

Information and decision support needs of parents considering amniocentesis: interviews with pregnant women and health professionals

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Abstract

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Objective Our aim was to clarify and categorize information and decision support needs of pregnant women deciding about amniocentesis.

Background Prenatal screening for Down's syndrome (implemented in routine practice) generates a quantifiable risk of chromosome abnormality. To increase certainty, chromosomal material needs to be obtained through amniocentesis or other diagnostic test. Amniocentesis carries risks of pregnancy loss.

Methods Semi-structured interviews were conducted with health professionals and pregnant women who had considered amniocentesis. The data were qualitatively analysed using a two-step thematic content analysis.

Results A sample of 17 health professionals and 17 pregnant women were interviewed. Professionals demonstrated little consensus regarding the miscarriage rate, the potential consequences of amniocentesis testing and the uncertainty associated with the tests. Furthermore, methods employed to communicate risks varied between professionals. Pregnant women reported heightened stress and anxiety. Twelve out of 17 women described the decision as complex and difficult to make while five participants were satisfied with the information and support provided. Women would have liked more information about the risks involved, the results, the consequences of an amniocentesis and associated emotional difficulties. Women highlighted the need for personalized information, presented in multiple ways, while remaining simple and unbiased.

Conclusions There is variation in the provision of information related to amniocentesis testing. The majority of pregnant women reported difficulties making a decision and identified dimensions of information and decision support where improvements were needed.

Introduction

Deciding whether or not to undergo amniocentesis is a complex and emotionally charged decision, often undertaken in a short period of time and, under current practice in the UK, with little systematic decision support. Amniocentesis is usually performed between 15 and 18 weeks of pregnancy and can be associated with a risk of foetal trauma, rupture of membranes, foetal cutaneous lesions, maternal infections and the loss of pregnancy.¹⁻³ The procedure is reported to have a 1% risk of miscarriage and the results of the chromosomal tests may lead to a decision to terminate the pregnancy.⁴⁻⁶ Pregnant women and their partners are expected to make a decision involving significant risks, complex information and far-reaching consequences in a couple of days or less. This decision often generates considerable levels of anxiety at a time of emotional vulnerability.^{7,8}

Over the past decades, maternal age has been the most common indication for amniocentesis testing.³ In the UK, screening tests for Down's syndrome are now offered as part of routine clinical practice to all pregnant women.⁹ Existing screening tests for Down's syndrome include second trimester maternal serum-screening tests offered between 15 and 18 weeks of pregnancy and the nuchal translucency ultrasound scan (offered privately) conducted between 10 and 13 weeks of pregnancy, to measure the thickness of fluid at the back of the baby's neck. Pregnant women who undertake screening tests for Down's syndrome may have to decide about amniocentesis and face the consequences this might have on her pregnancy, life and family. Expectant parents should be informed about the benefits, potential harms and implications of both screening tests and invasive diagnostic procedures such as amniocentesis before deciding whether or not to have the test. However, research shows that pregnant women commonly undertake screening tests for Down's syndrome without realizing they could then be offered an amniocentesis, receive a diagnostic of chromosomal abnormality and/or be offered a termination of pregnancy.^{10,11}

Green *et al.*¹² showed that women who were offered amniocentesis were not provided with sufficient information and were unable to make informed decisions in this area. A review conducted by Marteau¹³ highlighted the lack of understanding of women facing diagnostic tests. The risks associated with amniocentesis (e.g. risk of having a disabled child, of losing a healthy baby) and the range of chromosome problems being tested¹¹ are particularly misunderstood. Expectations regarding amniocentesis or prenatal testing are often unrealistic.¹⁴ Ferber *et al.*¹⁵ showed that expected pain and anxiety levels before the test were significantly higher than the actual pain and anxiety women experienced during the procedure. Furthermore, the information women receive when offered amniocentesis testing is complex, specialized and potentially difficult to assimilate. Understanding the risks associated with amniocentesis (e.g. risk of miscarriage or chromosomal abnormality) involves processing complex probabilistic information and numerical data at a time of heightened stress and anxiety. Studies show that individual differences in processing numerical information exist and significantly impact on performance.¹⁶ The ability to process complex numerical information significantly decreases under high-pressure or stress conditions.¹⁷

An additional difficulty is the recent implementation of a rapid genetic test: quantitative-fluorescent polymerase chain reaction test (QF-PCR test), which requires an updated approach to information provision. This test provides results in a shorter time frame but only detects the three most common chromosomal abnormalities: Down's, Edwards' and Patau's syndromes.¹⁸ Current practice for informing women and communicating risks has not kept pace with the introduction of the QF-PCR test. Reviews have shown that there is limited research on how best to provide information on amniocentesis testing^{12,19} and that decision support could be significantly improved.¹¹

The knowledge, perception, information and decision support needs of women who are offered prenatal screening tests for Down's syndrome has been researched extensively,²⁰⁻²³ in

contrast to the limited number of studies investigating similar issues surrounding amniocentesis testing. This seems counterintuitive as screening tests are non-invasive and do not involve any risk of direct harm to the mother or baby. Research on amniocentesis has focused mainly on the risk of miscarriage,^{24,25} anxiety^{26,27} and knowledge. Little research has been directed at identifying women's information and support needs surrounding the decision to accept or decline amniocentesis.²⁸⁻³⁰ While the amniocentesis decision is commonly described as complex and highly distressing, there is a gap in investigating or addressing psychological aspects, information or decision support needs associated with this test. Decision support technologies (DSTs) are interventions developed to support individuals when they face difficult decisions. They have been noted to facilitate decision making, to increase knowledge, increase active participation in decision making and decrease decisional conflict.³¹ The first step in developing a DST is a needs assessment with relevant professionals and patients, which we conducted with health professionals and pregnant women who had considered an amniocentesis, as the preliminary work for an amniocentesis DST. The aim of this study was to clarify and categorize pregnant women's information and decision support needs with regards to amniocentesis, by assessing how the provision of information and the communication of risks could be improved.

