

# Limited and Limiting Knowledges: Talking to Clients about Prenatal Screening

**Nadya Burton**

Ph. D., Assistant Professor Midwifery Education Program  
Faculty of Community Services, Ryerson University  
350 Victoria Street, Toronto ON M5B 2K3, Canada  
Phone: 416.979.5000 ext. 7982  
[nadya.burton@ryerson.ca](mailto:nadya.burton@ryerson.ca)

## **Abstract**

*This paper explores reflections from ten Canadian clinicians (nurses, midwives, family physicians and obstetricians) regarding their responses to women who decline prenatal screening. Additionally, it explores self-reported provider reflections on the biases they may bring into communicating with their clients/patients about these screens. Prenatal screening, while most often understood as a positive set of practices designed to provide pregnant women with helpful information about their unborn babies, touches on some of our most deeply held social, political and ethic beliefs. In this paper, prenatal screening is situated within social contexts of risk, disability, eugenics, and informed choice. As highly medicalized societies develop ever more accurate technologies, to test earlier, more accurately, with less risk and less expense, it is argued that we must simultaneously push for broad social reflection and analysis of the values, morals and ethics embedded in these screens.*

**Key Words:** Prenatal screening, informed choice

## **Introduction**

In this time and place, Canada at the beginning of the 21<sup>st</sup> century, the way we think and talk about prenatal screening, clinicians and lay folks alike, is most often positive; we speak the language of choice, control, knowledge and information. Prenatal screening is usually understood as a clinical practice; a range of procedures, which commonly involve some combination of blood work and ultrasound to help a pregnant woman begin walking down the path towards determining whether the fetus she is carrying has a structural or chromosomal anomaly. Undoubtedly, however, prenatal screening is also about life's biggest questions (Rapp, 1999; Katz Rothman, 2001); about what kinds of babies families want and are able to bear and raise; about who should live and who should not; about women's rights to make choices for their own bodies; about the role of parents, families, communities and societies in caring for and raising children born with disabilities. These are monumental issues, and when we bring them into the fold of our thinking about prenatal screening we are no longer talking only or even primarily about the clinical procedures of blood tests and ultrasounds, but about fundamental issues that touch on some of our most deeply held social, political and ethical beliefs.

This paper reflects on a set of interviews exploring how health care providers respond to those choosing *not* to test, as well as some of the biases they confront in themselves as they offer women the choice to test or not. At a rather practical level, it is about how clinicians grapple with the complex work of helping women make the decision that is best for them, about whether to screen or not, within a social context in which screening is both normative and ubiquitous. At the level of social and political

reflection, this paper is also engaged with examining the practice of prenatal screening through the lens of issues such as disability and eugenics, selective abortion and provider capacity to offer informed choice. As we look forward to what is facing us in the decades ahead - as the capacity to test with less risk, greater accuracy, at less cost, for greater and greater numbers of conditions increases, the imperative to engage in critical reflection simultaneously increases in significance. And I would argue that as we move ever forward, striving to offer more and better information to pregnant women and families about their unborn babies, we must simultaneously strive to protect, indeed to honour, the choice *not* to know, not to gather this information which is placed on the doorstep of pregnant women and families.

## **The Prenatal Screening Imperative**

Across Canada, as in many parts of the world with relatively well-funded health care systems, the majority of women are offered the choice to engage in prenatal screening, although certainly not all do. Currently approximately 67% of pregnant women in Ontario undergo some form of prenatal screening (Better Outcomes Registry and Network, 2011). This screening is usually considered a 'first step,' very literally a 'screen' that will provide results that are either reassuring or that indicate that further diagnostic testing is a possibility to gather more conclusive information about the health of the fetus one is carrying. This initial screening, often considered to be a minor intervention, cheap (for the publicly funded health care system), relatively risk-free (blood draw and ultrasound), is often administered routinely, with little fanfare, and indeed for many who take the test, it only stands out later, if the results are positive. In Canada, most clinicians involved in prenatal care - obstetricians, family physicians, midwives and nurses - are expected by their regulating bodies, to offer the screen uniformly. There are, of course, notable

exceptions to the routine offering of the tests, which are both compelling and complex, among these: some cultural or faith communities may have community standards that don't make offering the tests routine; some women come into care too late to be offered these tests; differing kinds of tests are available regionally across Canada; not all clinicians are equally committed to or comfortable with offering the screens. Nonetheless, the medical adoption of prenatal screening in Canada, as in many western industrialized contexts, is firmly established (Browner and Press, 1995; Katz, Rothman, 2001; Kelly, 2009; Gagnon et al. 2010; Markens, Browner and Press, 1999).

