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Exploring informed choice in the context of prenatal testing: findings from a qualitative study

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Abstract

Purpose This study explored whether and how a sample of women made informed choices about prenatal testing for foetal anomalies; its aim was to provide insights for future health policy and service provision.

Methods We conducted semi-structured interviews with 38 mothers in Ottawa, Ontario, all of whom had been offered prenatal tests in at least one pregnancy. Using the Multi-dimensional Measure of Informed Choice as a general guide to analysis, we explored themes relevant to informed choice, including values and knowledge, and interactions with health professionals.

Results Many, but not all, participants seemed to have made informed decisions about prenatal testing. Values and knowledge were interrelated and important components of informed choice, but the way they were discussed differed from the way they have been presented in scientific literature. In particular, 'values' related to expressions of women's moral views or ideas about 'how life should be lived' and 'knowledge' related to the ways in which women prioritized and interpreted factual information, through their own and others' experiences and in 'thinking through' the personal implications of testing. While some women described non-directive discussions with health professionals, others perceived testing as routine or felt pressured to accept it.

Conclusions Our findings suggest a need for maternity care providers to be vigilant in promoting active decision making about prenatal testing, particularly around the consideration of personal implications. Further development of measures of informed choice may be necessary to fully evaluate decision support tools and to determine whether prenatal testing programmes are meeting their objectives.

Introduction

Background and purpose

Although screening programmes have historically focused on promoting uptake to maximize population benefit, there is an increasing emphasis on the alternative goal of promoting informed choice, particularly where 'effectiveness' depends on how individuals value different outcomes.[1–3] Prenatal screening programmes for conditions such as Down syndrome (DS) and open neural tube defects (ONTDs) cannot ensure the health of foetuses screened. Rather, they provide information potentially useful for reassurance, or for decision making around continuing or terminating affected pregnancies and/or preparing for the care of a child with a disability. Evaluations of prenatal screening programmes therefore need to address how well services achieve the goal of promoting informed choice. Toward this end, Marteau and colleagues developed and validated the multidimensional measure of informed choice (MMIC)[4,5] based on the premise that an informed choice is 'one that is based on relevant knowledge, consistent with the decision-maker's values and behaviourally implemented'.[4,adapted from 6] The MMIC items (Box 1) include measures of both knowledge (derived from professional consensus[7]) and specific attitudes (believed to reflect combinations of underlying salient values).[4] Other studies of knowledge and consistency between values and behaviour in the prenatal screening context have used similar approaches.[8–10]

We conducted a study to explore whether and how a sample of women in Ottawa, Ontario made informed choices about prenatal testing. We used concepts from the MMIC,[4] including values, knowledge and behaviours, as a general framework for understanding women's testing experiences. We also explored women's interactions with health-care providers and the way in which testing appeared to be framed within the broader system of maternity care. Our aim was to generate knowledge useful for informing discussions of the design, delivery and evaluation of prenatal testing programmes.

Box 1 Summary† of multidimensional measure of informed choice (MMIC) items[4]

Knowledge
The conditions which the test screens for
The probability of a negative screening result
The meaning of a low risk result
The probability of a positive screening result
The meaning of a high risk result
Probability that baby has Down syndrome (DS) for women with a positive screening result
Possible consequences of amniocentesis or chorionic villus sampling (CVS)
What would be offered if the tests show the baby has DS
Attitudes
For me, screening test will be
Beneficial – harmful
Important – unimportant
Bad thing – good thing
Pleasant – unpleasant

†Topics addressed by MMIC items are given here; refer to Marteau *et al.*[4] for actual questions

Methods

Study setting

Since the early 1990s, pregnant women in Ontario, Canada (including the city of Ottawa) have been offered screening for DS and ONTDs.[11,12] Maternal Serum Screening (MSS or triple-marker screening), based on a blood test performed after 15 weeks gestation, was later replaced by Integrated Prenatal Screening (IPS), which involves blood tests (11–14 weeks gestation) and an ultrasound screen (15–17 weeks gestation). Women with positive screening results are referred to clinical genetics services for further counselling. Those who screen positive for DS are offered diagnostic testing by amniocentesis at 15–20 weeks of pregnancy, with a miscarriage risk of approximately 0.5–1 in 100 procedures.[13,14] Women known to be at higher risk for DS (i.e. women older than 35 years of age or who have previously had an affected child) may choose diagnostic testing by amniocentesis or chorionic villus sampling (CVS) (CVS is performed earlier in pregnancy, but with a higher risk of miscarriage)[14] without screening.

