

Maternal Decisions Regarding Prenatal Diagnosis: Rational Choices or Sensible Decisions?

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Abstract

The premise underlying prenatal testing is that knowing the health status of the fetus will enable expectant parents to make rational reproductive decisions. Accordingly, rational-choice perspectives have informed both counselling protocols and the majority of investigations into the psychological processes involved in making decisions about testing and selective abortion. However, because conditions inherent in the testing situation may not adhere to the basic assumptions of rational choice models, the use of these models may be inappropriate. The individualistic focus of rational choice models may be too narrow to encompass the social and psychological factors relevant to making a decision about testing. In light of these limitations, we make a case for adopting a contextual framework for conceptualizing decisions regarding the use of prenatal testing.

Résumé

L'hypothèse qui sous-tend le recours au dépistage prénatal est la suivante : le fait de connaître l'état de santé du fœtus permettra aux futurs parents de prendre des décisions rationnelles sur le plan génésique. Par conséquent, les perspectives de choix rationnel ont été à la base tant des protocoles de counseling que de la plupart des recherches portant sur les processus psychologiques mis en jeu dans la prise de décisions au sujet du dépistage et de l'avortement sélectif. Cependant, puisqu'il est possible que les conditions inhérentes à la situation du dépistage ne respectent pas les postulats de base des modèles de choix rationnel, l'utilisation de ces derniers peut s'avérer inappropriée. Le pôle individualiste des modèles de choix rationnel peut s'avérer trop restreint pour tenir compte des facteurs sociaux et psychologiques associés à la prise de décisions en matière de dépistage. Compte tenu de ces limites, nous plaidons pour l'adoption d'un cadre contextuel pour la conceptualisation des décisions en matière de recours au dépistage prénatal.

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INTRODUCTION

Prenatal diagnostic techniques have rendered decision making about procreation more complicated today than

in any preceding era. Prenatal testing (PT), including both diagnostic and screening procedures, has a clear effect on the experience of pregnancy for many women. PT offers expectant parents the potential for more control over the birth of a child with a disability by providing information about the genetic and health status of the fetus during pregnancy. However, because there are no therapeutic interventions for most conditions detected by PT, the options available to women if fetal disease or disability is detected are limited to preparing to parent a child with a disability or terminating the pregnancy.^{1,2}

Most research to date has been directed towards the medical and, to a lesser degree, the psychological implications of PT for pregnant women. Investigations regarding decision making have been largely guided by rational-choice models, which view the decision maker as an autonomous, rational, individualistic actor.^{3,4} Few studies have examined the reciprocal relations of individual, interpersonal, and societal factors in decisions regarding selective abortion (the termination of pregnancy following a PT diagnosis of fetal anomaly), even though the experience of most prenatal care practitioners is that a range of factors are important to women making these complex decisions.⁵

To address this discrepancy, this article examines the process of PT decision making from a social-psychological perspective. We illustrate that this specific complex situation is itself embedded within a series of complex individual, interpersonal, and societal systems. The reality of prenatal counselling protocols is that contextual factors may override the traditionally assumed autonomous model of decision making. Thus, we argue that the use of a contextual or systems approach as a framework for investigating selective reproductive decisions may be more appropriate than individualistic rational-choice models. Our goal is to provide clinicians with a comprehensive range of information that they will find useful in counselling pregnant women on these issues. Examining PT decision making with a model that

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encompasses the effect of social influences may encourage research into the possibility that women make sensible choices within the context of their personal and social lives, rather than make decisions that are strictly “rational” in the formal sense.

Data Sources

This article was developed as the result of discussions about recent research regarding contextual influences on PT decision making. This research has uncovered unexpected patterns of miscommunication regarding information needs between physicians and pregnant women contemplating prenatal testing use.⁶ To develop a better understanding of these findings and to ground them within relevant past literature, we searched two electronic databases (PsycInfo and PubMed), using the following search terms: prenatal diagnosis, prenatal testing, amniocentesis, maternal serum screening, decision making, and rational choice. Materials not available online (journals and books) were hand-searched, and attempts were made to locate unpublished work.

