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MIND THE GAP: SOCIAL ASPECTS OF WILLINGNESS FOR POST-MORTEM ORGAN DONATION IN SLOVENIA

Abstract. *This paper explores the willingness to donate organs after death in relation to selected socio-demographic characteristics and organ donation-related factors. The analysis is mainly based on the Eurobarometer 72.3 survey for the Slovenian population conducted in 2009 on a probability sample of residents aged 15 years or more. The central indicator of interest is the reported willingness to donate organs after death, studied in relation to basic socio-demographic characteristics, discussion of organ donation in family, legislation awareness, and past blood donation. The study confirms the relatively high reported donation willingness among Slovenians (61.3% of Slovenians report they are willing to donate their organs after death), but with significant variations across socio-demographic characteristics. It also shows the importance of communication and knowledge for the willingness to donate. The gap between the reported willingness and those who officially register for post-mortem organ donation calls for further empirical investigation with a broader set of psychosocial factors.*

Keywords: *post-mortem organ donation, willingness for organ donation, organ donor*

Introduction

Organ donation has the extraordinary nature of an exchange from one person to another. It is characterised by a network of complicated and emotionally charged relations between donors, recipients, families, and medical team members involved in a medical procedure, emphasising its psychological and social complexity, and its symbolic power (Fox and Swazey, 2013). Consideration of organ donation usually begins with premature and sudden death due to a fatal injury. Unexpected death, unfamiliarity with

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organ donation, and experiences associated with transplantation outcomes make initiating the discussion about donation procedures or obtaining the next-of-kin consent a challenging and emotionally exhausting experience (Sanner, 2007; Sque et al., 2007; Kesselring et al., 2006).

Transplantation methods are quite well socially accepted in Slovenia, as also reflected in the high level of willingness to make a post-mortem organ donation (Avsec and Šimenc, 2013). However, the official figures showing registration for post-mortem organ donation in Slovenia remain low; in 2015, there were only 4,711 designated deceased donors on the register in Slovenia (Avsec and Uštar, 2016). Slovenia has an opt-in post-mortem organ donation model in which family members or next of kin make the final decision on organ donation of the deceased. The rate of family refusals in Slovenia in 2015 was 19%, although it varies over the years (from 13% in 2011 to 37% in 2000) (Avsec and Uštar, 2016), reflecting the delicateness of the issue and its embedment in the wider social context. Despite some useful elaborations of these issues in Slovenia (Avsec and Šimenc, 2013), there is a lack of high-quality empirical data to allow comprehensive understanding of this matter at the level of the general population. Factors of organ donation-related behaviours vary greatly between groups, even in the context of a strong national identity and a relatively homogeneous cultural background (Schulz et al., 2006). Thus, developing effective strategies to stimulate organ donation depends strongly on understanding organ donation in a specific socio-cultural context. Sociological enquiry into the organ donation phenomenon is thus crucial.

This paper contributes initial insights into the willingness to donate organs after death in relation to selected sociodemographic characteristics and donation-related factors in Slovenia. It primarily focuses on the relations between the reported willingness to donate organs among Slovenians and its association with socio-demographic characteristics, family discussions on this matter, previous donation-related experience, and awareness of relevant legislation.

For the purpose of this study we use secondary data from the Eurobarometer survey of the general population (European Commission, 2012) gathered in 28 EU member states, namely, the latest available providing the most relevant indicators of post-mortem organ donation attitudes and behaviours. Although the indicators for this study were largely selected according to their (limited) availability, the analysis establishes the foundations for the further research agenda for identifying key predictors that may help direct new strategies to stimulate cultural acceptance of transplantation treatment and post-mortem organ donation behaviour, namely: discussing organ donation with family members, registering as an organ donor, or giving next-of-kin consent for organ donation in Slovenia.

The social context of post-mortem organ donation

The decision to become a potential organ donor after death is a complex and sensitive issue, it supersedes health matters. It is a practice in which legal, ethical, social, cultural and psychological problems that accompany medical encounters with human subjects and the process of therapeutic innovation are firmly embedded (Fox, 1970). In general, attitudes to organ donation are quite positive, but large discrepancies between the reported willingness to donate organs and actual donor registrations are commonly observed (Morgan, 2009). Further, immediate family members may be opposed to organ donation of the deceased, especially if they are unfamiliar with her/his wish to donate organs after death.

