

Termination of pregnancy for foetal indication in the French context analysis of decision-making in a Multidisciplinary Centre For Prenatal Diagnosis

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Analysis of decision-making in a Multidisciplinary Centre for Prenatal Diagnosis

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Conflict of interest statement

The authors have no conflict of interest to declare.

Highlights

What's already known about this topic?

MCPD activity is reported annually in statistical results by the French biomedical agency: number of acceptances and refusals, broad categories of indications.

What does this study add?

- The indications for foetal termination of pregnancy in a French MCPD
- The professionals' perspectives on their practice: the more complex decisions become in the field of antenatal diagnosis, the more professionals value collegiality within these structures.

Abstract

Objective: In France, termination of pregnancy (TOP) for medical reasons is legal, regardless of the term, after authorisation by a Multidisciplinary Centre for Prenatal Diagnosis (MCPD). This study analyses the elements supporting the TOP decision-making process faced with a foetal pathology.

Study design: Medical records of one MCPD were analysed for the period 2013 and 2014 and semi-structured interviews with MCPD members were conducted.

Results: Out of 265 files concerning foetal indications, all but one resulted in a decision for TOP. The main indications in number for TOP were malformations and chromosomal abnormalities. For indications such as trisomy 21, authorisations are generally given without discussion. Our results underline the importance that professionals attach to the collegiality of decisions, particularly in situations of uncertainty.

Conclusion: This study provides information about the activity of MCPDs within the field of prenatal diagnosis and shows the importance of these structures in supporting women and couples whilst respecting their autonomy. At present, the role of the MCPD is in the process of evolving and could become an information and advisory board for women, based on collegial expertise to guide their decision-making.

Key words: termination of pregnancy for foetal anomaly (TOPFA); prenatal diagnosis; collegiality; particular severity; decision-making

Introduction

- 2 Medical and technical advances in prenatal care have made prenatal diagnosis increasingly possible for a continually lengthening list of abnormalities presenting various levels of
- 4 severity, with sometimes-uncertain prognosis [1,2]. Meanwhile, therapeutic capabilities have not increased to the same degree, leading to the difficult situation of choosing
- 6 between continuation of pregnancy and abortion. Most developed countries have some form of prenatal screening for Down syndrome and other major foetal anomalies [3,4].
- 8 Legislations and practices vary from one country to another, but prenatal diagnosis and termination of pregnancy for foetal anomaly (TOPFA) raise important ethical dilemmas
- 10 everywhere in the world [5,6].

In France, termination of pregnancy (TOP) has been legal since 1975 [7] and has been

- 12 allowed without medical indication up to 14 weeks since 2001: "After this time period, a medical reason is necessary and abortion can be performed at any time [...] if there is a
- 14 strong probability that the child to be born has a particularly severe disorder, recognised as incurable at the time of diagnosis" [8].
- 16 TOP for medical reasons is performed at the mother's request after examination by a Multidisciplinary Centre for Prenatal Diagnosis (MCPD). These Centres were established by
- 18 the French bioethics law of 1994 and have been operating since 1999. Their mission is to assist medical teams and couples in the analysis, decision-making and follow-up of
- 20 pregnancy when foetal anomaly is detected or suspected [9]. After collegial discussion, they issue a TOP authorisation on medical grounds by certifying the seriousness of the situation.
- 22 However, a decree of June 2015 states: "The autonomy of pregnant women is a fundamental principle in prenatal diagnosis. Her will and choices are at the core of the
- 24 MCPD process and functioning"[10].

The cross expertise of different specialists and their plurality of values are at the heart of the

- 26 *modus operandi* of MCPDs. Their members take into account the nature and degree of the pathology, the possible treatment modalities as well as the specific situation and familial
- 28 environment. The process ensures the transparency of reasoned decisions as well as traceability. A MCPD comprises gynaecologists and obstetricians, paediatricians, geneticists,
- 30 sonographers, radiologists, paediatric surgeons, midwives, psychiatrists or psychologists and genetic counsellors. It must also ensure the collaboration of other specialists such as foetal
- 32 pathologists or biologists specialised in foetal abnormalities. It meets regularly, on a weekly basis, and functions through a collegial decision-making procedure. If the MCPD agrees, two
- physicians who are members of this MCPD must still ratify the decision, and the cost of theTOPFA is borne by the national health insurance. To date, there are 49 MCPDs throughout
- 36 the French territory.