Official guidelines from regulatory bodies are clear about the imperative to offer screening routinely (Dick, 1996; Summers, Langlois, Wyatt and Wilson, 2007; Chitayat, Langlois and Wilson, 2011). That there are regional and geographic disparities, that 'more and better' screening may be available in large urban centres, that not all clinicians are equally skilled or interested in offering screening, speaks to the diversity of health care practice across Canada's vast and multiple regions (Winquist, Ogle and Muharajine, 2008; Hull, Davies and Armour, 2012), but does not diminish the directive. The latest guidelines from the Society of Obstetricians and Gynecologists of Canada (SOGC) (Chitayat et al., 2011), are clear *both* about the imperative to offer testing, *and* about the imperative to allow for 'opting out' of screening. The very first recommendation in the 2011 Guidelines reads:

*All pregnant women in Canada, regardless of age, should be offered, through an informed consent process, the option of a prenatal screening test for the most common clinically significant fetal aneuploidies in addition to a second trimester ultrasound for dating, assessment of fetal anatomy, and detection of multiples* (Chitayat et al., 2011).

However it is immediately followed, by recommendation two, by what might be read as a caveat:

*Counseling must be non-directive and must respect a woman's right to accept or decline any or all of the testing or options offered at any point in the process* (Chitayat et al. 2011).

While the much newer College of Midwives of Ontario (CMO) does not have a specific clinical practice guideline pertaining to prenatal screening, practice in this area is understood to be guided by the CMO Informed Choice Standard (CMO, 2005). This standard defines the midwife's role in informed choice to be "facilitative, informative and supportive, in a collaborative and non-authoritarian manner," (CMO, 2005) and includes (excerpted from a fuller paragraph) the following:

*In order to be 'informed,' the client's choice of (...) tests (...) should include a discussion of the following: (...) potential benefits, risks, and alternatives; relevant community standards; relevant research evidence; (...) recommendations from the midwife related to the client's choices; implications, if any, of the client's potential choices; identification of the midwife's bias, if significant* (CMO, 2005).

As with the SOGC Guidelines, the intent is that clinicians offer the test, allow for informed discussion, and then support pregnant women in accepting or declining testing. Unlike many of the decisions that women have to make throughout their pregnancies, decisions that are accompanied by clear recommendations from their clinicians, the decision to engage in prenatal screening or not can be understood to be one that should be as 'un' influenced by provider opinion as possible. "It's too life changing" said one midwife, pointing out that she gives her clients information, devotes a considerable time to educating and talking with them, and then says, "It's a tough decision, and I know it's tough. Good luck with it and let me know what you want to do." (Midwife 3).

In fact, the literature suggests fairly strongly both that clinicians are often not able or willing to devote much time to this discussion with clients (Rowe, Fisher and Quinlivan, 2006; Gagnon et al., 2010) and that pregnant women overwhelmingly are either unaware of having made a choice to screen, are unclear of the implications of the choice to screen, or do not experience screening as an opt-in choice, but rather as routine and normative (Browner and Press, 1995; Goel et al., 1996; Carroll, Brown, Reid and Pugh, 2000; Green et al., 2004; Rowe et al., 2006; St Jacques et al., 2008). Given the clear directives from the regulatory bodies, and perhaps more importantly, the profound significance of this decision to gather information for the purpose of deciding not 'if' one will bear a child, but rather what 'kind' of child one is willing to bear, it seems both that clinicians should feel some degree of confidence in their ability to help women navigate this decision, and that women should feel they have actively made the decision that is best for them.

### Methods

In the winter and spring of 2012 I interviewed ten clinicians (four midwives, two obstetricians, two family physicians and two nurses) about how they offer informed choice or informed consent (as it is often framed in the medical model) about the decision to screen. Purposive sampling was used to identify clinicians who had a particular interest in prenatal screening, who were involved in research or who sat on professional committees that were grappling with these issues. Interviewees were primarily from downtown in Canada's largest urban centre, and were therefore mostly associated with relatively privileged hospitals and clinics that were actively engaged in research and thinking about how to best manage prenatal screening for their clients. The opportunities and constraints of this study are therefore that these are clinicians who offer us not a representative sample of

provider practice in this field, but rather a glimpse into the thinking and experience of a group of clinicians well situated to reflect on their practice.

All clinicians invited, agreed to be interviewed, and all interviews were conducted in person by the researcher (and in one case a research assistant), audio-recorded, transcribed, and analyzed with NVivo qualitative data analysis software (QSR International, Doncaster, Australia). Interviews typically lasted about one hour, and an interview guide was followed, asking primarily open-ended questions, and intended to guide reflection towards the challenges and successes in addressing prenatal screening with clients. Feminist grounded research theory guided the research method, and interviews tended to flow as conversations, allowing the interviewee to include information that they identified as meaningful and important in relation to this topic. Ethics approval for this project was obtained from the Research Ethics Board of Ryerson University.