Methods

A qualitative approach was adopted. Information and decision support needs were assessed using in-depth semi-structured interviews with women who had been offered amniocentesis (whether they accepted or declined the test) and with health professionals.

Participants

Pregnant women were identified and approached by midwives or screening midwives in two participating antenatal clinics (University Hos-

pital Wales and Llandough Hospital, Cardiff). To ensure that the views of women who had experienced chromosomal abnormality (after having accepted or declined an amniocentesis) were represented, a research advert was posted in the journal of the Down's Syndrome Association. In the antenatal clinics, women (any age) who had been offered an amniocentesis were informed of the study by midwives, whether they undertook screening tests for Down's syndrome (maternal serum screening, nuchal translucency scan) or not (advanced maternal age, mid-pregnancy ultrasound scan). Information leaflets were distributed by the midwives during the counselling session where women were offered an amniocentesis. Women interested in taking part gave verbal agreement for their contact details to be passed onto the research team. They were later contacted by research staff who answered any questions women had about the project and to fix an interview date. Participants were interviewed within 2 weeks following the counselling session. Women were excluded from the study if they had been offered another diagnostic test such as chorionic villus sampling (CVS) as the CVS is a different procedure that involves different information and risks.

In the journal of the Down's syndrome association, the research advert was directed to all women who had been offered amniocentesis (whether they accepted the test or not) and who received a diagnosis of chromosomal abnormality. Women were interviewed between one and seven years after having been offered amniocentesis testing.

Health professionals were mostly approached and recruited in the antenatal clinics where the study was being conducted. To ensure a breadth of responses, we recruited professionals from different specialities: obstetrics, midwifery, genetics and counselling. Professionals from the Policy and Public Health sector as well as directors from charities and organizations who support pregnant women faced with an amniocentesis decision were also recruited through networking and steering group meetings in England and Wales. The study protocol and materials were reviewed and approved by the

research and development committees of the participating sites and by the National Research Ethics Service.

Data collection

Interviews with pregnant women were carried out in the antenatal clinics, at the participant's home or over the phone, from May 2007 to February 2008. The semi-structured interview schedule consisted of 13 open-ended questions exploring women's experience of the amniocentesis decision, their information and decision support needs and how information and risks should be framed to facilitate understanding. Their reasons for accepting or declining amniocentesis, and their attitudes (satisfaction, regret, misunderstanding, etc.) following the decision were examined. Special attention was paid to new topics emerging such as the difficulties women faced in making their decision, the influence of others (partners, family) or the satisfaction/dissatisfaction with the information and support provided.

Semi-structured interviews with health professionals were carried out in the antenatal clinics or over the phone from April to September 2007. The interview was structured around 11 open-ended questions investigating the professionals' evaluation of women's information and decision support needs, their difficulties in making a decision, the factors they took into account when deciding and their attitudes post-decision. Special attention was paid to the professionals' opinions and preferences regarding the presentation of information and portrayal of risks to facilitate understanding. Interviews were conducted until theme exhaustiveness was reached and no new themes emerged. All interviews were conducted, recorded digitally and transcribed by the author (MA-D). Interview schedules are available from the corresponding author.

Data analysis

Interviews were qualitatively analysed using a two-step thematic content analysis derived from descriptive phenomenology,³²⁻³⁴ assisted by the

computer software ATLAS-ti (ATLAS-ti 5.2). The data collected with pregnant women and professionals were analysed separately and compared afterwards. The first analysis consisted of identifying women's information and decision support needs, from the women's point of view and from the professionals' point of view. In a second and more detailed analysis, the interview transcripts were coded according to the themes discussed in the interviews. Similar codes were merged and subsequently grouped into a family of codes representing the most salient themes emerging from the data. To ensure reliability of coding, two of the authors independently (MA-D and MS) rated six interviews (chosen for being representative of the overall sample), in order to agree on themes and family of codes to be applied to all remaining interview transcripts. Discrepancies among ratings were discussed until agreement was reached.

Results

Pregnant women

In the participating antenatal clinics, 18 women who had recently been offered amniocentesis were recruited and 12 women agreed to be interviewed. The reasons for declining the interview were the impossibility of making an appointment after the counselling session pre-decision ($n = 4$), the lack of time ($n = 1$), and the stress and anxiety associated with this decision ($n = 1$). Participants were interviewed in the antenatal clinics (76.5%) or at the participant's home (23.5%). Most women attended the interview alone (76.5%) and four women came with their partners (23.5%). Among women who were approached through the journal of the Down's Syndrome Association, seven women were recruited and five took part in a telephone interview. Two women had been offered CVS (first trimester diagnostic test) and were therefore excluded from the study. Interviews lasted between 10 and 50 min (23 min in average).