The rate of acceptance of TOPFA by MCPDs has remained stable over the last 5 years in

- 38 relation to applications. In 2010, 6949 particular severity statements for TOPFA acceptance and 119 refusals were recorded, and in 2015, 7084 applications were accepted and 132
- 40 refused;-the acceptance percentage remains around 98.5% [11].The objective of this study is to consider the decision-making process within MCPDs. First,
- 42 we analysed the elements supporting the professionals' decision to accept or refuse a TOP. Second, we investigate MCPD members' vision about their role, and how they interpret the
- 44 concept of particular severity according to the law. Finally, we explored their view on the evolution of diagnostic tools.

46 Methods

This study (file analysis and interviews) was carried out in 2015.

48 Files Analysis

This study consisted of a review of all TOPFA applications submitted to one MCPD selected

- 50 for its high level of activity and number of files studied each year. Files for the two consecutive years of 2013 and 2014 were studied. The following elements were gathered:
- 52 indications of TOP; number of presentations to MCPD; time between application and performance of TOP.
- 54 Semi-structured interviews with MCPD members

All MCPD professionals regularly present at MCPD meetings were contacted and eight

- 56 accepted to be interviewed: three obstetricians, three midwives, one psychologist and one geneticist (five women and three men). No paediatrician accepted to participate.
- 58 Each interview lasted between 20 and 30 minutes and was recorded with the agreement of the professional. The main themes explored were TOPFA for Down syndrome; the notion of
- 60 "particular gravity, serious disease or condition" in situations of uncertainty; the principle of women's autonomy; and collegiality. A qualitative analysis was performed from the
- 62 transcription of the interviews.

Ethical background: Data collection was strictly anonymous in accordance with medical

64 secrecy; a person from the healthcare team carried out anonymisation.

Results

66 Medical records analysis

We reviewed 280 files submitted to the MCPD for the period 2013-14. Fifteen files were not

- 68 included because they concerned maternal indications of TOP. Thus, 265 cases fell within our objectives of foetal indications. All but one (i.e. 264) resulted in a TOP acceptance. The
- 70 refusal concerned a case of mosaic Klinefelter syndrome.Table 1 presents the indications of TOP for all 264 applications authorised by the MCPD. The
- 72 majority correspond to malformations without chromosomal abnormalities that are classified according to the body regions affected. Chromosomal abnormalities also represent

- a high number of cases among which trisomy 21, which is responsible for Down syndrome, accounts for more than half of cases. Less frequently, indications correspond to genetic
- 76 disorders, infections or other unclassified situations.Table 2 presents the number of times files were presented to MCPD meetings. Depending on
- the indications, the cases required one or more meetings to reach the decision.In 203 cases out of the 264, the decision was reached in one meeting. Among them, 107
- 80 corresponded to chromosomal indications detected during the first half of the pregnancy: trisomy 21 for the majority (n=64); trisomy 18 (n=19); trisomy 13 (n=10); Turner's syndromes
- 82 (n=8); and others (n=6). Decisions reached in one meeting were found for 75 of the 123 indications of malformations, 11 of the 13 indications of genetic diseases, 2 of the 3
- 84 indications of foetal infections, and 8 of the 10 other unclassified indications.In 61 cases, consecutive meetings two to three weeks apart were required to reach the
- 86 decision. They corresponded to 48 malformations, 8 chromosomal abnormalities, 2 genetic disorders, 1 infection and 2 other indications.
- 88 When files were presented several times, the opinion of an organ specialist or new imaging exploration was required. The mean gestational age at TOPFA was delayed from 16 to 24
- 90 weeks of gestation (wg) according to the number of presentations in MCPD meetings (Table2). An analysis of the records shows that all women received at least one ultrasound and
- 92 chromosomal analysis and a discussion with their obstetrician.The term for carrying out TOPFA varies greatly: it extends throughout the pregnancy (Table
- 94 3) and depends on the number of MCPD presentations and on abnormalities. The majority are performed before 21 wg, but 5.7% are carried out after 30 wg. The average time elapsed
- 96 between the decision at the MCPD and TOP is 6.6 days and this period is often reduced at the request of the parental couple, especially in cases of trisomy 21 and 13 (5.4 days).

