### SCIENTIFIC CONTRIBUTION

# Access to assisted reproductive technologies in France: the emergence of the patients' voice

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**Abstract** Is there any ethical justification for limiting the reproductive autonomy and not make assisted reproductive technologies available to certain prospective parents? We present and discuss the results of an interdisciplinary clinical ethics study concerning access to assisted reproductive technologies (ART) in situations which are considered as ethically problematic in France (overage or sick parents, surrogate motherhood). The study focused on the arguments that people in these situations put forward when requesting access to ART. It shows that requester's arguments are based on sound ethical values, and that their legitimacy is at least as strong as that of those used by doctors to question access to ART. Results reveal that the three implicit normative arguments that founded the law in 1994, which are still in force after the bioethics law revision in July 2011—the welfare of the child, the illegitimacy of a "right to a child," and the defense of the so called "social order"-are challenged on several grounds by requesters as reasons for limiting their reproductive autonomy. Although these results are limited to exceptional situations, they are of special interest insofar as they give voice to the requesters' own ethical concerns in the ongoing political debate over access to ART.

**Keywords** Access to ART · Bioethics laws · France · Older parents · Surrogate motherhood · Reproductive medicine · Right to a child · Welfare of the child · Social order · Reproductive autonomy

#### Introduction

The role that states should play in regulating reproduction has always been a controversial issue. The question came to the forefront in the 1960s with the advent of the first birth-control pills, became more challenging in the 1970s with the debate about legalizing abortion, and even more complex in the mid-1980s with the development of assisted reproductive technologies (ART). Far from merely offering medical treatment for sterility, these techniques opened a Pandora's box from which "the potential for exploding the natural setting for reproduction escaped. (...) With medically assisted procreation, new mothers and new fathers symbolically arrived on the scene, along with a challenge to the traditional family model. From then on, the question of deciding who has a right to become a mother and who has a right to be a parent was raised." (Engeli 2010, p. 15). Referring to Salter (2007), Engeli writes that "the public policies chosen by Western countries show that their answers to new reproductive challenges have been more kaleidoscopic than convergent" (ibid. p. 17) and argues that each country's choice is the result of a specific combination of the respective weights in its own context of the three "I's": Institutions, Interests, and Ideas (ibid., p. 22).

In France, the first law on access to assisted reproductive technologies (ART) was adopted in 1994, after 10 years of heated debate, illustrative of the difficulties for a country to decide upon its reproductive policy. The controversy opposed proponents of the law arguing that unethical

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practices would creep in, in the absence of regulation, and opponents who held that even if a couple requests medical assistance, the decision to have a child is a private matter that should in no case be regulated by law.

The medical and scientific community had a major role in the debate. "Regulation of procreation: the affair of doctors, neo-Malthusians, and the State," writes Jennifer Merchant: in such a matter, "[medical and legal] professionals have always constituted a separate special-interest group, successfully exerting pressure on the State with the goal of defending their interests, and enjoying a privileged relationship [with it]" (Merchant 2003, p. 58).

Actually, Drs. Jacques Testard and René Frydman, fathers of the first IVF French baby, Amandine, born in 1982, were in the vanguard of the movement to put the topic on the public agenda in France, demanding legislative regulation of medical practice. The issue inflamed the public debate. An historical conference on "Genetics, procreation and law" was held in 1985, attended by many of the most famous French obstetricians, as well as social scientists and humanists (Actes Sud 1985). Some of the participants endorsed restrictive regulation, while others were more liberal. But gradually, "the fear of drifts and blunders supplanted public confidence in the wisdom of the medical profession and society as a whole. (...) Pleas in favor of regulation of these practices by public authorities were accumulating. The call for a law became increasingly imperious. The government (...) initially reluctant to suggest a framework for a sector that was so changeable, new, and sensitive, where private decisions are interlocked with public health, gradually allowed itself to be convinced of the need to pass laws" (Mehl 1999, p. 11).

So the advocates of regulation won the debate. And, as pointed out by Merchant, the legislation was mainly drafted on the basis of practitioners' recommendations (Merchant 2003, p. 58). It authorized a large number of new technologies, but strictly regulated their access. Since then, the law was revised twice, in 2004 and again a few months ago in July 2011. But the conditions for access to reproductive technologies remained almost the same. In France, ART are currently available only to male-female couples; both partners must be alive, and both must be of "reproductive age." Those requesting assistance must prove that they are living together as a couple, and that at least one of the two partners is medically infertile. The choice is clear: access to ART is possible, but for medical reasons alone; personal reasons, outside the bounds of the traditional family model, are not accepted. Moreover, the law gives doctors considerable leeway to judge certain aspects of ART that are not strictly medical. For example, one of the main provisions of the law stipulates that it is the prerogative of the health

care team to refuse access to ART, on a case-by-case basis, when they consider for one reason or another that "the welfare of the future child" might be endangered or compromised.<sup>2</sup>

It is in this political context that we launched in 2002 our clinical ethics consultation service in Hôpital Cochin, one of the biggest public university hospitals in Paris, housing the well-known Port-Royal maternity unit. These Port-Royal ART teams expressed immediate interest in having our clinical ethics team at the hospital. When they questioned the wisdom of granting a specific request for ART, one of their duties as defined by the law, they often sought our opinion. At the same time, because our ethics consultation services were also open to direct access for patients, we were being contacted by couples appealing to overturn an ART team's refusal. The questions brought to us by reproductive teams concerned for example a case where a 67-year-old (over standard age) man and his wife, age 37, had applied for donor insemination, due to the fact that the man had undergone treatment for prostate cancer some years earlier, without freezing his sperm. Another couple was seeking medical assistance in conceiving a baby, although both partners had cystic fibrosis. In a third case, the question was on what to tell a 45-year-old woman who had just met a new partner and wanted to bear his child, although she would need oocyte donation. The team wondered if she could suggest to her traveling in a foreign country since it is illegal in France to provide a woman at this age with a donated egg. On the other side, we heard the following pleas from couples arguing against the ART teams' refusal: a couple of 30-year-olds, in which the male had just recovered from testicular cancer, saw no reason for the rule that they must wait 2 years after cancer remission before obtaining restitution of his frozen sperm to try having a baby. In another case, a 75-year-old man who had had his sperm frozen in the bank 15 years earlier due to a cancer was encountering difficulties getting it back. ("It's mine, isn't it? Why are they hesitating?") His new companion, a 28-year-old woman, desperately wanted to bear his child, and the ART team was standing in their way.

