Title: Frames of decision-making in prenatal consultations in England and France. Towards a sociological, relational and processual approach to autonomy

Short running title: Frames of decision-making in prenatal consultations

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ABSTRACT

Rationale, aims and objectives

The article looks at how, during consultations, pregnant women identified as presenting an increased risk of giving birth to a child with an impairment, and practitioners in the field of prenatal diagnosis, decide whether or not to accept the risk of a miscarriage and proceed with a diagnostic examination.

Methods

We conducted 63 observations of consultations in France and 22 in England. Participants were women for whom an elevated risk of abnormality had been identified and the practitioners involved in their care.

Our analytical approach consisted in suspending the normative concepts of non-directiveness and autonomy, and in drawing on Goffman's (1974) notion of "frame" to take account of the experiential and structural aspects that the protagonists bring into the (inter)actions.

Results

We identified four frames: medico-scientific expertise, medical authority, religious authority and compassion. Observation of the ways in which the frames intertwine during consultations revealed configurations that facilitate or hinder the fluidity of the interactions and the decision-making process. The medico-scientific expertise frame, imposed by the guidelines, heavily dominated our observations, but frequently caused distress and misunderstanding. Temporary or sustained use of the compassion and/or medical authority frames could help to repair the

discussion and create the conditions that enable women/couples to reach a decision. Variations in configuration highlighted the differences between practitioners in the two countries.

Conclusions

Combining frames allows protagonists to exert reflective abilities and to maintain/restore interactions. The frame analysis promotes a vision of autonomy that is sociological, relational and processual rather than philosophical. The frames are anchored in different structural conditions in England and France.

INTRODUCTION

Pregnancy-related genetic counselling has developed significantly since the 1970s and the liberalisation of abortion. Eager to dissociate themselves from eugenic practices, practitioners placed women's decision-making autonomy at the centre of their work.[1] This orientation is more broadly embedded in the international context of the rise of bioethics, of women's and disability movements and of the shift over to the 'therapeutic modernity' model, characterised by more standardised healthcare practices, regulated away from the doctor-patient relationship by central bodies that articulate evidence-based medicine with a procedural and "juridicised" vision of ethics. [2,3]

In this context, the concept of autonomy is based on a Western, modern conception of individuals as rationale beings.[4] It goes hand-in-hand with the principle of "non-directiveness" that is now an integral part of the prenatal diagnosis (PND) guidelines.[5]

In the field of PND, the choice between two risks – that of a child being born with an impairment, versus that of the loss of a healthy child following amniocentesis – has strongly influenced the way pregnancy is monitored. The generalisation of antenatal screening and of increasingly effective imaging techniques now makes it possible to identify "high-risk

pregnancies" and detect a large number of anomalies, whilst limiting the loss of healthy foetuses.

ORGANISATION OF PRACTICES

In countries where abortion is legal, PND is based on a sequence of standardised decisions and actions. The first decision-action event is Down Syndrome (DS) screening, offered to all pregnant women in England and France, usually during their first pregnancy consultation.[6] There are nevertheless differences in screening uptake (75% of pregnant women in England, 85% in France).[7,8] Similarly, the threshold at which the risk is deemed sufficient to warrant a fetal karyotype examination varies (1:150 in England; 1:250 in France). Routine foetal ultrasound examinations carried out at different points during the pregnancy (two in England and three in France) enable practitioners to check that the foetus is developing normally and look for soft markers frequently associated with anomalies.[9]

Once identified as being "at increased risk", women are referred to PND centres located in public hospitals. Then follows the second decision-action event involving diagnostic tests. This usually means the extraction of amniotic fluid (amniocentesis) or sampling of trophoblast cells (Chorionic villus sampling: CVS) with an estimated 1% risk of triggering a miscarriage.[10] Whilst some abnormalities can be surgically repaired *in utero* or after birth, most of the anomalies discovered are incurable;[11] the women and couples may then begin a third sequence of decision-action in relation to a pregnancy termination.

