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Why do French women refuse to have Down's syndrome screening by maternal serum testing? A mixed methods study

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Abstract

Purpose: The study aims to analyse the reasons underpinning women's refusal to undertake Down's syndrome screening (DSS) by maternal serum testing (MST).

Methods: A retrospective, mixed methods sequential approach was used. An online survey on women's experience of prenatal testing followed by in-depth interviews were conducted, with women over 18 years old, who had been pregnant within five years prior to the study. Altogether, 1726 responses were gathered, of which 217 related to women who had refused MST. The study compares the women who refused MST with women who accepted it on sociodemographic characteristics, the evolution and experience of the pregnancy, their knowledge about Down's syndrome (DS). It also utilises survey comments and five in-depth interviews to explore, using Thematic Analysis, the reasons for refusing MST.

Results: To refuse MST is cognitively demanding. Indeed, women who refused MST were better educated, knew more about prenatal diagnosis sequences and DS than women who accepted it. This position is also emotionally challenging as women's interactions with practitioners can put them in difficult situations, where they have to defend their point of view. Reasons for refusing MST go beyond religious beliefs, negative attitudes towards abortion and/or medicalisation of pregnancy. Rather, women's position appears to be driven by a holistic conception of care-based monitoring, values of inclusivity and a desire to remain in control of their pregnancy.

Conclusions: It is essential that women feel accepted and supported in their choice to refuse MST. Consequently, it is important for professionals to remain cognisant of the diversity of factors underpinning women’s decision, the pressure this position generates and the challenges that come with it.

Keywords: Down’s syndrome screening; prenatal diagnosis; decision-making; women's experience

Introduction

The public health objective of Down’s syndrome screening (DSS) is to identify women whose risk of giving birth to a child with Down’s syndrome (DS) - a chromosomal anomaly with a prevalence of 3.2 per 1,000 pregnancies and 0.6 per 1,000 births - is higher than average, to offer them a diagnostic investigation.

In France, DSS is offered to all pregnant women, with the cost of the test covered by the health insurance. Since 2009, it is offered during the first trimester of pregnancy usually by gynaecologist-obstetricians, general practitioners (GPs), or other professionals such as midwives, depending on the type of practitioners women elect to monitor their pregnancy. Between 2010 and 2016, the role of GPs in prenatal monitoring has decreased whereas that of private midwives has increased (Enquête nationale périnatale, 2016). DSS involves a probabilistic calculation that incorporates maternal age and the measurement of fetal nuchal translucency (NT) and maternal serum (MS) (dosage of fetal and placental hormones circulating in the maternal blood). The 1/250 risk corresponds to the threshold from which a sample (amniotic fluid or trophoblast cells) is taken to investigate the fetal karyotype, which enables the diagnosis of chromosomal anomalies. The cost of these diagnostic investigations is also covered by the health insurance. These tests, however, carry a 0.1% to 0.2% risk of miscarriage (Haute Autorité de la Santé, 2018). DSS with MST has a detection rate of 89% to

97% with 5% false positives (Weingertner et al., 2010). In comparison, when used on its own, the fetal NT measurement has a detection rate of approximately 70%.

In 2014, non-invasive prenatal testing (NIPT) was introduced in France, and subsequently rolled out in 2019. Based on the analysis of small fragments of fetal DNA circulating in the maternal blood, this test eliminates the risk of miscarriage associated with diagnostic investigations. Although NIPT has a detection rate of 99% (Haute Autorité de la Santé, 2020), it is currently only offered as a follow-up to women whose DS risk is between 1/1000 and 1/51. Thus, today's prenatal screening/diagnosis landscape still relies heavily on MST. In 2018, 15% of French pregnant women did not screen for D using T (Agence de la iomédecine,) However, the proportion of those who actively refuse MST is more difficult to estimate. Indeed, some women are automatically referred for a diagnostic test, others are advised against MST, particularly with multiple pregnancies, or are past the gestational age recommended for this test.

