

MEDICAL LAW AND ETHICS



The Generosity of the Dead

A Sociology of Organ
Procurement in France

GRACIELA NOWENSTEIN

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THE GENEROSITY OF THE DEAD

Medical Law and Ethics

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Note to the Reader

Most of the informants who have contributed to this research were nurses and intensivists in charge of procurement activities in French hospitals, fulfilling respectively the functions of hospital coordinator and referent physician. They are referred to as Hospital Coordinator (HC 1 to 13) and Referent Physician (RP 1 to 12). Each of them is also referred to as 'she', whether male or female. More generally 'she' is adopted as the neutral form instead of he/she.

BDPD stands for Brain Dead Potential Donor.

Capital letters are used in interview quotes to mark a stress in the voice of an interviewee.

Unless otherwise noted, I am responsible for all translations from French (legal and academic texts, press articles and quotes from interviews with informants). The translation of quotes from interviews has not been an easy task. Interviews by nature have broken sentences and include colloquial expressions. I have tried to be as faithful as possible to the originals.

Mais, pensait Mme Michaud, on habille et on pare bien les morts qui sont destinés à pourrir dans la terre. C'est un dernier hommage, une preuve suprême d'amour à ce qui fut cher.

Irène Némirovsky, *Suite française*¹

1 'All the same, thought Madame Michaud, you dress and adorn the dead who are destined to rot in the earth. It's a final homage, a supreme proof of love to those we hold dear' (Némirovsky 2007: 37).

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Para Nora y Benjamín

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Introduction

French law stipulates that those who do not opt out of organ donation during their lifetime automatically become potential donors after death:

The removal [of organs for transplantation] may be carried out if the person has not objected, during her lifetime, to such a removal. This objection may be declared by any means, and in particular by recording it in the appropriate automated national register.

If the doctor is not directly aware of the wishes of the deceased, she must seek to ascertain from those close to the deceased whether she objected during her lifetime to the donation of organs¹

Here is how the head of an intensive care unit describes the situation in French hospitals:

... normally the law should allow us, from the moment there is no clearly expressed wish on behalf of the deceased, to assume that, implicitly, he is in favour of organ donation, which is not at all what happens in practice. ... in practice, we abide by the advice expressed by families. This happens, whatever the motivations behind their response may be, whether we think they are good or bad ...

This book is about the tension between these two approaches to decisions concerning post-mortem organ retrieval.² However, this is not to say that it is a study of a 'gap' between law and practice. Rather, it is a study of the relationship between the two, dealing with the flexibility of rules, legal and non-legal, as well as the dynamic relationship between the legal and non-legal rules themselves. These issues are explored through a study of how organs (and tissues) are made available for transplantation in France, in particular how the circulation of organs is organized and regulated within the country.

The relationship between law and practice is examined on the basis of the assumption that, whatever formal or normative differences one may posit between legal and non-legal rules, nothing allows us to take any differences for granted when it comes to understanding the practical fate of a legal rule. One must keep

1 Loi n° 2004-800 du 6 août 2004 relative à la bioéthique, article 1232-1.

2 Living donation is thus not dealt with in this book.

in mind that legal rules are generally applicable in contexts where non-legal rules are also likely to organize and regulate social action and interaction, and which rules are binding in practice often does not depend on their legal character but on local culture and local power relations. Thus the relationship between a law and social life can only be studied in context and with particular attention to the 'shop floor of social life', namely 'that concrete social situation where the social action and interaction that are the subject of legal regulation takes place' (Griffiths 2003: 19).

What is a rule? A rule is a general statement about how to interpret, and what to do in, certain situations. Each instance of the mobilization of a rule thus entails a move from the general to the particular. If we are interested in the effect that a rule may have in practice, we need to look at the relationship between the general statement and the case; in other words, at the process whereby a general statement becomes case-application. The meaning of a rule is neither unique nor fixed: knowing it does not amount to knowing the meaning of each of its terms and establishing its global meaning once and for all. Generally, the meaning of a rule is likely to vary according to the particular cases to which it applies. This is so because the meaning of words is flexible and social life is not made up of repetitions of the same situation. The meaning of a rule is also likely to vary according to the context in which it applies, namely to the characteristics of its field of application (Moore 1973). This does not mean to say that there are no regularities in rule application, but that these are the result of social practice and are not fixed in an initial general statement. Because a general statement can comprehend neither all the possible cases of its application nor the specificities of the social context where such cases will arise, it is only the study of the specific situations in which a rule applies that will give us the keys to access the subtleties, and regularities, of its meaning (Bloor 2002).