In nearly all these cases, the ethical conflict was the same: it was mainly about achieving a balance between respect for people's reproductive autonomy, on the one hand, and what doctors themselves saw as their responsibility to society as a whole, on the other. Loyal to a duty they understand as incumbent upon them because it was delegated by society, ART teams are usually reluctant to grant people access to ART for one or another of the three following reasons: (1) when there is a risk of departure from the traditional family model; for example, when the age of the prospective parents does not correspond to the

Art L.2141-1, French Public Health Code.

<sup>&</sup>lt;sup>2</sup> Art L.2141-10, French Public Health Code.

teams' definition of the reproductive age; (2) when there is a possible risk for the so-called "welfare of the future child"; for example, if a child might be orphaned, because his prospective father is in poor health; or (3) when they consider that the request doesn't deserve the technical assistance necessary; for example, if the chances of success of the procedure are not high enough for the trial to be attempted. According to ART teams, there is no such thing as a "right to a child." These three concerns happen to fall exactly where the law allows some latitude for the teams' interpretation of it. But the very existence of this latitude opens the possibility of another interpretation of the law, and it is exactly what the requesters do. They usually contest all the teams' arguments, one after another. Above all, their position is that doctors should not be stricter than the law; that is, they should not go beyond what the law does not explicitly forbid. Disappointed couples denounce what they feel is a medical abuse of power, claiming that health care professionals are preventing them from exercising their reproductive liberty, which they consider a basic human right.

Is reproductive autonomy or procreative liberty,<sup>3</sup> as Robertson calls it, really a basic human right? The literature, at least, usually "takes for granted the moral and practical necessity of such autonomy" (Purdy 2006). And Robertson says that "procreative liberty should enjoy presumptive primacy when conflicts about its exercise arise because control over whether one reproduces or not is central to personal identity, to dignity, and to the meaning of one's life" (Robertson 1994, p. 24).

Most of the ART cases that came to us as a clinical ethics consultation service led to sharp debate within our own ethics group. We wondered how we should reason ethically and if we should consider that respect for reproductive autonomy should have any limits; to which cases these limits should apply, and why. Moreover, it was not clear to us whether the fact that ART requires third-party intervention should change the nature of the ethical reasoning about the limits of reproductive autonomy; and if it did, why and in which cases.

Due to the difficulties we ourselves face in our daily work as a clinical ethics services, and because French bioethics law was scheduled for review in the near future, possibly leading to a reconsideration of the legislative limits of access to ART, we decided to carry out a research study on this specific topic. The intent was to give more voice to the requesters' own opinions as well as to the

views of the practitioners to whom the ART requests were addressed. We wanted to gain a better understanding of the arguments and ethical reasoning on both sides: exactly how do patients formulate their requests to access for ART and how do the doctors argue for granting or refusing such requests. In this article, we shall present the methods and results of our study, and then discuss them in the light of the international theoretical debate about respect for reproductive autonomy, and how each country develops public policy on access to ART compatible with its common values.

# Access to reproductive technologies: a clinical ethics study $^5$

Methods

Our approach as a clinical ethics consultation service is to provide an opportunity to anyone who requires it—health care teams as well as patients or proxies—to clarify the ethical challenges embedded in a specific medical decision, when the decision is felt to be particularly difficult because it raises something perceived as a conflict of values. When our help is solicited for a specific case, we interview all the people concerned by the upcoming decision, to refine our understanding of everyone's position and ethical reasoning. The team of ethics consultants is always multidisciplinary, composed of at least one physician and one non-physician (lawyer, psychologist, philosopher, etc.). Every member is trained for such consultations.<sup>6</sup> After having met all the people involved in the case, the ethics consultants present it for general discussion at the weekly conference of the whole multidisciplinary ethics group. Next, the consultants meet with the medical teams and patient/proxies to detail the content of the ethics group's discussion for both parties. We hope that this feedback and the whole process will make both parties involved more aware of the different values, intuitions and ethical challenges embedded in the case, and that this will help the decision-making process, ultimately improving medical practices (Fournier and Gaille 2007).

When planning our research study, we opted for a method based on our specific know-how as a clinical ethics support services. Our routine procedure as clinical ethics consultants involves meeting people, both patients and medical teams, on a case-by-case basis, before the final decision is made, and the method we adopted for our

 $<sup>^{3}</sup>$  For the purposes of this paper, the two terms are considered to be equivalent.

<sup>&</sup>lt;sup>4</sup> A provision that the law would be reviewed every 5 years was written into the first 1994 law, and carried over into the 2004 law, based on the principle that the law would have to be updated to reflect rapid scientific and technological progress in the field.

<sup>&</sup>lt;sup>5</sup> The study we present here was sponsored by the French Agency of Biomedicine.

<sup>&</sup>lt;sup>6</sup> For more details about the methods we use in our center, see: Fournier et al. (2009) and Rari and Fournier (2009).

research mirrored this approach. We tried to precisely understand the ethical reasoning on both sides: what the patients said in defense of their request, and how the medical team dealing with the request responded to it. But because we were doing research, not providing an ethics consultation, we didn't go through our whole routine process, with case conference and feedback on the ethical discussion to both parties.

We designed our protocol as a form of "action research" our goal being to understand the processes which lead to medical decisions. To reach that understanding, we needed to meet with people and to conduct indepth interviews with them. However, at the same time, we were aware that our interviews could have an impact on the situations being studied and on the decisions being deliberated, even if we did not make any formal decisional recommendation. We assumed that our role, even when meeting people as researchers, was not purely observational and non-interventional, but in some way active. Indeed, action research has two basic characteristics: it is "simultaneous" and "integrated": action and research proceed together, and are integrated, insofar as the data collected can enhance the comprehension of the people involved in the decision-making process itself and thereby have an incidental influence on their judgment in the final decision (Kelly 1999). For example, in the case of our study, some patients changed their minds, and withdrew their requests for ART, after having been interviewed by us. It seemed as if the conversation with a neutral tierce had made them more aware of the difficulties they would face in pursuing their plans. In the same way, some teams changed their minds and became less resistant to a specific request, once they heard themselves arguing aloud against

