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## 3.2 Taking a deceased organ donation decision at the crossroad of affective and public health issues

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### **Abstract**

Since 2007, Swiss organ donation awareness campaigns aim to stimulate informed consent among people on the basis of cognitive decision-making theories. Nonetheless, polls highlight that despite people agreeing that transplantation could save lives, individuals feel difficult to take a deceased organ donation decision and express it.

This chapter presents findings from a broad project, in which we used the methods of questionnaire, of interview and of focus group in order to study reluctance to organ donation in the Vaud County French-speaking population of Switzerland.

Data from the questionnaire and from the interviews allow us to suggest that people feel uncomfortable with the mechanistic, technical approach that prevails in the transplant medicine discipline. As a result, some respondents tend to avoid to take a deceased organ donation decision, for instance arguing that they are too old or in too bad health conditions to give organs after their death. Also, they prefer to let the next-of-kin decide, when necessary, consistently with his feelings. Within this context, the ICU caregivers that support families during the patient's illness and the organ donation decision develop several strategies to ensure that the patient, the family and themselves remain the main characters of the care and of the death, in an environment where technological approaches rhythm the activities. This attitude seems to play a key role in family's propensity to organ donation.

These results suggest that consent rates could be improved by assuming the role played by affective considerations in the organ donation decision and its expression.

### **Introduction**

In 2004, Switzerland endorsed a new Federal act on transplant medicine emphasizing the need to stimulate an informed consent among people. Thus, since 2007, awareness campaigns have been aimed at sensitizing the Swiss people to the need to inform about transplantation, take an organ donation decision and express it through a card and by communicating it to the next-of-kin. Nonetheless, the polls lead by the Federal Public Health Office show that only 11% of interviewees have an organ donor card and 40% know the organ donation decision of their close relatives. Actually, despite people agreeing that transplantation approach could save lives, individuals feel difficult to take a decision and explain it.

This result is consistent with the literature in the field: on the one hand, several authors highlight the barriers to the expression of an organ donation decision and the factors related with them (Conesa et al., 2004; Rodrigue, Cornell, & Howard, 2006; Sanner, 1994; Siminoff, Burant, & Youngner, 2004). On the other hand, some papers underline the strong affective dimension of this sensitive decision (Irving et al., 2011; Kesselring, Kainz & Kiss, 2007; Long, Sque, & Addington-Hall, 2008; Radecki & Jaccard, 1997).

In 2007, the Interdisciplinary Ethics Platform (Ethos), in collaboration with the Health Psychology Research Centre (CerPSa), the Center of Linguistics and Language Sciences (CLSL) and the Organ Transplantation Centre of the University Hospital Centre of Lausanne (CHUV) initiated an interdisciplinary reflection on the organ donation decision within the Swiss context at the University of Lausanne. The research project born from this collaboration aimed to study (1) the evolving and subjective nature of the organ donation decision and (2) organ donation and transplantation public discourses and their influence on the opinions and attitudes of people of the three linguistic regions of Switzerland.

The purpose of this paper is to specifically investigate people's reluctance to deceased organ donation and their possible origins. With regard to this aim, this paper presents the results from the first research axis, namely the evolving and subjective nature of the organ donation decision, following the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines<sup>1</sup>.

## 1 Material and methods

### 1.1 Study design

Within this cross-sectional study, we used a mixed methods methodology to study the evolving and subjective nature of the deceased organ donation decision. On the one hand, the methods of the questionnaire and of the interview were used in order to explore the organ donation decision as a "future possibility". On the other hand, we analysed retrospectively the concrete conditions that led to an organ donation decision through the use of the method of focus groups.

### 1.2 Material, data collection and setting

#### *Questionnaire*

From 2007 to 2008, the researchers of Ethos and CerPSa at the University of Lausanne created jointly a multiple-choice questionnaire on organ donation and transplantation social perceptions. The form was elaborated on the basis of the literature review and with the help of collaborators of the Swiss foundation for research in social sciences (FORS). Its validity was checked throughout quantitative and qualitative procedures. Firstly, the questionnaire was administered to 123 students of the Faculty of Social and Political Sciences of the University of Lausanne during an academic class: statistical analysis allow us to check its reliability, stability and sensitivity. Secondly, ten people were invited to fill the questionnaire and participate to an interview during which they had the opportunity to make comments about it. As a result of this process, two questions addressed the

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<sup>1</sup> The STROBE checklist used in this paper is freely available on the websites of the Annals of Internal Medicine at <http://www.annals.org/>.

topic of reluctances to give organs after the death. Their introduction and their possible answers were determined on the basis of the literature review and are displayed in Figures 1 and 2.