98

100 Semi-structured interviews with professionals (Table 4)

Consensus concerning Down syndrome

- 102 All the professionals interviewed confirm the decision-making consensus regarding Down syndrome and the lack of debate around this indication. Most of them explain that the fact
- 104 of carrying out a systematic prenatal screening is a choice of society. By setting up this screening, the French legislator initiates a list of foetal TOPs' indications leading to
- 106 consensual and "automatic" acceptance of TOP requests for Down syndrome. For this pathology, our study shows that the period of implementation of TOP is the shortest (under
- 108 one week).

In addition, seven of the eight professionals question the lack of research, care and

- 110 acceptance of children with Down syndrome, unlike in other countries, especially in Europe where these children and adults are better accepted and integrated into the school and
- 112 professional communities.

Situations of uncertainty and notion of particular severity

- 114 All professionals reported that some indications are still debated within the MCPD due to prognostic uncertainty. The most exemplary case is corpus callosum agenesis. Regarding this
- disorder, some point out an evolution in diagnosis leading to a decrease in TOP over the last15 years. They emphasised that more powerful diagnostic tools would reduce the degree of

118 uncertainty.

All agreed that the concept of "high probability" is difficult to determine. In their opinion,

120 face to the probability of a potential severe clinical picture, couples have full legitimacy to decide.

- 122 As regards the concept of a "particularly severe" disorder, most professionals do not believe that a list of foetal anomalies creating a right to TOP should be drawn up because new
- 124 therapies, particularly in genetics, will change the vision of some disorders in the future.

126 Role of MCPDs in relation to women's autonomy

The professionals recalled that the legal framework is based on women's autonomy. They
are also concerned by their role in protecting the foetus, especially in the event of a disability that is viable or accessible for treatment. Professionals all focused on the ability of
MCPD to refuse TOP if necessary, especially in the event of a disability that is viable or accessible for treatment. However, their responses show that they are aware of the fragility

- 132 of the legitimacy of the MCPD. Several stated that they are not opposed to those couples asking for a second opinion from another MCPD in case of a first refusal. They all recall
- 134 situations in which women were forced to continue their pregnancy, leading to severe postpartum depression, with all the harmful and possibly irreversible consequences on the
- 136 mother-child bond.

About collegiality

- 138 The decision of the MCPD relies on the principle of collegiality, defined in this case as multiprofessional expertise. All the interviewees stated that they are convinced of the importance
- 140 of this collegiality for themselves, but also for women and couples: also, each professional has his own position on what he considers important. This system provides support for
- 142 professionals and helps reassure them because a mistake is always possible. Professionals also think that it is important and reassuring for couples because of the guilt experienced
- 144 with termination of pregnancy. Finally, a midwife pointed out that the presence of an ethicist or philosopher would sometimes be a plus to take a step back from some complex
- 146 cases.

148 Discussion

Since the introduction of MCPDs, few studies have investigated their functioning and the

- 150 contribution of these centres to antenatal diagnosis and support for couples. Our results show that unfavourable opinions are exceptional. They represent one refusal out of 265
- 152 requests (0.37%). This tallies with the national percentage, with ranges from 0.24% to 0.31% of the files for the period 2011 to 2015, as reported by the French biomedicine agency [11].
- 154 This underlines the fact that files submitted to MCPDs following couples' requests are the result of high-quality evaluation by clinicians and constructive discussion with couples. This
- 156 leads to a better targeting of files presented to MCPDs. Malformations considered as not severe and able to benefit from surgery are referred directly to an adapted care pathway. In
- 158 contrast, severe malformations are examined by the MCPD and usually lead to an acceptance of interruption.
- 160 In our study, the majority of TOP indications are the result of pathologies of particular severity, recognised as incurable at the time of diagnosis. The main indications for TOP
- 162 found in the medical records were malformations without chromosomal abnormality and chromosomal abnormalities with or without associated ultrasound anomaly. These
- 164 represent the main indications at the national level, as shown in a 2010 study by Dommergues *et al.* [12] where the indications for TOP from 48 MCPDs where reported.
- 166 A number of chromosomal abnormalities such as trisomy 21 or trisomy 18 are paradigmatic examples of indications where the decisions have become consensual between MCDP
- 168 members and other specialists. Since the prenatal screening model and management for trisomy 21 became the norm, the consequence has implicitly been an automatic acceptance
- 170 of the principle of TOPFA. The legislation governing prenatal diagnosis requires that every pregnant woman has to be informed of the existence of trisomy 21 screening. It also