In total, 17 women who had been offered amniocentesis took part in the study. Ten women decided to undergo amniocentesis and

seven declined the test. Among women who underwent amniocentesis, seven women received a normal result and three women were given a diagnosis of Down's syndrome. One woman out of three decided to terminate the pregnancy. Among women who declined an amniocentesis, five women had a healthy baby and two women had a baby with Down's syndrome. The mean age of women in the sample was 36 years. Most women were British ($n = 15$), one was Turkish and one was Indian. The demographic characteristics of the participants are summarized in Table 1.

Information needs

Being offered amniocentesis testing led to a stressful, complex and upsetting decision making process for 12 out of 17 participants. For those

who had a screening test, the high chance result and subsequent offer of an amniocentesis was a shock, causing stress and anxiety.

They rang me at 8:30 at night and told me that the screening gave me a result of 1 in 10 which for somebody of my age should have been 1 in 600. I was completely shocked, obviously, I didn't expect anything like this and I didn't even know what Down's syndrome was. (F, age 33, declined amniocentesis)

Five out of 17 participants were satisfied with the overall information and decision support provided. Participants expressed the numerous information and decision support needs (Table 2).

First, pregnant women felt that more detailed information about the risks involved, such as the risk of miscarriage, the risk factors for miscarrying and other associated risks (infections, long-term consequences) should be provided. Women would have appreciated more consistency regarding the miscarriage rate as it was misleading to be given different percentages. The national miscarriage rate is one in a 100 procedure (1%) but most antenatal clinics will quote a local rate, generally lower than the national rate but based on little scientific evidence.^{4,5} Regarding the overall quantity of information provided, women's opinions diverged. Some women experienced information overload while others lacked information and felt the need to look for more information elsewhere (internet, books).

Table 1 Demographic characteristics of women who were interviewed ($n = 17$)

Amniocentesis	
Accepted	10
Declined	7
Maternal age	Range 28–47 years. Mean 36 years
Marital status	
Married	15
Cohabiting	2
Number of children	
0	6
1	8
2	3
Existing children with a chromosome disorder	2
Obstetric history	
Previous miscarriage	2
Previous amniocenteses	2
<i>In vitro</i> fertilization pregnancy	1
Outcome post-amniocentesis in $n = 10$ women who had the test	
Miscarriage	0
Normal result	7
Down's syndrome diagnosed	3
Termination of pregnancy	1
Outcome when amniocentesis declined ($n = 7$)	
Miscarriage	0
Healthy baby	5
Baby with Down's syndrome	2

Table 2 Themes identified in semi-structured interviews with women ($n = 17$)

Themes	Sub-themes
Information needs	Information about the risks Information about the procedure Information about the screening tests Personalised information
Emotions and decision support	Heightened stress and anxiety Addressing emotional difficulties
Reasons	Reasons for accepting an amniocentesis Reasons for declining an amniocentesis
Making a decision	Deciding with a partner Satisfaction or regret?

Regarding the procedure, participants were generally satisfied with the quantity of information provided but would have liked more information about the results, consequences and implications of an amniocentesis (abnormalities detected, termination of pregnancy). Women had difficulty in understanding what the test may or may not detect and lacked information about the details of each test (PCR test and Karyotype test).

Before being offered the test, eight out of 17 women would have liked more information about the screening tests available, their purpose, the uncertainty associated with the results and the implications of a high chance result. Three women who undertook the screening test and were subsequently offered amniocentesis regretted their screening decision and blamed it on a lack of information pre-screening test.

For me, that was a terrible rollercoaster, and I wish I've never even had the blood test. So I do feel that before you even have the blood test, more information should be given. Don't have the blood test if you don't know the rest of the consequences. (F, age 35, declined amniocentesis)

Most women interviewed wished to receive information tailored to their individual needs and presented in multiple ways to account for individual differences (educational levels, ethnic backgrounds, culture). Women reported that balanced and unbiased verbal and written information to take home should be combined as the stress and anxiety experienced during the counselling session (post-screening results) significantly limited their capacity to assimilate and recall complex information. Women felt that probabilistic information would be better understood if framed in multiple ways, using diagrammatic representations, flow charts, frequencies and percentages, with identical denominators to facilitate the comparison between the risk of chromosomal abnormality and the risk of miscarriage. Visual elements such as images and videos (e.g. video of the amniocentesis procedure) should be made available to women provided it remains optional. Five participants expressed the need to know about other women/couples' experiences, to be informed

about support groups or reliable internet forums.

Emotions and decision support

The anxiety women experienced between having the blood test and receiving the amniocentesis results (or give birth to a baby who was suspected to have Down's syndrome) fluctuated but never disappeared. Peak levels of anxiety were reported immediately after the screening test results, and when waiting for the amniocentesis results. Nine out of 17 women reported great difficulties dealing with overwhelming stress, anxiety or regret (regarding the screening test or the amniocentesis decision) while being pregnant, when they never anticipated to be offered an amniocentesis.

