

Information and decision-making process for selective termination of dichorionic pregnancies: some French obstetricians' points of view.

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26 Recent developments in prenatal technology have altered our representations of the fetus (Taylor,
27 1997) and our relationship with it. Three-dimensional ultrasound imaging conveys an impression of
28 the fetus occupying the same space as we do; and this has contributed to the increasing hold on the
29 collective imagination of a sense of the fetus as an individual in its own right, independent of the
30 mother (Dickens and Cook, 2003). Moreover, these technologies have made it possible for
31 biomedical systems of representation to treat the fetus as a patient (Wyatt, 2001; Dumoulin and
32 Valat, 2001). It is known as well that an increased incidence in fetal ultrasound procedures and
33 prenatal genetic diagnoses has contributed directly to the increase in interventions performed on the
34 fetus (Von Dadelszen et al., 1999).

35

36 Thus the responsibility to care for, protect, and prevent suffering in what is nowadays seen as a
37 fetus-individual-child-patient has been intensified by technology's capacity to forge an intimacy of
38 a visual, auditory, and even tactile nature among physicians, parents, society, and the fetus. In the
39 context of a system of representations of this kind and with most future parents viewing the fetus as
40 already a child (Dumez, 1997), when medical termination of pregnancy (MTP) is proposed
41 following prenatal diagnosis it is difficult for parents to conceive of putting an end to the fetus's
42 life.

43

44 When, in the case of a multifetal pregnancy, one of the fetuses has a serious disease, the
45 circumstances are even more complex. The choices open to the parents are to continue the
46 pregnancy as is, in the knowledge that one of the children will be born gravely ill and may die
47 prematurely, or to proceed with selective termination (ST). ST differs from the usual MTP because
48 it entails terminating the life of the sick fetus while allowing the development of the healthy sibling
49 or siblings to continue. At term the mother gives birth to a dead child and one or more living
50 children. ST thus entails decision making based on social, ethical, and professional-ethical factors
51 that go far beyond exclusively medical considerations. The conditions in which patients and, where

52 relevant, their partners receive information must take account of these specific factors. Ideally these
53 conditions should contribute to decision making that is as informed as possible and provide the
54 future parents with enhanced empowerment in their decision making.

55

56 With this perspective in mind, we wished to investigate the point of view of some French
57 obstetricians on: the best way, when ST is indicated, of informing patients and their partners; the
58 non-medical information that is important to transmit; and the degree of autonomy patients can
59 assume. This exploratory study yielded, among other results, the finding that through the course of
60 the decision-making process, from the moment of discovery of a fetal anomaly or pathology to the
61 moment of the decision about ST, there was great diversity among the practitioners met with as
62 regarded both practices adopted and perceptions of what is ethical.

63

64 In this article we first give a brief description of ST. We next provide an overview of the
65 methodological approach taken by our study. Then we address the two major themes that emerged
66 from the study interviews.

67

68 *Selective Termination*

69

70 ST consists of feticide performed during a multifetal pregnancy (most often a twin pregnancy)
71 because one of the fetuses has a grave and incurable disease as of the time of diagnosis (It is
72 important to differentiate between STs, which are performed in cases of fetal pathology, and
73 multifetal pregnancy reduction (MFPR), which consists of embryocide performed in cases of high-
74 order multiple pregnancies (more than three fetuses) to reduce the obstetrical and perinatal risks
75 inherent in this kind of pregnancy.) (Evans *et al.*, 1999). ST is indicated to allow a pregnancy to
76 continue for the sake of the healthy fetus or fetuses. It does however present a risk of miscarriage, a
77 risk that varies according to type of placentation and technique used (Rousseau and Fierens, 1994;

78 Bernard et al., 2006; Hern, 2004). It can also threaten the life of the other fetus or fetuses in other
79 ways, compromise their health, and increase the risk of premature birth (Bernard and al., 2006).
80 In France, there are no regulations or directives specific to ST. (Goussot-Souchet and al., 2008)
81 Given that there is legislation on MTP that is strictly applied (*Loi no 75-17 relative à l'interruption*
82 *volontaire de la grossesse, art. L 162-12*) and bioethics law on the donation and use of elements and
83 products of the human body, medically assisted reproduction, and prenatal diagnosis (Act 94-654,
84 29 July 1994), the regulatory void when it comes to ST raises important concerns.