A PRINCIPLE OF AUTONOMY DIFFICULT TO IMPLEMENT

When a risk is identified, practitioners must provide the woman/couple with "information on the nature of the suspected affection, on the means of detecting it and possibilities for prevention, treatment, or suitable care for the foetus or child born". [11,12] The aim is to enable women to make autonomous decisions and informed reproductive choices. Yet information

about Down syndrome is often absent from the consultations.[13] Research on women's decision-making emphasises the diversity of women's beliefs about ethics,[14] their interpretation of informed choice,[15] and their attitudes about knowledge sources.[16] Evidence also suggests that some women view choice as an individual right, while others prefer relying on practitioners' advice.[17,18] Other studies indicate that it is often difficult for practitioners to comply with neutrality and non-directiveness.[19]

Practitioners admit to being directive in certain situations,[17,20] as they make assumptions on women's scientific and linguistic skills, their religious beliefs, and knowledge of abortion legislation.[21,22] Direct observations of counselling practices demonstrate the complexity of women and practitioners' interactions, which is largely caused by differing interpretations of the concept of risk.[23] Schwennesen and Koch observed that the act of « doing good care », by minimising emotional suffering and supporting a pregnant woman's ability to make meaningful choices, is difficult to reconcile with the ideal of non-directiveness. [24]

The difficulty to adopt the recommended non-directive approach poses important questions. On one hand, it might reveal the persistence of a form of paternalism in the relationship between women and practitioners, with the latter possibly struggling to accept women's autonomy in decision-making. On the other hand, it might reflect a conception of autonomy that is too restrictive to take account of the relational dynamics taking place in clinical consultations. To address these questions, it is essential to examine what the interactions between women and practitioners consist of by suspending, during the analytical process, any normative reference to autonomy and non-directiveness.

In this article, we focus on the second sequence of decision-action in PND pathways, where women identified as being "at risk" are sent to referral centres where they must decide whether to continue with the investigations or not.

In line with pragmatic sociology, using Frame Analysis,[25] we first describe and categorise the interactions that take place during the consultations, the way women and practitioners engage and adjust to these interactions, as well as the conditions that facilitate or hinder the protagonists' expression of their reflective capacities. This then lead us to consider and challenge the philosophical conception of autonomy, and propose, instead, a sociological conception of autonomy that is both relational and processual, and which we discuss in relation to the organisation of PDN practices in England and France.

METHODS AND MATERIALS

Our analysis is based on observations of PND consultations to which women are referred when there is an increased risk of foetal anomaly. Sixty-three observations were conducted in France between 2010 and 2012 in a PND referral centre in the Paris region, which receives a high proportion of immigrant women, most of them from North Africa, and in a provincial centre which treats a mixed population. Twenty-two observations, involving a mixed population, were conducted in England in 2013, in a gynaecological and obstetric unit in a hospital that practices foetal medicine and in a foetal medicine unit in a referral centre. In our observations, the increased risk resulted from DS screening (39), ultrasound imagery (24), genetic/obstetric history (12), maternal age (8) and toxoplasma infections (2).

We must begin by pointing out a difference between the two countries in terms of health pathways. In England, women are informed of their risk and only sent to a referral centre if they consider that taking a sample is an option. A midwife then goes over the information on the risks before obtaining the woman's consent. An ultrasound examination is then performed; the consultant answers any questions the women may have and the sample is taken. In France, all women "at risk" are referred to a PND centre. Approximately one third of the consultations

follow the same format as those in England. The remainder are conducted by a midwife alone, who provides information. No medical act is performed.

The study received ethical approval in France from a Research ethics committee (Anonymised) and in England from the Health Research Authority (anonymised) and the University of (Anonymised) ethics committee. Consultations lasted between 25 and 70 minutes. 40 women attended the consultations on their own, 42 were accompanied by their partners and three by someone else. The authors were present during the consultations. Field notes were made to capture the communication's content and delivery as well as non-verbal expressions. In England, the consultations were also recorded and transcribed verbatim.

The analysis, conducted by both authors, draws on Grounded Theory.[26] It focuses on the nature and properties of the (inter)actions taking place during the consultations and how these are combined to enable a decision regarding the management of the pregnancy to be reached. These interactions are heterogeneous and relate to medical practices, their organisation and regulation. Yet most of these actions are "speech acts",[27] i.e. discourses which inform, reassure or worry, protect, advise, influence, etc.

Based on frame analysis,[25] the first analytical stage consisted of identifying the different frames mobilised by protagonists during the consultations. The frames act as guides to action, they convey ordinary meanings of what takes place in a situation and of the ways people behave therein. The second analytical stage, which draws on "combinatory pragmatics",[28] consisted of identifying from the combination of frames and their impact on the interactions, the different configurations of consultations and their outcome in terms of decision-making.

