

RELUCTANCE AND WILLINGNESS FOR ORGAN DONATION AFTER DEATH AMONG THE SLOVENE GENERAL POPULATION

ZADRŽKI IN PRIPRAVLJENOST DAROVATI ORGANE PO SMRTI MED SPLOŠNO POPULACIJO V SLOVENIJI

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ABSTRACT

Keywords:

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Introduction: The paper presents the findings of the first large-scale survey on post-mortem organ donation among the general Slovenian population. It focuses on the reported donation willingness, the barriers to joining the register of organ donors and the position towards consent to donate organs of deceased relatives.

Methods: A face-to-face survey was conducted on a probability sample of 1,076 Slovenian residents between October and December 2017. The performed analyses included estimations of means and proportions for target variables, an evaluation of between-group differences and a partial proportional odds model to study the relations between organ donation willingness and socio-demographic characteristics.

Results: The mean reported willingness to donate one's own organs after death was 3.77 on a 5-point scale, with less than a third of respondents claiming to be certainly willing. Only 6% of those at least tentatively willing to donate organs were certain to join the register of organ donors in the future. The most frequently reported barriers to registration were unfamiliarity with the procedure and a lack of considering it beforehand. The reported willingness to donate organs of a deceased relative strongly depended on the knowledge of the relative's wishes, yet 80% of the respondents did not discuss their wishes with any family members.

Conclusions: The findings confirm the gap between the reported donation willingness and joining the register of donors. Future post-mortem organ donation strategies need to consider socio-demographic and attitudinal factors of donation willingness and help stimulate the communication about organ donation wishes between family members.

IZVLEČEK

Ključne besede:

pridobivanje organov in tkiv, darovalci organov, ankete in vprašalniki, vzorčne študije, informirana soglasja

Uvod: Pripravljenost darovati organe po smrti je eden ključnih predpogojev za ustrezno delovanje sistema darovanja organov. Članek predstavlja rezultate prve namenske ankete o darovanju organov po smrti med splošno populacijo Slovenije. Osredotoča se na poročano pripravljenost za darovanje organov, ovire pri vpisu v register darovalcev ter stališča do dajanja soglasja k darovanju organov umrlih sorodnikov. Razumevanje teh vidikov je v slovenskem sistemu darovanja organov še posebno pomembno, saj odločitev o soglasju za odvzem organov sprejmejo svojci, ki se pogosto soočajo z nepoznavanjem želja umrle osebe.

Metode: Zbiranje podatkov je potekalo med oktobrom in decembrom 2017 z osebno anketo na verjetnostnem vzorcu 1.076 prebivalcev Slovenije. Vprašalnik je vključeval širok nabor vprašanj o stališčih, povezanih z darovanjem organov, vpisom v register darovalcev, splošno seznanjenostjo s tem področjem ter komunikacijo o darovanju z drugimi osebami. Analiza podatkov je bila izvedena z ocenami aritmetičnih sredin in deležev za ciljne spremenljivke, primerjavo razlik med skupinami ter modelom parcialno sorazmernih obetov za proučevanje odnosov med pripravljenostjo darovati organe in socio-demografskimi značilnostmi anketirancev.

Rezultati: Povprečna poročana pripravljenost darovati organe po smrti je bila 3.77 na petstopenjski lestvici, pri čemer je bila manj kot tretjina anketirancev prepričana v svojo željo darovati organe. Izražena pripravljenost je bila statistično značilno višja med ženskami, najvišje izobraženimi in ateisti v primerjavi z vernimi, nižja pa med starejšimi, ovdovelimi in prebivalci srednje velikih mest. Le 6 % anketirancev, ki bi bili vsaj morda pripravljeni darovati, je bilo prepričanih, da bi se v prihodnosti registrirali kot darovalci organov; med anketiranci, ki so bili prepričani v svojo pripravljenost darovati, je bilo takšnih 17 %. Najpogosteje navajane ovire za registracijo so bile nepoznavanje postopka ter odsotnost razmišljanja o tem, več kot 10 % anketirancev pa je med razlogi navedlo še neprepričanost v željo darovati in prepuščanje odločitve svojcem. Poročana pripravljenost darovati organe umrlega sorodnika je izrazito odvisna od poznavanja želja te osebe, vendar pa se 80 % anketirancev o svojih željah z bližnjimi sorodniki še ni pogovarjalo.