Numerous studies have analysed particular aspects of factors that influence willingness for organ donation behaviour, such as socio-demographic factors, knowledge, beliefs and attitudes about organ donation, normative beliefs, social representation, past experience, self-efficacy, moral norms etc. (Morgan et al., 2003; Falomir-Pichastor et al., 2013).

Socio-demographic characteristics have been shown to be an important factor of donation-related behaviours. Studies from other countries have consistently found that people with higher education and a better material position or higher social status exhibit more favourable attitudes to post-mortem organ donation. Donation willingness was also found to be higher among younger persons (Mossialos et al., 2008; Rumsey et al., 2003). Less consistent are the observations of differences by gender; while some studies report greater willingness among women (Thompson et al., 2003), others have found no significant differences between genders (Rumsey et al., 2003).

Positive knowledge and beliefs about organ donation have been shown to increase positive attitudes to donation (Caballer et al., 2000), willingness to donate, and registration rates. Some studies also reveal that past donation-related experiences, like blood donation or knowing someone who has donated organs, positively correlate with post-mortem organ donation attitudes (Kamin et al., 2016).

While the above factors of donation-related behaviours are central to the scope of this paper, it is important to briefly outline other key determinants reported in the literature to understand post-mortem organ donation in a broader social context. A recent systematic synthesis of such determinants (Falomir-Pichastor et al., 2013) emphasises religiosity, social cohesion, personality factors, social and moral norms and social representation. Religiosity is related to the plurality of body-self conceptions that affect the individual's perception of organ donation. However, the mechanism by which religion influences organ donation behaviour remains largely

unclear (Falomir-Pichastor et al., 2013). Some researchers indicate that the conservatisms associated with religious belief would be a better predictor of one's reluctance to donate than religiosity itself (Morgan et al., 2008).

Other studies suggest that positive attitudes to organ donation increase with social support and social insertion (Mossialos et al., 2008). Emotions like fear, anxiety, disgust or pride, and personal satisfaction associated with organ donation are also predictors of attitudes and behaviours related to organ donation (Morgan et al., 2008; Falomir-Pichastor et al., 2013). The perception of social and moral norms (e.g. pressure, approval of one's reference group) related to organ donation can have a positive or negative influence on organ donation. Positive attitudes of important others regarding organ donation increase willingness for organ donation and related discussions with others (Morgan and Miller, 2002).

Various theoretical frameworks have been tested to explain the individual's decision-making on registering for organ donation (Quick et al., 2016). The first models of willingness to donate leaned on Fishbein & Ajzen's (1975) theory of reasoned action, suggesting that (positive) attitudes influence behaviour through a positive effect on behavioural intentions (Horton and Horton, 1991; Kopfman and Smith, 1996; Morgan et al., 2002). Thus, according to the earliest organ donation willingness model developed by Raymond and Patricia Horton (1991), individuals' willingness to become an organ donor depends on their attitude to organ donation, which is a consequence of their knowledge about organ donation and their own, personal values. Besides willingness to donate, individual attitudes to organ donation also affect certain behaviours, such as signing a donor card or talking to family members about organ donation.

In models driven by the theory of reasoned action, variance in organ donation behaviour is generally explained by one's attitudes, social norms, and knowledge of organ donation. However, the explanatory power of such models is limited because they put too much weight on individual cognition and agency (Falomir-Pichastor et al., 2013) and fail to capture what is at stake in everyday-life intuitions about organ and tissue donation (Morgan et al., 2008) and to explain what are the emotional barriers to posthumous organ donation. Thus, scholars (Morgan et al., 2008; O'Carroll et al., 2011) have included non-rational factors or non-cognitive values like body integrity, the ick factor, the jinx factor, medical mistrust and perceived benefits of donation and advanced the predictive capabilities of these organ donation models.

