

## Article

# Prior family communication and consent to organ donation: using intensive care physicians' perception to model decision processes

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## Significance for public health

Knowing the reasons why potential organ donors do not become actual donors provides leverage for increasing the willingness of relatives of potential donors to give their consent. Public campaigns should focus on communicating one's willingness to donate one's organs or not to relatives or to a person of trust, mostly to prevent the relatives' scepticism from overturning a dead person's own wishes. Second, the importance of the donor card as an occasion for discussing the subject in families and as an aid to communication processes between doctors and relatives should not be underestimated. Thirdly it seems advisable to induce people to think about the issue, and to promote generally supportive attitudes. And finally information campaigns should inform people about the circumstances of real situations in which they might have to make a difficult decision, even at the risk of lowering support for organ donation in general.

## Abstract

Generally, the Swiss hold favourable attitudes to organ donation, but only few carry a donor card. If no card is found on a potential donor, families have to be approached about donation. The aim of this paper is to model the role that some family communication factors play in the family decision to consent or not to organ donation by a brain dead relative. Information was gathered in face-to-face interviews, using a questionnaire and recording open answers and comments. Eight heads of intensive care units (ICU) of Swiss hospitals and one representative from *Swisstransplant* were interviewed. Questions asked respondents to estimate the prevalence and effect of communication factors in families facing a decision to consent to donation. Answers were averaged for modelling purposes. Modelling also relies on a previous representative population survey for cross-validation. The family of the deceased person is almost always approached about donation. Physicians perceive that prior thinking and favourable predisposition to donation are correlated and that the relatives' predisposition is the most important factor for the consent to donation, up to the point that a negative predisposition may override an acknowledged wish of the deceased to donate. Donor cards may trigger family communication and ease the physicians' approach to family about donation. Campaigns should encourage donate-willing people to talk to their families about it, make people think about organ donation and try to change unfavourable predispositions.

## Introduction

Progress in transplantation medicine has been very successful in recent years, creating a situation in which the number of patients on

waiting lists increases, while the number of dead organ donors is not increasing proportionally. This results in a permanent shortage of donor organs and longer waiting periods for patients. To increase the number of dead donors, one can either improve detection of potential organ donors or attempt to increase the donation rate of detected donors. This study is exclusively concerned with the latter.

Research pertaining to the donation rate has focused strongly on the donor card and the influences on the decision to sign and carry such a card.<sup>1-3</sup> The problem with the donor card is that, as in other countries,<sup>4</sup> most of the people in Switzerland<sup>5</sup> are generally in favour of organ donation, but only very few of them carry a donor card or discuss the topic within their families. Aside from the donor card, the communication between intensive care medical personnel and family has received considerable attention,<sup>6-12</sup> and recently researchers have focussed on the role of family communication in the decision to consent to donation.<sup>1,2,6-8,13,14</sup> Other studies seek to discover to what extent psychological or attitudinal factors influence the willingness to donate one's own organs.<sup>15-17</sup> Horton and Horton<sup>18</sup> found evidence that the strongest predictors of willingness to donate organs are knowledge and attitudes. Especially knowledge about organ donation seems to be a strong predictor of willingness to sign a donor card.<sup>6,19</sup> Recent research shows that socio-demographic characteristics of a population such as gender or culture also seem to play an important role,<sup>5,15,17,20-23</sup> as will one's personal experiences, education, the social norms an individual adheres to, religious beliefs, and other forces.

Other studies tried to estimate the number of potential organ donors by reviewing hospital records to figure out whether all potential donors had been identified as such, and if so, whether family members had been approached about organ donation and whether they eventually agreed or not.<sup>24</sup> Politoski *et al.*<sup>25</sup> studied the communication between professionals and donor families and stressed the need for standardization of practice guidelines in hospitals.

Haddow<sup>26</sup> and Williams *et al.*<sup>27</sup> studied the physician's role in discussing organ donation with the families. Williams *et al.* focused on the fact that knowledge, skills, and attitudes necessary for physicians to promote a decision in favour of organ donation are widely variable from one hospital to another.<sup>27</sup> Other studies address the perceived support of medical staff as a pivotal factor in consent decisions.<sup>6</sup> The study of Siminoff *et al.* indicates the importance of the doctor's attitude.<sup>28</sup> The findings on family attitudes and their perception by doctors has incited us to attempt to estimate the relevant factors by inquiring about the intensive care physicians' perception of the relatives' knowledge of the deceased person's wishes, the intensity of relatives' prior thinking about organ donation and their attitudes to it in general.