Zaključek: Rezultati potrjujejo vrzel med poročano pripravljenostjo darovati organe po smrti ter vpisom v register darovalcev. Prihodnje strategije spodbujanja darovanja organov bodo morale upoštevati socio-demografske dejavnike in vpliv posameznikovih stališč na pripravljenost darovati organe ter pomagati pri spodbujanju komunikacije med družinskimi člani o njihovih željah glede darovanja.

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1 INTRODUCTION

Transplantation as a form of medical treatment is making substantial progress in terms of patient survival and new methods (1), but its potential strongly depends on the number of people willing to donate their organs. In addition to being a medical issue, organ donation is a complex psychological and social challenge that involves various groups of people: living organ donors and their family members, the family members of deceased organ donors, medical professionals and organ recipients.

Despite generally positive attitudes towards post-mortem organ donation in society, researchers commonly observe a substantial gap between the claimed willingness to donate post-mortem and joining the register of potential organ donors (2, 3). The analysis of indicators available in three nationwide surveys - two conducted at the European level and one at the Slovenian level (4) - revealed the existence of such a gap in Slovenia as well. The proportions of respondents who claimed to be willing to donate their organs after death was 61%, 55% and 75% in two Eurobarometer surveys (2009 and 2014) and in the 2013 Slovenian Public Opinion survey, respectively. However, a strikingly low proportion of Slovenian residents (0.2%) have joined the national register of organ donors (5).

Slovenia is among the countries where relatives are asked to consent to the donation of the deceased person's organs. This can be highly stressful for family members, particularly if they are unaware of the deceased's wishes (6, 7). In Slovenia, the proportion of organ donation requests refused by relatives has varied considerably from year to year, from 13% in 2011 to 37% in 2000 (8). Communicating an individual's position regarding organ donation when the person was still alive can remove part of the emotional pressure on relatives and has been shown to facilitate their willingness to consent to the donation (9-12).

In an opt-in organ donation system the individual's decision to join the register of post-mortem organ donors is the most explicit indication of donation willingness. However, with the low donor registration rates in Slovenia, the importance of communicating the wishes regarding organ donation between family members is further strengthened. An analysis of the 2009 Eurobarometer survey (4) found that 36% of Slovenian residents discussed post-mortem organ donation with the family, which is below the overall EU average of 40%. However, it is unclear whether the organ donation wishes were among the topics of these discussions.

Facilitating post-mortem organ donation requires an in-depth understanding of the attitudes, barriers to the registration of potential organ donors and the importance of communicating the wishes between family members in a particular social and cultural context. Until now, there

was a lack of empirical data on social aspects of organ donation in Slovenia. Even the above-mentioned surveys of the general population were not sufficiently detailed for a comprehensive investigation of the personal and social factors related to the issues of post-mortem organ donation. The presented study is based on the first large-scale survey on post-mortem organ donation among the general population in Slovenia. It was conducted on a probability sample and utilised a comprehensive questionnaire module about the topic. This paper focuses on the self-reported willingness to donate organs after death, the reasons for not registering as organ donors and the position towards consenting to donate relative's organs among the Slovenian general population.

2 METHODS

The data were collected with a survey questionnaire applied to a probability sample of adult Slovenian residents. The study design aimed to represent the general population well and to use methodologically sound measurement instruments. Face-to-face interviewing was conducted between October and December 2017 by the Public Opinion and Mass Communication Research Centre (CJM) at the Faculty of Social Sciences, University of Ljubljana. The interviewers were educated about post-mortem organ donation and trained to appropriately communicate with respondents about this potentially sensitive topic.

2.1 Sample

The target population were Slovenian residents 18 years and older, excluding those living in institutional households. The Central Register of Population, which provides a high coverage of the general population, was used as a sampling frame.

The sampling procedure was carried out by the Statistical Office of the Republic of Slovenia. A sample of 2,000 individuals was selected from the target population using two-stage probability sampling. During the first stage, 200 enumeration areas (EA) were selected, stratified by the region and the settlement type, with the probability of selection proportional to the number of inhabitants in the area. At the second stage, 10 individuals were selected in each selected EA using simple random sampling.

