose not to have PNT and those that chose to have PNT. The Self-Determination Theory (Deci & Ryan, 1985) was used as the theoretical framework.

Study Methods: 30 pregnant or recently pregnant women over the age of 35 participated in semi-structured interviews and completed a brief survey. Content analyses were completed on the interview transcripts, and correlational analyses were performed on the survey data.

Results: Women's personal values, feelings of social support, and perceived competence played major roles in the decision process. Some women in this study indicated the PNT choice gave them a feeling of control and offered feelings of reassurance, while some said having to make the choice was a burden that they found difficult to bear. Women in the testing group appeared to place a great importance on the need for information, while women in the no testing group placed greater importance on the need for social support. Each testing group also appeared to differ in facets of their personal values, such as religiosity (only women in the no testing group discussed this issue) and need for a sense of control (only women in the testing group discussed this issue). The women in the no testing group showed higher levels of uncertainty and decisional conflict, and lower levels of decisional self-efficacy than women in the testing group.

Conclusions: Each testing group appears to be individual in their needs during PNT decision making. The study findings suggest women should be counseled differently depending on their supports, values, and need for knowledge regarding testing. The findings suggest that women opting against PNT experience elevated decisional distress, and perceive themselves to be less competent and more conflicted over the decision than women choosing PNT. Special attention to these women during the PNT decision may improve their feelings of being socially supported during the decision.

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Dedication

This thesis is dedicated to Shawn and Beth. Thank you for supporting and loving, and laughing and crying with me through this process of creation. The completion of this thesis is the beginning of the rest of our lives together. Beth, may you be inspired to greatness because of what Mommy and Daddy were able to accomplish.

Table Of Contents

PERMISSION TO USE	i
ABSTRACT.....	ii
ACKNOWLEDGEMENTS.....	iii
DEDICATION.....	iv
TABLE OF CONTENTS.....	v
LIST OF TABLES.....	vii
1. INTRODUCTION.....	1
1.1 Prenatal Testing – The Technology.....	3
1.2 Past Research Investigating PNT Decision-Making.....	6
1.2.1 Sociodemographic Predictors.....	6
1.2.2 Societal Influences Affecting PNT Decisions.....	8
1.2.3 Physician Influences.....	9
1.2.4 The Role of Important Others.....	11
1.3 Post-Decisional Well-Being.....	12
1.4 Models of Decision Making.....	15
1.4.1 Rational Choice Models.....	15
1.4.2 Self-Determination Theory.....	21
1.5 Present Study–Overview and Objectives.....	23
2. METHOD.....	24
2.1 Participants.....	24
2.2 Measures.....	26
2.2.1 Interview Schedule.....	26

2.2.1.1	Factors Affecting Autonomy.....	26
2.2.1.2	Competence.....	27
2.2.1.3	Autonomy Support.....	28
2.2.1.4	Subjective Ratings of Basic Needs.....	29
2.2.2	Decisional Well-Being Indicators.....	29
2.2.2.1	Decisional Conflict Scale.....	30
2.2.2.2	Decision Self-Efficacy Scale.....	31
2.2.2.3	Decision Regret Scale.....	32
2.3	Procedure.....	32
3.	RESULTS.....	33
3.1	No Testing Group.....	34
3.1.1	Nancy’s Story.....	34
3.1.2	No Testing Group Results.....	35
3.1.1.1	Primary Reason Behind PNT.....	35
3.1.1.2	Autonomy.....	36
3.1.1.3	Competence.....	38
3.1.1.4	Social Support.....	39
3.1.1.5	Post-Decisional Well-Being.....	42
3.2	Testing Group.....	45
3.2.1	Tina’s Story.....	45
3.2.2	Testing Group Results.....	46
3.2.2.1	Primary Reason Behind PNT.....	46
3.2.2.2	Autonomy.....	46

3.2.2.3 Competence.....	49
3.2.2.4 Social Support.....	51
3.2.2.5 Post-Decisional Well-Being.....	54
3.3 Summary of Results.....	56
4. DISCUSSION.....	61
4.1 Implications.....	67
4.2 Limitations of the Study.....	71
4.3 Future Directions.....	72
4.4 Conclusions.....	73
5. REFERENCES.....	75
6. APPENDICES.....	82
6.1 Appendix A.....	82
6.2 Appendix B.....	86
6.3 Appendix C.....	90
6.4 Appendix D.....	92

List of Tables

Table 1 - Descriptive statistics for all study variables by testing group.....	58
Table 2 - Intercorrelations between study variables no testing group.....	59
Table 3 - Intercorrelations between study variables testing group.....	60

1. Introduction

Advancements in women's reproductive technology made in the last few decades have resulted in women having to face more decisions about technological interventions in their pregnancies, such as whether to have prenatal testing (PNT) performed through such procedures as amniocentesis, chorionic villus sampling, maternal serum screening, and ultrasound. However, there are no therapeutic interventions available to treat most anomalies that are detectable through PNT. Thus the only options available to women if they receive a result indicating their child has an anomaly are to either abort the fetus or to prepare themselves for life with a child with a disability (Rothenberg & Thompson, 1994). These facts have led disability group advocates and feminist commentators to claim that PNT is in actuality not providing women with greater autonomy in their reproductive decision making, as liberal feminists propose (Gregg, 1995), but rather is placing pressure on women to make decisions that meet society's norms and values, such as aborting a child with a disability (Kaplan, 1994).

Research regarding the process by which pregnant women reach decisions about the use of PNT has found evidence that women go beyond an examination of the pertinent medical information to integrate their personal experiences and relationship issues into their decisions. This indicates that women may make PNT choices using a combination of medical information, personal beliefs, family opinions and desires, and societal norms (Gregg, 1995), suggesting women may not be completely autonomous in their decisions

regarding the use of PNT. Specifically, significant others and medical and social norms appear to be salient factors that may influence women's PNT decisions.

Carroll, Brown, Reid, and Pugh (2000) found three main influences on women's decisions to undergo or decline PNT. These influences included women's personal values, women's feelings of social support, and the adequacy of information presented to women by their health care providers. Each of these factors can affect women's feelings of autonomy in the decision making process.

Moyer, Brown, Gates, Daniels, Brown, and Kupperman (1999) found that women perceive testing as having both positive and negative aspects. Positive qualities include feelings of choice, control, and reassurance, while negative qualities include feelings of interference, lack of choice, and anxiety.

Furthermore, the authors found that, while many women appreciate the opportunity to make their own decisions about PNT, some women feel it is too much of a burden to have to make this choice. These findings suggest that different women may have differing needs for autonomy during the decision making process.

The purpose of this research project is to explore the factors involved in women's decisions around PNT, and to assess the extent to which the decision making process differs between women who choose not to have PNT and those who choose to have PNT. Furthermore, the link between the social context surrounding women during their decision, their levels of knowledge about PNT, and their decisional well being will be examined by testing group. The Self-Determination Theory (SDT; Deci & Ryan, 1985) will be used as the theoretical

framework for this study, as the terminology within this theory appears to be very relevant to the PNT decision-making process.

The decision to submit to PNT can be a value-laden decision (Suter, 2002). Women face pressure from various sources to make the correct decision for themselves, their significant others, and their unborn child. These feelings of pressure may lead to a decrease in women's feelings of making the decision based on what they feel is the best choice, leading to reduced feelings of well being, potentially leading to an increase in feelings of stress and regret around their decision (Gregg, 1995). Determining the link between autonomy and well being in the context of PNT decisions may help to reduce feelings of pressure, and may inform protocols used by medical professionals and genetic counselors in a manner that would facilitate women's ability to make decisions with less tension.

1.1 Prenatal Testing – The Technology

Prenatal testing may occur through either screening or diagnostic procedures. Screening tests indicate whether a fetus is at increased risk for congenital abnormalities, while diagnostic tests indicate whether a fetus is affected with a congenital abnormality. Women who receive an unfavourable result on a screening test (an indication that the fetus may be affected with a congenital abnormality) may then be offered a prenatal diagnostic test if the chances of having an affected pregnancy are higher than the miscarriage risk associated with the testing procedure (Health Canada, 2002).

Maternal Serum Screening (MSS) is a prenatal screening test that is done at 16 to 18 weeks gestation. Blood is drawn from the pregnant woman, and the levels of three maternal serum fetal-placental proteins, i.e., alphafetoprotein, unconjugated estriol, and human chorionic gonadotrophin are measured. Results of the test are based on the woman's age-related risk of having a child with congenital abnormalities since risk increases with age, combined with the levels of the fetal-placental proteins present (Health Canada, 2002).

High levels of alphafetoprotein suggest an increased risk of fetal neural tube defects such as Spina Bifida or anencephaly, with a detection rate (the probability of testing positive when an abnormality is present) of 85% and a false positive rate (the probability of testing positive when an abnormality is not present) of 2% (Milunsky, 1998). High levels of unconjugated estriol and human chorionic gonadotrophin suggest a woman is at increased risk of having a baby with Down Syndrome or Trisomy 18. For women who undergo MSS, approximately 1 in 10 to 1 in 20 will have results indicating an increased risk of Down Syndrome or Trisomy 18. Of these women only 1% to 2% will have a pregnancy actually affected with Down Syndrome, Trisomy 18, or neural tube defects (Health Canada, 2002). This high false positive rate for detection of Down Syndrome or Trisomy 18 may lead women to consider an amniocentesis due to the feelings of uncertainty engendered by the MSS results (Santalahti, Hemminki, Latikka, & Ryyananen, 1998).

Amniocentesis is an invasive prenatal diagnostic test that is used to diagnose fetal chromosomal abnormalities. This procedure involves the insertion

of a long needle through the woman's abdomen into her uterus in order to withdraw a small amount of amniotic fluid. The amniotic fluid is cultured and the genetic karyotype of the fetus is produced, which is then analysed to determine if any genetic abnormalities are present (Gregg, 1995). The procedure related miscarriage associated with amniocentesis is 0.5% - 1.0% (Health Canada, 2002), and the results of the test are highly accurate (99.4% – 100%) in diagnosing chromosomal abnormalities (Amniocentesis, 2001).

Currently in Canada, MSS may be offered to any pregnant woman, while amniocentesis is typically only offered to women with specific risk factors that suggest they are at a higher risk for having a child with a congenital anomaly. These risk factors may include: being of advanced maternal age (defined as age 35 or older); having had a previous child with a congenital anomaly; having a family history of congenital anomalies; and being from a specific ethnic background (Health Canada, 2002). Advanced maternal age is the most common indication for amniocentesis (Health Canada). In a study submitted to the Royal Commission on New Reproductive Technologies, Hamerton, Evans and Stranc (1993) reported that approximately 22,000 Canadian women (5% of all pregnant women in Canada) were referred for prenatal diagnostic testing in 1990. For almost 80% of the women referred for PNT, advanced maternal age was the sole indication for testing (Hamerton et al., 1993). This suggests that with today's changing society in which women are waiting until they are older and more established to have children, PNT technology will impact more and more women as the technology becomes available. Furthermore, changing guidelines around

whether options for testing should be presented only to women of advanced maternal age (Society of Obstetricians and Gynaecologists of Canada and Canadian College of Medical Geneticists, 2001) suggest the study of how women make decisions around PNT is becoming more relevant to women of all ages.

The false positive rates associated with MSS and the risk of miscarriage associated with amniocentesis are procedure-related features of PNT that have been found to influence women's PNT decision making (Markens, Browner, & Press, 1999; Moyer et al., 1999). The next section summarizes the most salient findings from past research investigating women's PNT decision-making.

1.2 Past Research Investigating PNT Decision-Making

1.2.1 Sociodemographic Predictors

Past research focusing on PNT decision-making has examined the sociodemographic factors involved in women's decisions regarding PNT. Lesser and Rabinowitz (2001) found that women who chose to have an amniocentesis were older, more well-educated, and at a higher occupation level than women who chose not to have the amniocentesis.

Rapp (1994) found that women are influenced in their decisions around PNT by their social class, their individual reproductive history, and their life history. For instance, women in a lower social class may not have access to as much information about testing as women in a higher social class, and this lack of information may influence their decision. Women who have had a difficult time becoming pregnant may be more likely to decide against testing as they may feel

they will not have another chance to have a child and they would not consider abortion and therefore do not want to risk the pregnancy.