The importance of knowing the deceased person's wish was also confirmed in Smith *et al.*<sup>29</sup> Interestingly, they also found out that at the same time family discussion did not necessarily lead to getting the card witnessed by a family member.<sup>29,30</sup>

Additionally there are studies analyzing the problem of the family

being in a situation of shock when asked to assent to organ donation. Siminoff *et al.* for example say that *it is not reasonable to expect that family decision makers can or even should relinquish strongly held beliefs about organ donation when experiencing the severe stress of a loved one's death* (p. 76).<sup>28</sup> Also, Sque *et al.* draw the conclusion that there is a *need to stimulate family discussion about organ donation before they are involved in the situation of a sudden death* (p. 545).<sup>31</sup>

The purpose of this paper is to provide first hints on the role some factors of family communication and attitudes play in the decision to allow transplantation of a deceased relative's organs in Switzerland. It is therefore an exploratory study into an area that has not been researched in Switzerland so far. Three methods offer themselves for such a study: document analysis of medical records, interviews with families who had to make a decision on whether a dead relative should become an organ donor, and interviews with intensive care personnel involved in or observant to family decision making. As medical records will not contain much information on earlier family communication, if any at all, and as interviews with families raise a number of organizational, legal and ethical issues, we decided to rely on expert interviews with heads of intensive care units (ICUs).

We refer to potential organ donors as persons who are brain-dead and do not show any medical contraindications to becoming an organ donor. We do not address the medical question of which contraindications in the potential donor may prevent organ transplantation. Neither do we address issues of detection.

### Potential factors affecting family consent

The first factor we look at is the role of the donor card, which by law (article 8.5 of the Swiss National Transplantation law effective since July 1, 2007) is legally equivalent to a testament/last will, implying that the will of the deceased person prevails over the wish of the family.

Secondly, we selected three family communication factors for closer scrutiny: intensity of prior thinking on organ donation, family predispositions toward organ donation in general, and knowing the deceased person's wishes.

The level of prior thought was found to be a significant factor in organ donation decisions.<sup>32</sup> Besides, it is the latent assumption behind awareness campaigns that the more intensely a person has thought about organ donation the more willing he or she will be to donate organs or consent to a relative's donating.

Favourable family predisposition to organ donation can be considered an important factor in reaching a positive decision about organ donation in a particular case.<sup>28,33</sup>

Knowing the deceased person's wishes can also be considered intuitively as affecting consent to donation. The importance of this factor was already confirmed by Smith *et al.*<sup>29</sup> Three categories of this knowledge have to be considered: knowing that the relative wished to donate, knowledge that he or she preferred not to donate, and lack of knowledge. Knowledge is related to attitude toward donation as well as to proxy measures for intention to donate such as having signed a donor card.<sup>2,6,15,18,19,34-36</sup> Having a donor card is correlated with values, factual knowledge, attitudes and willingness to donate,<sup>18</sup> as well as with attitude towards death, prior blood donation, and age of the participant.<sup>19</sup> Radecki and Jaccard came to the conclusion that overall, studies show homogeneously that consent decisions are primarily influenced by prior knowledge of the deceased individual's wishes.<sup>6</sup>

All three family communication factors cover events that took place long before a relative died and became a potential organ donor. The analysis of these factors therefore links conditions that developed before the death of a relative with a decision the family has to make after one of them died.

## Design and Methods

### Procedure

Our research relies on expert face-to-face interviews. Interview partners were chosen according to their positions. We conducted eight interviews with doctors working in intensive care units, two from Ticino hospitals, four from the German-speaking part and two from the French-speaking part of Switzerland. The study thus comprised all but two of the transplantation centers of the country. Interviewees were heads of ICUs in seven of the eight cases because we expected them to be the person with the greatest experience and best overview of relevant aspects. Additionally we interviewed a former high official from *Swisstransplant*, the central organization responsible for the organization and coordination of transplantations in Switzerland. This person did not answer the questions used to compute the case numbers and conditions, as this might have led to double counting of the same cases. In total, our analysis is thus based on nine expert interviews. While basing conclusions on only nine interviews may seem ambitious, one should keep in mind the limited number of large hospitals and transplantation centers in Switzerland. External ethical approval of the interviews was not necessary.