The Rationality of Using Prenatal Testing

The premise underlying PT is that providing expectant parents with information about the health of the fetus will enhance reproductive autonomy by enabling them to make informed and rational decisions.⁷ Rational-choice perspectives have, therefore, informed most studies of decision making about prenatal testing and selective abortion.^{3,8,9} Rational-choice models, such as the health belief model¹⁰ and the theory of reasoned action,¹¹ assume that people are logical decision makers who will weigh the various options and choose a course of action they believe will maximize benefits and minimize risks. The process by which individuals arrive at a rational choice is a series of cost-benefit calculations in which the possible outcomes of each alternative are evaluated against one another in terms of their likelihood of occurrence and their importance to the decision maker.¹² The optimal (or most rational) choice is the one that promises to provide the decision maker with the greatest benefits, and therefore the greatest level of post-decision satisfaction.

Rational-choice decision making models are based on the fundamental assumptions that individuals are able to perform mental calculations in a logical manner and that they are able to function autonomously.¹² However, women do not make reproductive decisions in a vacuum. Rather, their decisions are made within social contexts that may constrain the choices they make. Personal beliefs and experiences, family circumstances, medical norms, and the contemporary sociopolitical climate all affect the use of PT and may limit the extent to which women make fully informed and autonomous decisions. Given that women may not engage in a rational-choice process in the strictest sense, it is doubtful

whether investigations based on rational-choice models can adequately examine the way women approach decisions regarding PT use. Although the decisions reached by women who are contemplating PT may not always appear rational when judged according to criteria stipulated by these frameworks,^{3,4} they may in fact be quite sensible when judged in the context of each woman’s life circumstances. An alternative model of decision making, encompassing both the autonomous and rational decision-making efforts of the individual and the wide range of systemic factors that may affect PT use, is needed. A contextual or systems perspective is a promising candidate.

Proponents of systems perspectives incorporate within these frameworks the contention that individuals develop and act against a backdrop of interconnected contextual systems.^{13,14} According to such proponents, the individual is situated within an evolving family unit, which in turn is embedded within larger societal contexts that also change over time. According to such systems theories, reproductive decisions cannot be understood by focusing simply on the level of the individual. Rather, these decisions are seen to occur within boundaries set by external relationships. Therefore, investigations of PT use and medical counselling protocols intended to aid decision making must attend to all the systems that affect, and are in turn affected by, an individual’s decision. The following sections examine decision making within each of the contextual spheres salient to systems frameworks in order to highlight the benefits of adopting a contextual or systems framework for examining the issue of PT use and selective abortion.

Immediate/Individual Level

The individual occupies a central position in contextual models such as the ecological systems theory,¹³ and individual factors such as attitudes, beliefs, and values, and personal goals, preferences, and abilities all affect decisions and subsequent actions. Considering the emphasis given to PT as a means of increasing personal reproductive autonomy, it is not surprising that most research regarding PT use and selective pregnancy termination has focused upon individual differences or personal variables that affect the decision-making process. For example, PT is most likely to be used by women of European/Caucasian background^{15,16} with higher socioeconomic status and education levels.^{15,17} Contradictory relationships have been found between religious practice and intention to use PT. In a general community sample, individuals who endorse stronger religious beliefs are less likely to state a desire to undergo PT, but religious beliefs have been found not to correlate with acceptance of PT and selective abortion among couples raising a child with a disability.¹⁷