Of the 2,000 individuals, 1,076 completed the interview. The final response rate according to the AAPOR2 standard was 60%. The yielded sample represented the target population well in terms of basic socio-demographic characteristics. Compared to the population, the sample somewhat overrepresented women, individuals over 60 years of age and those with higher education, while underrepresentation was noticeable for individuals

between the ages of 31 and 45, those with lower education, and people from the Central Slovenia region. Although the differences were relatively small, post-stratification weights were calculated using the raking method to match the population structure by age, gender, education and region.

2.2 Questionnaire and Analysed Items

The survey questionnaire covered various donation-related attitudes and behaviours. It was developed by considering an elaborated theoretical framework, and the key issues were identified by a preliminary search (4). Several previous studies were reviewed to select the most appropriate measurement instruments. The relevant questions were translated to the Slovenian language and adapted to the Slovenian socio-cultural context as needed. A preliminary pilot survey was conducted on a Slovenian Internet access panel to verify and adapt the questionnaire.

The final questionnaire consisted of 23 questions and was implemented as a module of an omnibus survey along with the longitudinal Slovenian Public Opinion Survey and the European Values Study. This approach will allow for future evaluations of the relations between attitudes towards organ donation and other social factors.

The main areas of interest in this study include the willingness to donate one's own organs after death, the reasons for not registering as an organ donor and the willingness to give consent to the donation of organs of a loved one that died. Basic socio-demographic characteristics (gender, age, education, marital status and settlement size) and self-declared religiosity were included as control variables to observe the differences in donation willingness among the respondents.

The willingness to donate was measured on a 5-point scale ranging from "certainly not" to "certainly yes". Because the reported willingness may be highly prone to social desirability, the use of such a scale is advantageous over the previous general population surveys in Slovenia that measured the willingness with binary yes/no questions. To better understand the barriers to registering as organ donors, the respondents who reported at least a tentative willingness to donate their organs after death and were not registered donors were asked to select the applicable reasons for not joining the register from a list (partially adapted from (13)).

2.3 Data Analysis

The data for all variables of interest were analysed using a combination of statistical methods for the estimation of means, proportions and between-group differences. A partial proportional odds model was used to explore the differences in the willingness to donate one's own organs by socio-demographic characteristics. Post-stratification weights, described in the sampling section above, were used for all the analyses.

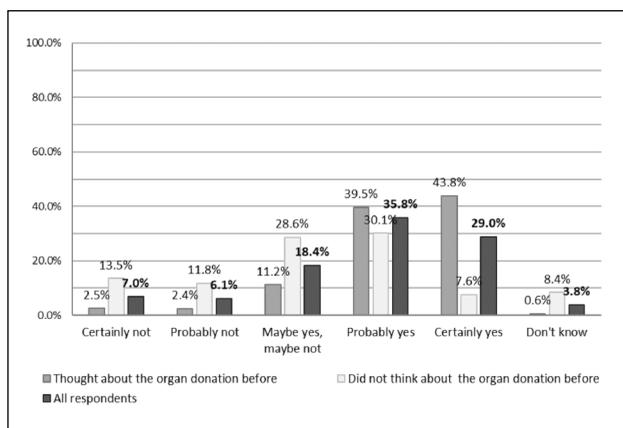
3 RESULTS

3.1 Willingness to Donate One's Own Organs after Death

The respondents claimed a relatively high willingness to donate organs after death. The mean rated likelihood of being willing to donate organs after death was 3.77 (CI95 [3.69, 3.84], P50=4, n=1,031) on a 5-point scale. The distribution of answers to this question for all respondents (the dark shaded columns in Figure 1) reveals that nearly two thirds of respondents claimed to be probably or certainly willing to donate their organs after death, while 13% were certainly or probably not willing. Less than a third of respondents were certain about their willingness to donate.

