

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

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

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

When, in the case of a multifetal pregnancy, one of the fetuses has a serious disease, the circumstances are even more complex. The choices open to the parents are to continue the pregnancy as is, in the knowledge that one of the children will be born gravely ill and may die prematurely, or to proceed with selective termination (ST). ST differs from the usual MTP because it entails terminating the life of the sick fetus while allowing the development of the healthy sibling or siblings to continue. At term the mother gives birth to a dead child and one or more living children. ST thus entails decision making based on social, ethical, and professional-ethical factors that go far beyond exclusively medical considerations. The conditions in which patients and, where relevant, their partners receive information must take account of these specific factors. Ideally these conditions should contribute to decision making that is as informed as possible and provide the future parents with enhanced empowerment in their decision making.

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

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

## **Selective Termination**

ST consists of feticide performed during a multifetal pregnancy (most often a twin pregnancy) because one of the fetuses has a grave and incurable disease as of the time of diagnosis (It is important to differentiate between STs, which are performed in cases of fetal pathology, and multifetal pregnancy reduction (MFPR), which consists of embryocide performed in cases of high-order multiple pregnancies (more than three fetuses) to reduce the obstetrical and perinatal risks inherent in this kind of pregnancy.) (Evans et al., 1999). ST is indicated to allow a pregnancy to continue for the sake of the healthy fetus or fetuses. It does however present a risk of miscarriage, a risk that varies according to type of placentation and technique used (Rousseau and Fierens, 1994; Bernard et al., 2006; Hern, 2004). It can also threaten the life of the other fetus or fetuses in other ways, compromise their health, and increase the risk of premature birth (Bernard and al., 2006). In France, there are no regulations or directives specific to ST. (Goussot-Souchet and al., 2008) Given that there is legislation on MTP that is strictly applied (Loi no 75-17 relative à l'interruption volontaire de la grossesse, art. L 162-12) and bioethics law on the donation and use of elements and products of the human body, medically assisted reproduction, and prenatal diagnosis (Act 94-654, 29 July 1994), the regulatory void when it comes to ST raises important concerns.

## Materials and Methods

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

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

With this approach in mind, we used a purposive sampling strategy. Eight semi-directed interviews were conducted with obstetrician-gynecologists practicing in these multidisciplinary centres for prenatal diagnosis in the Paris region: Cochin/Saint Vincent de Paul, Necker, Robert-Debré, Saint-Antoine, Antoine Bécclère, Lariboisière. Participants were selected based on their experience with ST. However, only STs done on bichorionic biamniotic twin pregnancies are reflected in the study, because in monochorionic pregnancy the progress of the pregnancy is more complex and the future of the healthy fetus even more uncertain (Bernard et al., 2006 ).

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

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

## Results

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

### Information transfer

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

#### *The Time Factor*

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

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

The physicians maintained that these strategies limit the number of decisions made in a hurry and reduce the guilt experienced by patients and their partners: “My worst fear is that parents will decide to resort to ST and then, three or four years later, will regret it .” (Julie, obstetrician, 2007). According to our informants, the time factor can contribute to reducing the psychological impact of the disclosure that there is fetal pathology, of the consequences of the pathology for the child and the pregnancy, and of the proposed procedures.

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

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

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

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

As for the supplementary information physicians deem it important to convey, all the interviewees mentioned the need to explain that ST presents the risk of termination of the whole pregnancy. In a different vein, three of our informants emphasized the impossibility of seeing the body if ST is done early. Three others believed, respectively, that the feelings of ambivalence that will be aroused by the dead child through the course of the pregnancy, the assumption of responsibility for disposal of the body after delivery, and the possibility of burial represent topics that must absolutely be broached. Last, one of the obstetricians brought up the importance of discussing the psychological impact of feticide, while another felt that the technical aspects of ST are underdiscussed. As for other topics, there were as many opinions as obstetricians.

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

### **Respect for Couples' Autonomy**

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

The following interview excerpt illustrates the implementation of this position:

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

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

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

## **Discussion**

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

As we saw above, this exploratory study on the points of view of some obstetricians in our French sample regarding information and decision-making processes in the context of ST yielded two major themes: information transfer, which subdivided into two strategies (the time factor and the nature of the information transferred); and respect for couples' autonomy.

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

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

Second, despite this consensus on the question of the time that should be devoted to information transfer, views differed on the kind of information it is useful to transmit. Other than the concerns about the fetal remains and advisories about the difficulty of living with a handicapped child, several obstetricians said they view provision of information that is not of a medical nature as falling outside their professional duties. Others deliberately choose to hide certain kinds of information in order to protect couples from what they consider to be needless suffering.

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

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

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

Although the physicians stated the final decision is up to the couples, our findings show a degree of tension and inconsistency between their perceptions of patients' level of autonomy and the limitations they impose on that autonomy. Some physicians showed a tendency in practice to influence couples' decisions by one means or another (withholding information, "helping" with the decisions, providing personal advice, and so on).

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

However, consultations that are completely free of directiveness are something of a fantasy. As Amann observes, "the state of medical art certainly consists of an ensemble of impersonal criteria, ... but every physician must resort to her or his own judgement at the moment of decision making ." (Amann, 2006 ). Thus "the criteria for medical decisions are never wholly independent of the subjectivity of the person to whom society has accorded the power to decide ." (Amann, 2006 ). Indeed, in the context of prenatal diagnosis, many physicians influence couples' decisions, with greater or lesser degrees of cognizance that they are doing so (Barjot and Levy, 1997 ; Lippman and

Wilfond, 1992 ; Wyatt, 2001 ). Several studies have shown that couples' decisions differ according to the different ways of presenting the risks associated with a genetic disorder (Lippman and Wilfond, 1992 ). As well, the role held by the person who provides the information (obstetrician, geneticist, pediatrician, genetic counsellor) influences the probability of opting to terminate pregnancy (Wyatt, 2001 ).

Thus while attitudes can be in greater or lesser measure directive, it would appear Utopian to think the information provided by physicians will be full and will not be affected by physicians' power to sway. Obstetricians can limit their influence but not really do away with it altogether. And because accompaniment in decision making is viewed differently by different practitioners, it is also difficult to define just what is meant by "helping with the decision" and how far this help can go before it abridges couples' autonomy.

## Conclusion

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

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

Despite all the problems associated with ST, in France there are neither State guidelines nor recommendations on the methods of information transfer and support in decision making to patients following diagnosis of a fetal pathology. It is of interest that none of our respondents expressed the need for such guidelines or recommendations.

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

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

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## Selective termination

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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?