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

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

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

4

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26 France

27

28 **ABSTRACT**

29 Rationale, aims and objectives

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

34 **Methods**

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

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

41 **Results**

42 We identified four frames: medico-scientific expertise, medical authority, religious authority
43 and compassion. Observation of the ways in which the frames intertwine during consultations
44 revealed configurations that facilitate or hinder the fluidity of the interactions and the
45 decision-making process. The medico-scientific expertise frame, imposed by the guidelines,
46 heavily dominated our observations, but frequently caused distress and misunderstanding.
47 Temporary or sustained use of the compassion and/or medical authority frames could help to
48 repair the discussion and create the conditions that enable women/couples to reach a decision.

49 Variations in configuration highlighted the differences between practitioners in the two
50 countries.

51 Conclusions

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

56

57 INTRODUCTION

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

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

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

73 pregnancies” and detect a large number of anomalies, whilst limiting the loss of healthy
74 fetuses.

75 *ORGANISATION OF PRACTICES*

76 In countries where abortion is legal, PND is based on a sequence of standardised decisions
77 and actions. The first decision-action event is Down Syndrome (DS) screening, offered to all
78 pregnant women in England and France, usually during their first pregnancy consultation.⁶
79 There are nevertheless differences in screening uptake (75% of pregnant women in England,
80 85% in France).^{7,8} Similarly, the threshold at which the risk is deemed sufficient to warrant a
81 fetal karyotype examination varies (1:150 in England; 1:250 in France). Routine foetal
82 ultrasound examinations carried out at different points during the pregnancy (two in England
83 and three in France) enable practitioners to check that the foetus is developing normally and
84 look for soft markers frequently associated with anomalies.⁹

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

92 *A PRINCIPLE OF AUTONOMY DIFFICULT TO IMPLEMENT*

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

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

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

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

118

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

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

129

130 **METHODS AND MATERIALS**

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

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

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

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

155

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

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

168

169 **RESULTS**

170

171 *FRAMES OF DECISION-MAKING AT WORK IN PND CONSULTATIONS*

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

176

177 **The medico-scientific expertise frame**

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

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

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

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

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

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

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

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

215

216 **The medical authority frame**

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

224 *Medical authority to repair the exchanges*

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

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

242

243 *Medical authority requested by women: delegating the decision*

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

249 *Woman: What do you think we should do?*

250 *Consultant: I can't tell you.*

251 *Woman: Of course you can!*

252 *Consultant: Our personalities are not the same.*

253 *Woman: You should still tell us.*

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

255 *Woman: I think you should.*

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

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

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

268

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

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

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

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

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

281 *Consultant: It is your choice.*

282 *Woman: But you think that’s good still to do?*

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

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

285 *Consultant: It’s slightly less than 1 in 100*

286 *Woman: So it’s worth it...*

287 *Consultant: Yes why not!*

288

289 *Imposed medical authority: orienting the decision*

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

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

305

306 **The religious authority frame**

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

312 In rare cases, couples explicitly refer to the religious authority frame when the practitioner has
313 finished speaking. *“Stop all the tests. I take full responsibility. Inshallah [...] I want this baby,
314 Down Syndrome or not, no problem. It’s fate.”* (African partner, France). In other cases, it is
315 the practitioners themselves who mobilise this frame, to explore the woman’s opinion
316 concerning the possibility of terminating the pregnancy. In the Paris centre, this strategy is
317 frequently employed on women, who are assumed to be Muslims. Having delivered the
318 standard information on the risk of DS and of miscarriage associated with taking a sample, the
319 midwife asks the woman:

320 *Midwife: “You must tell me if you want us to do this test”.*

321 *Woman “No”.*

322 *Midwife: “Why don’t you want it?”*

323 *Woman: “If there were no risk, I’d do it. In our country it’s not a good thing, because God
324 will punish us”.*

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

327 *Woman: “I can’t terminate”*

328 The midwife wants to be certain that the woman’s choice is truly rooted in religious authority
329 and not in a “false belief” concerning the risk of a miscarriage. The woman’s confirmation
330 generally puts an end to the interactions. Such situations often lead to reciprocal mistrust. This
331 can be seen in the post-consultation comment made by a French consultant concerning a
332 woman whose foetus is at risk of a genetic disease and who, for religious reasons, twice
333 rejected the offer of a diagnostic test: *“It’s not complicated. For us she just wouldn’t listen!”*.
334 The few times the woman spoke during the ultrasound examination shows how little she
335 believed in technology. When the obstetrician observes that *“the baby is not very big,*