The data emerging from the ten interviews was very rich, and this paper results primarily from analysis of two particular questions asked during the interview; the first was if there was anything that caused the clinicians to alter their usual informed choice (consent) discussion about prenatal screening, and the second asked interviewees to reflect on how their own personal experiences and beliefs affected the way they provided their informed choice discussions on this topic. The modest number of interviews allowed for detailed reading and analysis of responses to these two questions, out of which emerged two key themes; clinicians' responses to women declining testing, and provider bias in informed choice discussions. The transcripts were read for consistencies and contradictions, and for the variety or range of ways interviewees responded to these two questions. These two themes emerged as particularly interesting and salient for several reasons beyond the 'thickness' of the data. Firstly, the fact that the decision not to test was often an impetus for clinicians curtailing or altering their informed choice discussions both spoke to and supported guidelines from regulatory bodies about prenatal screening. The capacity for providers to offer information, adapt to women's particular choices, and to respectfully support those choices was reflective of both SOGC and CMO guidelines and standards, and thus stood out as potentially demonstrating strong and skilled practice in this area. Secondly, when read against the literature which suggests a less engaged process between pregnant women and their care providers in relation to prenatal screening (Browner and Press 1995; Goel et al. 1996; Carroll, Brown, Reid and Pugh 2000; Green et al. 2004; Rowe et al. 2006; St Jacques et al. 2008), these clinicians demonstrate a high level of thoughtful engagement in the face of those choosing the less usual path; the choice *not* to test. In a time and place of increased access to and increased range of testing, those choosing not to test may highlight the particular practices of clinicians who are able to rigorously offer and support choice in an

area that is often seen to be pre-determined.

Before turning more directly to the experiences of clinicians in relation to women declining testing and provider bias in providing informed choice, it is helpful to explore two of the significant backdrops against which prenatal testing takes place. While prenatal testing is always taken up (or declined) by women within the crucible of family, community and society; screening is of course also always *offered* within social and political context. Frameworks for understanding disability, risk and eugenics are all particularly salient in relation to prenatal screening because they are significant contexts that are often obfuscated behind notions of choice, control and empowerment that most often accompany thinking about prenatal screening. For this reason, they provide us an important lens through which to analyze and reflect upon practices in this area.

### Social Context of Disability

If we were able to bring the two SOGC recommendations together and ensure that clinicians were able to address the both/and implied by their relationship – that we must *both* offer testing to everyone uniformly and routinely, *and* we must create and protect space for people to decline this testing, and if we could truly meet the CMO standards of fully informed choice, we would likely be on our way to processes that could indeed empower women and families and provide them with helpful knowledge and information should they choose it. The stumbling block, however, is that for clinicians to be non-directive and to respect a woman's right to *decline* testing poses an ongoing challenge; and this is in part because we are not, of course, operating on a level playing field. This testing exists against the backdrop of a society that, for the most part, does not cherish those with disabilities (Newell, 1999; Klein, 2011; Garland-Thomson, 2012). Women are expected to test to ensure they have healthy babies – with the usually unarticulated assumption that they may well then go on to abort the 'unhealthy' ones; that is, there is nothing about testing itself that creates or renders more likely a healthy baby, it simply gives one the information to avoid having the 'not healthy' one. Studies on termination following positive diagnosis suggest rates up to 92% (Dommergues et al., 2010; Shaffer, Caughy and Norton, 2006; Skotko, 2009; Statham 2002, Summers et al., 2003), although a recent systematic review (Natoli, Ackerman, McDermott and Edwards, 2012) suggests rates may be declining. Raising a child with a disability in this time and place is understood to be a challenge, something to be avoided if possible, and testing is a 'responsibility' of pregnant women to circumvent this possibility. Despite the fact that the outcome cannot be changed through testing, that the information provided *may* be, but is not *necessarily* helpful to pregnant women, the highly individualized responsibility for 'healthy' pregnancies that falls squarely on the shoulders of pregnant women usually includes gathering all possible information. To refuse, to choose *not* to test, contravenes a profound social norm – pregnant women must act, as thoroughly as possible, in ways that ensure a healthy pregnancy (Browner and Press, 1995).