- 172 requires information to be given on the possibility of revealing other potentially identifiable conditions. This obligation to inform can be seen as a strong incentive for screening and
- 174 termination of pregnancy in the event of abnormalities [13,14]. For these indications, decisions are made within one meeting, generally.
- 176 For some malformations and some chromosomal abnormalities, diagnostic uncertainties or late detection require several meetings, usually one to three weeks apart, to better explore
- 178 the situation. Decisions are particularly critical when the viability threshold is reached. Indeed, the number of pregnancies with a foetal pathology that would previously have given
- rise to a TOP and that have been continued increased between 2011 (762) and 2015 (1296).For some well-defined pathologies, treatment protocols, most often surgical, are
- established. For others for which there is not necessarily a surgical indication, it is mainly a question of ensuring medical care from birth, deciding on the conditions of birth and
- preventing certain complications by organising paediatric follow-up.Following TOP authorisation, the discussion continues between the woman and the clinician,
- 186 to allow a period of reflection and maturation of the decision. The medical teams are in favour of a reflection period of not less 6 to 7 days, as recommended by law. Couples usually
- 188 want things to go fast. For professionals, the importance not to rush is essential to give to couples the time to accept the end of the pregnancy and the loss of the future child.
- 190 However, our results show that for some pathologies such as trisomy 21 and trisomy 13, the period is reduced according to the decisions of women and couples (see comments in Table

192 4).

What about a list of pathologies?

194 The advisability of drawing up an official list of pathologies that would lead to TOP in the framework of the law has been strongly debated. Such a list would give the practitioner the

- 196 security of knowing they were acting within a framework accepted by peers. It could on the other hand put pressure on doctors to adhere to that list [15].
- 198 The spirit of the French law is to leave discussion on a case-by-case basis, and there are a number of arguments against the establishment of such a list. First, the particular severity of
- 200 a situation has to be estimated on an individual basis, relying on medical expertise and on the familial context. Second, the risk of drawing up a list of pathologies would be able to
- 202 make TOPFA systematic. Then, It would **be** then transition from possibility to compulsory, thus contributing to an eugenic trend [16,17]. The risk would be a norm of decisions and an
- absence of discussion leading to an erosion of informed decision-making [18]. Furthermore, for the same pathology, the prognosis may differ from one individual to another; as
 diaphragmatic hernia.

Finally, updating this list with the evolution of knowledge and treatment seems difficult [15].

- 208 To date, genome research technologies allow to refine the prognosis of some malformations, such as agenesis of corpus callosum for example. At present the possibility of
- 210 carrying out prenatal diagnoses of genetic diseases with late onset (hereditary cancer) raises ethical issues [19, 20].
- 212 In France, the evaluation of conditions of particular severity is collegial within MCPDs. Our results underline the importance that professionals attach to this structure and to the
- 214 collegiality of decisions. Through the MCPD process, professionals agree that they do not have the task of imposing their own opinion and that the decision is based on collective and
- 216 shared validation. In France, the biomedicine agency clearly–specifies the methods for recording decisions and their traceability [21].
- 218 Considering the emergence of medical practices, such as voluntary termination of pregnancy and assisted reproductive technologies, the legislator has established In article 16 of the
- 220 French Civil Code, the principle of "respect for the human being from the beginning of his or

her life [22]. (Thus, the conceived child is not a "legal person", it is a "human person". It is

- this distinction which makes it possible to put in place abortion regimes based on women's freedom. It is clear that the desire of the woman and the couple is largely taken into
- 224 account since the majority of requests are accepted. The professionals recalled that the legal framework is based on women's autonomy and among the amendments to the law on
- 226 bioethics, TOP was introduced for "psychosocial distress", an act that can be carried out almost up to the end of the pregnancy [23].
- 228 What evolution and place for MCPDs to come?

Will it still be up to the medical profession in the future to decide what handicap or risk is

- 230 acceptable or not for couples? This question is all the more topical as professionals perceive possible shifts in the years to come, particularly because of the advent of non-invasive
- 232 technologies and the potential to analyse the full genome. Today, non-invasive prenatal diagnosis (NIPD) allows the detection of genetic abnormalities targeted to trisomy 21 and
- 234 other genomic anomalies at an early stage [24-26]. This test will be covered by the health insurance in France.-This may lead to the emergence of interruption requests for a number
- 236 of pathological predispositions.

