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Factors of the Willingness to Consent to the Donation of a Deceased Family Member's Organs Among the Romanian Urban Population

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ABSTRACT

Objectives. Romania ranks near the bottom of the European hierarchy of posthumous organ donation rates. Objectives of this study were as follows: (1) to assess the willingness to donate (WTD) a family member's organs in the inhabitants of a large Romanian city (Iasi) and to analyze its factors; and (2) to determine the most important behaviors of the medical staff for our respondents in a hypothetical donation decision scenario.

Methods. The study included a representative sample of the Iasi population. The instrument addressed WTD a family member's organs, both in general and in the particular situation of knowing that the deceased had a positive attitude toward organ donation, knowledge of transplantation-related issues, endorsement of beliefs concerning organ donation, and the importance of a set of medical staff's behaviors.

Results. The questionnaire was completed by 1,034 participants, 48% ($n = 496$) of whom would most likely consent to donate a family member's organs, 18% ($n = 191$) would most likely refuse and 34% ($n = 347$) were unsure. The following factors were found to influence this variable: believing in the possible reversibility of brain death ($P = .004$); believing that body integrity should be preserved after death ($P < .001$); believing that part of the deceased continues to live through the organ recipients ($P = .001$); and being concerned about mutilation after donation ($P < .001$).

Conclusions. The WTD the organs of a deceased next of kin in the Iasi population, even when the deceased had positive attitudes on the matter, is lower than that reported by other studies in other European countries. It is mainly influenced by knowledge and concerns regarding the posthumous manipulation of the body. Consent in a potential donation situation also depends on the way in which the medical staff interacts with the bereaved family.

ORGAN and tissue transplantation has gradually become not only an effective life-saving procedure, but also a cost-effective intervention, less restricted to the developed countries and increasingly available for residents all over the world. Nevertheless, worldwide the number of people waiting for an organ greatly surpasses the number of organs that are donated. This universal shortage of organs available for transplantation could be reduced by increasing the number of organs recovered from deceased donors. However, in many cases the bereaved families refuse to grant consent for donation.[1,2] The posthumous donation rates vary widely among countries; Romania ranks near the bottom of the European hierarchy, with 3.6 deceased donors per million of the population in 2011.[3] Moreover, earlier surveys[4] have revealed a similar reticence of Romanians regarding relevant attitudes and intentions, with only 34% of the Romanians indicating that they would agree to donate an organ from a deceased close family member—far below the European mean of 53%.

So far, there have been no large-scale investigations of the factors affecting Romanian attitudes and willingness

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to donate (WTD) their deceased next of kin's organs. Our aim was, first, to assess the willingness to give this consent in the inhabitants of a large Romanian city (Iasi), both in general and in the particular situation of knowing that the deceased had a positive attitude toward organ donation. Second, we aimed to identify the determinants of people's WTD their relative's organs in terms of sociodemographical characteristics, knowledge about brain death (BD), and beliefs or concerns about posthumous organ donation. Moreover, given the impact of medical staff behavior on the family donation decision,[5] we sought to determine the most important such behaviors for our respondents in a hypothetical donation decision scenario.

METHODS

Study Population

Iasi is the fourth most populated city of Romania, with ~300,000 inhabitants.[6] A representative sample of the city residents was selected through a 3-stage probability sample design. First, 46 city areas were selected through an area probability frame; second, housing units within each area were randomly selected and, finally, 1 adult randomly selected from each household. The questionnaire was administered by previously trained operators from February to March 2012. A total of 1,034 adults completed our anonymous survey (97% participation rate). The study was approved by our institutional Ethics Committee.

Variables Analyzed

The dependent variable was WTD a family member's organs, participants being required to choose among the following options: "most likely consent." "unsure," and "most likely refuse." The independent variables were: (1) demographic (sex, age, education, marital status, having descendents, religion); (2) knowledge of transplantation-related issues, assessed through 2 items: belief in the possible reversibility of BD, and self-assessed level of information on the concept of BD (low vs high); (3) a set of 5 beliefs or concerns about posthumous organ donation, revealed by earlier studies as having a significant impact on people's attitudes and intentions to donate their or their next of kin's organs: the belief that body integrity should be preserved after death,[7] mistrust of the organ transplantation system,[8] concern about transfer of personality traits from the donor,[9] concern about mutilation after donation,[10] and the belief that part of the deceased continues to live through the organ recipients, presumably supporting organ donation[11]; and (4) whether participants would donate their own organs.

