

Information-Sharing to Promote Informed Choice in Prenatal Screening in the Spirit of the SOGC Clinical Practice Guideline: A Proposal for an Alternative Model

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Abstract

The 2011 SOGC clinical practice guideline “Prenatal Screening for Fetal Aneuploidy in Singleton Pregnancies” recommends that clinicians offer prenatal screening to all pregnant women and provide counselling in a non-directive manner. Non-directive counselling is intended to facilitate autonomous decision-making and remove the clinician’s views regarding a particular course of action. However, recent research in genetic counselling raises concerns that non-directive counselling is neither possible nor desirable, and that it may not be the best way to facilitate informed choice. We propose an alternative model of information-sharing specific to prenatal screening that combines attributes of the models of informative decision-making and shared decision-making. Our proposed model is intended to provide clinicians with a strategy to communicate information about prenatal screening in a way that facilitates a shared deliberative process and autonomous decision-making. Our proposed model may better prepare a pregnant woman to make an informed choice about participating in prenatal screening on the basis of her consideration of the medical information provided by her clinician and her particular circumstances and values.

Résumé

La directive clinique de la SOGC intitulée « Dépistage prénatal de l’aneuploïdie fœtale en ce qui concerne les grossesses monofoœtales » et publiée en 2011 recommande aux cliniciens d’offrir, à toutes les femmes enceintes, un dépistage prénatal et des services de counseling prodigués de façon non directive. Le counseling non directif a pour but de faciliter la prise de décision de façon autonome et d’extraire du processus les opinions du clinicien à l’égard d’une option particulière. Cependant, de récentes

recherches menées dans le domaine du counseling en génétique soulèvent des préoccupations selon lesquelles le counseling non directif serait ni possible ni souhaitable et qu’il pourrait ne pas s’agir de la meilleure façon de faciliter un choix éclairé. Nous proposons un autre modèle de partage de l’information propre au dépistage prénatal qui combine les attributs des modèles de prise de décision éclairée et de prise de décision partagée. Le modèle que nous proposons a pour but de fournir aux cliniciens une stratégie pour communiquer l’information au sujet du dépistage prénatal d’une façon qui facilite un processus délibératif partagé et une prise de décision autonome. Le modèle que nous proposons pourrait mieux préparer la femme enceinte à faire un choix éclairé quant à sa participation au dépistage prénatal, en fonction de l’importance qu’elle accorde aux renseignements médicaux offerts par son clinicien, à son contexte particulier et à ses valeurs.

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INTRODUCTION

The 2011 Society of Obstetricians and Gynaecologists of Canada’s clinical practice guideline “Prenatal Screening for Fetal Aneuploidy in Singleton Pregnancies”¹ recommends that clinicians, most frequently physicians, nurses, and midwives, offer non-invasive prenatal screening for chromosomal anomalies and incomplete neural tube closures to every pregnant woman. The guideline recommends that clinicians provide “understandable” information about the screening tests in a “non-directive” manner in order to “ensure informed decision-making.”¹ This recommendation is consistent with the 2007 SOGC guideline on prenatal screening for fetal aneuploidy,² encouraging each woman to evaluate her options and consider her preferred course of action in relation to her

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particular situation, experiences, and personal values.^{1,2} However, recent research in genetic counselling has raised concerns that non-directive counselling is neither possible³ nor desirable^{4,5} and that it may not be the best way to facilitate informed choice.^{3,5,6} We consider here whether non-directive counselling may unintentionally create obstacles to the SOGC guideline's goal of an informed counselling process leading to autonomous decision-making, and we propose an alternative approach specific to prenatal screening that combines aspects of informative⁷ and shared models of decision-making.⁸⁻¹⁰

PRENATAL SCREENING FOR FETAL ANEUPLOIDY

The process of prenatal screening requires pregnant women to make a decision that is qualitatively different from most other patient decisions because of the necessity to understand and integrate complex and value-sensitive concepts when there is no single "right" decision. When deciding whether or not to participate in prenatal screening, a woman must consider the potential that additional decisions about diagnostic testing and pregnancy termination will be necessary,¹¹ as well as psychosocial risks to herself.¹²⁻¹⁵ These concepts are considered in conjunction with the woman's personal values and circumstances.^{16,17} As prenatal screening requires women to make a type of decision that is different from most other medical procedures, it requires a type of decision-making process that is different from that suggested by traditional models of informed consent^{18,19} or the models of informative⁷ or shared decision-making.^{8-10,20}