RESULTS

FRAMES OF DECISION-MAKING AT WORK IN PND CONSULTATIONS

We identified four frames from the interactions we observed. Three of these carry the rational resources that might guide the decision-making: the frames of medico-scientific expertise, medical authority and religious authority. A fourth frame offers resources that can mitigate the emotional charge and thus supports the interactions; we call it the compassion frame.

The medico-scientific expertise frame

This frame was predominant in our observations, articulating a moral stance that supports the actors' ability to make rational and autonomous choices[3,4] with a grid for understanding situations based on the medico-scientific rationale at work in evidence-based medicine. This is the frame that dominates the 'therapeutic modernity'.[2] Practitioners are tasked with helping women decide whether to continue with the investigations, and therefore accept the risk of miscarriage when a sample is taken. This presupposes that women have acquired sufficient expertise regarding the model for calculating risks and interpreting their significance, and that practitioners have provided clear information without engaging their own subjectivity. The actions taking place within this frame thus essentially involve providing/receiving/asking for scientific and technical information relating to the nature of the risks, their value and mode of calculation, how the medical acts are performed, and the aetiology and consequences of the suspected pathologies.

All the consultations we observed began in the medico-scientific expertise frame with the practitioner explaining the risk as being the reason for the consultation. "*I'm seeing you today to discuss the results of the blood test. It allows us to evaluate the statistical risk of having a*

192 *child with Down Syndrome. Your risk is…"* (Midwife, France). Detailed technical information
193 is then provided, depending on the type of risk.

194 *"It would appear that you have contracted a toxoplasmosis. […] The risk of transmission*
195 *increases with the term. At the beginning of the pregnancy it is 1%, at 9 months it is 80% of*
196 *babies who are contaminated. [but]the consequences are not the same. If it is before 15 weeks,*
197 *there can be serious consequences. Toxoplasmosis attacks the entire organism but the most*
198 *serious consequences are on the brain"* (Consultant, France).

199 Once the information on possible foetal anomalies has been given, the practitioner provides
200 details on the risk of miscarriage when a sample is taken. The risk is frequently weighted by
201 information on the expertise of the operator, designed to reassure:

202 *"The risk here is lower than the national average and the reason for that is because we do these*
203 *tests every day… and of course the consultants that do these tests do them all the time, so they*
204 *are experienced. So your risk of miscarriage as you enter the room is less" (Midwife, England).*

205 In England, practitioners also explain another risk, that of the culture of amniotic cells not
206 giving any meaningful result or ending in a 'laboratory failure', estimated at less than 1%.

207 Given the technical nature of the information, the medico-scientific expertise frame is a
208 demanding one as it requires the appropriation of complex knowledge. Therefore, practitioners
209 often employ sophisticated strategies such as the lottery metaphor, frequently used in the
210 consultations observed in the Parisian centre: "*Your risk is 1:197. It's as if your uterus was the*
211 *lottery chamber, there are 196 white balls and one red; but we don't know which one is in your*
212 *tummy*" (Midwife, France).

213

214 **The medical authority frame**

As a persistent form of doctor-patient relationship rooted in the "clinical tradition", in the medical authority frame and by virtue of their experience, clinicians can legitimately express opinions, give advice and orient the decisions of their patients.[2] This frame is difficult to reconcile with that of the medico-scientific expertise, which established itself as the opposite of the medical authority paradigm. It is, therefore, only brought into play when the course of (inter)actions requires some adjustment. The analysis of our observations reveals three reasons for turning to medical authority.

Medical authority to repair the exchanges

A situation may occur where the practitioner suddenly realises that the information he/she has just given, is upsetting the woman and/or her partner. It is often when he/she is coming to the end of his/her expert explanations by asking if there are any questions, that the woman expresses her concerns. At this stage, some practitioners use the medical authority frame as a way of "repairing" the emotional harm that the medico-scientific discourse has caused. This might mean a brief incursion during which the practitioner sets aside the neutral attitude and adopts that of the benevolent authority of someone who has the answers and can be trusted. At the very least, this comes in the form of a comment that qualifies the information that have just been given: "*You know the information now, don't think about that anymore […] we are very, very positive here in terms of the situation. I mean it sounds very good."* (Midwife, England)

The practitioner will occasionally engage his/her subjectivity before picking up the threads of the medico-scientific arguments. In the Parisian unit, repair sometimes goes hand-in-hand with a justification that the practitioner uses to free him/herself from the recommended principle of neutrality, so as to better adjust to the woman's distress: "*You are 30 years old. The neck is thin. I'm not worried but we have to have this conversation […] I have to give you the most reliable information possible"* (Midwife, France).

