Published in final edited form as:
Prenat Diagn. 2010 January ; 30(1): 77–82. doi:10.1002/pd.2343.

Ambivalence toward undergoing invasive prenatal testing: an exploration of its origins

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Abstract

Objective—This study explores ambivalence toward undergoing amniocentesis among pregnant women with overall positive attitudes. Its novelty lies in the characterization of the type and origins of the ambivalence.

Method—Thirty-six women between 35 and 44 years of age were recruited from a U.S. prenatal testing center to participate in structured telephone interviews.

Results—Thirty women chose to undergo testing. Attitudes toward undergoing amniocentesis were generally positive, although all participants simultaneously described feeling ambivalent. The women desired the information that amniocentesis could provide yet did not want to place their fetus at risk. Participants cited religious, moral, ethical, and intellectual values important in shaping their attitudes toward undergoing amniocentesis. Important referents such as partners, other pregnant women, family members, and physicians influenced their decisions.

Conclusion—Tensions were evident among the intellectual, moral, and spiritual values that contribute to ambivalence toward undergoing amniocentesis. Illuminating and discussing such tensions during the genetic counseling sessions prior to testing may resolve some of this ambivalence and thereby increase the quality of decisions women make.

Keywords

Informed Choice; Attitudes; Subjective Norms; Ambivalence; Amniocentesis

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Introduction

Pregnant women face an array of prenatal testing options, including amniocentesis and chorionic villus sampling (CVS), well-established invasive obstetrical procedures used to detect fetal chromosomal and genetic disorders. Until recently, guidelines in the United States recommended that invasive prenatal testing be offered to women with "high risk[1]" pregnancies (American College of Obstetricians and Gynecologists (ACOG), 2001). Pregnancy loss rates associated with amniocentesis at the time of this study was conducted had been estimated to be 1:200 to 1:300 (Rhoads *et al.*, 1989;Jackson *et al.*, 1992;Eddleman *et al.*, 2006). In 2007, ACOG modified their guidelines to recommend that diagnostic prenatal testing be available to all pregnant women, regardless of maternal age (ACOG, 2007).

These guidelines, past and present, emphasize and promote the importance of personal, informed decision-making in diagnostic testing. Many women offered testing undergo genetic counseling to learn about what the tests can provide and to consider potential risks and benefits both to themselves and their fetuses. Outside of attitudes toward abortion, the underlying values and beliefs that predict test uptake are largely unexplored, and much remains unknown about the process of making a decision whether to have amniocentesis (Learman *et al.*, 2003, Marteau, 2001; Marteau and Dormandy, 2001; Suter, 2002).

The Theory of Planned Behavior (TPB) (Ajzen, 1991) has been used successfully to explain and predict a range of behaviors. The components of the TPB – attitudes toward the behavior, subjective norms, and perceived control - are strong predictors of a variety of health behaviors, including uptake of prenatal screening (Marteau, 2001; Marteau and Dormandy, 2001; Dormandy *et al.*, 2006;Vergani *et al.*, 2002). Attitudes toward prenatal screening have been generally assessed without exploration of their origins, specifically, the underlying values and beliefs that lead to them.

While attitudes have been shown to be predictive of screening uptake, ambivalence toward undergoing prenatal screening has been shown to modify this relationship, making attitudes less predictive of screening behavior (Dormandy *et al.*, 2006). Ambivalence can be defined as "the simultaneous existence of positive and negative evaluations of an attitude object" (Conner and Sparks, 2002). Ambivalence has been identified in the attitudes of the general public regarding prenatal diagnostic testing (Jallinoja *et al.*, 1998) and in studies of prenatal screening (Marteau *et al.*, 2001, Dormandy *et al.*, 2006), but the origins of this ambivalence remain unclear. Attitudes comprise an important component in a validated model of informed choice (Dormandy *et al.*, 2006) suggesting that choices made in the context of ambivalence may be less informed. Understanding women's ambivalence toward prenatal testing may contribute to the design of interventions to enhance informed choices about prenatal testing (Dormandy *et al.*, 2006).