For this research, we constituted a specific research team, made up of four scholars from different disciplines (law, philosophy, sociology, and medicine), all belonging to our clinical ethics group. Next, we decided to focus our study on three of the typical clinical situations currently challenging the ART teams in France from an ethical point of view. The three situations we chose were the following: (1) Group 1: advanced parental age, (2) Group 2: at least one of the two parents diagnosed with a severe or fatal disease, (3) Group 3: request for an illegal ART technique; in this case, surrogate motherhood. These three situations also supposedly present differences in the types of issues they raise: more "social," for what concerns advanced parental age; more "medical," in the case of a prospective

parent diagnosed with a severe or fatal disease, more "legal," when the request was for surrogate motherhood. For Group 1 (advanced parental age), conflict arises because French law does not stipulate a precise age limit for either father or mother. It simply states that parents must be "of reproductive age." The ambiguity of the term is actually a loophole enabling medical teams themselves to evaluate the advisable limits, and even whether such limits should exist. Doctors usually formulate the question as follows: might it not be detrimental to the child's welfare to have older parents than in traditional families? To compensate for the absence of official limits, doctors usually choose to adopt some systematic guidelines, rather than making decisions on a case-by-case basis, in an effort to minimize the risk of discriminating unfairly against certain couples. For this study, we interviewed requesters whose ages exceed the limits currently applied in clinical practice today in France: 60 years for a male and 43 years for a female.8 Group 2 requests are a challenge because at least one parent presents a severe and/or fatal disease. Medical teams often perceive authorizing access to ART in such situations as ethically questionable, again in reference to the "welfare of the future child," even if the only practices explicitly forbidden by the law are post mortem embryo transfer or insemination. Group 3 concerns illegal requests for surrogate motherhood. Although surrogate motherhood has been strictly prohibited in France since 1994, it is estimated that a few dozen couples per year circumvent this prohibition by going to a foreign country (according to Le Monde, Courrier International, 2010). Actually, when we began our study, there was a heated surrogate-motherhood debate going on in France.

We assumed that screening for these three different situations would enable us to identify whether the ethical reasoning of either party, the requesters or the medical teams, adjusts to the specificity of the situation, or if the conflict is always voiced in the same general terms, and mainly surrounds the proper balance between respect for reproductive autonomy and the protection of society's moral choices.

Our screening procedure was designed to include enough cases in each of the three groups to capture as many elements as possible of each situation, until we reached a saturation point, where adding new cases provided no new

<sup>&</sup>lt;sup>7</sup> Kelly (1999) "Action research has two basic characteristics: to be "simultaneous" and "integrated": action and research proceed together and are integrated insofar as the collected data can enhance the comprehension of the people involved in the decision-making process itself."

<sup>&</sup>lt;sup>8</sup> See the limit for reimbursement by public funding, fixed March 11, 2005 by the Union nationale des caisses d'assurance maladie, Livre II Classification commune des actes médicaux, § 09.02, JO du 30 mars 2005: the woman must be under 43 years. For what concerns the male age, the limit for the Centre d'études et de conservation des oeufs et du sperme (CECOS) of the Cochin hospital, who sent to us the major part of people that were included in our study, is 60 years. It must be noted that the limit recommended by the French Fédération Nationale des CECOS actually is of 55 years (http://www.cecos.org).

elements that could be applied to the meaningful interpretation of the study (Glaser and Strauss 1967). In this perspective, we sought a panel of about 20 cases in each group. For the male-age-limit and parental-disease groups, cases were referred to us by the ART teams; for female-age-limit and surrogate motherhood (group 3), we got referrals mainly from patient organizations, due to the fact that practices concerning such patients are outside the purview of a French ART team.

We met all the couples sent to us for inclusion, and conducted semi-directive interviews lasting at least one hour with them, based on a personal narrative. We structured our interviews to reflect the main objective of our study: clarifying what the most concerned people on the daily clinical ground have to say about the place that society should let for respect of people's reproductive autonomy. In this perspective, we systematically explored the topics listed below:

- Their ART history: the reasons why they had to resort to ART, the medical path they had been following, for how long, the number of attempts, the techniques used, the various teams solicited throughout the process, and the relations between them.
- What was motivating them: why did they want a child at this point in their lives, was it a matter of crowning this particular relationship, was it a child just for the sake of having a child, or for the sake of expanding a family, or as a means of rectifying something perceived as an injustice, etc.
- Whether they are considering the welfare of the child and of the other persons involved in the plans (their partner, the sperm or oocyte donor, the surrogate mother, her husband, children, etc.)
- The place and role of money in these matters: did they have anything to say about the potential for a drift towards commercialism? Should the donor or surrogate mother be paid, and how much, should the expenses for this particular type of ART, and ART in general, continue to be covered by the national health insurance system, etc.
- Their relationship to the law: what did they think of it?
  How did they envisage possibly placing themselves in a position that violated the law?
- How their close friends and family circle had reacted to their plans.
- How the healthcare staff had reacted to their plans, and how they understood this reaction.
- How they reacted when we informed them of the type of ART case presented by other requesters, belonging to other groups in the study.

For each case, we also met with at least one member of the health care team involved: i.e., the referent ART doctor that received the request, in order to hear the arguments on both sides.

To analyze the interviews contents, we used a datadriven methodology rather than a hypothesis-driven one, a form of the "grounded theory" as developed by Glaser and Strauss (1967) and further refined by Charmaz (2006): "The groundedness of this approach fundamentally results from these researchers' commitment to analyze what they actually observe in the field or in their data. If they find recurrent themes or issues in the data, then they need to follow up on them, which can, and often does, lead grounded theorists in unanticipated directions" (K. Charmaz, cited in Pidgeon 1999, p. 79). Thus, grounded theory stresses the everyday context of medical decision-making over controlled situations, as well as the iterative creation of hypotheses from the data through a process of "constant comparison" between new theory and data, until the categories which have emerged are adjusted to "fit" the reality studies and become "saturated."

#### Population of the study

The study lasted from January 2008 to November 2009. It included 52 cases, corresponding to one or another of the three clinical situations we had selected: 48 of the requests came from couples, 4 concerning single women; 23 of the 52 inclusions belonged to Group 1 (parental age); 15 to Group 2 (severe parental disease); and 14 to Group 3 (surrogate motherhood).

In Group 1, 15 couples were referred for male age over 60 years. The men's mean age in the group was 66 (extremes: 59–75; 4 of them were over 70) and the women's mean age was 34. The average age difference within the couple was 32 years. One couple in the sample presented extremes, the man being 75 and the woman 28 years of age. In 13 of these 15 cases, the woman was the man's second wife. In 12 cases, the men already had children; 5 of these 12 men were seeking a second or third child by the same wife. In 12 cases, the reason for requesting ART was male sterility, with 2 of them having frozen sperm in the bank, due to previous cancer. In 3 cases, the reason for ART was female sterility, but the couple's access was challenged because of male age.

The sub-group for female age was composed of 8 women. Their mean age was 46 (43–48). Seven had live-in male partners; one was single. Five of them had been trying to bear a child with the help of ART for over 5 years, and had already experienced more than 5 failures. When we met them, all of them said they had already gone abroad to seek access to ART (in Spain, Belgium, the Czech Republic, or Croatia).