A study of Mexican-origin women and their decision about amniocentesis following an unfavourable result on MSS found that there were no significant differences in age, educational background, income, or reproductive history for women who decided to have the amniocentesis versus those who decided against PNT. There was also no difference in religious background and practice for the two groups. However, the women who accepted the amniocentesis placed higher importance on their physicians' recommendations and felt that the results of the testing would provide them with reassurance and help their doctors with medical decisions. The women who declined the amniocentesis felt that the results of the test were not very accurate and placed a low value on the scientific information the results of the test would offer. These women were also more likely to believe their fetus was healthy than the women who accepted testing (Browner, Preloran, and Cox, 1999).

Evers-Keibooms, Denayer, Decruyenaere, and Van den Burghe (1993) assessed the relationship between religious beliefs and the desire to undergo PNT within a community sample. People with stronger religious beliefs reported that they were less likely to undergo PNT. Within this sample, people who had a greater number of children were also less likely to state they would participate in PNT. However, when couples already had a disabled child, their level of religious beliefs was not correlated with their acceptance of PNT. In a study of the influence of women's perceptions of the costs and benefits of raising a child with

a disability on their likelihood to choose to undergo PNT, Lawson (2001) found that women who anticipated few rewards in raising a child with a disability were more likely to state a willingness to undergo PNT.

Past research investigating how sociodemographic factors affect women's decisions around PNT confirms that PNT decisions are multi-faceted in that no two women will have exactly the same factors influencing their decisions. The next section summarizes the societal influences women consider when making their PNT decision.

1.2.2 Societal Influences Affecting PNT Decisions

Some critics of PNT have posited that society holds pregnant women responsible for producing a healthy child and this attitude may result in covert pressure to undergo PNT (Lippman, 1991). Past research supports this position. A recent study concluded that women who either choose not to have PNT or choose to give birth to a child with a disability following a PNT diagnosis are perceived by both general society and physicians as less deserving of sympathy and social aid to help them raise their child. It is likely that pregnant women are aware of these perceptions and may even have internalized this point of view resulting in feelings of pressure to undergo PNT (Lawson, 2003).

Suter (2002) also proposes that social norms affect women's decision-making by inducing the belief that good parents participate in PNT. For example, society places a high value on knowledge, information, and technology. PNT may lead to greater levels of knowledge and information and the technology is available; so from society's perspective, why would women choose not to use it

(Suter)? These social pressures may limit women's reproductive autonomy by highlighting to women that they must not only make their decision based on what they feel is best for them and their families, but also based on what others suggest is best for society.

1.2.3 Physician Influences

Another factor impacting women's reproductive autonomy is the manner in which their physicians present PNT information. Although the stated goal of providing women with information about PNT is to enhance women's reproductive autonomy by enabling them to make informed, objective decisions about their need for PNT, many authors note that this is not always achieved (Marteau, Plenicar & Kidd, 1993; Rothman, 1986).

Marteau et al. (1993) observed that physicians present incidence information (the frequency with which congenital abnormalities occur) to women in a manner that emphasizes the increased risk of having a child with a genetic disorder, while de-emphasizing the risk of having any complications from the procedure itself, even though the probability of each of these events is very similar (Down Syndrome = 1:112; miscarriage due to amniocentesis = 1:100). In addition, physicians also typically present the likelihood of an abnormality occurring in the fetus as more salient than the likelihood of normality (for example, the five percent chance the child will suffer an anomaly is emphasized over the ninety-five percent chance the child will be healthy).

Regardless of the manner in which the information is relayed, women often report that they do not fully understand the complicated genetic information

(risk ratios, probabilities, etc) that is being relayed to them (Rothman, 1986).

Oftentimes, physicians stress that prenatal testing /screening is a normal part of prenatal care, and therefore neglect to discuss the conditions that may be detected through PNT or the choices available to women following an unfavourable diagnosis (Marteau et. al. 1993). In fact, Santalahti et al. (1998) found that half of the women in their study who had had MSS presented to them as voluntary considered participation in the test as being routine and self-evident. If, as Gregg (1995) suggests, the majority of women attempt to incorporate all of the pertinent information available to them while they are contemplating their options around PNT, the above observations suggest that women may not be receiving or comprehending enough of the required objective medical information to be able to competently make an autonomous informed decision regarding PNT.

All these informational factors may converge to increase compliance with testing in a manner that undermines autonomy through a reduced feeling of competence in the decision making process. Women not presented with all the information needed to make a decision or who do not understand the information presented cannot be expected to make a decision with a feeling of confidence that they have all the pertinent facts required. The impact of the physician's stance on testing is one further factor that may shape the way women make decisions around PNT.

1.2.4 The Role of Important Others

Social relationships have also been observed to play a role in women's decisions regarding PNT. Rothman (1986) reported that women who chose to have the amniocentesis typically experienced either pressure to have the amniocentesis or neutrality from their physicians, husbands, and other family members and friends. However, rarely did the women she studied experience discouragement to have the amniocentesis from these significant others. Women who decided not to have amniocentesis were typically receiving their social support from intimate friends when making their decision. When these women discussed their decision with their friends, the majority were neutral in their views, while one quarter of the friends actively discouraged the woman from having the amniocentesis. One fifth of the women in Rothman's study who decided not to undergo amniocentesis did not consult their husband during the decision making process. In the cases where the women did discuss it with their husbands, almost half the husbands were neutral in their involvement.

All the women in a study by Gregg (1995) mentioned significant others' feelings about PNT when discussing how they made their decision. One woman whose nephew was born with a neural tube defect underwent PNT because she felt she was at greater risk for having a child with an abnormality. Her mother and sister believed she should have testing because of her greater risk and their opinions factored in to her choice. Furthermore, the woman's husband indicated he could not live with a child with Down Syndrome. The effect of these significant

others' feelings about PNT influenced this woman's decision to choose to have testing.

The above findings suggest that social supports and influences play an important role in women's decision making around PNT. The way in which information around the potential outcomes and the risk ratios is presented to women can influence women's choices, as can physician attitudes. Encouragement or discouragement by family or friends as to which decisional outcome is appropriate (to have or not have testing) also plays a large role in the decision making process. Each of these social influences may limit women's feelings of autonomy in the PNT context.

1.3 Post-Decisional Well-Being

As the above discussion illustrates, women must come to terms with innumerable influences on their PNT decision and must consider multiple consequences of their decision. The myriad facets of the decision-making process may lead women to feel a sense of uncertainty while making their decision, as well as prompt women to feel less autonomous in their decision. If women do not feel a sense of autonomy and if feelings of uncertainty are not resolved by the conclusion of the decision-making process, women may experience reduced feelings of post-decisional well-being (Rothman, 1986). Decreased post-decisional well-being may materialize through greater feelings of conflict and lower feelings of decisional self-efficacy while making the decision, and higher feelings of post-decisional regret following the decision (O'Conner, Jacobsen, and Stacey, 2002).

According to the North American Nursing Diagnosis Association, decisional conflict is “the uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret, or challenge to personal life values” (as cited in O’Conner, Jacobsen, and Stacey, 2002, p. 571). Feelings of conflict may arise over the PNT decision as this context involves considering such factors as the potential risks of the available procedures, uncertainty of outcomes in the MSS situation, and anticipated regret over the positive aspects of rejected options, such as being able to prepare for life with a child with a disability. Furthermore, many women who are pregnant at age 35 or greater have either delayed childbearing or have been attempting to conceive for a long period of time. Therefore, these pregnancies are usually planned and wanted, which could make the feelings of uncertainty or conflict in the decision making process even more extreme.

A further influence on decisional uncertainty or conflict may be due to women feeling they do not have all the information needed to be able to make their decision (O’Conner, 1995). As described previously, the way in which PNT is presented to women may result in women not having a full understanding of the necessary probabilistic information, which could heighten feelings of uncertainty. These factors may lead women to feel they will regret whichever choice they make (Janis and Mann, 1977). Regret is defined as “remorse or distress over a decision” (Brehaut et al. 2003, p. 282), and may be particularly relevant to the PNT situation as there is no *correct* decision among the many options women must consider. This anticipation of regret may lead to higher

levels of distress over the decision, resulting in decreased post-decisional well-being. Furthermore, the PNT context is fraught with indeterminate information about the options available to women, such as actions available if a congenital abnormality is diagnosed or the potential severity of abnormalities. These features may further contribute to the uncertainty surrounding this decision, increasing the likelihood that women may anticipate regretting their decision.

Self-efficacy is defined as a belief in one's capacity to organize and carry out the action required to achieve a goal (Bandura, 1997). Applied to the PNT situation, self-efficacy should only be apparent for women who felt they had all the information needed to make a competent decision. Furthermore, as discussed previously, women making a decision about PNT may face many social support challenges such as pressure from their doctors or significant others. Women who feel that they are supported in the decision-making process should show greater self-efficacy and therefore higher post-decisional well-being than women without this support and feeling of competence.

As the above discussion illustrates, various factors are likely to impact women's reproductive autonomy in the face of PNT decisions. Although much useful information regarding the role of sociodemographic factors, social norms, medical practices, and significant others has resulted from research in this area, one criticism of the current state of the literature is the fragmented nature of the investigations. Furthermore, the majority of past research in the area of PNT decision-making has been purely descriptive and atheoretical in nature. To fully

capture the complexity of the decision-making process, investigations that integrate the various factors under a unified theoretical framework are necessary.

1.4 Models of Decision Making

In order to deduce the most fitting framework with which to study decision making around PNT, an examination of a select number of theoretical models of decision making is necessary. The discussion that follows describes two decision-making perspectives that may be applicable to the process of making a decision about PNT. These perspectives include: (a) Rational Choice Models (the Health Belief Model; HBM; Maiman & Becker, 1974; and the Theory of Planned Behaviour; TPB; Ajzen & Fishbein, 1980); and (b) the Self Determination Theory (SDT; Deci & Ryan, 1985), a theory of motivation and personality.

1.4.1 Rational Choice Models

Much research in the area of PNT decision-making has used rational choice models (RCM) of decision making as a framework. Rational choice models assume people make decisions in a logical manner, in that they consider all the available alternatives, weigh them against each other, and then choose the option that will give them the most benefits. The most rational choice then is the one that provides the decision maker with the most post-decisional satisfaction (Janis, 1984).

The Health Belief Model (HBM; Maiman & Becker, 1974) is an example of a rational choice model of decision-making. The HBM was developed to explain decisions around individuals' participation in preventative health care. The HBM

hypothesizes that peoples perceptions about their susceptibility to a condition and the perceived seriousness of the effects of the condition along with the perceived benefits and barriers associated with the action or treatment available will influence whether they will participate in preventative health care activities (Maiman & Becker). Numerous researchers have used the HBM in an effort to determine the most salient factors contributing to PNT decisions (French, Kurczynski, Weaver, & Pituch, 1992; Rowley, Loader, Sutura, Walden, & Kozyra, 1991).

Applied to the PNT decision-making process, the perceived susceptibility to the condition is equivalent to the risk of having a child with congenital abnormalities based on maternal age, family history and outcome of previous pregnancies. The perceived severity corresponds to women's feelings of what effect giving birth to a child with congenital abnormalities will have on their life and their family. The perceived benefits may be the decreased anxiety that accompanies a favourable test result or the options for continuing or terminating the pregnancy that are available to the woman. Finally, perceived barriers to PNT could include the fear, pain, and risk associated with the testing procedure (French, Kurczynski, Weaver, and Pituch, 1992).

The HBM assumes that the evaluation of the risk of having a child with a congenital abnormality provides the motivation for making the decision to have or not have PNT (Kessler, 1990). However, as discussed during the above summary of research regarding PNT decision making, many factors have been observed that may have an influence on women's motivation to have/not have

PNT. The HBM only takes into account some of these factors and therefore does not comprehensively incorporate all these factors when applied to women's decision making. Furthermore, women often have difficulty accurately assessing the risks associated with PNT (Rothman, 1986). As the HBM is predicated on the correct evaluation of risk, this model may not be the most appropriate framework upon which to study the PNT decision-making process.