Rational-choice investigations also focus upon the individual in attempts to delineate the factors salient in the decision-

making process.^{3,4} For these researchers, the pertinent questions have been, "What medical and personal aspects associated with PT use are most important for women contemplating PT use?" and, "How do these individuals evaluate the costs and benefits in order to reach a decision about PT use?" The general findings suggest that individuals do engage in a rational evaluation of the costs (e.g., risk of pregnancy loss, risk of fetal anomaly) and benefits (gaining reassurance, enabling selective termination) in the process of making a decision about whether or not to use PT.^{3,4} However, the limited ability of rational-choice models to predict PT decisions fully indicates that this framework is not sufficient to portray the situation of women contemplating PT. It may be that the ultimate outcome that expectant parents evaluate during this process has been misconstrued. PT is not an end but a means. That is, expectant parents undergo PT to gain information about the status of the fetus and to decide whether to continue the pregnancy if a fetal anomaly is identified. In essence, most individuals contemplating PT are motivated to have a child, but not necessarily an unhealthy child. It is the possibility that the fetus may have a disease or disability that drives the use of PT.

Therefore, rather than examining how prospective parents view testing-related factors, as has been the case in previous rational-choice investigations, it may be more appropriate to examine how they evaluate their possible future as a parent of a child with a disability. The relevant questions now become, "What is it about the prospect of parenting a child with a disability that may sway individuals toward using PT and selective abortion?" and (in keeping with the traditional evaluative framework), "What are the costs and rewards associated with parenting a child with a disability? Do they differ from the costs and rewards associated with parenting in general? Does evaluation of these costs and rewards predict a willingness to use PT and to have a selective termination?"

In recent explorations of these questions, it was concluded that parenting a child with Down syndrome (DS) was viewed as significantly less personally rewarding and slightly more costly than parenting a child that did not have a disability^{18,19} In a general community sample, parenting a child with DS was perceived to provide parents with fewer personal enrichment rewards (such as pride, love, and fun), less family continuity (such as family traditions and the anticipation of grandchildren), and more costs (social isolation and financial, physical, and emotional burdens) than parenting a healthy child.¹⁹ Further, in support of the contention that the social context is an important variable to consider, the participants perceived that they would receive less social support from family and friends in their parenting efforts if they were raising a child with DS as opposed to a healthy child.

However, not all of the variables targeting expectations of parenting were related to personal willingness to use PT or to have a selective termination following a diagnosis. After controlling for stereotypical attitudes towards persons with DS, which itself emerged as a significant predictor, only the anticipation of low personal enrichment rewards and reduced social support associated with parenting a child with DS predicted a willingness to terminate pregnancy in the event of a fetal diagnosis of DS.¹⁹ The costs associated with parenting a child with DS were not associated with endorsement of selective termination. This suggests that costs may be an inherent and accepted part of the parenting experience, and it is the lack of anticipated rewards that may sway individuals toward PT use and selective abortion.

These findings prompt the need to ask whether these negative views of parenting a child with a disability are realistic. Most (60%) of the respondents within these studies reported that they had no personal experience of persons with Down syndrome or another form of intellectual disability. These respondents held more prejudiced attitudes towards persons with DS in general, and towards parenting a child with DS specifically, and would be more likely to use PT and selective termination.¹⁹

These observations underscore the importance of including a discussion of these expectations in medical counselling protocols. Current prenatal testing information protocols focus on transmitting risk-related information, such as the probabilities of abnormalities being detected and the risks associated with testing procedures. Rarely is information regarding the experiences of parents raising a child with a disability relayed to those contemplating prenatal diagnosis and selective termination, even though past research has concluded that parental experiences are more positive than societal stereotypes would suggest.^{20,21} The relation between perceptions of parenting a child with a disability and willingness to terminate a pregnancy subsequent to a prenatal diagnosis¹⁹ suggests that this is a salient factor for many individuals. Including a realistic discussion of these issues within medical protocols may help to broaden the scope of pertinent information available to enable prospective parents to make these reproductive decisions.

Proximal Social Context

Beyond the individual level, factors within the immediate social context of pregnant women are also likely to be salient to decisions regarding PT use. Most women make these decisions in conjunction with people in their social sphere who are important to them. Spouses, parents, siblings, friends, and, very importantly, medical care providers all approach PT with their own attitudes, values, and desires.