85

86

87 ***Materials and Methods***

88

89 For this exploratory study on information and decision making around ST, we adopted a qualitative,
90 empirical-inductive approach that would allow for the development of knowledge about “*a*
91 *phenomenon on the basis of data gathered [rather than on the basis of] the confirmation of a*
92 *theoretical hypothesis*” (Vittrant, 2005). In contrast to quantitative research, which requires few
93 variables and large numbers of cases, qualitative research explores many variables on the basis of a
94 small number of cases.

95 Descriptive, qualitative studies are appropriate when, as is the case here, a topic has not been
96 previously explored on the basis of large sample sizes. Thus although qualitative studies are
97 descriptive and their results cannot be generalized, they play a crucial role in raising questions
98 and generating hypotheses. They allow for handling subjects in depth while concentrating “*on*
99 *participants' perspectives, their meanings, their subjective views*” (Sulmasy DP and Sugarman J,
100 2001; Creswell, 2007).

101

102 With this approach in mind, we used a purposive sampling strategy. Eight semi-directed interviews
103 were conducted with obstetrician-gynecologists practicing in these multidisciplinary centres for

104 prenatal diagnosis in the Paris region: Cochin/Saint Vincent de Paul, Necker, Robert-Debré, Saint-
105 Antoine, Antoine Béclère, Lariboisière. Participants were selected based on their experience with
106 ST. However, only STs done on bichorionic diamniotic twin pregnancies are reflected in the study,
107 because in monochorionic pregnancy the progress of the pregnancy is more complex and the future
108 of the healthy fetus even more uncertain (Bernard et al., 2006).

109

110 The interview guide was developed by a team at the *Laboratoire d'éthique médicale et de médecine*
111 *légale* (laboratory for medical ethics and forensic medicine) at Université Paris Descartes. As can
112 be seen in Table 1, the questions were designed to initially gather general information on the
113 physicians' profiles and their experience with ST. The questions then broached the physicians'
114 perceptions of ST in relation to the law, the differences they saw between ST and MTP, their
115 strategies for providing information on the condition of the fetus and on the procedure, their views
116 on the ideal degree of patient involvement in decision making, and their views on the criteria that
117 should apply for recourse to ST.

118 The interviews were recorded and transcribed in full. The discursive material was then classified
119 and analyzed using the methods of inductive qualitative research. Each interview was handled
120 individually. The data were classified under themes by means of a coding process, i.e., by reducing
121 the data to meaningful segments and assigning categories to the segments (Creswell, 2007). Then
122 the codes were combined under broader themes and the themes were described and illustrated with
123 anonymized quotations from respondents.

124

125

126 **Results**

127 Two major themes emerged from the interviews: information transfer and respect for couples'
128 autonomy.

129

130 **Information transfer**

131 The theme of how the obstetricians handled information arose in connection with two matters of
132 strategy: the time factor and the nature of the information transferred.

133

134 ***The Time Factor***

135 All the physicians interviewed stressed the importance of the time factor in the process of
136 information transfer in the context of fetal pathology and proposed ST. They believed it is
137 necessary to prolong individual consultations in order to convey sufficiently full information and
138 foster informed decision making.

139

140 Similar reasons were given for a preference for distributing the information over “*several*
141 *successive consultations*” (Alice, obstetrician, 2007), because ST requires an adequate period for
142 reflection. They believed spacing out consultations allows for time to process the information
143 received and reflect on the alternatives presented. One of them described this approach very
144 effectively: “*There’s a first stage, the stage when the pathology and the prognosis are disclosed.*
145 *After that I always allow couples a week to work out their own path. When they’re seen again,*
146 *we’re at the questioning stage: What will we do, what have they understood, where will we go?*”
147 (Antoine, obstetrician, 2007).

148

149 The physicians maintained that these strategies limit the number of decisions made in a hurry and
150 reduce the guilt experienced by patients and their partners: “*My worst fear is that parents will*
151 *decide to resort to ST and then, three or four years later, will regret it.*” (Julie, obstetrician, 2007).

152 According to our informants, the time factor can contribute to reducing the psychological impact of
153 the disclosure that there is fetal pathology, of the consequences of the pathology for the child and
154 the pregnancy, and of the proposed procedures.