Medical authority requested by women: delegating the decision

Women may turn to the medical authority frame by explicitly asking for the practitioner's opinion. More often than not, the practitioner will maintain a neutral stance: *"I'm not the one who will be holding this baby in my arms. It would be dishonest of me to say 'in your position I would do it'",* (Midwife, France), which sometimes causes tension in the discussion as seen from this consultation in England:

Woman: What do you think we should do?

Consultant: I can't tell you.

Woman: Of course you can!

Consultant: Our personalities are not the same.

Woman: You should still tell us.

Consultant: Doctors can't tell you what to do in these circumstances.

Woman: I think you should.

The neutral attitude can sometimes be interpreted as the practitioner's disengagement from the clinical relationship, thus causing the women to feel abandoned.[29]

More rarely, practitioners will accept delegation of the decision following an explicit request from women who do not wish to engage in an expert approach and who wish to leave it up to professionals. The asymmetry is chosen and accepted with due regard for the protagonists. In France for example, with a certain amount of assurance, a woman of African origin interrupts the obstetrician's explanations by saying: "*Doctor, it's you who decides, because we don't know anything about all this!*" The request is understood and the practitioner accepts the delegation. He questions the couple on several occasions so as to adapt his advice to suit their expectations, understands that for religious reasons abortion is not an option, and to the satisfaction of the

couple, concludes: "*In my opinion no sample should be taken. You say I am the doctor and that I must advise you. That is my advice.*" (Consultant, France).

Although certain English practitioners sometimes accept to give an opinion, this does not mean that the neutrality and objectiveness, characteristic of the medico-scientific expertise, are set aside. Each opinion is accompanied by a technical argument to such an extent that the frames of expertise and medical authority are very much entwined.

For example, during the ultrasound examination preceding a planned CVS, and when the development of the foetus seems to be normal, the woman is submerged by doubt:

Woman: So, do you think we should still go for the CVS?

After explaining the advantages and limitations of imaging and karyotyping, the consultant concludes: *"It's true that the scan is not 100% reliable, okay? So it's two complementary things".*

Woman: So because the nuchal scan was 2.8mm, that's why we want to go ahead and get this done.

Consultant: It is your choice.

Woman: But you think that's good still to do?

Consultant: Yes! If you want to have peace of mind, this is not unreasonable.

Woman: And the chance of miscarriage is so small that you think...

Consultant: It's slightly less than 1 in 100

Woman: So it's worth it...

Consultant: Yes why not!

Imposed medical authority: orienting the decision

In some cases, medical authority is imposed without being requested by the woman/couple. This is often the case in France when women are hesitating to have a sample taken. They are often dissuaded from doing so if they are determined to keep the child they are carrying. For example, the midwife explained to a couple carrying the drepanocytosis gene: "*We can make the diagnosis before birth, but we need to ask what we're going to do. If [the foetus] is affected, are we going to terminate the pregnancy?*" Following the woman's negative response, she continued: "*the only thing we can do is an amniocentesis. But there's a risk of miscarriage. That's why, if you wish to keep this child, it's better not to do [the amniocentesis]"* (Midwife, France).

Finally, the practitioner's attitude can be clearly directive when there is a strong presumption of anomaly. In France, for example, the consultant immediately told a 45-year-old woman: "*As you have unfavourable blood results, with a very high level of hormones, this suggests a risk of chromosomal anomaly. It would be a good idea to rapidly have an amniocentesis to reassure you."* When facing what is considered to be a high risk, there is pressure to move fast.

The religious authority frame

The religious authority frame is sometimes mobilised during consultations. For some women, the underlying world order cannot be reconciled with the possibility of losing a foetus due to a sample being taken, and even less with a termination of pregnancy. Procreation is seen as a gift from God; neither women nor doctors have the right to change the course of the pregnancy.

In rare cases, couples explicitly refer to the religious authority frame when the practitioner has finished speaking. "*Stop all the tests. I take full responsibility. Inshallah […] I want this baby,*

Down Syndrome or not, no problem. It's fate." (African partner, France). In other cases, it is the practitioners themselves who mobilise this frame, to explore the woman's opinion concerning the possibility of terminating the pregnancy. In the Paris centre, this strategy is frequently employed on women, who are assumed to be Muslims. Having delivered the standard information on the risk of DS and of miscarriage associated with taking a sample, the midwife asks the woman:

Midwife: "You must tell me if you want us to do this test".