The Theory of Planned Behaviour (TPB; Ajzen & Fishbein, 1980) is a rational choice model that links beliefs, attitudes, social influences and perceived behavioural control to intentions and ultimately to behaviors. The TPB posits that in making a decision regarding a target behaviour, an individual evaluates the potential outcomes of performing the behaviour, her own beliefs and attitudes, her perceptions of what significant others think they should do, and how difficult it will be to accomplish the behaviour and then forms the intention to carry out the behaviour if these components converge to support the behaviour.

Within the PNT decision-making process, however, the outcomes of testing are non-definitive in that the severity of a diagnosed congenital abnormality cannot be determined and the alternatives and consequences often cannot be defined unambiguously, as women report that they do not fully understand the complicated genetic risk ratios and probabilities that are relayed to them (Rothman, 1986). The ambiguity of the information available to women in the PNT decision-making situation is a further limitation to the use of the TPB as a framework for examining women's decisions. Furthermore, undergoing PNT may cause pain to the mother as well as lead to increased levels of anxiety due

to the potential risks of the procedures, whereas refusing PNT can lead to increased levels of anxiety due to not knowing if the fetus has congenital abnormalities. Both acceptance and rejection of PNT can result in women feeling reduced perceived behavioural control.

Janis (1984) has observed that when an individual is under stress or is facing decisional conflict, she may *not* be able to go through all the decision-making stages required to make the rational choice. In the PNT decision-making situation, women may be facing a high degree of stress, in that they are facing a time limited decision as the options for testing are not usually presented to women until an appointment close to the time when the brief window for testing is open. Furthermore, a decision must be made between different outcomes, none of which may be seen as positive (e.g., miscarriage from amniocentesis or having a child with Down Syndrome; Shiloh, 1996). This situation further suggests rational choice models may not be fully able to depict all the factors influencing women's decisions.

An additional aspect of rational choice models of decision making that suggests these models are not appropriate for examining women's decision making around PNT is that rational choice models focus on the outcomes of the decision, rather than the process. Therefore, in order to make the most rational decision, one must be aware of all the potential outcomes that may occur as a result of the decision. Gregg (1995) suggests that for pregnant women, it is not possible to know all the potential outcomes of their decision. For example, PNT may indicate that a child has a congenital abnormality such as Down Syndrome,

but no indication of the severity of the disorder is possible. Moreover, the woman has no way to gauge what changes having a child with congenital abnormalities will have on her and her family's future lifestyle and day-to-day activities. Furthermore, it is the process of coming to the decision rather than all the potential outcomes of the decision that is important in developing counselling programs that facilitate reproductive autonomy.

Another area of concern suggesting rational choice models may not be the most suitable models to use as a framework for examining the factors that influence women's decisions around PNT is that society often holds pregnant women responsible for producing a healthy child, which may result in women feeling pressure to undergo PNT (Lippman, 1991). This finding implies that there is only one rational choice that is acceptable in the PNT decision-making process, and that is to uptake PNT (Scholtz, 1992). Santalahti, Hemminki, Latikka, and Ryyanen (1998) studied Finnish women's decision-making about PNT. They found that several women felt that there was pressure from society to have PNT, either through the implication that because the testing is available good mothers would have testing, or through attitudes towards a woman having a child with a disability. One woman stated, "nowadays one does not have the right to produce a disabled child, because today it is possible to find out beforehand" (p. 1072). Green and Statham (1996) also propose that because the technology for PNT is available, it implies that PNT is worth having, because if there was no need for PNT, the technology would not have been developed.

In both the HBM and the TPB, the effect others have on the decision maker and their decision is thought to be derived from pressure to conform to society's or others expectations about what the correct decision is believed to be (Gregg, 1995). However, Gregg found that the women she studied made their decisions in a "relational way" (p. 130) in that when making their decisions they looked to their significant others for support in the decision-making process, and considered what life would be like for those close to them if they gave birth to a child with a congenital abnormality. In the PNT decision making situation, women have indicated that their significant others or health care providers played a role in their decision (Burke & Kolker, 1993). The impact that other people have on women's decisions around PNT suggests that a model of decision making that takes into account the social context and support surrounding women and their decisions is needed in order to look at the decision process in a more comprehensive way.

In summary, many aspects of rational choice models make them unsuitable as a framework for examining women's decision-making processes regarding PNT. Rational choice models require a correct evaluation of risks and benefits, which is difficult in the PNT context. Furthermore, this decision is often made under a great deal of stress, which is not the ideal situation for making a rational choice. Finally, societal pressure may result in women feeling there is only one rational choice available to them, yet many women make the decision to choose not to have PNT, suggesting other factors are influencing their decision. As the purpose of this study is to examine women's subjective perceptions of

reproductive autonomy within the context of PNT, rational choice models of decision making do not allow for an all-encompassing inquiry into the decision making process. However, Self-Determination Theory may provide such a framework.

1.4.2 Self-Determination Theory

The Self Determination Theory (Deci & Ryan, 1985) is a general theory of motivation and personality that theorizes about “the interaction between an active, integrating human nature and social contexts that either nurture or impede the organism’s active nature” (Deci & Ryan, 2002, p. 6). This theory proposes that if behaviour is self-determined, elevated feelings of well-being and mental health will result; and if behaviour is not self-determined decreased feelings of well-being and motivation will be the result. Self-determined behaviour is evinced through an individual acting in an independent and autonomously motivated manner (Ryan & Deci, 2000). Autonomously motivated actions are those that the individual engages in because she has internalized the reasons behind the behaviour. Controlled motivation for behaviours occurs when individuals feel extreme external pressure to undertake certain actions (Deci and Ryan, 2002).

The basic needs mini-theory of SDT proposes three basic needs that must be met in order for behaviour to be self-determined (Deci & Ryan, 2002). These needs are: (a) autonomy; (b) competence; and (c) relatedness. The need for autonomy represents the tendency to be the perceived origin or source of one’s own behavior. Individuals experience their autonomous behavior as an expression of the self and as acts emanated from their interest and integrated

values (Deci and Ryan). The need for competence refers to the tendency to feel effectiveness in one's ongoing interactions with the social environment and to experience opportunities to exercise and express one's capacities. Competence is not an attained skill or capability, but rather is a felt sense of confidence and effectance in action (Deci & Ryan). It differs from Bandura's (1997) concept of 'self-efficacy', which is a cognition based form of expectations regarding one's future actions, whereas competence is the feeling of being effective, capable and successful that accompanies one's behavior (Deci & Ryan). Finally, relatedness refers to a tendency to feel connected to others and to care for others and be cared for by those others. It involves having a sense of belongingness both with other individuals and with one's community. It concerns the psychological sense of being with others in secure communion or unity (Deci & Ryan).

The basic needs mini-theory suggests individuals who have a social context supportive of the fulfillment of their basic needs are more likely to have their basic needs met. Those who have their basic needs met are more likely to be able to act in an autonomously motivated manner, which leads to increased feelings of well-being.

SDT details the social and contextual conditions that influence autonomous versus controlled motivation to perform a behaviour such as having or not having PNT. According to this theory, the social environment has to provide support for the satisfaction of basic psychological needs. People have to have options regarding their future course of actions, have to have enough

information and reassurance in their competence to make the right decision and feel care and love from their important and concerned others.

As discussed earlier, the reproductive autonomy of women in the PNT context appears to be oftentimes thwarted, and, while never truly tested in a systematic fashion, previous authors have posited that a relationship exists between the experience of decision making and the women's subsequent well-being (Rothman, 1986). The SDT appears to be a comprehensive framework with which to explore the relationship between the decision-making experience and its underlying influence on women's decisional well-being.

1.5 Present Study – Overview and Objectives

Past medical programming and research have focused heavily on the importance of ensuring the autonomy of women during the PNT decision process. By observing the factors women identify as salient within the decision making process, it may be possible to question if this is a justified practice. For example, it may be that the past emphasis on autonomy has resulted in current medical protocols that maximize autonomy and competence for women contemplating PNT decisions. However, it is possible that the attention to autonomy and decisional competency has been accompanied by a relative neglect of the social support needs of women. In fact, within this context, some physicians may view social support as antithetical to maximizing autonomy due to the fact that physicians are strongly admonished to maintain an objective clinical stance towards this issue and to stress to women that it is their decision alone (Brunger and Lippman, 1995). Although these actions do reduce the risk of

physician interference in the decision, women also may perceive them as a lack of support. Further, the past societal struggle for women's reproductive rights may have led others in a woman's social sphere (partner, friends and family) to promote her autonomy during this decision rather than provide the support that some women need.

Although SDT has not been applied to the context of PNT decisions, there is evidence that women identify multiple factors that map onto the basic needs mini-theory as salient to their decision-making process, e.g., medical information, personal beliefs, family opinions and desires, and societal norms (Carroll et al., 2000; Gregg, 1995). Exploring the PNT decision making process using the terminology of SDT may assist in clarifying the aspects of the PNT decision making process that are most relevant in promoting psychological well-being among women contemplating PNT.

The purpose of this study was to explore the how women who decided against PNT differed from women who decided to partake in PNT, as well as to inform potential interventions directed at improving the self-directedness of women's decisions and ensure that women's feelings of post-decisional satisfaction are enhanced.

2. Method

2.1 Participants

Thirty women who were currently pregnant or recently pregnant participated in the study. All women met the criteria for PNT due to advanced maternal age; i.e., 35 years of age or older at the time of delivery. They were

selected from a group of women who previously completed a mail out survey regarding the psychosocial determinants of PNT use. The mean age of the women participating was 37.6 years (range=35-46 years).

The gestational stage of the women ranged from 2 months prior to delivery to 22 months post-delivery (mean=8.3 months post-delivery). The women interviewed included women who underwent PNT (MSS - 9 women; amniocentesis - 6 women) and women who did not participate in any prenatal testing (15 women). Ten women were pregnant with or had recently given birth to their first child, while the other twenty women had given birth prior to this pregnancy. All but one of the women were married or in a relationship at the time of the decision. All women interviewed were from Saskatoon, Saskatchewan and surrounding areas.

Women were the focus of this study rather than men, or the couple together. Even though the PNT decision is frequently shared between the woman and her partner (Rothman, 1993), and the results of the decision affect the male as well as the female partner (Gregg, 1995), it was desirable to limit the scope of this study as it is an initial investigation. Furthermore, although it is important to acknowledge the effect this decision may have on the male partner, it is the woman who must undergo the risk and discomfort of prenatal testing (Mahowald, 1994), and women have historically been the ones who give the majority of care to a child with a disability (Kolker and Burke, 1998).

2.2 Measures

2.2.1 Interview Schedule

The interview schedule was semi-structured to allow for specific areas of interest to be targeted and for exploration of emergent themes and issues. Women were asked a set of specific questions and were then probed for further information based on their responses to the questions. Women were not probed in all areas, but rather the interviews were structured so that the women's stories of the process around their decision-making could emerge. See Appendix A for the interview schedule.

The interview questions were derived from the Health-Care, Self-Determination Theory Questionnaire Packet (Williams, Ryan, and Deci, 2004). This packet contains three questionnaires designed to assess motivation style, perceived competence, and autonomy support in health care decision making. All questions were revised to reflect the PNT situation.

2.2.1.1 Factors affecting autonomy. The interview questions used to examine the factors affecting the women's feelings of autonomy of the women in their decision around PNT were derived from the Treatment Self-Regulation Questionnaire (TSRQ; Williams, Grow, Freedman, Ryan, and Deci, 1996). This questionnaire assesses the degree to which a person's motivation for a particular behavior or set of behaviors is autonomous. There are three subscales to the TSRQ: the autonomous regulatory style (influenced by features within the person); the controlled regulatory style (influenced by features external to the

person); and amotivation (being unmotivated or indifferent about the decision).

The following are some examples of questions contained within the TSRQ:

1. Did this decision enable you to take responsibility for your own/baby's health?
2. Would you feel guilty or ashamed if you had made a different decision?
3. Did you find that you did not really think about the issue?