It is a very stressful time, a very worrying time and I think that perhaps people who deal with it every day don't realise what the average person is going through. (F, age 28, undertook amniocentesis)

Most women felt that emotional difficulties should be addressed and more decision support made available through support groups or relevant charities. Decision support was also provided through discussion with their partner, family, friends or health-care providers. Three women reported that unbiased decision support should be provided whatever the decision may be. Two women felt forced into having an amniocentesis and received very little support, if not disapproval, for declining the test or continuing the pregnancy. Three women felt that health professionals lacked neutrality regarding disability and pregnancy termination.

Reasons for accepting/declining an amniocentesis

In total, 24 reasons to accept or decline an amniocentesis were reported (Table 3). Among 10 women who had an amniocentesis, six participants chose to have the test to find out if the baby had a problem as they felt unable to cope with stress and anxiety for the rest of the pregnancy. Five women opted for an amniocentesis as they felt incapable or unwilling to look after a disabled child. Three out of 10 women undertook the test to have the option to terminate the

Table 3 Reasons influencing decision making about amniocentesis: overlapping and independent views of pregnant women ($n = 17$) and health professionals ($n = 17$)

Reasons reported by	Reason
Women and health professionals	To avoid anything that may harm the baby (risk of miscarriage)
	View on termination
	To find out if the baby has a problem (stress of not knowing)
	Feel incapable or unwilling to look after a disabled child
	To prepare if problem is found
	To have the option to terminate pregnancy
	Existing children
	Previous amniocentesis
	Previous miscarriage
	Risk of miscarriage compared to risk of a problem
	Age
	Medical complication/obstetric history
	Family history of chromosome disorder
	Knowledge and/or experience of children with Down's syndrome
	Existing child with Down's syndrome
	Partner's views
	Difficulty getting pregnant
	Religious beliefs
	Views of friends, family
	Obstetrician's expertise in conducting amniocenteses
Women only	Risk for her age compared to risk in similar age group
	Difference between the woman's screening result and the screening cut-off limit
	Anomalies detected on the mid-pregnancy scan
	Practical reasons (husband away, unable to rest for a few days, etc.)
Health professionals only	Cultural characteristics
	Professional's influence
	Couple's stability
	Knowledge about amniocentesis
	Concerns about people's reactions

pregnancy if a problem was found. Three women had an amniocentesis to prepare for the birth of a baby with a chromosomal abnormality. Three out of 10 women decided to have the test as they already had children and were con-

cerned about the impact of a disabled child on siblings. Other less-common reasons are reported in Table 3.

The seven women who declined an amniocentesis based their decision on the risk of miscarriage and on the conviction that they would not terminate the pregnancy if a problem was found. Additional reasons for declining the test were medical complications such as bleeding during the pregnancy or twin pregnancy ($n = 2$), previous obstetric history such as an IVF pregnancy or difficulties getting pregnant ($n = 2$) and the risk of miscarriage being higher than the risk of chromosomal abnormality ($n = 2$).

Making a decision

When making a decision about amniocentesis, four out of 17 women disagreed with their partners.

My husband was very keen for me to have the test. Over the time, I decided I didn't really want this test. So, it was very difficult, it did cause conflicts between us because obviously, at the end of the day, it is my body and I don't want to be in a position where I am feeling guilty, if anything happened. So that was a difficulty, it really was. (F, age 35, declined amniocentesis)

All women who decided to have an amniocentesis, including women who received a diagnostic of chromosomal abnormality, reported no regret about their decisions to have had the test. Despite weeks of constant worry, none of them regretted having had an amniocentesis.

I am happy that we went ahead with it, the results were clear so we got reassurance from that. Because up until that point, I don't feel that we could have started planning adequately for the baby. (F, age 39, undertook amniocentesis)

Women whose amniocentesis results showed Down's syndrome ($n = 3$) felt positive about their decision, as the test enabled them to prepare for the birth of a disabled child or to terminate the pregnancy. All women who decided not to have an amniocentesis were satisfied with their decision and did not experience regret. However, most women reported fluctuating anxiety regarding the risk to give birth to a baby with a chromosomal abnormality.

I feel that I've made the right decision. I suppose I am a little bit nervous. It is a worry I've got to be honest with you, it's gonna be 6 months of worry thinking what if. (F, age 39, declined amniocentesis)

Professionals

The sample of 17 professionals consisted of six consultants in obstetrics and gynaecology, four midwives, one screening midwife, two geneticists, two coordinators of the national antenatal screening programme, the local director of the Down's Syndrome Association and the director of a national charity supporting parents during the antenatal testing process. Interviews lasted between 11 and 52 min (27 min in average). The following themes were identified in the interviews (Table 4).

Information needs

Most professionals highlighted the need for women to understand the harms, benefits and implications of each option and to be clear that miscarriage was a risk. Some health professionals insisted on the necessity for women to balance and make sense of the risk of miscarriage against the risk of chromosomal abnormality.

Table 4 Themes identified in semi-structured interviews with health professionals ($n = 17$)

Themes	Sub-themes
Information needs	Lack of consensus around the risks involved Detailed information about the procedure Consequences of an amniocentesis Screening test purposes Framing probabilistic information
Emotions and decision support	Peak stress and anxiety levels Ways of providing decision support
Reasons for accepting/declining an amniocentesis	Women/professionals consistency
Perceptions	Deciding with a partner Improved understanding

Professionals were inconsistent on the risk of miscarriage to quote (local rate or national rate). Paradoxically, they also insisted on the need to provide consistent information across professionals.