There are currently debates about the conditions under which this test can be used, in

- 238 particular for predictive risk markers of disorders such as cancer [20, 27]. It is anticipated that, in the event of a result with potential risk, parents' and health professionals'
- 240 preferences may be different. The latter may be "subjected" to pressure further to women's requests [28].
- These ongoing developments [29] will lead to questions surrounding the role and missions of the MCPDs in coming years. As NIPD can be performed at an early stage, ultrasound is
- completed, this will allow for the opportunity of abortion within the legal timeframe of pregnancy interruption without evaluation by a MCPD.

- 246 Under French law, this timeframe is 14 weeks of amenorrhea, but an extension of the legal delay to 16 weeks of amenorrhea is currently debated. Before this deadline, some couples
- 248 may opt for abortion, even when doctors consider the risk of illness low or the potential "anomaly" of low severity. NIPD may also open up the possibility of sex selection of the
- 250 future child or access to genetic testing for other markers of pathologies as well as determining risk factors, broadening the debate [30-32]. While respecting women's and
- 252 couples' autonomy, it will be important to evaluate and monitor the quality of the information delivered to women and their understanding of the issues at stake.
- In this context, the advisory role of the MCPD would be enhanced, based on collegial expertise to guide women in their decision-making. Limits of the study. The present work
- 256 was performed five years ago in one MCPD. It is important to emphasise that within the legal framework, MCPDs may have different organisational modalities. However, the data
- 258 collected form the medical files in this study reflect those collected at the national level by the French agency of biomedicine, justifying the interest of this study. The interest of our
- study also lies in the qualitative approach to the experience of professionals.

262 Conclusion

The decision-making process in the MCPD is based on discussion and multi-professional

- 264 collegiality faced to complex choices. The analysis of the files and the approach of the professionals by interview showed how the latter take into account, on the one hand, the
- 266 interest of the foetus and, on the other hand, the expectations of women and couples. How couples envision future possibilities for their unborn child remains a challenge. This study
- 268 provides information about the place and the role of MCPDs within the field of prenatal diagnosis. These structures are essential in supporting women and couples whilst respecting
- their autonomy.

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Table 1: Foetal indications for medical termination of pregnancy

