Ontario Maternal Serum Screening Program: practices, knowledge and opinions of health care providers

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Abstract

Objective: To determine the practices, knowledge and opinions of health care providers regarding a prenatal genetic screening program in Ontario.

Design: Cross-sectional self-reported survey.

Setting: Ontario.

Participants: Random sample of 2000 family physicians, all 565 obstetricians and all 62 registered midwives in the province. Among subjects who were eligible (those providing antenatal care or attending births) the response rates were 91% (778/851), 76% (273/359) and 78% (46/59) respectively.

Main outcome measures: Which patients were offered maternal serum screening (MSS), how results were being communicated, knowledge of the test's sensitivity, likes and dislikes about MSS and recommendations regarding the program.

Results: Most (97%) of respondents stated that they were offering MSS to the pregnant women in their practices; 88% were offering it routinely to all pregnant women (87% of the family physicians, 90% of the obstetricians and 100% of the midwives). Most (92%) of the respondents stated that they communicate positive results to their patients personally as soon as they are received; 23% did so for negative results. The respondents correctly identified the initial positive rate but underestimated the false-positive rate. About one-third did not respond to these knowledge questions. Of those who gave feedback on the screening program, 50% recommended that it not be changed, 29% suggested that it be changed, and 22% recommended that it be scrapped.

Conclusions: Participation in the Ontario Maternal Serum Screening Program by health care providers has been good, although knowledge about MSS is far from ideal. Many providers have reservations about the program. In light of concerns raised about the high false-positive rate and the anxiety such results generate in pregnant women, there is a need for more education of providers and patients and a better understanding of women's experiences with genetic screening.

Résumé

Objectif : Déterminer les pratiques, les connaissances et les opinions des fournisseurs de soins de santé au sujet du programme de dépistage génétique prénatal en Ontario.

Conception : Enquête transversale d'auto-évaluation.

Contexte : Ontario.

Participants : Échantillon aléatoire de 2000 médecins de famille, les 565 obstétriciens et les 62 sages-femmes autorisées de la province. Parmi les sujets admissibles (ceux qui fournissaient des soins prénataux ou effectuaient des accouchements), les taux de réponse se sont établis à 91 % (778/851), 76 % (273/359) et 78 % (46/59) respectivement.

Principales mesures des résultats : Patientes auxquelles on a offert un examen du sang maternel (ESM), façon de communiquer les résultats, connaissance de la

Evidence

Études

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This article has been peer reviewed.

Can Med Assoc J 1997;156:775-84

sensibilité de l'examen, ce que l'on aime et que l'on n'aime pas au sujet de l'ESM et recommandations au sujet du programme.

Résultats : La plupart (97 %) des répondants ont déclaré offrir un ESM aux femmes enceintes qui les consultent à leur pratique; 88 % l'offraient de routine à toutes les femmes enceintes (87 % des médecins de famille, 90 % des obstétriciens et 100 % des sages-femmes). La plupart (92 %) des répondants ont déclaré communiquer eux-mêmes les résultats positifs à leurs patientes dès qu'ils les reçoivent; 23 % le font dans le cas des résultats négatifs. Les répondants ont établi correctement le taux positif initial, mais sous-estimé le taux des résultats faussement positifs. Environ le tiers n'ont pas répondu à ces questions sur les connaissances. Parmi ceux qui ont commenté le programme de dépistage, 50 % ont recommandé de ne pas le modifier, 29 % ont suggéré de le modifier et 22 % ont recommandé de le laisser tomber.

Conclusions : La participation au Programme d'examen du sang maternel de l'Ontario par les fournisseurs de soins de santé a été bonne, même si les connaissances sur l'ESM sont loin d'être idéales. Beaucoup de fournisseurs ont des réserves au sujet du programme. Compte tenu des préoccupations soulevées au sujet du taux élevé des résultats faussement positifs et de l'anxiété que ces résultats créent chez les femmes enceintes, il faut informer davantage les fournisseurs et les patientes et mieux comprendre les expériences des femmes face aux examens de dépistage génétique.

On July 1, 1993, the Ontario Ministry of Health introduced a province-wide maternal serum screening (MSS) program as a pilot project. The intent of the program was that all pregnant women be offered MSS with counselling about the test, possible outcomes, options for further testing, and risks. Educational material for health care providers and for pregnant women and their families was distributed to all family physicians, obstetricians and midwives at the start of the program. Regional genetic centres provided genetic counsellors and resources for health care providers and women requesting further information.