Sample selection

The study was approved by the Ottawa Hospital Research Ethics Board. Women who gave birth at the Ottawa Hospital in 1994–95 or 1999–2000 were identified through its obstetrics database; the two time periods correspond approximately to the periods of MSS and IPS screening, respectively. At the first stage of sampling, English-speaking women who were at least 18 years of age were invited by a letter from the chairman of obstetrics and gynaecology, who was independent of the study, to be screened for study eligibility. The names of women who consented to be screened were then released to the research team, who reviewed their charts for eligibility. Women were excluded if the charts indicated a history of stillbirth or early neonatal loss (to avoid potential emotional or psychological distress) or pregnancy affected by major congenital anomaly (these women would not have undergone 'routine' testing). Women with a history of previous miscarriage were eligible as miscarriage is a relatively common event. Potential participants ($n = 52$) were then contacted by telephone to arrange for an interview; 38 interviews were completed. Data analysis took place concurrently with the interview process, such that the decision to stop interviewing was made when we judged that new themes were no longer emerging from the data. This purposive sampling strategy resulted in a sample of women at varying ages and stages of family completion, all of whom had been offered prenatal tests and had some time to reflect upon their experiences.

Data collection and analysis

A research assistant conducted 30- to 60-min semi-structured interviews with participants during 2004 and 2005. Women discussed their understanding about genetics and prenatal screening and testing, their own experiences with pregnancy, screening and testing and their values about the appropriate use of prenatal and other genetic tests. We also collected limited demographic data, including current age, number of children, age of youngest child and current employment. We did not capture data on either level of education (to avoid any perception that women were being 'tested') or religious affiliation (we felt it was more appropriate for women themselves to identify this if relevant). Interviews were audio taped, fully transcribed and verified for analysis.

The transcripts were read multiple times by BP and NO. Themes relevant to informed choice in prenatal testing were identified across interviews by consecutively coding the first 22 transcripts: a list of categories was organized into themes, which were reviewed and redefined as the analysis progressed (Box 2). Although the coding process was guided by the MMIC components (values, knowledge and behaviour)[4], we allowed the meanings of these concepts to emerge inductively from our interview data. Thus, our eventual notions of 'values' and 'knowledge' differed from the conceptual and operational definitions used in the MMIC (see Discussion). Transcripts were coded by one researcher and verified by the other (QSR NVivo v2.0.163; QSR International, Cambridge, MA, USA). Following agreement on the final set of categories and themes for this set, the coding scheme was applied to the remaining 16 transcripts, using the same process.

In addition, each transcript was summarized as a whole, and BP and NO independently judged whether or not the participant had made an informed choice (discrepancies were resolved by discussion). Finally, for those women who reported discussing prenatal testing decision/s with a maternity care provider, we explored these discussions, including how prenatal testing was perceived in the context of maternity care.

Box 2 Example demonstrating coding process for analysis of transcripts

As an example of how transcripts were coded, 'pregnancy experiences' was a category used to code women's comments about aspects of their pregnancies that were relevant to their decisions about prenatal testing. This category was later included within the higher order theme of 'experiential knowledge'.

Results

At the time of the interview, the 38 participants were aged 30–47 years, had families of one to four children, and were either pregnant or had a youngest child aged 9 years or younger (Table 1). Twenty-five participants had a prenatal screening and/or diagnostic test in at least one pregnancy explicitly for foetal anomaly detection. Women often discussed multiple pregnancies and/or testing experiences collectively, as they shared common elements relevant to decision making. Thus, to reflect women's own accounts of their experiences, we did not distinguish between screening and diagnostic tests (collectively termed 'tests') in our analysis.

The values that underpinned women's attitudes towards testing were broadly expressed in terms of women's moral views about pregnancy termination and/or their beliefs about how 'life should be lived'. Knowledge was considered women's 'understanding of the implications of testing' (p. 17, [15]), not simply the recall of technical information. In exploring 'sufficient knowledge' for making an informed choice, we therefore considered how each participant integrated *relevant* technical information with a process of *thinking through* the personal implications of prenatal testing, demonstrating 'personalized knowledge'. To account for situations where values made some technical information unnecessary (e.g. for women who declined testing based solely on strongly held values against pregnancy termination), we judged the technical knowledge that was relevant for each woman on the basis of her expressed values.