Recent studies of post-mortem organ donation also point to the usefulness of social representations theory (Moscovici, 1998; Moscovici and Hewstone, 1983) because it offers a unique framework for the social scientific study of how groups of people communicate about and make

sense of a phenomenon that people have less direct experience with in everyday life and thus gain the majority of their information about it from the media (Morgan, 2009). Social representation theory assumes that social and individual views of organ donation reflect a combination of mass media framing of organ donation, individuals' cognitions about organ donation, and interpersonal, everyday communication on the subject (Morgan, 2009).

The hitherto lack of theoretically founded empirical research of post-mortem organ donation in Slovenia limits the possibility of evaluating organ donation models in the Slovenian context. However, some surveys of the general population regarding organ donation do exist (Hafner-Fink et al., 2014; European Commission, 2015). The widest set of indicators for analysing the relations between willingness to donate organs and certain key predictors like knowledge about organ donation, past behaviour, crucial socio-demographic factors, and some emotional factors that act as possible barriers to posthumous organ donation is offered by the Eurobarometer survey of post-mortem organ donation (European Commission, 2012), that we will base our study on.

Methodology

This study uses secondary data obtained by the Eurobarometer 72.3 survey (European Commission, 2012) as the main data source. The survey was conducted in 2009 in all EU member states and certain other European countries using face-to-face data collection on a probability sample of residents aged 15 years or more. In Slovenia, a total of 1,031 people were interviewed.

We selected this study after comprehensively reviewing general population surveys on organ donation in Slovenia (European Commission, 2012; Hafner-Fink et al., 2014; European Commission, 2015). The selected study offered the most appropriately operationalised question on general willingness to donate organs after death and several other indicators for identifying relevant predictors of post-mortem organ donation willingness. Although the data collection was conducted in 2009, the data remain relevant and allow valuable scientific findings to emerge. Further, past research shows that post-mortem organ donation attitudes are relatively stable over time (Moloney et al., 2005).

The primary indicator of interest is reported willingness to donate organs (question QE3). Respondents were asked whether they would be willing to donate one of their organs to a donation service immediately after their death. "Do not know" responses were treated as valid answers and were not excluded from the analysis.

Other indicators, mainly analysed in relation to the post-mortem organ donation willingness, include discussions of post-mortem organ donation or transplantation with the family (question QE1), knowledge of legislation on post-mortem organ donation in the country (QE2), past donation of blood (QE6), and socio-demographic questions: gender (D10), age (D11), marital status (D7), education measured by age when finished full-time education (D8), settlement type (D25), and social status as a self-perceived level in society (D61). Reported willingness to agree on the donation of organs of a deceased family member (QE4) and the main reasons that respondents would be unwilling to donate their organs after death (QE5) are also evaluated.

The analysis begins with a descriptive overview of key indicators. A multinomial logistic regression of the above predictors on the reported willingness to donate is subsequently employed. The main aim is to gain understanding of the isolated relationships between willingness to donate and other variables of interest rather than attempting to establish any firm causal relationships. Finally, the reported factors that may discourage respondents from post-mortem organ donation are analysed.

Results

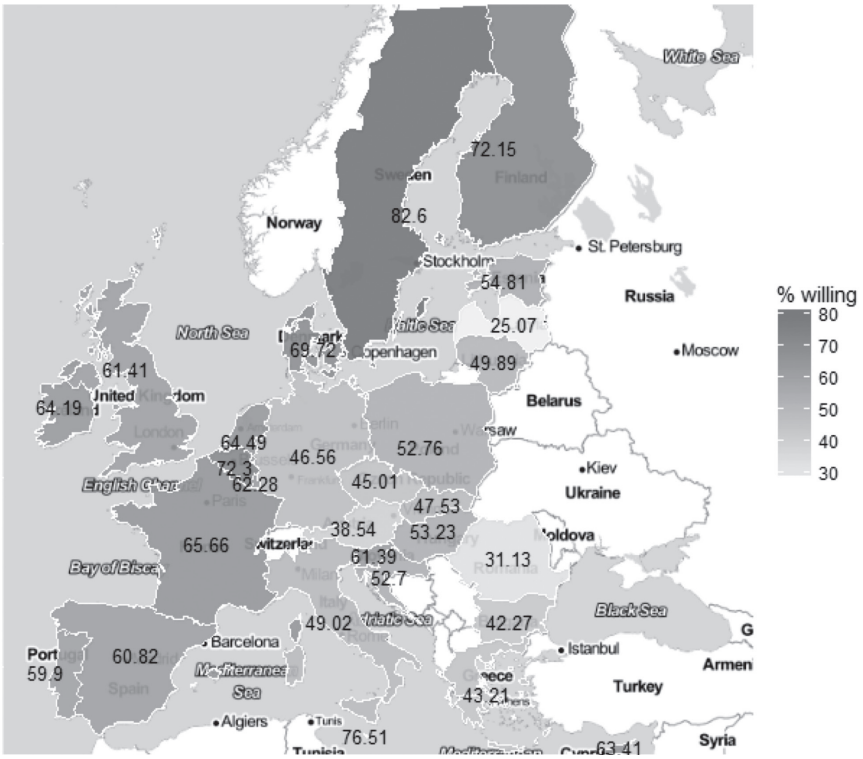
Willingness to donate organs in Slovenia and the EU