Answers were noted on the questionnaire. Excel files were later assembled for documentation. As there were but nine cases, analyses were done by simply counting cases and computing percentages and averages with a desk calculator.

### Measures

Most questions required the interviewees to estimate a case number or percentage based on their personal experience with potential organ donors and transplantation medicine, providing an assessment of the prevalence of the donor card and the three factors of family communication. Later the consent rate under different conditions had to be estimated. A special problem was posed by the assumption that intensity of prior thinking is likely to be correlated with both predisposition and knowledge of the deceased person's wishes. The first problem was solved by a special estimation procedure in the questionnaire, the second by ex post facto considerations. Details will be provided below. The relevant parts of the questionnaire are documented in the Appendix.

The estimation of the scope of relatives' prior thinking and their predisposition to organ donation was asked using a small matrix. This allowed determining the potential correlation between these two entities. Interviewees were offered a 2x2 cross-tabulation and asked, in two steps, to distribute 100% into the four cells (see Appendix with the questionnaire). For estimating the share of relatives allowing organ donation under different conditions, a second matrix was employed. The conditions were offered in a 2x2x2 cross-tabulation, distinguishing among: i) relatives who know and those who do not know the deceased wished to donate; ii) who had thought or not about the issue before and iii) who were generally in favour or opposed to organ donation. For each of these eight cells, we asked the doctors to assess the likelihood that the relatives would agree to organ donation. This means eight separate judgments had to be made, each about the likelihood of consenting to donation under a different condition. The results are not concerned with comparing individual answers, but with constructing a kind of collective perception of decision processes. We therefore calculate averages of percentages and sums of case numbers, and use these for further analyses. In documentation, ranges of the replies are usually also given. Using averages of expert perceptions of events they have not witnessed is certainly, under usual circumstances, a dubious method to depict social reality. Given that ours is the first explorative venture into the area of Swiss family communication patterns on organ donation and their impact on real decisions about donation, this appears to us permissible. We con-

cede that all results based on average calculations have to be interpreted with caution. Figure 1 visualizes and summarizes, in the blue bold-framed boxes and the blue arrows, our conception of the decision process that leads to a family's agreeing or objecting to organ donation in a particular case. The green arrows show the anchor points of our data collection. One-sided arrows indicate percentage or case number estimations we inquired about; two-sided arrows indicate the physicians' estimation of the likelihood of decisions in either direction. The third and last of these two-sided decision arrows pertain to the crucial issue, consent to donation. This decision was inquired about under the conditions shown at the left side of the figure. The dotted arrow beginning at the last decision point shows that we did no further inquiries into the cases where the relatives are aware the deceased did not wish to donate his or her organs. All these cases were counted as lost for donation. No inquiries were made, for the sake of simplicity, into the cases where a donor card was found. These cases were counted as donations.

### Prior thinking and predispositions

As described, ICU heads were asked to estimate how many of all persons approached about organ donation by a deceased relative had ever thought seriously about the issue, and how many were favourable or unfavourable to organ donation in general. As mentioned, they had to fill in a 2x2 matrix in a way that the four cells added up to 100%. Unfortunately, only five of nine respondents did this in a coherent manner. Thus, Table 1 gives the average and ranges of the estimates provided by five doctors.

Doctors saw the relatives split about the question of whether they favoured or opposed organ donation in general, and they indicated that a majority of almost two-thirds of the relatives had not given serious thought to organ donation before their personal, direct confrontation with the issue. The predisposition is probably more positive than estimated by the physicians. Our survey in 2004 resulted in almost 60% of respondents in Switzerland saying they would be willing to

## Results

### The role of the donor card

In answer to the question of how many detected potential donors carry a donor card, intensive care physicians' answers ranged from 0 to 5%, with one respondent estimating the share higher, at 20%. Almost all of them added that they usually do not find the card but would not rate the share of cardholders at 0% flatly as there occasionally are patients with a donor card. And according to their experience, if the patient does not carry the donor card with his/her personal belongings, the card is unlikely to surface. A 2004 representative telephone survey conducted by the University of Lugano showed that approximately 15% of the Swiss population claimed to have a donor card.<sup>5</sup> If both the estimation by intensive care physicians in this study and our 2004 survey are close to reality, this means that a sizeable proportion of donor cards filled in and signed do not surface when they are needed. The second qualification of the role of the donor card is that doctors ask relatives for their consent even in the presence of a donor card, as already shown in the model in Figure 1. This is surprising because, as mentioned above, the donor card has the legal status of a testament, potentially overruling the relatives' preferences.