When the TSRQ is utilized as a questionnaire, the responses to the items designed to assess autonomous motivation and controlled motivation are averaged and then the controlled motivation subscore is subtracted from the autonomous motivation subscore to obtain an Autonomous Motivation Index (Williams et al., 1996). For the current study, the items derived from the TSRQ were used as probes in a semi-structured interview in order to delve into women's feelings of autonomy and the factors that may have influenced their feelings of autonomy during their decision.

2.2.1.2 Competence. The interview questions assessing competence were derived from the Perceived Competence Scale (PCS), which assesses feelings of competence about following through on a commitment, such as having or not having PNT. Feelings of competence are theorized to be important both because they facilitate goal attainment and also provide a sense of need satisfaction from the engagement in an activity in which participants feel effective (Williams & Deci, 1996). The PCS is composed of four items that were designed to assess the extent to which participants felt confident and capable in their behaviour. The following are examples of items included within the PCS:

1. Did you feel confident in your ability to make the decision to have/not have testing?
2. Did you feel capable in your ability to follow through with your decision?

When the PCS is utilized as a questionnaire, the responses to the items are averaged to obtain a perceived competence score (Williams & Deci, 1996). For the current study, the items derived from the PCS were used as probes in a semi-structured interview in order to delve into women's feelings of competence and the factors that may have influenced their feelings of competence during their decision.

2.2.1.3 Autonomy support. The interview questions targeting the autonomy supportiveness of the women's significant others (physician, spouse, and others) were derived from the short form of the Health Care Climate Questionnaire (HCCQ; Williams et al., 1996). The short form of the HCCQ is composed of six items designed to assess patients' perceptions of the degree to which their doctor was autonomy supportive. The following are examples of the items included within the HCCQ:

1. Did you feel that your physician understood how you saw things with respect to testing?
2. Did you feel your physician had confidence in your ability to make this decision?
3. Did your physician listen to how you would like to proceed regarding testing?

For the current study, the items derived from the HCCQ were used as probes in a semi-structured interview in order to explore women's feelings of being supported during their decision, and what that support looked like. The questions were all revised to reflect physician autonomy supportiveness, spouse autonomy supportiveness, and significant other's autonomy supportiveness.

2.2.1.4 Subjective ratings of basic needs. In order to assess the women's experienced levels of the three basic needs posited by SDT, the women were asked to rate, on a scale of one (low) to ten (high), how autonomous, competent, and socially supported they felt during the decision making process. Women were also asked three questions designed to assess how important it was to them to feel autonomous, competent, and supported while making their decision, in order to determine whether some basic needs were more important to the women than others. Ratings of the importance of being autonomous, competent, and socially supported during the decision were reported on a scale of one (not important) to ten (extremely important).

2.2.2 Decisional Well-Being Indicators

Following the interviews, women were asked to complete a self-administered questionnaire to assess their feelings of decisional conflict, decisional self-efficacy, and decisional regret during and following their decision. The questionnaire was based on three different scales: the Decisional Conflict Scale (DCS; O'Conner, 1999), the Decision Self-Efficacy Scale (DSES; Bunn & O'Conner, 1996), and the Decision Regret Scale (DRS; Brehaut, O'Connor,

Wood, Hack, Siminoff, Gordon, & Feldman-Stewart, 2003). Each scale was tailored to the PNT context for this study. See Appendix B for the questionnaire.

2.2.2.1 Decisional conflict scale. The DCS (O'Conner, 1999) is a 16-item scale that was designed to measure feelings of uncertainty during the decision-making process, the effect of lack of information and support on decision making, and feelings of satisfaction with the decision made. Examples of the items included in the DCS follow:

1. This decision was easy for me to make.
2. I was aware of the choices I had for prenatal testing.
3. I made this decision without any pressure from others.
4. I am satisfied with my decision.

The response options for the DCS are on a five point Likert scale, ranging from one (strongly agree) to five (strongly disagree). To obtain an overall score for the DCS the scores are summed and then divided by the number of items, resulting in a score of one indicating low decisional conflict and a score of five indicating high decisional conflict.

The internal consistency of the DCS has ranged from .78 to .92 in past research (O'Conner, 1995), and when the scale was used with women over 35 years of age considering amniocentesis, the Cronbach's alpha was equal to .92 (O'Conner, 1999). The test-retest reliability coefficient for the DCS was found to be .81. The DCS has also been found to discriminate between women who are unsure as to whether to have testing or not and those who find the decision

making easier, i.e., whether they accept or reject testing (O'Conner, 1999). The internal consistency for the DCS in the current study was .73.

2.2.2.2 Decision self-efficacy scale. The DSES (Bunn & O'Conner, 1996) is an 11-item scale that measures the individual's confidence in her ability to make a good decision. Examples of the items from the DSES follow.

While I was making a decision about prenatal testing, I felt confident that I could

1. Get the facts about the prenatal testing choices available to me.
2. Understand the information enough to be able to make a choice.
3. Handle unwanted pressure from others in making my choice.

The response options for the DSES are on a five point Likert scale, ranging from zero (not at all confident) to four (very confident). To obtain an overall score for the DSES the responses for each item are multiplied by 25 and then the transformed item scores are summed and then divided by the number of items, resulting in a score of 0 indicating extremely low self-efficacy and a score of 100 indicating extremely high self-efficacy.

The internal consistency of the DSES has been reported to be .92, and the scale is correlated with the decisional conflict subscales of feeling informed ($r=.47$) and supported ($r=.45$; Bunn & O'Conner, 1996). The internal consistency for the DSES in the current study was .88.

2.2.2.3 Decision regret scale. The DRS (Brehaut et al., 2003) is a five item scale that measures the feelings of unease that may be experienced after making a decision. Examples of the items from the DRS follow:

1. It was the right decision.
2. I regret the choice that I made.

The response options for the DRS are on a five point Likert scale, ranging from one (strongly agree) to five (strongly disagree). To obtain an overall score for the DRS items 2 and 4 must be reverse coded so that for each item a higher number indicates more regret. Following the reverse coding, one is subtracted from each response and the remainder for each item is multiplied by 25. The transformed item scores are then summed and divided by the number of items, resulting in a score of 0 indicating no regret and a score of 100 indicating high regret.

The internal consistency of the DRS has been found to range from .81 to .92. The DRS is negatively correlated with satisfaction with the decision ($r=-.40$ to $-.60$) and overall rated quality of life ($r=-.25$ to $-.27$) and positively correlated with decisional conflict ($r=.31$ to $.52$; Brehaut, et al., 2003). The internal consistency of the DRS in the current study was .61.

2.3 Procedure

Participants were contacted via telephone in order to set up an appointment for an interview. Interviews were conducted at a time and place convenient for the participants. Twenty-six of the thirty interviews were conducted

in the participant's home, while the other four interviews were conducted in restaurants.

Prior to the commencement of the interview, participants were informed of the information contained within the consent form, that is the purpose and objectives of the study, the study procedure, how the information obtained from the study would be used, participants rights to and procedures for ensuring confidentiality, and potential benefits and risks of the study. Participants were asked to indicate their consent to participate by signing the consent form (see Appendix C).

Upon signed consent, the interview commenced. Women were interviewed for approximately 30 minutes about their experiences with the process of coming to a decision about PNT. Upon completion of the interview, participants were asked to complete a self-administered questionnaire to assess their feelings of decisional conflict, regret, and self-efficacy.

To ensure the accuracy of the data the interviews were audio-taped and transcribed. Participants were provided with a copy of their transcript to review and verify. The participants were asked to make any desired revisions to the transcript and then authorize its release to the researcher for use in the study by signing a transcript release form (see Appendix D).

3. Results

All results reported in this section are grouped by testing status. The two testing status groups include: a) women who chose not to participate in PNT (n=15), and b) women who chose to have PNT [either MSS (n=9) or

amniocentesis (n=6)]. Thematic analysis of the interview data was carried out within the groups in order to examine for emerging themes of decisional autonomy, competence and social support within each testing group. The emergent themes within each group were then compared in order to examine for decisional characteristics that may distinguish the testing groups. To introduce each testing group, a fictional 'case study' representing a composite of the salient themes emerging within that group is presented at the beginning of each section. In order to further examine the relations between study variables and to detect differences and similarities between the two testing groups, quantitative analyses were also carried out. The results of these quantitative analyses are embedded within the thematic analyses for each group, and summarized in Tables 2 and 3 at the end of the results section.

3.1 No Testing Group

3.1.1 Nancy's Story

Nancy¹ decided not to have testing because she did not plan to terminate her pregnancy if she received a result indicating that her child had congenital abnormalities. She felt that if she took part in testing and received a bad result, she would then be extremely worried throughout the rest of her pregnancy, and this was something she wanted to avoid. Nancy also felt that God was looking after her baby, and whatever child God decided to give her and her husband was the child they were meant to have.

¹ Nancy represents a composite of the women in the no testing group.

Although Nancy was confident that not having testing was right for her, she was still uncertain while coming to this decision. Nancy was given enough information about the tests, but she was not sure what was important to focus on. She felt her doctor left the decision too much up to her and that the information her doctor presented to her was not really clear as far as what choice she should make. While Nancy was making her decision she felt that if the doctor had given her more information at an earlier date it would have made the decision process easier. She also felt very uncertain while deciding what to do because she did not really understand how having testing may be useful to her.

Nancy's doctor was very supportive while she was deciding whether or not to have testing, but Nancy's husband left the decision too much up to her. Nancy was able to discuss her decision with some close friends who had made the same decision during their pregnancies.

Throughout the rest of her pregnancy after the window for testing had passed, Nancy was still somewhat uncertain about whether she had made the right decision. However, she took solace in the fact that God was looking after her baby.

3.1.2 No Testing Group Results (N=15)

3.1.2.1 Primary reason behind PNT decision. Almost fifty percent of the women in this group (7/15) chose not to participate in PNT because they would

not terminate if they received an unfavourable result. One third indicated they chose not to have testing because having testing might cause them to experience excessive stress or guilt during their pregnancy. A small minority of the women (2/15), gave as their primary reason for not having testing that they instinctively felt that their baby was fine, therefore they did not need to have testing. One woman's primary reason for refusing testing was that the tests carried too much risk to her baby.

3.1.2.2 Autonomy. Eight of the fifteen women in the no testing group were strong-minded in their decision not to have testing. For example, one woman stated "I just felt, for me, that it wasn't what I needed to do. It wasn't the right thing for me to do or the expedient thing or the helpful thing." Another said, "It was just really clear...We both read the information and my opinion was not to have testing..."

Ten of the fifteen women within the no testing group felt that by having testing they would expose themselves to additional stress during their pregnancy. These anticipated feelings of stress contributed to their decision not to have testing in that they felt that if they did have testing, their autonomy would be threatened because they did not want the added responsibility that would come with the knowledge of their baby's developmental status. For example, one woman stated:

I just didn't want to know. I know my doctor said knowledge is power and that line kept flipping through my head, but I just thought "what will I do with the knowledge?" which isn't a hundred percent...I just

would have been crying at night and it would have made a really positive time in my life really negative.

A further theme related to stress discussed by two of the women in the no testing group was that they would prefer not to have to make the decision because they did not want to “take blame if something went wrong”. These women indicated that they felt the “weight of the decision was on their shoulders”, and that the effect of this was that they were paralyzed in their ability to make the decision.

Eight of the fifteen women indicated that termination of their pregnancy would not be an option, so there was no reason for them to expose themselves and their fetus to the stress of PNT. One woman indicated that having made the decision not to abort was all she needed to be able to decide to not have testing. She said, “Once that decision was made [not to abort] the decision was easy.”

Three of the women in the no testing group indicated that they instinctively knew their baby was healthy. This affected their decision regarding PNT. Three other women in this group felt that God was looking after the baby or that God would give them the child they were meant to have.

An examination of the quantitative relation between perceived basic needs revealed that within this group, autonomy was related to perceived social support. This finding suggests that women who felt more autonomous during the decision making process were more likely to report higher levels of social support, $r(13)=.56$, $p=.03$. For women in this group, perceived feelings of autonomy were not related to perceived competence, decisional conflict,

decisional self-efficacy, or decisional regret. However, women who reported that feelings of autonomy were important in the decision process were more likely to say they had higher levels of perceived competence while making their decision, $r(13)=.53, p=.04$.