INFORMED CHOICE AND AUTONOMY

A narrow conception of autonomy may be problematic in light of the social and cultural contexts within which women make decisions about prenatal screening.²¹ Code,²² Sherwin,²³ Sherwin et al.,²⁴ and McLeod and Sherwin²⁵ posit that the way autonomous informed choice is enacted can be problematic for patients who do not fit the ideal of the autonomous decision-maker; the model of autonomous decision-making assumes patients to be self-sufficient, independent, articulate, accustomed to making decisions, and possessed of the resources necessary to allow a range of choices. In addition, physicians are assumed to have the time, knowledge, and communication skills to provide the patient with complex information, evaluate the patient's

comprehension of the information, and encourage the patient to make a decision on the basis of her values and preferences, without regard for health care costs or legal liability.²⁴ In many instances, these traits and circumstances of the ideal autonomous decision-maker and the ideal decision-facilitator may not co-exist. Thus, pregnant women may not be in an ideal position regarding informed choice in considering prenatal screening.

NON-DIRECTIVE COUNSELLING

The SOGC guideline's recommendation for non-directive counselling when offering prenatal screening¹ is intended to encourage informed choice that reflects each woman's individual values and circumstances. Non-directive counselling is one of the principal tenets of genetic counselling,^{5,26-28} and is important because it aims to promote autonomous informed decision-making.⁵ However, others have argued that non-directive counselling may not be the best way to achieve autonomous decision-making.^{3-6,27,29} There are many descriptions of non-directive counselling, each with its own particular nuances,³⁰ and the SOGC guideline does not identify a particular model of non-directive counselling or describe how this strategy should be used in the context of prenatal screening.¹ The following sections will examine some of the arguments against the strategy of non-directive counselling, and propose an alternative approach to encouraging autonomous decision-making about prenatal screening.

Is Non-Directive Counselling Possible?

The capacity for non-directive counselling is constrained by the broader context in which prenatal screening is presented.^{30,31} It has been argued that non-directive counselling may not be possible, given the barriers to dissolving the persuasive authority embodied in the offer of a medical procedure by a health care provider in an institutional setting,⁵ funded through a universal health care program.³² In these circumstances, the offer of prenatal screening may imply a recommendation to accept prenatal screening, thus rendering the goal of non-directive counselling unachievable.³³

The possibility of non-directive counselling may also be constrained by whether or not the counsellor is able to identify and avoid directive elements.²⁸ For example, in a study of genetic counsellors, it was difficult for the counsellors to determine what verbal and non-verbal cues could be considered directive.³⁴ Further, directive cues may include commonly used terminology such as "abnormalities" or "risks."^{14,35,36} In addition, deciding what information to present and how to present it can itself

ABBREVIATIONS

IDM	informative decision-making
SDM	shared decision-making

be directive.^{3–5,37,38} Further, clinicians' perspectives and opinions on prenatal screening may be different from those of their patients, making neutrality difficult to achieve. This may be problematic³⁹ because of the power and knowledge differential between patients and clinicians.^{40,41}

Seventy-two percent of genetic counsellors (who have received training in non-directive counselling and are allotted longer periods of time to counsel patients than physicians) acknowledge that they sometimes counsel directly.³⁴ For example, clinicians have reported choosing to counsel directly when they perceived that their patients could not comprehend the information because of low education level, cultural or language differences, or low socioeconomic status,^{34,42} when the clinician thought there was a "better choice" for the woman,³⁴ or when the woman was having trouble making a decision.³⁴

Is Non-Directive Counselling Desirable?

Observational research on non-directive counselling sessions has found that practitioners counselling non-directively often do so by using indirect speech, such as "some people may want to . . ." when outlining various choices or considerations.⁴³ This strategy may lead to confusion on the part of women about whether the information applies to them, and it does not invite women to state their values.⁴³ Genetic counsellors have reported that non-directive counselling constrains their ability to counsel actively and impedes their wish to share the information that is most relevant to a particular woman.⁵ For example, a clinician who sees an incompatibility between a woman's decision and her expressed values may wonder about incomplete or incorrect understanding and may wish to counsel more actively.^{5,44} Non-directive counselling may be even more challenging for practitioners who do not normally practise in a non-directive way, especially considering that in other circumstances (such as regulating blood sugar or controlling hypertension) non-directiveness may be seen as a problematic way of practice.^{4,45} Time constraints in primary care medicine may be an additional obstacle to non-directive counselling.⁴⁶