Against this normative backdrop, what influences the ways in which clinicians offer the choice to test or not,

and how do they respond when women choose not to test? Simply providing the two options, and asking women to choose; test or not test may not really create a space for choice; in some sense the choice is predetermined by a social context in which one of those two choices is so clearly the normative one. When presenting this issue to pregnant women, clinicians might have to actually talk longer, explain more, possibly even overtly speak *on behalf* of not testing in order to raise it to the level of serious consideration.

### Social Contexts of Risk and Eugenics

The new landscape that prenatal testing has created comes with some perhaps unintended side effects. One of these is the need to raise the possibility of fetal anomalies, and ultimately of the decision about termination, in the very first few prenatal visits. Added then, to the tasks of early pregnancy is the task of thinking through and making decisions about what kind of pregnancy one is willing to carry. One midwife comments that she finds it “very difficult and problematic that we’re having that discussion at the very, very start of care” (*Midwife 2*);

*I started [work as a midwife] when the first few visits were almost uniformly positive, hopeful and reassuring. I find it quite difficult to look at this chart and talk about how there’s a 2-3% chance in every 100 of a baby having a congenital anomaly. So the conversation about pregnancy has now been transformed into a discussion of numbers. It’s been transformed into a discussion of statistics, and risks, and the potential for bad news. (Midwife 2)*

The necessity to address screening interpolates women and families into profound decisions about parenting and disability and abortion – in the very first moments of their pregnancies. And in this way, the very existence of the tests, their newfound normative ubiquity, changes the landscape of pregnancy, both contributing to and enmeshed within, the culture of risk that has transformed so many aspects of modern society.

In situating prenatal screening as a straightforward and individual clinical practice unencumbered by social baggage, we are sidestepping some very important social discussions. In focusing, as clinicians may tend to do, on the tremendous complexity of these tests (whether to select the one you can get results from earlier but that comes with more false positives, or the more accurate one that will leave you less time to terminate), on the important explanations of the distinction between screening and diagnostic tests, and on helping pregnant women make sense of concepts such as risk, and false positives, of the possibility of abortion – we have put aside, for the most part, discussions of eugenics.

When we really start to think about the

issues raised by prenatal screening, it seems impossible *not* to think about eugenics; and yet we do it all the time. The desire to separate genetic screening from eugenic implications is both prevalent and understandable given its complex and troubled history of associations with the atrocities of the Second World War. Our collective struggle to distinguish the history of fascist eugenics and racial cleansing from the liberal and humanist program for the pursuit of health and happiness makes it troublesome to think consciously about screening and eugenics at one and the same time. But prenatal screening is about, at least in part, creating a norm away from which others will deviate. In our attempts to spare women pain, to avoid the suffering of those with disabilities, to “improve the human condition” (Atkin 2003: 95), embedded in these compassionate and well-meaning desires we “create the potential for ‘deviance’ and ‘pathology’, which prioritizes the well-being of a dominant group over the individual – something that, at its most extreme, has parallels with the eugenics project” (Atkin 2003: 95). As a society, these are questions we must be grappling with, and they are issues that coexist, however uncomfortably, alongside our decisions to reflect upon, grapple with, make use of, and refuse testing (Katz Rothman 1989, Browner and Press 1995). When clinicians offer screening, and women and families make decisions about whether to use them or not, these issues of disability, of risk and eugenics are at play; in many ways creating an unarticulated backdrop against which discussions are held and decisions are made.

### Talking to Clinicians: Declining the Test

When pregnant women refused testing, clinicians in this study reported that they were fairly comfortable stepping back; they seemed to be able to incorporate the both/and of the SOGC guidelines to, on the one hand routinely offer screening through a process of informed consent (choice), and on the other, respecting women’s choices to decline testing. They tended to depart from their usual informed choice/consent discussion about screening, especially when the decision was one the pregnant woman had likely made in advance, or when the woman seemed certain.

*I’ll ask the question about genetics, and [if] the answer is a clear cut ‘no,’ they would not do any kind of screening anyway, regardless – at least I’ve presented them with the options and I tell them to go home, and if they change their mind, they [can always talk more]. (Nurse 2)*

*She may cut me off and say, ‘ok, I’m not interested, I’m not doing that, we don’t need to talk about it any further.’ And then I’d say ok, fine. (Midwife 3)*

*...if they’re starting to respond to some of the things I’m saying, [then] that might influence what I say. Like if they’re simply not interested, the conversation gets stopped right away. (Obstetrician 1)*

These reflections emerged in response to

questions about what might lead a clinician to alter his or her usual or planned informed choice/consent discussion in relation to testing. Consistently clinicians reported attempting to give very 'balanced' information about screening and to set up the decision to screen or not as one that truly fell to the client. Whether the clients who refused did so as result of a well constructed informed choice discussion, as a result of strongly held beliefs that made testing undesirable, or whether they knew before arriving to care that they would not screen, is not captured through this study. What we see, however, are providers self-reporting that they are striving to offer choice; that they want to avoid the "undesirable situation that these prenatal tests may be performed 'routinely,' in the sense that the possible consequences are not considered before testing" (Verweij, Oepkes and de Boer, 2013: 398). They seek to follow through on the intent to create good conditions for client choice by shifting their usual screening talk when clients' preferences and choices begin to emerge.