The MSS measures 3 serum markers: α-fetoprotein, human chorionic gonadotropin and unconjugated estriol. A pregnant woman's risk of having a baby with Down syndrome, an open neural tube defect (NTD) or trisomy 18 is calculated from the values of these markers, combined with maternal age for the chromosome disorders.

Studies have shown that the rate of detection of Down syndrome through triple-marker screening ranges from 48% to 91% (median 58%; 95% confidence interval 44%–72%).[1] This is much higher than the rate of 30% with amniocentesis among all women over 35 years.[2-6] The false-positive rate of MSS varies from 4% to 10% for Down syndrome.[3,7,8] For open NTDs the serum α-fetoprotein has a detection rate of about 80%.[9] Initially 2% to 4% of women screened will have a positive result for NTD, but only 2% to 3% of those screened positive will have a fetus with an open defect.[10,11] For trisomy 18, MSS can detect 70% to 85% of cases; initially 0.15% to 0.5% of women will have a positive result.[12,13] Overall, about 10% of the initial results of MSS will be positive, but only 2% to 3% of these will be true-positive results.

As an example, Fig. 1 shows the outcomes of MSS in a community with 10 000 births per year. Only about 19 of the babies would be affected (10 would have Down syndrome, 8 NTD and 1 trisomy 18).[2,8,12,13] About 6 babies with Down syndrome and 2 with NTD might not be detected through MSS. This example assumes that all 10 000 women would choose to be screened, when it is more likely that 50% to 75% would undergo MSS.[14] It also assumes that all women found to be at increased risk for having a baby with Down syndrome would undergo confirmatory amniocentesis, when in reality only 70% to 80% do so.[1,14] The false-positive rate and the positive predictive value of MSS for Down syndrome will also vary depending on the proportion of women over 35 in the population screened.

Much has been written about the MSS test itself, but there is little in the literature about health care providers' response to this type of genetic screening. American and British studies showed that most obstetricians surveyed (89% in the United States and 94% in Britain) were offering MSS for Down syndrome.[15,16] In the US study, family physicians were offering it significantly less often than obstetricians and were more likely to offer testing only to women at high risk and those who requested it.[15] Physicians in Britain reported concern that women did not understand the test and that there were inadequate resources for counselling.[16]

In Canada, Manitoba has had a prenatal genetic screening program since 1985, but only 1 of the 3 serum markers is measured (α-fetoprotein).[11] In a 1992 survey of Manitoba family physicians and obstetricians, Chodirker and Evans[11] found that only 38% of the respondents were offering this test to all of their patients and were doing the test with consent and that 22% were doing the test automatically for all patients as part of routine blood work. Dillon and associates[17] reported on the decision not to implement routine MSS in the Sioux Lookout Zone in Ontario because of "resistance to the concept by First Nations people," difficulty in communication and "geographical and logistical difficulties."

Evaluation of the Ontario Maternal Serum Screening Program is vital to decisions about the future of the program. It is also vital to decisions about how similar programs will be introduced in other provinces, especially since the Canadian Task Force on the Periodic Health Examination's recent statement that there is fair evidence (grade B recommendation) to offer MSS to pregnant women under 35 and that MSS may be offered as an alternative to amniocentesis or chorionic villus sampling in women 35 and older.[1]

The objective of this study was to assess the practices, knowledge and opinions of health care providers regarding the MSS program in Ontario. We wanted to answer the following questions: Was MSS being offered to all pregnant women? If not, who was included and who excluded? Were characteristics of health care providers and their practices (e.g., age, location, type of practice) influencing the use of MSS? How were the providers communicating the test results? What was their knowledge of MSS? What did the providers like and dislike about the test? What were their recommendations about the program?

Methods

Survey sample

We included 2000 Ontario family physicians randomly selected from the membership list of the College of Family Physicians of Canada, all 565 obstetricians from a list provided by the Ontario Medical Association and all 62 registered midwives from a list provided by the College of Midwives of Ontario. Only those who were currently pro-