In Group 2, the parental disease was cystic fibrosis in 6 cases. In 3 cases, the woman was ill; in 2 cases, the man

was ill; and in 1 case, both parents were ill. Their mean age when requesting ART was 30 years. In 6 other Group 2 cases, the clinical team had been reluctant to grant access to ART because the male partner had cancer. In 4 of these 6 cases, the prognosis was uncertain or severe; one of the four was already in palliative care and in 2 cases, the patient had been in remission for less than 2 years. The last three cases in Group 2 involved miscellaneous diseases: in one case, the female partner was prone to thrombosis, making pregnancy potentially life-threatening; in another case, there was a 50 % risk the mother would transmit a homozygous PAX6 gene mutation causing bilateral aniridia and blindness; and in the last case, the problem was the father's rare neurovascular disease, the cause of a disability which was likely to worsen.

In Group 3, we interviewed 14 people who were unable to bear a child without the help of surrogate motherhood. We saw 10 of the 14 before they had decided to begin the procedure, and 4 who had already gone through with it and had children. In 11 cases, they were couples (mean age 33 years) and in 3 cases single women (mean age 29 years). In 10 out of the 14 cases of the group, the sterility had been known for more than 10 years: women born without a uterus in 5 cases (Rokitansky syndrome); women with other chronic clinical circumstances in 4 cases (hysterectomy due to a car accident at the age of 15 years in 1 case; to uterine cancer in 1 case; risk of fatal pregnancy due to severe and repeated pregnancy-induced hypertension in 1 case; and hemolytic disease in 1 case); in 1 case, the requesters were a couple of male homosexuals. In 4 cases, the indication for surrogate motherhood was due to emergency hysterectomy to remedy life-threatening conditions: pre-eclampsia in 3 cases and cancer in 1 case. In addition, for this group, we decided to meet 4 surrogate mothers and one young adult who had been born by this technique. Although we do not include the details of these last five interviews in the results, we felt that meeting these individuals would give us added insight into this challenging issue. For the same reasons, we decided to meet some eggdonors in the sub-group of female age.

## Results

On the whole, it was striking how much the qualitative content of requesters' interviews was coherent from one case to another, with individuals in different groups and sub-groups expressing very similar concerns. We will structure the presentation of the results around a few keywords that emerged from the interviews.

First of all, most of the requesters we met were angry, due to what they perceived as an intrusion in private life and medical abuse of power. They said that deciding to

have a child is a private matter, and that they alone should be entitled to make the decision: "It's our business; society has no say in it... Leave us alone." They were angry because they had come to hospital for help, and expected kindness and support; instead, they felt they had been judged, and burdened with the threat that their request would be rejected on moral grounds rather than medical ones: "They [the clinic staff] taught me a real moral lesson, saying, 'Aren't you ashamed to be coming here, at your age?"" They perceived the ART teams as assessing their private lives and the quality of their couple-relationship, and sensed that the doctors expected them to prove their ability to be "good parents." They resented these burdens as violations of their rights. Their anger seemed to be directed more at doctors and medical teams than at society as a whole. In their opinion, the doctors should have been on their side. The doctor's duty is to help people who are suffering, not to police public morality: "Medicine is supposed to help people... so that each person is entitled to happiness." This primary theme of anger is present in all three groups of requesters. In Group 1, couples deny that doctors should play a role in defining social rules: "Every woman has a right to bear a child. Who has the right to say that such or such a woman shouldn't have a child?" argued a man who was already a father. Sterile due to age, he wished nevertheless to give a child to his new young partner. In Group 2, people accused ART doctors of abuse of their power for citing parental disease as an insurmountable obstacle to the requesters' plan to procreate. Life must go on, in spite of the bad news: "I see absolutely no reason to deprive myself of having a child just because I no longer have a left arm." This way of telling things shows the requesters' feeling that regardless of their health status, the decision to have a child is up to them, not the doctors, and they should be entitled to access to ART. Even in Group 3, almost all the couples we met expressed strong anger, not so much against doctors, but against society because of the persistent illegality of surrogate motherhood. They perceive the fact that theirs is the only case of medical infertility to be denied access as profoundly unjust: "I don't have a uterus, so in relation to the law, I don't exist. It's the only case the law refuses to consider. No uterus, no child... it's not fair."

Time was another recurring theme in people's narratives. It was especially common in the subgroup of women over standard age: "For many years, making babies was not my top priority... When you earn an advanced degree, you want to have a brilliant career, and after that, it's too late." "I put aside the desire to have a child, and I didn't see myself aging. (...) I should have been told to pay attention to the biological clock." When these women realize the clock is ticking, they abruptly embark on a race against time, with a great feeling of urgency. They become

extremely stressed, so impatient that they can hardly bear the fact that doctors are taking some time to scrutinize them and their motivations: "I blame medicine for wasting my time." They know that the longer they wait, the less successful the outcome is likely to be, and therefore, they pressure medical teams to act more quickly. Parenthood plans become a large part of their lives. Many of them grow obsessed with the ambition to have a child and are unable to speak of anything else. "It's the only thing I'm living for. I'm desperate." "At the moment, I have trouble being open to planning a couple relationship (...) I'm too obsessed with this idea of having a child." These obsessive tendencies disturb the doctors, who interpret them as a sign the individual is somewhat unstable and lacks self-control. It is one of the factors that make health care teams suspect their patients will fail to be "good enough" parents. Moreover, feeling justifiably pressured by time, these women frequently attempt to rush the ART teams, who resist, citing the "no right to a child" argument. Finally, this subgroup of requesters is the one whose relationships with doctors are the most conflict-ridden, mainly because of this tension concerning time.

However, time is also a key theme in the narratives of the other groups. For example, in Group 2 (at least one parent with severe and/or fatal disease), time is also frequently voiced as an important motivating factor: "If I weren't sick, we'd have waited a little longer," said a young man, recently diagnosed with a cerebral glioma. Or: "It has to be now; I don't know if 3 years from now, the disease will still permit it", we were told by a 31-year-old woman with cystic fibrosis, aware that her lung condition was not likely to improve, with passing years. "We'd like to start a pregnancy now, so that he will have known his father, just in case," said the wife of a male cancer patient in our sample. In such cases, it seems that the disease hastened plans to have a child, the acceleration being exactly proportional to the severity of the prognosis. Under such circumstances, further delay is nearly unbearable for the requester. Conversely, reluctant to take action under pressure, the medical team tends to resist the urgency of the requesters, slowing the process even further. In the sub-group of men over standard age, medical teams often used time in the same way, postponing a decision for months and months, frustrating the requesters even more. Like the above-cited women, they resented having to wait for a decision from the team, whom they perceived as having little respect for their right to plan their own lives. Thus, time is frequently a cause of tension between requesters and ART teams, the former expressing a need to hurry, and the latter using their right, given by the law, to deliberate before making a decision, knowing perfectly well that postponing a decision will frequently lead to a no answer, in the end.