3.1.2.3 *Competence*. Ten of the fifteen women in this group were very knowledgeable about the PNT process and potential results. One woman said:

I felt quite capable...with the assistance of the statistics and information from my doctor. If I just had to fill out a form and couldn't have asked questions about it then that would have moved my level of competence down to about a five [out of ten]...having someone there to discuss it and provide the information really helped quite a bit.

Some of these women (3/10) felt that their doctor was good at making sure all the information was presented to them, which increased their feelings of competence. Others (7/10) indicated that they felt competent due to their own search for knowledge on the topic of testing.

Most other women in the no testing group (4/15) relayed they did not feel very confident that they had all the information they needed to make the correct decision. They felt that the MSS was not conclusive and that they did not know the right questions to ask. One of them said:

it's a decision that I don't know a lot about. I talked to my doctor about it and asked a lot of questions, but sometimes you don't know

the right questions to ask, either, as to whether or not you should be doing this.

Most of these women (3/4) who were not confident also reported they felt uncertain about which choice was best and that there were too many options for testing available. For example, one woman had a great deal of difficulty with this decision. She stated, "I was really bothered by it [the decision], because my doctor had said knowledge is power. And I thought, yes it is but what am I going to with that knowledge?"

Other reasons related to women's reduced feelings of competence included feeling that they did not receive enough information from their doctor, that they did not receive the information early enough in their pregnancy to be able to have enough time to make a competent decision, and that the information they did receive was not always clear.

To examine the relation between competence and decisional well-being measures for women in the no testing group, correlational analyses were performed. Feelings of competence were weakly negatively correlated with decisional self-efficacy, $r(13) = -.37, p = .09$, and regret, $r(13) = -.40, p = .07$. There was no association between perceived competence and decisional conflict for this group of women.

3.1.2.4 *Social support.* The majority of women in this group related that their spouses had input into the decision not to have testing. One woman said:
...as soon as he [the doctor] offered it [PNT] I said I'll take that under consideration and I went home and talked to my husband...we came

to sort of a happy resolution for both of us and felt good with the decision.

Five of the fifteen women also indicated their spouse was supportive during the decision-making process. One woman indicated she did not discuss her decision with her spouse.

Four of the women said that their spouse ultimately left the decision up to them. For example, one woman stated:

My husband and I talked about it a lot, but he ultimately left it up to me to make the final decision, because he knows it's my body and he knows that I want to have complete control as much as I can over what happens to and inside and around my body. So it was ultimately my decision to make.

Three of the four women who stated their husband left the decision up to them felt somewhat resentful that they had to make this huge decision on their own. One woman, in talking about not receiving enough support from her spouse, indicated that she felt her husband was not participating for two reasons. She felt he did not want her "to feel pressured into making any decision about the baby with his pressure." She also said that she did not think that her husband really understood the importance of the decision. She stated:

I don't think he realized how in depth this could have been had we had a false positive then we would have had to do amnio...amnio could have resulted in spontaneous miscarriage; you lose the

pregnancy, find out it would have been a perfectly fine baby – what would you do with that? I don't think he carried it to that extent.

These women felt that their spouse did not fully understand the importance of the decision.

Some of the women in the no testing group (4/15) related they had additional support during their decision making from other significant others in their life. Two of the women discussed PNT with friends who had had a negative experience with testing. God also played a role in the decision for three of the women. For example, one woman stated, "In my case I just felt this was the right thing for us and that God was looking after this pregnancy, and this baby was going to be who we needed."

Five of the fifteen women indicated their doctor was very supportive during the decision-making process, and five women sensed that their doctor was neutral in this support. Three women reported that their doctor was good at giving them all the information they needed to make the decision. One woman felt low levels of support from her doctor. She said:

She's [the doctor] so busy busy busy and I come with lots and lots of questions and she gets stressed out and says 'you've got to make another appointment I don't have time for this.' I don't know why I keep going to her and inflicting so much stress on me.

Four women also stated that they felt pressured in their decision by their doctor.

One said:

I felt somewhat pressured by my doctor that this was something that I should do for everyone's best interest. I felt a little pressured when she said "well you know, knowledge is power and you know some people that find out that they're going to have a Down's [sic] baby will read up on it and get a support system put in place so that when the baby does come it's not a surprise and they've got things in place."

Another stated:

It was a decision that my doctor and I made ultimately in the end together because she felt – she said it was still up to me but she thought that there was no risk involved [due to my age], so that I probably didn't need the prenatal testing.

Women in the no testing group who indicated they had higher levels of social support showed lower levels of decisional conflict, $r(13) = -.64$, $p = .005$, and higher levels of decisional self-efficacy, $r(13) = .57$, $p = .01$.

3.1.2.5 Post-decisional well-being. For the women in the no testing group, feelings of decisional conflict were negatively correlated with decisional self-efficacy, $r(13) = -.75$, $p = .001$. Decisional self-efficacy was marginally positively associated with decisional regret, $r(13) = .42$, $p = .06$. Four of the fifteen women who chose not to have PNT showed some level of uncertainty with their decision. All of these women indicated that their spouse ultimately left the decision up to them.

One woman demonstrated her feelings of uncertainty through searching for a great deal of reinforcement of her decision from others. She commented that she discussed the options with friends and medical personnel. She stated, "I needed to make the right decision but I needed some guidance to get there." She discussed several instances of approaching other people for advice and reassurance about her decision. For example, she said, "I talked to friends and I basically made a gut decision and then reinforced it with other friends and then I ended up speaking to a doctor...and after I spoke to her I didn't have any qualms about the decision." She indicated that she was not confident in her decision making, and therefore having others to be able to discuss her decision with was a necessity. She specifically stated:

I needed to talk to people. I needed to talk to friends that had been presented with the same thing; I had a friend in the medical field so I phoned her right away. And then when I happened to speak to that one doctor at the office, when I had a question and she was available to answer it for me, once that was cleared up for me then I was quite confident. But up until then, I knew what I should do, like morally and ethically and all those things, but I needed the facts to back that up I guess.

She also said:

You want somewhere to bounce your opinions off of and hopefully get the echo back that you're wanting to hear, as it happened with

the doctor that I phoned at the doctor's office. You can't just make the decision in a vacuum.

Three of the four women who were uncertain about their decision were not confident in the information they had on PNT. This lower level of confidence decreased their feelings of competence, which increased their feelings of uncertainty with their decision. Two women indicated they did not receive the information from their doctor early enough. Both women indicated that if the window for making the decision was larger, they would not have felt so uncertain. One woman envied her husband's ability to be done with the decision after it was made. She stated:

I told him the pros and cons of how I was feeling and said I didn't feel comfortable taking that risk, that something would go wrong with her, or that we would miscarry and he said he agreed. That was about it. It was always in the back of my mind because I even brought it up a couple times afterward, and for him it was done at that point. It wasn't even an issue [for her husband], but for me it [the decision] was still an issue [after it had been made].

The other eleven women in the no testing group felt very certain about their decision, and did not report any feelings of decisional regret. These women all indicated that the decision was relatively easy to make and that they felt they made the right decision. Three of these women were especially confident in their decision due to their belief that God was looking after their baby.

3.2 Testing Group

3.2.1 Tina's Story

Tina² chose to have testing so that she could feel reassured that her child was healthy. Tina also felt that if the results came back indicating an abnormality she would have time to prepare for life with a child with a congenital abnormality. Tina likes to have a feeling of control at all times. She felt that by choosing to have testing she could have some control over the outcome of her pregnancy.

Although Tina knew a great deal about PNT, she did not really know the extent of the high false positive rate associated with the MSS. She was still very strong-minded in her decision to have PNT however.

Tina felt a great deal of support from her significant others during the decision. Her spouse listened to the options and discussed them with her, but then ultimately left the decision in her hands. Tina's doctor was also supportive, and indicated that the decision was Tina's to make. Tina was also able to discuss her decision with other family members.

Although Tina felt basically confident with her decision, she still felt an element of uncertainty as to whether she had made the correct decision.

² Tina represents a composite of women in the testing group.

3.2.2 Testing Group Results (N=15)

3.2.2.1 *Primary reason behind PNT decision.* Many of the women (5/15) chose to have PNT in order to gain reassurance that their baby was healthy. Four women in the testing group indicated that they chose to have PNT in order to be able to prepare themselves and their family for life with a child with congenital abnormalities if the results came back indicating an abnormality was present. Some women (4/15) reported that they had PNT in order to determine if they should terminate their pregnancy. Two of the women reported that by having PNT they could maintain a feeling of control over their pregnancy.

3.2.2.2 *Autonomy.* Ten of the fifteen women in the testing group were strong-minded in their decision to have PNT. One woman felt that all decisions around her pregnancy, including having PNT should be up to her and her husband. She stated:

I don't think we would have felt intimidated or guilty by a doctor telling us that maybe you should have that done or not, just because we were pretty informed about it, and felt that this was something we should be able to make our own decision about and that somebody shouldn't be telling us about.

One woman stated, "I guess for me it was just a question of I know amnio was there, I was going to have it. I didn't really have to think too much about it." Another said, "I was just relieved that I didn't have to fight for it, because I know that there are people that do have to fight for the testing. But I didn't have to. [My doctor] told me that I could and I was glad." The majority of the women who

chose to have amniocentesis seemed to know right from when they discovered they were pregnant that they wanted to have the testing and they would *not* take no for an answer.

Seven of the women in the testing group conveyed that they wanted to have the MSS so they could be reassured about the health of their baby. Three of these women reported that the high false positive rate of the MSS did not matter in their decision. They felt that the benefit of knowing their fetus was healthy outweighed the possibility of receiving a false positive result. Other women who chose to have the MSS mentioned that the test carried no risk to their baby and that it appeared to be standard procedure, suggesting that the MSS may be becoming a standard part of pregnancy in the eyes of some women.

Seven of the fifteen women who chose to have PNT commented that they needed to have a feeling of control, and being able to have PNT gave them the feeling of control that they needed in their pregnancy. One woman stated:

...for me, I want to know everything and then I'll make the decisions, I don't want other people making those decisions on my behalf...to me the control is just like a power to know no matter the outcome that you have had some way of directing it. It's just not something that happens to you, but there's a conscious role for you. I guess it's a way of dealing with situations whether the outcome is positive or negative, knowing that you've done everything you can.

Another said:

I'm a kind of take no prisoners, take no hostages kind of person...but I'm always flying by the seat of my own pants, so I feel like if I ever make a bad decision then it's nobody's fault but my own. I have nobody to blame but me, and that's the kind of freedom of choice, freedom of expression, freedom of lifestyle that if it's one thing that this country can afford to give us...within this country, we at least have some sort of democratic or autocratic level of being, of choosing...I'm glad I can draw these decisions on my own with the medical information there at the ready as well as other mothers, other friends, other health participants. So I think that's very important, that individuals get to choose on their own with the best information they have available; however many times they want to ask their doctor the same question. I think it's very important that they choose on their own...

Finally, a third woman reported, "I need to live with the circumstances of what my results would be...and I felt that I needed to control...I needed to make the decisions on what we were going to do as a family..."

The importance of the need for autonomy was related to the importance of the needs for competence, $r(13)=.89$, $p<.01$; and social support, $r(13)=.67$, $p<.01$; for women in the testing group. This suggests that women who felt being autonomous was important also felt it was

important to be competent and socially supported while making their decision.

3.2.2.3 Competence. Ten of the fifteen women in the testing group had a great deal of knowledge about the process and results of PNT. One woman said:

My doctor explained it to me and I read up on it in a couple books and just said yeah, I want it. I want to have it done. So it wasn't a big decision. I just wanted to get it done.

Another stated, "I know they test for most things and I know how accurate it is. I know the risks involved and I know that they're very low...I was very confident in making the decision and following it through."

Three of the women in the testing group indicated that they had high information needs. For example, one woman said, "I'm one of these people who need all the information I can possibly have within limits...I want to know what's out there."

One woman placed a high importance on the need for unbiased information. She felt that scientific evidence was very important while making decisions about PNT. She stated:

I can make my evaluation...how am I going to perceive that as an expectant mother? Can it protect me against less educated comments when I'm out there? It's like knowledge is power, I read this, and I've had it verified by my GP or my obstetrician-gynaecologist...then that will give me that satisfaction of my own piece of mind, my own formed opinion based on some kind of grounded fact.