Few studies have targeted the salience of the proximal social context compared with individual or personal factors in decisions about PT. Most investigations focusing on social context have examined the role of medical care providers or, to a lesser extent, the role of spouses.^{7,22–29} However, these studies have generally taken a non-theoretical approach, examined single elements of the social context in isolation, and largely served to emphasize the ways in which these important others impede the reproductive autonomy of women. For example, many studies document the way medical counselling protocols for PT may be biased in a way that increases testing compliance rather than providing balanced information that fosters informed and autonomous decision making.^{7,23–27} Recent Canadian studies indicate that physician characteristics, values, and attitudes are related to the uptake of maternal serum screening (MSS) by patients.^{22,28,29} However, these studies were not designed to examine women's perceptions of their entire proximal social context to identify the individuals important to the women or the factors hindering or fostering their reproductive autonomy.

A recent exploratory examination of these issues used self-determination theory (SDT) as a framework for examining the proximal influences on women's PT decisions.^{6,30} SDT posits that all individuals experience three basic psychological needs in all spheres of functioning: the need for relatedness with important others (social support), the need for competence, and the need for autonomy. These three basic needs can be met or thwarted by those in our social context. Social contexts that support the basic needs by providing social support, bolstering competence, and maximizing autonomy will facilitate healthy decision making.

A preliminary study explored pregnant women's perspectives of all the proximal social influences they identified as salient to their PT decision-making process.⁶ Thirty women referred for PT because of advanced maternal age underwent in-depth interviews and completed self-report measures of post-decisional well-being (decisional conflict, decisional competence and self-efficacy, and regret). Of these women, 15 (50%) had opted for no testing, nine (30%) underwent MSS, and six (20%) proceeded directly to amniocentesis.

The interviews focused on the experienced levels of the three basic psychological needs outlined by SDT, and the extent to which the women felt that the important others they identified in their social context responded to these basic needs. Only the basic need of social support emerged as a predictor of decisional well-being. Women who reported making their PT decision within a socially supportive context reported higher decisional competence and lower decisional conflict. The women identified their physicians and their husbands as the most important individuals from whom they

needed support. Although autonomy was not related to decisional well-being, perceptions of autonomy appeared also to rest on experiences of social support.

Women who felt supported by their physicians and their husbands also felt the most autonomous in their decisions. Conversely, women who felt the least support and autonomy were those whose husbands and physicians continually emphasized that the decision should be theirs (the women's) alone. Although they did recognize that the intention likely was to enhance their autonomy, they relayed feelings of resentment towards significant others they perceived had abandoned them in this important decision. Further analyses of group differences indicated that the women who decided against testing reported significantly lower levels of social support from important others in their social context and subsequently experienced the lowest levels of decisional well-being.

Taken together, these findings indicate that the proximal or surrounding social context is very important in the PT decision. It is clearly evident that the need for social support may predominate over the need for autonomy. One implication is that the current emphasis in counselling protocols on individual autonomy may not be meeting the basic needs of all women.^{7,8,31,32} Further, the current focus within medical counselling protocols on attending to the needs of women who choose to undergo PT may be limited, as the women who opt not to undergo testing may be a particularly vulnerable group.

Distal Social Context

The most distal social context that may exert an influence over use of PT and selective termination of pregnancy for fetal disease or disability includes factors such as societal norms and values, media portrayals, governmental and medical policies, and legislation. Although there has been very little empirical research elucidating the potential role of societal factors in PT use, these factors have been the focus of many critiques of PT.^{24,33–35} For example, societal prejudice against people with disabilities has long been posited as having a critical influence on expectant couples making PT decisions. Many disability group advocates charge that negative attitudes and intolerance towards persons with disabilities served as the impetus for the development and advancement of PT.^{24,33} They argue that the use of tests to diagnose specific disorders and the sanctioning of selective abortion based on the detection of these disorders make a clear statement about the social unworthiness of people with certain disabilities.³⁴ Thus, in their view, the use of PT both reflects and reinforces societal norms that promote selective abortion as a means to reduce the incidence of disability within society.