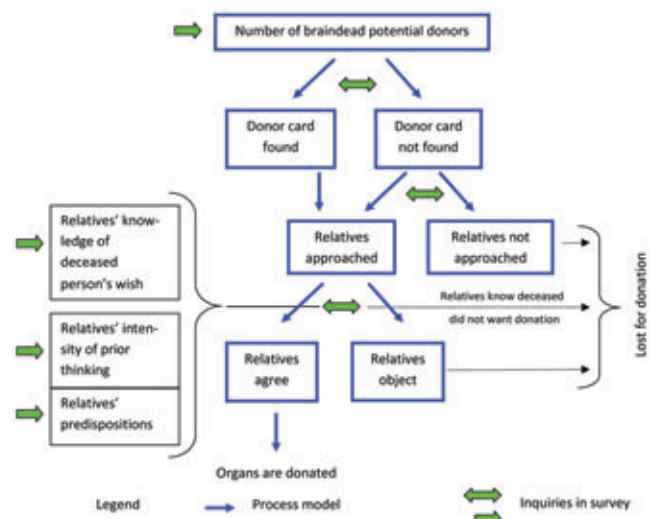


Figure 1. Process model of decision making and questionnaire items.

Table 1. Estimates of the frequency of intensive prior thinking about organ donation among relatives and the frequency of favourable and unfavourable attitudes. Averages of estimates by five intensive care physicians. Ranges are indicated in brackets.

	Intensity of thinking about organ donation prior to death of relative		Sum
	Had not given serious thought to organ donation	Had seriously thought about organ donation	
Generally in favour of organ donation	23% (0-55)	27% (10-52)	50% (10-70)
Generally opposed to organ donation	40% (25-80)	10% (5-16.5)	50% (30-90)
Sum	63% (38-80)	37% (20-62)	100%

Table 2. Estimation of donation rate by three conditions: families' prior thinking, their predisposition and their awareness of the deceased person's wishes. Averages are shown of estimated donation rates under different conditions, given by five/six intensive care physicians, respectively, depending on the number of usable answers. Ranges are indicated in brackets.

		Had not given serious thought about organ donation	Had seriously thought about organ donation
		Relatives do not know potential donors wishes	Generally in favour of organ donation
	Generally opposed to organ donation	13% (0-50)*	31% (0-95) <sup>o</sup>
Relatives know the deceased wished to donate	Generally in favour of organ donation	88% (45-100)	78% (50-100)
	Generally opposed to organ donation	21% (0-90) <sup>#</sup>	41% (5-90)

\*50% is an outlier; all other respondents gave percentages of 10% or lower; <sup>o</sup>estimations tend towards the extremes: four respondents gave estimations of either 0% or 10%, the other two of 70% and 95%; <sup>#</sup>90% is an outlier; all other respondents gave percentages of 10% or lower.

donate their organs, and somewhat less than 30% indicating they were probably willing to agree to this.<sup>5</sup> Surveys from other countries show large majorities being favourably disposed to organ donation in general,<sup>4</sup> but disposition is something very different from making a real decision after a relative has just died, or is about to die. The physicians perceive intensity of prior thinking and predisposition as correlated. The average estimates indicate that almost two-thirds of the relatives who had not thought seriously about organ donation beforehand are generally opposed, while almost three-fourths of those who had thought about it are perceived as being generally in favour of donation. The largest group, in the doctors' perception, is the relatives who had not seriously thought about organ donation and are predisposed against it in general.