This book examines the procurement of cadaveric organs in France through the prism of the professionals in charge of the decisions to retrieve organs and of the organization of procurement processes. Some may find its content at times unsettling. The topic has its crude sides and this book contains detailed accounts of tragic situations involving loss, death, corpses and body parts. The use of this material is not gratuitous, nor is it done to shock the reader. It is due to the fact that to understand organ transplantation today, aspects of organ procurement that are generally kept in the shadows must be made visible. Most discussions about how to respond to the ever-increasing demand for organs tend to leave precisely that which is fundamental to the activity of transplantation and the problem of shortage to one side: the origin of the organs. This is not to say that there is an attempt to hide the fact that organs come from recently deceased people. It is the implications of this fact for all participants in the situation of organ retrieval that are often overlooked. Nevertheless, these are important, for it is differences in how these situations are dealt with by those involved that explain the most enduring regional and historical variations in procurement rates.

In these situations, the shock and pain of those who have brutally lost a loved one are confronted by the needs of the community to have access to the body of the newly dead person as a source of healing material. Thus, to pose the question of organ retrieval entails the re-enactment of fundamental socio-political relations: between the individual and the state, between the individual and the community, between the individual and her network of close persons, between this network and the state and between fellow citizens. It also entails the mobilization by participants in these situations of representations about death and dying, about body and personhood, about medical authority and biomedical expertise.

Existing laws regulating organ retrieval establish the conditions under which organs from the dead can become available. They are based on the principles of gratuity and voluntariness and structured around systems of presumed or of express consent, also known as opting-out or opting-in systems. Both systems amount to the regulation of a form of generosity or solidarity by the state. The evolution of practice in French hospitals since the first law of presumed consent was enacted in 1976 (involving movement toward active participation by the relatives of the potential donor in the decision-making process) reflects broader social changes in the legitimacy and scope of projects of social engineering with the law. This evolution also reveals the changing conceptualization in French society of the relationship between the individual and the state, and between the private and the public spheres. It also reflects recent changes in the status of medical professionals as figures of authority and agents of state policy. Last but not least, the distance between a formal legal approach that presumes 'the consent of the dead',³ and the approach that in daily life guides the physicians and nurses in charge of decisions to retrieve organs, makes the tension between the formal legal conceptualization of persons as isolated individuals, and the more sociological view of persons as embedded in relational networks, particularly salient. While the law considers potential donors as individual legal actors, in practice in most cases, it is the network of affective relationships of the potential donor that is central to decision making about organ retrieval.

Chapter 1 presents a brief history of the biomedical revolution that in the 1960s made organ transplantation possible. The activity of organ transplantation was surrounded by an aura of fascination at the time, for it seemed a biomedical miracle rendered possible by an enchanted form of generosity: the gift of life. As transplantation activity increased, human organs became a scarce resource and shortage a problem to be managed, leading in many countries to the enactment of laws and development of policies. Comparisons in procurement rates have regularly been made since the beginning of the activity, revealing national differences that are very high. The reasons for these differences have been and still are endlessly discussed in the international arena, which is mainly composed of medical, legal and ethical actors. These discussions often appear rather detached from shop-floor reality and often focus on legal factors. Closer to practice, some authors stress the

3 The expression is from sociologist Paterson (1997).

importance of organizational factors for understanding variations in procurement rates. Both approaches tend to place little or no importance on the situational aspects of the question, particularly on the relational factors that influence the decision-making process in hospitals.

Chapter 2 discusses how French political and legislative authorities have responded to the 'demand' for organs produced by the development of transplantation medicine. In the 1970s, the nationalization of corpses was rejected and the presumption of the generosity of the dead was presented and adopted as the best solution to the problem. The first law of presumed consent was approved in 1976 in an atmosphere of faith in biomedical progress and in the law as a tool that would enhance this progress. Solidarity and the development of bioscience marched side by side, as the protagonists in a perfect French republican tale. In the mid-1990s and 2000s the law was discussed in parliament on two occasions, with legislators appearing increasingly disenchanted. The law had failed, it was said: the presumption of consent was not being applied in hospitals, where families were generally acknowledged to have the final word on retrieval. Nevertheless, the principle of presumed consent was not contested and was re-confirmed twice by the French legislature. The history of presumed consent in the French parliament has thus moved from a position of faith in social engineering with law to disillusioned support for the law as text.