	UT CHROI	MOSOMAL ABNORMALITIES)	123 (46,6%)
BRAIN			40
Anencephaly	16	Septal agenesis	1
Severe degrees of abnormality	5	Holoprosencephaly	1
Agenesis of the corpus callosum	3	Hydrocephalus	1
Hemimegalencephaly	2	Thymic hypoplasia + vermis agenesis	1
Agenesis of the corpus callosum + arachnoidian cysts	2	Arachnoidian cysts + asymmetry of two cerebral hemispheres	1
Craniosynostosis	1	Ventriculomegaly	1
Exencephalia	1	Cerebellar vermis hypoplasia	1
Ischemo-haemorrhagic lesions	3		±
POLYMALFORMATIVE SYNDROME			20
Rachis			20
Spina bifida	17	Severe abnormality (not described)	1
Caudal regression	2		
HEART			16
Complex Heart Disorders (not described)	8	Atrioventicular Communication	1
Tetralogy of Fallot	4	Double inlet left ventricle	1
Aortic atresia	2		
RENAL SYSTEM			13
Megacystis	5	Renal dysplasia	3
Bilateral renal agenesis	4	Severe abnormality (not described)	1
Hygroma			9
ABDOMEN (DIAPHRAGMATIC HERNIA)			3
УЕМВЕР / / / / / / / / / / / / / / / / / / /			2
Femoral Agenesis	1	Hand reduction abnormality	1
		R WITHOUT AN ULTRASOUND ANOMALY)	115
		N WITHOUT AN OLINASOUND ANOMALI	113
			(43.6%)
Trisomy 21	65	Trisomy 22	1
Trisomy 21 Trisomy 18	65 22	Unbalanced Translocation 18.9	
Trisomy 21 Trisomy 18 Trisomy 13	65	Unbalanced Translocation 18.9 Chromosome 2 deletion	1
Trisomy 21 Trisomy 18 Trisomy 13 Turner	65 22 11 9	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion	1 1 1 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy	65 22 11	Unbalanced Translocation 18.9 Chromosome 2 deletion	1 1 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9	65 22 11 9 2 1	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed)	1 1 1 1 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 Gen	65 22 11 9 2 1	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed)	1 1 1 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 GEI Spinal muscular atrophy	65 22 11 9 2 1	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed)	1 1 1 1 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 GEI Spinal muscular atrophy Cystic fibrosis	65 22 11 9 2 1 NETIC DIS	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed) SORDERS Steinert's myotonia Osteogenesis imperfecta	1 1 1 1 1 1 13 (5%)
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 Gen Spinal muscular atrophy Cystic fibrosis Tuberous sclerosis	65 22 11 9 2 1 NETIC DIS 3	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed) SORDERS Steinert's myotonia Osteogenesis imperfecta Sickle cell anaemia	1 1 1 1 1 1 3 (5%) 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 GEI Spinal muscular atrophy Cystic fibrosis	65 22 11 9 2 1 NETIC DIS 3 2	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed) SORDERS Steinert's myotonia Osteogenesis imperfecta	1 1 1 1 1 1 13 (5%) 1 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 Gen Spinal muscular atrophy Cystic fibrosis Tuberous sclerosis	65 22 11 9 2 1 NETIC DIS 3 2 2 2	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed) SORDERS Steinert's myotonia Osteogenesis imperfecta Sickle cell anaemia	1 1 1 1 1 1 1 3 (5%) 1 1 1 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 GEI Spinal muscular atrophy Cystic fibrosis Tuberous sclerosis Achondroplasia	65 22 11 9 2 1 NETIC DIS 3 2 2 2 1	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed) SORDERS Steinert's myotonia Osteogenesis imperfecta Sickle cell anaemia DiGeorge syndrome	1 1 1 1 1 1 1 3 (5%) 1 1 1 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 GEI Spinal muscular atrophy Cystic fibrosis Tuberous sclerosis Achondroplasia	65 22 11 9 2 1 NETIC DIS 3 2 2 1 1	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed) SORDERS Steinert's myotonia Osteogenesis imperfecta Sickle cell anaemia DiGeorge syndrome	1 1 1 1 1 1 1 (5%) 1 1 1 1 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 Ger Spinal muscular atrophy Cystic fibrosis Tuberous sclerosis Achondroplasia Duchenne muscular dystrophy	65 22 11 9 2 1 NETIC DIS 3 2 2 1 1 1 INFECT	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed) SORDERS Steinert's myotonia Osteogenesis imperfecta Sickle cell anaemia DiGeorge syndrome	1 1 1 1 1 1 1 3 (5%) 1 1 1 1 3 (1.1%)
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 Ger Spinal muscular atrophy Cystic fibrosis Tuberous sclerosis Achondroplasia Duchenne muscular dystrophy Cytomegalovirus	65 22 11 9 2 1 NETIC DIS 3 2 2 1 1 1 1 1 1 1	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed) Steinert's myotonia Osteogenesis imperfecta Sickle cell anaemia DiGeorge syndrome	1 1 1 1 1 1 1 1 1 1 1 1 1 1 3 (1.1%) 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 Gen Spinal muscular atrophy Cystic fibrosis Tuberous sclerosis Achondroplasia Duchenne muscular dystrophy Cytomegalovirus Parvovirus B19	65 22 11 9 2 1 NETIC DIS 3 2 2 1 1 1 1 NFECT 1	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed) SORDERS Steinert's myotonia Osteogenesis imperfecta Sickle cell anaemia DiGeorge syndrome	1 1 1 1 1 1 1 (5%) 1 1 1 1 3 (1.1%) 1 10 (3,7%)
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 GEI Spinal muscular atrophy Cystic fibrosis Tuberous sclerosis Achondroplasia Duchenne muscular dystrophy Cytomegalovirus Parvovirus B19	65 22 11 9 2 1 NETIC DIS 3 2 2 1 1 1 1 NFECT 1 1 1 2 4	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed) SORDERS Steinert's myotonia Osteogenesis imperfecta Sickle cell anaemia DiGeorge syndrome NONS Rubella	1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1
Trisomy 21 Trisomy 18 Trisomy 13 Turner Triploïdy Trisomy 9 Gen Spinal muscular atrophy Cystic fibrosis Tuberous sclerosis Achondroplasia Duchenne muscular dystrophy Cytomegalovirus Parvovirus B19	65 22 11 9 2 1 NETIC DIS 3 2 2 1 1 1 1 NFECT 1 1 1 0THE	Unbalanced Translocation 18.9 Chromosome 2 deletion Chromosome 4 deletion Mosaic (undisclosed) SORDERS Steinert's myotonia Osteogenesis imperfecta Sickle cell anaemia DiGeorge syndrome	1 1 1 1 1 1 1 1 1 1 1 3 (1.1%) 1 10 (3,7%)

