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### **Psychosocial Determinants of Organ Donation Intentions and their Relevance for Public Campaigns**

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## Psychosocial Determinants of Organ Donation Intentions and their Relevance for Public Campaigns

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### Abstract

*There is a universal shortage of organs available for transplantation, which could be reduced by increasing the posthumous organ donation rates. The present paper presents an overview of the various sets of factors that have been proven to influence people's decision to consent to the donation of their deceased next of kin's organs, as well as their intention to become organ donors. We highlight the essential part played by the individual's attitudinal beliefs about organ donation for his/her intention to donate and briefly present the most relevant theoretical models and influences in this area. Across this synthesis, we also describe the key features of a series of public campaigns promoting organ donation that intended to address some of these psychosocial factors as a way to increase people's willingness to donate.*

### Keywords:

*organ donation, transplantation, willingness to donate, intentions, attitude, beliefs, organ donation campaigns*

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### Introduction

Organ and tissue transplantation has gradually become an effective intervention, saving or at least improving the lives of many people. In spite of its increasing availability from the technological standpoint, the gap between the number of people waiting for an organ to be transplanted and the numbers of donated organs deepens each year all over the world. This universal shortage of donated organs could be diminished by increasing the numbers of organs retrieved from deceased donors. In turn, this option is dependent on the consent or refusal of the appropriate parties. Some countries regulate this issue through an opt-in system, in which organ retrieval is possible only if the deceased had expressed his consent to donation in a certain legally – acceptable manner, such as a donation card. In other countries, individuals are presumed to consent to donate their organs posthumously unless they opt-out of donating, a system that has been shown to increase donation rates significantly (Abadie & Gay, 2006). In both cases, an essential part in the actual donation situations is played by the deceased's family members, who are entitled to give consent to donation under the opt-in legislative systems or, conversely, to refuse donation in many of the countries with an opt-out system. Furthermore, some investigations (e.g. Garrison et al., 1991) suggest that the bereaved families' denial to grant consent for the donation of their deceased next of kin's organs is the main impediment for the loss of potential donors.

The present article aims to provide a synthesis of the psychosocial issues relevant for the topic of the individual's consent to organ donation, from two parallel perspectives. On the one hand, we present the most important determinants of people's willingness to donate their or their deceased next of kin's organs, as revealed by previous empirical studies on various populations, grouping them into their appropriate categories. On the other hand, the public campaigns aimed at increasing people's openness towards donation have targeted various psychosocial factors delineated in our analysis. We illustrate these various efforts in relationship to their appropriate psychological or social benchmarks, in order to develop a comprehensive account of the mechanisms in which the public's intentions to donate can and sometimes have been enhanced. The last category of factors, pertaining

to people's attitudes and beliefs on organ transplantation, has been the target of the majority of the public campaigns developed so far; consequently, it is also our main focus of analysis.

### **Layers of determinants of organ donation intentions**

Generally, studies have revealed that the factors influencing the family members' decisions regarding organ donation from their deceased next of kin belong to several layers. First, the moment of this decision is emotionally charged, the shock of the close one's death hindering the donation consent (Lauri, 2006). As such, the behavior of the medical staff in general, and in particular of those who ask the family's permission to retrieve his/her organs becomes paramount. Specifically, the request pattern employed in this discussion (Siminoff et al., 2001) and its timing (Rodrigue, Cornell, & Howard, 2006), the family's satisfaction level with the medical care received by the deceased (Martinez et al., 2001) and with the behavior of the transplant team representative (in terms of sensitivity to their drama) can impact the family's decision. Moreover, even the knowledge and attitudes of medical staff on organ transplantation influence the outcome of the decision-making process undergone by the family members (Duke et al., 1998), as well as the information provided to the next of kin before asking their consent (Tymstra et al., 1992), particularly regarding the state of "brain death" (Jasper et al., 1991).

Beyond these situational factors, which can equally affect all individuals faced with such a decision, the second layer of determinants includes the interpersonal influences that can shape and change people's attitudes and intentions to donate. The most important type of such influences are those exerted by the individual's family members (Irving et al., 2012) ones; for instance, individuals whose life partners have a positive outlook on organ donation tend to have positive attitudes on this topic themselves (Ríos et al., 2007). Consequently, the aforementioned situational factors affect the donation decisions especially when the wishes of the deceased concerning organ donation are unknown to his family. When family members had been informed by the deceased about his intention to donate his organs posthumously, most of the families give their consent (Rodrigue et al., 2006). Nevertheless, in most of the cases the next of kin are not aware of these

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donation intentions, since the deceased had not expressed them to any family member (Corlett, 1985). Given the importance of family discussions about organ donation, public campaigns in the West, such as “Donate Life America” (Morgan et al., 2008) have focused on convincing people to engage in such discussions, that would presumably lead to more frequent donation consent rates. On the other hand, studies show that family discussion can also have the opposite result, due to the negative reactions of the other family members, enforced by the current social norms that oppose donation. Thus, merely engaging in discussions of organ donation hardly ensures the increase in people’s willingness to donate.