The construct of subjective norms in the TPB is composed of an individual's beliefs with respect to an important referent (normative beliefs), and the motivation to comply with the referent's perspectives. Subjective norms were not predictive of prenatal screening in a quantitative study in the UK (Marteau *et al.*, 2001). Yet, in qualitative studies of prenatal screening conducted by Press and Browner (1993; 1997), compliance with medical professionals, desires to do what was best for their babies, and a strong sense of prenatal care as a maternal responsibility were themes that emerged. Less is known about the

[1]Clinically, a pregnancy was considered to be high risk if maternal age was greater than or equal to 35 at the time of delivery, if results from maternal serum screening were abnormal (e.g., results which match or exceed the risk of a 35 year-old woman), if a genetic abnormality was present in a family member or previous pregnancy, or if ultrasound findings were suggestive of an abnormality in the fetus (ACOG, 2001).

subjective norms perceived by women deciding whether to undergo prenatal testing. Women who are ambivalent may be more likely to consult important referents in making their choices (Crano and Prislin, 2006; van Berkel and van der Weele, 1999).

This study, as framed by the TPB, explores attitudes toward prenatal testing, ambivalence about testing (a mediator of the relationship between attitudes and test choice), and subjective norms among pregnant women facing decisions about undergoing amniocentesis. The focus of our analysis is on the underlying values and beliefs influencing women's attitudes and characterizing their ambivalence. As a goal of genetic counseling is to facilitate decision-making, results from this exploratory study offer insight into the origins of attitudes and ambivalence and their role in making a decision about prenatal testing. Our findings can inform quantitative studies on the source and degree of ambivalence with the intention of ultimately designing interventions to reduce ambivalence by helping women reconcile conflicting feelings and beliefs.

Methods

Participants and Recruitment

Thirty-four participants were recruited from a private prenatal testing center in the United States, two responded to newspaper advertisements. The center has a high uptake rate (~95% of women who have a genetic consult for amniocentesis elect to undergo the procedure) and was targeted with the intent to explore ambivalence among a population of women expected to have positive attitudes towards prenatal testing. Women who had scheduled appointments for amniocentesis from June, 2004 to March, 2005 were recruited sequentially over the telephone by a genetic counselor (SD or SZ). Most women contacted expressed an interest in participating and were screened for eligibility. Women were eligible to participate if they spoke English, were currently receiving prenatal care, were 35 years of age or older at the expected time of delivery, and had no history of known risk factors to the fetus other than advanced maternal age. Women who had undergone invasive prenatal testing or non-invasive prenatal screening with the current pregnancy or any prior pregnancy were ineligible. The National Human Genome Research Institute Institutional Review Board approved this study. The authors declare no potential financial conflicts of interest.

Study Design

Each appointment for amniocentesis at the study center included a genetic counseling session immediately prior to the scheduled test. Two telephone interviews were conducted with the participants. The first interview prospectively explored knowledge of amniocentesis, attitudes and ambivalence toward undergoing amniocentesis, the underlying values and beliefs participants felt contributed to these attitudes, and the role of referents in decision-making by asking participants to reflect on each of these. The interview preceded genetic counseling by 3–5 days to explore these concepts prior to any influence from the genetics providers, to focus on the initial decision-making process, and to preempt the potentially confounding effects of reassuring outcomes. The second interview assessed test decision but preceded the disclosure of the test results for those women who chose to undergo amniocentesis.

Data Analysis

Transcripts of the first interview responses were analyzed to identify broad themes in participants' responses. A codebook was developed and used to categorize responses using constructs in the TPB as a framework (Sandelowski, 2000; Mason, 2002). The codebook was revised further based upon the content of the interviews using an iterative approach. The primary coder (JS) coded all transcripts. A second coder (ES) independently reviewed and

coded five transcripts to ensure consistency in coding text. Any discrepancies that emerged were discussed and resolved. Coded text was imported electronically into QSR-NUD.IST®, a qualitative database, to facilitate analysis.