Woman "No".

Midwife: "Why don't you want it?"

Woman: "If there were no risk, I'd do it. In our country it's not a good thing, because God will punish us".

Midwife: "If you knew for certain that the child had Down Syndrome, what would you do? We terminate the pregnancy or we continue?"

Woman: "I can't terminate"

The midwife wants to be certain that the woman's choice is truly rooted in religious authority and not in a "false belief" concerning the risk of a miscarriage. The woman's confirmation generally puts an end to the interactions. Such situations often lead to reciprocal mistrust. This can be seen in the post-consultation comment made by a French consultant concerning a woman whose foetus is at risk of a genetic disease and who, for religious reasons, twice rejected the offer of a diagnostic test: "*It's not complicated. For us she just wouldn't listen!"*. The few times the woman spoke during the ultrasound examination shows how little she believed in technology. When the obstetrician observes that *"the baby is not very big, especially the head",* she retorts: *"my first child also had a small head, but afterwards it grew"* (African woman,

France). Women's mistrust of medicine can also be found in England: "*the doctor told me that a baby would have disability but when the baby is born …it was a minor problem"*

The religious authority frame may remain latent in many situations; women turn to this frame to make a decision, without necessarily offering any justification, either because they feel it is a private matter, or because they fear a negative reaction or insistence from practitioners.

The compassion frame

Compassion offers no cognitive resources with which to make a decision; it is used to calm the anxiety which often increases as information is provided, and thus supports, or even re-establishes, interactions. Compassion supposes that distress is recognised. It may be used in conjunction with the medico-scientific expertise frame to demonstrate empathy and benevolence, or when the practitioner becomes aware of the anxiety that the information has caused. Resources are numerous and heterogeneous; therefore, the compassion frame can be easily intertwined with other frames. It can be confined to demonstrations of neutral concern, such as the use of softly spoken verbal phrases ("it's alright my darling", "don't worry about it"), or to gentle and kind-hearted gestures, such as passing a box of tissues to a woman who is crying, placing a hand on her arm, or using humour. The practitioner might signal his/her availability by suggesting another appointment or a telephone call: "*if you are still worried when you get home, give me a ring"* (Midwife, France). In certain cases, practitioners may suggest postponing the decision to a later date or term. Finally, the compassion frame can also be used in conjunction with that of medical authority, when the practitioner engages his/her subjectivity in the assessment of a test result: "*in your case the risk is very, very low".*

COMBINING FRAMES

The second analytical stage consisted of examining how the protagonists combine the different frames taking account of the eventual ruptures and adjustments that occur in the short time that consultations last, and their impact upon the nature and degree of fluidity of the interactions.[30] This systematic approach revealed a range of consultation configurations. We will focus on the three most frequent ones.

When protagonists mobilise the same frame

In several cases, the medico-scientific expertise frame is common to both practitioners and women – the latter are often already informed but require additional information to make or confirm their decision. The protagonists thus engage in continuous and fluid interactions, the scientific and technical content of which is rooted in evidence-based medicine.

In the following extract, a couple has been referred to the French provincial centre for a risk of DS of 1:130. The woman wants more information about the risk of miscarriage, which the midwife estimated to be 1:200. The woman initiates the dialogue and concludes with her decision to have the amniocentesis:

Woman*: "It is very important to me to understand what you are telling me. If we don't understand, the decision is not very informed".*

The midwife writes her calculation on a piece of paper. X=100/130. The woman uses her calculator: *"That gives 0.77. There is a 0.77 chance out of 100 that there is a problem [with the foetus]".*

Midwife: "Tell yourself it's a little less than 1%".

Woman: "I have less chance of losing the child because of a miscarriage, than of there being a problem".

Three conditions favour fluid and continuous interactions in the medico-scientific expertise frame. Firstly, women must be engaged in this frame, of which they have some understanding, and be ready to receive or ask for scientific and technical information to make or confirm their decision. Secondly, it must be possible to contain the emotions that are generally aroused when talking about the risks of pregnancy. These two conditions are more easily met when women have been informed of their risk prior to the consultation and have already begun to think about it. Thirdly, there must be an opportunity for women to interact with practitioners. This means that either women feel it is legitimate to spontaneously interact or that practitioners encourage them to do so.

When protagonists mobilise frames difficult to concile

It is not rare for protagonists to approach a consultation using different frames. Such situations tend to rigidify interactions and sometimes lead to distortions likely to hinder the decision-making process.