155

156 *Lack of Uniformity in the Nature of the Information Transferred*

157

158 Although all the physicians agreed about spreading out the transfer of information in time, the
159 nature of the information they provide varied. The differences relate mainly to: (1) information
160 about living with a gravely ill or handicapped child; (2) the importance assigned to certain kinds of
161 supplementary information; (3) the forms of information preferred; and (4) what we have termed
162 the fullness of the information disclosed.

163

164 The majority (six) of the obstetricians interviewed believed the provision of information on the
165 difficulty of living with a gravely ill or handicapped child must form an integral part of the care
166 given to pregnant women for whom ST is indicated. Although two of these physicians convey this
167 information themselves, the other four turn to outside parties. Among these four, two refer patients
168 and couples to associations of parents of handicapped children, reasoning that *“information
169 provided by parents who volunteer with these associations could be more explicit, clearer, and
170 simpler for the future parents.”* (Antoine, obstetrician, 2007). The other two call on the services of
171 specialist physicians, *“colleagues whose job it is to follow children with the same kind of pathology,
172 so that couples can receive the most honest information possible.”* (Julie, obstetrician, 2007). In the
173 view of these two physicians, the advice given by parents’ associations is biased and reflects *“only
174 one way of thinking, which, while it’s not without interest, is partial and tainted with emotion.”*
175 (Julie, obstetrician, 2007).

176

177 The only other obstetrician who answered this question (only seven out of the eight did so) saw the
178 whole issue very differently: *“I believe it falls outside our purview to take responsibility for these
179 types of considerations ... and couples usually broadly receive all the necessary information. I think
180 that’s sufficient.”* (Louis, obstetrician, 2007).

181

182 As for the supplementary information physicians deem it important to convey, all the interviewees
183 mentioned the need to explain that ST presents the risk of termination of the whole pregnancy.

184 In a different vein, three of our informants emphasized the impossibility of seeing the body if ST is
185 done early. Three others believed, respectively, that the feelings of ambivalence that will be aroused
186 by the dead child through the course of the pregnancy, the assumption of responsibility for disposal
187 of the body after delivery, and the possibility of burial represent topics that must absolutely be
188 broached. Last, one of the obstetricians brought up the importance of discussing the psychological
189 impact of feticide, while another felt that the technical aspects of ST are underdiscussed. As for
190 other topics, there were as many opinions as obstetricians.

191

192 The variation in the fullness of the information disclosed, or in other words, the intentional
193 omission by some physicians of information they consider to be of secondary importance or
194 needlessly distressing, represents an especially troubling aspect of the circumstances surrounding
195 ST-related decision making. For example, one physician mentioned that he does not consider it
196 useful to inform couples of the rates of in utero fetal death in cases of trisomy 18 and 21. Another
197 physician, who gave as his reason his reluctance to frighten patients needlessly, resorts to what he
198 called “*disguised lies*” when he discusses the products and techniques used for feticide. From these
199 practitioners’ perspective, holding back some kinds of information does not incur the risk of
200 altering or influencing couples’ final decision. In their view, parental cognizance of certain facts
201 would make the decision harder to reach.

202

203 **Respect for Couples’ Autonomy**

204

205 All the physicians interviewed consider themselves to be very respectful of couples’ autonomy.
206 “*The relationship with the couple is fundamental. You can’t decide for them.*” (Marc, obstetrician,
207 2007) is one example of the way they positioned themselves on this.

208

209 The following interview excerpt illustrates the implementation of this position:

210 *“When I began practicing, I was more ready to take on the responsibility for making the*
211 *decision. I used to say that in the end it was comforting to the parents not to have the burden*
212 *of choice imposed on them. As I grow older, I realize this doesn't necessarily do them a*
213 *favour, because I rob them of the decision making. At the time they're comforted, but in the*
214 *medium and long term this is something that can't be managed.”* (Julie, obstetrician, 2007).

215

216 However, some may find it hard to implement the position in practice, as this next excerpt makes
217 clear: *“Making the decision to terminate the life of a child is very hard. For some people, it's*
218 *impossible. If we try not to help and guide them in their decision, they won't be able to make this*
219 *decision.”* (Claire, obstetrician, 2007).

220

221 The interview questions about patients asking physicians, *“What would you do if this were your*
222 *child?”* can be quite revealing of the attitude to patient autonomy. One physician said, *“I go ahead*
223 *and give them my opinion pretty willingly, especially here..., where lots of parents turn up who are*
224 *in difficult, hard-to-manage circumstances.... I tell them, 'In your place ..., in this situation, I'd do*
225 *this”* (Julie, obstetrician, 2007). The others stated that they never answer this question.