These estimates are somewhat higher than those by the Eurobarometer 72.3 and 82.2 surveys (61% and 55% willing, respectively) and lower compared to the 2013 Slovenian Public Opinion survey (75%). However, the figures are not directly comparable due to the different question formats employed by the studies, with the previous studies using yes/no questions instead of the likelihood scale. The use of a scale with a mid-point answer category ("maybe yes, maybe not") also helps to explain the substantially lower proportion of "don't know" responses. There were 4% of such respondents in the current study compared to the 15% to 20% observed by the previous studies.

The mean willingness was significantly higher among 59% of the respondents who had been thinking about their wishes regarding post-mortem organ donation prior to participating in the survey (4.20 vs. 3.07, $F=236.78$, $p<0.05$, $n=1,017$). The difference is also reflected in the distribution of answers between the two groups as presented in Figure 1. In particular, the likelihood of being certain in their willingness to donate organs is profoundly higher among the respondents who had been thinking about organ donation beforehand.



n=1,065

Figure 1. Self-reported likelihood of being willing to donate one’s organs after death for all respondents and by previous consideration of organ donation.

Tables 1 and 2 further explore the differences in the willingness to donate by selected socio-demographic characteristics. The former table compares mean estimates among the socio-demographic groups to provide a simple outline of the patterns of differences, while the latter is based on a partial proportional odds model to isolate the effects of individual independent variables. We focus our interpretation on the latter table, as it provides more in-depth insights into the relation of individual socio-demographic characteristics and the willingness to donate.

Table 1. The rated likelihood of being willing to donate organs after death by socio-demographic characteristics of respondents.

		Mean	Std. dev.	95% CI
Sex	Male	3.73	1.06	3.62-3.85
	Female	3.80	1.25	3.70-3.91
Age group	30 or below	3.85	1.01	3.69-4.01
	31-45	3.96	0.97	3.82-4.09
	46-60	3.77	1.14	3.61-3.93
	61 or above	3.54	1.39	3.39-3.69
Education	Primary or less	3.48	1.17	3.27-3.70
	Vocational secondary	3.62	1.21	3.45-3.79
	Technical secondary	3.82	1.07	3.68-3.96
	General secondary	4.08	0.86	3.86-4.29
	Short-term higher	3.67	1.52	3.33-4.00
	Professional higher	3.85	1.13	3.61-4.09
	University or more	4.14	0.95	4.01-4.28
Marital status	Married	3.75	1.17	3.64-3.86
	Registered partnership	4.00	1.01	3.83-4.17
	Widowed	3.23	1.45	2.94-3.52
	Divorced, separated	4.00	1.20	3.65-4.35
	Never married or in reg. part.	3.79	1.04	3.64-3.95
Settlement size (inhabitants)	2,000 or less	3.76	1.13	3.65-3.88
	2,000-10,000	3.78	1.19	3.62-3.94
	10,000-50,000	3.69	1.13	3.51-3.87
	50,000 or more	3.85	1.22	3.63-4.06
Self-reported religiosity	Religious	3.64	1.18	3.54-3.73
	Non-religious	3.85	1.13	3.68-4.02
	Declared atheist	4.28	0.93	4.12-4.45
Total		3.77	1.16	3.69-3.84

n=963

Note: Included are respondents with valid data on all listed socio-demographic variables. The minimum and maximum ratings on a five-point scale are 1 and 5 respectively across all demographic subgroups. The median rating is 4 across all subgroups, except for declared atheists with the median rating of 5.

Table 2. Odds ratios and marginal effects of the socio-demographic characteristics of respondents on the reported willingness to donate organs.