### The effect of family communication factors on consent to donation

Due to incomplete data in the estimations of consent rate under different conditions, the analysis can only be based on the answers of six doctors, not all of whom, in addition, filled in every cell. Estimates were averaged across as many respondents as possible in each case. Table 2 indicates that, in the physicians' perception, knowing the deceased person's willingness increases the probability that relatives will agree to donating, whatever their predisposition and previous thinking about the issue. When relatives are favourably predisposed, whether or not they have thought seriously about the issue is secondary: the estimates are too close to draw any meaningful conclusion. In other words, if relatives are favourably predisposed, the one thing which seems to matter is whether or not they know their relative's wish. The situation is quite different for relatives with a negative predisposition. In this case, having thought about the issue increases the perceived probability of their agreeing to donation by an order of magnitude. Looking more closely at the spread of the data for the case where relatives do not know the wishes of the potential donors and are generally opposed to organ donation, it appears that four of the 6 respondents gave similar estimates for the situations with and without prior thinking, while two consider that the prior thinking has a very significant positive impact. If we compare this to the case where

relatives do not know the deceased wish to donate, all but one think that prior thought has a significant impact on the decision.

### Quantifying the flow of decisions leading to transplantation

The relative prevalence of family communication factors, the average estimated consent rate under different communication conditions, and the sum of estimated detected potential donors per year allows the computation of a model that provides estimates of how many cases per year are lost to donation for the different family communication conditions. The model starts out with the total annual number of detected potential organ donors. Eight respondents related such numbers, ranging from 10 to 80, with most doctors mentioning figures not above 20. Some doctors gave ranges instead of precise numbers. If the figures are added up, the number of potential organ donors in the institutions covered ranges between 189 and 211. Conveniently, the middle of that range is 200, and this number will serve as the basis for everything that follows. The calculations are shown in Table 3. As doctors indicated that even when a donor card was found, they would still discuss the matter with the potential donor's relatives, we do not differentiate between cardholders and non-cardholders. Hospitals are legally required to mention the possibility of organ donation to relatives whenever this is a medical option. In reality, however, this will not happen in each and every case. On average (8 doctors again), the estimated share of cases where donation is indeed mentioned to relatives is 94%. This means 6% or 12 potential donors are lost because medical staff does not see a chance to raise the issue with relatives. The next steps distribute the remaining cases into the different family communication conditions. First is the relatives' knowledge of the deceased person's preferences. On average, eight doctors estimated the share of relatives who knew these wishes at 49%. That is to say: of the remaining 188 potential donors, 92 fall in the condition that the relatives know the dead person's preferences, and 96 in the condition that relatives do not. Next, doctors were asked in how many cases (among the 92 with relatives knowing their family member's wishes) relatives thought the deceased had been in favour or against donating his organs. Estimates for this question again vary widely, but on average they came down to 70% in favour and 30% opposed. This means that there are, in a given year, 64

**Table 3. Computation of number of cases lost for donation in different conditions.**

	Number of cases*	Relatives' prior thinking and predisposition	Distribution in percentage <sup>o</sup>	Cases in condition	Percent family consents to donation <sup>#</sup>	Number of donations	Number of cases lost for donation
Relatives not approached about donation	12	All lost for donation					12
Relatives know deceased did not want to donate	28	All lost for donation					28
Relatives know deceased wished to donate	64	Have thought, favourable	27	17	78%	13	4
		Have thought, unfavourable	10	6	41%	2	4
		Have not thought, favourable	23	15	88%	13	2
		Have not thought, unfavourable	40	26	21%	5	21
		Sum	100	64		33	31
Relatives do not know the deceased person's wishes	96	Have thought, favourable	27	26	57%	15	11
		Have thought, unfavourable	10	10	31%	3	7
		Have not thought, favourable	23	22	53%	12	10
		Have not thought, unfavourable	40	38	13%	5	33
		Sum	100	96		35	61
Grand total	200					68	132

\*As mentioned in text; <sup>o</sup>from Table 1; <sup>#</sup>from Table 2.



possible donors whose relatives are certain the deceased wished to be a donor, and 28 for whom relatives say they know the deceased was opposed to donation. The latter are counted as lost for donation.

The cases remaining in the model were then distributed across the prior thinking/predispositions groups (using the percentages shown in Table 1). This was first done under the unrealistic assumption of no correlation between intensity of prior thinking and knowledge of the deceased person's wish. A more complicated model accounting for such a correlation was also computed, based on an earlier representative population survey.<sup>2</sup> The computation produced rather similar figures. We therefore stick to the simpler model. In the final step, the estimated transplantation rates (shown in Table 2) were applied cell-wise, that is: for the different family communication conditions.

