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## NOT QUOTE OR CITE

# Promoting Organ Donation: Social and Legal Aspects

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### Abstract

*If emotion has long been opposed to reason, our research will consider emotions as determining elements of social sciences. We shall study them in the various areas concerned by the problematic of organ. With regard to the expression of organ donation, the choice of related words by the media and public authorities seems crucial. How can it be explained that organ donation is neither a donation in the legal sense nor a donation in the sociological sense? In the same way, how can the government release neutral information in a campaign for organ promotion?*

### 1. Introduction

While the Federal Office for Public Health recently launched a call for tenders to inform the public on questions of transplant medicine for the next years, in line with the open access policy to legislative texts on transplants<sup>1</sup>, it can be noticed to this date that Swisstransplant is in charge of both informing the public on transplant medicine and promoting organ donations...and, not least of all responsible for allocating organs. There appears to be a gap between these two missions. The first does not aim at transmitting neutral information. The second, however, may deploy all means of communication to justify the legitimacy of its message. Among this arsenal, and in particular within the context of organ transplants in life and death situations, it is possible to move the public to achieve this goal.

As for a doctor who must announce a patient's death to family members and loved-ones and also solicit organ donation, he is advisable to show compassion...What more can be said regarding the altruistic values suggested in the term "organ donation"? What can be said regarding families' refusals to authorize heart removal, the heart being largely regarded as the seat of love...

With regard to these circumstances, emotions certainly influence persons' positions with respect to organ removal.

This study, the aim of which is to analyze the role of emotions for organ donation, will primarily examine the scope of emotions (I). This analysis, which will also consider language, will adopt a critical view of the terminology used with regard to organ donation (II).

### 2. Review of emotions

This study presents on the one hand a retrospective review of the manner with which organ donation is referred to, and on the other a particularly sensitive review of current and developing reference modes used by transplant promoters with regard to recent social factors related to legal upheavals due to the draft of a Federal law on transplants.

How do people refer to organ donation? What messages and information does the public at large receive on this issue? It is important to point out the various arguments that are put forth in the discourse on organ donation. The next step is then to define the role that emotions play in this process.

<sup>1</sup> Federal legislation on organ, tissue and cell transplants, October 8, 2004, FF 41 5115.

The approach of emotions here is neither cognitive nor physiological, rather in line with the point of view of Patrick Charaudeau for whom “the object studied in discourse analysis can be neither what the subjects truly perceive [...], nor what motivates them to feel or act [...], nor general norms that regulate social relations and constitute determined categories of behavior within social groups” [5]. Emotions are regarded as a discursive category,<sup>2</sup> as a rhetorical element capable of becoming part of a “micropolitics” of persuasion, of influence on the social behavior of individuals, whether intentional or not. Emotions do not, however, necessarily fulfill a function of a donation trigger. They can also lead to negative attitudes and set off negative reactions, in the case of the disclosure of organ trafficking, for example, as in the case of people sentenced to death in China<sup>3</sup>, which strongly offends our sense of morality, or when a transplant turns into a scandal, as in the recent case of Rosemary Voser in Zurich, Switzerland. The emotions that accompany the vast range of information given to the public at large, then, lead both to trust and hope, and mistrust and indignation.

The definition of this emotional factor is in itself, however, not an easy task. With regard to the canonical distinction and the hierarchy between emotional and rational, the heritage of several centuries of western thought, passions and feeling are considered as inferior to reason and interest<sup>4</sup>. Many authors are nevertheless now questioning this categorization of feelings as insignificant or irrational phenomena [5], [3], [6]. The growing interest in emotions in social sciences has led to the understanding that they are not a residue of reason or action, but that they are to be considered as an integral part of cultures and of self-awareness [1]. We tend today to stress the “debatable nature of emotions” [15]. In this respect they become fully part of the tactics of persuading and convincing. Reason and emotion are today no longer so strictly and definitely opposed.

For a first approach to the question studies in sociolinguistics and discourse will be considered (in particular [16], [8], [4], [13], [17]) with the purpose of distinguishing different arguments based on an exploratory analysis of the language used to refer to organ donation.

Without misjudging their quantitative force, it is hereby legitimate to identify several registers within the medical profession, within society as a whole or among individuals (the larger public or patients): a technical and scientific register, centered on the skills as well as on reason and progress of knowledge, which enforces public trust in the necessity and trustworthiness of the given technique; an epideictic register recalling Aristotle’s category that focuses on praise and admiration (of a surgeon, of a donor); an ethical-legal register that stresses institutional and normative plans, encouraging trust in the system and the organization, and to limit erroneous applications and abuse (professional ethics and norms, respect of the human body), an axiological register that regards the choice of post-mortem organ donation as a gesture of solidarity, of altruism and of generosity, even of sacrifice, in a nutshell, a series of positive values. An economic register can also be identified, the reference to which is society as a whole, when the cost for kidney transplanting and medical follow-up is arguably lower than dialysis treatment over several years. The economic argument is significant for the patient himself but also, in the long run, for insurance companies and society as whole.