Many studies have examined the factors associated with DSS uptake. Different care pathways and professional practices have been linked to varying DSS rates uptake across Europe (McNeill., 2009; Crombag et al., 2014). The high DSS uptake in France may be explained by the fact that the test is an integral part of the national prenatal care strategy, covered by health insurance, thus appearing highly recommended. Additionally, evidence points to time constraints in addressing DSS during consultations in France, with on average, only three minutes spent discussing it (Vassy and Champenois-Rousseau, 2014). Women also usually get little information about DSS prior to their appointment, potentially negating its significance (Vassy et al., 2014), and about what DS is and what it may involve (Vassy and Champenois-Rousseau, 2014).

Sociodemographic characteristics, including low level of education and ethnic minority status, are associated with lower DSS use (Khoshnood et al., 2004; Dormandy et al., 2005; Fransen et al., 2010). However, this relationship appears less consistent when the focus shifts from accessing MST, to accepting or refusing MST. Evidence suggests that migrant women and those expressing religious beliefs more frequently refuse MST, this finding generally being associated with refusal of abortion (Press and Browner, 1998; Khoshnood et al., 2004). However, while some women refusing MST directly link abortion to religious belief (Lewando-Hundt et al., 2001; Liamputtong et al., 2003; Gitsels-van der Wal et al., 2014), others relate it to personal beliefs and values (Williams et al., 2005; Reid et al., 2009). In particular, women who refuse MST often put forward ‘expert’ arguments (test’s unreliability, false positive results, adverse consequences of potential invasive tests), while women accepting MST more often perceive DSS as part of routine care (Reid et al., 2009; Crombag et al., 2013). Finally, certain attitudes are also motives for accepting or refusing DSS, including the wish to avoid anxiety (Markens et al., 1999; Liamputtong et al., 2003; Reid et al., 2009) or acting in the 'child’s best interest' (Crombag et al., 2013).

While insightful, most of these studies were conducted outside France, and are somewhat dated. Thus this study aims to understand why, in France, in an evolving prenatal screening/diagnosis landscape, some women still refuse MST. The focus on MST refusal rather than DSS more generally, is based on the fact that data pertaining to MST are available for the general population, as opposed to data relating to NT measurement and broader DSS.