Three very specific criteria must be satisfied to substantiate the existence of current social norms promoting selective termination.³⁶ First, for a social norm governing any behaviour to develop, the means by which individuals practise that specific behaviour must be available and accessible. The current situation clearly meets this criterion, as the prenatal diagnostic technology is available and accepted within the medical community, and termination of pregnancy is legal within Canadian society. Second, a specific behaviour will not become widespread enough to develop into a social norm unless the majority of society members perceive personal advantages for engaging in this behaviour.³⁶ As previously discussed, there is clear evidence that decisions regarding PT use and selective termination are influenced by prejudicial attitudes towards persons with disabilities^{19,37} and the lack of rewards associated with parenting a child with a disability.^{18,19,38} There is also a perceived inability for most people to cope with parenting a child with a disability.¹⁷ Social norms are initially nothing more than an agreed upon solution to a perceived common problem.³⁹ The findings that the prevailing societal attitude towards raising a child with a disability is not favourable and that the majority of members of society indicate a desire to use PT in the event of a pregnancy indicate that most people perceive such a parenting experience as a problem.^{15,17,40,41} Therefore, these personal behaviours and attitudes would support the development of social norms that endorse the practice of selective termination following a prenatal diagnosis of fetal disease or disability. However, the third criterion is that individual patterns of behaviour achieve the status of social norms only when they become "part of the culture and the society indoctrinates its members to conform more or less closely to the norms by implicit or explicit rewards and punishments."³⁷ That is, social norms are enforced by society, through either formal or informal means.

Theoretically, individuals who adhere to social norms are rewarded with the resources that society has to offer (e.g., with acceptance, praise, inclusion, and access to all of the rights granted to full members of the society, such as financial resources and the means to meet basic physical and emotional needs). Conversely, those who violate social norms are punished for their actions (e.g., with disapproval, expulsion, and limited access to social resources). But we must ask why society, as a collective, would have any stake in the issue of selective termination. What are the benefits of this specific behaviour, on a societal level?

One potential answer is the presentation of PT and selective abortion as a public health issue. In Canada, PT for women defined as at-risk for fetal disability is included in the universal health coverage net. Thus, access to PT and selective abortion services is not limited by individual financial means.

Rather, all citizens indirectly bear the costs of these services through taxes in the same way that the population base funds the social welfare system. The burden that disability places on the medical and social welfare systems is high from a strictly economic point of view,⁴² and there is a strong motivation to allocate scarce resources in an efficient manner. Because PT and selective abortion can be construed as cost-effective when weighed against the medical and social programming costs of disability, PT use can be portrayed as meeting a public health need.³⁴

Implicit in this concept of PT as serving public health is the notion that not to use PT technology constitutes irresponsible social behaviour. Various commentators have argued that a woman who makes use of PT is seen as a responsible mother-to-be who is acting in the best interests of the fetus, her family, and her community.^{43,44} Conversely, a pregnant woman who either does not comply with a referral for testing or decides to continue to carry a fetus in which a disability has been detected is viewed by others as irresponsible, irrational, and selfish.⁴⁵ In this way, the birth of a disabled child has been transformed from an unfortunate event into a regrettable event that the mother could have (and perhaps should have) prevented.⁴⁴ Thus, the perception that the birth of a child with a disability could have been avoided through PT use creates the potential for the development of a social norm endorsing selective abortion, to the extent that society (a) places the blame for disabled children on women who do not make "proper" use of PT and (b) condones social punishment against these women.