Still other registers can be identified that involve the personal implication of the donor through empathy, he or she projecting him or herself as a patient or parent of a patient (“What if I needed an organ?”, “What if my child needed an organ?”) or considering epidemiological arguments such as “Chances are ten times higher that you will need an organ transplant than that you are likely to become a donor”. Semprini ([18]) also lists a pathemic register, referring to the sharing of similar or identical feelings and emotions.

A certain number of emotions that are considered as fundamental are activated thanks to these discursive registers: joy is part of the epideictic register, fear arises within the discourse on epidemiological risk to one’s own potential need of a transplant, or even shame within the axiological register, when the values promoted are not respected. It goes without saying that this

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<sup>2</sup> The *efficiency* and *legitimacy* of resorting to the emotional register in this specific case will be discussed at a later stage in the research, and will measure the results of this part of the study to those of other empirical fields.

<sup>3</sup> Au Coeur du trafic d’organes. Le Monde, 25 April 2006.

<sup>4</sup> There are, of course, numerous exceptions to this state of fact. We may consider, on another level, the Weber’s distinction (Weber 1995) between two forms of rationality, one relative to the equation of means and ends (*Zweckrationalität*), the other relative to ultimate ends founded on value (*Wertrationalität*).

list is incomplete and that it needs to be tested against various modes of discourse (narrative, didactic, scientific, etc.)

In addition, this draft of categories is but a Weberian ideal, the borders of which, in reality, are far from being as static and as contrasted as they appear. We can therefore even wonder whether the emotional dimension should not be treated as a transversal category, in the sense that the pathetic register designates less of a strict content than a way to express things.

It appears incidentally that the choice of terms is not haphazard and that their ambiguous nature is welcome...

### 3. A deliberate choice of ambiguous terms

A preliminary step to any research in social sciences consists in a study of the qualification itself of the object of study, because this qualification is never neutral and does not come naturally. As the foundations of social constructivism remind us, qualification is part and parcel of the manner in which a phenomenon has been socially and politically construed [11].

In the present case, it has become customary to speak in terms of organ *donation* as a reference to the manner in which organ donation between individuals is organized and coordinated by the medical staff. It must be stressed, however, that from an anthropological and legal standpoint, this denomination appears as questionable.

From an anthropological perspective, the term "donation" seems equally inappropriate. Indeed, donation, as it is explained by Marcel Mauss [14] cannot simply be transposed to the circulation of organs [2], [9], [19], see also Godout and Caillé, [10]. The exchange of organs does not correspond to the spirit of Maussian donation, the triple obligation of giving, receiving and returning not being fulfilled. In addition, the function of donation identified by Mauss, is to produce social ties, whereas the function of organ donation lies primarily in contributing to survival, and regards individuals.

From a legal perspective, part of the legal doctrine contests the use of the term *donation*, as the body is not dispensable – i.e. it cannot be transferable or assignable – and therefore does not *belong* as such to the person inhabiting it. To certain commentators, the situation of presumed consent appears as the most problematic with regard to the status of a person and of a human body. [20]. According to Carlo Foppa, organ donation relies on the notion that the body belongs more to the species than to the individual: "given that the body [...] cannot belong to someone in the same way as an object does, therefore the word "donation" is very vague", because "something that is not on the market cannot be signed over, not even gratuitously, not being subject to any will whatsoever" [7]. If the individual cannot sign over his or her body, its products or its elements for profit, he or she cannot sign them over for free either, even after death. The idea of "donating", as a means for circulating organs, would make sense only within a system where the sale of organs would also be possible as an alternative means of circulation. All the more so within a legal framework marked by presumption of consent (which was the case in France and Vaud before the enactment of the Federal law); "it would be much more accurate to speak in terms of the obligation to make organs available rather than to donate them" [7].

It is necessary then to pursue the interrogation on the social effects on the larger public of such a qualification, in particular of the connotation that then is given to organ donation, morally, for example, outside the medical profession. Indeed, there is no doubt that the term donation refers to a specific semantic field, partially emotion-laden to the extent that the notions of altruism, generosity, and solidarity go hand in hand with the term donation. This has led certain authors to reject the word: as altruism is a social obligation, one can no longer truly speak of altruism but of "forced and camouflaged hypocrisy" [7]. In this sense, Alain Girard [9] questions, with regard to the French notion of presumed consent including a record of refusal, whether the use of the term *donation* does not veil *the right to refuse*.

It appears then that the term *donation* is questionable not only from a legal standpoint, but also that this term is inherently emotion-laden. The notion of *donation* may be on the one hand regarded as a way to connect individual responsibility to certain altruistic values, and on the other a substitute solution to the ethical impossibility of making organ removal mandatory. In brief, the system appears fully moral, but what lies beyond the surface?

The circulation of organs is then neither organized around a market model, nor around legal obligation, but solely on individual choice (whether choosing to consent or to refuse).