The Eurobarometer 72.3 survey (European Commission, 2012) shows that 61.3% (CI_{95}[58.2%, 64.4%]) of Slovenians claimed to be willing to donate their organs after death, 19.3% CI_{95}[16.9%, 21.9%] were unwilling, and 19.3% CI_{95}[16.9%, 22.0%] undecided (answered "do not know").

This relatively high level of reported willingness for post-mortem organ donation is consistent with other more recent surveys conducted on probability samples of the Slovenian general population. In Eurobarometer 82.2 (European Commission, 2015), the reported willingness among Slovenians to donate at least one type of tissue after death was 55.3% CI_{95}[52.0%, 58.6%], while in the Slovenian Public Opinion 2013 survey (Hafner-Fink et al., 2014) it reached 75% CI_{95}[72.3%, 77.7%]. The comparatively high level measured by the latter survey can be partly attributed to the emphasised life-saving role of post-mortem organ donation in the question wording, which might have encouraged recipients to express socially desirable answers.

At the level of all EU-28 countries in Eurobarometer 72.3, the reported willingness to donate organs was somewhat lower, amounting to 54.8% CI_{95}[53.9%, 55.8%] of the total population. The proportion of undecided individuals was similar as in Slovenia (18.6% CI_{95}[17.8%, 19.3%]).

Figure 1: PROPORTIONS OF RESPONDENTS DECLARING THEMSELVES WILLING TO DONATE ONE OF THEIR ORGANS AFTER DEATH IN EU COUNTRIES



Data source: European Commission (2012).

There is high variation in the reported willingness to donate between European countries, spanning from one-quarter of respondents in Latvia to over 80% in Sweden (Figure 1). The willingness is generally higher in Western and Northern than in Eastern and Southern Europe, although the patterns do not fully correspond to the conventional regional divisions of the continent. The reported willingness in Germany and Austria is more similar to the countries of Eastern than Western Europe, while in Spain, Slovenia and Portugal it is more similar to the Western than the Southern European countries.

Despite the generally high reported willingness for post-mortem organ donation, the Eurobarometer 82.2 (European Commission, 2015) data confirm that only a small fraction of individuals officially register themselves as potential donors. While at the EU level 10% of respondents reported being officially registered, this is considerably contributed to by a few countries that have high proportions of registered donors. Most notable are Denmark, the Netherlands and Sweden with proportions of reported registered

donors exceeding 30%. In Slovenia, just 3.4% of respondents claimed to have registered as donors and even this proportion appears to be highly overestimated; the national register of donors reveals that a mere 0.23% of the Slovenian population has actually registered as a potential post-mortem organ donor (Avsec and Uštar, 2016).

The willingness to donate own organs after death is strongly related to the willingness to donate organs of deceased close family members. In Slovenia, 80% of respondents willing to donate their own organs would also consent to the donation of a family member's organs, while 72% of those unwilling to donate their own organs would not consent to that ($F = 176.9$, $p < 0.05$). Similar patterns are observed at the EU level: 82% and 71%, respectively ($F = 2025.8$, $p < 0.05$).

