Med Health Care and Philos (2013) 16:41–44
DOI 10.1007/s11019-012-9428-2

EDITORIAL

The French bioethics debate: norms, values and practices

Véronique Fournier · Marta Spranzi

Published online: 14 July 2012

Abstract In 1994, France passed bioethics laws regulating assisted reproductive technologies, organ donations and prenatal diagnosis. These laws were based upon a few principles considered as fundamental: the anonymity and gratuity of all donations concerning the elements of the human body, free and informed consent, and the interdiction of all commercial transactions on the human body. These laws have been the object of heated debates which continue to this day. On the basis on a few clinical ethics studies conducted by the Center for clinical ethics at the Cochin Hospital in Paris, the articles presented in this special issues explore several aspects of the bioethics debate, and relate it to the more general question of the complex relationship between norms, practices and values.

Keywords France · Bioethics laws · Norms · Practices · Values · Anonymity · Assisted reproductive technologies · Prenatal diagnosis · Living organ donation · Eugenism · Surrogacy

V. Fournier (✉) · M. Spranzi
Public Health, Centre for Clinical Ethics, Cochin Hospital, 27, rue Fbg. St. Jacques, 75014 Paris, France
e-mail: veronique.fournier@cch.aphp.fr

M. Spranzi
e-mail: marta.spranzi@club.fr

M. Spranzi
History and Philosophy of Science, University of Versailles, Versailles, France

M. Spranzi
CERSES, University of Paris Descartes, Paris, France

France passed bioethics laws as early as 1994, before many other European countries. The need for such laws had been under discussion for several years. Indeed, doctors and scientists were the most vocal in requesting legislation on the ethical issues raised by biological and medical advances. They made it clear that the burden of ethical responsibility for the consequences of their own unsettling innovations should be borne by the society at large, rather than by the medical community alone.

The 1994 bioethics laws deal for the most part with the donation and use of elements and parts of the human body, with assisted reproductive technologies, and with prenatal diagnosis.[1]

It was easy to achieve a consensus on the first issue, namely donation and use of human body parts, tissues, and products. The law does not contradict current medical practices and confirms some basic ethical principles: donations of any element of the human body must be free and anonymous, the human body cannot be the object of a commercial transaction (*non-patrimonialité du corps humain*), and the free and informed consent of concerned people must be sought at all times. By the same token, the law strengthens the regulatory power of the governmental agencies which are in charge of ensuring that guidelines for good practices are abided with.

The second part of the law concerning issues raised by ART has been much more controversial, especially with respect to the status of the human embryo: embryo research and the fate of extra embryos. Regarding access to ART, lawmakers have taken existing reproductive practices as a

[1] Law n. 94-654 of July 29th, 1994 relative to the donation and use of elements and products of the human body, to assisted reproduction technologies and to prenatal diagnosis. Law n. 94-653 of July 29th 1994 relative to the respect of human body.

model: they have authorized ART only in cases when medically sterility can be certified, and for "normal" couples—a man and a woman, of reproductive age and having lived together for at least 2 years. The choice was clear: assisted reproduction techniques could only be used to compensate for the medical impossibility to procreate, and not as a means for fulfilling a need which is social rather than medical (*convenance personnelle*). Moreover, the law has allowed the medical teams to deny a couple access to ART, should they suspect that the welfare of the future child is not ensured.

This section of the law also modified the conditions entitling a woman to medical (as opposed to voluntary) termination of pregnancy, which had previously been regulated by the Veil law of January 17th, 1975. From 1994 onwards, in order to have access to termination of pregnancy for medical reasons, a woman must be granted permission from a prenatal diagnosis center, the staff and procedure of which are defined by the law. Doctors must certify that the procedure is necessary either because the pregnancy poses "a serious danger to the mother's health" or because the child has "a high probability of being affected by a disease of extreme severity which is recognized as incurable at the time of the diagnosis." Lastly, the 1994 law explicitly authorizes preimplantation diagnosis under strictly defined conditions. It is restricted to a specific pathology and carried out only by specially certified teams. The law has a special provision against organizing the selection of persons for eugenic reasons; this concern explains the tight control over termination of pregnancies for medical reasons, prenatal and preimplantation diagnosis.

Finally, a rider to the first bioethics laws in 1994 provides for systematic revision of the legislation every 5 years. Indeed, lawmakers considered that medical and scientific progress, as well as societal changes, proceed at such a fast pace that new ethical questions are likely to emerge.