When engaged in the medical authority frame, women do not expect a general explanation of pregnancy risks but the practitioner's opinion of their personal situation. Above all, they seek reassurance and/or guidance. The medico-scientific expertise frame, which orients the practitioner's attitude, and the medical authority frame which directs that of the women, thus enter into opposition. Waiting for an opinion on her personal situation that does not come, the woman may start to think that the technical information she is receiving is a prelude to the announcement of bad news. The length of time it takes to provide this information increases her distress further. In France, after quietly listening to the midwife explain the way DS screening works, receiving information on the pathology, with photos of children with the syndrome, a woman, of African origin, begins to cry and her partner, who can no longer keep quiet, interrupts the midwife: *"Excuse me, but does this concern us?"*.

404 The tension caused by the confrontation between the two frames generally leads to a high
405 emotional charge that hinders the fluidity of the interactions. It can nevertheless be reduced by
406 exposing the gap between the woman's expectations and the demands of the medico-scientific
407 expertise frame. This is what the midwife attempts to do when she begins her consultation with
408 a preamble destined to reassure the couple: *"The first thing we need to be clear on is that baby*
409 *might be absolutely normal, OK? This is a risk assessment*" (Midwife, England). However, the
410 concept of risk is not always well understood and the preamble not always enough to contain
411 emotions. These situations have different outcomes. The decision might be postponed and a
412 new appointment made, as is often the case in France. The woman might also choose to have
413 the sample taken as a way of resolving the distress caused by the expert discourse.

414 The women/couples who approach pregnancy and its monitoring through the frame of religious
415 authority do not begin consultations with the intention of gathering information that will help
416 them to make a decision. Their decision has already been made. Yet they are rarely given the
417 opportunity to express their position from the outset and some women feel that they do not have
418 the legitimacy to interrupt the practitioner and assert their point of view. As for the practitioner,
419 providing neutral, objective scientific and technical information is a regulatory duty.
420 Practitioners must obtain signed consent from women before taking a sample. As they do not
421 know how their colleagues informed the patient, or how the information had been understood,
422 they repeat the entire content. When the opinion is based on medico-scientific expertise, there
423 is no major problem. However, when the decision (not to have a sample taken) has been made
424 in the religious authority frame, the situation is very different. The practitioner's pursuit of
425 his/her role to inform can be interpreted as a lack of respect, as the invalidation of the couple's
426 point of view, a way of asserting that only medico-scientific expertise can legitimately form the
427 basis for a decision. Again, the length of time taken to provide the information tends to increase
428 the emotional charge which then translates into mistrust and resentment, and which can lead to

an obstinate silence or, sometimes, definitive remarks: *"Doctors don't know anything; only God knows"* (France). This consultation configuration does not provide the conditions required for fluid interactions. The tension can sometimes be resolved when the content of the interactions shifts towards the routine monitoring of the pregnancy. It can reach a peak when the practitioner looks to protect him/herself from any legal action by noting in the medical file that the woman, after receiving all of the required information, refuses to undergo a diagnostic examination.

When protagonists adjust frames to restore fluid and continuous interactions

In situations where dialogue is blocked or where the emotional charge is high, temporarily or definitively abandoning the frame of medico-scientific expertise can sometimes be, for practitioners, the only way of restoring interaction. A shift into the repertoire of medical authority or compassion, repeated as many times as is necessary, can revitalise interactions.

So when explanations relating to DS are interrupted by the partner of a woman, who asks *"Excuse me, but does this concern us?",* the midwife realises that the information has not been understood. She therefore momentarily ceases to impart knowledge to the couple, and brings her subjectivity into play to reassure them: *"You are 30 years old, I'm not worried, but I have to talk to you like this; it's so that I can explain".* The incursion into the reassuring medical authority frame enables the midwife to return to that of medico-expertise. The interactions continue, the midwife pays attention to the couple's needs and mobilises resources to support her actions:

Midwife: *"Amniocentesis is the only way to be sure".*

Partner: *"As you said, there's a risk, so it's better not to do that".*

Midwife: *"It all depends on what is important for you. If this pregnancy is very important and you don't want to risk a miscarriage, then I say 'fine'. If you tell me that you don't want a child with Down Syndrome, then I also say 'fine'".*

Partner: *"It's her decision".*

Midwife: *"We can take our time. We can meet again in a few days so that I can explain again.*

Woman: *"I prefer to think about it.* […] *What if we redo the ultrasound to look again at the neck?"*

Midwife: *We only do that at the start of the pregnancy".*

The decision is deferred, the midwife notes down the information she has given to the woman and a new appointment is made.