In Group 3, time is also a frequently cited theme, although not in terms of the relationship with the ART

teams and their tendency to "play the time card" against requesters. Like patients in other groups, Group 3 people mentioned time in describing how long they have wanted to have a child, their commitment to this undertaking, and why they had decided to seek ART at this point in their lives: "My child has been gestating for 10 years," a young Rokitanski woman told us. "People like me nourish these hopes when they are single, and then reconstruct the plans when they marry." Another one told us how, after an emergency hysterectomy following eclampsia, she organized everything to carry out her next pregnancy with surrogate motherhood, right when she would have been planning to conceive her next child (had she been able), 2 years after the birth of the first, like in "normal" families. Her story is a good illustration of the importance of time in the life plans of the requesters, and how bitterly they resent having to submit to outside opinions—the judgment of the ART teams, for instance—on the course they have decided upon for their own lives.

The third keyword in the requesters' discourse was normality. For them, to be normal is to live the same life as everyone else, and having children is part of this normality. "It's normal to have a child; it's part of the construction of a family," said a couple of parents over standard age. Any "normal" person wants to have children, especially when he or she is deeply in love with his or her partner. "It's natural for a couple to have children together." Our respondents generally see having a family as one of the key elements in living a happy and fulfilling life. A 47-year-old woman who was childless told us: "I've had everything in life, but there is still this emptiness I can't fill: having a child is such an essential part of life." In Group 2 of requesters with severe illness, looking forward to raising a child helped them remember what a normal life is. "Life must go on, normally," they said, "Otherwise, it's impossible to hang in there, and distance yourself from your disease." "To get perspective on the disease, so it doesn't submerge us." It is important "to keep going, despite the twists of fate, life has to win out, we plan to have a child, and we refuse to let anyone stop us." People in group 3 (those needing the help of surrogate motherhood) expressed the same ideas about normality as people in the other groups: having a child is normal life, "actually, it is life,"; "it's inevitable for a woman to be a mother, it goes without saying" and: "It is absolutely normal for people who decide to live together to have children."

What we understood at the core of these people's desire for "normality" is the feeling they are merely asking to fulfill a basic human need, not something exceptional. In fact, the underlying message was that they might feel their lives had failed if they didn't succeed in fulfilling this basic (normal) need. We heard the same claim of "a right to be normal" from people requesting ART to have a second

child: "It is normal to want a complete family. Why must I remain the mother of an only child if I wish a second one to complete my family?" was what we heard from a woman who had lost her uterus after delivering her first baby. Another said, "I would like two children at least, to have a real family." The claim for the second or the third child is as strong as for the first one, and still founded on the same plea for normality.

The fourth message we noted from these people's narratives is striking, and deserves to be discussed in detail: it is their indifference to legal considerations. The great majority are ignorant of the law, and even more say they would risk illegal action to achieve the goal of being normal and having a child: "To have a child is more important than to obey the law," a couple who already had two children with surrogate motherhood told us. "If they say no in France, due to legal considerations, we will not hesitate to go somewhere else. France is not the entire world," said another couple, in which the male partner was over standard age. And another one: "Why is France so different from other European countries, do we consider that foreigners are immoral?" Instead of the law, the major reference of requesters is what they consider to be current social norms, which they perceive as accepting all sorts of families. In their eyes, the law defends an idea of what the "social order" should be: it utterly fails to reflect current social realities. People deplore that legislation lags behind changes in social attitudes. They readily admit that laws are necessary to define public policy on reproduction, but judge current French legislation to be inadequate: "As it stands, the law intrudes on people's private lives; it should simply protect people." For example, the purpose of the law should be to guarantee the quality and safety of the care provided: "The current limitations are too moralistic."

Nevertheless, some people in Group 3 express strong guilt feelings in relation to their children, whom they have placed in an illegal situation by having them abroad, through surrogate motherhood, forbidden in France. One of their chief concerns is their children's citizenship status: due to the illegality of the birth conditions, it is impossible for the parents to register their children in France and confer upon them French status, family status, and citizenship. Thus, even though (like those in the other two groups), they are indifferent to breaking French laws for themselves, they fear the consequences their actions may have for their children. The law is not perceived as a moral barrier, to be respected on its own merits, but as an external constraint that might be detrimental enough to the family to

discourage violating it. "I don't know what I will decide if the law doesn't change, because of the civil consequences for my child," said one woman in our sample. Only one person in Group 3 stood out from the rest. She said: "Won't my daughter resent me for the way she was conceived... and resent us for creating a family according to our own judgment?" In this case, the guilt expressed was due not only to the legal consequences for the child of not having a French citizenship birthright; it was more. Actually, this couple doesn't seem to be very much at peace with their own choices. It was the only one in the sample to say they had concealed the conditions of their child's birth from their friends and family. In almost every other case, in all three groups, requesters asserted that all their proxies, friends, relatives, and co-workers, are fully supportive of their plans to have a child.

Furthermore, when the interviewees were asked whether they think the requests from people from the other two groups in the study could be challenged on ethical grounds, they all gave the same answer: "The decision to have a child is a private matter." Their own experience of how intrusive and brutal it is to be challenged on such questions prevented them to judge others.

About commercial issues, and generally the place money should have in such matters, the message was quite clear, once more, and very similar from one group to another. People were very concerned about the question of justice. They say they are attached to equality of access to health care for all, and opposed to discriminating against less wealthy people. They would understand a refusal to cover ART based on the argument of other national priorities, should society decide that ART is too expensive, or not among the top healthcare priorities. And they also sharply denounced the risks of a drift towards a "baby business." The subgroup of women over standard age told us they were frequently confronted with what they called business and commercial abuses when they sought ART at private, for-profit clinics in France: "I had in vitro fertilization at a for-profit ART clinic, and they did the egg-retrieval procedure in the basement. There were about 40 of us patients, and they did it assembly-line style, 15 min per patient. It was ugly." Similar experiences were reported in foreign countries: "There, it was definitely a business. I was shocked, because it was like a factory. I didn't expect that, they really don't care about people; they even didn't take my name, history, or identity. All they were interested in was my money." Justice is also an important theme in surrogate motherhood group narratives. People mentioned the high cost of the procedure: they feel they are exploited by middlemen and agencies when they go abroad: "It is so expensive, it is really a problem, not everyone could afford it." Speaking of the fee to be paid to the surrogate also made them uneasy: paying a fee is important, to avoid

<sup>&</sup>lt;sup>9</sup> See, most recently: Cass. Civ. 1<sup>ère</sup>, April 6, 2011 (3 rulings), *Revue Dalloz* 2011, p. 1522; commentary by L. Brunet et D. Berthiau. C. Neirinck has published another commentary on the decision (comm. no 14. *Droit de la famille*. May 2011). For an overall analysis of French law in the area, see Brunet (2010).

feeling indebted to the woman, but "it is something impossible to pay for, no amount of money is enough." All the people we interviewed, from all three groups, expressed concern about the potential for undue inducement of surrogate mothers. Although they see no reason to forbid a woman from carrying another woman's baby if she really has volunteered to do so, they recognize the risk the procedure will be commercialized, and financially vulnerable women exploited: "A baby should in no case be assimilated with an object to be bought and sold. This entire matter should be totally free of financial considerations." In their opinion, the danger of commercialization is a good reason to legalize surrogate motherhood, for prohibition always maximizes the risks a black market will develop.