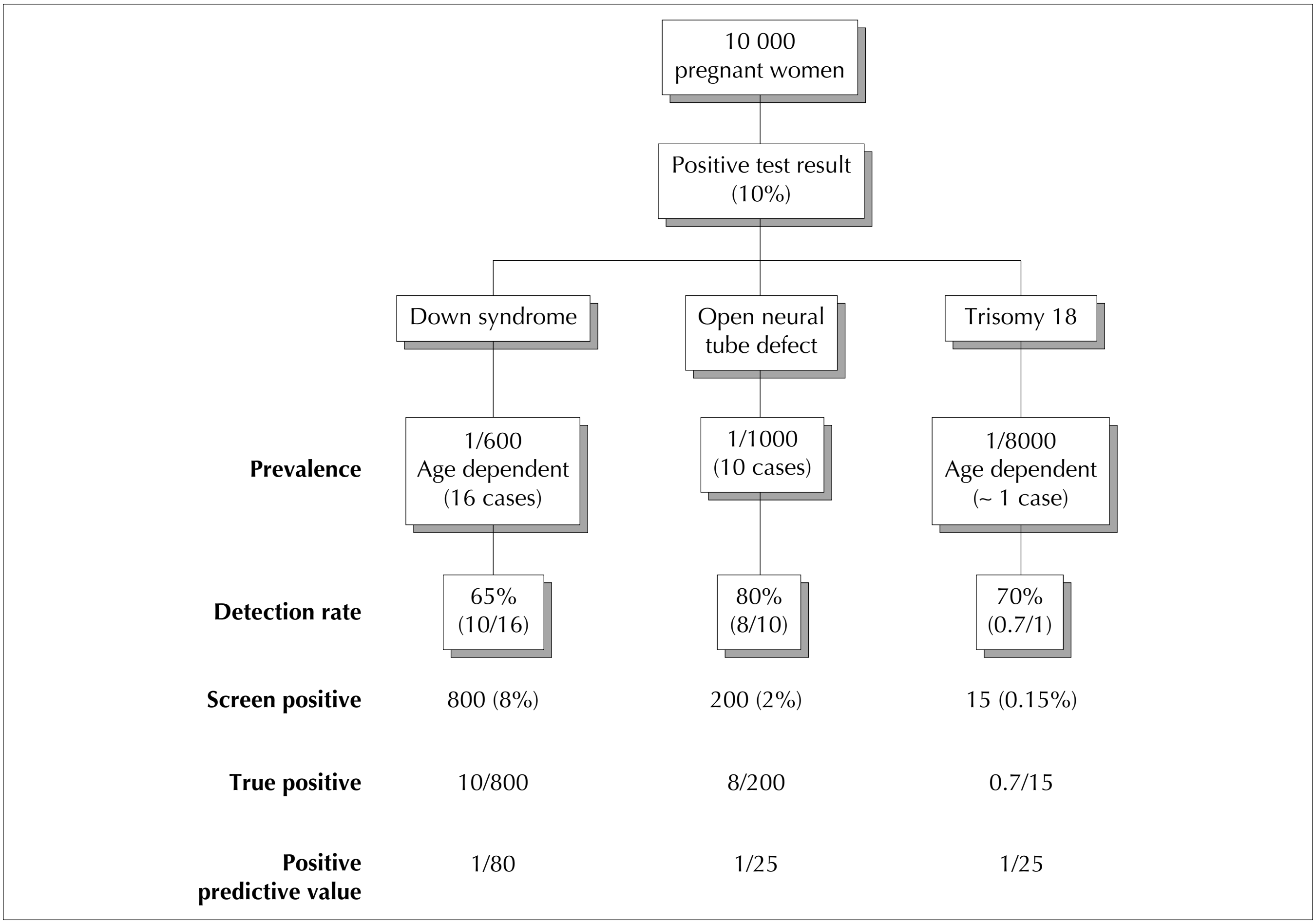

Fig. 1: Outcome of maternal serum screening in community with 10 000 births per year, assuming that all 10 000 women would agree to be tested.

viding antenatal care or attending births were eligible for the study.

A random sample of 26% of the nonresponding family physicians and 35% of the nonresponding obstetricians were telephoned. The proportion of this sample found to be ineligible was assumed to apply to the remaining nonrespondents.

Questionnaire

A cross-sectional self-reported survey design was used. We designed a questionnaire from our clinical experience with MSS as family physicians, obstetricians and midwives. A preliminary version was given to 200 randomly selected family physicians early in 1994 as a pilot test.

Additional feedback on the draft questionnaire was obtained from 2 focus groups, in Thunder Bay and Toronto, involving family physicians, obstetricians and midwives. The focus groups were audiotaped. Some of us listened to the tapes independently, searching for common themes and key words. Any concerns or issues about the MSS program not already included in the questionnaire were added. The focus groups helped to achieve face validity for the survey.