According to the attribution-affect-action (AAA) model of helping,^{46,47} individuals are held more to blame for a negative event when it is perceived as being under their control or preventable.⁴⁸⁻⁵⁰ In addition, attitudes towards these individuals are likely to be negative, and they are less likely to receive help and support from others.^{46,47,51,52}

Supporting both the extension of the AAA model into the realm of PT and the existence of a social norm facilitating PT use, community members and physicians assign higher levels of blame to a woman who gives birth to a baby with a disability after declining testing than they do to a woman who was not offered testing by her physician.^{40,53} Further, women who decline PT, or who choose to continue the pregnancy after a positive diagnosis of fetal anomaly, are viewed both by members of general society and by physicians involved in prenatal care as less worthy of sympathy and less deserving of social services and financial aid after giving birth to a child with a disability than are women to whom testing was not made available.⁴⁰

Women are unlikely not to be aware of these attributions and the potential personal repercussions of their PT choices. In one survey of pregnant women, 75% reported finding it too

difficult to decline testing when a physician recommended it.⁵⁴ In addition, 78% believed that they would not receive any sympathy or social support if they gave birth to a disabled child after not complying with a testing referral or after choosing to continue with a pregnancy in which a defect had been detected.⁵⁴ Further examples of placing responsibility at an individual level include instances in which insurance companies have offered to cover the costs of aborting a diagnosed fetus but have refused to provide insurance to cover the disability-related medical expenses if the child is born, and social commentaries that promote financial and legal repercussions for women who do not use PT to prevent the birth of a child with a disability.^{27,42,55–58}

These findings illustrate the importance of closely monitoring the prevailing social norms governing PT use and selective abortion subsequent to fetal diagnosis, in terms of both societal opinion and the actual allocation of social resources as the technology advances. True reproductive autonomy necessarily involves striving for a social context in which parents who choose not to undergo testing, or who choose to raise a child with a disability, would be supported. The main task should be to ensure that PT is implemented in a manner that enhances the ability of individuals to have healthy families, while also respecting and upholding the diversity of society.

Implications for Future Research

The adoption of a contextual systems framework for conceptualizing the factors salient to women making decisions in this area could expand the scope of future research in a way that highlights the interconnectedness of women and the social spheres in which they act. For example, research examining the individual and contextual factors affecting PT decision making should be designed to examine further the perceptions of parenting a child with a disability, the origin of these perceptions, and the implications that perceptions formed from stereotypes rather than personal experience may have for informed decision making. Further studies investigating the contextual needs of pregnant women making decisions about PT are necessary in order to validate the preliminary findings that a sense of connection and support from significant others (especially spouse and physician) may be more important for well-being than feelings of individual autonomy.⁶ There is also initial evidence that women who opt not to undergo testing may constitute a vulnerable group in terms of subsequent decisional well-being. Therefore, future research should examine the decision-making processes of this sub-group, to identify the specific factors that may impede their perceptions of social support for their decision and their subsequent decisional well-being. Future investigations into the choices of women within the context of their personal and social lives by examining PT decision

making within a systems framework may inform the development of medical PT protocols that address both the needs of pregnant women and the informational needs of prenatal care providers.

CONCLUSION

The use of PT as an increasingly routine part of prenatal care is inevitable. Decisions to use or not use prenatal tests appear to be influenced by multiple factors. The challenge is to examine how prospective parents approach the task of making decisions about their pregnancy. Systems perspectives posit that individuals act against a backdrop of interconnected contextual systems. Applying the situation of PT decision making to these frameworks, the individual pregnant woman is situated within interpersonal relationships (with her partner, her fetus, and her physician) that are in turn embedded within larger societal contexts (social, legal, and medical norms). The factors that influence the PT experiences of women can be more fully elucidated by acknowledging and investigating the interconnected roles of personal, familial, medical, and societal influences on the use of PT. Such research not only holds the potential to identify multiple avenues for facilitating reproductive decision making across multiple contextual domains, but also to highlight that, although women's reproductive decisions may not be strictly "rational," they may be quite sensible in the context of their lives.

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