Finally, and to conclude this section about the important messages of the requesters, it was clear that they strongly refute the three implicit normative arguments doctors oppose to their requests on the basis of the 1994 law. As we said, the law allows doctors some latitude in interpreting its meaning, and deputizes them (a) to check if the conditions are good enough to guarantee the child's welfare; (b) to avoid assisting people in constituting families that differ significantly from traditional models, namely with important confusion between generations due to parents' age; (c) to resist a tendency towards something like "a right to a child," with medicine being obliged to grant anyone access to any existing techniques, on the basis of their request alone. On these three points, the messages were the following: all the people we met deny that somebody else might know better than them what is good for the welfare of their future child: "Parents should decide because they are the ones who will rear the child." We never felt the parents we met were behaving selfishly and without thinking of their future child's welfare. The topic was of primordial concern to them, and they spoke of it spontaneously and easily. For example, several of the men in Group 1, whose age was above the standard limit, said that they were less involved in their careers than they were earlier in life, and would have more time to devote to the care of the new child than they had had for previous ones: "I will be a better father than when I was 40 and had to go out to work every day. I will have time for her." Moreover, they contested the assumption they will not live long enough to raise their child: "I might live another 30 years, more than enough to bring him up to adult age." These men also expressed pride and joy in their ability to provide fully for the material needs of both the child and mother: "At my age, I have no more financial problems; the welfare of my child will be far more guaranteed than that of my sister-in-law's children in Colombia." In Group 2, parents with serious diseases, interviewees unanimously expressed how concerned they are by the welfare of their future child. Actually, often this concern was "the" main topic for them: "Raising him to the age of 20, that's my goal," said a prospective mother with cystic fibrosis. "I must not wait too long, or I won't be around long enough to raise him." Or another: "Any child can become an orphan due to life accidents. What is most important for the child is to be sure that he was wanted."

Regarding the second point and the necessity to respect the so-called "social order" without emphasizing that ART techniques can help constitute unconventional families, all groups argue that, in view of the variety of family situations they see around them, there is no reason for their family arrangement to be subjected to undue scrutiny. Doctors should take in account the evolution of society: the model of traditional family has changed quite drastically over the ages. Couples are less stable, parents become older, and rearing children alone or as a homosexual parent is not so rare. The normative model of the normal/ideal family structure has changed. Why should they be obligated to conform more closely to a "social ideal" than others? Just because they need ART? Isn't it unfair that society seems to demand more from them than from others?

They also contest the third argument they frequently hear from their opponents: that there is no such thing as the right to have a child. They argue that the "right to have a child" is precisely the idea that spawned ART and made it a success. Furthermore, to have a child is one of the best ways for them to give meaning to their lives and their relationships with their partners. In fact, their argumentation on this theme is the same as the reasoning we reported on normality: it is normal to want a child, part of a fulfilled life. As humans, we are responsible for seeking personal fulfillment and gratification by every means available. Of course, these prospective parents are aware that even with the help of reproductive technologies, there is no guarantee they will ever have a child. But they believe they are entitled to every chance to do so, and that society owes them as much solidarity as it can muster, technically and financially. More than a right to a child, they plead for a right to have access to the existing techniques and to topnotch medical advice and skills. They unanimously accept limits due to medical risks and never contest a refusal based on such arguments; the main role of medicine, in their opinion, is to guarantee the quality and safety of a procedure. But, for them, doctors have an ethical duty to provide treatment to alleviate human suffering, not to defend some vaguely defined concept of what constitutes a "good" family.

According to our study design, for each requester case, we also interviewed the referent physician, if not the entire ART team, in order to hear both sides of the story. We were able to meet with 20 medical teams. This approach enabled us to collect specific data from the opinions of healthcare

providers, on 40 of the 52 cases that were included in the study (some of the 20 teams we met with were in charge of more than one case from our sample). Of these 20 ART teams, three were not French: one practiced in Belgium and the other two in Spain. These were the teams chosen by the people in our sample who decided to go outside France to obtain access to ART. The 12 cases for which we were unable to interview any referee team belonged to Group 3, the surrogate motherhood group. The reason was either that the requesters had not yet finalized their decision to request surrogate motherhood at the time of our study, or that they had already sought the procedure abroad, too far away for us to contact the teams.

Regarding the content of ART team interviews, we will not go into as much detail as we did above, with the requester interviews. Instead, we shall highlight the most striking characteristics of the physicians' responses to our questions: whether public policy should put doctors in charge of regulating reproductive autonomy, and if so, to what extent.

The attitudes of doctors, to whom the law gives some leeway in ruling on ART requests, tend to fall into two categories. Some professionals believe they are duty-bound to refuse access to ART in cases that are borderline from an ethical point of view. Others are more permissive, because they feel uncomfortable intruding upon the private life of their patients and passing moral judgment on them. On the whole, 80 % of biologists and public-hospital staff tended to be part of the first group, whereas 90 % of clinicians in private practice belonged to the second one.

The practitioners in the first group we identified tend to take a conservative, restrictive approach. They understand the law as having given them the final decision, on each case: "What will society think of our profession if I grant the request?" They take their task as the interpreters of the spirit of the law seriously, and feel honor-bound as professionals to assume it: "I do not wish to give up my responsibility as a practitioner." In their estimation, the law is founded on the three implicit normative elements outlined above: the "welfare of the child", the so called "social order" and the "no right to a child". As the ultimate judges, they consider it is their duty to refuse access to ART if they have any doubts concerning one or another of these three elements: "Is this man really capable of assuming a father's role? For how many years?" "Every time, I ask myself if I can imagine this couple with a child."