During the 15 years that followed the enactment of the first law in 1976, organ transplantation moved from being a new experimental technique to something closer to a routine therapeutic treatment. Organ procurement practices similarly followed a process of normalization, moving from heterogeneous to standardized practices. Chapter 3 examines this process. Until the mid 1980s, local retrieval practices were very different, depending on the hospital where the decision was taken as well as the staff in charge at a specific time. Sometimes organs were retrieved without letting the relatives know. At times, relatives would be informed in advance that organs were going to be taken before the body of the deceased was released. Sometimes relatives would be asked by hospital staff about the wishes of the deceased or about their own wishes with regard to the fate of the corpse. In some hospitals an intensive care physician would talk to the relatives about organ retrieval, in others it would be a transplantation surgeon, or an intensive care nurse. However, since the early 1990s these procedures have occurred in the same way in all French hospitals: the relatives are consulted by a specialist nurse and/or an intensive care physician, and they enjoy a paralegal right to veto organ retrieval. This chapter provides contextual and structural historical keys to understanding this evolution.

Chapters 4, 5 and 6 reveal in detail how physicians and nurses describe the situation in which decisions about organ retrieval are made. Such situations are considered quite exceptional by those involved in the daily routine of intensive care units, and as particularly difficult to manage and cope with for all involved. The fact that potential donors are in a state of brain death is the first difficulty that participants must face (Chapter 4). While relatives are told that their loved one is

dead, what they see is a body that is warm and that has a heartbeat, with blood still circulating and lungs being filled with air pumped by an artificial respirator. The announcement of brain death is a counter-intuitive expert statement that can only be accepted if the relatives trust those who make it.

While families need time to comprehend what they are being told, to digest and reflect upon what is being asked of them, the medical, organizational and institutional times are constrained (Chapter 5). The brain-dead body is unstable and needs close monitoring. The process of organ retrieval requires tight organizational procedures: one potential donor implies the possibility of many organs and tissues to be retrieved, each organ or tissue will be extracted by a different team, often coming from different hospitals all over the country, and all this needs to be coordinated with the central transplantation agency which allocates the organs. As one of the nurses interviewed observed: families need time 'and we have no time'. The strain caused by the time pressure is increased by the feeling professionals have that they are not always trusted by the relatives of a potential donor. In the absence of trust, it becomes almost impossible for relatives to accept organ retrieval. Trust depends on the kind of relationship that has been established between the relatives and hospital professionals. It also depends on the pre-existing symbolic and practical relationship between the family and medical, political and health institutions. This, combined with the fact that a number of actors and variables intervene in the procurement process, gives procurement specialists the feeling of not being fully in control of these situations.

Professionals describing their encounters with relatives depict an extreme situation of social breakdown, a moment in a world of codified social interactions in which all the basic assumptions that relatives have brought with them fall apart (Chapter 6). A person who was in good health is suddenly said to be gone, yet the so-called 'dead' person does not look completely dead. The hospital staff, whose function it was to try to save this person, have failed and are now also asking the families concerned to accept a sacrifice: the opening up of the body of their loved one and the extraction of body parts in order to save others' lives. In a state of affective and cognitive shock, the reactions of the relatives are not only difficult to predict but can also be extreme. The level of pathos that can be reached in an intensive care unit is at its highest in these situations.

In the situation described and analysed in Chapters 4, 5 and 6 the presumption of consent is in practice not mobilized by hospital professionals and no retrieval decision is made against the families' will. Chapters 7 and 8 take a broader view and deal with the relationship between law and practice and bring broad social relations and policy to the centre of the discussion. The law of presumed consent goes against a number of basic assumptions about social life that the actors involved share (Chapter 7). A fundamental social assumption which the law seems to violate is that a gift is something that cannot be presumed. The basis for this idea is that a gift must be an active and personal gesture. Therefore, a presumed gift is not really a gift. Physicians' and nurses' discourse and practice reveal that in order to feel justified in taking the organs, they need to believe that a gift has *really* been