We quote a 1% risk of miscarriage, a 1 in 100 and that is the national, Welsh national risk so that is the only figure that we can give them and again it is not discerning between foetuses that have chromosomal abnormalities and those that have not. (F, midwife)

Well, the national Welsh recommendation is 1 in 100 and our unit figure is 1 in 300. So I usually say to them, it's between half and 1 percent and that sort of covers everything. I think, within our unit, I don't see why we shouldn't be using our own figures. If that is what the risk is in our unit, that is what the risk is in our unit! (F, consultant obstetrician & gynaecologist).

Some health professionals felt that practical and detailed information about the amniocentesis procedure, its consequences and implications should be systematically offered to women and their partners. Their evaluation of women's information needs regarding the results was consistent with women's reported needs. Furthermore, four professionals highlighted the need to specify that a normal amniocentesis result cannot guarantee a healthy baby.

It's getting them to understand that you can have all of the tests done and have a very disabled baby born. The tests answer the question that has been asked: Are chromosomes 18, 13 and 21 structurally normal? And the answer is yes. That doesn't say the baby is normal. And I think that is the key sentence and that's the thing they don't like us for; understandable. (F, geneticist)

There was no consistency among professionals on the amount of information to provide about potential chromosomal abnormalities and whether or not to raise the issue of the pregnancy termination.

I think health professionals should anticipate that level of not understanding and be very explicit about what a termination of pregnancy is and how you do a termination, because women may not understand, and are consenting to things they don't understand. (F, coordinator of the national antenatal screening programme)

I think that's just one step too far of the process. Because if you start describing the whole process including the details of how you do a termination, it's too much to take in. (M, consultant obstetrician & gynaecologist)

Most professionals insisted on the importance of understanding the screening test purposes, results and implications (deciding about amniocentesis, possible diagnosis of abnormality, decision to continue/terminate the pregnancy) before embarking on prenatal screening for Down's syndrome. Six professionals reported that the false-positive and false-negative results associated with prenatal screening, especially relevant with maternal serum-screening tests, should be communicated and understood.

The professionals' assessment of how best to present general and probabilistic information was consistent with women's reported needs. The majority of professionals felt that information should be tailored to women's individual needs and framed in multiple. However, methods for communicating risks varied from one professional to another: hard facts only, analogies, diagrams, flow charts, etc. Furthermore, most professionals highlighted the need to provide updated information, to use precise but simple language and to make the information provision gradual and optional. Finally, a minority of professionals suggested that women should be given enough time to decide and should be reminded of the possibility to change their mind at any time. One professional believed that people would assimilate more information if they were given more time to decide.

As with anybody who is getting bad news, the key thing they need is time. I think it's no good just telling them what they need to hear. It's giving them the time to understand what they need to hear because people view risk in different ways and, hear it in different ways. (F, geneticist)

Emotions and decision support

Most health professionals recognized that the amniocentesis decision was associated with peak anxiety levels and subsequent difficulty to

assimilate information. They unanimously reported that women experienced highest anxiety levels at the time of the screening test results.

It's just shock, horror, because they were two fit, healthy people. Why was that happening to them? They want answers, they want to know why. They wouldn't have had the test I don't think if they thought it was going to come back as high risk. (F, midwife)

Four professionals believed that prompting women to reflect on the reasons for having/not having an amniocentesis (e.g. for reassurance, to be able to terminate the pregnancy if a problem is found) would prove beneficial to decision-making:

I say, well, what would you do? Would you terminate the pregnancy or is it just for your information? because that's what they need to know, isn't it? They need to use that as part of their decision and very often they don't know. (F, screening midwife).

Alternatively, considering the impact of a disabled child on their life and family might also affect their decision, and health professionals felt this needed to be addressed explicitly. Finally, helping women decide what the worst possible outcome would be: to give birth to a child with a chromosomal abnormality, to miscarry a healthy baby or to terminate a pregnancy following a diagnosis of chromosomal abnormality, was perceived to facilitate the decision-making process.

Four professionals reported the tendency to seek professionals' advice.

I often get asked: what do I think they should do? And I always decline to actually give any kind of weighted personal opinion on that. The truth is, I don't actually know what I would do myself faced with that decision. And secondly, the birth of a child with Down's syndrome is likely to mean something very different to different people, it wouldn't be right for a health professional to try to tell somebody what's right for them. (M, consultant in obstetrics)

Reasons for accepting/declining an amniocentesis

Based on their experience with the amniocentesis decision, health professionals identified 25 reasons they believed affected women's decision

about amniocentesis. The consistency between women and professionals was high as 20 out of 25 reasons identified by health professionals were consistent with women's reported reasons. However, professionals also believed that the couple's stability, cultural characteristics, the information about amniocentesis, the professionals' influence and concerns about people's reactions to their decision would affect women's decision about amniocentesis, but women did not report these reasons as influential.