		OR	SE	Marginal effects on response categories ^{a)}				
				1	2	3	4	5
Sex	Male (<i>reference</i>)							
	Female	1.31**	0.17	-1.7%	-1.3%	-2.6%	+0.3%	+5.4%
Age^{b)}				+0.2%	+0.1%	-0.1%	-0.2%	0.0%
	1 vs 2-5	0.97**	0.01					
	1-2 vs 3-5	0.97**	0.01					
	1-3 vs 4-5	0.99	0.01					
	1-4 vs 5	1.00	0.01					
Education	Primary or less (<i>reference</i>)							
	Vocational secondary	1.04	0.23	-0.3%	-0.2%	-0.4%	+0.1%	+0.8%
	Technical secondary	1.16	0.25	-1.0%	-0.7%	-1.5%	+0.3%	+2.8%
	General secondary	1.57	0.45	-2.6%	-2.1%	-4.6%	+0.0%	+9.3%
	Short-term higher	0.97	0.30	+0.2%	+0.2%	+0.3%	-0.1%	-0.6%
	Professional higher	1.08	0.31	-0.5%	-0.4%	-0.7%	+0.2%	+1.4%
	University or more	1.66**	0.38	-2.9%	-2.3%	-5.1%	-0.2%	+10.5%
Marital status	Married (<i>reference</i>)							
	Registered partnership	1.09	0.22	-0.5%	-0.4%	-0.9%	0.0%	+1.9%
	Widowed	0.64*	0.15	+3.2%	+2.3%	+4.3%	-1.4%	-8.3%
	Divorced, separated	1.45	0.46	-1.9%	-1.6%	-3.6%	-0.9%	+8.0%
	Never married or in reg. part.	0.78	0.17	+1.6%	+1.2%	+2.4%	-0.5%	-4.8%
Settlement size (inhabitants)	2,000 or less (<i>reference</i>)							
	2,000-10,000	1.00	0.16	0.0%	0.0%	0.0%	0.0%	0.0%
	10,000-50,000	0.72*	0.13	+2.3%	+1.6%	+3.2%	-0.8%	-6.3%
	50,000 or more	0.90	0.18	+0.7%	+0.5%	+1.1%	-0.1%	-2.2%
Self-reported religiosity	Religious (<i>reference</i>)							
	Non-religious	1.34*	0.23	-1.9%	-1.4%	-3.0%	0.5%	+5.8%
	Declared atheist	2.99**	0.58	-5.1%	-4.3%	-10.6%	-4.4%	+24.5%

n=963, $F_{(20, 943)}=4.92$, $p<0.05$

** $p<0.05$

* $p<0.10$

Notes:

^{a)} Indicates predicted change in the frequency of individual response selection due to each of the socio-demographic characteristics. For the continuous age variable, the value represents an instantaneous rate of change. The values of response categories are: 1: certainly not, 2: probably not, 3: maybe yes, maybe not, 4: probably yes, 5: certainly yes.

^{b)} Coefficients for individual categories are displayed due to violation of the parallel lines assumption according to the Brant test ($p<0.05$).

Table 2 presents the marginal effects on the odds of selecting each of the five response options in the donation willingness question. The expressed likelihood of being willing to donate organs after death was significantly higher among women than men. The effect of age was only significant at the lower end of the donation willingness scale, with older respondents having significantly higher odds of probably or certainly not willing to donate. The donation willingness tends to increase with education, although the effect only reaches significance when comparing the lowest and highest educated respondents. A lower likelihood of donation willingness was also found among widowed respondents and residents of mid-size towns, but both effects are only marginally significant. Donation willingness was found to differ by self-declared

religiosity as well. Particularly, declared atheists were substantially more likely to express a higher certainty of donation willingness than religious individuals.

3.2 Barriers to Registering as Organ Donors

Consistent with previous studies, a substantial gap was observed between the claimed post-mortem organ donation willingness and joining the register. Less than 4% of respondents reported being registered organ donors, and 9% reported that they had signed a Red Cross donor card (which indicates the individual's wish to donate organs, but is not recorded in a register of potential organ donors). However, even the measured low proportion of registered individuals is overestimated, considering that

only 0.2% of the Slovenian population has joined the national register of organ donors according to the register data. The overestimation in the survey is likely due to the social desirability tendencies of some of the respondents. Among 83% of respondents who were at least tentatively willing to donate their organs after death but had not decided to join the register, only 6% were certain about joining the register in the future, 28% were likely, and 44% were tentative. Even among the respondents who were certain in their willingness to donate organs after death, less than a fifth (17%) were also certain to join the register in the future.

The reasons for not becoming a registered organ donor yet, as reported by these respondents, are presented in Table 3. The most common reasons were a lack of knowledge of the registration procedure and not previously thinking about joining the register. Other reasons that at least 10% of respondents used, are as follows: not being sure enough regarding donation willingness, preferring to leave the decision about organ donation to relatives, and having various reasons not listed among the response options (such as old age, health issues and procrastination).