The temporary abandon of the medico-scientific expertise frame and the incursion into that of medical authority for reasons of solicitude allowed to restore the course of interactions. In France, many consultations demonstrated this type of adjustment.

More rarely, the practitioner's recourse to the medical authority frame causes a turning point in the course of the consultation. In France, a woman of Muslim faith consults the geneticist who had monitored her when the child she had given birth to one year ago died of a genetic disease only a few days old. Pregnant again, she is terrified that it might happen again:

Woman: I don't know what to do. I'm lost.

Consultant: Let me simplify. There are two attitudes, both of which are acceptable. It's up to you to decide which is the best for you.

Woman: That's what's difficult. I can't make a decision.

Consultant: Let me summarise. If we don't do anything […] three times out of four everything will be fine. One time out of four the child will have the same disease as [first child] and

unfortunately there'll be nothing we can do. It will die during the first few days of its life. Second solution, we perform a biopsy at 12 weeks. We'll have the results one week later. Three times out of four there'll be nothing, and you can relax. […]

Woman: In fact I'm scared of taking the risk of losing a child who is not ill.

Consultant: Unfortunately, that can happen. […]"

Woman: What is the risk of me miscarrying?

Woman: No, I'd never get over it!" […] What do you think I should do?

Consultant: I fear that you're never going to be able to relax during this pregnancy […] exceptionally, I'm going to allow myself to give you my opinion. It's up to you to make the decision. It's maybe worth taking the 1% risk. Even though you don't know what you'll do afterwards".

The change of frame gives the woman the opportunity to mention her partner's refusal to have a sample taken, a refusal rooted in the religious authority frame. She fears a possible miscarriage, for which she would be blamed. The geneticist, adapting to the situation, offers to take some of the responsibility by producing a letter addressed to the partner, and that he vocally records in the woman's presence: *"we believe that the benefit you will get from knowing the status of your child, healthy or ill, is a real one, because it will allow you to project yourselves into this pregnancy. Something that you are having trouble doing."*

This form of benevolent directiveness shows the woman that her distress and needs have been taken seriously. By looking together at the available possibilities, the woman and the practitioner engage in pragmatic reflexivity and create the conditions for reaching a decision together.

DISCUSSION

Over the past three decades, genetic counselling has undergone many transformations, increasing regulation and standardisation of PND consultations. Although the objective is to take better account of women's viewpoints in a decision-making process, these changes give PND consultations a particularly restrictive framework. The obligation placed upon practitioners to inform women, in an objective, neutral and accessible way, of the two types of risk that they are facing (that of having a disabled child and that of having a miscarriage) tends to make interactions more rigid. Our observations confirm the obstacles that stand in the way of this objective. They demonstrate the distress women experience when having to make a decision that affects the life of the child they carry,[31] and the difficulty for practitioners to maintain neutrality in light of the heterogeneity of women's backgrounds, their beliefs, level of understanding as well as social and ethnic origins.[21] Our study suggests that in most situations the stated objective of neutrality is unachievable. However, one might also question what the objective of these consultations actually is. If the objective is to guarantee women's and couple's freedom of choice, our analysis suggests several ways to achieve it. Reaching a decision on whether or not to have a sample taken, after understanding everything that is at stake, is just one of several modalities for achieving this objective. Furthermore, as we have seen, this modality supposes that the protagonists engage in a common frame, that of the medico-scientific expertise, that emotions do not run too high and that women feel that they can legitimately interact with the practitioners. Yet these conditions are far from being systematically met.

The first lesson learned from our analysis is that the protagonists can participate in the consultation by navigating between different frames, which can lead to communication problems and distortions. For the practitioner engaged in the medico-expertise frame, the act of informing in a neutral and objective manner is the condition for respecting the woman's

autonomy, whereas for the woman engaged in the medical authority frame, it can be a sign of imminent bad news. Designed to help the woman make her decision, information instead causes distress and hinders her reflective capacities. Similarly, whilst for the practitioner the act of informing is a prerequisite of consent, for the woman engaged in the religious authority frame, it can be interpreted as the negation of her opinion – an opinion she is not even asked to give. Once brought to light, it should be possible to find practical solutions for these distortions.