The second group of ART practitioners see their role quite differently. Doctors in this group do not feel they possess the skills to interpret the law in cases where it is not explicit: "I do not see what gives me the prerogative to oppose their plans." They see their knowledge as purely technical, and are quite comfortable with using it to fulfill a patient's request.

In spite of their strong argumentation, the professionals in the first group often shared their doubts with us. They said they feel destabilized because their position has recently come under greater attack as compared to a decade ago. As we noted, opinion among health-care providers is divided. Liberal-leaning attitudes are becoming more common, both among colleagues working in ART, and among those from other medical disciplines. For example, doctors treating the patients' main disease, like pneumonologists caring for patients with cystic fibrosis or oncologists treating patients with cancer, are often in favor of allowing their patients to have access to ART: "It seems logical to me, to give them the means to give life." Likewise, the conservatism of certain ART professionals is quite often challenged nowadays by scholars working in the field of medical ethics, such as philosophers like Ruwen Ogien, psychoanalysts like Geneviève Delaisi de Parseval or social scientists like Anne Cadoret, Irène Théry, or Dominique Mehl, even though within their own disciplines, opinion is still divided: "Intellectuals trained in the humanities disagree with each other even more than doctors. (...) This kaleidoscope of opinion is a sign of how deeply bioethics reasoning is rooted in subjective, personal beliefs" (Mehl 2011, p. 201). Increasingly, doctors are accused of abuse of power, of using their professional position to impose a moral one. Nevertheless, the doctors in favor of restricting access remain very much concerned by the ethical dimension of their duties. They fear ethics will go by the wayside, and they explicitly stated they feel the profession would be diminished if it is reduced to providing technical services alone.

#### Discussion

As we noted in our introduction, we will discuss the results of our study from the perspective of the debate about the necessary respect for procreative autonomy versus the importance for a democracy to have a public policy on access to ART, compatible with the values shared by its people.

Our study broadened the debate and made it more democratic by giving a voice to the citizens who are most directly concerned by access to ART. Due to the recent emergence of these techniques, the group of ART requesters is only now forming; as a political movement, it is still embryonic. Commenting on the recent debate surrounding the last revision of the bioethics law in France, Dominique Mehl notes: "The people who are most directly concerned, those who physically experience being deprived of a child, who privately submit to the flaws and prohibitions decreed by the law, are beginning to come out into the open. (...) They are contributing new testimony to the

discussion, forged from their experiences, day-to-day and in the past" (Mehl 2011, p. 187). Combined with findings from similar research studies, the statements by the people in our study constitute a pragmatic corpus of references that "transcends the usual ideological rifts" (Mehl 2011, p. 187). Little by little, these new voices are growing louder, amplified by the growing number of articles and essays exploring these issues, reporting similar concerns (Mehl 2008; Pulman 2010; Fournier 2010). Furthermore, the results of such research consolidate many of the claims of the new patients' associations that have formed over the past few years, each of them lobbying for a special grouporganizations lobbying to recognize same-sex parenting, to legalize surrogate motherhood, to liberalize egg donation, to oppose sperm-donor anonymity, etc. Sooner or later, the emergence of these grass-roots groups, made up of citizens directly concerned by the law, will change the terms of the controversy. Concerned citizens will gradually gain more ground, alongside the doctors and other special-interest lobbies who have monopolized the discussion so far. 10 Thus, it is quite likely that the political issue of the proper balance between the respect for the right to reproductive autonomy, to which citizens requesting access to ART are entitled, and public policy on bioethics, will soon be debated from more varied perspectives (Montpetit 2005; Engeli 2010).

One of the principal outputs of our study concerns the growing strength of the demand for respect for reproductive autonomy. We showed how firmly people are opposed to the intrusion of doctors in their private life, questioning their ability to be good-enough parents, and contesting the individual right to decide when to start a family. Our respondents resented the medical team's prerogative as an unbearable abuse of power, regardless of the group involved-whether the ART team had challenged prospective parents on standards for age or for severe/fatal disease, or the need to resort to surrogate motherhood (still illegal in France). Our interviewees made such a convincing, eloquent case for reproductive autonomy that the doctors' position, as defined by French legislation, seems weak by comparison. According to the literature, the respect due to reproductive autonomy is "central" (Purdy 2006); "it is a negative human right" Robertson says: "It means that a person violates no moral duty in making a procreative choice and that other persons have a duty not to interfere with that choice" (Robertson 1994, p. 22). The State should not violate this civil right without really solid reasons, he adds, expressing an opinion similar to that of Herring, for whom: "It would be wrong of the state to prevent a couple seeking access to IVF treatment on the basis that the state believed they would make inadequate parents" (Herring 2010). Thus, for such authors, a clear threat to fundamental values is the only justification for public policy decisions restraining access to ART and therefore reproductive autonomy. Nevertheless, our study also showed that in 1994, the three implicit reasons founding the doctors' right to deny access to ART-if the welfare of the future child might be compromised, if the request does not conform to the traditional family model, or if the request resembles undue pressure put on doctors to out-perform themselves, and therefore a sort of drift towards a "right to a child" -, were criticized with reasonable objections by the requesters and could not conclusively be shown to endanger fundamental values. We will not emphasize the debate that surrounds these three specific issues, which is beyond the scope of this article. We will merely note that they have already been extensively covered in the literature, and in and of itself, the fact that such issues remain so controversial justifies exercising great caution when curtailing people's reproductive autonomy and denying access to ART on such grounds.

We do not mean to say that it is illegitimate for a democracy to adopt any regulations in matter of reproduction, and namely in matter of access to ART. For example, if surrogate motherhood was legalized in the wake of a national consensus about the necessary respect for reproductive autonomy, this principle should initially be applied to checking the freedom of the surrogate mothers themselves. Are they really volunteering, or acting under some kind of undue inducement? Regulations for checking and guaranteeing the surrogate mother's should be extremely precise.

Another example of regulation has been suggested by Robertson himself, even when pleading for total freedom in access to new reproductive technologies: "If we consider that procreative liberty is a negative (human) right," he says, then, as for other negative rights, "it means that other persons have a duty not to interfere with that choice, but it does not imply the duty of others to provide the resources or services necessary to exercise one's procreative liberty, despite plausible moral arguments for governmental assistance" (Robertson 1994, p. 22). If the most ardent supporters of reproductive autonomy rights do not claim that they are absolute, to what extent is there a positive obligation on states to provide treatment for those suffering from infertility? Robertson suggests making a distinction between public authorization and public providing and/or funding of ART. This proposal might be perceived as especially provocative in France, where all access to health care in general and ART in particular is publicly provided

<sup>&</sup>lt;sup>10</sup> For example, remarkably enough, one of the chief architects of the 2011 update to French bioethics legislation, the author of several important reports to Parliament, is a physician/MP, Jean Leonetti. He also exerted significant influence on the reception, in France, of the concept of "medical autonomy" when the French law on end-of-life care, commonly referred to as the "Leonetti Law", was up for vote.

as well as funded. It might be one of the reasons why the debate is more controversial in France as compared to other European countries, where ART receives very little public funding.