In addition, participants were required to express their WTD the organs of a family member who had a positive attitude toward organ donation, as well as to assess how important a set of medical staff behaviors would be for them in a hypothetical donation decision scenario, as rated on a 6-point Likert scale from "completely unimportant" to "extremely important." The set included 6 behaviors regarding the way the medical staff manage the donation request situation (such as clarifying the BD diagnosis or addressing all concerns about donation) that earlier studies[5,12] found to influence the family decision.

Data Analysis

Descriptive statistical analysis was performed on each variable. The differences between those WTD and not WTD a family member's organs were examined with the use of the chi-square test (or Fisher exact test) or independent t tests. Logistic regression was used to examine the influence of the independent variables that emerged from the bivariate analysis as significantly associated with one's willingness to donate a family member's organs. P values of $<.05$ were considered to be significant. All analysis were performed with the use of SPSS 15.0 software.

RESULTS

Willingness to Donate

In this study, 48% of the respondents ($n = 496$) were most likely consent to donate a family member's organs, 18% ($n = 191$) were most likely refuse, and 34% ($n = 347$) were unsure. In the hypothetical scenario of knowing that the deceased next of kin had positive attitudes toward organ donation, 11% would refuse to donate his organs ($n = 112$), 70% would consent ($n = 723$), and 19% were unsure ($n = 199$). Regarding the posthumous donation of one's own organs, 59% would consent ($n = 615$), 16% would refuse ($n = 160$), and 25% were unsure ($n = 259$).

Variables Associated with the WTD a Family Member's Organs

Comparing the participants who expressed consent to donate a family member's organs with those who expressed refusal, we found 2 of the demographic variables to be significantly related to this dimension (Table 1): marital status ($P = .003$), with those married being more willing than those widowed or divorced (75% vs 50% and 70%, respectively); and religion, with orthodox and catholic participants (73% and 77%, respectively) expressing higher rates of consent than the protestants (43%).

There was a significant relationship between the dependent variable and one of the knowledge-related items, namely, believing in the possible reversibility of BD ($P < .001$); those who do not hold this belief expressed higher rates of consent: 81% versus 60%. Four of the 5 beliefs and concerns were found to have significant effects on the WTD a family member's organs. Three of them have a negative impact on this variable, namely, belief that body integrity should be preserved after death ($P < .001$), mistrust of the organ transplantation system ($P = .001$), and concern about mutilation after donation ($P < .001$). For example, participants who believed that the integrity of the body should be preserved were less willing to donate a family member's organs (50% vs 81%). Conversely, the belief that part of the deceased continues to live through the organ recipients was found to be positively related to the dependent variable ($P < .001$), those who hold this belief expressing higher rates of consent: 78% versus 59%. There was also a significant positive relationship between the WTD one's own organs after death and the WTD a family member's organs ($P < .001$).

Multivariate Analysis

The results of the multivariate analysis indicated that the following remain as significant factors of one's WTD

