

Maternal serum screening in the Sioux Lookout Zone

Complicated test for an unspecified need

SUMMARY

We investigated whether the incidence of fetal abnormalities among patients in Sioux Lookout Zone differs from incidence elsewhere in Canada, whether First Nations people would agree to screening, how information could be disseminated, and what practical considerations would affect implementation. Incidence appears to be similar to elsewhere, but First Nations people's cultural and spiritual beliefs and the difficulty of taking action once results are confirmed make current screening programs inappropriate.

RÉSUMÉ

Nous voulions savoir si l'incidence des malformations fœtales chez les patientes de la région Sioux Lookout était différente de l'incidence canadienne, si les Autochtones accepteraient le dépistage, s'il était possible de diffuser de l'information et s'il existait des considérations pratiques capables d'affecter la mise sur pied de ce programme. L'incidence semble la même qu'ailleurs mais les croyances culturelles et spirituelles des Autochtones et la difficulté de la démarche décisionnelle suite à la confirmation des résultats rendent le dépistage irréaliste.

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MICHAEL DILLON, MD, CCFP
TACK LAM
NELLIE BEARDY
JANET GORDON
JOSEPH DOOLEY, MB, CCFP
STEWART HARRIS, MD, CCFP

RECENTLY, THE ONTARIO MINISTRY of Health introduced a maternal serum screening program for antenatal diagnosis of neural tube defects and Down syndrome.¹ The program involves testing pregnant women's serum at (ideally) 16 to 17 weeks' gestation for:

- α -fetoprotein (AFP),
- estriol, and
- human chorionic gonadotropin (HCG).

Values for each of these are compared to "normal" values for the gestational age (as accurately determined by ultrasound

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Dr Dillon is Assistant Professor in the Sioux Lookout Program of the Department of Family and Community Medicine at the University of Toronto.

Mr Lam is a student in the Department of Family and Community Medicine at the University of Toronto. **Ms Beardy** is Executive Director of the Sioux Lookout First Nations Health Authority. **Ms Gordon** is Executive Assistant of the Sioux Lookout First Nations Health Authority. **Drs Dooley and Harris** are Assistant Professors in the Sioux Lookout Program of the Department of Family and Community Medicine at the University of Toronto.

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examination), and the statistical probabilities for each of the conditions is determined. Results are transmitted to ordering physicians or midwives for discussion with expectant mothers.

Researchers suggest that expectant mothers should be routinely offered such testing, the intent being to provide a convenient, relatively noninvasive method of antenatal diagnosis of two potentially serious fetal conditions and to decrease the need for more risky and expensive amniocentesis.² (personal communication from Chodirker B, Department of Pediatrics and Child Health and Human Genetics at the University of Manitoba in Winnipeg).

The concept of even offering such maternal serum screening during pregnancy raises many practical concerns for women and health care practitioners living in more isolated regions. This paper is the result of a collaborative process involving health care providers (the Sioux Lookout Program of the University of Toronto), First Nations*

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*Native and First Nations are used throughout this article to refer to the indigenous and aboriginal inhabitants of Canada and their descendants.

representatives involved in developing health policy and programs (the Sioux Lookout First Nations Health Authority), and members of the community served.

Sioux Lookout Zone

The Sioux Lookout Zone is a remote area of northwestern Ontario bounded on the south by the Canadian National Railway line, on the north by Hudson Bay, on the west by the Manitoba border, and on the east by the Moose Factory Zone (the term Zone refers to an administrative area for Health Canada's Medical Services Branch programs).

Native Cree and Ojibway are the main inhabitants of this region, part of the Nishnawbe-Aski Nation. Most live

on reserves ranging in size from less than 100 to nearly 2000 persons. While most communities have full-time airstrips, stores, and radio or television stations, most lack running water, sewers, and centrally heated houses – things taken for granted in most of Canada.

The birth rate is nearly 30/1000 yearly² (double the national average); consequently, pregnancy and childbirth are important health care concerns.

Antenatal care for pregnant women in the Sioux Lookout Zone is shared between outpost nurses, community health representatives, family physicians in the field or at the Zone Hospital, and sometimes obstetricians from the larger centres. Most deliveries take place at Sioux Lookout Zone

Caring for mothers and children in northern Ontario: *Babies arrive for physician visits in a tikinagan (carrying pack) in Sioux Lookout.*



Photos: Dr. Mark Quigg

Hospital, but many occur at tertiary care centres.

To facilitate shared obstetrical care, several protocols and standards of practice have been developed, on issues from routine antenatal management to more complicated problems, such as hypertensive disorders and diabetes.²

The issue of routine maternal serum screening raises many questions that must be dealt with in a considered and consistent manner. A program must be developed for use in the Zone. We approached the Sioux Lookout First Nations Health Authority, which has a mandate to assess community health needs and develop programs and policies, to assist with this process.