A revised draft of the questionnaire was pilot tested among several colleagues. Minor word changes were made for clarity. The final questionnaire contained 16 questions about the health care providers' personal and practice characteristics, 38 quantitative and multiple-choice questions about the MSS program and 7 open-ended questions about the program. We report the responses pertaining to practice, knowledge and opinions regarding the program (10 questions). (A copy of the questionnaire is available from the authors upon request.)

The survey was conducted between November 1994 and March 1995. We used a modified Dillman technique:[18] an initial mailing followed by a thank-you or reminder postcard, and a second mailing to nonresponders.

Analysis

The survey data were analysed using the SAS System, version 6.10 for Windows (SAS Institute Inc., Cary, NC). Frequency distributions were generated for categorical data; means and standard deviations (SDs) were obtained for continuous data. The χ^2 test and analysis of variance were used to identify differences between the 3 groups of providers. The χ^2 test was used to examine provider characteristics associated with recommendations about the MSS program. Findings were considered statistically significant at a p value of 0.01 or less. Stepwise logistic regression analysis was used to examine correlates of providers' willingness to keep the MSS program as it exists.

Two of us (J.C.C. and S.D.) independently read 50 responses for each open-ended question and then compared each of our categories of responses to agree upon a categorization system. We independently read and categorized another 50 responses. Interrater reliability was greater than 90%. The remainder of the responses to the open-ended questions were then coded using the categorization system by 1 of us (J.A.P.-W.).

Results

The response rates were calculated as shown in Fig. 2. Many of the respondents were ineligible because they did not provide antenatal or intrapartum care, had retired or had moved. After they were excluded, the final response rates were 91% for the family physicians, 76% for the obstetricians and 78% for the midwives.

Fifty of the family physicians who completed the survey were asked to complete the identical survey a second time in order to check for reliability in terms of consistency of responses; 29 (58%) complied. Any variation, no matter how small, from the original response was considered a different response. For the 5 questions about practice characteristics and opinions regarding MSS, reliability was greater than 86%. For the 2 knowledge questions, reliability was 45%.

Personal and practice characteristics

The family physicians and the midwives were significantly younger and had been in practice fewer years than the obstetricians (Table 1). All of the midwives were women, as compared with about 50% of the family physicians and 25% of the obstetricians. The family physicians were more likely than the others to practise in small towns or rural settings. The family physicians and the midwives were more likely than the obstetricians to be in a group practice. The obstetricians cared for significantly more pregnant women and attended more births in the past year than the family physicians or midwives. The midwives and the obstetricians reported having significantly more pregnant women over 35 years of age in their practices than the family physicians (22%, 17% and 12% respectively, $p = 0.0001$). All of the obstetricians and midwives attended births, as compared with 43% of the family physicians; the remaining family physicians provided antenatal care only. Each of the 3 groups had respondents representing all 6 geographic planning regions, except that no midwives were practising in the Northwest region at the time of the survey. Almost half of the obstetricians and midwives practised in the Central East region.

Practices regarding MSS

Overall, 97% of the respondents stated that they were offering MSS to the pregnant women in their practices (100% of the obstetricians and midwives, and 95% of the family physicians), and 88% were routinely offering it to all pregnant women (100% of the midwives, 90% of the obstetricians and 87% of the family physicians). Of the 125 who did not offer MSS to all pregnant women 109 offered it mainly to women over age 35 at their due date, 106 offered it to women with a family history of Down syndrome or NTD, and 93 offered it to women who asked to be tested.

Most (92%) of the respondents stated that they communicate positive results to their patients personally as soon as they are received. As for negative results, 23%