So far, the individual’s willingness to donate his organs or to consent to donation from his deceased next of kin have been shown to be a product of the context he is placed in, either in the actual situation of being required to give his consent, or in the social context that had gradually shaped his intentions. Finally, the third layer of relevant factors includes people’s personal attributes that can render them more or less open towards consenting to donate their own organs or those of their next of kin. Generally, social scientists have focused on two main categories of such internal factors, namely the individual’s knowledge of organ transplantation – related issues and his/her attitudes towards donation.

### **Knowledge and attitude toward organ donation and transplantation**

First, the amount of the public’s information has been presumed to be an important determinant of overall organ donation rates. There are studies confirming this assumption, revealing that people’s willingness to donate is associated to their knowledge on the essential issues of transplantation, especially those concerning the brain death concept (e.g. Ríos et al., 2008). Another type of information proven to influence people’s approach on donation is their awareness of the massive need for organs, of the large number of people on the transplant waiting lists (Creedy, Wright, & Berg, 1992). Subsequently, some scholars suggest that the major aim of public campaigns should be increasing people’s awareness of the necessity of organs to be transplanted (Wong, 2010). For instance, a national organ donation campaign implemented in

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Malta in 1995 focused on this awareness – enhancing objective, ulterior assessments (Lauri, 2006) indicating its positive effects on people’s donation intentions.

Nevertheless, other studies suggest that correct knowledge might be only a necessary, but insufficient condition for organ donation consent (Morgan, Miller, & Arasaratnam, 2003). An illustration of its weakness in determining people’s willingness to donate is offered by the investigations revealing that high public awareness can coexist with low intentions to donate (Morgan & Miller, 2002; Horton & Horton, 1990). Such results highlight the necessity of a deeper psychological concept, responsible for people’s intentions to donate, that should be taken into account and targeted by the public campaigns developers. The concept that has received most of the attention in this respect, in terms of empirical researching, theorizing and motivating campaign efforts is one’s attitude toward organ donation and transplantation. Across its various definitions, the core of the attitude concept entails the individual’s positive or negative evaluation of the respective object. In the organ donation area, the according hypothesis concerning its role is that people’s willingness to donate can be increased by shifting their attitudes towards the positive end.

An example of a public campaign based on this assumption is that implemented in southern California from 2001 to 2003, targeting the attitudes towards organ donation among the Hispanic community. Its intention was to highlight, in an emotional and empathy – provoking manner, the fact that the members of the audience could save a life by consenting to donate their organs after death, when they would “no longer need it” (Frates, Bohrer, & Thomas, 2006; p. 686).

Generally, studies indicate an association between people’s attitudes toward donation and their actual donation-related behaviors, such as signing a donor card (Skumanich & Kintsfather, 1996; Morgan et al., 2002). Nevertheless, some problematic issues have also been raised concerning the efficiency of targeting attitudes in order to increase organ donation rates. First, there are empirical results that reveal very low or even null effects of attitudes on donation intentions (e.g. Feeley & Servoss, 2005). Second, the rationale of investing efforts in enhancing the public’s positive attitudes toward organ donation has been contested, since they already seem to be overwhelmingly prevailing. Particularly in

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the Western countries, people have strong favorable attitudes toward donation, even in the absence of any organized effort to enhance their willingness to donate (e.g. Cosse & Weisenberger, 2000). A third issue is that due at least in part to this already high level of social approval of donation, many of the attempts to improve attitudes toward organ donation have failed to attain their objective.

### **Theoretical models of attitudes towards organ donation**

On the one hand, this diversity of findings could stem from the variations in the measurement instruments employed in the assessment of people's attitudes. On the other, it highlights the need for more complex theoretical models concerning the effects of attitude on behavior, which should be called upon and tested in the area of organ donation.