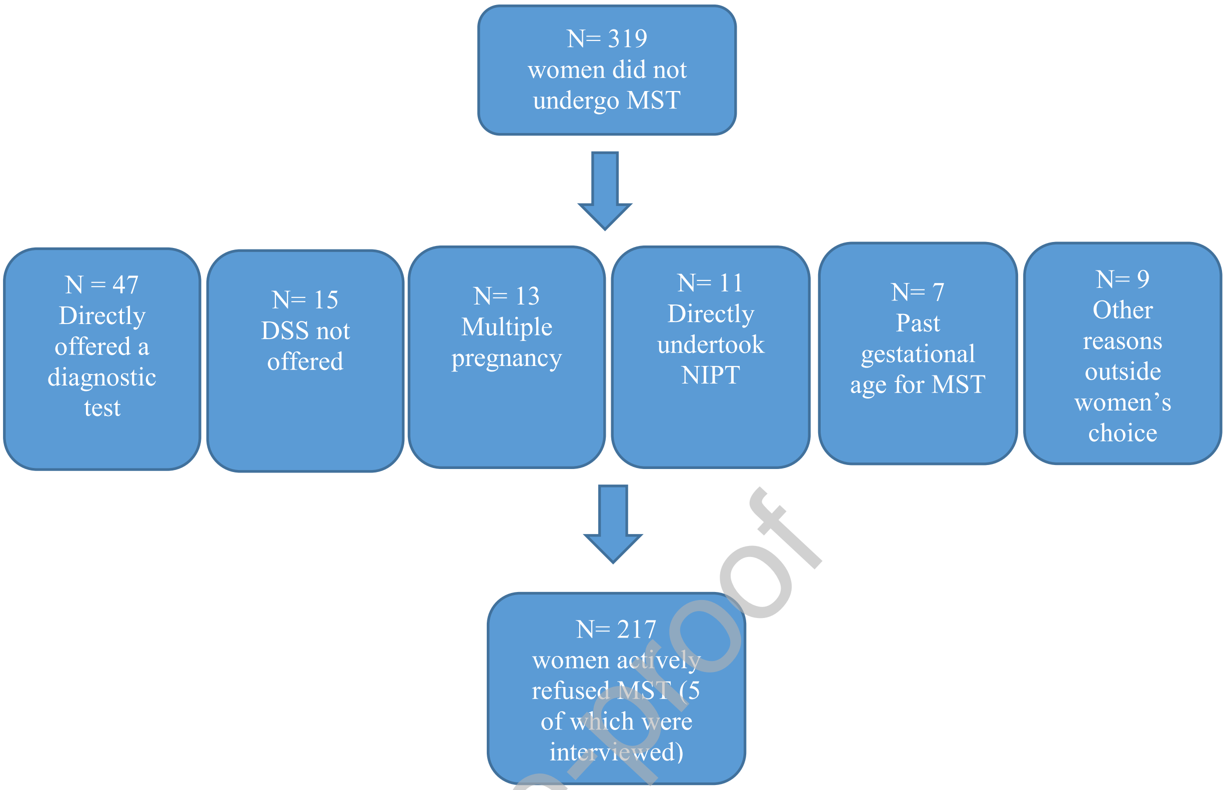
Methods

This article reports data collected as part of a project examining women’s experiences of prenatal screening/diagnosis in France, between May 2015 and February 2018. The project used a retrospective, mixed methods sequential approach, as the objectives were to describe, measure and then explore women’s experiences of prenatal screening/diagnosis (Creswell and Plano Clark, 2007). The study comprises an online survey using closed and open questions, followed by in-depth interviews. The use of a mixed methods design was deemed appropriate to address the diverse study aims, namely to gain information from different perspectives and obtain a comprehensive understanding of women's experiences. Furthermore, when used together, quantitative and qualitative methods complement each other and compensate for each other's limitations (i.e. lack of granular information, and inability to generalise the results (Creswell and Plano Clark, 2007; O'Cathain et al., 2008).

For the online survey, a convenience sample was used. Participants were recruited through professional networks, parenting online forums and magazines, and support organisations. Recruitment adverts included basic information about the study and a link to the online survey. Some were also placed in waiting rooms of prenatal diagnosis (PND) centres. Women over 18 years old who had had a pregnancy in the five years prior to the study were eligible. No restrictions were placed on pregnancy outcomes (e.g. healthy/ill baby, miscarriage, medical termination). Of the 1,726 participants, 210 (12%) did not fully complete the questionnaire. 319 responses were from women who stated that they had not used MST (18.5%). However, for 102 women, this was not a deliberate choice (see Figure 1), thus the study focuses on 217 women (12.6%) who actively refused MST.

The survey comprised questions on various pregnancy milestones: the way DSS was presented, the information provided, the interactions with practitioners, the role of the entourage and the media, and satisfaction with pregnancy care and birth experience. Open questions were available to elicit more in-depth commentary. Thirty nine percent (n = 85) of women who refused MST (vs 18% of those who accepted it) provided feedback, representing 6,490 words. The survey was created and piloted in partnership with (anonymised) an organisation whose mission is to inform women on pregnancy-related issues. This ensured that the questions were appropriate for the audience. Quantitative data were analysed using SAS 9.4 version. Author 3 predominantly conducted the quantitative analysis.

Figure 1 –Sample composition of women who refused MST



For the qualitative part, participants were recruited among those who indicated, at the end of the survey, being willing to be interviewed (n= 564). Purposive sampling was used to explore a range of experiences: 1) women for whom a fetal anomaly was suspected prenatally and had either: given birth to a healthy baby, or a baby with anomalies, had lost the baby, or terminated the pregnancy; 2) women whose baby was born with anomalies discovered postnatally; 3) women who had refused all/some aspects of DSS. Of the 564 women agreeing to an interview, 99 were invited and 67 (67.6%) were interviewed. Of those, five had refused MST, which is the focus of this article.