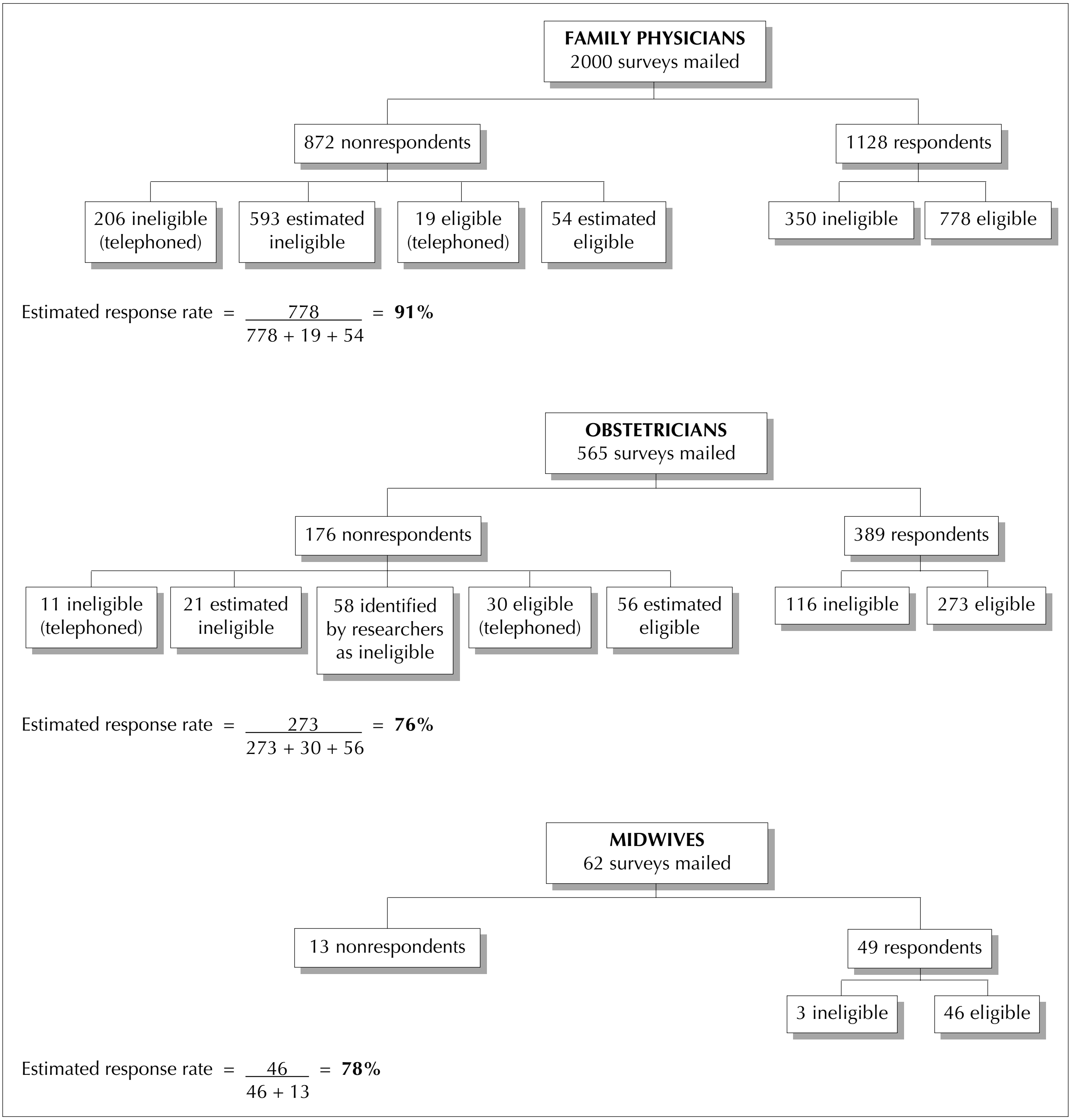

Fig. 2: Response rates to survey on Ontario Maternal Serum Screening Program sent to randomly selected sample of family physicians and to all obstetricians and midwives in the province.

stated that they communicate them personally as soon as they are received, 62% communicate them personally at the next visit, and 11% delegate the task to someone else; 4% stated that they do not communicate negative results.

Knowledge of MSS

When asked what proportion of pregnant women would have an initial positive MSS result, the mean response of 7.8% (SD 8%) was in the correct range of 6% to 8%; however, about 30% of the respondents did not answer the question. When asked what proportion of women with an initial positive result would have babies with Down syndrome or an NTD, the mean response of 15.9% (SD 23%) was well over the correct range of about 2% to 3%; nearly 38% of the respondents did not answer this question. Knowledge did not differ significantly between the 3 groups.

Table 1: Characteristics of health care providers who responded to a survey on the Ontario Maternal Serum Screening (MSS) Program

	Group; no. (and %) of respondents*			
Characteristic	Family physicians *n = 778*	Obstetricians *n = 273*	Midwives *n = 46*	*p* value
Mean age, yr (and SD†)	38.7 (7.5)	48.0 (10.4)	40.9 (7.1)	0.0001
Sex	*n = 763*	*n = 268*	*n = 46*	0.001
Male	410 (53)	201 (75)	0	
Female	363 (47)	67 (25)	46 (100)	
Practice location	*n = 769*	*n = 273*	*n = 43*	0.001
Urban	529 (69)	250 (92)	35 (81)	
Small town or rural‡	240 (31)	23 (8)	8 (19)	
Practice type	*n = 739*	*n = 265*	*n = 44*	0.001
Solo	196 (27)	147 (55)	4 (9)	
Group	543 (73)	118 (45)	40 (91)	
Mean no. of pregnant women cared for in the past year (and SD)	32 (30)	276 (147)	47 (20)	0.0001
Mean no. of years providing antenatal care (and SD)	10 (8)	17 (11)	8 (4)	0.0001

*Unless otherwise specified.
†SD = standard deviation.
‡Population less than 50 000.