It has been argued that non-directive counselling may not be desirable because counselling in this way may omit discussion of controversial issues related to prenatal screening,⁴⁵ such as issues of disability or pregnancy termination.^{40,45} If a woman feels a sense of discomfort or moral distress, she may not be able to identify what issue is causing discomfort, which may prevent her from considering the source of that discomfort when making a decision.⁴⁷ In addition, counselling in a non-directive way may make it difficult for a woman to identify directive elements that may creep unintended into the counselling.⁴⁸ In this way, non-directive counselling may

harbour unacknowledged directive elements and therefore may be more disempowering than a counselling model in which directive elements are explicitly acknowledged so they can be considered by the woman.^{49–51} Women may also perceive the option of prenatal screening as a medical directive, rather than a choice,⁴⁷ even if the information is presented in a non-directive manner. For example, 37.4% of Canadian women surveyed about their reasons for participating in maternal serum screening reported that they participated because the "doctor told me I should have [the] test"⁵²

We propose an alternative model to non-directive counselling that retains the spirit of the SOGC guideline's emphasis on the imperative of informed decision-making by encouraging providers to counsel actively in a way that supports women to make their own informed choice about prenatal screening.

PROPOSED ALTERNATIVE MODEL OF INFORMATIVE DECISION-MAKING AND SHARED DECISION-MAKING

To accommodate the specific circumstances of prenatal screening, we propose an alternative model of decision-making that combines aspects of informative decision-making^{7,8} and shared decision-making^{8–10} (Table).

In informative models of decision-making^{7,8} the health care provider gives the patient scientific and clinical information, and the patient deliberates and makes a decision on her own. In contrast, shared decision-making^{8–10} promotes an exchange of clinical information and personal values from both patient and provider, leading to a shared deliberative and decision-making process.

Shared decision-making was developed in the context of decision-making about life-threatening illness,¹⁰ and while it has much to offer clinicians who counsel about prenatal screening,^{6,53,54} the value-sensitive context of prenatal screening requires careful consideration. Charles and colleagues⁹ conceptualize the process of SDM as consisting of three stages: information exchange, deliberation, and decision-making. Charles and colleagues also recognize the value of flexibility between SDM and an informative approach, stating that in practical use, clinicians may need to change frameworks midstream.⁸ We propose a particular hybrid model for the context of prenatal screening, recognizing that each stage depends on the one before and the end goal of counselling (encouraging the patient to make an autonomous, informed decision) must guide the clinician's approach through all stages of the counselling session.

Proposed hybrid model for informed and autonomous decision-making in prenatal screening

	Non-directive counselling ⁴⁸⁻⁵¹	Informative decision-making ⁷	Shared decision-making ⁸⁻¹⁰	Proposed hybrid model
Information-sharing	Clinician imparts objective, clinical, value-free information	Clinician imparts objective, value-free information	Clinician and woman “exchange” clinical information and values	Clinician and woman share clinical information, personal values (woman), and professional values (clinician)
Deliberation	Woman only; clinician cannot express opinion to avoid being directive	Woman only; deliberation is simplified to “selection” in this model.	Clinician and woman engage in interactive deliberation, suggesting and discussing treatment options and preferences	Clinician counsels actively in a way that supports the woman to fully understand the information and its implications
Decision-making	Women only	Woman only	Clinician and woman together	Woman only

*“Woman” may also include partner or anyone else the pregnant woman decides to include in decision-making.

Légaré and colleagues, who found that both pregnant women and family physicians are willing to participate in SDM when considering prenatal screening, call for more “theorization and development of strategies” to facilitate this process.⁵³ Our proposed hybrid model of decision-making in prenatal screening begins with the information-sharing phase of SDM, uses a particular hybrid of SDM and IDM in the deliberative phase, and ends with the decision-making phase of IDM (Table). Our model modifies “information exchange” from the model of Charles and colleagues⁸ to “information sharing,” to explicitly acknowledge that information can be, but is not always, provided by both parties and to reflect a collaborative approach.

Information-Sharing Phase

The information-sharing phase of the hybrid approach follows the model of SDM in that information is shared between the pregnant woman and her obstetrical care provider, with each sharing both medical knowledge and values. Echoing Freire’s writing on education,⁵⁵ Charles and colleagues⁸ emphasize that patients are not “empty vessels”⁵⁵ waiting to be filled up with technical knowledge. Rather, patients come to the clinician’s office with their own beliefs, values, fears, experience, and, often, medical knowledge from friends, family, or other sources. A woman’s individual perspectives on prenatal screening, parenthood, disability, and abortion will affect the way she interprets the information received from her clinicians; therefore, it is important that clinicians initiate conversations about values and perspectives so that the information shared is more relevant to their patients. Bhogal and Brunger⁵⁶ have written that it is important for clinicians to make an effort to be aware of their own perspectives and to recognize the influence their personal and professional values may have on the ways they think and speak about prenatal screening and testing.⁵⁶ In