226

227 **Discussion**

228

229 The methodological approach we adopted does not allow for generalizing our findings to all French
230 obstetricians. However, as we show below, several works in the literature confirm our findings.

231

232 As we saw above, this exploratory study on the points of view of some obstetricians in our French
233 sample regarding information and decision-making processes in the context of ST yielded two

234 major themes: information transfer, which subdivided into two strategies (the time factor and the
235 nature of the information transferred); and respect for couples' autonomy.

236

237 First, in connection with ST and feticide, the time factor is obstetricians' most important ally. The
238 time factor is at the heart of two approaches: (1) an increase in the time devoted to informing
239 patients and their partners; (2) the spreading of the provision of this information over several
240 consultations. Extending consultation time allows physicians to provide all the information they
241 consider necessary and ensure it's thoroughly understood; and by spreading the information over
242 several consultations, physicians allow patients more time for reflection and decision making.
243 Through recourse to these approaches, the obstetricians aim to reduce the guilt and suffering that
244 could be associated with hasty decisions. Their view is that doing so reduces the risk of
245 psychological suffering flowing from what could appear down the road to patients and their
246 partners to have been a bad decision.

247

248 Certain European authors writing in French stress the significance of the time factor. Barjot and
249 Levy maintain that, while everything surrounding proposed ST creates a climate of urgency,
250 *“reintroducing the time factor makes it possible to de-dramatize the situation and approach it as*
251 *calmly as possible, while allowing the parents time for reflection.”* (Barjot and Levy, 1997).
252 Similarly, it is recommended that consultation time be extended in the context of prenatal
253 diagnosis, with the sole purpose of informing patients (Alouini et al., 2007).

254

255 Second, despite this consensus on the question of the time that should be devoted to information
256 transfer, views differed on the kind of information it is useful to transmit. Other than the concerns
257 about the fetal remains and advisories about the difficulty of living with a handicapped child,
258 several obstetricians said they view provision of information that is not of a medical nature as

259 falling outside their professional duties. Others deliberately choose to hide certain kinds of
260 information in order to protect couples from what they consider to be needless suffering.

261

262 Yet the approach revealed by interview responses about the role of the physician in information
263 transfer and the intentional omission of information should change, in view of the literature shows
264 patients' growing desire for a maximum of information. For instance, according to a French study
265 on couples' opinions of the care they received in connection with an MTP, 49% of patients stated
266 they had not received sufficient information on feticide and its technical aspects (Garel et al., 2001).
267 In another study, out of a sample of twelve patients, only two stated they had thoroughly
268 understood the information they received about the risks associated with ST and were satisfied with
269 it (Alouini et al., 2007).

270

271 Third, the theme of patient autonomy is at the heart of an opposition between patients' (or, where
272 appropriate, couples') decision-making power (Ainsworth-Vaughn, 1998; Britt, 2006; Britt and
273 Evans, 2007) and that of physicians.

274 However before going further, we should emphasize the distinctness of France in connection with
275 respect for patient autonomy. Whereas respect for autonomy is at the basis of medical ethics in the
276 USA, French physicians tend to apply the principle of beneficence and thus to focus on protecting
277 patients. As Maio has written, in the French context, the physician-patient relationship remains
278 imbued with traditional paternalism; and the doctrine of consent does not hold the same
279 foundational status as in English-speaking countries (Maio, 2002). This should be borne in mind in
280 connection with the analysis that follows.

281 Although the physicians stated the final decision is up to the couples, our findings show a degree of
282 tension and inconsistency between their perceptions of patients' level of autonomy and the
283 limitations they impose on that autonomy. Some physicians showed a tendency in practice to

284 influence couples' decisions by one means or another (withholding information, "helping" with the
285 decisions, providing personal advice, and so on).

286

287 This approach suggests in the context of ST, physicians' attitude needs to evolve, because
288 parents are currently laying claim to the power to take ownership of decisions about procreation and
289 child rearing. These parents claim a total freedom of choice because "*they know that they'll have to*
290 *provide for the economic, moral, and social needs of their children and will not accept limitations*
291 *placed on their freedom by society by means of medical practice.*" (Barjot and Levy, 1997). In a
292 democratic society, it is hard to conceive of an authority better placed to speak for the fetus than its
293 parents (Gold et al., 1995).