Table 3 further compares the frequency of reasons for not joining the register by the certainty of being willing to donate organs after death. Although lacking procedural knowledge and not thinking about joining the register beforehand are among the most commonly reported reasons in all groups, the frequency of the former increases and the latter decreases with the certainty of being willing to donate organs. Unsurprisingly, almost a third of respondents who were hesitant regarding their willingness to donate organs indicated their uncertainty as a reason for not joining the register.

Other significant differences between groups are more subtle, yet important to recognise. The respondents who were certain about their donation willingness more frequently endorsed the complexity of the registration procedure and time demands as barriers to registration, while the concerns of tempting fate, undecidedness and preference of leaving the decision to relatives were less frequent. In contrast, the hesitant respondents were also specific in mentioning the lack of trust in doctors somewhat more frequently.

Table 3. Reported reasons for not registering as an organ donor among respondents who claimed to be at least possibly willing to donate their organs after death.

Reason for not joining the register	The likelihood of being willing to donate organs after death			
	Total	Maybe, maybe not	Probably	Certainly
The registration procedure is too complex.**	3.3%	1.1%	2.4%	6.2%
Registration would take too much of my time.**	3.0%	0.0%	1.7%	6.9%
I don't know what the registration procedure entails. **	44.5%	30.6%	47.3%	50.3%
I don't think the registration is necessary.	5.8%	5.2%	6.3%	5.5%
I didn't think about joining the register before participating in the survey.**	44.3%	51.4%	46.4%	36.5%
I don't want to tempt fate by joining the register.	4.1%	5.4%	5.0%	2.1%
I don't trust doctors to do everything to save my life if I am on the register.**	4.1%	7.7%	2.7%	3.4%
I am not convinced that I want to donate organs. **	14.3%	32.0%	13.1%	3.6%
Joining the register would not be in line with the wishes of my loved ones.	1.7%	2.4%	2.2%	0.7%
I want my relatives to decide about the donation of my organs upon my death.**	12.4%	16.2%	14.5%	6.9%
Other reasons.**	11.8%	3.8%	11.9%	17.2%

n=807

(respondents who may at least be willing to donate organs after death excludes 3% of eligible respondents who were unable to say why they did not join the register)

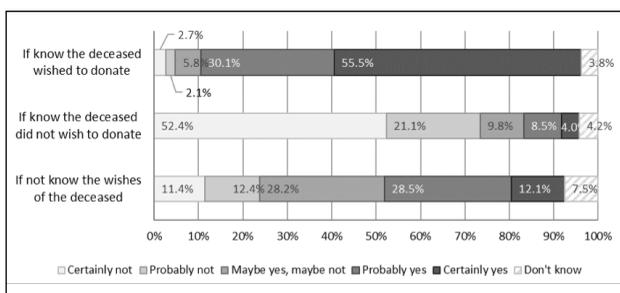
** $p < 0.05$

3.3 Consenting to the Donation of Organs of Loved Ones

The reported likelihood of agreeing to post-mortem organ donation from a person close to the respondent strongly depends on whether the wishes of this person are known to the respondent (Figure 2). The mean likelihood of respondents agreeing to donate the organs of a person close to them was 4.39 (CI95 [4.33, 4.45]) if that person wished to donate their organs, 1.86 (CI95 [1.78, 1.93]) if

the person did not wish to donate their organs, and 3.19 (CI95 [3.11, 3.27]) if the wishes of the deceased were unknown to the respondent. A minority of respondents would be willing to act against the wishes of the deceased, although a somewhat higher proportion would at least probably agree to organ donation despite knowing the deceased did not wish to donate.

The variation of responses is particularly high when the wishes of the deceased were unknown. Although more than 40% of respondents would at least probably agree to organ donation in such a case, only 12% would certainly do so. Furthermore, over 35% of respondents chose a mid-point answer ("maybe yes, maybe not") or were not able to answer the question, which indicates a high level of hesitation. This observation is especially important considering that only 20% of all respondents talked to any relatives regarding their wishes about post-mortem organ donation.



n=1,061/1,062

Figure 2. The reported likelihood of being willing to donate the organs of a deceased loved one by knowing or not knowing their wishes regarding the organ donation.