Of the ten clinicians interviewed, there was only one who said that in some circumstances she would *encourage* screening, regardless of the client's leanings. While she would be fine with younger women making the choice not to screen, when she was working with older women or anyone who had a relevant family history, even if they had stated that they would not go on to diagnostic testing and would not terminate as a result of the tests, this clinician acknowledged "I would kind of encourage them in that area – to have more testing done." She added, "I will always, if they decline, [get] them to sign a waiver that we have discussed it and they have declined it." (Nurse 1)

This response, a stronger push or encouragement to women to screen, or to meet with a genetic counselor to help with the decision, in seeming contravention of SOGC guideline two and the CMO Informed Choice Standard, to respect women's choice to decline screening, was unique amongst this group of clinicians. It is here that we can see with perhaps particular clarity the social contexts of both risk and disability at play. Both maternal age and family history serve as notable markers of potentially increased risk for fetal anomaly, and while choice for younger mothers with no particular risk factors may be easier for some clinicians to accommodate, in this case a dis-ease with choice, or with a 'not knowing' that may result in undetected fetal anomaly was present. More common, however, was the response that 'declines' simply get charted (without the woman having to sign anything). One midwife explained her approach when women were sure either way (sure they wanted to test or sure they didn't):

*I think, to be honest, sometimes someone will say something with such clarity that I think it would be wrong to keep going at it. And so just as I would with someone who*

*said, 'I want genetic screening,' [in that situation] I don't go back and say, 'Are you sure, you know, within our society this could harm our social policy ability for disabled people?' No, I don't go back to that. So I think I do that kind of in the same way [with people who decline]. (Midwife 2)*

The reasons given for women's decision not to test (and these are of course filtered through the eyes of the clinicians) varied considerably, and for the most part didn't generate much surprise or concern for the practitioners in this study (see Rapp 1999 for good discussion of the myriad and complex reasons women refuse testing). Some of the reasons seemed to garner more respect – for example when women were choosing not to engage with screening because their faith or culture discouraged abortion; while others were seen as somewhat misguided – for example, women who claimed there had never been a problem in their previous pregnancies, or in any of their relatives' pregnancies. Regardless, however, of the reasons given, the majority of the clinicians self-reported respectful response to women choosing not to test. It is notable that nine of the ten clinicians interviewed all reported feeling comfortable, profoundly at ease in fact, with women choosing *not* to know. Perhaps this should not surprise us – these are clinicians many of whom have devoted considerable time and thought to ways to ensure that women are in fact engaging in an active rather than passive choice. This self-reported comfort might demonstrate a particularly successful implementation of prenatal screening. If we accept that "[c]ounseling for prenatal screening to facilitate informed reproduction choices should maintain the fundamental basis of prenatal screening programs, [s]pecifically, women should retain their 'right not to know'" (Verweij, Oepkes and de Boer, 2013: 398) then these providers are striving to engage in fully informed choice that results in both choosing to know, and choosing not to know.

#### Talking to Clinicians: Provider Bias

Despite the comfort with women declining, providers were aware of their own biases, and of the influences in their lives that may have impacted the way they think about and even present the testing options to their clients. Some of these influences were clinical and came from their experiences providing care over many years; sometimes the effects of the more risky diagnostic testing (amniocentesis) influencing how they felt about the initial screening tests:

*I've participated in a couple of miscarriages following amnios. So I don't think it put a bias on me trying to ever convince someone to not [screen]... I try to be very, very neutral. But it's certainly had an effect on me for sure, watching somebody go through a miscarriage following an amnio. (...) And when I do sway, I'm pretty strict with myself to point out, this is maybe a bias of mine or this is the experience that I had rather than, you should... (Midwife 3)*

*I've also done some medical legal work and there were a few cases that came up around wrongful birth and the failure to test or inform people that the testing was available. And I had a personal experience in my practice of a woman [who didn't get testing], it was forgotten. And she had a kid with spina bifida. And that really struck home. I mean the significance of these things, you know, what its effects are. (Family Physician 1)*

In other cases, clinicians were reflective about their own personal belief systems, their systems of morals and ethics – all so centrally entwined with this issue – as undoubtedly having an impact on how they think about and present screening.