Many of the particular models centered on the attitudes toward organ donation on which research in this field is based on derive from the reasoned action framework (Fishbein & Ajzen, 1975). According to this theory, one's intention to behave in a certain way generates his respective behavior; in turn, one's intention is influenced by his attitude toward that behavior and his subjective norms, their apprehensions concerning the way the behavior is perceived by those important to him. The theory of reasoned action proved to be useful in predicting people's organ donation-related behaviors (e.g. Morgan & Miller, 2001). The role and the complexity of the norms one perceives as ruling organ donation were highlighted by a set of results (Park & Smith, 2007) showing that one's intention to become an organ donor depends on five types of relevant norms. They concern not only the degree in which the individual perceives the respective behavior as frequent among and endorsed by those important to him (the personal and subjective norms), but also by his fellow citizens in general (the societal norms). Consequently, organ donation campaigns should also target each of these multiple perceived norms, for instance by claiming and insisting on the fact that organ donation is gradually becoming more frequent and valorized in the respective cultural space.

The successive version of this model – the theory of planned behavior (Ajzen, 1985) – adds to the previous set of variables one's perceived behavioral control over the situation as a predictor of his

intentions to display the respective behavior. A similar refinement of the initial framework was brought by the integrative model of behavioral prediction (Fishbein & Cappella, 2006), developed in the realm of health-related behaviors. It asserts that the essential predictors of one's intention are attitudes, subjective norms and self-efficacy (i.e. one's confidence in his abilities to perform the behavior). Studies employing this extended model (e.g. Bresnahan et al., 2007) have also provided support for his validity in the area of organ donation intentions.

A further theoretical development was introduced by Morgan et al. (2002) in their Organ Donation Model, which tailored the reasoned action framework to the specific psycho-social circumstances of organ donation. In this model, one's intention is determined by attitude, knowledge on the topic and subjective norm; furthermore, this set of variables is influenced by others: the information one is exposed to, the benefits he perceives as brought by the behavior and his non-cognitive (or "irrational") beliefs on the matter of organ donation and transplantation. The model inspired a multi-channel public campaign in the US ("The Worksite Organ Donation Promotion Project", Morgan et al., 2002) mainly aimed at increasing favorable attitudes toward organ donation and the rate of signed organ donor cards. The eight-month campaign utilized two channels of communication. First, mass media was utilized, through newspaper articles about employees who decided to consent to the donation of a next of kin's organs, or about those on the transplant waiting lists; billboards and intranet websites with messages contradicting misconceptions about donation or presenting information on the high necessity of organs; radio announcements. Second, several types of means of interpersonal influence were also employed, such as educational sessions on organ donation.

### **Attitudinal beliefs about organ donation**

A key factor in the determination of one's attitude toward organ donation and, subsequently, of his intentions to donate are his beliefs about the issues of donation and transplantation. The relevance of beliefs is explicit in the Organ Donation Model presented above. Moreover, one of the most influential theoretical models in the area of attitudes in general, namely the expectancy-value model (Fishbein & Ajzen, 1975), states that the individual's beliefs about the object are at



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the core of his attitude. Consequently, many of the current instruments addressing people's attitudes toward donation require them to express their endorsement of a specific set of statements, each of which assert a particular characteristic of donation and transplantation. Hence, in order to increase people's positive attitudes, it is mandatory to persuade them that organ donation has desirable consequences (such as the fact that it saves other lives), and to contradict and eliminate their beliefs that oppose donation (such as that it prevents future resurrection).

It is important to note that beliefs have also been investigated independent from the concept of attitude in relationship to their presumed effects on people's intentions to become an organ donor. Generally, the purpose of such studies was to explore people's motivations for consenting or refusing organ donation; hence, the psychological area that beliefs were theoretically presumed as being relevant to was not attitudinal, but motivational. For instance, Amir & Haskell (1997) explored the "reasons" of those opposing organ donation (for instance, because it is "against religion"), while Lawlor et al. (2010) revealed a set of "concerns" shared by those not willing to donate their organs. The fact that beliefs have been conceptualized as relevant for both motivation and attitudes does not imply their theoretical ambiguity. In fact, there is a close psychological proximity between the two perspectives on belief, as they represent different layers of analysis of the same phenomena. More precisely, one's beliefs, representing the core of his attitudes toward the object, can stem from various motivations concerning that object. Therefore, beliefs can be conceptualized as both structuring one's attitude and as generating from one's deeper personal motivations. A study carried out by Wang (2012) illustrates this double-layered approach on beliefs: the author developed a scale assessing people's "Attitude Functions for Organ Donation", comprising a set of attitudinal beliefs distributed in three motivational factors (utilitarian, ego-defensive and value-expressive) derived from Katz's (1960) attitude functional theory. The utilitarian set includes items such as "Being a posthumous organ donator would make it hard for my family to cope with the event", stating the perceived personal costs of donating. An example of the value-expressive beliefs included in the instrument is "Being a posthumous organ donator would show I am an altruistic person", assessing the degree in which organ donation is part of the