## ***Interviews***

As the literature review conducted for this project highlights that the organ donation decision is commonly discussed in terms of cognitive theories and investigated through quantitative methods, we decided to complete our approach with qualitative methods. Within this context, semi-structured interviews were used to investigate this decision in its concrete context. Thus, interviews were led with 10 lay people on the basis of a phenomenological-oriented outline (Giorgi, Knowles, & Smith, 1979). On the one hand, this approach allows placing a special emphasis on the subjective experience of events and, secondly, the themes explored by the phenomenological interviews – namely the time, the space, the others and the finitude – seem especially relevant for addressing the experiences of the organ donation decision.

## ***Focus groups***

Within the context of this study we used focus groups in order to study the concrete conditions of the organ donation decision bedside of a deceased person. As well as interviews, the focus groups were also led on the basis of a phenomenological grid.

## **1.3 Data analysis methods**

### ***Questionnaire***

The numerical data gathered were analysed using PAW Statistics 18.0 software. In all statistical tests, the confidence interval (CI) was established at 95%.

### ***Interviews and focus groups***

After transcription and anonymisation, the discursive data collected were analysed using QSR NVivo software (version 8) in order to identify, analyse and report constants in meaning (“patterned meaning”) that characterize a data set (Braun & Clarke, 2006).

## **1.4 Participants**

### ***Questionnaire***

After the Institutional Review Board (IRB) approval, the questionnaire was sent, together with a reply envelop, by post early January 2010 to 3000 inhabitants of the Vaud French-speaking County. Lay people were chosen randomly among the lists given by the poll firm AZ Direct SA with respect to sex, age and the district inhabitant densities. No reminders were subsequently sent to encourage people to answer. 21% of inhabitants sent back a filled form: their socio-demographic characteristics are displayed in the Table 1.

**Table 1:** Socio-demographic characteristics of the survey sample

	<b>Inhabitants</b>
<b>Age</b>	52.6 ± 15.9 years
<b>Men in the sample</b>	50.5%
<b>Family members</b>	1.9 ± 0.8 adults
	0.7 ± 1 children

## Interviews

After the IRB approval, we sent an email to the technical and administrative staff of the University of Lausanne to explain the context and the aims of the study. Ten lay people were by then quickly recruited to participate to the interviews: their description is displayed in the Table 2.

**Table 2:** Socio-demographic characteristic of the interviewees

<b>Lay people</b>	<b>Age</b>	<b>Marital status</b>	<b>Profession</b>
Interview 1, Mrs A	48 y.o	Married, with one young child	Laboratory assistant in biochemistry.
Interview 2, Mr B	About 60 y.o	Separated, with two adult daughters	Photographer.
Interview 3, Mrs C	42 y.o	Married, with one young daughter	Accountant agent in a genetics laboratory.
Interview 4, Mrs D	41 y.o	Married, with two children (9 and 19 y.o)	Chemical engineer in a laboratory making research on the breast cancer.
Interview 5, Mrs E	53 y.o	Married without children	Laboratory assistant in biochemistry.
Interview 6, Ms F	28 y.o	In a relationship, without children	Human resources secretary.
Interview 7, Mr G	31 y.o	Separated, with one young son	He is biologist and works in a laboratory making genetic research.
Interview 8, Mrs H	About 60 y.o	Married, with two adult children	Engineer in a laboratory.
Interview 9, Mr I	41 y.o	Married, with one young son	Officer in the public administration.
Interview 10, Mrs L	52 y.o	Married, with one young daughter	Secretary, she worked at the Red Cross.