Participants were asked to provide a narrative of their experience, and questions were used to explore the reasons why they had refused MST. The interview schedule was reviewed by [Anonymised/organisation], but was tailored to each participant based on their survey responses. Interviews were conducted face-to-face, in French, and lasted between 40 minutes and one hour. They were recorded and transcribed verbatim. Qualitative data (interviews and open comments) were merged analysed using Thematic Analysis, a flexible method enabling the mix of data sources (Braun and Clarke, 2006). The analysis followed Braun and Clarke's guidelines (2006). All authors familiarised themselves with the data through reading and re-reading the transcripts. Author 3 then coded the data, and created an initial coding framework that was then discussed with Authors 1 and 2. Author 3 then further refined the themes to ensure they reflected the data accurately, with the final coding framework validated by the team. Amendments were discussed and agreed within the team. Where relevant qualitative and quantitative data were integrated.

The project was registered to the National Commission on Informatics and Liberty (Anonymised) which controls survey protocols, ensuring that participants' anonymity is respected and informed consent is obtained. No other authorisations were needed, as women were not recruited by practitioners and participated in the research in a private capacity. Nonetheless, the study was conducted in accordance with research ethical standards (American Psychological Association, 2017). The team had extensive expertise in researching sensitive topics, and was well versed in managing potential participant distress. To protect the participants' identity, identifiable information have been removed.

Results

1. Study population

Altogether, 1,726 responses were gathered, covering pregnancies between 2010 and 2017, when DSS was conducted in the first semester of pregnancy and before the introduction of NIPT as a routine test. Participants were geographically spread, with an over-representation in the Greater Paris (Ile-de-France) region (24%). Respondents differed from pregnant women in the general population during the same period with an increased risk rate, sampling and positive diagnosis (Table 1). These differences could be due to women being more often willing to share negative experiences.

Table 1: Study population compared to French population[1]

	General population (2012-2015)[2] 823,000 – 799,000	**Study population** 1,726
MST screening rate	83.6% - 85.1%	81.2%
% of "increased risk"	4.1% - 4.2%	18.1%
% diagnostic test	5.9% - 3.9%	18.3%
% positive diagnoses	9.8% - 12.3%	35.1%

The number of screenings and diagnostic tests is compared to the number of live births (Insee sources). The number of women with "increased risk" is compared to the number of women screened; the number of positive diagnoses is compared to the number of women from whom diagnostic tests were taken (*Source: Agence de la Biomédecine).*

[2] 75% of the pregnancies covered by the study began between 2012 and 2015.

Women participants were also better educated than those in the general population, 60% had a level of education of at least two years after the baccalaureate vs. 32% in the general population.

1.1. Characteristics of the women accepting/ refusing MST

Comparisons were made between women who refused MST (n=217, 12.6%) and those who accepted it (Table 2). Women refusing MST were better educated and more likely to have at least two children. Their education level and experience of previous pregnancies might explain their greater awareness of the possibility of having a diagnostic test if they were at increased risk of DS. They were also more likely to have had contact with a person with DS. Nearly 75% of women answered the survey question "What do you think are the consequences of DS on the life of the child, medically, intellectually, in terms of relationships?” A word frequency analysis was conducted using NVivo to group words with a common root (e.g. cardiac, cardiopathy) and synonyms (e.g. happy, joyful). It shows that the terms ‘mental’ or ‘intellectual impairment’ were often associated with DS, especially among women who accepted MST (38% vs. 32%), whilst ‘medical complications’ were more often mentioned by women who refused it (20% vs. 15%). Women refusing MST more often described people with DS as ‘affectionate’ and ‘endearing’ (17% vs. 7%), having a propensity for happiness (8% vs. 2%), and possessing certain abilities (8% vs. 1%).

The decision to accept/refuse MST was associated with the modalities of pregnancy monitoring and childbirth. Women who refused MST more frequently entrusted early pregnancy monitoring to midwives, while those accepting MST more often turned to gynaecologist-obstetricians. A higher number of those refusing MST also chose to give birth at home (Table 2).

Finally, accepting/refusing MST was also linked to women's pregnancy and childbirth experiences. Women who refused MST less frequently reported being worried in late pregnancy and the first weeks after birth. No significant differences were observed between women who accepted or refused MST regarding pregnancy outcome (e.g. healthy/ill baby, miscarriages, medical termination).