*In my heart I can't really believe that we could be [testing for] eugenic [reasons], I can't believe we could be that way. I know trisomy 21 [can bring] huge health issues, but they are just a lovely population group, the loveliest people I know. I never ever talk about it this way, but I'm sure there's a bias that probably creeps in a little bit. (Midwife 3)*

Often, clinicians echoed the socially (and medically) normative idea that information can really only be helpful, that there is not only no harm in knowing, but that *not* knowing somehow disadvantages one. That there could be value in the 'not knowing'; that it might leave one more free to relish the pregnancy, to come to love the baby that one has, to worry less (Katz, Rothman, 2001), is not a broadly accepted notion in our current social and medical climate. We live in a social and cultural context where it is almost always understood to be better to know than not to know. The desire *not* to know is for the most part understood to stand out from, and against, the prevailing values of our time; it is often read as a kind of epistemic irresponsibility, a choice that resonates with archaic anti-modern values of faith and irrationality against reason. Choosing not to know is to remain ignorant, parochial, to have our heads buried in the sand. And so, as this obstetrician articulates, knowledge here is a right, and perhaps in the case of prenatal screening, even a responsibility:

*[W]omen need information. Everyone should have information. It doesn't matter whether they're black or blue or forty or twenty. Everyone should have the same information and they're entitled to it. That's just my basic belief. And then they need to make a decision about what they want to do with that information. (Obstetrician 1)*

As expected, the context of abortion is inevitably present in discussions of prenatal screening, constituting as it does, a site of some moral and ethical concern. While abortion debates are

notably less volatile and considerably more muted in Canada than in some other contexts, clinicians included their beliefs in relation to this issue as a place from which bias might originate. In particular feelings about abortion were acknowledged as barriers or facilitators as clinicians were acutely aware that testing was the first step in a potentially much larger decision that could encompass decisions about termination. This clinician was careful, as were all those interviewed, to acknowledge her ongoing efforts to ensure her own biases did not creep into her care:

*I'm Catholic; I cannot bring myself to do an abortion. During my training I avoided it. It's just not something that I can personally do. But I strongly believe that my beliefs should not come in to it, they should have nothing to do with it. (...) I cannot, I never have, performed an abortion but I can't stop other people from having to make their own decision about it. It's not my decision. So I don't have trouble with this, you know. I don't know, one day if my maker will have trouble with it but I just feel that it isn't my decision. My job is to provide information, educate, counsel. But then the person has to make the decision of what they want to do. (Obstetrician 1)*

*I think my own beliefs and experiences actually are really open in this area... I'm pro-choice; I don't have a problem either way, so I think that helps me. I did work with a colleague in genetics education who was not pro-choice, and who found it extremely difficult to have the prenatal screening conversation. I talked to him about how your own personal biases can affect how you give the information and can then affect the choice. So I think you need to do a little soul searching to think about how you feel. (Family Physician 2)*

While beliefs about abortion creep into the room as clinicians provide informed choice discussions about testing, an equally sizeable issue that lurks within these discussions is disability. Dis-ease and discomfort with disability exist of course, amongst clinicians as much as amongst the general population. Desires for perfect babies, for lives filled with less economic hardship, with raising children into autonomous and productive members of society, fears of difference, of grief and pain, state and social inability to support those with disabilities - all mark disability as problematic. Additionally, concerns about liability, responsibility for 'poor' outcomes and professional responsibility to ensure pregnant women have all the information they need follow obstetrical clinicians everywhere. So it is imperative to ask how beliefs, personal as well as professional, enter clinicians' practice in offering screening:

*I had to examine my own thoughts about disability. I had someone who contacted me ... who is quite an advocate for an open and honest discussion about the disabilities and disorders and feeling that physicians don't always give a full enough idea about the positive side. And she had a child with*

*quite a severe chromosomal disorder and felt the assumption was that she would abort that child. So that experience with that woman really made me think about how I talk about it. Just to sort of challenge me to say, are you being neutral or, what are you doing here? I mean you also don't realize your own biases so it's good when someone forces that a little bit. (Family Physician 2)*

Generally, the clinicians interviewed were both humble about their biases and were often willing to acknowledge them, but were usually fairly certain that their biases weren't affecting the way they provided informed choice about testing. However, on a revealing note that should give us pause, one of the clinicians interviewed remembered sitting on an interdisciplinary committee that was addressing prenatal screening in the early 1990s. She recalled:

*So I remember being at the table and the midwife saying, you know I present it neutrally to everybody and no one has it. And the obstetrician said, well I present it neutrally and everyone has it. No one said well I present it neutrally and you know 50 [percent of women have it]... and we all just laughed. And we said well how are you presenting it? And we gave our story and we could see that we all thought, in all honesty that we were being neutral. So I mean it's pretty humbling when you really examine it, where are the biases that you don't realize? (Family Physician 2)*