This is why organ transplant promoters must convince individuals to explicitly state their choice before dying. This effort to persuade the public reveals itself as all the more crucial in the

light of the model approved by Federal law on transplants that will be put into effect in early 2007. Indeed, if the current situation in Switzerland much resembles a “prescriptive patchwork” [12], in the sense that the field of organ transplant is governed by disparate cantonal laws and by directives of the Swiss Academy for Medical Science, Federal law establishes the model of (explicit) consent. Given current circumstances, this model of consent cannot drastically reduce the gap between supply and demand of organs in Switzerland. This law will most probably incite transplant promoters to double their efforts in informing the public, even to define their communications strategies, individuals being the privileged target of measures designed to increase organ donation.

How to then reconcile the neutrality of the Confederation recommended by the Federal Council in its message to Parliament, and the struggle to increase organ donation in Switzerland?

When considering the principle, that most people never express themselves with regard to the question of organ donation during their lifetime because they don’t have the opportunity to discuss the question with their kin, and that they would if they simply were informed on the matter, it is important to note that the vocabulary used to *inform* the public is not unambiguous, regarding the role of the State and of international organizations in informing (*lato sensu*) on transplants.

The French word *information*, which is often encountered (Council of Europe, Federal law, cantonal legislation, French public health code) is neutral according to its definition in the Petit Larousse French Language Dictionary (2003): “*renseignement sur quelque chose*”, as it is in English according to the Merriam-Webster Online Dictionary (2006): “the communication or reception of knowledge or intelligence”. It is thus strictly speaking a neutral term, devoid of proselytism, which is not the case of other terms commonly used. Other texts – or even the same texts – make use of more militant terms such as *promoting* and *increasing awareness*; promotion of organ donation consists in favoring development, and increasing donation, whereas increasing awareness toward organ donation suggests sensitizing the public, making it receptive to organ donation.

With regard to Federal law on transplants, article 61 suggests dispensing objective information with the aim to reassure the Swiss people, in particular through opting for transparency regarding all the medical practices involved in organ transplants. The Federal Council’s message favors, in the name of the State’s neutrality, “objective and neutral” information.

This policy is in sharp contrast to the attitude that has prevailed until now in the cantons. If Geneva<sup>5</sup> and Berne<sup>6</sup> seem to this day to adopt a policy of pure information, Valais<sup>7</sup> and Vaud<sup>8</sup> encourage organ donation and financially support information campaigns, particularly regarding organ removal. Here it is difficult to speak in terms of neutrality. As for Jura legislation, it is even more explicit, as article 31 2° of the health act “encourages everyone agree to [organ] donation”.

As for international organizations of which Switzerland is a member, the WHO has assigned itself the mission to encourage donation of human material, and if the additional Protocol requires member States to inform the public, the information appears as biased<sup>9</sup>. Resolution (78)29 relative to transplant legislation<sup>10</sup> invites member States to “intensify their efforts, with the use of all appropriate measures, in order to inform the public and to increase awareness among doctors of the necessity and the importance of donating [human] substances”.

Certain texts or additional texts that imply that authorities are supporting and promoting organ donation without openly admitting it, is a source of conflict. Why promote with the pretense of giving objective information? The same controversy exists in France and has been denounced by Dominique Thouvenin [20], who doesn’t understand why French lawmakers do not condone the

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<sup>5</sup> Art. 11 of the May 20<sup>th</sup> 1998 enforcement ruling to the March 28<sup>th</sup> 1996 law on organ and tissue removal and transplants.

<sup>6</sup> Art. 35a of the December 14<sup>th</sup> 1990 health law: “The population must be duly informed of its rights and duties regulating organ donation.”

<sup>7</sup> Art. 48 of the February 9<sup>th</sup> 1996 health law: “Encouragement to organ donation the State supports awareness campaigns aiming at encouraging organ donation.”

<sup>8</sup> Art. 27c of the May 29<sup>th</sup> 1985 law on public health.

<sup>9</sup> Art. 8 of the additional Protocol to the Convention of human rights and biomedicine relative to human organ and tissue transplant: information on the need for organs and tissues and regarding the conditions of organ removal and transplant, but not at all on alternatives to organ transplant for example.

<sup>10</sup> Resolution (78)29 on the harmonization of legislation among member States with regard to removal, graft and transplant of substances of human origin adopted by the Committee of Ministers on May 11<sup>th</sup> 1978.

appropriation by society and modern medicine of cadavers as a supply for organs, instead of covering up this procedure as presumed consent to organ donation.

As for the denounced shortage in organ donation, those throwing stones, are they not advocates of naturalism when claiming “32 patients have died for lack of organs”<sup>11</sup> or “32 patients have died from lack of donors”<sup>12</sup>, instead of stating that “32 people have died in 2003 from disease while on a shortlist for organ transplant”? Do they not attempt thereby to stir emotion and guilt among the public?

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<sup>11</sup> Information pamphlet from the French Establishment for Grafts entitled “Don d'organes. Donneur ou pas...Pourquoi je dois le dire à mes proches. Le guide”, 2004.

<sup>12</sup> Swisstransplant activity report 2004.