Results

A total of 36 pregnant women participated. Thirty chose to undergo amniocentesis, three chose not to have testing and three decisions are unknown. Table 1 describes the socio-demographic characteristics of the participants. All participants understood that there was a risk of miscarriage associated with undergoing amniocentesis, and that if a fetal chromosome abnormality were detected, they would have the option to terminate or to continue with the pregnancy.

Attitudes toward undergoing amniocentesis

Most participants, as expected, described amniocentesis as beneficial or worthwhile. Even women who described significant negative feelings towards undergoing amniocentesis also cited benefits.

Participants commonly described themselves as “information seekers”, with the information garnered from the procedure's results being the most frequently mentioned benefit.

> I feel like, the more information I have, I'm armed with more knowledge and I'm able to make informed choices and informed decisions. (35/tested)

Time for preparation in the event that the fetus was identified as having a chromosomal disorder was also significantly valued.

> And if there is something wrong, then—then, you know, above all, we want to be prepared and not shocked. You know, you already have enough to deal with just having a baby that the last thing you would want is to be surprised by something like that. (37/tested)

An important and seemingly implicit benefit of the results of amniocentesis alluded to by most participants was that the information might have an impact on the fate of the pregnancy.

> Well, I guess the biggest reason that we have chosen to go forward with it would be to find out if there were, you know, a chromosomal disorder, and if there were, we would probably terminate the pregnancy. (35/tested)

Despite its perceived benefits, amniocentesis was also widely described as harmful or potentially harmful and/or anxiety-provoking. All participants acknowledged the risk of miscarriage following amniocentesis upon being asked about their feelings toward the procedure. In addition to the risk of miscarriage, women identified several other ways in which undergoing the procedure could lead to harms, such as getting bad news or facing a difficult decision.

> I guess I would have to say that I'm scared, because I've never had this done before and – and there are risks. (37/tested)

Ambivalence

While most participants' attitudes toward undergoing amniocentesis were generally positive, all participants simultaneously described some negative feelings. The most common manifestations of this ambivalence were women's expressions of nervousness, fear, or anxiety about the procedure and how these feelings were in conflict with the value of the information that testing could provide. Some women mentioned their fear of the procedure

while simultaneously stating their intentions to accept it, reflecting a tension between a desire to responsibly gather information and a desire to protect the pregnancy from harm.

> I mean, I'm scared to death, but, I mean, I know it's something that I should do. (37/tested)

Similarly, a proportion of participants expressed more serious reservations about the perceived trade-off between the risks and benefits of the procedure, expressing more pensive reluctance.

> …if I could get away with not having it done, I wouldn't have it done. (37/tested)

Just under a third of the participants (n=9) expressed outright indecision when describing their feelings about undergoing amniocentesis. These women used terms like “conflicted,” “ambivalent,” “on the fence,” and “second-guessing” to describe their feelings toward undergoing amniocentesis and their decision-making processes. Participants did not always express confidence in their intended decisions and they also described feeling torn between conflicting desires.

> I'm not 100 percent sure I'm making the right decision to have the amnio, and yet I am going ahead with it. So, my feelings are quite conflicted. (37/tested)

> I want everything to be OK with the baby and I don't want the amniocentesis to cause any problems with the baby. So I mean, there's – you're caught in between… you're damned if you do and damned if you don't. (36/tested)

Origins of Attitudes

When participants were explicitly invited to share their personal values and beliefs behind their attitudes toward undergoing amniocentesis, responses reflected a diverse range of thoughts and feelings. The perceived importance of fetal health information generated through amniocentesis reflected or extended the value of being an “educated health-care consumer.” Participants also strongly believed in their roles as the protector of the fetus, and described anxiety and fear when considering the idea of subjecting the pregnancy to potential harm. Allusion to religious faith, most often personal beliefs over official doctrine, was common.

> I was raised a Catholic. Everybody in the Catholic church I would go to says don't do that. But I think that it has to be everybody's personal opinion. I don't let my religious beliefs tell me what to do as far as, if something happened, if I had to make a decision on either continuing or ending a pregnancy (35/tested).

Intellectual values also contributed to the development of women's attitudes. While some women appreciated the technological nature of amniocentesis, a few participants were wary about what they perceived to be a high level of medical intervention.