## Focus groups

After the IRB approval, 7 intensive care unit (ICU) nurses, that are also organ donation and transplantation coordinators, 2 ICU physicians and a chaplain were recruited to participate to two focus groups. Table 3 displays the description of the people involved in this phase of the research.

**Table 3:** Description of the participants of the focus groups

	Description
<b>Focus group A</b>	
Mrs A	ICU nurse and organ donation coordinator in a transplant centre. She made a training in systemic psychology during her classes.
Mrs B	ICU nurse and organ donation coordinator in a peripheral hospital.
Mrs C	Formerly ICU nurse and organ donation coordinator in a transplant centre, she is currently transplantation coordinator in a transplantation centre.
Mr D	Physicians and chief of the ICU in a transplantation centre.
Mrs E	Chaplain, she intervenes at the ICU on the request of the families.
<b>Focus group B</b>	
Mrs F	Formerly organ donation coordinator, she is currently responsible of the activity of the organ procurement local network.
Mrs G	ICU nurse and organ donation and transplantation coordinator in a transplantation centre, she follows currently a specialisation. She writes in this context a report about the families' consent to organ donation.
Mrs H	ICU nurse and organ donation and transplantation coordinator in a transplantation centre, she follows a training in which she writes a report on donors' families' needs during and after the organ procurement process.
Mrs L	Physicians and chief of the ICU in a transplant service.

Because we interviewed small samples and because we cannot guarantee their representativeness, all the results displayed below should be interpreted and generalized with caution.

## 2 Main results

### 2.1 People's reluctances to deceased organ donation

In the questionnaire, the question 27 asked the participant to choose, in a list of twelve options, the reasons that could prevent them from giving *their* organs after their death. The Figure 1 shows the most chosen items in their increasing order.

The main-components analysis performed on the most chosen items – i.e. items which frequency is higher than the median – highlights that they could be distributed into two groups. On the one hand, the items 7, 10 and 11 seem to recall a certain fear of, or mistrust in, the medical dispositive surrounding organ donation and transplantation. On the other hand, the items 8, 9 and 12 seem to be based, in opposition, on a subjective evaluation of the own health condition that is more compatible with the desire to avoid this decision.

The question 28 asked the participants to tick the reasons that could prevent them from giving a *close relative* organs after his death. The Figure 2 shows the most chosen items in their increasing order.

The Figure 2 confirms the tendencies highlighted by Figure 1. On the one hand, it highlights that people are more concerned by the manipulation of a close relative's body than their own. Also, the main-components analysis performed on the most chosen items – i.e. items which frequency is higher than the median – points out, once more, that people could fear or mistrust the medical dispositive surrounding organ donation and transplantation (items 6, 8 and 9) and that they could prefer avoid this decision (item 7). On the other hand, the high frequencies observed at the item