Table 1 Brief description of the sample (n = 38)

Current age	Range: 30–47 years Median: 39 years
Number of children	Range: 1–4
Ages of youngest children	Range: 1–9 years (three women pregnant) Youngest child aged ≤2 years or pregnant: 13 participants Youngest child aged 3–5 years: 15 participants Youngest child aged ≥6 years: 10 participants

Values

Acceptability of pregnancy termination and the role of fate

Values were reflected in two major themes: acceptability of pregnancy termination and the role of fate. Many women directly associated testing decisions with potential decisions about abortion. This discourse fell into four categories:

Abortion was unacceptable, therefore testing information would have no value:

> …it's my belief that abortion is not an option…it's hard for me to think about killing anything and to me that's what it would be all about, whether it was perfect or not. (41 years old, 3 children, youngest child 7 years old)

Abortion was acceptable:

> I wasn't very much conflicted (…) I wanted to know, if I could know. And I would have terminated the pregnancy so it was a pretty easy choice. (45 years old, 2 children, younger child 2 years old)

Abortion at a late stage of pregnancy was undesirable, so the timing of testing information was crucial:

> Now if it had been a positive, we would have been in a mess…the thought of aborting an old fetus really turns me off, personally. I don't know that I would have done that. (35 years old, 2 children, younger child less than 1 year old)

Abortion was the 'moral' choice in terms of an affected child's likely quality of life:

> …I would have thought about it before I made my decision, but I think my decision probably would have been to abort the baby. (…) I didn't want to bring somebody into the world who would not be able to enjoy life as one would expect. (…) I don't think it would be fair to a child. (40 years old, 3 children, youngest child 5 years old)

A belief in 'fate' was summed up by the idea that 'things happen for a reason'. It was discussed in connection with both declining and accepting testing:

> I honestly think that a lot of things happen for a reason, and I do believe in fate, and I think that sometimes if we test too much and things aren't accurate enough then it causes way too many problems for people. (37 years old, 2 children, younger child 7 years old)

The role of religious beliefs

Some women explicitly associated values with religious beliefs. This was particularly evident in discussions about the morality of pregnancy termination but was not exclusively associated with declining testing:

> God has chosen you to have children and He's decided what kind of children you should have…if He decides to send you a child that's not quite as healthy as we'd want well gee, life's not perfect, you know? (37 years old, 3 children, youngest child 1 year old)

> I don't know what I would have done. I mentioned that I was practising Catholic,(…) I had emotional debates as to what I was going to do with this information, and should I even have this information. (44 years old, 2 children, younger child 6 years old)

Knowledge

Women often spontaneously discussed technical issues (e.g. false positive results, risk of procedure-related miscarriage) and demonstrated their understanding of the concepts. However, the discourse was dominated by what knowledge women actually wanted and the ways in which they prioritized and interpreted information. To understand prenatal testing, women integrated 'factual' information with 'personal' information. Two key themes identified the ways in which women acquired 'personalized knowledge': 'experiential knowledge' and 'imagining coping'.

Experiential knowledge

Experiential knowledge captures how women drew on both *personal* experiences (either in previous pregnancies or with the tested conditions) and the experiences of *others* to interpret testing information. For example, for one woman with a personal history of multiple miscarriages, the knowledge that amniocentesis carried a miscarriage risk was prioritized:

> …'cause I had so many miscarriages, I didn't want to take any risk that was going to make me have a miscarriage (…) any risk was too high. (36 years old, 3 children, youngest children 1 year old twins)

Another participant had personal experience working with people with DS. She prioritized information on disease severity, which testing could not supply:

> …as she had explained it, it doesn't tell you the severity, it just tells you that you have the chromosomal abnormality but not if it's going to be high-functioning or low-functioning and then we thought well if they're high-functioning we're terminating the pregnancy because of their appearance, I guess…so I said enough of that…because I work or I coach with high-functioning Down Syndrome and a lot of them do well. They are productive members of society. (40 years old, 2 children, younger child 3 years old)

The experiences of *others* also provided 'knowledge' that influenced decision making. For example, one woman recounted her friends' experiences with false positive results:

> I was afraid of the extra stress with the false result that you could receive…I've heard a lot of friends of mine that have done the tests and that have been scared throughout their whole entire pregnancy because of this false positive, and everything turned out being fine at the end. (30 years old, 3 children, youngest children 2 year old twins)

Another woman 'knew' the difficulties in raising a disabled child through her friend's experience:

> …having a best friend with a [child with] Down syndrome, discussing it with her what are the impacts on your life and what you give to your other child as a life, it was easy to decide, that we didn't want to go that way, we preferred to go through the abortion. (41 years old, 1 child, pregnant at time of interview)