> I don't have a moral or religious objection to it. It's more of an intervention thing. And if I don't need it, why do it? (39/tested)

Finally, when mentioning moral or ethical values that contributed to their beliefs, many participants cited quality of life or the moral consideration of the future child's welfare. Many women referenced this value yet varied in what constitutes a course of action that would be `best for the child.' For some women, having prenatal testing was important because they felt that having advance knowledge of any complication would allow them to be better prepared, that is, “better” parents.

> As far as moral values, to me I feel like I have the moral obligation to know all about - as much as I can - about my children. And if that means that one of my children is going to have problems, if that means I'm going to carry the baby to

> term, then I need to learn as much as I can so that I can - I can be the best mother that I can be to that child. (35/tested)

Other women were equally concerned about their future child's welfare, yet intended to terminate an affected pregnancy to ensure that a minimum standard of quality of life was obtained.

> And I think it is my responsibility, if I found out my child had a severe problem for me to prevent that child from being put into a world which would not allow them to be happy and healthy…quality of life is very important to me. (35/tested)

Subjective Norms

In addition to seeking input from their healthcare providers, who were overwhelmingly perceived as neutral, women also relied on family, friends and other women in their peer group (namely other pregnant women over 35) to share their experiences with amniocentesis. Several participants mentioned the importance of this information to their decision-making, particularly when they felt ambivalent about it.

> …I did have some hesitancy in terms of whether to do the procedure…so I consulted with, you know, relatives that were pregnant recently or were at the same age, and whether they had decided to go ahead with it or not. So, it's been a factor…when I was—on the days I was on the edge, it definitely gave me some comfort that it was the right thing to do. (36/tested)

Women wanted to know from others who had undergone amniocentesis how the procedure was done, whether it was painful, how the results were communicated, and whether a miscarriage resulted or a diagnosis was made. In fact, many of this study's participants seemed to identify with other pregnant women over age 35 and distinguished themselves as part of a distinct group at higher risk and with special concerns and considerations.

> But, as far as, you know, from these women telling me, they all feel the same - having to do it, you know, because they're all in the same age group as me. (40/tested)

Spouses and partners served in a slightly different capacity than friends and peers. For most women, the role of their spouse was described as `supportive' in nature, leaving women to resolve their ambivalence and come to decision on their own.

> We don't talk about it that much…because I'm the one that does the research and the one with all the conflicting emotional and medical and moral and religious viewpoints on it…he pretty much just supports me. (40/declined testing)

Discussion

As expected, women's attitudes toward undergoing amniocentesis were predominantly positive. Our findings include the values and beliefs that contribute to these attitudes: information, desire for preparation, reassurance, and the option to terminate the pregnancy were all highly valued. Participants readily identified and elaborated on personal factors that shaped to their attitudes, describing personal values and beliefs stemming from religious upbringing, moral beliefs, and feelings of responsibility towards their unborn child. Interesting contrasts in these underlying beliefs were seen within this sample, highlighting the disparate values and lived experiences present among these women. For example, a strong sense of moral obligation for a future child's quality of life was evident in some participants' intentions to use the results of amniocentesis to plan for the birth of a child with special needs and in other participants' beliefs that a pregnancy should be terminated because a minimum standard for quality of life was unlikely to be met. These origins of our

participants' attitudes are consistent with Potter and colleagues' definition of values as expressions of moral views or statements on beliefs of how life should be lived (Potter *et al.*, 2008). Considering undergoing amniocentesis was, for our participants, a balancing of their moral, ethical, and intellectual beliefs about pregnancy and motherhood, medical intervention, and protecting a desired, if potentially tenuous, pregnancy from harm.

