MATERNAL SERUM SCREENING IN RURAL MANITOBA

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Maternal Serum Screening

• Genetic screening to assess risk for genetic abnormalities including Down Syndrome, Trisomy 18 and open neural tube defects

• Blood test offered in first trimester between 15 and 20+6 weeks gestation

• All maternity patients are eligible – no longer restricted by age (i.e. >35 years at time of delivery)

• Covered for all MB maternity patients

• Completely voluntary
Project Focus

• Assess the rate of maternity patients choosing to have MSS in Morden and compare to rates from larger urban settings

• Determine what may influence decision making within this community and explore the standardization of care provided

• Is there room for improvement in the standard of care?
Hypothesis

• Expected rates to be lower than documented rates in urban settings elsewhere in Canada

• With recent changes to MSS eligibility it was predicted that most patients opting in for screening would be >35 years of age at time of delivery
Methods

- EPR analysis to determine uptake of MSS in Agassiz Clinic (Morden) within a time constraint
- Survey physicians to assess preferences regarding MSS and look for signs of standardized practice
- Subdivide EPR results by physician/nurse practitioner to track any trends with MSS uptake and preferred practice
- Second subdivision of results by patient age
- Interview nursing staff primarily involved with all maternity patients and review their standard of care
- Contact WRHA re: Winnipeg and regional statistics of MSS uptake
- Review uptake of MSS from previous studies in Canada and preform comparison to statistics of Morden, MB
Methods – Survey Overview

- Distinguished those that regularly provide maternity care up to and including delivery
- Assessed frequency of discussing MSS
- Questioned comfort level in discussing MSS with patients
- Questioned care providers on their predictions of MSS uptake in the region based on personal practice
Results

• Average uptake of MSS in Morden within the prescribed time constraint was 12.01%
  ➢ Likely contributors to the “assumed” decreased rate are:
    o Cultural influences of the community (i.e. Mennonite, Hutterite backgrounds)
    o Rural setting – family physician based maternity practice

• NO Winnipeg results – regional statistics regarding MSS in MB have not been assessed at this point in time

• Ontario rural MSS uptake 40% - compared to 80% uptake in central Toronto in 2007-2009
Results

- Maternity patients all receive the same information regarding MSS and other expected testing during pregnancy from nursing staff before first maternity office visit
  - Standardized information package
MB MSS brochure

Are You Pregnant?

The Manitoba Maternal Serum Screen is a test that:

- will give you important information about your baby
- involves only a blood sample taken from your arm
- is best done around 16 weeks
- is voluntary

IT'S YOUR CHOICE

What is Maternal Serum Screening?

Maternal Serum Screening (MSS) is a blood test available to pregnant women in Manitoba as part of their prenatal care. This test can tell you about your chance of having a baby with a problem such as Down syndrome, trisomy 18 or Smith-Lemli-Opitz syndrome (SLOS). It can also detect openings in the baby’s eyes or be told through a neural tube defect, or in the abdomen or back cavity (called neural wall defects). Most of these problems occur in families where there is a previous history of babies born with such problems. The MSS helps identify families who may be at increased risk for these defects, and offers them further testing.

MSS does not tell if your baby is healthy, but it can tell you if there is a higher or lower chance of your baby having a problem. Some women find having MSS is reassuring. Others feel that they do not need or want information. It is your choice whether to have MSS and it will only be done if you want it. Your choice about having this test will not affect the care you receive.

How is the test done?

A small amount of blood is taken from your arm. Maternal serum screening is best done around 16 weeks of pregnancy.

What can this test tell me?

The test looks at certain natural substances in the mother’s blood that are made by the baby and placenta. By taking a sample of your blood, we can measure the level of each of these substances. This will tell us if your baby appears to be developing normally.

If the levels are what is expected, your test is called “screen negative”, and the chance of your baby having Down syndrome, trisomy 18, SLOS, a neural tube or ventral wall defect is low. About 80 out of 100 pregnant women who have this test get normal results and no further tests are suggested. Although more women get a normal result have a healthy baby, this is not a guarantee. A screening test cannot identify all mothers who will have a baby with a problem.