Prevalence

The first consideration is the prevalence of the conditions being screened, to determine whether the problems are as common in this First Nations population as in the general population. Obviously, there would not be as pressing a need for such a screening program in a population at lower risk than others (for example, compared with women of Celtic background, who have the highest rate of neural tube defects in the world.) Some information suggests that the prevalence of open neural tube defects in First Nations populations is lower than expected, yet anecdotal information from certain communities appears to contradict this observation (personal communication from Chodirker B, Department of Pediatrics and Child Health and Human Genetics at the University of Manitoba in Winnipeg).

In a retrospective review of all birth records on women from the Sioux Lookout Zone from 1980 to 1992, all open neural tube defects and cases of Down syndrome were noted, as were cases of intrauterine growth restriction and polycystic or absent kidneys.

Over the period studied, 5248 babies were born (5149 live and 99 stillbirths). There were seven cases of spina bifida and seven anencephalic births.

Overall, the incidence was 2.7 per 1000 births. This is somewhat higher than the expected rate of 1.6 per 1000 in Canada.³

Four babies were born with Down syndrome, yielding a rate of 0.8 per 1000 births. This is somewhat less than the rate in the overall population (1.25 per 1000 births). In a recent analysis of maternal age from the Zone Hospital records during the year 1993, the median age was 23; many were younger mothers, and their youth could account for a somewhat lower rate of Down syndrome.

It must be noted, however, that because the number of actual events (either Down syndrome or open neural tube defects) was low, the margin of error is quite high, so it is impossible to say that any differences noted are statistically significant.

Normal values

Another issue related to racial differences is that of the expected normal values for the serum levels of AFP, estriol, and HCG. Each laboratory is expected to define a median value for each substance and to compare maternal serum specimens with this reference value. A woman's risk of open neural tube defects and of Down syndrome is determined on the basis of ratios to the median values for the population tested, or the multiples of median.

It is uncertain whether the levels of AFP, estriol, and HCG are any different among Natives or whether it is reasonable to use mean values derived from different racial groups to define normal for the rather homogeneous First Nations population in the Zone. In Manitoba, where a maternal AFP program has been in operation for several years, values for Native people have been found to be between 4% and 5% higher than the general population; however, a corrective calculation is not considered necessary at present, as the sensitivity of the test would be diminished for Native people if a higher median value were used

(personal communication from Chodirker B, Department of Pediatrics and Child Health and Human Genetics of the University of Manitoba in Winnipeg).

As it stands, in order to achieve a reasonably sensitive screening tool, the false-positive rate for a test such as triple screening must be relatively high.

Individual and community wishes

Assessing interest. A second consideration is whether women and families in the Sioux Lookout Zone are, in fact, interested in any sort of antenatal diagnostic screening. In any such health program, the cultural and spiritual beliefs of First Nations people need to be recognized.

To address this issue, we obtained assistance from the Sioux Lookout First Nations Health Authority. Health liaison workers visited many of the communities on behalf of the health authority, and informal discussions were held with community health representatives, clients, and others.

We sought guidance from community members comprising the Board of Directors of the First Nations Health Authority. The Board of Directors reported that there was little interest in widespread application of this sort of testing. Reasons given for this included:

- widespread objection to therapeutic termination of pregnancy in any circumstance,
- not wanting to know about such problems until the baby is born, and
- not wanting to deal with the further testing and worry associated with a test result that in many cases will be false positive.

Culturally, babies with deformities have been accepted by the family and community and given the special help necessary to meet their needs. Some of the younger women in northern communities, however, might not hold the same ideas, especially toward acceptance of abortion. As such, community

members recommended that maternal serum screening information be made available in clinics for women who wish for it.

Disseminating information. The Ontario Ministry of Health has published an information brochure that *must* be read before a woman declines or accepts the screening test.⁴ On review of this publication with the health authority, we found that the language and content were too technical for most women, few of whom have had a high school education.

A translation of the brochure into the Cree language is available from the Ministry of Health.⁵ Unfortunately, most women of childbearing age are unable to read Cree syllabics, even though their first language is often Ojibway-Cree.

This brochure was reviewed by the First Nations Health Authority and found to be written in a Cree dialect that would be poorly understood by most of the Ojibway- and Ojibway-Cree-speaking people in the Sioux Lookout Zone, indeed in most of the Nishnawbe-Aski Nation. Extensive retranslation and reinterpretation into syllabics would be necessary.

Geographical and logistical considerations

Some of the greatest difficulties with implementing a maternal serum screening program are related to the remote location of most of the communities in the Sioux Lookout Zone.