Imagining coping

Imagining coping describes how women used self-reflection as they *thought through* the testing process to better understand the personal consequences of different potential outcomes. Women reflected on their own and their family's needs and coping capacity, in order to 'know' whether they could cope with the information provided by testing or with raising a child with a disability:

> I think it's just personally that I'm the type of person that I like to know there's a problem and if there is one we'll find a solution and we'll deal with it so (…) that's how I approached it. It was there, I took it, and, hope for the best. (33 years old, 2 children, younger child 1 year old)

> We were thinking when the child is, you know, 16, 17, 20, how old are we going to be? If it's a special-needs child, are we going to be able to cope with it? …[later in the interview:]…You have to consider the whole family unit. How it's going to affect everybody in the house. (46 years old, 2 children, younger child 8 years old)

Informed choice

Most women made an informed choice about prenatal testing: they were aware they had a choice, demonstrated sufficient knowledge (personal implications of testing and relevant technical information were considered) and made a decision that was consistent with their values. However, the interplay between knowledge and values was different for each woman. For this woman, who made an informed choice to accept testing, personal experiences with ONTDs and her perceived ability to cope influenced her values (the moral questionability of bringing into the world a child destined to suffer):

> I know some people are really strongly being able to cope with stuff like that, but I know who I am. I think I would have not wanted to bring someone into the world just seeing how [my friend's] baby is suffering. (40 years old, 3 children, youngest child 5 years old)

In contrast, for this woman, who made an informed choice to decline testing, the absolute unacceptability of abortion meant that the only important piece of technical information was that testing *could* lead to a decision about abortion:

> I mean, if God gives me a kid with those things, we'll deal with it…And so it was just about two seconds, oh no, I don't want that. (35 years old, 2 children, younger child 5 years old)

Many women who did not make an informed choice did not perceive that there was a choice to be made; they felt they were not given a choice by their provider or they saw prenatal testing as 'routine care'. They tended to receive testing:

> I guess we kind of thought it was something that you had to get done, I didn't really know there was a choice. (39 years old, 2 children, younger child 2 years old)

Some women who made an uninformed decision appeared to have actively made a choice, but it seemed inconsistent with their expressed values or they were ambivalent about their values. For example, one woman seemed to have thought a lot about screening and expressed mostly negative views toward it. However, she experienced anxiety about the health of her foetus, and, despite uncertainty about testing, ultimately decided to have screening based (apparently) on a rushed conversation with her partner:

> …we were busy and one morning I said 'I got to decide today' and my husband said 'just do it' so I went ah…fine. And I walked in. It was not the best thought out process. My inclination is almost always non-intervention so…I just think that all of these medical tests of all sorts are all kind of over-used personally…[Later in the interview:]…Being able to abort a fetus that might have one of these diseases, definitely a negative development to me. (35 years old, 2 children, younger child less than 1 year old)

The health professional and system in informed decision making

Interactions with maternity care providers

We noted that, among the women who accepted testing without appearing to make an active decision, testing was often viewed as a standard component of routine prenatal care:

> …it's sort of a recommended thing. It's sort of like 'this is what we do now, and this is what you get now, and this is how we do it now', and so here you go. And you just go and do it. (36 years old, 3 children, pregnant at time of interview)

Many women who made an informed choice already had knowledge gained through previous pregnancies, personal research or discussions with family or friends. Some interactions with health-care providers appeared to be non-directive and neutral:

> And, I did bring it up with the doctor, like always, the doctor was very open-minded to discuss it, but because we just weren't pursuing it he didn't keep bringing it up or didn't mention it. (36 years old, 3 children, youngest children 1 year old twins)

In contrast, in other interactions, the health professional was perceived as trying to steer the woman or couple towards a certain type of decision. In particular, some women had to actively resist their providers' recommendations:

> …it was offered and it felt like it was being pushed on me, it was not just 'would you like to have this done?' This doctor really was pushing for me to have it and I had to tell him 'no' a couple of times and I didn't appreciate that. (…) I remember just saying to him 'no, I definitely don't want to have it so don't try to convince me that I should'. (41 years old, 3 children, youngest child 7 years old)

Screening as part of the maternity care system

The existence of a screening programme as part of a system of health care seemed to send different, but important messages, to different women. For some women, the fact that screening was routinely *offered* acted as an endorsement of its value:

> And all the tests that you can get possible should be done…[later in the interview:]…Just, 'cause, I mean, it's out there. So you might as well use it, to know what's going to happen. (33 years old, 2 children, younger child less than 1 year old)

Other women found the need to make a decision to be a burden:

> I don't want to have to make those decisions, they're hard decisions and if I choose not to get tested, it will be a white knuckler just because the test exists and they're tough decisions to make when it's all out there. Resisting them is hard. (35 years old, 2 children, younger child less than 1 year old)

Most of the participants, including those who had strong personal objections to screening, seemed to offer the view that all expectant mothers should nevertheless be provided with full information and offered the choice to make up their own mind:

> I truly think that having the testing done or not having it done is a really personal decision. And what you do with the results, the results are a very personal decision. Some people think that it's a means to an end and other people think it's a means to a beginning. (42 years old, 2 children, younger child 2 years old)

Discussion

We concluded that many women in our sample seemed to have made informed decisions about prenatal testing: they were aware that a decision had to be made, had sufficient relevant technical information, had thought through the personal implications of testing, and made a choice that seemed consistent with their values. We also found that both values and personalized knowledge were interrelated and important components of informed choice, consistent with previous work emphasizing values and knowledge in this context.[4,5] Our findings provide unique insights that may help us to better understand these elements and how women construct knowledge, which we argue is important in designing tools for evaluating the performance of prenatal screening programmes and in developing interventions and configuring services most likely to promote this goal.

Values

We defined values as expressions of moral views or statements reflecting beliefs about how life should be lived. This definition differs from the concept of values in the decision support literature,[16] which reflects preferences for outcomes rather than underlying ideals. It also differs from the MMIC, where values were operationalized as a woman's attitude toward taking a prenatal screening test,[4] based on Rokeach.[17] Differences in the definition and application of the construct of 'values' both across and within disciplines are well-documented,[18,19] emphasizing the need to be clear about how they are measured in a particular study. Although the term 'values' is not consistently used in the way we defined it, other studies support the importance of moral views or attitudes toward pregnancy termination and other 'values-type' notions as contributors to women's decision making about prenatal screening.[20–23] Thus, it may be that in the context of prenatal testing, the definition of 'values' that emerged from our data is particularly relevant. Values often dominated discussions about prenatal testing decisions among women who were morally opposed to pregnancy termination.

Knowledge

Our eventual conception of 'knowledge' as a component of informed choice went beyond quantifying women's knowledge of technical details of screening (as operationalized in the MMIC[4]). While we agree that, on the whole, an understanding of these issues is important, technical information was largely irrelevant for women who considered that testing a foetus for a condition not treatable *in utero* was morally wrong; while for others much more understanding was necessary to be sure of informed decision making. Thus, we suggest, as have others,[8,9,24] that women have varying needs for information about screening that depend on personal values.

Our study also highlighted the need to consider the importance of other (non-technical) types of knowledge invoked by women which may drive a great deal of decision making. Self-defined knowledge, gained through experience, stories or self-reflection, appeared to dominate some women's decision making and was used to prioritize and interpret 'objective' information. Our notion of personalized knowledge draws partly on Lippman's idea of embodied knowledge ('a subtle reshaping of some of the concepts of biomedicine and their interweaving with other experiences and sources of expertise and with 'inside' information in ways which make biomedical "facts" a woman's "own"'. (p. 270, [25]) and relates to others' descriptions of experiential or situated knowledge.[26,27]

Personalized knowledge in our analysis also included what we termed 'imagining coping', or reflecting on the personal consequences of the potential testing decision (similar to Anderson's concepts of 'hypothetical' or 'reflective' thinking[28]). This relates strongly to the 'thinking through' aspect of understanding emphasized clearly by Green and colleagues:[15] having an idea of where decision making might take a woman and being ready for the emotional impact of the results. The notion of imagining coping or thinking through also highlights the importance of the *process* of decision making as an aspect of informed choice in prenatal testing; Van den Berg and colleagues addressed this in their measure of informed decision making through the concept of 'deliberation'.[24] Bekker and colleagues have also used a process-oriented assessment of informed decision making to evaluate a prenatal testing decision aid.[29,30]

Taking all of this together, we begin to see that pursuing a goal of more informed decisions in prenatal testing requires both taking account of the personalized nature of knowledge that may dominate decision making (and making sure that serious misconceptions are identified and addressed) *and* promoting 'thinking through' issues in a personalized or self-reflective manner.