### Conclusion

Every once in a while we go through a deep cultural shift, often one based on the availability and widespread use of a new technology; a stepping through the looking glass moment, from which there is no return. Those of us of a certain age might think of the arrival of the internet as such a shift, taking place in a microscopically short period of time in any historical sense; a shift we have lived through and can

examine, we remember ourselves both before and after in a way our children will never be able to do. These are moments of deep cultural transformation; when the terrain of what we know and how we understand the world seems to irrevocably shift. Often, perhaps always, that shift happens before, not after, the debates about the impact of the change, before not after the reflections on the values, morals and ethics that accompany the brave new world. However in our self-reflexive society, these discussions come quickly, following hurriedly on the heels of the new landscape.

Prenatal screening is, as noted, both normative and ubiquitous in Canadian prenatal care. That there are pockets and places where screening is not available, or is less available, does not belie this reality, in fact lack of access to such screening would most often be presented as a problem to be addressed as any health care deficiency might be. The kind of prenatal screening women have access to today is a matter of years old (Chitayat et al., 2011). It's predecessor is only decades old (Summers et al., 2007). And we sit on the cusp of widespread availability of ever 'improved' screens; screens that can be used earlier in a pregnancy, with more accuracy, to test for more conditions. In some ways we are in the midst of a social experiment, one that *should* be accompanied by a strong social dialogue. One midwife suggested that one of the problems with the way new technologies are applied in maternity care has to do with what she called the highly 'scientized' way in which technology gets applied. The practice is looked at primarily through the lens of technology and science; it gets, in some ways, depoliticized. I would argue that the effect of this, the effect of diminished or limited social discussion of prenatal screening, is that the complex social questions, the ones that can't be answered by appealing to science or technology, are downloaded onto the hearts and bodies of individual women and families – and that by privatizing this very social topic, we are missing an opportunity for a social conversation that should help to inform the very practical day to day work of obstetrical care providers, as they work in the front lines, to carefully, respectfully and skillfully help pregnant women and families make decisions about prenatal screening and all that may follow on its heels.

### References

- Atkin, K. (2003). Ethnicity and the politics of the new genetics: principles and engagement. *Ethnicity and Health*, 8(2): 91 - 109.
- Better Outcomes Registry and Network. Highlights from the BORN Ontario LHIN Region Reports for 2009-2010. August 2011. Retrieved on June 15, 2012 from: [http://www.bornontario.ca/documents/LHIN%202009-2010%20Reports/Perinatal%20Health%20Report%202009-2010\\_Provincial%20Overview%20Presentation.pdf](http://www.bornontario.ca/documents/LHIN%202009-2010%20Reports/Perinatal%20Health%20Report%202009-2010_Provincial%20Overview%20Presentation.pdf)
- Browner, C.H. and Press, N.A. (1995). The normalization of prenatal diagnostic screening. In Ginsburg, F. and Rapp, R. (eds), *Conceiving the New World Order: The Global Politics of Reproduction*. (pp. 307-321) Berkeley: University of California Press.
- Carroll, J.C., Brown, J.B., Reid, A.J., Pugh, P. (2000). Women's experience of maternal serum screening. *Canadian Family Physician*, 46(3): 614-620.
- Chitayat, D., Langlois, S., Wilson, R. (2011). Genetics Committee of the Society of Obstetricians and Gynaecologists of Canada; Prenatal Diagnosis Committee of the Canadian College of Medical Geneticists. Prenatal screening for fetal aneuploidy in singleton pregnancies. SOGC Clinical Practice Guidelines, No. 261, July 2011. *Journal of Obstetrics and Gynaecology Canada*, 33: 736-50.
- College of Midwives of Ontario (CMO). (2005). Informed Choice Standard. Registrant Binder. Retrieved on December 10, 2013 from: <http://www.cmo.on.ca>

