



Are midwifery clients in Ontario making informed choices about prenatal screening?



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ABSTRACT

Background: Informed choice is often lacking in women's decisions about prenatal screening.

Aim: The aim of this study is to evaluate how well midwives in Ontario, Canada are facilitating informed choice in this area.

Methods: An Internet-based survey was used to investigate 171 midwifery clients' knowledge, attitude towards and experience of prenatal genetic screening tests, and to determine the proportion of study participants who made an informed choice about prenatal screening.

Findings: All participants demonstrated adequate knowledge of prenatal screening. The vast majority (93.0%) of participants made an informed choice. Participants who chose to screen had lower knowledge scores than those who opted out of screening. Client satisfaction rates in regard to care received in this area ranged from 97% to 100%.

Conclusions: Results of this study suggest that Ontario midwives are effective in conveying information on prenatal genetic screening, contributing to high levels of client knowledge and satisfaction in comparison to similar studies in other jurisdictions.

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1. Introduction

Prenatal screening tests are blood tests, sometimes offered with an ultrasound, that are carried out prior to the 20th week of pregnancy. Maternal serum screening was first introduced in Ontario in 1991 and the standard tests, which are currently covered by provincial health insurance include screening for open neural tube defects, Down Syndrome, Trisomy 13, and Trisomy 18, beginning in the 11th week of pregnancy.¹ Among the well resourced countries in which prenatal screening has become increasingly normative, there is variation in the types of tests available as well as their timing and insurance coverage.^{2,3} However, comparison of international screening guidelines reveals a common purpose of the tests: to inform pregnant women of the probability that they are carrying a child affected by one of these conditions.⁴ Echoing similar recommendations internationally, the Society of Obstetricians and Gynecologists of Canada (SOGC)

recommend that the screening tests be offered to all pregnant women in the country.^{1,4}

In many ways, this is an accurate description of prenatal screening. However, prenatal screening is also related to some of life's biggest questions: about what kinds of babies women want and are able to bear and raise; about who should live and who should not; about the role of mothers, families, communities and societies in caring for and raising children born with disabilities.⁵ In this light, prenatal screening is more than a set of clinical procedures of blood tests and ultrasounds; it is a point of care that touches on some of our most deeply held social, political and ethical values and beliefs.

2. Literature review

Despite the weight of these issues, the process of deciding whether to undergo screening is one that is normalised to the point of invisibility within regular obstetrical care.^{6,7} Indeed, the literature suggests that many women undergo routine prenatal screening with relatively little knowledge of the conditions they are testing for or the efficacy of the test, and without much discussion with their caregiver about the advantages and disadvantages of testing.⁸⁻¹¹

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Still, research suggests that women want to be offered screening through a comprehensive process in which they are given enough unbiased information to make a decision that reflects their personal values and ethics.^{12,13} Their desires echo the widely used definition of informed choice as a decision based on relevant knowledge in which an individual's decision to screen or not is consistent with their attitude towards screening and their personal values.¹⁴

National and international screening guidelines reflect the intention of providing informed choice through "non-directive" counselling and respect for a woman's "right to accept or decline".^{4,15,16} While the Association of Ontario Midwives has not published midwifery-specific guidelines in this area, they follow SOGC recommendations to universally offer prenatal screening tests and the decision to undertake or decline prenatal screening is made by each pregnant woman through a process of informed choice. The principle of informed choice is, in fact, one of the pillars of the model and philosophy of midwifery care in Ontario. As such, the College of Midwives of Ontario's (CMO) *Informed Choice Standard* applies to the process of informed choice in every facet of midwifery care. In this document, informed choice is defined as that which:

[t]akes into account factual information, risks and benefits, the clinical experience of the midwife, and the experience, feelings, beliefs, values and preferences of the woman ... [r]espects and encourages the individual autonomy of the woman as the primary decision-maker ... [and] ... [r]esults in a decision which is made by the woman, which is then supported by the midwife.¹⁷