This woman also indicated that she felt it was better to get information from multiple sources in order to ensure that you are able to look at all sides of the issue before making a decision.

For women in the testing group, feelings of competence were associated with perceived social support, $r(13)=.60$, $p=.02$. Four of the women reported that their doctor gave them all the options, and two women said they discussed the options with their husband. Two women who chose to have MSS indicated they were not confident in their decision. One said:

You know, the only information I focused on was whether there was risk to the baby, well there wasn't so why wouldn't I [have testing]? Not thinking that it might give me some grief with the false positive stuff so I guess I felt capable at the time but when I look back on it now I didn't have enough information to make that decision.

Other feelings of not being competent within the group of women who chose MSS were as a result of women not having enough knowledge of MSS (3/9) or feeling they were presented with too many options about testing (1/9). One woman suggested it would be helpful if the doctor had given her more information regarding testing earlier in her pregnancy. All of the women who chose to have amniocentesis (6) implied that they felt competent with their decision. For women in the testing group, women who felt more competent showed lower levels of levels of decisional conflict, $r(13)= -.54$, $p=.02$, and higher levels of decisional self-efficacy, $r(13)=.47$, $p=.04$.

3.2.2.4 *Social support.* Five of the fifteen women in this group reported they made the decision with their husbands' input. One woman described her husband's input in the following way:

The support from him was just being there right from the beginning and going to every doctor's appointment with me, being involved in the discussions I had with the doctor, and then us two [she and her husband] talking on our own about it – you know, here's what's out there, what do we want to do.

Some of the women (5/15) conveyed that their spouse placed the decision about PNT in their hands. One woman described the support this gave her in the following way: "he [her spouse] is very good that way. He's very good at talking things out and then kind of letting me come to something." Another stated that her husband had indicated he trusted her with any decision she made in regard to PNT. One woman summarized her husband's support in the following way:

When the doctor did make that statement about you both will make this decision but ultimately it will come to you [the woman], he [my husband] was nodding his head. So I think if he [my husband] was here he might say "I would have supported her even if I wasn't quite as convinced as she was."

An additional woman described the process as follows: "he [her husband] said 'it's in your hands, he says it's your final decision.' He said 'you're the one who has to bear this burden for the next nine months, until we get out of this...it is up to you.'"

Two women who chose to have MSS revealed they wanted input from their spouse in the decision. One woman wanted her spouse to participate in the decision so she did not have to make the decision alone. The other felt that her spouse had a right to have some say in the decision because the fetus was his child too. One woman's spouse pressured her to have the MSS. She stated:

He was really concerned if the baby was healthy – where some people might be “oh I’m sure it’s fine,” he was like “let’s make sure. Let’s be safe.” So he was all for the blood work too, because again, safe, no risk, why not do it? So I mean, would it have been different if I decided not to do it, I don’t know. To have it, he was like “yeah, absolutely, why not?”

One woman reported she felt so much that the decision was hers alone that she did not discuss the decision with her husband.

Two women imparted they had a great deal of support from significant others while making their decision, while one woman indicated she was very isolated during this part of her pregnancy, and that the only person she discussed the decision with was her doctor. One woman reported she felt pressure from her immediate family while making her decision. Her family members felt that she and her husband may not have enough support in their current living situation to deal with a child with congenital abnormalities. The woman stated:

...we started talking with family members and there was pressure there to find out [the status of the fetus]. It was like, “Well do you

really want to bring a child like that into the world? Here's you two, you're a professional couple and you have no extended family anywhere to lend support; really think about this, whether if there was an issue you don't want to do it all alone or just stop and don't go on with the pregnancy."

Nine of the fifteen women in this group conveyed that their doctor was very supportive during their decision making process. Some of these women reported their doctor was neutral in this support. One woman indicated she wished that the doctor would tell her what decision to make. She described her conversation with the doctor as follows:

I don't know what's right. I'm not a doctor. So just tell me, you know? I always wanted the doctor just to tell me what to do. And he's pretty good, he says well, it's not my decision, but he'd say there's no risk to this test and it will reassure you or whatever. I guess, because of how I am, no, I'd prefer not to make the decision.

One woman said she did not need the support of her doctor. She stated:

I think if you were somebody that wasn't knowledgeable about the process of it then it would be necessary to have the support of your physician on it. But I just sort of basically said to her [the family doctor] well you'd better refer me – I didn't really need her support. I just needed her to make the referrals. So it [the doctor's support] really wasn't that important.

One woman who chose to have amniocentesis conveyed that she felt pressure from her doctor not to have the amniocentesis. She said:

Well, I could feel a little bit of pressure [from my doctor] not to have it [the amniocentesis]. It's not that she came out and said, you know you shouldn't have it, but she really stressed the risks of it and that the odds of the pregnancy not being normal were very small, because I had three normal pregnancies and three healthy children.

Women in the testing group who reported high levels of perceived social support were marginally more likely to experience lower levels of conflict while making their decision, $r(13) = -.37, p = .09$.

3.2.2.5 Post-decisional well-being. For women in the testing group, decisional conflict was negatively correlated with decisional self-efficacy, $r(13) = -.67, p = .003$, and positively correlated with decisional regret, $r(13) = .54, p = .02$. For these women, decisional self-efficacy was also negatively related to decisional regret, $r(13) = -.47, p = .04$.

Three of the fifteen women in the testing group were not fully satisfied with their decision to have PNT (all three were women who chose to have MSS). One woman felt the information about PNT was not presented early enough in her pregnancy. Two of the women indicated they would have preferred to have more information about the testing. One woman said, "I guess I felt capable at the time but when I look back on it now I didn't have enough information to make that decision." One woman would have preferred not to have to make the decision.

She stated, "I don't know what's right. I'm not a doctor. I always wanted the doctor just to tell me what to do."

One woman conveyed that she questioned her decision due to pressure from her immediate family to make a different decision. She stated:

I think what it [pressure from family] might do is add to second guessing or maybe an element of guilt...have I made the right decision, have we thought about everything, have we really taken the best interest of the child to mind or are we being selfish in that decision?

She also indicated that she felt the decision affected others as well as herself and the baby. This contributed to her feelings of uncertainty about making the correct decision for her.

The other twelve women in the testing group were strong-minded and confident in their decision to have PNT. One woman explained the process of making her decision as follows: "It wasn't even a big decision for me. My doctor explained it [PNT] to me and I read up on it in a couple books and just said yeah, I want it. I want to have it done." One woman in making the decision to have amniocentesis went through the following thought process: "it [the decision] was just like an automatic okay this is what I'll do. This is how old I am. This is what I'll do. Never thought about it." These statements typify the assurance of these twelve women in their decision to have PNT.

All six women who chose to have amniocentesis exhibited strong feelings of satisfaction with their decision. Three of these women had unplanned

pregnancies. These women felt that due to the unplanned nature of their pregnancy, they had not taken all the precautions suggested by the medical establishment as far as ensuring their baby developed normally (e.g., not drinking, eating right, etc.). Therefore, they believed if they chose to have the amniocentesis they would be able to determine if their child had congenital abnormalities as a result of being unplanned, which would allow them to terminate the pregnancy if necessary. This contributed to this group of women's feelings of satisfaction with their decision.

3.3 Summary of Results

The primary reason behind not testing for the no testing group was that they would not terminate if the testing showed an abnormality. These women also believed that if they had PNT they would experience higher levels of stress during their pregnancy because the knowledge that their baby did have an abnormality was not wanted. In contrast, for the testing group, the primary reason behind testing for the majority of women was that testing would allow them to gain the knowledge they needed to give them a sense of control and a feeling of power over their pregnancy. They would use this knowledge for reassurance that their child was healthy, in order to prepare for life with a child with congenital abnormalities, or to terminate.

While making the decision whether or not to partake in PNT, approximately fifty percent of the no testing group felt very strong-minded with their decision. Many of the women in this group indicated they did not want the knowledge they would gain from having PNT. The majority of the women in the

testing group were very strong-minded in their decision, deciding almost immediately upon learning they were pregnant that they knew they wanted PNT, and that they wanted the knowledge testing would bring.

Nearly half of the women in the no testing group felt very knowledgeable about PNT, compared to the majority of women in the testing group who indicated they felt very knowledgeable regarding PNT. For the testing group, these feelings of competence were negatively related to decisional conflict and positively related to decisional self-efficacy, whereas for the no testing group, there was no relation between feelings of competence and well-being. A vulnerable sub-group of the no testing group of women related that they were not presented with enough information to be able to make their decision without some doubt.

The majority of women in the no testing group perceived high levels of support from their spouse and their physician. However, a small minority did not perceive social support from their spouse and they felt resentful due to this lack of support. Women in the testing group indicated high levels of social support from their spouse and physician. Levels of perceived social support were negatively related to feelings of decisional conflict for women in the no testing group, while there was no relation between perceived social support and well-being for women in the testing group. The theme of God as a support in making the PNT decision was unique to the no testing group.

In relation to ultimate feelings of decisional well-being, a small minority of women in the no testing group reported feelings of uncertainty during and

following their decision. These women also indicated they did not receive the support they needed from their spouse. Overall, women in the no testing group evidenced higher feelings of decisional conflict, $r(28) = -.38, p = .02$, and lower feelings of decisional self-efficacy, $r(28) = .37, p = .02$, than women in the testing group. Women in the testing group were generally satisfied with their decision. However, three of the women who had MSS indicated they were not satisfied with their decision. See Table 1 for a summary of the descriptive statistics for the study variables by testing group. Table 2 summarizes the correlations between all study variables for the no testing group and Table 3 summarizes the correlations between all study variables for the testing group.

Table 1

Descriptive statistics for all study variables by testing group.

Study Variables	No Testing		Testing		p
	M	SD	M	SD	
Perceived Autonomy ^a	9.2	1.1	9.3	.90	.72
Autonomy Importance ^a	9.0	1.9	8.6	2.8	.67
Perceived Competence ^a	9.0	1.2	9.5	.92	.16
Competence Importance ^a	9.5	.83	9.0	2.2	.45
Perceived Social Support ^a	9.2	1.4	9.6	.90	.39
Social Support Importance ^a	8.3	2.5	7.9	3.2	.66
Decisional Conflict ^b	16.5	10.2	9.4	7.7	.04
Decisional Self-Efficacy ^c	78.3	17.4	89.4	10.0	.04
Decisional Regret ^d	5.0	6.3	8.3	12.6	.37

^aPossible scores range from 1-10 with 10 indicating high levels of need or high importance or need. ^bPossible scores range from 1-100 with higher scores indicating higher decisional conflict.

^cPossible scores range from 1-100 with higher scores indicating higher decisional self-efficacy.

^dPossible scores range from 1-100 with higher scores indicating higher decisional regret.

Table 2

Intercorrelations between study variables no testing group.

Study Variables	df	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Experienced Autonomy	13	-	.32	.09	-.03	.56*	-.13	-.006	.03	.26
2. Autonomy Importance	13		-	.53*	.00	.29	-.23	.006	.05	-.25
3. Experienced Competence	13			-	-.30	-.03	-.35	-.04	-.37	-.40
4. Competence Importance	13				-	-.12	-.01	.32	-.13	.14
5. Experienced Support	13					-	-.33	-.64*	.57*	.21
6. Support Importance	13						-	.27	.21	.35
7. Decisional Conflict	13							-	-.75**	-.34
8. Decisional Self-Efficacy	13								-	.41
9. Decisional Regret	13									-

* $p < .01$. ** $p < .001$

Table 3

Intercorrelations between study variables testing group.

Study Variables	df	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Experienced Autonomy	13	-	-.11	-.06	-.04	-.03	-.16	.15	-.01	.27
2. Autonomy Importance	13		-	-.21	.89**	-.25	.67**	.32	.03	.16
3. Experienced Competence	13			-	-.25	.60*	-.37	-.54*	.47	-.32
4. Competence Importance	13				-	-.22	.60*	.48	-.24	.31
5. Experienced Support	13					-	-.31	-.37	.34	-.08
6. Support Importance	13						-	.45	-.34	.43
7. Decisional Conflict	13							-	-.67**	.54*
8. Decisional Self-Efficacy	13								-	-.47
9. Decisional Regret	13									-

* $p < .01$. ** $p < .001$

4. Discussion

The purpose of this study was to explore the factors women identify as salient to their PNT decisions, women's experiences of the three basic needs posited by SDT during their decision making, and to assess the extent to which the decision-making process differed between women who decided against PNT and those who decided to partake in PNT.