- Dick, P.T. (1996). Periodic health examination, 1996 update: prenatal screening for and diagnosis of Down syndrome. Canadian task force on the periodic health examination. *Canadian Medical Association Journal* 154(4): 465 - 479.
- Dommergues, M., Mandelbrot, L., Mahieu-Caputo D., Boudjema, N., Durand-Zaleski, I. (2010). Termination of pregnancy following prenatal diagnosis in France: how severe are the fetal anomalies? *Prenatal Diagnosis*, 30(6): 531 - 539.
- Gagnon, S., Labrecque, M., Njoya, M., Rousseau, F., St-Jacques, S., Légaré, F. (2010). How much do family physicians involve pregnant women in decisions about prenatal screening for Down syndrome? *Prenatal Diagnosis*, 30(2): 115 - 121.
- Garland-Thomson, R. (2012). The case for conserving disability. *Bioethical Inquiry*, 9(3): 339 - 355.
- Goel, M., Glazier, R., Holzapeel, S., Pugh, P., Summers, A. (1996). Evaluating patient's knowledge of maternal serum screening. *Prenatal Diagnosis*, 16(5): 425 - 430
- Green, J., Hewison, J., Bekker, H., Bryant, L., Cuckle, H. (2004). Psychosocial aspects of genetic screening of pregnant women and newborns: a systematic review. *Health Technology Assessment* 8(33): 1 - 109.
- Hull, D., Davies, G., Armour, C. (2012). Survey of prenatal counselling practices regarding aneuploidy risk modification, invasive diagnostic procedure risks, and procedure eligibility criteria in Canadian centres. *Journal of Obstetrics and Gynaecology Canada*, 34(7): 626 - 636.
- Katz Rothman, B. (1989). *Recreating Motherhood: Ideology and Technology in a Patriarchal Society*. New York: Norton.
- Katz Rothman, B. (2001). Spoiling the pregnancy: prenatal diagnosis in the Netherlands. In Devries, R. (ed.), *Birth By Design: Pregnancy, Maternity Care, and Midwifery in North America and Europe* (pp. 180 - 198). New York: Routledge.
- Kelly, S. (2009). Choosing not to choose: reproductive responses of parents of children with genetic conditions or impairments. *Sociology of Health and Illness*, 31(1): 91 - 97.
- Klein, D.A. (2011). Medical disparagement of the disability experience: empirical evidence for the 'expressivist objection'. *AJOB Primary Research*, 2(2): 8 - 20.
- Markens, S., Browner, C., Press, N. (1999). 'Because of the risks': how US pregnant women account for refusing prenatal screening. *Social Science and Medicine*, 49(3): 359 - 69.
- Natoli, J., Ackerman, D., McDermott, S., Edwards, J. (2012). Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995-2011). *Prenatal Diagnosis* 32(2): 142 - 153.
- Newell, C. (1999). The social nature of disability, disease and genetics: a response to Gillam, Persson, Holtug, Draper and Chadwick. *Journal of Medical Ethics*, 25(2): 172 - 175.
- Rapp, R. (1999). *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*, New York: Routledge.
- Rowe, H., Fisher, J., Quinlivan, J. (2006). Are pregnant Australian women well informed about prenatal genetic screening? A systematic investigation using the multidimensional measure of informed choice. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 46(5): 433 - 439.
- Shaffer, B., Caughey, A., Norton, M. (2006). Variation in the decision to terminate pregnancy in the setting of fetal aneuploidy. *Prenatal Diagnosis* 26(8): 667 - 661.
- Skotko, B. (2009). With new prenatal testing, will babies with Downs syndrome slowly disappear? *Archives of Disease in Childhood*, 94(11): 823 - 826.
- St-Jacques, S., Grenier, S., Charland, M., Forest, J.C., Rousseau, F., Legare, F. (2008). Decisional needs assessment regarding Down syndrome prenatal testing: a systematic review of the perceptions of women, their partners and health professionals. *Prenatal Diagnosis*, 28(13): 1183 - 1203.
- Statham, H. (2002). Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences. *Fetal and Maternal Medicine Review*, 13(4): 213 - 247.
- Summers, A., Farrell, S., Hunag, S., Meier, C., Wyatt, P. (2003). Maternal serum screening in Ontario using the triple marker test. *Journal of Medical Screening*, 10(3): 107 - 111.
- Summers, A., Langlois, S., Wyatt, P., Douglas Wilson, R. (2007). SOGC Genetics Committee, SOGC Committee on Prenatal Diagnosis; SOGC Diagnostic Imaging Committee. Prenatal Screening for Fetal Aneuploidy. SOGC Clinical Practice Guideline no. 187, February 2007. *Journal of Obstetrics and Gynaecology Canada*, 29: 146 - 61.
- Verweij, J., Oepkes, D., de Boer, M.A. (2013). Changing attitudes towards termination of pregnancy for trisomy 21 with non-invasive prenatal trisomy testing: a population-based study in Dutch pregnant women. *Prenatal Diagnosis*, 33(4): 397 - 399.
- Winquist, B., Ogle, K., Muharajine, N. (2008). Exploring physicians' views and values in relation to maternal serum screening. *Journal of Obstetrics and Gynaecology Canada*, 30(7): 564 - 572.