Table 1. Variables Associated with the WTD a Family member's organs

Variable	Most Likely Consent ($n = 496$)	Most Likely Refuse ($n = 191$)	*P* value
Sex			.230
Male ($n = 318$)	237 (48%)	81 (43%)	
Female ($n = 365$)	257 (52%)	108 (57%)	
DK/NA ($n = 4$)	3	1	
Mean age	39 ± 16	42 ± 18	.117
Education			.089
Primary ($n = 41$)	25 (5%)	16 (9%)	
Secondary ($n = 365$)	259 (53%)	106 (56%)	
University ($n = 275$)	209 (42%)	66 (35%)	
DK/NA ($n = 6$)	2	4	
Marital status			.003
Married ($n = 358$)	269 (54%)	89 (47%)	
Single ($n = 242$)	176 (36%)	66 (34%)	
Divorced/separated ($n = 37$)	26 (5%)	11 (6%)	
Widowed ($n = 50$)	25 (5%)	25 (13%)	
Religion			.006
Christian Orthodox ($n = 579$)	423 (85%)	156 (82%)	
Catholic ($n = 69$)	53 (11%)	16 (8%)	
Protestant ($n = 24$)	10 (2%)	14 (7%)	
Atheist/agnostic ($n = 15$)	10 (2%)	5 (3%)	
Descendants			.636
Yes ($n = 303$)	216 (44%)	87 (46%)	
No ($n = 384$)	280 (56%)	104 (54%)	
Level of information about the BD concept (self-assessed)			.154
Low ($n = 487$)	344 (70%)	143 (75%)	
High ($n = 200$)	152 (30%)	48 (25%)	
Belief in the possible reversibility of BD			.000
No ($n = 394$)	319 (64%)	75 (39%)	
Yes ($n = 293$)	177 (36%)	116 (61%)	
Belief that body integrity should be preserved after death			.000
No ($n = 473$)	385 (78%)	88 (44%)	
Yes ($n = 214$)	107 (22%)	107 (56%)	
DK/NA ($n = 4$)	2	2	
Mistrust of the organ transplantation system			.002
No ($n = 301$)	235 (48%)	66 (35%)	
Yes ($n = 380$)	255 (52%)	125 (65%)	
DK/NA ($n = 6$)	4	2	
Concern about transfer of personality traits from the donor			.134
No ($n = 412$)	305 (62%)	107 (56%)	
Yes ($n = 269$)	185 (38%)	84 (44%)	
DK/NA ($n = 6$)	4	2	
Belief that part of the deceased continues to live through the organ recipients			.000
No ($n = 209$)	123 (25%)	86 (45%)	
Yes ($n = 472$)	368 (65%)	104 (55%)	
DK/NA ($n = 6$)	4	2	
Concern about mutilation after donation			.000
No ($n = 525$)	425 (86%)	100 (52%)	
Yes ($n = 158$)	67 (14%)	91 (48%)	
DK/NA ($n = 4$)	1	3	
WTD one's organs after death			.000
Most likely refuse ($n = 121$)	22 (4%)	99 (52%)	
Unsure ($n = 108$)	69 (14%)	39 (20%)	
Most likely consent ($n = 458$)	405 (82%)	53 (28%)	

Abbreviations: DK/NA, does not know/no answer; BD, brain death; WTD, willingness to donate.

Table 2. Variables Influencing the WTD a Family Member's Organs (Multivariate Logistical Regression Analysis)

Variable	Regression Coefficient	SE	OR (CI)	*P* value
Belief in the possible reversibility of BD				.004
Yes			1	
No	0.571	0.199	1.771 (1.200–2.614)	
Belief that body integrity should be preserved after death				.000
Yes			1	
No	0.874	0.211	2.397 (1.585–3.626)	
Belief that part of the deceased continues to live through the organ recipients				.001
No			1	
Yes	0.646	0.200	1.908 (1.290–2.822)	
Concern about mutilation after donation				.000
Yes			1	
No	1.269	0.227	3.556 (2.320–5.450)	

Abbreviations: OR, odds ratio; CI, confidence interval; BD, brain death.

a family member's organs after death: not believing in the possible reversibility of BD (odds ratio [OR] = 1.647); not believing that body integrity should be preserved after death (OR = 2.397); believing that part of the deceased continues to live through the organ recipients (OR = 1.908) and not being concerned about mutilation after donation (OR = 3.556; Table 2).

Importance of Medical Staff Behavior

All 6 behaviors received high ratings of importance (Table 3). The within comparisons revealed that 2 of the behaviors were rated as significantly more important than the others: giving clear information about the BD diagnosis (mean 5.31) and clearly addressing concerns about organ donation (mean 5.24). The least important behavior in the set was showing respect for the grief of the bereaved family (mean 4.83), and the differences among the remaining 3 items were not significant. The 3 groups defined by their WTD a family member's organs (consent, refuse, and unsure) differed significantly on all 6 items, with participants who expressed their consent giving higher importance ratings than those who were unsure, and those refusing donation giving the lowest importance ratings.

DISCUSSION

There are large variations among European countries regarding both cadaveric organ donation rates and people's attitudes and intentions to donate, including consent to the donation of their deceased next of kin's organs.[4,13] The present investigation of an urban sample of the Romanian population revealed higher levels of WTD a family member's organs than earlier statistics from the general population.[3] Nevertheless, the rates of potential consent to donation, both of one's own organs and of those of a deceased family member (48% and 59%, respectively), found in the present study are below those reported in similar investigations of the public's relevant intentions and

Table 3. Importance of the Medical Staff's Behaviors in the Organ Donation Process (Mean and SD)

