Women’s experience of maternal serum screening

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OBJECTIVE To explore the ideas, opinions, feelings, and experiences of women regarding prenatal genetic screening, specifically maternal serum screening (MSS).

DESIGN Qualitative technique of focus groups.

SETTING Northern, rural, inner-city, urban, and suburban communities in Ontario.

PARTICIPANTS Women who had given birth to babies from January 1994 to May 1996, but who were not currently pregnant (n = 60).

METHOD Six focus groups composed of women living in various communities who had recently given birth to babies explored the experience of MSS.

MAIN FINDINGS Women want informed choice about prenatal genetic screening. Three factors influenced women’s decisions to undergo or decline prenatal genetic screening: their personal values, including their philosophy of life, moral, and religious values, and attitudes regarding Down syndrome and disability; social support including their partners, families, and friends; and quality of information from health care providers. Women want their providers to give them information personally; they want to receive the information as early as possible in prenatal care to allow time for reflection; and they want unbiased, accurate information in order to make a decision that is in keeping with their personal values and beliefs.

CONCLUSIONS Knowledge of women’s ideas, opinions, feelings, and experiences regarding MSS suggests specific ways health care providers can facilitate informed decision making in prenatal screening. Providing information about genetic testing needs to be individualized, with women actively participating in the decision-making process. Information needs described by these women could apply to other prenatal genetic tests that might be available in the future.

OBJECTIF Explorer les idées, les opinions, les sentiments et les expériences des femmes concernant le dépistage génétique prénatal, en particulier le dépistage sérologique chez la mère.

CONCEPTION Une méthodologie qualitative de groupes témoins.

CONTEXTE Des collectivités ontariennes du Nord, du noyau central de villes, de milieux ruraux, urbains et de banlieues.

PARTICIPANTES Des femmes vivant dans diverses collectivités qui avaient donné naissance à un enfant entre janvier 1994 et mai 1996, mais qui n’étaient pas présentement enceintes (n = 60).

MÉTHODE Six groupes témoins composés de femmes vivant dans diverses collectivités qui avaient récemment donné naissance à un enfant ont passé en revue l’expérience du dépistage sérologique chez la mère.

PRINCIPAUX RÉSULTATS Les femmes aspirent à faire un choix éclairé quant au dépistage génétique prénatal. Trois facteurs influencent les décisions des femmes de procéder ou non au dépistage génétique prénatal: leurs valeurs personnelles, notamment leur philosophie de vie, leurs principes moraux et religieux, et leur attitude à l’égard du syndrome de Down et de l’invalidité; le soutien social provenant, entre autres, de leur partenaire, de leur famille et de leurs amis; ainsi que la qualité des renseignements fournis par les dispensateurs de soins de la santé. Les femmes attendent de leurs soignants qu’ils leur donnent de l’information personnellement; elles souhaitent avoir l’information au moment le plus approprié dans les soins prénataux pour leur donner le temps de réfléchir; et elles veulent des renseignements exacts, sans préjugés, de manière à prendre une décision qui soit conforme à leurs valeurs et à leurs croyances personnelles.

CONCLUSIONS La connaissance des idées, des opinions, des sentiments et des expériences des femmes à l’égard du dépistage sérologique chez la mère suggère des façons de faciliter une décision éclairée au sujet du dépistage prénatal. Les renseignements entourant le dépistage génétique doivent être adaptés au cas par cas et les femmes doivent participer activement à la décision. Les besoins d’information décrits par ces femmes pourraient s’appliquer à d’autres épreuves génétiques prénatales susceptibles d’être disponibles à l’avenir.
Maternal serum screening (MSS) is becoming increasingly available as a method of antenatal screening for increased risk of Down syndrome, open neural tube defects, and trisomy 18. A 2-year pilot project using triple markers (α-fetoprotein, human chorionic gonadotropin, unconjugated estriol) was launched throughout Ontario in 1993. The experience in Ontario, as well as in Europe and the United States, has left providers with many concerns about this kind of screening test.

There is widespread agreement that participants in prenatal screening programs should understand the nature and purpose of the screening and should be given an opportunity to consent to or refuse screening. Because of the complexity of prenatal genetic screening and the limited time physicians have for appropriate counseling, however, women and their families might not have an opportunity to seriously consider the implications of testing. Nor might they fully understand interventions that might follow positive results.

Several studies have documented that women do not really know much about the disorders being tested for with MSS and the meaning of the results. This raises ethical concerns regarding informed decision making. Providers have also expressed concern about the high false-positive rate of MSS results and the anxiety this generates in patients.