The findings from this study suggest that many factors are significant to women while making their PNT decision. Several of these factors do map on to the basic needs posted by SDT. Further, there may be psychological differences between women who choose to have PNT and those who choose not to have PNT. The following section provides a psychological analysis of the women in both the no testing and testing groups. This section will delineate some of the similarities and differences between the groups, and emphasize the extreme vulnerability of the women who chose to not have PNT.

The majority of women in both groups made the decision they did regarding testing in order to reduce their stress levels while pregnant. In the no testing group, this same reasoning was used to support their decision, that is, having PNT would increase their stress levels. These findings are supported by a study by Browner and Press (1995) where women declined testing because they would not abort their child, and they did not want to worry throughout their pregnancy about an unfavourable result when they were not prepared to abort their pregnancy. In the testing group women indicated that they chose testing to avoid the stress of wondering if their baby was healthy. Some women in the no

testing group also reported that they felt that if they made the 'wrong' choice the responsibility for the decision was theirs alone.

Some women in the no testing group indicated that God played a role in their decision to not have testing. These women had the belief that there was no point in having testing, because in the end the outcome of their pregnancy was in God's hands. Some women in the no testing group relayed they felt it would be morally and ethically wrong to have testing. This may be related to their religious values, or to feeling that if termination was not an option, there was no reason to submit to testing. This finding is supported by Evers-Keibooms, Denayer, Decruyenaere, and Van den Burghe (1993), who determined that people with stronger religious beliefs reported they were less likely to undergo PNT. None of the women in the testing group indicated that God played a role in their decision, nor did they speak of the moral and ethical aspects of testing.

Almost fifty percent of the women in the testing group revealed that having testing gave them a feeling of control. This suggests that having concrete knowledge about the status of the baby increased women's feelings of control over their pregnancy. The women in the no testing group may have felt that by deciding not to have testing, they were giving up some measure of control over their pregnancy. This may have resulted in an inner conflict between their need for control and their moral feelings about testing, resulting in higher feelings of uncertainty for this group of women as to the 'rightness' of their decision.

Some women in the no testing group reported they were not completely confident in their competence around the PNT decision. This decreased confidence may be a result of women feeling that information regarding PNT was not presented to them early enough. Women in this group suggested that if the information had been presented earlier, they would have more time to be able to examine all sides of the decision and as a result feel more competent in their decision.

Some of these women also indicated they did not know what part of the information around testing to focus on while they were making their decision. Through discussions with the women, three decision points they would have found helpful during the decision-making process emerged:

1. Would you make the decision to terminate the pregnancy following an unfavourable result?
2. Would you like the time to prepare for the birth of a child with congenital abnormalities?
3. Would you prefer to live with whatever happens at the time of birth?

Women felt if these three choices were presented to them, it would help greatly in their decision-making.

Most of the women in the testing group reported they knew all about the procedure, risks, and results of testing. Perhaps for this group, a context supportive of competence was not needed because the women were already competent in their decision. However, some women who chose to have MSS reported that they thought MSS was a standard part of prenatal care. As Gregg

(1995) suggests, this finding may indicate that some women are not receiving or comprehending enough of the available medical information to be able to competently make an autonomous informed decision, and further, perhaps for these few women, they chose MSS without considering all the implications of the decision.

The majority of women in the no testing group made their testing decision in partnership with their spouse. This finding is in contrast with Rothman's (1986) study where one fifth of women who decided not to undergo amniocentesis did not consult their husband during the decision making process. Furthermore, a small subgroup of women in the no testing group indicated they were somewhat resentful of their spouse after he told them the decision was theirs to make. This corresponds with Rothman's findings in that 50% of the women who discussed their decision with their spouse received neutral support. Perhaps women who decide against testing would prefer more active participation from their spouse in the decision. These women may feel that if their spouse participates more in the decision, then they do not have to shoulder all the blame for making a wrong decision, which may help to reduce their feelings of uncertainty.

Within the testing group, some women who had the MSS reported feeling pressure from their spouse to have testing, and that the decision was one that affected others as well as herself and the baby. Both these influences may have reduced the feelings of autonomy for this subgroup of women, in contrast to the

women who chose amniocentesis; many of these women were adamant in their desire for the amniocentesis.

Women who showed the greatest amount of decisional self-efficacy and lowest levels of decisional conflict were more likely to say they had support from their physician, and less likely to say they discussed their decision with significant others. For example, women in the testing group were more likely to report that their physician was supportive during their decision than women in the no testing group. It may be that women who choose to have testing require social support, as long as it does not compromise their feelings of autonomy. Women in the no testing group appear to need the additional social support in order to feel secure in their autonomy.

Women in the no testing group had more themes of uncertainty than women in the testing group. This group also showed lower decisional self-efficacy and higher decisional conflict in accordance with Rothman (1986) who found that women who feel decreased autonomy and increased uncertainty while making their decision experienced reduced feelings of post-decisional well-being.

Many women in the no testing group discussed how feelings of anxiety played into their decision. An additional factor that may have contributed to the uncertainty of these women was the fear of the unknown. Some of the women in this group indicated that if they did not have testing, they would not know about a congenital abnormality and therefore they would not have to worry about it. The belief by women that MSS is standard in the prenatal care process may

also have contributed to the increased feelings of uncertainty of the women in the no testing group. If these women believed that testing was standard in prenatal care, this belief may have caused them to feel they were going against society's norms by deciding against PNT, increasing their feelings of decisional conflict.

Women in the testing group reported wanting testing primarily in order to terminate if their fetus had a congenital abnormality. This rationale may be a factor in this group's increased feelings of decisional well-being. These women had already made a firm decision that they would terminate if necessary, which may have enabled them to feel more confident in their decision. This finding is surprising as this group is most likely to have to face negative consequences such as potential miscarriage or termination because of their decision.

The basic needs theory of SDT appears to fit well to the PNT decision making context. Women in this study had strong needs for feelings of autonomy, competence, and relatedness during their decision making. As demonstrated within the interviews, the need for a feeling of control during the decision varied by testing group, suggesting women in the two groups differed in their needs for autonomy during their decision. Women also appeared to differ in their need for a feeling of competence, with the women in the no testing group having a lower need for competence, and the women in the testing group showing a greater need for competence. Women in both groups felt that having the support of their significant others while they were making their decision was important, suggesting that the need for relatedness also plays a role during PNT decision

making. These findings suggest that SDT may be a useful framework for understanding the PNT decision.

4.1 Implications

Women in this study made PNT choices using a combination of medical information, personal beliefs, family opinions and desires, and societal norms as Gregg (1995) proposed. Through using all of these sources of information and integrating them into their decisions, women's autonomy in the decision appears to be increased. These different sources of influence and information appear to be combined and assimilated by the women, allowing them to still be autonomous in their decision while using these different influences.

Women who perceive themselves to be highly competent in their decision making were more likely to have lower feelings of decisional conflict and higher feelings of decisional self-efficacy. These findings are expected, as it would be anticipated that in most cases the more knowledge you have about a decision i.e., risks, benefits, potential challenges and outcomes, the more likely you are to feel good about the decision you made. This result also parallels SDT in that the more competent you feel, the more autonomous you are able to be, resulting in higher feelings of well being. O'Conner (1995) suggests that if women feel they do not have all the information needed to make the correct decision, they will feel greater decisional conflict. This supposition was supported within this study context. Women who felt lower levels of competence with their decision showed higher levels of decisional conflict.

The testing group reported elevated feelings of competence and confidence in their decision. Many recounted that they did not spend a great deal of time on the decision to have PNT, suggesting these women felt very little conflict and indecision. Women in the testing group in this study appeared to be at reduced risk for uncertainty. It appears that as long as the information is available to these women that is all they require. They do not appear to have a significant need for additional social support.

Women who encountered a context supportive of their need for relatedness and those who experienced high levels of support while making their decision were more likely to have lower feelings of decisional conflict and higher feelings of decisional self-efficacy. This finding makes sense in that women who receive no pressure support from their significant others should be more likely to feel autonomously motivated in their decision, resulting in higher feelings of well-being. Women in the no testing group who discussed feeling pressure from their physician either to choose or not to choose PNT evinced higher levels of uncertainty while making their decision. Furthermore, a greater proportion of women in the no testing group reported they did not receive the needed support from their spouses. These findings suggest that women who choose not to have testing may require additional assistance while making their decision, because in some cases it appears that their spouse may not understand the importance and potential ramifications of the PNT decision and their physician may be applying pressure during the choice.

An additional factor that may impact feelings of uncertainty shown by women who choose not to have testing is societal expectations that if testing is available it should be used. Perhaps, as Lawson (2003) suggests, pregnant women internalize society's view that testing is the correct choice, resulting in increased feelings of pressure to undergo PNT which leads to increased feelings of uncertainty. The influence of this factor on women who choose not to have testing may mean that these women search for additional support from others to validate their decision to go against society by deciding against testing.

As in the study by Carroll et al. (2000) women's personal values, feelings of social support, and the adequacy of the information provided by physicians had a major role in the decision process. Further, as Moyer et al. (1999) found, women appeared to have differing needs for autonomy during the PNT decision process. Some women in this study indicated the choice gave them a feeling of control and offered feelings of reassurance. Some women in the no testing and MSS groups reported that having to make this choice was a burden that they found difficult to bear.

Many women who chose testing made this choice based on previously established beliefs, as also observed by Gregg (1995). For example, some women who chose amniocentesis stated that because they were pregnant, they would have the amniocentesis. This awareness may have contributed to the lesser feelings of decisional conflict experienced by these women. In comparison, the no testing group showed elevated feelings of decisional

uncertainty. Perhaps for these women, the decision not to test was influenced more by contextual factors.

Women in the no testing group appeared to make their decision based on instinct or feelings of what was morally right, while the testing group appeared to make their decision based on their knowledge of testing and what the results could provide for them. This distinction is emphasized through the finding that for the testing group, feelings of competence were associated with decreased feelings of decisional conflict, while for the no testing group competence was not related to decisional conflict. Furthermore, it seems that for women in the no testing group, being socially supported is more important in augmenting feelings of decisional well-being, while for the testing group, social support is not as important in their decisional well-being.

It appears that if women are very certain and have their needs for autonomy, competence and relatedness met, the effect of pressure from external sources on their autonomy in the decision is minimized. However, if women do not have all three needs met, these factors have greater influence. The enhanced feelings of uncertainty and decreased feelings of competence of the no testing group suggests that women who have PNT are not the vulnerable population, as is typically believed, but rather it is women who choose not to have testing that are in need of extra attention during the decision making process.

4.2 Limitations of the Study

The present study asked a very small sample of women to recall their decision-making experiences. The small numbers may result in reduced generalizability of the findings of this study. The women who participated were all over the age of 35 and all but one were married. As a result of the homogeneous nature and small numbers of this study, the findings are relevant to only this group of women.

The study design was cross-sectional, in that women were interviewed only once following their PNT decision. This design did not allow women to be followed throughout the decision-making process. The retrospective nature of the interviews is an additional limitation. In all cases, women in the testing groups had already received their PNT results, and all women in the no testing group had given birth to a healthy baby without congenital abnormalities which may have impacted their feelings of post-decisional well-being. Furthermore, as the decision had been made some time in the past, women may not have correctly recalled all the factors that were important to them in making their decision about testing.

The women who participated in this project self-selected themselves to participate. Women that participated in this study may have been more highly educated, and had a more difficult time with the PNT decision than women that did not volunteer to participate. Potential differences between women that chose to participate and those who did not may have resulted in the women in this study feeling greater levels of decisional conflict or searching for more

information regarding testing than women that did not volunteer to participate. Future research in this area should attempt to gather testing and demographic information on women declining to participate in order to determine if there are basic differences between these two groups of women.