When a baby has Down syndrome, trisomy 18, SLOS, an open neural tube or ventral wall defect, the levels of these substances are usually different.

I will get my results:

At 1 week, your results will be sent to you or a nurse who will explain them to you. They will also be kept in a database that is to keep track of the samples and help us understand the problem. We will record whether pregnancy ended normally or if there were any issues with your or your baby’s health. This can help us determine how the screening program is working.

Definitions:

Amniocentesis: This is a test where a needle is inserted through the mother’s abdomen into the amniotic fluid and a sample of fluid from around the baby is taken. The test can check for chromosome problems such as Down syndrome or Turner syndrome or other conditions such as SLOS.

Chromosomes: The number of genetic information. Chromosomes come in 23 pairs, one of each pair coming from the mother and one from the father. Down syndrome and trisomy 18 are due to extra copies of chromosomes.

Down syndrome: This is the most common chromosomal cause of mental disability. Children with Down syndrome have three copies of chromosome 21 instead of the normal two. They have a characteristic facial appearance and may have certain birth defects including heart problems. This condition occurs in about 1 in 500 babies and is more common in babies born to older mothers.

Neural tube defects: These are birth defects where the spinal cord or brain fails to form properly. They can cause problems with bladder and bowel control and difficulty walking, and can be serious to abnormal spinal cord development, hip dysplasia or a lethal brain malfunction (anencephaly). About one in every 1200 babies is born with a neural tube defect.

Smith-Lemli-Opitz syndrome (SLOS): A genetic condition that causes birth defects and mental retardation.

Trisomy 18: Babies with trisomy 18 have three copies of chromosome 18 instead of the normal two. About 1 in 4000 babies is born with this condition. Trisomy 18 is very severe, often results in fetal demise at 14 weeks.

Ventricular Wall Defects: If the ventricular or intracranial (intracranial) wall is not properly formed, the function and often organs may be affected. This is related to an enlarged and thickened wall (ventriculomegaly) or through a fluid-filled cavity on either side of the brain. Sometimes these problems can be corrected after birth with a long-term effect on the baby. In other cases, especially when there are other malformations, there may be serious complications or early death. About 1 in 4000 babies is born with a ventricular wall defect.
Results

- Physicians vary in having their own discussions with patients regarding MSS
  - Some providers are reliant on patient discussion with nurses
  - Others routinely discuss with every patient
  - Some discuss when they remember, based on patient age, or if patient brings up topic

- Small trend towards increased MSS uptake with physicians that proactively discussed MSS with patients
  - Small survey sample, therefore inconclusive observation

- There was a noticeable increase in uptake of MSS for patients 35 years and older at time of delivery (20%)
  - Compared to 10-12% uptake by those <20 years old and 20-34 years old (there was not much difference between these cohorts)
Conclusions

• There is a presumed decrease in MSS uptake in rural MB specifically in the community Morden based on studies and statistics in Ontario.

• Possible influences on this decreased rate include cultural values, rural settings with family based practice for maternity care and physician bias (lack of standardized care).

• There seems to be an increase in screening for patients >35 years old that would correlate with prior eligibility requirements of MSS and general increased risk of fetal abnormalities.

• Decisions to proceed with MSS is completely under the discretion of the patient but it is the responsibility of the health care team to provide all information in order for a fully informed choice.
Limitations

- Self reporting nature or surveying participants – lead to possibility of bias

- Small number of physician survey response
  - Cannot make any conclusions from small sample size

- EPR query constraints
  - Not able to eliminate those outside of screening range during the time frame

- Absence of Winnipeg and Manitoba regional statistics for comparison
Future Direction

- Wider surveying for physicians and nursing staff at Agassiz Medical Center

- Survey/interview patients and get understanding of expectations and feelings towards options available

- Collaboration with Cadham Provincial Laboratory
  - Document rates between regions in Manitoba as well as within Winnipeg
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References

Questions?