Serum screening for Down syndrome and neural tube defects is only one of many prenatal genetic tests that are being developed and could be available in the future. Because both the medical profession and the public have expressed widespread concern over this kind of testing, we thought it was important to gain a more complete understanding of women’s feelings about MSS.

This study explored ideas, opinions, feelings, and experiences of women regarding prenatal genetic screening, MSS in particular.

**METHOD**

The qualitative technique of focus groups was used in this study. Focus groups have been used to examine patients’ interactions with the health care system and have been suggested as a good way of studying people’s understanding of genetic risk.

Ethics approval was obtained from the Human Subjects Review Committee at the University of Toronto, Ont.

Focus groups were conducted at each of six sites across Ontario, including northern, rural, inner-city, urban, and suburban sites. These sites were used during an earlier study on prenatal genetic screening. Focus groups were conducted in the spring and summer of 1996.

Nurses involved in the study identified family physicians, obstetricians, and midwives willing to recruit women for our study. These health care providers were asked to approach eligible women in their practices who might be interested in participating in the study. A sign inviting women to participate in a study of women’s experiences with MSS was posted in each office. Women contacted the study nurse if they were interested, and consent and demographic information were obtained at this time. Women were eligible if they had given birth to a baby since January 1994 but were not currently pregnant, were able to speak and understand English, and had not delivered a baby with any of the conditions detectable by MSS. This meant that women with true-positive and false-negative test results were excluded. We believed that these women’s opinions would be more appropriately obtained in a future study.

Nurses attempted to recruit 12 women for each focus group. In order to create heterogeneous groups, women were selected who reflected a range of ages, education levels, income levels, marital status, number of children, and cultural backgrounds.

The research team developed a semistructured interview guideline for use in the focus groups (available on request). Focus groups were moderated by one of the investigators (J.C. or A.R., both family physicians).
physicians) and observed by the research associate (P.P.). Women in the focus groups were unknown to any members of the research team. Moderators were introduced to the participating women with a few details about their background and training. Focus groups were conducted in a room in the local hospital. After each session, researchers compared field notes and discussed the group process. Each focus group, lasting approximately 2 hours, was audiotaped and transcribed verbatim.

Using basic content analysis, researchers examined focus group transcripts independently. Each transcript was analyzed to isolate central issues that emerged in the groups. This was achieved by beginning with the key words, phrases, or concepts used by participants during discussion. Analysis and interpretation were carried out concurrently rather than sequentially. After every two focus groups, researchers met to compare and combine their independent analyses. This allowed them to explore and expand on themes from earlier focus groups at subsequent sessions. This continued until researchers found no new themes emerging in the focus groups.

The next phase of team analysis involved determining similarities, contrasts, and potential connections among key words, phrases, and concepts within and among each of the focus groups. In the final step of the analysis, the main themes and subcategories of all focus groups were identified and summarized. In addition, phrases or quotes that most accurately illustrated themes were identified.

**FINDINGS**

Of the 113 women approached to participate in the focus groups, 74 (65%) agreed to participate. From this cohort 14 (19%) did not appear for their designated focus group session. The final number was 60 women participating in the six focus groups with an average of 10 women per group.

Participants ranged in age from 16 to 44 years (16-19 = 1, 20-34 = 41, 35-39 = 16, 40-44 = 2). Most were married (58/97%) and had an average of two children (range 1 to 4). Most were born in Canada (49/82%) and identified English as the language spoken in their homes (55/92%). Completion of some type of post-secondary education was reported by 34 (57%) participants. Some participants declined to answer the question regarding family income; however, most were within an income bracket of $40,000 to $69,999. Maternal serum screening had been offered to 58 of the 60 women (97%); 35 (60%) decided to proceed with the screening test. The only demographic difference between women who did and did not appear for the focus groups was marital status; 21% of the “no shows” were single.

The overriding theme that emerged from the focus groups was that the women wanted informed choice. Paramount was their request to be active participants in the decision-making process:

There has to be a choice; that's the thing with genetic screening. You can't have the government some day step in and say, 'You have to have a test,'... or the doctors pushing it... without giving you the option.

Three secondary themes were evident: factors that influenced women's decisions to accept or decline prenatal genetic screening. These were their personal values, their social supports, and their information needs.

**Personal values**

Women's philosophies of life were a determining factor in their decision to have MSS. Some women had a greater need for reassurance about, certainty of, and control over their babies' well-being, whereas others were willing to let nature take its course and deal with the outcome.

[A] lot of people said it would give me a false sense of security, but it made me feel a little bit better during my pregnancy, so I felt better having it done.