Table 2. Factors relating to MST use

	MST Use			
	Total	MST refused	MST accepted	X^2 *p*-value
	N=1726 (100 %)	n=217 (12.6 %)	N=1509 (87.4 %)	
Education level:				
≤ 2 yrs higher education	591 (34.2)	57 (26.3)	534 (35.4)	7.0**
> 2 yrs higher education	1135 (65.8)	160 (73.7)	975 (64.6)	
Number of children:				
0 or 1	929 (53.8)	97 (44.7)	832 (55.1)	8.3**
2 or more	797 (46.2)	120 (55.3)	677 (44.9)	
Aware of diagnostic sequence				
that could follow	1266 (82.3)	175 (87.5)	1091 (81.5)	4.2*
Yes	272 (17.7)	25 (12.5)	247 (18.5)	
No				
Contact with person with DS				
Yes	848 (49.1)	142 (65.4)	706 (46.8)	26.4***
No	878 (50.9)	75 (34.6)	803 (53.2)	
Early pregnancy monitored by				
Gynaecologist-Obstetrician	846 (49.0)	79 (36.4)	767 (50.8)	
Midwife	234 (13.6)	67 (30.9)	167 (11.1)	65.5***
General Practitioner	183 (10.6)	24 (11.1)	159 (10.5)	
Maternity-Hospital	463 (26.8)	47 (21.7)	416 (27.6)	
Diagnostic test				
Offered	390 (24.2)	17 (8.2)	373 (26.6)	33.3***
Not offered	1218 (75.7	190 (91.8)	1028 (73.4)	
Home birth				
Yes	29 (2.1)	13 (6.6)	16 (1.3)	23.1***
No	1362 (97.9)	196 (93.4)	1195 (98.7)	
Late pregnancy experience[1]				
Relaxed	813 (58.1)	146 (74.5)	667 (55.4)	25,1***
Other	586 (41.9)	50 (25.5)	536 (44.6)	
Experience during first weeks[2]				

Reassured	839 (68.8)	136 (77.7)	703 (67.3)	7.5**
Other	380 (31.2)	39 (22.3)	341 (32.7)	

[1] Responses proposed in the questionnaire: I was relaxed and not worried about my baby's health; I was not completely at ease but did my best not to worry; I was quite worried and unable to stop thinking about the worst that might happen

[2] I was reassured; I was quite reassured, but remained vigilant; I remained worried

The five women interviewed were aged between 27 and 32 years old. All were educated at postgraduate level and were first time mothers. Four babies were born healthy and one baby was born with DS.

1.2. Reasons for accepting/refusing MST

Most women in the study accepted MST. However, although 87% were aware of the test, only 29% decided to proceed before being informed by their practitioner. Most agreed to the test on the practitioner's advice, because they thought it was routine or to be reassured. Only 17% said they agreed for fear of having a child with DS (Table 3). In the open comments, 76 women who accepted MST stated that they did not really consent to the test: it was presented to them as mandatory and they were unaware they could opt out; some reported pressure from practitioners.

Table 3. Main reasons for accepting/refusing MST

Reasons for accepting	**%**	**Reasons for refusing**	**%**
Seen as routine	58%	Would not terminate the pregnancy because of DS	53%
Doctor's advice	47%	Not worried	19%
For reassurance	35%	Keen to restrict the number of tests	12%
Already decided to have it	29%		
Afraid of having a child with DS	17%		

A small majority of women associated their MST refusal with wanting to keep the child if it turned out to have DS (Table 3). For some, pregnancy termination was not an option, but open comments show that other women who refused MST considered it for pathologies they deemed more severe.

"If there really is brain death, well not brain death, but no activity, then we might give it some thought" (interview n°5).

Noteworthy, for most women (including 64% of those refusing MST), the fetal NT measurement had been conducted; it was often presented as mandatory, and sometimes taken without women's consent.

This questions the way in which women are informed of the ins and outs of DSS, the consequences of a positive result, and the way in which their consent is obtained. In this context, the experience of women who refused MST and the reasons for their choice appear particularly enlightening. In the remainder of the article, we will analyse the comments left by women who refused MST and the interviews conducted with five of them.