Table 2: Respondents' opinions on what they liked about MSS*

	Group; no. (and %) of respondents		
Opinion	Family physicians *n = 236*	Obstetricians *n = 92*	Midwives *n = 21*
Is an alternative to amniocentesis and chorionic villus sampling in women > 35 yr; could decrease amniocentesis rate	54 (23)	30 (33)	9 (43)
Provides reassurance	37 (16)	12 (13)	2 (10)
Is easy to perform and is noninvasive	34 (14)	10 (11)	2 (10)
Offers early identification of abnormalities; is a good screening test	28 (12)	13 (14)	2 (10)
Provides increased choice for women	16 (7)	3 (3)	6 (29)
Allows detection of Down syndrome for women < 35 yr	12 (5)	11 (12)	0
Has good availability	12 (5)	3 (3)	2 (10)
Other†	34 (14)	12 (13)	1 (5)
There is little or nothing to like	38 (16)	7 (8)	1 (5)

*Multiple responses were possible.
†Includes the following: "patient brochure helpful," "is cost-effective" and "promotes discussion of abnormalities."

Opinions

One-third of the respondents answered the question on what they liked about MSS. Table 2 provides a list of categories that had 5 or more responses. Mentioned most often was that MSS provides an alternative to amniocentesis for women over 35 years of age.

> [I find MSS] particularly helpful to women age 35–37 who screen negative for Down syndrome and may elect to forgo amniocentesis.

Also mentioned was the role of MSS in reassuring women, the test's noninvasiveness, early identification of abnormalities, increased choice for women, detection of Down syndrome in women under 35 and availability.

> It encourages discussion with the mother regarding her feelings towards fetal anomalies and provides women with choices. Even if they don't want the test, they know their options.

A small group took the opportunity to answer this question by indicating that they liked nothing about the test.

Half of the respondents replied to the question of what they disliked about the test. Most expressed concern about the anxiety they felt women experienced by undergoing MSS and about the test's false-positive rate (Table 3). Other concerns were raised, including the complexity of the test, cost-effectiveness, timing issues, possible false-negative results, increased use of ultrasound and ethical issues. In contrast to those who commented on what they liked about MSS, many who responded to this question did so with great passion and sometimes vehemence, often filling the entire page. A few comments are provided here.

> It is a risk calculation and not the answer the patient really wants — there must be further education of the public as to what "risk" percentages mean versus actual outcome.

> Scrap it unless you can reduce the rate of "false positives" — in my practice the misery of a false positive that clouds the entire pregnancy far outweighs any advantage.

> I feel that testing for Down's conveys to the patient that a child with this is undesirable regardless of the patient's feelings. Women who choose not to have the test or not to terminate the pregnancy if the test is positive may be affected socially (i.e., guilt).

> Society has to decide how to cope with the results morally, ethically and financially.

Table 3: Respondents' opinions on what they disliked about MSS*

	Group; no. (and %) of respondents		
Opinion	Family physicians *n = 394*	Obstetricians *n = 124*	Midwives *n = 30*
Has high false-positive rate	172 (44)	60 (48)	9 (30)
Causes anxiety	111 (28)	30 (24)	6 (20)
Is complex (hard to explain, hard to understand, difficult to communicate concept of screening test and risk)	43 (11)	12 (10)	1 (3)
Raises timing issues (is performed late in pregnancy, is arranged in small window of time)	36 (9)	11 (9)	3 (10)
Is not cost-effective	36 (9)	9 (7)	1 (3)
Involves extra time to be spent counselling and filling in requisitions	34 (9)	11 (9)	0
Raises ethical issues	37 (9)	1 (1)	7 (23)
Involves increased use of ultrasound	31 (8)	5 (4)	4 (13)
Has high false-negative rate (gives illusion that negative result means normal baby, detects only 70% of babies with Down syndrome)	12 (3)	3 (2)	2 (7)
Does not give results soon enough	7 (2)	2 (2)	0
Offers inadequate payment for time spent counselling	8 (2)	1 (1)	0
Other†	43 (11)	22 (18)	4 (13)

*Multiple responses were possible.
†Includes the following: "loss of normal babies with amniocentesis," "too disease oriented" and "increased amniocentesis in women under 35."