The second lesson learned from our analysis is that the emergence of a decision does not come about in a unique action frame that should be preferred. On the contrary, we were able to identify different configurations resulting from distinct arrangements of the frames used during consultations. This might mean repeated incursions into the compassion and/or medical authority frames to contain emotion, to then return to the medico-scientific expertise frame; or an assumed distancing from the role of expert; or a voluntary and assumed delegation to medical authority. In other words, despite the considerable constraint that practice regulations impose upon the coordination of actions, in certain situations the protagonists manage to restore fluid and continuous interaction, adapted to their expectations and values and orienting them towards a decision.[4] This observation clearly demonstrates the limited relevance of abstract notions such as neutrality and non-directiveness when it comes to qualifying and taking account of the work done by protagonists during consultations. The various configurations of consultations identified in our analysis indicate that, on the contrary, practitioners' relational involvement, and even in some cases practitioners' directiveness, might be necessary to maintain/ restore interaction and enable women and couples to exert their reflective capacities.

Aiming for women's autonomy as conceptualised in the philosophical tradition as rational individuals' capacity for self-determination, may therefore not be appropriate to 'real-life situations' of PND consultations. Indeed, women's enfranchisement from material and social considerations that underpins this definition was seldom observed in our consultations. Instead,

547 a sociological concept of autonomy based on a relational process involving all protagonists and
548 enabling a mutual adjustment of actions might be better suited to generating a reflective
549 approach to practice. From that perspective, respecting women's and couples' autonomy would
550 be less about maintaining a neutral and non-directive attitude, and more about facilitating the
551 expression of their reflective capacities.

552

553 The frame analysis provides insights into the constraints that govern interactions. The way
554 protagonists define the situation as well as their expectations reflect past experiences, which
555 are themselves anchored in social structures and practices. For example, the medico-expertise
556 frame is rooted in the 'therapeutic modernity' era: PND practitioners have acquired a specific
557 conception of their mission and have developed routines for their consultations – based on their
558 training, their experience, and on a certain number of rules – and have learned to adapt them to
559 suit individual situations. By contrast, the medical authority frame is rooted in the "clinical
560 tradition".[2] Women who engage in that frame tend to defer to its representative and expect to
561 be reassured, or at least advised on their particular situation. "People therefore must manage
562 the plurality of frames, as well as the eventual ruptures of frames that rise in the course of
563 interactions".[30] Being cognisant of this plurality might encourage practitioners to consider
564 women's viewpoints, and thus promote interactions. It might also result in making the medico-
565 expertise frame intelligible to women, for example, by making it clear that the information they
566 are about to receive is not specific to their situation but is given to all women, and is designed
567 to "train" them in scientific reasoning to help them make a decision.

568

569 It would seem hazardous to compare PND practices in England and France on the basis of our
570 data due to the small number of observations and the diversity of the populations. Moreover,
571 the way pregnancy monitoring is organised is different. It appears to be more delineated in

England, thus making it possible to limit the number of acts and, therefore, better control spending. This can also be seen in the legal framework governing practices, with regard to the thresholds at which samples may be taken (higher in England) and in the lower number of ultrasound examinations that are recommended. This observation is reminiscent of public fund management practices found in England since the 1980s and the way in which the new rules and procedures introduced by the State have durably guided the behaviour of health actors.[32] In France, pregnancy monitoring is more flexible, and although PND practices have been subjected to greater regulation since the 1990s, practitioners retain relative autonomy.[33]

As we observed, in England these differences lead to the virtual absence of recourse to the religious authority frame, because women who are engaged in this frame and refuse to take the risk of miscarriage, generally do not move on to the second decision-action sequence that constitutes the subject of this study. By the same reasoning, due to this filtering of the care pathway, women who are not opposed to a sample being taken tend to be better informed about their situation and more familiar with the medico-scientific logic than the women observed in France.

Yet more subtle differences can also be observed. English practitioners seem to more frequently adopt attitudes of neutrality and non-directiveness and demonstrate a stronger attachment to the medico-scientific expertise frame, whereas French practitioners do not hesitate to distance themselves from it. English practitioners also appear to be more involved in the mission to educate women – something that is especially evident in the level of detail in the information provided that is greater than in consultations in France. Here we find the expression of a form of incorporation of the tools that regulate practices and provide guidelines.[32] This avenue of interpretation nevertheless needs to be verified in a later study, as these differences might also be attributed to practitioners adapting to women's individual characteristics and might reflect the work culture in operation in the establishments in which we conducted our observations.

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Conflict of interest

The authors have no conflict of interest to declare.

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