SDM, health care providers attempt to be explicit about their values with patients⁸⁻¹⁰ and to recognize that their patients’ values may differ; clinicians using our proposed hybrid approach will be aware that they will later ask each woman to make her own decision and that providing extensive information about the clinician’s own values may unduly influence the woman’s decision. Nonetheless, clinicians using our proposed hybrid approach will keep their personal values in mind, and they might wish to share values related to their clinical expertise and experience, especially when this would assist in exploring the values or opinions the woman expresses during counselling. For example, clinicians might acknowledge that, in their experience, prenatal screening can provoke anxiety, especially for those who are not sure what they would do in the event of a result indicating high risk. This can be an opportunity to explore issues of anxiety, the time frame for receiving results, and feelings about interpreting uncertain results. Genetic counsellors have acknowledged the utility of sharing their own values, calling for support and guidance in doing this productively^{5,57,58} and arguing that patients can make use of the attitudes and opinions of their counsellor without being unduly influenced.⁵¹

Deliberation Phase

In the IDM model,⁷ the patient has full control over deliberation and decision-making, and the clinician’s role is limited to providing additional information, if needed, or correcting misunderstandings. In SDM, the clinician is an active partner in deliberation, suggesting ideas and making recommendations.

As in SDM, our proposed hybrid model envisions the clinician participating actively in the deliberation process. In contrast to SDM, clinicians using the proposed hybrid model will counsel actively without expressing any

preference for a particular course of action. For example, the clinician may encourage a woman to think critically about the implications of particular courses of action and the ways in which her personal values may come to bear on these different choices.⁵⁹ In this way, the provider is a valuable participant in the deliberative phase as a caring, informed individual who has some understanding of the patient's values and a strong understanding of the possible implications of different courses of action.

To illustrate the contrast, there is no deliberation phase in IDM: a clinician provides the information needed to make the choice, assesses the woman's comprehension, and then asks her to deliberate without clinician participation.⁷ In SDM, the deliberation process involves the clinician and the patient sharing thoughts and opinions and discussing the clinician's recommendations.⁸⁻¹⁰ The SDM clinician may offer a recommendation and a rationale, while encouraging the patient to express and discuss reasons for her proposed course of action. The proposed hybrid model is distinct from SDM in that the clinician does not make recommendations but assists the woman in considering the available options and their possible implications, including how these options may fit or conflict with the patient's values.

Of course, some women may prefer that their clinicians take a more or less active role in deliberation. For women who are clear about their values and desires, a prolonged deliberation process may not be necessary or desirable. If the process is to be acceptable to all parties, open communication about roles and expectations is essential.¹⁰ Deliberation may also include other people the pregnant woman chooses to involve in her decision-making: Charles and colleagues⁸ recognize that a patient's decision-making process often includes consultation with family, friends, or other health care professionals.

Decision-Making Phase

At the time of decision-making, our proposed hybrid model follows the IDM model,⁷ which encourages a patient to make an autonomous decision about participation in prenatal screening that reflects her particular situation and values. It proposes that the patient makes the decision on her own, or in consultation with her partner or family (as she prefers), on the basis of the information provided by the clinician. There is no role for the clinician in the decision-making process other than to support and facilitate the course of action chosen by the patient.

Our proposed model further follows the IDM model, because this approach is more suitable than SDM for decision-making about prenatal screening given the

uncertain nature of the results and the morally sensitive nature of the decision. In this type of situation, it is necessary that the provider not have an investment in the decision a woman makes. Prenatal screening is an example of a decision in which clinician investment would "go beyond the boundaries of an appropriate clinical role because the provider might harm the patient by inadvertently steering her in a certain direction."⁷⁸ While the application of a clinician's experience and knowledge to treatment decision-making may be appropriate in other situations, decisions about prenatal screening do not have one best answer or right way forward. They "are too personal and too devastating to be made by anyone other than the woman or the couple involved."⁴¹

CONCLUSION

The SOGC clinical practice guideline on prenatal screening for fetal aneuploidy encourages each woman to make her own decision, informed by comprehensive information about the screening tests and reflective of her personal situation and values. Rather than non-directive counselling as the best model to serve this goal, we propose a hybrid approach that combines informative decision-making and shared decision-making in a strategy to encourage pregnant women and clinicians to discuss prenatal screening in a way that promotes informed choice that is based on a woman's particular circumstances and values. We recognize that the hybrid approach may impose additional requirements on clinician time, but we believe it will assist clinicians in supporting women to make informed choices regarding prenatal screening.

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