The clinical ethics center, located in the Cochin Hospital in Paris, was founded in 2002; its missions include contributing to the public debate surrounding the ethical issues raised by the bioethics laws. Indeed, some of the clinical situations examined in the clinical ethics consultations are related, in one way or another, to the main topics regulated by the law: living donations, access to ART, prenatal diagnosis and access to medical termination of pregnancy End-of-life issues, which constitute a large part of the cases examined by the clinical ethics center are not covered by the bioethics law. Rather, a specific law was passed in 2005 which deals specifically with patients' rights in relation to futile care and end-of-life decisions.[2] Furthermore, in 2008, some members of the clinical ethics center decided to form a specific research group called GREC (Groupe de Recherche en Ethique Clinique) in order to conduct multidisciplinary research on the ethical questions raised by the clinical ethics cases that are taken up at the Center.

This special issue is composed of six papers, all of them written by members of the GREC research group. They deal with the interrelations between norms (be they ethical or legal) and practices (be they social or medical), as observed from the perspective of the daily clinical practice and concerning different topics regulated by the bioethics law. We opted to look at these general issues from the perspective of the concerned agents—patients, proxies, or requesters on the one hand; doctors and other members of health care teams on the other. Indeed, our daily activity as a clinical ethics consultation service puts us in a crucial position for observing and understanding the values people cite to justify their choices, especially when requesting access to certain controversial medical practices. In that respect, our consultations give us an opportunity to look at norms from a bottom-up, rather than top-down, perspective. Indeed, patients are often aware that not "anything goes," and that medical decisions have to make sense to themselves and to others, especially doctors. As real moral agents, they often bring forth arguments and interpret principles and norms in new and enlightening ways. Thus, we are not interested in patients' preferences as such, but in the reasons they give, to themselves and to others, to justify these preferences. Also, our position offers us a special window on the uneasy alliance between medical practices, legal norms, and societal values today. Hopefully, new insights will emerge from a closer analysis of the justifications and moral beliefs of the main stakeholders—patients and doctors. This, at least, is what we hoped for when we put together this special issue. In what follows, we will describe the content of each paper and explore how the complex relationship between norms and practices plays out in each of the relevant medical fields.

The first paper ("The ethics of living donation for liver transplant: Beyond donor autonomy") addresses the issue of the ethics of living donation for liver transplant (LDLT). Two doctors (Véronique Fournier and Nicolas Foureur) and a psychologist (Erini Rari) review the results of a follow-up study on liver donors who had been interviewed prior to donation. The purpose of the study was to find out what they thought of the ethics procedure after the fact, regardless of whether they had been harvested. The results confirm, from the point of view of the concerned parties, what some scholars have already argued, namely that it is difficult to certify donors' free and informed consent. The study also shows that the informed consent procedure's strictures put candidates for donation in a defensive position and tend to disturb the privileged relationship between

[2] Law n. 2005-370, April 22nd 2005.

donors and doctors who team up with a common purpose of saving the patient's life. Also, donors claim that more medical as well as psychosocial follow-up would be appropriate. Indeed, the main values stressed by the legal procedure, donor's autonomy and freedom, are necessary but not sufficient to ensure the ethical nature of living organ donation. They should not prevail over other values like donor's altruism, medical beneficence and the respect of recipient's autonomy, which are also of paramount importance.

The second article ("Access to assisted reproductive technologies in France: The emergence of the patients' voice") is written by a doctor (Véronique Fournier), a philosopher (Julie D'Haussy), a legal scholar (Denis Berthiau), and a sociologist (Philippe Bataille). The authors discuss the results of a clinical ethics study on access to ART in cases considered as problematic in the French context, namely when the "welfare of the future child" is at stake. In situations where either prospective parent, or both, has a life-threatening disease, or when the father is beyond the required "reproductive age," doctors may contribute to the birth of an orphaned child. Finally, some couples request a procedure which is still illegal in France, surrogate motherhood. In all cases, the study shows, couples challenge the rules that medicine holds against them—either national laws or professional guidelines—as stemming from society's outdated "moral order." They argue that medical practice is shot through with values which are not their own, and that doctors and the law should support patients' reproductive autonomy, instead of interfering with it.

The third paper is entitled "Gamete donation in France: The future of the anonymity doctrine," and concerns the anonymity doctrine in ART through sperm donation. The authors, a legal scholar (Laurence Brunet) and a doctor involved with gamete conservation (Jean-Marie Kunstmann), reconstruct the origins of the anonymity doctrine. The authors show how the anonymity doctrine was elaborated to accommodate both doctors and prospective parents: doctors could thereby play down the transgressive nature of assisted reproduction, and mimic more closely the process of natural reproduction. Thus, in 1994, norms, medical practice, and societal values came together to uphold the anonymity of sperm donations. However, the article shows that this alliance is currently under severe strain. Indeed, for about 10 years, doctors have adopted a new strategy in defense of the anonymity doctrine, hailing intentional, as opposed to genetic paternity and above all recommending that parents disclose to their children the fact that an anonymous donor has contributed to their conception. But in other domains of family law, legal norms have undergone a rapid change: they uphold the right of children to have free access to their own origins. Thus, in the case of the anonymity doctrine it is the law and changing societal values, rather than the medical interests of prospective parents and patients, which might in the near future motivate a change in this particular provision of the laws concerning ART.