Blood samples taken at nursing stations are transported by air to Sioux Lookout. Usually, this takes a day. From Sioux Lookout, the specimens must be sent to the regional cytogenetics laboratory in Sudbury, Ont (the regional laboratory for this test only). This process takes a further few days. By the time the specimens are processed and the reports returned to Sioux Lookout, 10 to 14 days or more may have passed. (In our experience it has been closer to 14 days to receive

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the results, although positive results can be expedited for quicker delivery.)

The implication of waiting for the results is that, if a woman *did* wish to consider a therapeutic abortion on the basis of a positive screening test, there would be very little time to organize a confirmatory test (either repeat serum screen, detailed ultrasound, or amniocentesis). If this test were in turn positive, it would be virtually impossible to terminate the pregnancy at an appropriate gestational age, let alone to allow the woman and her family the time to receive appropriate counseling and arrive at a difficult decision. It should be noted that, in this part of northern Ontario, resources to facilitate therapeutic terminations are scant, and generally the procedure is not done past 20 weeks' gestation.

Implications

The introduction of a maternal serum screening program for neural tube defects and Down syndrome poses many difficulties for health care providers and residents in the Sioux Lookout Zone. Although the risks of open neural tube defects and Down syndrome among the regional First Nations population seem to be similar to those among the population at large, there are many compelling reasons not to perform such screening routinely. These reasons include:

- resistance to the concept by First Nations people;
- difficulty in transmitting the necessary information about the conditions tested for, the test itself, and the implications and management of positive test results; and
- geographical and logistical difficulties that make action on positive results extremely difficult.

Other First Nations communities. As First Nations peoples regain power and responsibility in such areas as health care, it is mandatory to seek appropriate consultation before introducing new services and programs. Many First Nations communities,

especially those far from large population centres, have health priorities quite different from those of people living in urban areas. Provision of safe water, adequate housing and sanitation facilities, and increased health care education will inevitably have greater effect on overall health than any one specific program or screening test.

Currently, many First Nations are working to prioritize their health care needs. Health care providers and governments must acknowledge the social and cultural differences that could account for quite different priorities in these communities.

Other remote areas. The introduction of the maternal serum screening program has met with much resistance from many practitioners involved in mother and child care in northwest Ontario. At several recent regional perinatal and other professional meetings, many have expressed anger and disappointment at being "left out" of the consultation process. The program is frequently perceived as being developed to reflect the wishes of caregivers and clients in the larger southern Ontario centres, but not to reflect adequately the needs and realities of practice in more remote areas.

Maternity care in small hospitals can be as safe and effective as larger centres.⁶ For many practitioners in smaller centres, bigger and newer is not necessarily better. There is no evidence, for example, that routine ultrasonography has any beneficial effect on pregnancy outcome. Pregnant women can be safely cared for in smaller centres lacking ultrasound facilities, yet such testing has become almost routine where ultrasound facilities exist.

The fact that the technology exists to allow widespread maternal serum screening does not necessarily mean that it should be used routinely. Further, because ultrasound confirmation of dates is advised for accurate interpretation of maternal serum results, women from communities without ultrasound services would not

only need to decide on the maternal serum test itself, but also whether they would be prepared to undergo the inconvenience and expense of traveling many hours for ultrasonography. Given these choices, many women choose not to have either test.

When women do choose to have the test, there will inevitably be positive results, many of which will be false positive. These results must be investigated further, and this leads to more stress on the individual and the health care system in more remote areas.

For example, the Regional Perinatal Centre in Thunder Bay, Ont, has pointed out that the number of diagnostic amniocentesis procedures done increased nearly threefold (most would be negative) in the first few months after the program was introduced. With a decreasing number of gynecological specialists in the region, one wonders whether this is an appropriate use of resources.

Conclusion

In collaboration with the Sioux Lookout First Nations Health Authority, we have decided that, at present, the program for routine implementation of maternal serum screening as it stands in the Sioux Lookout Zone does not meet the needs of the local population. Nurses and community health representatives in northern communities will be educated on the test, and resource material will be made available to those wishing to participate in the testing voluntarily. Culturally appropriate material is being developed with the assistance of the Sioux Lookout First Nations Health Authority, and community education programs will follow.

We hope that in future the concerns of those living and practising in rural, remote, and First Nations communities are taken into consideration before introducing programs such as this. As a first step, we have attempted to demonstrate a model of how the medical community and First Nations

representatives can work in collaboration to determine specific community needs and develop appropriate research and intervention strategies. ■

Requests for reprints to: Dr Michael Dillon, Dept of Family and Community Medicine, Sioux Lookout Program, Box 4000, Zone Hospital, Sioux Lookout, ON P8T1K2

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