2. What leads women to refuse MST

2.1. Awareness of the implications of MST and the emotional charge it may imply

MST was not refused *per se*, but for its implications, be it a diagnostic test with its inherent risk of miscarriage or pregnancy termination. This perspective led women refusing MST to consider that, taken in isolation, MST provides little information – hence their refusal.

"At the end of the day we decided not to do the tri-test as the test doesn't seem sufficiently reliable. In any case, we would probably have refused an amniocentesis and kept the child if it had Down's syndrome" (open comments).

The stance taken by women refusing MST was based on an understanding of the test's implications in the medium- and long-term, and a solid understanding of DS. However, the information provided at the time of screening did not systematically inform woman about the next steps and the consequences of the pathology. Indeed, 70% of women said they were informed that should their DS risk be high, they would be able to have a diagnostic test, and 54% that if DS was diagnosed, they would be able to terminate the pregnancy. Several respondents mentioned only receiving factual and incomplete information when presented with the test, and thus, considered themselves lucky to have had prior knowledge about it and DS.

"You are told: 'there is a blood test to see if there is a risk', but you are not told what choices you will have to make after that [...] what are the consequences? They don't explain what Down's syndrome is. [...] I'm sure there are women who, as a result, have abortions when they could manage very well and that later on they regret it" (interview 4).

MST generated anxiety due to having to wait for the results, possible bad news and difficult decisions. Although a third of women who accepted MST said they did so to reassure themselves, it was also in the hope of having a problem-free pregnancy that women refused it.

"I wouldn't have terminated my pregnancy for Down's syndrome, so what's the point of worrying during the pregnancy on the basis of tests that only offer probabilities?" (open comments).

The first-trimester ultrasound: a test sufficiently reassuring

For most women refusing MST, the NT measurement - a measurement in which they had more confidence - was conducted.

"I refused the blood test, which I found caused unnecessary anxiety, given that I did not want

an amniocentesis, but I was happy to have the nuchal translucency measurement, which I felt gave reliable information” (open comments).

NT measurement is integrated into the first-trimester ultrasound which examines the fetus. A significant event for women who often visualise their baby for the first time, the NT measurement is usually not the most prominent part of the examination and may even go unnoticed. Consequently, some women did not associate it with DSS, especially as MST and NT measurement are performed in different places and by different professionals.

"As far as I was aware, nuchal translucency related to the ultrasound and not to the screening [...] on top of that it's different appointments [...] I didn't know it was related" (interview n°3).

The different perception of the two tests also stems from the fact that they are rooted in separate registers of medical practice. The ultrasound is perceived as a clinical tool used to care for a tiny patient who becomes tangible through the image provided. By contrast, MST relates to a risk calculation and is explicitly designed to detect anomalies. From this standpoint, MST refusal is not incompatible with:

“a screening that is, let’s say, to some extent natural, where we see the baby. But not by carrying out an investigation, whether it be in my blood and therefore his blood, or by amniocentesis for example. [...] There’s a real difference between seeing that the baby is there, giving him his place, giving him his freedom and not being intrusive, and carrying out an investigation on him [...] I see it far less as a screening than as a little visit to the baby to see if everything is fine. It is more of a check-up than a screening. In my opinion, a screening, I find it quite intrusive for the baby, where we look for some little thing that’s not right" (interview n°2).

Although women refusing MST considered that "pregnancy is not a disease", they did not necessarily reject its medicalisation.

"if there really are things that can be detected beforehand, such as organ deformities that can be detected and save [the baby's] life at birth, and enable operations to be carried out very quickly after the birth, I think it's very useful" (interview no. 2).

Moreover, five of the 10 women offered a sample collection following a suspicious ultrasound image, chose to accept it with four terminating their pregnancy as a result. And while some of them accepted the risk of DS, this choice seemed to be guided less by religious convictions (only two women mentioned this) than by an outlook on life marked by tolerance.