individual's identity. Finally, items such as "I might be pronounced dead by the doctors if I am an organ donor" correspond to the ego-defensive function of one's negative attitude towards donation, in the sense that they address the individual's defense mechanisms, which he uses in order to rationalize his profound opposition to donation. Thus, according to this theoretical grid, the individual's endorsement of each such belief is, in fact, a manifestation of a certain motivation; at the same time, the beliefs he endorses – positive or negative towards organ donation – reflects his attitude on the matter. One potentially useful suggestion of this approach is the tailoring of campaign messages promoting donation on the motivational profile of the audience members. For instance, the registration as an organ donor could be promoting through messages stating that non-registration is incompatible with the values prevalent in the respective cultural space (Wang, 2012).

### **Sources of attitudinal beliefs about organ donation**

Beyond these theoretical nuances, a key element that any researcher should take into account when investigating attitudinal beliefs is their possible sources. In order to comprehend the psychological underpinnings of people's intentions regarding organ donation, it is important to go beyond the simple list of beliefs that might be relevant for their attitude, and to understand their deeper factors.

Since there are large variations between countries in actual organ donation rates, there have been many investigations of the socio-demographic variables that predict attitudes toward donation in each cultural space. Among them, the most frequent factors that emerged as significant predictors are age (Sander & Miler, 2005), education (Rosel et al., 1999), socioeconomic status (Boulware, 2002), gender (Chen et al., 2006), ethnicity (Spigner et al., 2002) and religious background (Randhawa, 1998). Another factor is the individual's previous experience with aspects that are relevant to organ donation and transplantation, such as knowing someone who received an organ or having personally donated blood (Conesa et al., 2003).

The results of the investigations of the psychological factors of organ donation attitudes and, consequently, intentions have revealed several categories of such influences. First, some might be produced by more internal motivations, as in the aforementioned perspective adopted

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by Wang (2012); other such motivational beliefs, revealed by studies employing this framework, are the desire to respect the limits set by God or nature (Sanner, 1994) or to avoid upsetting family members who reject organ donation (Birkimer et al., 1994). Also mentioned above, knowledge about the topic in general, and particularly of the brain death concept (Conesa et al., 2003), represent a significant predictor.

Aside from the personal lack of awareness and knowledge about these issues, an important type of knowledge-related factor is the belief in the mass-media propagated “myths” about organ donation and transplantation (Morgan, 2008), such as the belief that brain death would be prematurely declared by the medical staff in the case of those who had consented to donate their organs. These false beliefs can be induced by various types of media contents that relate to organ donation; for instance, Morgan et al. (2007) revealed that the entertainment television shows in the U.S. employ several frames when representing this topic, most of them negative (e.g. “Donors are sources of spare parts”). In turn, these associations put forth by the media in their portrayal of organ donation – related events can spur various negative beliefs in the general public, fueling their negative attitudes toward the issue. Since these false beliefs tend to be widely spread among the public, various scholars (e.g. McIntyre, 1990; Morgan & Miller, 2002) have urged public campaigns to address and contradict them. For example, the aforementioned “Worksite Organ Donation Promotion Project” aimed, among others, to contradict a potentially dangerous belief shared by its audience, namely that signing an organ donor card guarantees their becoming donors. The campaign used billboard messages informing people that they also had to communicate their donation wishes to their families (Morgan et al., 2002).

The level of trust one has in the medical system in general (Morgan et al., 2008), but also in his current attending physician (Alden & Cheung, 2000) also influence his attitude toward organ donation. Relatedly, people who doubt the utility of organ transplantation have low intentions to donate their organs (Lopez et al., 2012). The psychological relationships people have with their own mortality also matter in this respect: acceptance of mortality positively influences their attitude toward organ donation (Lopez et al., 2012), while the refusal to think about death has a negative effect (Sanner, 1994). Among the personality

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factors that have been found to impact people's attitudes on this issue are empathy (Skumanich & Kintsfather, 1996) and locus of control (Cleveland, 1975), the more empathic and more internally controlled people showing more positive attitudes. The personality trait that has been most extensively researched in this respect is altruism (e.g. Morgan et al., 2003). For instance, Newton (2011) explored the multifaceted nature of altruism in the area of organ donation intentions. He categorizes the altruistic beliefs revealed across several studies on this topic into four relevant aspects that people consider as brought by organ donation: it helps those in need, it helps the broader community, it implies indirect reciprocity and it avoids social or cultural isolation. A related personality concept affecting organ donation attitudes is humanitarian impulses (Cleveland, 1975).