Professionals' perceptions of the amniocentesis decision

Five professionals noted significant decision-making difficulties within the 'pregnant couple' (e.g. conflicts, incapacity to decide together) and believed that health professionals should act as facilitators. Three professionals noted that men were generally leaving the decision to women.

As a consequence of improved information and decision support over the past 5 years, some professionals believed that women were better informed. Three professionals believed that women had a good understanding of the procedure and of Down's syndrome. However, two professionals noted significant difficulties dealing with statistics and understanding the limitations of amniocentesis testing. Three professionals felt that making a decision in a short time frame and balancing the risk of miscarriage against the risk of a problem could prove difficult. Finally, two health professionals believed that women experienced information overload.

Synthesis

Most women and health professionals reported or witnessed emotional and cognitive difficulties making a decision about amniocentesis (stress, anxiety, difficulty assimilating probabilistic information, information overload). They felt that the provision of better services would reduce the emotional challenges of this period. They unanimously highlighted the need to address women's difficulties by providing per-

sonalized and interactive information, presented in multiple ways (numbers, diagrams, videos, women's experiences), in order to account for individual differences in processing complex information. Both women and health professionals highlighted the need to understand the risks associated with amniocentesis testing (risk of miscarriage, risk of infection). Nevertheless, health professionals were inconsistent regarding the miscarriage rate to quote (local or national rate), which was reflected by women's confusion and difficulty in dealing with different miscarriage rates. Women recurrently reported the need to receive comprehensive information about the risks involved, the results of the chromosome tests and potential consequences of an amniocentesis whereas health professionals reported different opinions regarding the nature and quantity of information needed chromosome problems and uncertainty associated with the tests. The majority of women would have liked to receive information about the termination of pregnancy whereas health professionals expressed diverging opinions about the necessity to describe the pregnancy termination. Both women and professionals highlighted the need to provide detailed information about amniocentesis before the screening tests, as existing information and consent arrangements seemed insufficient. Besides, women felt that decision support should be reinforced. Finally, the reasons for having/not having amniocentesis were generally consistent between women and health professionals. Women reported 24 reasons for or against having an amniocentesis while professionals identified 26 reasons, 20 of which were consistent with women's reported reasons.

Discussion

The present findings expose unmet needs for information, decision support and emotional support associated with amniocentesis testing. Significant decision-making problems (e.g. difficulty assimilating probabilistic information, information overload) and emotional difficulties (e.g. stress, anxiety, regret) were also reported. The professionals' report of the reasons that

influenced women when deciding about an amniocentesis was consistent with that of women and both emphasized the period of elevated stress and anxiety that was triggered by the decision and its aftermath. However, the need to reinforce and strengthen existing emotional and decisional support, highlighted by majority of women interviewed, was only identified by a minority of professionals. The assessment of women's information needs also varied between health-care providers. Together, these results indicate an important gap in perception between users and providers on the decision-support needs of women and couples considering amniocentesis.

This study is the first to have conducted an in depth assessment of the decision-making process, information and decision support needs associated with amniocentesis testing. While a minority of women were satisfied with the overall information and support provided, most participants would have appreciated more personalized and interactive information. Specifically, the decision to undertake amniocentesis was associated with recurrent stress and anxiety. Elevations in anxiety levels were reported after a higher chance screening test result and prior to receiving amniocentesis results as has been documented previously.^{26,35,36} While women felt that emotional and decisional support should be reinforced, professionals tended to focus on answering women's information needs only. The focus on information needs may reflect areas of expertise that health professionals feel most competent carrying out and a genuine gap in understanding of patients emotional needs. In either case, the results point to the need for health professionals to divert greater attention to these unmet needs as they appear from these interviews to be as important as unmet information needs.

Professionals expressed diverging opinions regarding the nature and quantity of information needed about the risk of miscarriage, potential chromosomal abnormalities, uncertainty associated with the tests and about the termination of pregnancy. Such inconsistencies

may not only be due to limitations of current policies and guidelines (i.e. miscarriage rate), but may also be imputed to gaps in the general or specialized (i.e. genetics) knowledge of health care providers. Inadequate knowledge related to the presentation and meaning of prenatal screening test results has been reported.³⁷⁻³⁹ Furthermore, research evidence suggests that health professionals tend to overestimate their own levels of knowledge.^{40,41}

The risk of miscarriage was the most often reported reason for declining an amniocentesis while finding out if the baby had a problem to reduce intense stress and anxiety was the main reason for undertaking the test. Previous research evidence suggested that maternal age was the main reason for undertaking amniocentesis testing.^{28,42,43} As prenatal screening for Down's syndrome is offered as part of routine clinical practice, maternal age is not the only indication for having the test. Various factors such as the risks involved, the possibility to terminate the pregnancy, and views on termination or on disability have a raised impact on women's decisions.

Strengths and limitations

Strengths of this study were the quality of the interview sample selected and structure of the interviews. The interview sample included women who declined the test, women who received normal and abnormal amniocentesis results, women with experience of chromosomal abnormality or pregnancy termination.

The structure of the interview gave women freedom to broaden the themes raised in the interview while still focusing on the amniocentesis decision making process.