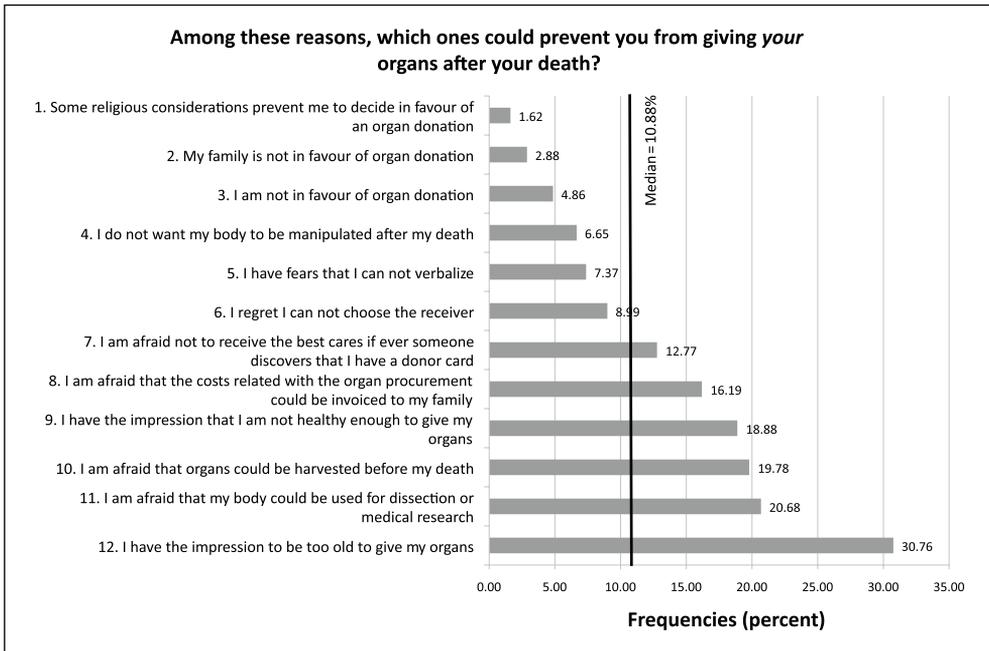


Figure 1: Frequencies of the answers chosen by inhabitants of the Vaud County at the question 27

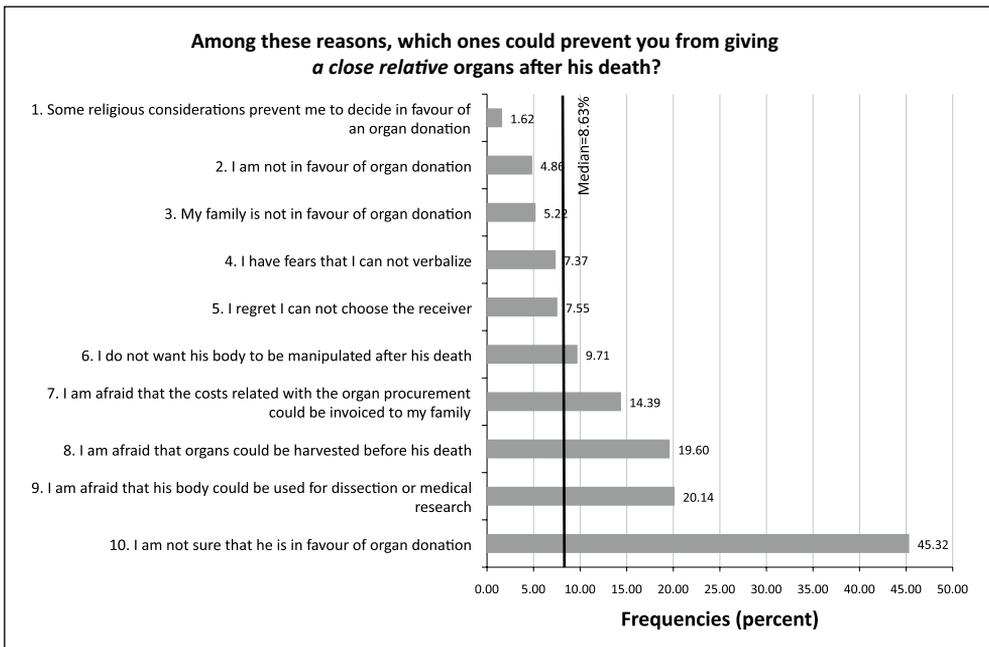


Figure 2: Frequencies of the answers chosen by inhabitants of the Vaud County at the question 28

10 highlight that the will to respect the wishes of the deceased person is a main component of the decision to donate his organs.

## 2.2 Insights from the interviews

Interviews allow us to learn something more about the possible origins of these reluctances.

On the one hand, they show that the trust that people have in medical institutions is constructed on the basis of their concrete experiences in medical settings. Actually, it seems that people who had bad experiences develop mistrust in the general goals of medicine. For instance, two people seem to think that the physicians might be concerned of other interests than those of the patient. For one of them, they are economic; for the other, they are scientific. A third person criticises the attitude of some physicians that seem to consider the patient as a mere body. In opposition, individuals that had positive experiences with medicine seem able to generalize the trust that physicians and nurses inspired them to the entire institution.