The authors of the fourth paper ("Prenatal diagnosis as a tool and a support for eugenics: Myth or reality in contemporary French society?") are a geneticist (Geraldine Viot) and a philosopher (Marie Gaille). They base their position on interviews conducted prior to prenatal genetic testing. Prospective parents, who are the main concerned parties, are oblivious to eugenics considerations when requesting genetic testing. In other words, they do not aim at having a perfect, or even near-perfect, child. They are mainly anxious that their future child be healthy enough to be able to function normally in the society: medical and contextual data about the child's expected life are taken into account. Decisions to terminate pregnancies, in turn, are based on the ways in which prospective parents can—or cannot—anticipate such normal functioning. Here, medical practice and patients' values are at odds with what the ongoing bioethics debate would have us believe—and with the genetic drift that the bioethics laws are designed to forestall.

Two articles complete our special issue by examining the interaction between norms, values, and practices from a more general perspective. One is written by a philosopher and the other by a legal scholar. They draw on the examples cited in the previous articles in order to show how and why a reflection on this general theme can be not only relevant and interesting in its own right, but also useful in suggesting directions and ways in which legal norms should evolve to accommodate changing values as well as medical and social practices.

Marta Spranzi, a philosopher, shows how regulations as well as other kinds of norms (ethical, deontological, etc.) might—and should—evolve in close interaction with practices. She argues that a closer look at practices—understood in a general way as complex patterns of decisions and actions, relatively stable across time and space—reveals that they are closely intertwined with values. Contrary to a long-standing philosophical tradition, when it comes to practices, facts and values are closely connected. Also, values are indirectly defined by the actions and decisions implemented by concerned agents, and are simply the reasons whereby these agents justify these actions and decisions to themselves and to others. Norms, in turn, slowly and imperceptibly evolve by responding to changing practices and values. Thus, norms do not create or enshrine values but adjust to them by taking on various presumptive forms.

Finally, in a paper entitled "Law, bioethics and practice in France: Forging a new legislative pact," a legal scholar,

Denis Berthiau, reconstructs the way in which bioethics laws have emerged in France in response to the questions raised by both practitioners and patients. In France, legal norms put doctors in charge of enforcing certain restrictive rules and implicitly appoint them as "gatekeepers" of certain values—both ethical and societal—implicit in several innovative medical procedures (ART, PGD, living donation). However, the author shows that the credibility of the legal provisions and the quality of care would gain if a new legislative approach adopted a more positive presumption in favor of patients' requests. Medical practices and the doctors who are in charge of them should adjust to changing patients' values rather than the opposite. He argues that norms should be more morally neutral and restrict their role to guaranteeing best practices and patients' support.

In accordance with the revision provision, bioethics laws in France have been revised twice since 1994, once in 2004 and more recently in July 2011. Each time, the revision process has taken place amid intense public debate and heated discussions in the society as a whole. Actually, the two revisions were slight, and the new version has maintained all the major restrictions that have guided medical practices, especially ART, since 1994: the qualified interdiction of embryonic stem-cell research, the anonymity of gamete donations, limited access conditions to ART, restrictions on prenatal diagnosis, and above all the interdiction of surrogacy.

The articles published in this issue are based on a few clinical ethics studies and provide some hints for understanding the reasons for this relatively and specifically French conservative approach. The authors show that to this day there is a de facto alliance between legal regulations and the values which were endorsed by the majority of the medical community as well as by the society, at the beginning of the 1990s. However, today this alliance is increasingly under threat, despite the very recent confirmation of the main provisions of the bioethics laws. Indeed, as all papers show, each of them from its own particular perspective, societal values are changing, and sometimes in a direction contrary to medical values. On the one hand, patients' vindication of autonomy goes well beyond informed consent: patients envisage medical procedures like ART, living donations, and PGD as a way of implementing their own values. Therefore, abiding by the regulations does not provide sufficient justification for these practices, even when they include several protective provisions (informed consent, banning eugenic considerations, protecting both children and prospective parents in ART). On the other hand, the medical community is torn between two equally legitimate goals: to respect the principles embedded in the legal regulations (informed consent, banning eugenic considerations, protecting both children and prospective parents in ART) and to embrace patients' changing values.

We hope that the clinical ethics perspective we have adopted, with its emphasis on the way all concerned parties daily negotiate difficult medical decisions, will enlighten medical practice and enrich the public debate about general bioethics issues. Indeed, we trust that this bottom-up approach will suggest some possible directions for future change based upon a new balance between practices, norms, and values: a balance more respectful of the patient's voice.