Limitations of the study were the differences between the sample of patients recruited in the antenatal clinics and recruited through the *Journal of the Down's Syndrome Association*. Women recruited through the Down's Syndrome Association were interviewed between 1 and 7 years after having been offered an amniocentesis. The passage of time, involving a possible change in clinical practice and provision of information, is likely to introduce

biases. Besides, women recruited through the journal were self-selected from a specific website whereas women recruited consecutively in the clinic were systematically approached by screening midwives, and this may have introduced bias.

Conclusions

The findings suggest that basic information, decision and emotional support needs remain unanswered. There is therefore a scope for improving the quality of information and support provided by developing high-quality DSTs capable of providing structured guidance in making a decision about amniocentesis. The data collected with patients and professionals also highlighted concerns about the quality of information provided to women prior to prenatal screening tests and about the validity of consent obtained. Information about the characteristics, limitations (false-positive and false-negative results) and consequences (further invasive diagnostic tests offered) of screening tests for Down's syndrome should be systematically provided to women.

The findings highlight the need for further emotional and decisional support. The offer of an amniocentesis and subsequent test results often coincides with heightened stress, anxiety and emotional upheaval. Women do not generally expect to be offered an amniocentesis and are totally unprepared to face a decision with far-reaching consequences. Existing arrangements for providing emotional support during the diagnostic phase of the pregnancy are not adapted to women's needs. There is a scope for developing interventions, which do not only provide comprehensive information but also address emotional and decisional difficulties. Finally, with the objective to answer patients' needs and to create DSTs that are accepted and implemented by health-care providers in clinical settings, DSTs should be developed in collaboration with both patients and professionals. Such educational materials do not aim to replace but supplement face-to-face interactions with health professionals.

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References

- 1 Vilar Coromina N, Vicente Villa A, Puigarnau Vallhonrat R, Vela Martinez A, Gonzalez Ensenat MA. Skin dimpling: a complication of amniocentesis. *Anales de Pediatria (Barcelona)*, 2007; **66**: 407–409.
- 2 Borrelli AL, Cobellis L, Di Domenico A *et al.* Fetal and maternal amniocentesis complications. *Minerva Ginecologica*, 2006; **58**: 423–427.
- 3 Palo P, Piironen O, Honkonen E, Lakkala T, Aula P. Transabdominal chorionic villus sampling and amniocentesis for prenatal diagnosis: 5 years' experience at a university centre. *Prenatal Diagnosis*, 1994; **14**: 157–162.
- 4 Gaudry P, Grange G, Lebbar A *et al.* Fetal loss after amniocentesis in a series of 5,780 procedures. *Fetal Diagnosis and Therapy*, 2008; **23**: 217–221.
- 5 Tabor A, Philip J, Madsen M, Bang J, Obel EB, Norgaard-Pedersen B. Randomised controlled trial of genetic amniocentesis in 4606 low-risk women. *Lancet*, 1986; **7**: 1287–1293.
- 6 Asch A. Prenatal diagnosis and selective abortion: a challenge to practice and policy. *American Journal of Public Health*, 1999; **89**: 649–657.
- 7 Robinson JO, Hibbard BM, Laurence KM. Anxiety during a crisis: emotional effects of screening for neural tube defects. *Journal of Psychosomatic Research*, 1984; **28**: 163–169.
- 8 Sarkar P, Bergman K, Fisk NM, Glover V. Maternal anxiety at amniocentesis and plasma cortisol. *Prenatal Diagnosis*, 2006; **26**: 505–509.
- 9 Saller DN Jr, Canick JA. Current methods of prenatal screening for Down syndrome and other fetal abnormalities. *Clinical Obstetrics and Gynecology*, 2008; **51**: 24–36.