I felt if something is going to go wrong,... if the baby does have something,... nature will take care of it.... If it's not strong enough, there's a reason for it to be.... I'll take whatever I can get.

Participants had quite diverse views about abortion and the ethics of prenatal genetic testing. They wanted to be offered the choice of prenatal genetic testing, however, no matter what their moral or religious beliefs.

There is a moral decision... that you and your partner make about your future and what you believe in and those sorts of things, and that more or less drives whether or not you want to go for these tests.

Another moral issue concerning participants was the effect of genetic testing on society. Some believed it was wrong to bring children with disabilities into the world. Others were worried about genetic engineering and intolerance of imperfection.

If there's something wrong with the baby,... we would not have the baby,... It's hard enough to make it in the world as it is.

I find it frightening a little bit. It's almost like we're playing with nature, and... we want a perfect population.
Personal experience with children with Down syndrome or neural tube defects strongly influenced decision making, but this influence could be either in favour of or against testing, depending on the woman’s experience. “I know a little girl with Down syndrome who is perfect;... she’s perfect in my eyes.”

Down syndrome and spina bifida were two of my biggest worries...having worked with those children, and that’s the main reason that I had the test.... I know my husband couldn’t handle one of those kids, and I’m not sure I could, either.

Thus the woman’s or her partner’s perceived ability to cope with a child with Down syndrome influenced her decision. Three distinct perceptions emerged: some believed strongly they could not cope with a disabled child; some believed they could cope; and some believed they needed time to prepare for a child with special needs.

Social supports
Women turned to their social supports for help in making these decisions: their partners, families, and friends. The degree of involvement of women's partners ranged from couples who had extensive discussions about the risks and benefits of MSS to women who independently decided whether or not to have the screening test.

Other family members, particularly women’s mothers, had a great influence on their decisions. Your mother sort of knows you better than anybody else.... She basically sat me down and said, “I know you well enough to know that if you were to have a baby with Down syndrome, you couldn’t handle it.”

Women’s shared experiences and stories from friends affected their decisions on whether to have MSS. In particular, shared bad experiences, often in the context of false-positive results, had a profound effect on how women viewed MSS.

I had a friend who had the test done, and when it came back, she came back as high risk and worried her whole pregnancy, and the baby was born fine. So I was kind of against having it done at first because I figured it’s not 100% true or accurate.

Information needs
The third critical area for women, shaping their experience with MSS and feelings of informed choice, related to information about MSS.

Who should give information about prenatal genetic tests? Women clearly saw their physicians as the key source of information.

When should information be given? Women wanted information about genetic screening as early as possible in their prenatal care, preferably at the first or second prenatal visit. This would give them time to access additional information, talk to family and friends, and ultimately make an informed choice about testing.

They should give you the pamphlet, the information earlier on so you can make your decision talk to your husband or whoever so that you can decide if you want to have it done or if you don’t. When they hand it to you right then and there, you can’t make an accurate decision....

What information should be given? Before making their decisions about testing, women wanted information about what the test could tell them, positive and negative aspects to testing, and how to interpret results. They wanted to know all the possible steps and outcomes and all the options they would have to consider, including talking about abortion.

You have an idea what you’re going to do when you get your results;... you should take that into consideration before you even have the test;... like what am I going to do if it comes out positive?

Throughout the whole process, no one would really say you’re doing this so that you have the option of terminating the pregnancy.... I really didn’t know what spina bifida was.... I was too shy to ask [for] information up front.

How should information be given? Participants stressed the need for health care providers to give this information in an accurate, unbiased manner. They emphasized that these genetic screening tests are not like other tests and cannot just be added to routine bloodwork.

When you’re offering tests for women who are having a baby, please don’t just pass it off like it’s... just a blood test checking if you’re iron-deficient. [This] is serious, you know.

I really appreciated their unbiased opinion.... You have to make your own decision based on the information.

Understanding risk. Many women were confused about the difference between a screening test and a diagnostic test. It’s like having no answer. [It] wouldn’t be reassuring to me at all.

I remember I used to go off to summer day camp, and I’d ask my mum, “Is it going to rain today?”... because it affects what you’re going to bring, you know. “Well there’s a 60% chance of rain.” And I would say, “But is it going to rain today?” You know it doesn’t really tell you much;... so I want to know; I want 100% I don’t want zero.
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Many women were surprised to discover that the test could be falsely negative.

He just told me it was negative, and so I thought, “Okay, fine; I don’t have a Down syndrome child or spina bifida or anything like that;” so I thought there’s no problem. [But] if I had had a child that had it, I think I would be really shocked… I would have thought this test didn’t really tell me anything.