2.2. A tolerant attitude towards difference

While acknowledging the difficulties associated with the consequences of DS, women commented on the potential of people with DS of living a happy life and enjoying some autonomy.

"Among the children and adults I've known with Down's syndrome, if I had to remember one thing, it was their 'joie de vivre'. In spite of their disability, they are always laughing and happy"; "children can develop very well, they can even be independent. They can go to school, have a job and live alone" (open comments).

There were also mentions of the difficulties of integrating people with DS, who *"may find it difficult to find their place in society due to their difference and to the way others see them"; "because nowadays they are seen as errors of nature, rather than as people like any others"* (open comments).

The validity of DSS was sometimes questioned.

"Why is there so much concern about Down's syndrome, when in my opinion, many other things, which are not detectable, are more serious and consequent for the child and his or her entourage (...) even if I know that Down's syndrome can be serious, is not a disability which, as far as we are concerned, is incompatible with having a good life." (interview n°1).

Especially as PND could be perceived as an obstacle to the inclusion of people with disabilities.

"In France, it is not very easy to manage disability. [...] if the only alternative offered to parents whose baby in-utero is disabled is medical termination of pregnancy, then that's not likely to get us anywhere" (open comments).

However, many women felt that each situation is unique and that the choice of whether or not to accept the child's disability is an individual one.

"I don't in any way judge parents who decide not to carry a pregnancy to term with Down's syndrome because it's tough to have a disabled child and I understand that some people don't feel able to cope". (interview n°1).

3.4. A personalised and holistic approach to pregnancy monitoring

Refusing MST was also part of a broader conception of pregnancy, seen as a natural process, which cannot be reduced to a medicalised pathway. Women who refused MST counted upon practitioners to provide them with information and discussions that respected their expectations and choices.

"One of the objectives of midwives [...] is to give pregnant women and couples the opportunity to be actors in their own pathways. I really have the impression that my follow-up appointments were made in collaboration with our midwife. She advised us on books to read. She gave us all the information we wanted. We really didn't feel like she was the one with the

knowledge. She gave us bits and pieces and made available everything she knew so that we would be as well-informed as her in order to make all the decisions together.” (interview n°1)

Some professionals (often midwives practising outside hospital structures) sought to accompany women and couples in coming to an autonomous decision, an attitude which could lead to more people refusing MST.

“There are many patients who do not have this screening, but I think it is mostly because [...] as midwives open up a dialogue on this subject and encourage reflection, I think that there are more parents who really ask themselves the question" (interview n°1).

Women's desire to be actors in their pregnancy was sometimes put to the test by professionals (often hospital professionals) who tended to deny them this aptitude and make them feel guilty.

"The gynaecologist who was doing the ultrasound did not welcome the fact that we didn't want to do the test. For her it was inconceivable that we didn't want to know” (open comments).

A woman who did not have a first-trimester ultrasound was told by her gynaecologist-obstetrician that *"it was a loss of opportunity for the child that might even be fatal due to the lack of proper care required during the first few days after birth! [...] He made me feel very guilty!”* (open comments).

Women who refused MST, far from being passive, tried to resist these pressures by choosing a practitioner they trusted.

"I first consulted a gynaecologist for my pregnancy who [...] refused to consider me not taking this test. So I continued to monitor my pregnancy with the general practitioner” (open comments).

Some women went so far as to implement strategies to maintain an acceptable relationship with the practitioner, while maintaining their free will.

She [sonographer] said to me, 'did you have a blood sample taken?' I said, 'no, no, I still haven't'. In fact, I had somewhat prepared my answer in advance because my husband and I have a bit of a sense of humour and we thought it would be good to relax the atmosphere. [...] So I said: 'as soon as we have three babies with Down's syndrome, we'll stop having children'. [...] That broke the ice a bit. Afterwards she was more relaxed with us." (interview n°2).

Discussion

This study sought to examine the reasons why some pregnant women in France decline MST. Results show that while some are determined to do so from the outset, the majority make their decision early in pregnancy, during interactions with professionals. Furthermore, accepting or refusing MST seem to be separate processes. Accepting MST often appears as the default option, confirming that testing is still largely perceived as routine or even mandatory (Reid et al., 2009; Crombag et al., 2013), and that the choice is illusory (Garcia et al., 2008).