Recommendations

Of those who made recommendations regarding the MSS program 450 (50%) stated that it should be kept as is, 261 (29%) recommended that it be changed, and 198 (22%) said that it should be scrapped (Table 4). The recommendations did not differ significantly between the 3 groups ($p = 0.05$), although the obstetricians responded the most favourably.

Suggested changes from respondents are shown in Table 5. Generally these respondents were concerned about decreasing the false-positive rate, advocating more selective use of MSS, reducing the costs of the program and improving patient-education packages. Several suggested that there was a need to show the program's cost-effectiveness.

The χ^2 test was used to examine provider characteristics associated with the recommendation to keep the MSS program unchanged. Providers' attitudes toward abortion appeared to affect their opinions of MSS. Of those willing to refer a woman for abortion if she requested it in the event Down syndrome or NTD was confirmed, only 18% recommended scrapping the program, as compared with 47% of those unwilling to refer a patient for abortion under these circumstances ($p = 0.001$). Of those who always offer MSS, only 20% recommended scrapping the program, as compared with 65% of those who do not offer MSS and 31% of those who selectively offer it ($p = 0.001$). In addition, the respondents who agreed with the following statements were significantly more likely than those who disagreed with them to want the MSS program scrapped: "Too many normal pregnancies have positive MSS results," and "MSS causes too much anxiety for women" ($p = 0.001$).

Dummy variables were created for sex of health care provider, provider type, planning region, location (urban v. rural) and teaching status. These were entered into a stepwise logistic regression analysis along with work hours and

Table 4: Respondents' recommendations regarding the MSS program

	Group; no. (and %) of respondents		
Recommendation	Family physicians *n = 646*	Obstetricians *n = 231*	Midwives *n = 32*
Keep the program as is	303 (47)	132 (57)	15 (47)
Change it	188 (29)	62 (27)	11 (34)
Scrap it	155 (24)	37 (16)	6 (19)

Table 5: Respondents' suggestions for changing the MSS program*

	Group; no. (and %) of respondents		
Suggestion	Family physicians *n = 188*	Obstetricians *n = 68*†	Midwives *n = 11*
Offer to select group of women only (i.e., those at high risk)	49 (26)	9 (13)	1 (9)
Decrease false-positive rate	33 (18)	12 (18)	1 (9)
Offer only to women > 35 yr	23 (12)	6 (9)	2 (18)
Ensure cost-effectiveness	9 (5)	14 (21)	0
Improve patient information (explain screening and risk prediction, increase public awareness, develop educational videotape)	18 (10)	4 (6)	1 (9)
Make offering the test elective	21 (11)	2 (3)	0
Change timing of test (make it earlier, shorten time to get results and thus allow earlier amniocentesis)	8 (4)	5 (7)	3 (27)
Offer financial compensation to providers for counselling	9 (5)	3 (4)	0
Have women pay for test	10 (5)	2 (3)	0
Fund differently from global health budget	7 (4)	4 (6)	0
Improve health care provider information	7 (4)	1 (1)	0
Other‡	42 (22)	19 (28)	5 (45)

*Multiple responses are possible.
†Although 62 obstetricians indicated that the MSS program should be changed, 68 offered suggestions.
‡Includes the following: "exclude Down syndrome," "mention abortion," "need guidelines for women over 35" and "no routine dating ultrasound."

number of years providing antenatal care so that we could compare factors related to the recommendation to keep the program with those related to scrapping it or changing it. Only 1 group of variables was found to be important. The respondents in Toronto and its surrounding area were significantly more likely than those in other geographic planning areas to recommend that the program be kept as is (65% v. 46% in the Southwest, 44% in the Central West, 40% in the Northeast, 34% in the Eastern and 7% in the Northwest region) ($p = 0.001$).

Discussion

The MSS program in Ontario is one of the largest province-wide prenatal genetic screening programs to be introduced in Canada. Health care providers in the province have demonstrated good compliance with the program despite some lack of knowledge and concerns with the test.

Most of the health care providers we surveyed were offering MSS to all of the pregnant women in their practices. A concern of the Manitoba study was that 22% of the physicians surveyed did the maternal serum α-fetoprotein test as part of routine screening without specific consent.[11] We did not address this question specifically in our survey; however, the respondents stated overwhelmingly that they were discussing MSS personally with the women in their practices.