The purpose of this study is to evaluate how midwives in Ontario are applying this standard to prenatal screening among a sample of their clients. The incidence of informed choice among midwifery clients is assumed to serve as an indicator of the quality of care provision in this area.¹⁸ Similar studies have been employed in other jurisdictions such as the Netherlands,^{1,19} Australia^{20,21} and the United Kingdom.^{22,23} This is the first study of this kind among midwifery clients in Canada and is part of a larger project that explores how information around prenatal screening is given and received by maternity care providers and pregnant women in the province of Ontario.²⁴

3. Participants and methods

3.1. Survey

An Internet-based survey questionnaire was designed to measure the incidence of informed choice based on the Multi-dimensional Measure of Informed Choice (MMIC)¹⁴ as well as the definition of informed choice published by the College of Midwives of Ontario.¹⁷ The questions assess clients' knowledge of and attitudes towards screening. When knowledge scores are deemed adequate, and an individual's decision to screen or not reflects their attitudes towards screening, the decision can be deemed to be one based on informed choice.¹⁴

Knowledge was assessed by a series of 14 true or false statements about the aims, process and significance of screening. The items in this section were derived from a review of survey instruments used in similar studies,¹⁸ the MMIC, and the information booklet, *A Guide to Understanding Prenatal Screening Tests for Women and their Families*²⁵ given to prospective parents by various health care providers in Ontario. Responses to these statements assess various knowledge domains, including knowledge of the conditions being screened for, reasons for screening and capabilities of the tests. They reflect the knowledge domains

developed by Schoonen et al. through expert consensus, although we have adapted them to suit the Ontario context.²⁶

Attitude towards prenatal screening tests was assessed using Schoonen's adaptation of Marteau's attitude assessment from the MMIC.^{14,18} The items utilise a 7-point Likert scale by which participants rate prenatal screening as harmful versus beneficial, important versus unimportant, and so on.

Action or decision in regard to opting in or out of screening was assessed by asking whether the participant underwent or intends to undergo prenatal genetic screening tests for their current pregnancy, with response options "yes", "no" and "unsure". Additional questions using the same response categories explored the participant's self-assessment about whether she made an informed choice, whether she felt her values and beliefs about screening were respected by her midwife, and whether she felt supported in her choice to screen or not.

The questionnaire also contained several open-ended, short answer questions exploring whether any other resources were used or desired, and other factors that may have affected the screening decision. The findings based on this qualitative data will be presented in a separate paper.

3.2. Recruitment and data collection

Ethics approval for this study was obtained from the Research Ethics Board at Ryerson University. Invitations to act as recruitment sites were mailed to each of the 93 operating midwifery practices in Ontario. Clinics in urban, suburban, and rural Ontario were all represented among the 40 practices that agreed to act as recruitment sites for this study. Current midwifery clients were invited to respond to an online survey via posters and fliers at participating midwifery clinics. The chance to win one of four \$50 grocery gift cards was offered as an incentive to participate. Consent was obtained by an Internet-based form that preceded the on-line survey. Those who had begun midwifery care after 20 weeks gestation were excluded from participating in this study. All the data were gathered during the summer of 2012. A total of 171 women responded to the survey.

3.3. Analysis

Correct responses to the knowledge questions were summed to form a knowledge score with a maximum of 14 points. Zero points were given for incorrect or unanswered knowledge questions. As in similar studies, a participant with a knowledge score of 50% or higher (in this case, seven or more correct answers out of 14) was deemed to have adequate knowledge.^{18–23}

Responses to the attitude questions were summed to form a score ranging between 4 (most negative) and 28 (most positive) and then divided by 2.8 to produce a final attitude score between 1 and 10. As in the MMIC, the midpoint was used to distinguish positive and negative attitudes.¹⁴ Thus, participants with an attitude score of 5.5 and below were classified as having a negative attitude towards screening, while participants with a score above 5.5 were deemed to have a positive attitude towards screening.

An informed choice to decline screening was defined as a knowledge score greater than 5 (out of 10), an attitude score of 5.5 or less, and the decision not to undergo screening. An informed choice to undertake screening was defined as a knowledge score greater than 5, an attitude score greater than 5.5, and the decision to undergo screening. Cases with incomplete responses in the attitude or decision to screen categories were excluded from analysis.

Chi-square tests were performed to explore the relationship between nominal or categorical variables such as the decision to

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