336 *especially the head*”, she retorts: *“my first child also had a small head, but afterwards it*
337 *grew”* (African woman, France). Women’s mistrust of medicine can also be found in
338 England: *“the doctor told me that a baby would have disability but when the baby is born ...it*
339 *was a minor problem”*

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

343

344 **The compassion frame**

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

360

361 *COMBINING FRAMES*

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

367

368 **When protagonists mobilise the same frame**

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

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

377 Woman: *“It is very important to me to understand what you are telling me. If we don’t*
378 *understand, the decision is not very informed”.*

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

382 Midwife: *“Tell yourself it’s a little less than 1%”.*

383 *Woman: “I have less chance of losing the child because of a miscarriage, than of there being*
384 *a problem”.*

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

394

395 **When protagonists mobilise frames difficult to concile**

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

399 When engaged in the medical authority frame, women do not expect a general explanation of
400 pregnancy risks but the practitioner’s opinion of their personal situation. Above all, they seek
401 reassurance and/or guidance. The medico-scientific expertise frame, which orients the
402 practitioner’s attitude, and the medical authority frame which directs that of the women, thus
403 enter into opposition. Waiting for an opinion on her personal situation that does not come, the
404 woman may start to think that the technical information she is receiving is a prelude to the
405 announcement of bad news. The length of time it takes to provide this information increases
406 her distress further. In France, after quietly listening to the midwife explain the way DS

407 screening works, receiving information on the pathology, with photos of children with the
408 syndrome, a woman, of African origin, begins to cry and her partner, who can no longer keep
409 quiet, interrupts the midwife: *“Excuse me, but does this concern us?”*.

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

421 The women/couples who approach pregnancy and its monitoring through the frame of
422 religious authority do not begin consultations with the intention of gathering information that
423 will help them to make a decision. Their decision has already been made. Yet they are rarely
424 given the opportunity to express their position from the outset and some women feel that they
425 do not have the legitimacy to interrupt the practitioner and assert their point of view. As for
426 the practitioner, providing neutral, objective scientific and technical information is a
427 regulatory duty. Practitioners must obtain signed consent from women before taking a sample.
428 As they do not know how their colleagues informed the patient, or how the information had
429 been understood, they repeat the entire content. When the opinion is based on medico-
430 scientific expertise, there is no major problem. However, when the decision (not to have a
431 sample taken) has been made in the religious authority frame, the situation is very different.

432 The practitioner's pursuit of his/her role to inform can be interpreted as a lack of respect, as
433 the invalidation of the couple's point of view, a way of asserting that only medico-scientific
434 expertise can legitimately form the basis for a decision. Again, the length of time taken to
435 provide the information tends to increase the emotional charge which then translates into
436 mistrust and resentment, and which can lead to an obstinate silence or, sometimes, definitive
437 remarks: *"Doctors don't know anything; only God knows"* (France). This consultation
438 configuration does not provide the conditions required for fluid interactions. The tension can
439 sometimes be resolved when the content of the interactions shifts towards the routine
440 monitoring of the pregnancy. It can reach a peak when the practitioner looks to protect
441 him/herself from any legal action by noting in the medical file that the woman, after receiving
442 all of the required information, refuses to undergo a diagnostic examination.

443 **When protagonists adjust frames to restore fluid and continuous interactions**

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

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

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

457 Partner: *“As you said, there’s a risk, so it’s better not to do that”*.

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

461 Partner: *“It’s her decision”*.

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

464 Woman: *“I prefer to think about it. [...] What if we redo the ultrasound to look again at the*
465 *neck?”*

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

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

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

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

476 *Woman: I don’t know what to do. I’m lost.*

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

479 *Woman: That’s what’s difficult. I can’t make a decision.*

480 *Consultant: Let me summarise. If we don't do anything [...] three times out of four everything*
481 *will be fine. One time out of four the child will have the same disease as [first child] and*
482 *unfortunately there'll be nothing we can do. It will die during the first few days of its life.*
483 *Second solution, we perform a biopsy at 12 weeks. We'll have the results one week later.*
484 *Three times out of four there'll be nothing, and you can relax. [...]*

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

486 *Consultant: Unfortunately, that can happen. [...]"*

487 *Woman: What is the risk of me miscarrying?*

488 *Consultant: One in a hundred. It's not very high, but when it happens ...*

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

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

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

501 This form of benevolent directiveness shows the woman that her distress and needs have been
502 taken seriously. By looking together at the available possibilities, the woman and the

503 practitioner engage in pragmatic reflexivity and create the conditions for reaching a decision
504 together.