By contrast, refusing MST can be cognitively demanding. It is associated with a solid understanding of prenatal screening/diagnosis practices and their sequence, facilitated by a high level of education, multiple experiences of maternity, and a better understanding of the consequences of DS (Bakker et al., 2012), sometimes obtained through contact with the people concerned. This knowledge, acquired before pregnancy, would compensate for the lack of information provided during pregnancy, linked in particular to the difficult transmission of probabilistic reasoning (Hunt et al., 2006) in an emotionally charged context (Ville and Lafarge, 2020). Additionally, organisational constraints in France limit the time practitioners can devote to providing this information (Vassy et al., 2014), often causing them to skip information on potential future decisions (diagnostic test, pregnancy termination), and the pathology being screened for. This selective information produces forms of ignorance (Proctor and Schiebinger, 2008) which may generate an attitude of passive acceptance.

Refusing MST is often equally emotionally demanding. While its aim is to enjoy a worry-free pregnancy by avoiding anxiety-inducive screening practices, some women still feel they are undergoing an ‘ordeal’ They have to justify themselves to practitioners and defend a conception of pregnancy monitoring clearly different from the norm. Sometimes this ordeal can only be resolved by changing practitioner. Other women, anticipating these difficulties, prefer to avoid it by developing strategies to manage the relationship with the professional.

Consistent with Press and Browner (1998), the findings show that not all women refusing MST would continue their pregnancy at all costs, nor do all women accepting it always associate screening with the possibility of abortion (Markens et al., 1999; Garcia et al., 2008). Women who refused MST generally favour some form of medicalisation of pregnancy in the service of a type of care that sees the foetus as a patient and recognises women’s abilities to engage with practitioners on pregnancy-related decisions (Mol, 2008). This is why the NT measurement is more readily accepted than that of MS; it is viewed as one of many elements that constitute the examination of the patient-fetus.

Conversely, women who refused MST reject a particular orientation of the medicalisation of pregnancy, which has become the norm and emphasises the prevention of disabilities. To them, this approach seems irreconcilable with clinical practices centred on the patients. This stance leads some women to turn to community-based facilities where midwives provide care more in line with their expectations.

Women often linked their personal experiences of these practices to negative social attitudes towards disability. More than an opposition to progress and science dictated by religious beliefs or attitudes towards a 'nature' that should not be thwarted, it is in fact a moral and political act that women in our study perform by refusing MST.

This study has limitations, one of which is the sample bias. Indeed, the over-representation of women from privileged sociodemographic backgrounds prevents us from generalising the results to all women refusing MST. However, paradoxically, this same bias enabled us to uncover a particular stance regarding prenatal testing/diagnosis and pregnancy monitoring practices.

Conclusions and implications

The results indicate that women refuse MST for reasons that go beyond religious beliefs, negative attitudes towards pregnancy termination and/or the medicalisation of pregnancy. Rather than the expression of a somewhat dogmatic attitude, this position appears to be driven by values of inclusivity and a desire to remain in control of their pregnancy. It is therefore important for practitioners to remain cognisant of the diversity of factors underpinning women's choices and avoid making assumptions as to what these might be. The results also suggest that refusing MST is an emotionally challenging and cognitively demanding position to hold. Women often go to great lengths to justify their choice whilst ensuring that practitioners do not feel undermined by it. Consequently, it is important that women feel supported in their choice, and that professionals acknowledge the pressure this stance may generate. This is particularly relevant in the context of an evolving prenatal testing/diagnosis landscape Indeed, new tests such as NIPT may, at first glance, simplify women's decision-making regarding DSS by reducing the need for diagnostic tests associated with a risk of miscarriage. However, as NIPT is not yet a diagnostic test, DSS still relies on MST to identify pregnancies at risk of D   As such, women's self-questioning about whether to accept or refuse MST is still highly relevant.

Credit authors Statement

Caroline Lafarge: Validation, Investigation, Formal analysis, Data curation, Writing (Original Draft, Review & Editing), Visualization, Project administration

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