Family discussions, legislation awareness and blood donation

Discussions of post-mortem organ donation and transplantation with family members occur somewhat less among Slovenians than among all EU residents: 35.5% CI_{95}[32.5%, 38.7%] and 40.2% CI_{95}[39.3%, 41.2%], respectively. The opposite is true for legislation awareness where 33.3% CI_{95}[30.3%, 36.5%] of Slovenians claim to know the regulation regarding post-mortem organ donation compared to 29.0% CI_{95}[28.2%, 29.9%] of all EU residents.

Slovenians are substantially more likely to donate blood: 47.7% CI_{95}[44.5%, 50.9%] of them report to have donated blood before, while the proportion at the EU level is 37.4% CI_{95}[36.5%, 38.3%].

Relationship between reported willingness to donate organs after death and other observed characteristics

Table 1 presents the results of the multinomial logistic regression model of the reported willingness to donate organs after death, where socio-demographic characteristics and selected donation-related variables were included as predictors.

The odds of being willing to donate organs after death and being decided on this matter (i.e. those not answering "do not know") significantly decrease with age and increase with social status. The same is true for education; compared to the respondents with a lower education, the odds of being willing to donate organs increase among those with a higher education. The relationship between willingness to donate organs and other socio-demographic indicators (gender, marital status, and settlement type) is not significant, with the exception of single or divorced people exhibiting higher odds of being undecided rather than unwilling to donate compared to those who are married.

The discussion of organ donation or transplantation in the family, awareness of organ-donation legislation, and previous donation of blood are all significantly and positively related to the willingness to donate organs. The difference in willingness to donate is particularly large between those who did and those who did not discuss the matter with their families. While this is consistent with past studies, the currently available data do not enable causal relationships to be established between the observed variables.

Table 1: MULTINOMIAL LOGISTIC MODEL OF WILLINGNESS TO DONATE

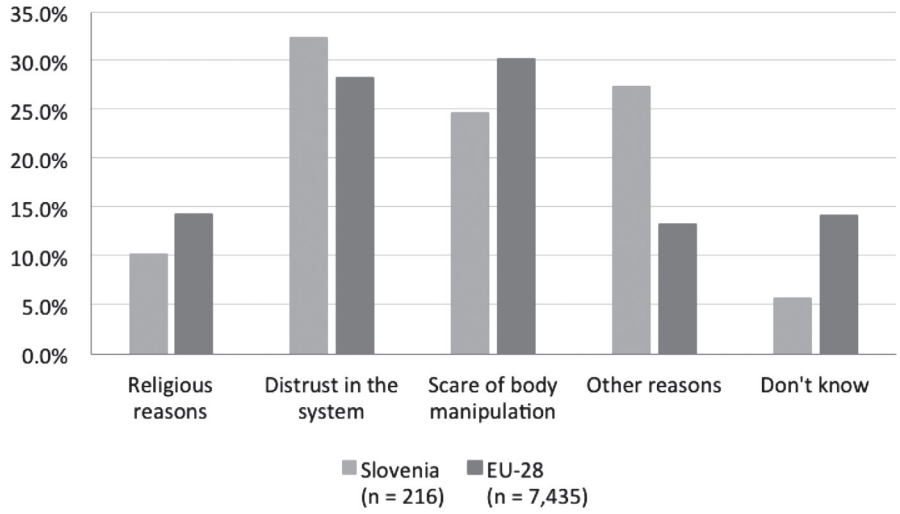
	Model parameters				Adjusted prediction of willingness to donate		
	Willing relative to unwilling		Does not know relative to unwilling				
	b (SE)	|*t*|	*b* (SE)	|*t*|	Willing	Un-willing	Doesn't know
Gender							
male (ref.)	-0.01 (0.21)	0.03	0.29 (0.26)	1.14	64.6%	19.9%	15.5%
female					61.9%	18.7%	19.4%
Age	-0.02 (0.01)	2.92**	-0.02 (0.01)	2.34**	-0.002	0.003	-0.001
Marital status							
married (ref.)	0.48 (0.40)	1.19	-0.17 (0.47)	0.35	60.7%	18.9%	20.4%
living with partner	-0.08 (0.28)	0.30	-0.74 (0.38)	1.94*	71.4%	15.1%	13.5%
single or divorced	0.17 (0.28)	0.60	0.05 (0.35)	0.13	65.8%	22.4%	11.9%
widowed	-0.41 (0.54)	0.75	-0.19 (0.57)	0.34	64.5%	17.5%	18.0%
other					54.4%	23.7%	21.8%
Completed education age							
15 years or less (ref.)	0.47 (0.26)	1.86*	-0.23 (0.32)	0.71	50.6%	24.0%	25.4%
16–19 years	0.84 (0.31)	2.71**	-0.07 (0.38)	0.19	62.8%	20.2%	17.0%
20 years or more	1.11 (0.52)	2.14**	0.21 (0.62)	0.34	68.5%	16.0%	15.4%
still studying					70.7%	13.0%	16.3%
Settlement type							
rural or village (ref.)	-0.10 (0.22)	0.44	-0.16 (0.28)	0.60	64.9%	18.7%	16.4%
small/middle town	-0.14 (0.26)	0.54	0.30 (0.30)	0.99	64.5%	20.3%	15.3%
large town					58.9%	18.8%	22.3%
Social status	0.14 (0.07)	2.07**	0.26 (0.08)	3.31**	0.001	-0.023	0.022
Discussed in family							
no (ref.)	1.08 (0.23)	4.68**	-0.36 (0.31)	1.13	54.8%	22.2%	23.0%
yes					79.2%	12.3%	8.5%
Legislation awareness							
no (ref.)	0.90 (0.23)	3.90**	0.80 (0.28)	2.82**	60.4%	22.3%	17.2%
yes					69.6%	11.6%	18.8%
Ever donated blood							
no (ref.)	0.81 (0.22)	3.71**	0.41 (0.26)	1.59	57.7%	23.6%	18.7%
yes					69.5%	14.3%	16.2%