294

295 However, consultations that are completely free of directiveness are something of a fantasy. As
296 Amann observes, "*the state of medical art certainly consists of an ensemble of impersonal criteria,*
297 *... but every physician must resort to her or his own judgement at the moment of decision making.*"
298 (Amann, 2006). Thus "*the criteria for medical decisions are never wholly independent of the*
299 *subjectivity of the person to whom society has accorded the power to decide.*" (Amann, 2006).

300 Indeed, in the context of prenatal diagnosis, many physicians influence couples' decisions, with
301 greater or lesser degrees of cognizance that they are doing so (Barjot and Levy, 1997; Lippman and
302 Wilfond, 1992; Wyatt, 2001). Several studies have shown that couples' decisions differ according
303 to the different ways of presenting the risks associated with a genetic disorder (Lippman and
304 Wilfond, 1992). As well, the role held by the person who provides the information (obstetrician,
305 geneticist, pediatrician, genetic counsellor) influences the probability of opting to terminate
306 pregnancy (Wyatt, 2001).

307

308 Thus while attitudes can be in greater or lesser measure directive, it would appear utopian to think
309 the information provided by physicians will be full and will not be affected by physicians' power to

310 sway. Obstetricians can limit their influence but not really do away with it altogether. And because
311 accompaniment in decision making is viewed differently by different practitioners, it is also
312 difficult to define just what is meant by “helping with the decision” and how far this help can go
313 before it abridges couples’ autonomy.

314

315 **Conclusion**

316

317 Our findings lead us to believe that there can be significant differences among obstetricians’
318 approaches to informing patients and to patients’ decision-making processes. These differences
319 relate to: (1) the heterogeneousness of the information disclosed by different physicians; (2)
320 discrepancies in the implementation of the commitment to providing full and non-directive
321 information transfer; (3) representations of what constitutes ethical support; and (4) how physicians
322 engage with couples’ autonomy. Realistically, it would appear difficult to fully respect couples’
323 demand for autonomy through the whole of the decision-making process (Wyatt, 2001). For Wyatt
324 – and our study bears out this point of view – although autonomy has a clear theoretical meaning, in
325 the context of the reality of fetal medicine, it’s an extremely subtle, hard-to-apply concept. *“The*
326 *truth is that the goal of genuine neutrality in areas as emotive as procreation and abortion is*
327 *impossible and even inhumane.”* (Wyatt, 2001).

328

329 Thus the physicians interviewed showed a strong desire to respect couples’ autonomy in connection
330 with the decision to be made. However, the withholding of some information and the lack of
331 uniformity in the kinds of information disclosed are indicative of a significant degree of
332 directiveness, deliberate or not, on the part of some physicians.

333

334 Despite all the problems associated with ST, in France there are neither State guidelines nor
335 recommendations on the methods of information transfer and support in decision making to patients

336 following diagnosis of a fetal pathology. It is of interest that none of our respondents expressed the
337 need for such guidelines or recommendations.

338 Thus it could be considered acceptable to allow variation in medical practices according to the age
339 of the fetus, the severity of the pathology, non-medical criteria, and the psychology of the couple.
340 Perhaps it is reasonable to ask whether the creation of State guideline for information transfer is
341 appropriate, given that each couple is a singular case and must be considered as such.

342
343 This exploratory study was conducted in order to better understand the attitudes of obstetricians in
344 the context of ST and the ethical problems these situations can give rise to. Based on our findings, a
345 comparative study has been undertaken in France and Quebec. It will be conducted with a higher
346 number of respondents. The study will also examine couples' considerations in these situations.

347

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352

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TABLE I : PLAN OF INTERVIEWS WITH OBSTETRICIANS

1	How many MTPs do you perform per year?
2	How many STs do you perform per year?
3	What methods do you use to perform STs?
4	Given that there is no legislation on ST, what guidelines do you refer to?
5	What information do you provide to a patient who will undergo ST, beyond what you would provide in connection with an MTP?
6	How do you inform the couple?
7	Do you believe that you must provide information about life with a handicapped child for the patient information to be as full as possible and the decision to be as informed as possible? If so, why?
8	Do some couples ask you “What would you do if it were your child?”?
9	If so, how do you respond? How do you react?