Another major psychological background of organ donation intentions is the emotional one. Most of the studies in this area focused on the fears that the individual feels in relationship to certain perceived risks of consenting to organ donation. We mentioned above the media-induced belief shared by some people in the premature declaration of death in the purpose of organ harvesting; this belief has also strong affective consequences, as the fear of premature pronouncement of death was revealed as an important factor for people's low intentions to donate their organs (Lopez et al., 2012). Among other anxieties that emerged as significant predictors of these intentions are: the fear of disfigurement of the body in the process of organ extraction (Skowronski, 1997); the fears that organs might be used for medical research, that doctors would not do everything possible to save one's life, of being cut up alive or having pain after death (Loch et al., 2010). Similarly, studies revealed as important in this area the fear of death and burial (Cleveland, 1975), of organ donation preventing resurrection or reincarnation and of organs being used improperly or unfairly (Lopez et al., 2012). Some of the influential fears are specific to certain body parts; for instance, Sque & Payne (1996) found that anxieties related to the possible need for eyes in the afterlife are associated to low intentions to donate this type of organ. In the same field of body-related concerns, Besser, Amrir, & Barkan (2004) found that organ donor cardholders have better body image perception than nondonors.

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Another type of negative emotional experience affecting people's attitudes and intentions regarding organ donation is the dislike felt towards having one's organs in someone else's body (Loch et al., 2010). In the opposite realm, there are also positive affective connotations of organ donation and transplantation, which contribute to positive intentions on the matter, such as the pride of being an organ donor (Parisi & Katz, 1986).

Given the massive impact that donation – related emotions can have on the relevant intentions, one of the main aims of the social marketing efforts promoting donation should be the alleviation of people's negative emotions (particularly fear) concerning this issue (McIntyre, 1990). As most of these fears stem from various concerns about the consequences of donation, many of them propagated by the media, the public campaigns targeting these “myths” would also presumably address and alleviate people's fears.

### **The Romanian case – suggestions for future organ donation campaigns**

In the Romanian context, the results of an investigation on a representative sample of the residents of Iasi pinpoint four factors of the public's attitudes towards posthumous organ donation for transplantation (Holman, 2013). The first, labeled “altruism towards those in need of organ transplantation” includes beliefs stating various positive consequences of organ transplantation from for the organ recipient (such as “prolongs the life of other persons”). The second, labeled “lack of information”, is comprised of statements asserting false beliefs about transplantation, such as that “the donor would recover from brain death”. The third factor relates to the religious concerns about donation; labeled “transgressing the sacrality of the donor's body”, it includes items such as “Organ transplantation from deceased donors is against God's will”. Finally, the fourth factor, labeled “the donor's family suffering relief”, includes items such as “Consenting to organ donation from a deceased relative is a good deed through which his family can ease their suffering”. The practical value of these results is that they offer a clear frame of the four categories of psychological elements that should be addressed by potential organ donation campaigns. In short, they suggest that the public's attitudes towards posthumous donation are

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more likely to be improved by campaigns with a twofold aim. On the one side, they should disseminate correct information on the key issues of donation and transplantation and address the negative religious concerns opposing donation. In this respect, the involvement of the Church representatives would be beneficial. On the other hand, the public campaigns should further highlight the positive consequences of organ donation for the two sides involved in the transplant situation: the organ recipient as well as the donor's family.

### **Conclusion**

Beyond their apparent diversity, the various types of sources of organ donation attitudes and intentions are closely articulated. The emotions people feel when thinking about these issues are, at the same time, motivational basis for their high or low intentions to become a donor. The relevant personality factors also have affective and motivational consequences for the respective individual in what regards the topic of organ donation. Most of these sources have a common psychological ground that translates them into one's attitude toward this object: attitudinal beliefs. The correct or false beliefs (including the media-induced myths) one holds on organ donation and transplantation inform on his level of knowledge concerning these issues. Similarly, the relevant emotions and motivations have been empirically assessed through the statements endorsed by the individual. For instance, the fears one might have towards donating his organs are accompanied by a set of beliefs that articulate them. On the other hand, we have pinpointed the manner of revealing people's internal motivations to accept or refuse organ donation through the assessment of their beliefs on the matter. Moreover, even general influences, such as those of religiousness or personality factors, manifest themselves into relevant beliefs. Consequently, by focusing on the layer of beliefs in the evaluation of people's attitudes on organ donation and transplantation, one can gain access to the entire realm of possible sources of these attitudes, which offers a deeper understanding of their psychological underpinnings than merely asking for general evaluations or intentions. The development of public campaigns could benefit from these results, which highlight the main issues to be addressed and contradicted or

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