n = 958, $F_{(30,928)} = 5.39$**
* $p < 0.10$,** $p < 0.05$
Data source: European Commission (2012).

Reasons for unwillingness to donate organs after death

The reasons for unwillingness to donate organs after death statistically significantly differ between Slovenian respondents and respondents from other EU-28 countries (Figure 2). Among Slovenians who declare themselves as unwilling to donate organs, distrust in the system is the most frequently reported main reason for their unwillingness. Slovenians more frequently report this reason than all EU residents who are unwilling to donate, while the opposite is true for the fear of body manipulation. Religious reasons are substantially less frequently reported as the main factor discouraging donation, although they are somewhat more frequent at the EU level than in Slovenia. A relatively large proportion of Slovenian respondents mentioned other reasons, but a more detailed specification of such answers was not provided.

Figure 2: MAIN REASONS THAT DISCOURAGE DONATION AMONG RESPONDENTS WHO ARE UNWILLING TO DONATE



$F = 10.36$, $p < 0.01$
Note: Only respondents who declared themselves unwilling to donate their organs after death are included.
Data source: European Commission (2012).

Although this variable was not included in the above model due to the small sample sizes in some cells and the lack of a more detailed operationalisation of potentially discouraging factors in the questionnaire, this question was also presented to respondents who declared themselves willing to donate. This allows us to observe what proportion of respondents who

report different main discouraging factors still declare themselves willing to donate (Table 2).

Table 2: REPORTED WILLINGNESS TO DONATE ORGANS AFTER DEATH BY REPORTED MAIN REASONS THAT WOULD POTENTIALLY DISCOURAGE RESPONDENTS FROM DONATING

	Willing to donate	Unwilling to donate	Do not know	Total (n)
Religious reasons	24.6%	63.8%	11.6%	100% (32)
Distrust in the system	49.8%	29.2%	21.1%	100% (217)
Fear of body manipulation	48.4%	30.8%	20.8%	100% (165)
Other reasons	73.2%	12.2%	14.6%	100% (438)
Total	61.4%	19.3%	19.3%	100% (852)

Notes: Row percentages are calculated. Respondents who did not provide a substantive answer about the main potential reason for unwillingness to donate were excluded from the analysis.
Data source: European Commission (2012).