505

506 **DISCUSSION**

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

527 The first lesson learned from our analysis is that the protagonists can participate in the
528 consultation by navigating between different frames, which can lead to communication
529 problems and distortions. For the practitioner engaged in the medico-expertise frame, the act
530 of informing in a neutral and objective manner is the condition for respecting the woman's
531 autonomy, whereas for the woman engaged in the medical authority frame, it can be a sign of
532 imminent bad news. Designed to help the woman make her decision, information instead
533 causes distress and hinders her reflective capacities. Similarly, whilst for the practitioner the
534 act of informing is a prerequisite of consent, for the woman engaged in the religious authority
535 frame, it can be interpreted as the negation of her opinion – an opinion she is not even asked
536 to give. Once brought to light, it should be possible to find practical solutions for these
537 distortions.

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

552 might be necessary to maintain/ restore interaction and enable women and couples to exert
553 their reflective capacities.

554 Aiming for women’s autonomy as conceptualised in the philosophical tradition as rational
555 individuals’ capacity for self-determination, may therefore not be appropriate to ‘real-life
556 situations’ of PND consultations. Indeed, women’s enfranchisement from material and social
557 considerations that underpins this definition was seldom observed in our consultations.
558 Instead, a sociological concept of autonomy based on a relational process involving all
559 protagonists and enabling a mutual adjustment of actions might be better suited to generating
560 a reflective approach to practice. From that perspective, respecting women’s and couples’
561 autonomy would be less about maintaining a neutral and non-directive attitude, and more
562 about facilitating the expression of their reflective capacities.

563

564 The frame analysis provides insights into the constraints that govern interactions. The way
565 protagonists define the situation as well as their expectations reflect past experiences, which
566 are themselves anchored in social structures and practices. For example, the medico-expertise
567 frame is rooted in the ‘therapeutic modernity’ era: PND practitioners have acquired a specific
568 conception of their mission and have developed routines for their consultations – based on
569 their training, their experience, and on a certain number of rules – and have learned to adapt
570 them to suit individual situations. By contrast, the medical authority frame is rooted in the
571 “clinical tradition”.² Women who engage in that frame tend to defer to its representative and
572 expect to be reassured, or at least advised on their particular situation. “People therefore must
573 manage the plurality of frames, as well as the eventual ruptures of frames that rise in the
574 course of interactions”.³⁰ Being cognisant of this plurality might encourage practitioners to
575 consider women’s viewpoints, and thus promote interactions. It might also result in making
576 the medico-expertise frame intelligible to women, for example, by making it clear that the

577 information they are about to receive is not specific to their situation but is given to all
578 women, and is designed to “train” them in scientific reasoning to help them make a decision.

579

580 It would seem hazardous to compare PND practices in England and France on the basis of our
581 data due to the small number of observations and the diversity of the populations. Moreover,
582 the way pregnancy monitoring is organised is different. It appears to be more delineated in
583 England, thus making it possible to limit the number of acts and, therefore, better control
584 spending. This can also be seen in the legal framework governing practices, with regard to the
585 thresholds at which samples may be taken (higher in England) and in the lower number of
586 ultrasound examinations that are recommended. This observation is reminiscent of public
587 fund management practices found in England since the 1980s and the way in which the new
588 rules and procedures introduced by the State have durably guided the behaviour of health
589 actors.³² In France, pregnancy monitoring is more flexible, and although PND practices have
590 been subjected to greater regulation since the 1990s, practitioners retain relative autonomy.³³

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

598 Yet more subtle differences can also be observed. English practitioners seem to more
599 frequently adopt attitudes of neutrality and non-directiveness and demonstrate a stronger
600 attachment to the medico-scientific expertise frame, whereas French practitioners do not
601 hesitate to distance themselves from it. English practitioners also appear to be more involved

602 in the mission to educate women – something that is especially evident in the level of detail in
603 the information provided that is greater than in consultations in France. Here we find the
604 expression of a form of incorporation of the tools that regulate practices and provide
605 guidelines.³² This avenue of interpretation nevertheless needs to be verified in a later study, as
606 these differences might also be attributed to practitioners adapting to women’s individual
607 characteristics and might reflect the work culture in operation in the establishments in which
608 we conducted our observations.

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613

614 **Conflict of interest**

615 The authors have no conflict of interest to declare.

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