Role of health-care providers

Despite the apparent importance of informed decision making in prenatal testing, the routinization of screening as a standard component of prenatal care is widespread.[8,31–34] In our study, evidence of routinization manifested in three different ways. First, some women were unaware that they had a choice (owing to minimal discussion about testing) and the system was structured so as to make acceptance the default option. Second, some women perceived the existence of testing as an endorsement of its value, even when accompanied by non-directive counselling. Finally, some women who did not want screening felt so persuaded (coerced) by their provider that, more than declining, they actively resisted testing.

Strengths and limitations

We used several strategies to ensure methodological rigour in our study. For example, purposive sampling led to a range of perspectives being included. To enhance credibility in our interpretation of women's experiences, we used a multifaceted approach to the analysis (using coding to identify key themes across interviews and detailed summaries to better understand each interview as a whole) and we were flexible in our application of a previously published framework to the data, using participants' comments to guide the definitions and interpretations of key concepts such as values and knowledge. To ensure dependability, all interviews were tape-recorded, transcribed and verified. Further, two researchers coded and analysed data independently, verifying each other's work.

Nonetheless, there were several limitations to our study. Firstly, we interviewed women well after they had made decisions about prenatal testing. This was a deliberate strategy designed to explore how views might have evolved over time. However, we cannot differentiate between this evolution of views and 'inaccurate' recall, and acknowledge that subsequent experiences or less-than-faithful memories may influence our findings.

Secondly, we were not able to compare differences in informed choice across types of prenatal tests (MSS vs. IPS, screening vs. diagnosis) as women often did not distinguish among tests or even between pregnancies. While our analysis accounts for women's experiences from their own perspectives, research generating a better understanding of the differences in decision making across tests would likely help to inform policy.

Further, our study may have appealed mainly to women who were interested in discussing the issues (common to qualitative research), so the transferability of our results beyond our sample may be limited. We did not collect information on the sociocultural backgrounds of participants (e.g. religious affiliation, education level, ethnicity) and recognize that women with different backgrounds may have different values and experiences that influence decision making. We also included only English-speaking women and our final sample included only women aged 30 and older. As well, we excluded women from the study whose charts indicated a history of pregnancies affected by major congenital anomalies, and cannot comment on their perspectives, which would likely provide important and distinct insights into the experience of decision making in prenatal testing.

Finally, we were not able to explore how the type of provider (e.g. midwife, obstetrician, genetic counsellor, etc) influenced women's decision making. Directiveness of interactions may differ between types of providers but further research in a larger sample of women will be required.

Implications for policy and service provision

This study supports the position that the goal of informed choice is appropriate for prenatal testing decisions. Many women in our sample seemed to make informed decisions. However, some perceived prenatal screening as a routine or endorsed element of prenatal health care and/or felt pressured into accepting it, consistent with a model that seeks to maximize screening uptake over deliberative decision making. That some participants made uninformed decisions suggests a need for providers to be vigilant in providing balanced information and facilitating women's decision making about accepting or declining prenatal testing.

In particular, our results suggest that provision of technical information (e.g. false-positive rates) should be complemented by a discussion of the personal implications of testing. A recent study of prenatal diagnostic testing consultations suggested that, even when counselling is provided by a trained genetics specialist, there may be a disconnect between the information considered important by a provider and that prioritized by a particular pregnant woman.[35] One way to facilitate women's informed decision making may be to incorporate tools such as decision aids into prenatal consultations. Decision aids offer information (such as decision options and probabilities of different outcomes), examples of others' decision-making experiences, and guidance on decision-making steps.[36] Several decision aids have been developed for prenatal testing[30,37–40] and have been found to promote informed choices and/or reduce decisional conflict.[30,37,38] In the context of prenatal testing, our results suggest that decision aids should consider values that encompass moral views and beliefs rather than simply preferences for particular outcomes. Sociocultural characteristics are likely related to values and decision aids may also need to be flexible enough to reflect such diversity. For example, although we were not able to address this in our study, other research suggests that the determinants of prenatal testing decisions and the degree to which women make informed choices may be influenced by ethnicity and socioeconomic status.[41,42]

To further evaluate decision support tools and to assess whether prenatal screening programmes are meeting the goal of promoting informed choice, future research should refine methods for evaluating the components of informed choice. Important existing measures in this area[4,24] could be enhanced by exploring how technical and personal concepts of knowledge, as well as values, relate to the deliberative aspects of decision making. Addressing these additional considerations with a measurement tool that is useable on a broad scale poses both conceptual and practical problems, but will be an important way to promote and evaluate an informed choice model of care in prenatal testing.

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