A third example of possible social compromise in such a matter was offered by Pennings, when he suggested that States recognize reproductive tourism: "Allowing reproductive tourism is a form of tolerance that prevents the frontal clash between the majority who imposes its view and the minority who claim to have a moral right to some medical services. (...) Reproductive tourism is moral pluralism realized by moving across legal borders" (Pennings 2002, p. 337). Following a dramatic reversal, this is the solution that was just recommended by the Grand Chamber of the European Court of Human Rights in the case of S.H. v. Austria, dated November 3, 2011, concerning the right to access to assisted reproduction. The Court grants the Council of Europe member states, signatories to the European Convention on Human Rights, a wide margin of appreciation in authorizing the implementation of various techniques for medically-assisted procreation. In this case, it did not strike down Austria's ban on oocyte donation and IVF when this procedure is associated with a sperm donation. However, as if to apologize for the sudden swerve towards a more conservative position (a violation of reproductive autonomy) it notes "there is no prohibition under Austrian law on going abroad to seek treatment of infertility that uses artificial procreation techniques not allowed in Austria and that in the event of a successful treatment the Civil Code contains clear rules on paternity and maternity that respect the wishes of the parents" (§ 114). This opinion is somewhat disturbing. The very authorities who so often invoke ethical concerns about child welfare and the health of the surrogate mother as valid reasons for restricting access to ART seem to be endorsing the idea that they merely apply within national borders, and are irrelevant elsewhere. Such reasoning is likely to weaken the potential for compromise presented by tolerance for reproductive tourism.11

# Conclusion

In this paper, we mainly reported the views of patients who have been denied access to ART by the health care teams. In France, their voices have rarely been heard, because until now, they have never formed a united front or movement, although certain individuals have been active in patients' associations for years. However, the majority of the people we met in the course of our inquiry were not

affiliated with associations. Most of our interviewees were simply individual patients, referred to us directly by the ART teams with whom we designed our study. Of course, our sample was not representative of all people seeking ART, but the borderline cases we were able to encounter and investigate are significant, because they highlight conflicts in values underlying assisted reproduction. Likewise, our respondents' message regarding the right to reproductive autonomy is coherent and consensual, regardless of the reason for which their request for access to ART was challenged.

Requesters mainly demand respect for their reproductive autonomy. They were quite angry and considered that health care teams are frequently guilty of abuse of power when they prevent access to ART. The requesters founded their position on their right to lead a happy and fulfilled life. To want a child is a normal claim for everyone, on the grounds that all citizens are entitled to the pursuit of happiness, they said. As Robertson writes, they argued that to be respected in one's reproductive autonomy "also has primary importance as an expression of a couple's love or unity" (Robertson 1994, p. 24).

The results of our study support the views of Dominique Mehl, a French sociologist who has written widely on bioethical issues. She sees a major change taking place in prevailing attitudes in France: "In 15 years, the outlook has changed. New players have emerged on the scene, significantly modifying the way the public perceives these social issues. The voice of people aspiring to become parents is now being heard in the public arena. (...) The individual citizen's experience is being admitted to the public debate. The monopoly held by experts and intellectuals is crumbling." (Mehl 2011, p. 234).

Considering Engeli's model of a specific combination of the respective weights of the "three I's" (Institutions, Interests, and Ideas) as an explanation of each country's choice in matter of reproductive policy (Engeli 2010, p. 22), the emerging clout of this important new interest group, the requesters themselves, should have had some impact on the overall balance of power, an impact that would have been reflected by the revision of French bioethics law in July 2011.

Nevertheless, nothing happened. The law did not change at all. The revision process has resulted in what Dominique Mehl calls "a conservative apotheosis." To explain this outcome, she cites the absence of political consideration in France for "critical movements." "Grass-root movements that are respected and influential in other democracies are looked down upon in France, where they are believed to lack legitimacy and so are pushed to the edges of decision-making circles." Another reason for this immobilism is "the special French conception of the proper means for regulating science and medicine, which has resulted in the

See the dissenting opinion of four judges published following the ruling on S.H. v. Austria, § 13. See also on this point Hervieu (2011).

'French exception on bioethics,' so proudly brandished everywhere as an example by our national ethicists and decision-makers, and which ultimately has been the most powerful brake on any evolution." Mehl then outlines the sub textual foundations of this model: the famous "no right to a child"; the doctor's right to be considered as an individual with his own autonomy and personal convictions, not merely the provider of technical skills; French society's traditionally strong resistance to individualist trends and cultural relativism; the fact that there is no need to change the law when so few people are concerned ("Protection for minorities is not one of the good bioethicist's top priorities"); and the ability to ignore that the law is quite different in other European countries: in such matters, "the French exception is a virtue" (Mehl 2011, pp. 243-244).

Thus, the emergence of new voices does not suffice to change public policies. The way questions are worded when they are written on the political agenda is also important: "Since a multiplicity of definitions for a problem is always possible, what is at issue in the agendabuilding process is not just which problems will be considered but how those problems will be defined. Such definitions serve not only to structure subsequent policy choices but also give affirmation to a particular conception of reality" (Cobb and Elder 1983, p. 115). For example, our study interestingly shows that, contrary to what is usually claimed, people requesting access to ART (and this is even truer of those who do so in borderline situations) do not believe they have the right to a child for its own sake as an object of personal desire. Rather, they primarily claim the right to a normally fulfilled life; a child, as well as a loving couple and the family they might construct, is part of this general human aspiration to the achievement of a common good. Testimony of this sort might help reconfigure what the issues are for people facing challenges for access to ART, and should be taken into greater consideration in political debates.

"We shall meet again, in 2018," Dominique Mehl promises (Mehl 2011, p. 247), referring to the next time French bioethics law comes up for revision. Until then, requesters are unlikely to stop seeking other ways to gain access to ART. The chances are that reproductive tourism will thrive even more. But frustrated requesters might even appeal to the European Court of Human Rights, which is likely to favor respect for reproductive autonomy more than our own national legislation. Will the Court continue to shirk its responsibility, the way it did in the ruling on S.H. v. Austria on November 3, 2011? Can it continue to ignore the need to extend reproductive autonomy by making States accountable for a positive right? The issue has nothing to do with recognizing a theoretical right to a

child. It is simply a case of recognizing the right to access to all the techniques made available by medical progress.

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