While religious reasons are infrequently selected by the Slovenian respondents as the primary discouraging factor of organ donation, most respondents who did select it declare themselves unwilling to donate organs after death. The willingness is also substantially reduced among those whose main concerns are due to distrust in the system and the fear of body manipulation. Those reporting various other concerns are more likely to declare themselves willing to donate, which may indicate that such concerns are seen as less critical.

Conclusion

Organ donation is a peculiar health promotion issue, primarily because it is embedded within the dialectically opposed relationship between life and death (Moloney and Walker, 2000). Motives for or against organ donation are related to contemplation of one's own mortality (Morgan and Miller, 2002), which is probably one of the most intriguing and challenging aspects of organ donation. The psychological and social complexity of organ donation emphasises the need for further inquiry into the factors that influence individuals' participation in various donation-related behaviours, such as registering as a post-mortem organ donor, discussion of post-mortem organ donation with family members, and giving consent for the donation of deceased family members' organs. Each of these behaviours constitutes a key step towards the actual act of donation of an individual's organs after his or her death.

Programmes for promoting post-mortem organ donation deal with behavioural change that requires people to anticipate their own death,

which involves their cognitive and affective processes. Inviting people to engage in recommended behaviour like discussing organ donation with family members, registering as an organ donor or giving a next-of-kin consent to organ donation is thus an extremely complex issue that distinguishes the promotion of post-mortem organ donation from all other health-related issues.

The results of our study largely agree with the findings of studies from other countries. There is a high reported willingness to donate organs, but it varies significantly across socio-demographic characteristics. Those who are older, have a lower social socio-economic status and are less educated are significantly less willing to donate their organs after death. This should be particularly carefully considered when taking measures to stimulate post-mortem organ donation. However, the large discrepancy between the share of self-reported registered post-mortem organ donors and the actual number of individuals on the register of designated donors questions the true nature of 'willingness' explicated in current social surveys.

The strong relations between post-mortem organ donation willingness, discussions with family members, and reported awareness of organ donation legislation indicate an important role of communication and knowledge in donation-related behaviour, although the available data do not allow unambiguous causal relations to be established between these factors. Further, the increased willingness to donate organs after death among those who previously donated blood suggests that similar underlying mechanisms exist for different types of donation. This is promising in view of the success of many blood donation campaigns in Slovenia.

The focus on sociodemographic and a limited set of available donation-related variables is insufficient to ensure thorough understanding of the mechanism of post-mortem organ donation. The presented study offers important insights for designing further research that would allow a better understanding of post-mortem organ donation in Slovenia. Further investigation of values, attitudes and other psychosocial factors, particularly the non-cognitive ones, will help provide more definite answers regarding the types of donation-related concerns that have to be overcome in Slovenia. Already this study shows that some concerns regarding donation, such as religious reasons, may not be frequently reported, but appear to have a strong effect on reported willingness to donate organs. Other reasons were also reported, but they were not specified. We thus need to gain a better insight into the already exposed and unrevealed obstacles.

Besides, the discussion of organ donation within the family seems an important predictor of organ donation willingness, yet in Slovenia a considerable number of people have never discussed the issue with their families. Future research should focus more on the reasons that people do

not discuss post-mortem organ donation with their family members: the main obstacles and the encouraging factors. This is particularly important because the promotion of organ donation is unlike other health-related promotions due to its extreme complexity: recommended behaviours, like discussing post-mortem organ donation with family members, registering as a designated deceased donor and giving a next-of-kin consent to organ donation, require individuals to anticipate their own death or the death of their close ones, which engages their cognitive and affective processes. A lack of information on pro-donation and anti-donation factors in Slovenia prevents segmentation and the development of tailored programmes for an effective educational, promotional and political agenda from limiting achievement of the full potential of transplantation medicine. The presented study provided some initial insights into the differences in willingness to donate organs after death among the general population of Slovenian residents and identified research gaps that need to be covered in future theoretically grounded empirical research of post-mortem organ donation in Slovenia.

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