Variable	Most Likely Consent	Unsure	Most Likely Refuse	Overall
Give clear information on the BD diagnostic	5.54 (0.84)	5.20 (1.08)	4.91 (1.54)	5.31 (1.11)
Clearly address my concerns about organ donation	5.47 (0.91)	5.15 (1.06)	4.82 (1.57)	5.24 (1.14)
Allow me time to say goodbye to the deceased	5.34 (1.10)	5.07 (1.23)	4.78 (1.66)	5.14 (1.28)
Avoid any pressure toward obtaining our consent to organ donation	5.28 (1.08)	4.99 (1.16)	4.83 (1.54)	5.10 (1.22)
Allow my family to discuss in a private space before making the decision	5.26 (1.04)	5.00 (1.17)	4.72 (1.58)	5.08 (1.22)
Show respect for our grief	5.09 (1.16)	4.63 (1.35)	4.54 (1.63)	4.83 (1.34)

Abbreviation: BD, brain death.

attitudes in other European countries, particularly in the Western ones.[10,14]

Some of the demographic factors, such as age, sex, and education, reported by similar investigations conducted elsewhere as influencing people's intentions to donate[7,15–17] were not found to be associated with our participants' willingness to grant permission for donation. On the other hand, knowledge about the topic, specifically regarding the irreversibility of BD, significantly predicted swillingness. Because many of our respondents shared false beliefs regarding BD, there is still a large space for improvement in people's relevant knowledge. In turn, as our results suggest, such knowledge enhancement could increase Romanians' openness toward organ donation.

People's beliefs and concerns about organ donation were found to influence their potential consent to donation of their deceased next of kin's organs. Most of the concerns included in our investigation have a negative impact; specifically, lower rates of WTD were found among those who believe that body integrity should be preserved after death and that organ donation entails mutilation. These concerns have been revealed as important in the donation decision by earlier investigations in other countries.[7,18] Beyond people's personal fears, these beliefs also have a religious background. Consequently, a stronger involvement of religious representatives in the public debates on the topic, clearly affirming their support for posthumous organ donation and contradicting these negative concerns, could be beneficial. Another way in which religious figures as well as future public campaigns could support donation is through the endorsement of the beliefs that have positive influences on people's attitudes on the matter, such as the belief in the continued existence of the deceased through organ donation.[19]

The willingness to comply with the deceased's intention to donate organs in our Romanian sample was lower (70%) than that found in other studies on this topic. For example, López et al (2012)[14] reported a 92.5% WTD rate in the scenario of the deceased relative being favorable to donation in their Western European sample, compared with an 80.4% rate in the Eastern European sample. Beyond these variations, our results suggest that the beneficial effect of expressing one's positive attitude toward donation to family members[10,20,21] might not be universal. Although the rates of consent in this situation are still higher than in the absence of any reference to the deceased's wishes, we should be aware that merely communicating one's positive intentions does not ensure that they would be respected by the next of kin. Moreover, earlier studies have revealed unintended consequences of family discussions on this topic, such as the activation of and negative influence of anti-donation social norms. Thus, the simple expression of intent does not automatically lead to actual donation; the manners in which the individual resists negative familial reactions and persuades his next of kin to respect his decision are equally important.

Finally, behaviors of the medical staff in the donation request situation were rated as very important. The 2 most important ones concern the manners in which physicians address the uncertainties, knowledge gaps, and concerns of the bereaved family regarding BD and donation.[22,23] The 2nd important cluster concerns the way the medical staff handles the temporal aspect of the situation. Although time is an important factor in organ transplantation, the potential donors of their next of kin's organs highlighted the importance of diminishing or avoiding any pressure to obtain their consent. Furthermore, the participants with high levels of WTD also gave the highest overall ratings of importance. Thus, their positive intentions appear to be conditioned in some degree by their perception of the physicians' behaviors in the actual donation situation. Disrespecting their wishes and terms can lead to their refusal to consent to donation, despite their and even the deceased's positive attitudes.[24]

In conclusion, the willingness to consent to the donation of their deceased next of kin's organs in the Iasi population, even when the deceased had positive attitudes in the matter, was lower than that reported by studies in other European countries, in line with the earlier international rankings. Its factors rely on 2 areas: insufficient knowledge and negative concerns about the consequences of organ donation. Therefore, public campaigns aimed at disseminating correct information on the topic and voicing religious representatives' endorsement of donation are called for. Also, the role of the medical staff in addressing family members' concerns and avoiding pressure toward obtaining their consent appear as paramount in actual donation situations.

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