4 DISCUSSION

The analysis revealed a relatively high proportion of respondents who would be willing to donate their organs after death, which is consistent with other recent studies in Slovenia (4, 8) and elsewhere (14, 15). However, less than a third would be certainly willing to do so. An important observation is the higher willingness among respondents who had been thinking about organ donation before participating in the survey.

Although the causal relationship has not been currently established, the role of established personal position warrants further elaboration as it relates to the willingness to donate. Identifying the stages of change within the transtheoretical model of behaviour change theory (16) could help elaborate this further. According to this theory, the decision for registration and actual registration in the organ donor register needs to be thought of as a process. The model suggests that people go through several stages before they decide to behave in accordance with the

proposed behaviour. In the case of registering as a potential organ donor, these stages are pre-contemplation (not thinking about organ donation), contemplation (thinking of registering for organ donation), preparation (preparing for registering for organ donation), action (register for organ donation) and maintenance. Although these stages do not necessarily follow each other linearly, they do stress that people would be hesitant to express their intentions for behaviour change if they have not at least thought about it previously.

This model brings important practical insights to the designers of interventions for promoting organ donation by emphasising that people need different encouragements to move towards an intention for an actual behaviour, depending on the stage within which they are currently positioned (17). Those who have thought about organ donation before are likely already consciously evaluating the personal relevance of registration as an organ donor. Those who expressed certainty in willingness to become an organ donor (29% in the case of our study) need interventions that would minimise the barriers that keep people away from actual registration. This requires a further study of the reasons that keep people in a particular stage of the behaviour change process.

As previous researchers have cautioned (14, 18), organ donation-related behaviours vary greatly between groups, even in the context of a relatively homogeneous cultural background. The identified differences in the post-mortem organ donation willingness among socio-demographic groups provide some important guidance for promoting organ donation. Although most of the effects are not large, it may be beneficial for potential programs and campaigns to consider generally lower expressed willingness among men, less educated and older respondents. To accomplish this, the obstacles to organ donation willingness within these groups need to be further studied. As reported in some other studies (19), religious respondents reported substantially lower donation willingness compared to atheists. A further investigation using the collected data will be performed to better understand the role of religion and spirituality.

This study further supports the earlier observation of a substantial gap between the reported organ donation willingness and the actual registration as organ donors in Slovenia (4). Since less than a fifth of respondents, who were certain in their organ donation willingness, were also certain in joining the register in the future, it is essential to understand the reasons for such hesitation to stimulate the registration of potential organ donors. It is particularly important to consider the key reported barriers to registration, such as lacking procedural knowledge, not considering the registration, hesitating in regard to donation willingness and preferring to leave the decision to others.

Finally, some important observations were made regarding the likelihood of consenting to the donation of organs of a loved one. Consistent with studies from other countries (12, 20), the likelihood of consent strongly depends on the awareness of the deceased's wishes regarding post-mortem organ donation, with a minority of respondents willing to act against the wishes of the deceased. Unsurprisingly, being unaware of the wishes results in the highest variation of responses and uncertainty regarding the decision. This strengthens the need to communicate the organ donation wishes between family members, which were done by less than a fifth of respondents. Since close relatives of the deceased need to make a decision regarding the organ donation consent, fostering communication about organ donation between family members may be one of the most essential aims of future campaigns for increasing donation rates.

5 CONCLUSIONS

Planning and implementing measures to foster post-mortem organ donation requires an interdisciplinary approach to understand the roles, attitudes and concerns of individuals in the process of organ donation for transplantation. This empirical study was the first to collect large-scale survey data on a probability sample of the general population in Slovenia using a wide-ranging set of indicators that are relevant for organ donation. The initial exploration of the willingness to donate one's own organs and organs of a loved one after death and the barriers to joining the register of organ donors presented in this paper is an important first step towards more comprehensive elaboration of key individual and social issues related to organ donation.

CONFLICTS OF INTEREST

The authors declare that no conflict of interest exists.

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ETHICAL APPROVAL

The ethical approval for the empirical study was received from the Research Ethics Committee at the Faculty of Social Sciences of the University of Ljubljana (approval number 801-2017-033/BD).

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