On the other hand, interviews highlight that respondents' perceptions of transplantation medicine and its goals seem to be influenced by such considerations. Indeed, although all the interviewees agree on the fact that transplantation could save lives, people that had bad experiences in medical settings tend to not express their decision and prefer to let the next-of-kin decide, if necessary, on the basis of his feelings. Within this context, the reluctance to decide in favour of an organ donation could be associated to the feeling that a mechanistic view of the body implies that the body of the deceased person would be treated disrespectfully. That could explain that people choose more frequently the item 10 in the question 28 than its corresponding in the question 27. Incidentally, Mrs C says that:

*"We should rather consider the whole person as someone who might want to give his body to someone he knows, or an institution he knows, or maybe... Well, I would say 'at least it is used for something good'. I would make things a little more ... human, perhaps, less technical, in fact, and not: 'one needs a liver, well... I take it to give it to another, you're dead, all the better'. I'm maybe exaggerating a little but... The proof is that I would have said 'yes' right away for my husband and now I am asking myself if I would have done the same for someone else."*

In opposition, the interviewees that subscribed a donor card share the impression that the body is not useful after the death: transplantation becomes, within this context, a way to rehabilitate it. With regard to this consideration, they think that the decision to donate organs does not refer to the family, which they just inform of their position. Mrs E says about it:

*"When I am dead, if ever something can serve, they can take it. In my opinion, they can after [the death] throw [my body] into a bin."*

On the other hand, several participants seem to easily accept that making an organ donation could contribute to the development of transplant medicine and agree with this fact:

*"I think that more transplantations we will do, the most transplant medicine will progress in its researches. The outcomes will improve subsequently, it is an evidence."*

In conclusion, these results suggest that the interviewees' lack of expression of an organ donation decision could be the consequence of the impression that the medical institutions, which function

as intermediaries, could have another representation of the given object (the organ) and of the purposes of transplantation (the receivers' recovery).

## 2.3 Insights from the focus groups

The data gathered through focus groups are consistent with these findings. Actually, they show that ICU caregivers that support the patient and his family believe that, although trust is necessary for the care, it should not be taken for granted. In this context, several strategies are developed to ensure that the patient, the family and themselves remain the main characters of the care and of the death, in an environment where techno(-)logical approaches rhythm the activities. For instance, the interviewees make special efforts to be available when relatives need to ask questions. Also, they are constantly explaining to the family what they do and what will happen to the unconscious patient. Mrs G says about it:

*"Finally, what does these families understand? What they understand of the seriousness of what is going on? Because if a person is at the ICU, the reason is, on the one hand, that the injury is really serious. But, on the other hand, this person is lucky because at the ICU something could be done. They could feel a kind of ambiguity: they know that its serious, but they also know that there are technics, there are competences..."*

This attitude has two main issues. Firstly, when the patient has symptoms of brain death, the trust built up over several meetings seems particularly important. First, because brain death is not visible to the lay people, families have to trust the caregivers:

*"We explain to the families, that [their relative] died. However, they must make a leap of faith, believe unconditionally to what we told... Because they see nothing, they see someone who is coloured, which is hot, they see all the parameters, the scope, the monitor shows exactly the same pressure and the same frequency."*

Secondly, it seems that the personal involvement of ICU caregivers with the patient and with the family is perceived by the latter as evidence that their relative was not an ordinary patient. This impression seems to contribute to create the conditions for a gift:

*"What I would also say is that families are very concerned with the involvement of caregivers. We have acknowledgement to such or such other caregivers, they also ask us to find who was the nurse who was there and supported them so much. Or typically, I got feedback after an organ donation, saying: 'But this doctor was really ... he was crying when he told us of the [organ] donation'."*

These results suggest that ICU caregivers play a key social role in families' propensity to organ donation. Indeed, family consent to organ donation could depend on their ability to bridge the hospital practices and the family's needs. This result is consistent with literature in this field (Jacoby, Breitkopf, & Pease, 2005; Kesselring et al., 2007; Sque, Payne, & Clark, 2006).

### 3 Discussion

These results are interesting in two main respects: the first is related with interviewees' discomfort with a fragmented body concept. The second seems connected with mistrust in the medical system and the legal frame that surround transplantation practices. Although these two aspects are not independent, they are presented separately for more intelligibility.

#### 3.1 Discomfort with a fragmented body concept

The questionnaire and interview data highlight consistently that reluctance to organ donation could be related to the fact that participants seem to refer to a holistic, embodied vision of the body (Le Breton, 1990; Santiago-Delefosse, 2011) that clearly differ from the dominant mechanistic perspective in transplantation medicine (Joralemon, 1995).