Relaying results. Women wanted timely, accurate results, whether positive or negative, to be given personally by their physicians. They were adamant that positive results be given personally and were not satisfied that contact would be made only if results were abnormal.

I mean, to not get calls because it’s negative… you’re not talking about a throat infection here; we’re talking about something really serious, and I think you should be called whether it’s positive or negative.

When I had mine done, he said, “When you have this test done, if you don’t hear anything from me, it’s negative.” So like you sit by the phone waiting, or if the phone rings, you know… I was like that for 2 weeks;… okay, everything was fine, he didn’t call.

Participants stressed that saying the results were positive or negative was very misleading, that women who were told positive automatically assumed that their babies had Down syndrome; those told negative assumed their babies were normal.

Women begin the decision-making process about prenatal genetic testing with a set of internal values. As they move toward making an informed choice, they call on their social supports and gather specific information from their health care providers. They weigh reassurance, peace of mind, and the chance to prepare for a child with special needs versus the potential anxiety and uncertainty generated by the screening process. Opportunity for informed choice needs to be given at every step of the decision-making process.

DISCUSSION

All the women in our study wanted informed choice about prenatal genetic screening. Studies of women of mixed parity and social class from the Netherlands,23 United Kingdom,24-26 Canada,10 and France27 have shown, however, that many pregnant women have a poor understanding of MSS. Some have questioned the adequacy of information about prenatal screening tests given to women before they undergo testing, because of the large numbers of women screened in some hospitals.25 Further, prenatal screening tests have often been presented as routine tests that do not require women’s participation in the decision-making process.24,27

Our findings suggest that the process of informed choice was influenced by many factors. Most studies reported in the literature have not looked at the influence of personal values on informed choice. This could be because women’s thoughts and feelings are not being elicited. For example, Marteau and colleagues24 reported that women’s attitudes toward aborting an affected fetus were seldom sought. In contrast, Jorgensen28 reported that women who had personal knowledge of handicapped people in their own families were more positive about α-fetoprotein screening than women without such knowledge.

Social support influences decision making, and this was evident in our findings.9,30

A strong need for reassurance as a motivation for having prenatal genetic screening was also found by Roelofs and associates23 in their study of women delivering at a university hospital in the Netherlands. Most women in their study expected to be reassured by the results, and 65% were unaware of possible drawbacks to the test. Roelofs and associates23 comment on the necessity to balance the need for reassurance against the risk of anxiety and uncertainty while awaiting results.

This study has important clinical implications. Discovering women’s personal values, social supports, and need for reassurance will help health care providers determine their information needs. Women acknowledged physicians’ important role and influence on their decisions and wanted physicians to be unbiased. This finding highlights the importance of self-awareness on the part of health care providers.12

They need to be aware of their own personal and professional biases, particularly around topics such as abortion, which are heavily value laden.

The study by Marteau and co-workers24 of maternal serum α-fetoprotein screening in England showed that the nature of the information given to women and the way the test was presented influenced whether screening took place. Marteau and co-workers also found that women with less knowledge were less likely to undergo α-fetoprotein screening for spina bifida than those with more knowledge, suggesting that failure to undergo testing might have been the result of poor information. Statham and Green26 showed that the better informed women were, the more likely they were to undergo prenatal testing.

Our findings revealed a range of opinion and expectations of how results should be delivered.
However, all women wanted to hear negative results as soon as they were obtained. This finding is compatible with previous studies. The communication policy of no news is good news is unacceptable to women. Women also stressed the importance of explaining the meaning of negative results. Studies of participants’ understanding of prenatal genetic screening showed that women did not understand negative results and might have interpreted results too globally, as an assurance that the baby was healthy in all respects.

Key points
- This qualitative study examined women’s opinions, feelings, and experiences regarding prenatal maternal serum screening.
- Women overwhelmingly wanted informed choice about genetic screening. They sought unbiased, accurate information given personally by a caregiver in time to make a decision compatible with their personal values.
- Three factors influenced their decisions: personal values, social support, and quality of information from care providers.
- Providing information about genetic testing should be individualized to allow women to participate actively in decisions to have maternal serum screening or not.

Conclusion
Women's decisions about MSS were influenced by their personal values, beliefs, and experiences; social support from their families and friends; and the quality of the information they received. They wanted physicians to ask about these influences and be sensitive to their individual needs for information. Women wanted informed choice at every step of the decision-making process. They identified their physicians as the most important source of both information and results and wanted accurate, unbiased, timely information from them.

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