- 10 Dormandy E, Michie S, Hooper R, Marteau TM. Informed choice in antenatal Down syndrome screening: a cluster-randomised trial of combined versus separate visit testing. *Patient Education and Counseling*, 2006; **61**: 56–64.
- 11 Jaques AM, Halliday JL, Bell RJ. Do women know that prenatal testing detects fetuses with Down syndrome? *Journal of Obstetrics and Gynaecology*, 2004; **24**: 647–651.
- 12 Green JM, Hewison J, Bekker HL, Bryant LD, Cuckle HS. Psychosocial aspects of genetic screening of pregnant women and newborns: a systematic review. *Health Technology Assessment*, 2004; **8**: 1–128.
- 13 Marteau TM. Towards informed decision about prenatal testing: a review. *Prenatal Diagnosis*, 1995; **15**: 1215–1226.
- 14 Marteau TM. Prenatal testing: towards realistic expectations of patients, providers and policy makers. *Ultrasound in Obstetrics and Gynecology*, 2002; **19**: 5–6.
- 15 Ferber A, Onyeije CI, Zelop CM, O'Reilly-Green C, Divon MY. Maternal pain and anxiety in genetic amniocentesis: expectation versus reality. *Ultrasound in Obstetrics and Gynecology*, 2002; **19**: 13–17.
- 16 Booth JL, Siegler RS. Developmental and individual differences in pure numerical estimation. *Developmental Psychology*, 2006; **42**: 189–201.
- 17 Beilock SL, DeCaro MS. From poor performance to success under stress: working memory, strategy selection, and mathematical problem solving under pressure. *Journal of Experimental Psychology. Learning, Memory, and Cognition*, 2007; **33**: 983–998.
- 18 Mann K, Petek E, Pertl B. Prenatal detection of chromosome aneuploidy by quantitative fluorescence PCR. *Methods in Molecular Biology*, 2008; **444**: 71–94.
- 19 Hunt LM, De Voogd KB, Castaneda H. The routine and the traumatic in prenatal genetic diagnosis: does clinical information inform patient decision-making. *Patient Education and Counseling*, 2005; **56**: 303–312.
- 20 Michie S, Dormandy E, Marteau TM. Informed choice: understanding knowledge in the context of screening uptake. *Patient Education and Counseling*, 2003 July; **50** (3): 247–253.
- 21 Van den Berg M, Timmermans DRM, Ten Kate LP, Van Vugt JMG, Van der Wal G. Informed decision making in the context of prenatal screening. *Patient Education and Counseling*, 2006; **63**: 110–117.
- 22 Dormandy E, Michie S, Hooper R, Marteau TM. Informed choice in antenatal Down syndrome screening: a cluster-randomised trial of combined versus separate visit testing. *Patient Education and Counseling*, 2006; **61**: 56–64.
- 23 Garcia E, Timmermans DR, van Leeuwen E. The impact of ethical beliefs on decisions about prenatal screening tests: searching for justification. *Social Science and Medicine*, 2008; **66**: 753–764.
- 24 Kozłowski P, Knippel A, Stressig R. Individual risk of fetal loss following routine second trimester amniocentesis: a controlled study of 20,460 cases. *Ultraschall in der Medizin*, 2008; **29**: 165–172.
- 25 Wilson RD. Pregnancy loss rates after midtrimester amniocentesis. *Obstetrics and Gynecology*, 2007; **109**: 451–452; author reply 2–3.
- 26 Beeson D, Golbus MS. Anxiety engendered by amniocentesis. *Birth Defects Original Article Series*, 1979; **15**: 191–197.
- 27 Tabor A, Jonsson MH. Psychological impact of amniocentesis on low-risk women. *Prenatal Diagnosis*, 1987; **7**: 443–449.
- 28 Cederholm M, Axelsson O, Sjoden PO. Women's knowledge, concerns and psychological reactions before undergoing an invasive procedure for prenatal karyotyping. *Ultrasound in Obstetrics and Gynecology*, 1999; **14**: 267–272.
- 29 Lesser Y, Rabinowitz J. Elective amniocentesis in low-risk pregnancies: decision making in the era of information and uncertainty. *American Journal of Public Health*, 2001; **91**: 639–641.
- 30 Malkiel A, Granat M, Sagi M, Brezis M. Can we improve the content and quality of information delivered prior to amniocentesis? *Harefuah*, 2008; **147**: 16–20, 96, 5.
- 31 O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, Tait V, Tetroe J, Fiset V, Barry M, Jones J. Decision aids for people facing health treatment or screening decisions (Review). *Cochrane Database Syst. Rev.*, 2003; (2): CD001431.
- 32 Denzin NK, Lincoln YS. *Handbook of Qualitative Research*. Thousand Oaks: Sage Publications, 2000.
- 33 Holloway I. *Qualitative Research in Health Care*. Maidenhead, England: Open University Press, 2005.
- 34 Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *British Medical Journal*, 2000; **320**: 114–116.
- 35 Michelacci L, Fava GA, Trombini G, Zielezny M, Bovicelli L, Orlandi C. Psychological distress and amniocentesis. *Gynecologic and Obstetric Investigation*, 1984; **18**: 40–44.
- 36 Ng CC, Lai FM, Yeo GS. Assessment of maternal anxiety levels before and after amniocentesis. *Singapore Medical Journal*, 2004; **45**: 370–374.
- 37 Wilkins-Haug L, Hill L, Schmidt L, Holzman GB, Schulkin J. Genetics in obstetricians' offices: a survey study. *Obstetrics and Gynecology*, 1999; **93**: 642–647.
- 38 Carroll JC, Reid AJ, Woodward CA *et al.* Ontario maternal serum screening program: practices, knowledge and opinions of health care providers. *Canadian Medical Association Journal*, 1997; **156**: 775–784.

- 39 Sadler M. Serum screening for Down's syndrome: how much do health professionals know? *British Journal of Obstetrics and Gynaecology*, 1997; **104**: 176–179.
- 40 Hunter A, Wright P, Cappelli M, Kasaboski A, Surh L. Physician knowledge and attitudes towards molecular genetic (DNA) testing of their patients. *Clinical Genetics*, 1998; **53**: 447–455.
- 41 Tracey JM, Arroll B, Richmond DE, PM B. The validity of general practitioners' self assessment of knowledge: cross sectional study. *British Medical Journal*, 1997; **315**: 1426–1428.
- 42 Kukulcu K, Buldukoglu K, Keser I *et al.* Psychological effects of amniocentesis on women and their spouses: importance of the testing period and genetic counseling. *Journal of Psychosomatic Obstetrics and Gynaecology*, 2006; **27**: 9–15.
- 43 Moyer A, Brown B, Gates E, Daniels M, Brown HD, Kuppermann M. Decisions about prenatal testing for chromosomal disorders: perceptions of a diverse group of pregnant women. *Journal of Women's Health & Gender-Based Medicine*, 1999; **8**: 521–531.