With regard to this result, the reluctance observed could be related to the fact that the body of the deceased has to be left to the caregivers for the organ to be harvested. Actually, in respondents' perceptions, a mechanistic view of the body is associated with the impression that the body will not be treated with respect and that the wishes of the family will not be taken into consideration during the organ procurement procedures. With regard to the first concern, interview and focus group results show that interviewees seem to refer to cultural norms tending to emphasize the "peace of death". Concerning the second one, the Swiss legal framework, that considers organ donation as an individual decision, could reinforce this impression. As a result, for those that emphasize the embodied nature of the body and its role in the family's mourning, the decision to donate, although it is often positive, is rarely made public through a donor card in order to allow the family to decide, if necessary, contingent on its feelings. In opposition, people that think that the organ donation decision is individual and that are less concerned with the symbolic function of the body are more likely to subscribe an organ donor card.

#### 3.2 Mistrust in the medical system

Data from the questionnaire and the focus groups highlight that reluctance to an organ donation could be connected with some mistrust in the medical system. These results are consistent with other studies in the field (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Sanner, 1994; Siminoff et al., 2004). Actually, interviews tend to show that the trust that people have in medical institutions is constructed on the basis of their concrete experiences in medical settings. On the one hand, it seems that people who had bad experiences develop mistrust in the general goals of medicine. For instance, two people seem to think that the physicians might be concerned of other interests than those of the patient. On the other hand, individuals that had positive experiences with medicine seem able to generalize the trust that physicians and nurses inspired them to the entire institution. Results from the interviews highlight that respondents' perceptions of transplantation medicine and its goals seem to be influenced by such considerations. Indeed, although all the interviewees agree on the fact that transplantation could save lives, people that had bad experiences in medical settings tend to not express their decision and prefer to let the next-of-kin decide, if necessary, on the basis of his feelings.

With regard to our study findings, we assume that accepting an organ donation and overcoming the reluctance to donate could be related with the capacity to develop trust in the medical system. Results from the focus groups suggest that ICU caregivers play an important role in this process.

### 3.3 Overcoming reluctance to an organ donation

Results from the focus groups highlight the conditions that tend to foster organ donation in the intensive care units. Actually, in deceased organ donation, the donor and recipient are separated by intermediaries, guarantors of anonymity. Within this context, the relationship between the family and caregivers in charge of the request of consent can become a prominent aspect in organ procurement. Consistent with others (Jacoby, Breikopf, & Pease, 2005; Kesselring et al., 2007; Sque, Payne, & Clark, 2006), our results suggest that ICU caregivers play an important role in families' propensity to organ donation. Indeed, they act as gatekeepers between the hospital/health service logics and the family's and the patient's needs. This attitude seems to introduce trust in their relationship with the family and, consequently facilitate the acceptance of the brain death diagnosis. Also, the concern expressed by the caregivers could be seen by the family as a proof of the fact that they do not consider the potential organ donor as an ordinary patient. With regard to this consideration, the special care dedicated to the unconscious relative could function for the family as a "clinching gift", i.e. a gift that opens a new cycle of gifts and compel the donor and the recipient to engage in a gift-relationship (Gouldner, 1960; Mauss, 2007). In the Swiss legal framework, where informed consent and not organ donation is promoted, the fact that ICU caregivers' attitude could involve the family in a gift-relationship opens up important ethical questions. Actually, even if this is done out of good heart – and not because caregivers may want the families to consider organ donation –, the risk exists that relatives could feel uncomfortable if they do not give organs as a counter-gift.

## 4 Conclusion

The data gathered in this study show that thinking about, making and expressing an organ donation decision seems to depend more on concrete experiences of the health services than on information provided to the public. With regard to these results, we suggest that cognitive decision-making models could not be appropriate to promote informed consent about organ donation. As a result, we suggest that organ donation decision rates could be improved by considering the affective, relational, dimension of this act in the public discourse and communication. For instance, the Federal awareness campaigns could acknowledge the role played by the family in the organ donation decision and their distress when no decision has been taken by the potential donor.

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