Table 2: Indications present in the medical files according to the number of MCPD presentations

	Case presented				
TOP Indications	one time	two times or more			
	number (%)	number (%)			
Chromosomal	107 (93)	8 (7)			
abnormalities	75 (61)	48 (39)			
Malformations	11 (84,6)	2 (15,4)			
Genetic diseases	2 (66,7)	1 (33,3)			
Infections	8 (80)	2 (20)			
Others					
Amount	203 (76,9)	61 (23,1)			
Mean gestational age at	16	24			
TOPFA (wg)	16	24			

Indications	Week of Gestation					
	< 13	13-20	21-25	26-29	>32	Amount
Malformations	30	32	32	21	8	123
Chromosomal abnormalities	54	46	11	2	2	115
Genetic diseases	2	4	3	1	3	13
Infections		2		1		3
Others		5	3		2	10
Amount %	86 31.7	89 34.3	49 18.9	25 9.4	15 5.7	264 100

Table 3: Gestational age at TOPFA according to indications

Table 4: Professional comments from semi-directed interviews

Consensus concerning Down syndrome

"MCPDs don't work in isolation; they work within society." (Midwife)

"The organization of screening for Down syndrome in France is a kind of machine for professionals and pregnant women." (Obstetrician)

"The antenatal screening is focused on Down syndrome. When a woman asks for an abortion in this context, her request is accepted. Nothing to discuss!" (Geneticist)

"Actually, there is no question, there is a consensus at the MCPD level." (Obstetrician)

"We are one of the only countries to be focused on trisomy 21. In England, for example, screening is not organised. There is a greater acceptance of disability." (Obstetrician)

"Most of the time, women and couples take their decision early, when the exams are prescribed. Their choice is already made at the time of the results. So, the MCPD would not feel legitimate in refusing their request, and this leads to automatic acceptance." (Midwife)

Situations of uncertainty and notion of particular severity

"So, we have to consider life this child could have after birth." (Obstetrician, Geneticist)

"After parents have met the different specialists, pediatrician, psychologist and others, at the end we will follow them in their request." (Obstetrician)

"Couples are very anxious about the uncertainty of the prognosis. In doubt, they don't want to take any risks. Then, -the professionals reach a collegial agreement to terminate pregnancy taking into account the suffering of the couple". (Psychologue)

"In such cases, we can speak of precaution: the "absence of prognosis" makes it impossible to refuse the application request for a termination of pregnancy for medical reason". (Midwife)

About collegiality

"It works well"; "it's like a firewall" (Midwife, Geneticist, and Obstetrician).

"Each person provides a little of his reality." (Psychologist).

"You think you are less likely to make a mistake when there are many of you who think the same thing." (Obstetrician, Midwife).

"The couples understand that they have been heard and understood by a collective and feel more accompanied" (Psychologist).

"The presence of a neutral person, such as a philosopher or ethicist, would be very relevant and might lead prenatal medical professionals to think a little more or differently." (Midwife)

Time between decision and termination of pregnancy for medical reason / Importance of the medical support

"Couples want to move fast. The concern is to alleviate the anxiety of couples as fast as possible." (Midwife)

"Consulting the specialist is not a time loss whatever the decision on the outcome of the pregnancy." (Obstetrician)

"Termination of pregnancy for medical reason is never urgent. However, compassion makes us inclined to go faster to relieve couples." (Obstetrician)

"For chromosomal abnormalities, the discussion does not take place at the MCPD but rather upstream when informing parents of the screening. So, it seems logical to me that the termination of pregnancy for medical reason be carried out as soon as possible after the diagnosis" (Midwife)

"This time is incompressible. I don't know if rushing is good for people? A termination of pregnancy for medical reason is a milestone in a couple's life." (Midwife)