The decisional regret scale used for this study had very low internal consistency. This result may be due to the retrospective nature of this study, in that all women knew the status of their baby prior to completing the scale.

4.3 Future Directions

Future research in the area of PNT should focus on women who make the decision not to have testing. These women appear to be the most vulnerable population, in that they have lower well-being and appear to have difficulty having all their basic psychological needs met during their decision making process.

An additional focus of future research should be on determining what personality variables may be related to deciding to have or not to have PNT. For example, it appears that women who choose no testing may be more religious, more anxious, and feel they are making the socially unacceptable choice, while women in the testing group appear to have higher levels of self-efficacy during their decision. There also appears to be a difference between the two testing groups in their need for a feeling of control regarding PNT. Future studies in this area could delineate different personality factors that may have an influence on the choice women make regarding testing in order to assist practitioners to identify those women more at risk for lower decisional well-being.

Additional research applying the SDT to the PNT decision would also be valuable. The administration of the interview probes used in this study as questionnaires to a larger group of women currently in the process of making their PNT decision could strengthen the appropriateness of the application of the SDT to the PNT decision making process. Moreover, future research looking at the different aspects of contextual support for the basic needs individually would assist in determining the relationship of the contextual support for each of the 3 different needs to the levels of needs being met within the PNT situation.

The basic needs theory applied to the PNT context should be explored cross-culturally in order to determine if this theory applies to the PNT situation within other societies. Furthermore, grouping women by socioeconomic status may help to determine if women within different SES groups are treated in the same way when they are making the PNT decision.

4.4 Conclusions

Each testing group appeared to be distinct in their needs during PNT decision making. Women in this study who chose not to have testing possessed a less significant requirement for knowledge about testing and the status of their child. The need for social support during their decision played a foremost role, potentially due to their belief that they were opposing society's views on the need for testing. Women who chose to have testing seemed to have a greater requirement for knowledge about testing and the status of their child, possibly due to this group of women making their decision using more of a medical model of decision making. Each group also appeared to differ in facets of their

personal values, such as religiosity and need for a sense of control. These findings suggest women should be counseled differently depending on their supports, values, and need for knowledge regarding testing.

The decision-making processes of women opting against PNT should be further explored as the present study suggests that these women may experience elevated decisional distress. They perceive themselves to be less competent and more conflicted over the decision than women choosing PNT. Further examination of these issues may illuminate unique aspects in the social context surrounding these women that are limiting their perceived competence, and offer suggestions for how to improve their feelings of being socially supported during the decision.

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6.1 Appendix A

Interview Schedule

1. What are the main reasons that you made the decisions regarding testing that you did?

2. Tell me about the process of coming to the decision.

Probes:

- Did this decision enable you to take responsibility for your own/baby's health?
- Would you feel guilty or ashamed if you had made a different decision?
- Did you believe it was the best thing for your/baby's health?
- Would others have been upset with you if you made a different decision?
- Did you find that you did not really think about the issue?
- Did you think carefully about this decision and decide that testing/not having testing was very important for many aspects of your life?
- Would you have felt bad about yourself if you had made a different decision?
- Was this a decision that you really wanted to make?
- Did you feel pressure from others to choose testing/not testing?
- Did you feel it would be easier to do what others told you to do rather than think about it carefully?
- Was the decision to test/not to test consistent with your life goals and values?

- Did you decide to have the testing/not have the testing so that others would approve of you?
- Was having/not having the testing important for you so that you/your baby would be as healthy as possible?
- Was it important to you that others know about the decision you made?

3. Overall, on a scale of 1 to 10, with 1 being others and 10 being you, do you feel you made the decision to have/not have testing based on what you thought you should do, or based on what others thought you should do?

4. On a scale of 1 to 10, with 1 being not important and 10 being very important, how important was it to you to make the decision to have/not have testing on your own?

5. Did you feel confident in your ability to make the decision to have/not have testing?

What factors contributed to this?

6. Did you feel capable to make the decision to have/not have testing?

What factors contributed to this?

7. Did you feel confident in your ability to follow through with your decision?

What factors contributed to this?

8. Did you feel capable in your ability to follow through with your decision?

What factors contributed to this?

9. On a scale of 1 to 10, with 1 being not competent and 10 being very competent, how competent did you feel in your decision to have/not have testing?

10. On a scale of 1 to 10, with 1 being not important and 10 being very important, how important was it to you to feel competent in your decision to have/not have testing?

11. Can you tell me about the support you received/did not receive from your physician?

Probes:

- Did your physician provide you with choices and options about testing?
- Did you feel that your physician understood how you saw things with respect to testing?
- Did you feel your physician had confidence in your ability to make this decision?
- Did your physician listen to how you would like to proceed regarding testing?
- Did your physician encourage you to ask questions about testing?

If yes, did you feel your physician answered your questions fully and carefully?

- Did your physician try to understand how you saw things before suggesting any course of action?

12. Can you tell me about the support you received/did not receive from your spouse?

Probes:

- Did you feel that your spouse understood how you saw things with respect to testing?
- Did you feel your spouse had confidence in your ability to make this decision?
- Did your spouse listen to how you would like to proceed regarding testing?
- Did your spouse try to understand how you saw things before suggesting any course of action?

13. Was anyone else important to you in making this decision? (friends, parent, siblings, etc.)

Probes:

- Did you feel that your 'other' understood how you saw things with respect to testing?
- Did you feel your 'other' had confidence in your ability to make this decision?
- Did your 'other' listen to how you would like to proceed regarding testing?
- Did your 'other' try to understand how you saw things before suggesting any course of action?

14. Overall, on a scale of 1 to 10, with 1 being not at all and 10 being very much, did you feel supported by the significant others in your life while making this decision?

15. On a scale of 1 to 10, with 1 being not important and 10 being very important, how important was it to you to feel supported by the others in your life while making your decision to have/not have testing?

6.2 Appendix B

This questionnaire asks you about things you may have thought about when you were making your decision about whether to have prenatal testing or not. Please read through each item carefully and circle the answer that best reflects your opinions or feelings.

SECTION I

Listed below are things that might be involved in making a decision about having prenatal testing. Thinking back to when you were making the decision, please indicate how confident you felt that you were able to accomplish each of the following. Please record your response by circling a number from 0 (not at all confident) to 4 (very confident) for each item listed below.

While I was making a decision about prenatal testing, I felt confident that I could:

	Not at all confident				Very confident
	0	1	2	3	4
1. Get the facts about the prenatal testing choices available to me.	0	1	2	3	4
2. Get the facts about the benefits of each choice.	0	1	2	3	4
3. Get the facts about the risks and side effects of each choice.	0	1	2	3	4
4. Understand the information enough to be able to make a choice.	0	1	2	3	4
5. Ask questions without feeling dumb.	0	1	2	3	4
6. Express my concerns about each choice.	0	1	2	3	4
7. Ask for advice.	0	1	2	3	4
8. Figure out the choice that best suited me.	0	1	2	3	4
9. Handle unwanted pressure from others in making my choice.	0	1	2	3	4
10. Let the doctor know what was best for me.	0	1	2	3	4
11. Delay my decision if I felt I needed more time.	0	1	2	3	4

SECTION II

Listed below are some comments made by women after they have made a decision about using prenatal testing. Thinking about the choice you made about using prenatal testing, please indicate if these statements apply to your decision by circling a number from 1 (strongly agree) to 5 (strongly disagree) on the scale below.

	Strongly Agree		Neither Agree nor Disagree		Strongly Disagree
12. This decision was easy for me to make.	1	2	3	4	5
13. I was sure what to do when making this decision.	1	2	3	4	5
14. It was clear what choice was best for me.	1	2	3	4	5
15. I was aware of the choices I had for prenatal testing.	1	2	3	4	5
16. I felt I knew the benefits of prenatal testing.	1	2	3	4	5
17. I felt I knew the risks of prenatal testing.	1	2	3	4	5
18. I was clear about how important the personal benefits were to me in this decision.	1	2	3	4	5
19. I was clear about how important the personal risks were to me in this decision.	1	2	3	4	5
20. I was clear which was more important to me (the benefits or risks).	1	2	3	4	5
21. I made this decision without any pressure from others.	1	2	3	4	5

22. I had the right amount of support from others in making this decision.	1	2	3	4	5
23. I had enough advice about the options.	1	2	3	4	5
24. I feel I made an informed choice.	1	2	3	4	5
25. My decision showed what was important to me.	1	2	3	4	5
26. I expected to stick with my decision.	1	2	3	4	5
27. I am satisfied with my decision.	1	2	3	4	5
28. It was the right decision.	1	2	3	4	5
29. I regret the choice that I made.	1	2	3	4	5
30. I would go for the same choice if I had to do it over again.	1	2	3	4	5
31. The choice did me a lot of harm.	1	2	3	4	5
32. The decision was a wise one.	1	2	3	4	5

6.3 Appendix C

CONSENT FORM

You are invited to participate in a study entitled “A Qualitative Examination of the Decision to Use Prenatal Testing”. Please read this form carefully and feel free to ask questions you might have.

Researchers: Nicole Wohlgenuth and Dr. K. Lawson, Dept of Psychology, phone: 966-2524

Purpose and Objectives of the Study: The number of pregnant women being referred for prenatal testing is growing daily and with the development of new tests it is likely that testing could soon become a routine part of medical care for all pregnant women. When things advance this quickly, the opinions of those most affected are often not taken into account before new medical procedures or policies are put in place. In fact, very little is known about how pregnant women feel about prenatal testing, and that is why we are conducting this interview.

This interview examines the issues that women feel are important to them in making the decision of whether or not use prenatal testing. We believe that your opinions should be considered before new procedures are put in place. This survey will provide information that could be used to guide policy decisions in a manner that reflects the needs of women.

Procedure: Participants will take part in an interview examining the issues that they identify as important to their decision regarding prenatal testing use. The interview will last approximately one hour. The interview will be audiotaped, and the audiotapes will later be transcribed. Participants will be provided with a copy of the transcript to review and verify. The participants can make any desired revisions to the transcript before authorizing its release to the researcher for use in the study. During the interview, participants will also be asked to complete a brief questionnaire regarding aspects of their decision-making process.

Use of Information and Confidentiality: The information gathered from the interviews will be used to prepare manuscripts for publication in academic journals and for conference presentations. In order to maintain confidentiality, the information from the interviews will be de-identified prior to inclusion in manuscripts or presentations. Pseudonyms will replace names in order to prevent the identification of any individual participant.

Possible benefits of the study: The results of this study will help clarify the issues that women identify as relevant to their decision regarding prenatal testing use, and can also provide information that could be used to guide policy decisions in a manner that reflects the needs of women faced with the option of using prenatal testing. Participants in the study will be provided with the opportunity to discuss issues related to prenatal testing that are important to them and will be given access to the results of the study.

Possible Risks: This interview will ask you about very personal opinions and experiences, but because these are issues that touch all pregnant women contemplating prenatal testing, there are no real risks to participating. However you are free to decide not to continue the interview at any time with no penalty. You can also decide not to answer any specific question that makes you uncomfortable. In the event that you find any of the issues discussed during the interview upsetting and wish to speak to a counselor, please contact Dr. Lawson (contact information above) for a referral.

This research project has been reviewed and approved on ethical grounds by the University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research on Sept. 11, 2003.

I, _____, have read the above description and agree to participate. The procedure and its possible risks have been explained to me by the researcher, and I understand them. I understand that I am free to withdraw from this study at any time without penalty of any type. I also understand that the data from this study will be used solely for research purposes and that my identity will be kept confidential. I also confirm that I have received a copy of this consent form for my records.

Signature

Date

Researcher
Department of Psychology
University of Saskatchewan

If you have any concern about this study, or your rights as a participant, please contact the Office of Research Services, (306) 966-4053

6.4 Appendix D

An Examination of the Decision-Making Process Around Prenatal Testing

Transcript Release Form

I, _____, have reviewed the complete transcript of my personal interview in this study and have been provided with the opportunity to add, alter and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with Nicole Wohlgemuth. I hereby authorize the release of this transcript to Nicole Wohlgemuth to be used in the manner described in the consent form. I have received a copy of this Data/Transcript Release Form for my own records.

Signature of Participant

Date

Signature of Researcher

Date