Notably, all participants simultaneously described varying degrees of conflicting thoughts and feelings originating from contrasting values and beliefs. Tensions among participants' underlying values and beliefs seem to contribute to this ambivalence. Ambivalence has recently been recognized as apparent in relation to many health-related behaviors (Conner and Sparks, 2002; Lawson *et al.*, 2009). Many participants were deeply ambivalent toward undergoing amniocentesis, a finding that has not been previously explored in this population. Participants viewed undergoing amniocentesis to be a responsible and empowering choice but this belief was in conflict with the desire to protect the pregnancy from harm. Documenting the nature of women's ambivalence toward undergoing amniocentesis serves as a basis for further investigation and exploration of this important dimension of women's experience when considering prenatal testing.

Participants clearly articulated the ways in which they use important referents when deciding about amniocentesis, particularly when they felt ambivalent. Other women's experiences, both of accepting and declining amniocentesis, were valued as models of different outcomes and served to inform their decision-making. Many participants mentioned their status as being of “advanced maternal age” and were aware of the specific challenges and expectations associated with being pregnant later in life. They alluded to the pressure placed on them because of this status and were aware that younger women were not offered (or were faced with) this choice, and were drawn to understanding how other women who shared their status had made a decision in the face of similar conflicting thoughts or feelings. One way women may seek to reduce their ambivalence is to expand their experiential knowledge of others' choices (Etchegary *et al.*, 2008).

Marteau and colleagues developed and validated the multi-dimensional measure of informed choice. This defines informed choice as a decision that is based upon sufficient understanding of high-quality information and consistent with the decision-maker's values (Marteau *et al.*, 2001). One of the goals of prenatal genetic counseling is to ensure that the components of informed choice are accessible to decision-makers. Helping women identify their attitudes toward undergoing prenatal genetic testing, the ambivalence embedded within their attitudes, and how these attitudes are informed by their personal underlying values may increase the likelihood of women making informed choices. This adds a novel approach to existing interventions such as decision aids used to facilitate such decisions (Bekker *et al.*, 2004). When women articulate conflicts or tensions among their values and beliefs, addressing them may help to clarify and evaluate the more overarching ones and strengthen the relationship between their attitudes toward prenatal testing and their ultimate choice.

This study is limited by selection bias inherent in the recruitment of the clinic population, as only women who had already scheduled an appointment for amniocentesis were eligible to participate in this study. Likely, those with more negative attitudes were excluded. In addition, the majority of participants were well-educated Caucasians. Although these demographic characteristics reflect those of the clientele of the recruitment site, the findings of this study may not be generalizable to underrepresented minorities nor the general population of women considering amniocentesis. Yet, the strength of this study is the demonstration of ambivalence and an examination of its presence and nuances among knowledgeable women with generally positive attitudes toward amniocentesis.

Conclusions

This study described ambivalence toward undergoing amniocentesis among a knowledgeable group of pregnant women with overall positive attitudes toward undergoing the procedure. Ambivalence was reflected in the discrepancy between participants' appraisals of testing as a responsible and empowering health behavior and their own worries and concerns about risking their pregnancies. The extent of ambivalence suggests a need for clinicians to go beyond a weighing of the pros and cons of undergoing amniocentesis to help women identify, clarify, and reconcile at least some of their conflicting values and beliefs in making the decision. Future research on the extent of ambivalence and its role in decision-making may ultimately lead to the development of interventions aimed at enhancing the quality of decisions women make about prenatal testing.

Acknowledgments

The authors wish to thank Dr. Harvey Stern and the staff of Genetics & IVF Institute, Fairfax, VA, for their crucial assistance in the design and execution of this project. We are also deeply grateful to all of the women who participated in this study. This work was supported by the Division of Intramural Research in the National Human Genome Research Institute, National Institutes of Health.

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Table 1

Sociodemographic Characteristics of Participants

Participant Characteristics	**n = 36**
Average age	37 years
Range	35–44 years
Level of Education	
Advanced Degree	14 (39%)
College Graduate	13 (37%)
Some College	8 (22 %)
High School Graduate	1 (3%)
Ethnic Identification	
Caucasian	28 (78%)
Latina	2 (6%)
Asian	4 (11%)
Caucasian/Latina	2 (6%)
Chose Amniocentesis*	30 (90%)
Declined Amniocentesis*	3 (10%)

*Three participants were lost to follow-up; the amniocentesis decisions of these participants are not known.