Following this procedure, we can estimate (Table 3) that among the 64 cases where relatives know the deceased had favoured organ donation for himself, only 33 will lead to transplantation, while 31 (or 48%) are lost as organ donors. Among these 31 lost cases, there are 21 instances where the relatives had not thought about organ donation before, but were predisposed against it nevertheless. Among the 96 cases where relatives had no knowledge of the deceased person's preferences, only 35 result in transplantation while 61 (or 64%) are lost. Of these, 33 fall in the condition no prior thinking/predisposed against.

Incidentally, the number of 68 transplantations yielded by the model corresponds by and large to the real number of organ donors that *Swisstransplant* reports for 2007: 81 cases all in all (2006: 80 donors, 2005: 90 donors), of which about three fourths are performed in the transplantation centers of the large hospitals where our respondents come from. This cannot be overinterpreted, though, as for instance some information in our survey may be based on identical cases. But the closeness of the estimated number of organ donors in our model to the real figure suggests the model may have some bearing.

If we summarize, starting from 200 potential organ donors a year, about two thirds of the cases are lost for donation. The single largest group of losses consists of cases where the relatives are not aware of the deceased person's wishes, have not thought about donation and are unfavourably predisposed. This is the group with the lowest transplantation rate (13%, Table 2); it makes up 25% (33 of 132) of the losses. This group unites all factors that impede a decision for donation and may therefore be hard to persuade; but still much can be won here. Also almost anything that can be said in a campaign to advance organ donation addresses this group's impediments. The second largest group of losses (28 in 132 or 21%) are the families who say their deceased relative did not wish to donate his or her organs. Nothing much can be done about these cases, except to encourage persons who are willing to donate to share this wish with their families. The third largest group is the one where unfavourable predisposition among relatives and lack of thinking overrules the deceased person's readiness to donate organs. We find 21 among 132 or 16% of the losses in this group. Here communication that aims at respecting one's relatives' preferences may be called for. And finally a group of also 21 (10+11 among 132) creates a sizeable proportion of losses, consisting of people with favourable predispositions (irrespective of level of thinking) who object presumably because they do not know the deceased person's wishes. Here again, encouragement to share one's preferences with one's family is called for.

## Discussion

The added value of our study is to map the starting points for future campaigns encouraging organ donation. We identified crucial points in the decision process, that is to say: the points where many potential donors are lost in the process of becoming actual donors. These points are the obvious places where measures to improve communication and

to raise awareness should focus in an effort to increase the number of organ donations in Switzerland. Details on this are already spelled out in the last paragraph of the Results section.

Specifically on the donor card, the fact that so few are found on detected potential donors suggests that a sizeable proportion of donor cards filled in and signed do not surface when they are needed. A tentative conclusion then would be that some encouragement is called for, directed at persons who have signed a card, to carry it around all the time. The fact that a donor card is rarely found might lead to the conclusion that campaigns promoting that people sign and carry such a card have little value. However we would draw a different conclusion: the donor card is still worth being promoted. Firstly, by law a card weighs more than the family's preference. Secondly, and probably more importantly, although doctors usually renounce to refer to the law during the discussion with the family, the existence of a card helps them a lot when approaching relatives. Thirdly, it is a first step, encouraging people to think about the issue, to face the idea of one's own death and can thus be a useful stepping stone to convincing other people to start thinking and to accept discussing this delicate matter. And fourthly, an existing donor card might make it more difficult for relatives to misrepresent the deceased person's willingness to donate, should they be so inclined. Interestingly, in a former study about the knowledge and attitudes of the Swiss population towards organ donation, Schulz *et al.*<sup>5</sup> indicated that most people were sure their relatives would take the right decision for them, should the situation arise. At the same time, the majority of respondents admitted that they did not know their relatives' attitude. The difference between the answers of cardholders and non-cardholders in that study is noteworthy. Almost 80% of cardholders answered that they were sure that their relatives would make the right decision (right meaning what they would have wanted themselves) and 43% of them knew about their relatives' wish to donate their organs or not. This share is nearly twice as large as the respective percentage for non-cardholders: only 25% of this group knew the preference of their relatives. These numbers illustrate not only that there is a discrepancy between what people think others know about them and what they actually know. They also indicate that cardholders are more likely to talk with their family about organ donation: only this can explain the fact that they seem to know much more about their relatives' attitudes than the opponents to organ donation or the undecided fraction. This fits our assumption that beyond its function as a record of the person's wish, the card is also, and possibly foremost, a vehicle to initiate communication with relatives. This is particularly important as in our culture death has become a taboo: while in the past people were confronted with death early in life (siblings or grandparents dying at home), this happens much less frequently today. We need to find ways to break the taboo on death and dying to make families talk about organ donation, and the donor card seems a promising approach.