As in the Manitoba study, a small number of our respondents stated that they were offering MSS only to women with a family history of Down syndrome or NTD. This is of concern. This screening test uses population-based risk ratios. It is inappropriate to recommend MSS to women in high-risk groups, who should more appropriately be referred for genetic counselling rather than for MSS. Further education is needed in this regard.

Considerable concern was expressed by the respondents regarding the increase in patient anxiety associated with false-positive results. This concern was also voiced by the physicians participating in the Manitoba and British studies.[11,16] In our study the respondents overestimated the true-positive rate by 10-fold and significantly underestimated the false-positive rate. Therefore, the issue of anxiety surrounding MSS may be even greater than they realized. Physicians in the Manitoba study also overestimated the sensitivity of the α-fetoprotein test. Over one-third of the respondents in our survey did not answer this question, and in the reliability testing there were inconsistent responses. All of this suggests inadequate knowledge in this area.

Refinements in the MSS test to decrease the false-positive rate should be a focus of research, since this rate remains a major concern of providers. Alternatively, the cutoff value at which amniocentesis is offered could be changed. Raising it would lower the false-positive rate; however, fewer cases of Down syndrome would be detected.[6,19]

Less than 25% of the respondents stated that they communicate negative results to women as soon as they are received. Given the anxiety surrounding MSS screening, it may be better to communicate the results immediately, rather than use a “no news is good news” policy.

Some of the respondents expressed concern that public funding of prenatal genetic screening implied that babies with these conditions were unacceptable to our society. Others indicated that they would feel more comfortable if the test could be offered earlier in pregnancy. Several respondents wanted more public discussion of the ethics of genetic screening so that practitioners and their patients do not have to address these difficult issues in isolation.

The perceived benefits of MSS included detecting Down syndrome in women under age 35 and perhaps reducing the amniocentesis rate among women over 35. Respondents were concerned about the cost of the MSS program and wished to see Ontario data about how it has affected utilization of health care resources.

About half of the respondents surveyed wanted to keep the MSS program as it now exists, although there were significant regional differences in opinion. Providers in the Toronto region were the most positive about the program. It is the largest metropolitan area in Ontario, with nearly 25% of the province’s population. It is also where prenatal genetic testing of this type first began in Ontario and is the home of several genetic centres. Providers in this area were likely to have had greater exposure to MSS and to have learned more about it before the program began. Their patients might also have been more aware of MSS testing, which could have influenced the providers’ feelings about the test. The findings of the Manitoba study were similar: physicians outside of Winnipeg were less likely to do the α-fetoprotein test and knew less about it than those in Winnipeg.[11] Another explanation for the regional variation may have been that the system for handling MSS tests and obtaining results was already in place in the Toronto region, whereas providers in the other regions may have experienced difficulty transporting specimens to genetic centres or in receiving results.

Our study had several limitations. Although the results can be generalized to Ontario midwives and obstetricians who provide care to pregnant women, they may not fully reflect the attitudes of all primary care physicians attending births or providing antenatal care. The sample of family physicians was drawn from the membership list of the College of Family Physicians of Canada. Members differ from nonmembers in that the latter are somewhat older and are less likely to have undergone family medicine residency training.[20] We were unable to obtain the names of general practitioners practising obstetrics from the provincial insurer or medical association, and we felt that the number of ineligible physicians in an undifferentiated list of general practitioners would be prohibitive.

There are always limitations to self-reporting, and there is no way to determine whether respondents are practising as they have reported. Open-ended questions were asked in some areas, which probably led to underreporting of opinions. Although the overall response rate was high, some questions had low response rates, which limits their reliability. Also, the number of female patients over 35 differed significantly between the 3 groups. This may have influenced the respondent's practice and attitudes toward MSS.

Conclusion

Since the introduction of the MSS program in Ontario, health care providers have been offering MSS to most pregnant women. However, there appear to be some gaps in their knowledge about the test. In addition, only half of the providers want to keep the program as is, and they were most likely to be located in the Toronto region. Almost one-quarter want the program scrapped, and more want it changed.

MSS is complex, both to explain and to understand. Because of the potential anxiety associated with MSS and the false-positive rate, health care providers must give women the information they need to make an informed choice about prenatal genetic screening. More provider and patient education about MSS is needed. The test should be refined to decrease the false-positive rate and to allow testing earlier in pregnancy. As well, there is a need for societal debate regarding the ethical issues surrounding MSS.

We thank the Ontario Maternal Serum Screening Steering Committee for its support of this project.

The study was funded by a grant from the Ontario Ministry of Health.

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