## Implications

A key implication of this study is that future communication campaigns for organ donation should focus on the determination of communicating one's willingness to donate one's organs or not to relatives or to a person of trust (article 8.6 of the 2007 transplantation law), so that, in case of an accident, they can make an informed decision. Relatives are put in an extremely stressful situation and their decision is biased by their own attitude, up to the point where they might overrule what the deceased person would have decided. To prevent the relatives' scepticism from overturning a dead person's own wishes, it appears to be advisable to emphasize one's determination to become an organ donor in case of death in family discussions. Any campaign should emphasize the importance of communicating this determination within families.

Second, the importance of the donor card should not be underestimated. Filling in the donor card may also lead to discussions with friends and colleagues which may again be an incentive to mention the

topic within the family as well. Additionally the communication process in the hospital between doctors and relatives is most important although it seems that doctors are generally behaving in compliance with the law. Finally, as the fact of not having thought about organ donation and/or holding adverse general attitudes to it emerged as major factors in generating the loss of potential donors to transplantation medicine, possibly overruling a sizeable number of cases in which relatives thought they knew their deceased family member was ready to donate organs, it seems advisable to induce people to think about the issue, and to promote generally supportive attitudes. Any campaign to urge people to tell their relatives what they wish seems to be to a large degree pointless when relatives are predisposed against organ donation. Awareness campaigns should rather (or at least also) address these adverse predispositions. There is some tension between a generally favourable attitude to organ donation that emerges in population surveys and the fact that doctors on average see relatives split at 50:50 in favour and against organ donation. If we accept that the doctors' observations are realistic, this raises the question: why does the favourable attitude in general not translate, when a decision must be made about the body of brain-dead relative, into a behaviour in which doctor recognize a person predisposed in favour of donation. This is a subject for further research. A likely answer to this question is that the abstract favourable attitudes visible in surveys break down when relatives are confronted with the real decision in a real situation. If that is true, information campaigns should inform people about the circumstances of real situations in which they might have to make a difficult decision. Even if such information campaigns were to lower support for organ donation in some sections of the population, this appears to be an acceptable consequence, for in a concrete situation, these people would be unlikely to demonstrate a favourable attitude anyway. On the other hand, information on the conditions under which they would have to decide whether a relative was to become a potential donor may prepare some favourably predisposed relatives for the toughness of the decision to make, and thus strengthen their resolve to consent to organ donation when a decision comes up.

## Limitations

The main limitation of our study is that our data only consists of nine face-to-face interviews. However we contacted the main public hospitals in Switzerland that have transplantation centers on their premises, and managed to interview the head of intensive care units of at least two hospitals per language region. Moreover, our interview partners, who represent the most important hospitals of the country, are among the most experienced in this field in Switzerland. Another problem is the possible bias of the doctors' memory of the situations they experienced throughout their career. One of the interview partners mentioned that he/she was more likely to remember the dramatic cases than the ones who agreed to organ explanation without any problem. Hence the results may be biased in a negative way. Finally, the study treats families as if they were in agreement on donation issues. Future studies should address how conflicting views within families affect their consent to donation. A further limitation is that we necessarily treated family communication about organ donation by a recently deceased close relative as if it existed isolated from a larger social or cultural context. Not studying this context does not imply to deny its importance. To the contrary: as attitudes and the readiness to donate one's organs differ between countries or between the micro-cultural entities within countries such as the language groups in Switzerland,<sup>5,15,17,20-23</sup> so will family cohesion and communication pattern, taboos on death, knowledge of one's families preferences be strongly affected by cultural backgrounds. To receive a full picture of organ donation decision making, these factors will eventually also have to be considered.

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