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Original research article

Awareness and perceptions of the Slovenian public regarding organ donation after brain death

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Abstract
Background: Awareness and understanding of organ donation after brain death can significantly influence an individuals' perceptions of the issue.
Objectives: The aim of this study was to determine the current level of awareness and perception of the Slovenian public regarding organ donation after brain death.
Methods: A cross-sectional study was conducted using a questionnaire to collect data from a sample of 784 individuals. Inferential statistics were conducted using IBM SPSS version 25.
Results: The research sample of the studied Slovenian population demonstrated support for organ donation after brain death, despite a relatively low level of awareness of the topic. Significant demographic differences emerged in respondents' perceptions of organ donation. Female respondents, individuals with higher levels of educational attainment, and those working in health and social care exhibited more positive attitudes. In contrast, the age group of 50 years and above obtained the lowest scores. Statistically significant differences in awareness levels were only observed among different work sectors, with individuals working in health and social care showing higher levels of awareness. A positive yet weak correlation was found between the awareness and perceptions regarding the topic.
Conclusion: Raising public awareness is essential for promoting organ donation. This can be achieved through the dissemination of information on the subject by experienced professionals.

Keywords: Awareness; Organ donation; Perception; Public opinion; Quantitative study; Transplantation medicine

Introduction

Organ transplantation is an established treatment option for many patients suffering from chronic organ failure. In cases of end-stage liver, lung, and heart failure, transplantation is the only viable and effective treatment option (Fung et al., 2014; Špirudová and Nol, 2014). In Slovenia, the most effective and prevalent system is the deceased donor programme, which is activated upon confirmation of brain death (Avsec and Šimenc, 2021).

Since 2002, organ donation in Slovenia has been overseen by the Slovenia-Transplant Organ and Tissue Transplantation Institute (Avsec and Šimenc, 2021). The Institute's main responsibilities include ensuring the effectiveness of the donation programme, maintaining the quality and safety of donated and transplanted organs, facilitating discussions with the relatives of potential donors about organ donation, and regularly communicating with the media and the public (Lušicky and Avsec, 2019). Since 2000, Slovenia has also been a member of Eurotransplant, a non-profit organisation for organ and tissue exchange. This membership has significantly enhanced the survival prospects of Slovenian patients, especially in high-urgency situations (Avsec and Šimenc, 2021). Globally, Slovenia ranks high in terms of successful heart and lung transplants, and also performs kidney, liver, and pancreas transplants (Uštar et al., 2022).

The global field of transplantation medicine regularly faces a shortage of donors (Stephan, 2017). As noted by Hodge and Saitta-Gill (2015), countries have addressed the problem of organ shortage through various strategies, such as regulatory arrangements (*e.g.*, allowing HIV-positive-to-HIV-positive transplants), targeted education initiatives for individuals (especially minorities), and enhancement of donation procedure protocols. Organ availability can also be increased by modifying the standards for organ donation from irreversible loss of brain function to irreversible loss of cardiac function, or by encouraging individuals to actively opt for posthumous organ donation by either registering in the donor registry or obtaining consent in the case of brain death of a relative (Hodge and Saitta-Gill, 2015).

In general, there are two primary systems in place for organ donation after death: the opt-in system, which is based on explicit consent, and the opt-out system, also referred to as

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presumed or deemed consent (Lewis et al., 2021). In Slovenia, the opt-in system is used, where individuals must actively give their consent for their organs to be procured after death. In contrast, the opt-out system assumes consent as the default option (Avsec and Šimenc, 2021). The choice between these two systems has triggered extensive policy debates and led several countries including Wales, the Netherlands, England, and Scotland to transition from opt-in to opt-out systems (Lewis et al., 2021). There is substantial evidence suggesting that the transition to the opt-out system can potentially lead to an increase in organ donation rates. For instance, if organ donation becomes the default option, this will facilitate the conversion of an intention to donate into an actual donation (Arshad et al., 2019).

However, despite concerted efforts by the relevant institutions, a 2017 survey conducted among the Slovenian population (Berzelak et al., 2019) revealed a gap between reported willingness to donate organs after death and actual registration in the donor registry, with only a minority of respondents deciding to register as donors. Quantitative studies conducted by Slovenia-Transplant in 2008 and 2010 show that while approximately 70% of people support organ donation after death, only 13–26% register as donors in the donor registry (Avsec and Šimenc, 2013). These figures are in line with international research findings: the problem of this "passive affirmation" is being addressed in several European countries (Levitt, 2011) and globally (Cantarovich, 2018). For instance, in China, although 88.9% of participants were in favour of organ donation, only 39.7% were willing to donate their organs (Zhang et al., 2015). Cantarovich (2018) highlights that many people are only partially aware of how widely accepted and organised organ transplantation has become. Individuals often overlook the possibility of needing a transplant during their lifetime and tend to avoid contemplating their own mortality until they experience the loss of a loved one. What is more, they may not realise that after death their body can serve as a valuable source of life for others.

The aim of the study was to assess the current level of awareness and perceptions of the Slovenian public regarding organ donation after brain death.

Materials and methods

Study design and objectives

The study employed a quantitative, empirical, non-experimental, cross-sectional design. The aims of the study were to:

- determine the differences in awareness and perceptions of organ donation after brain death among different demographic groups (gender, age, work field, education) within the Slovenian public;
- determine the correlation between the awareness and perceptions of organ donation after brain death among the Slovenian public.

Research instrument

The research instrument was a section of the 2017 Slovenian Public Opinion Survey questionnaire (Uhan et al., 2021) related to organ donation. Permission to use this section of the questionnaire was obtained. The section was divided into three parts and comprised 38 statements. The first part contained questions to collect demographic data: gender, age, level of education, and employment status. The second part of the questionnaire addressed the general public's perceptions of organ donation after brain death and included 27 statements which could be rated on a four-point scale, with 1 representing "strongly disagree" and 4 representing "strongly agree". Due to their negative phrasing, the 18 statements included in this part of the survey were reversely coded. Respondents' ratings were converted into scores (ranging from 27 to 108), with scores between 27 and 47 indicating a very negative perception, scores between 48 and 67 indicating a negative perception, scores between 68 and 87 indicating a positive perception, and scores above 87 indicating a very positive perception. Cronbach's alpha for this part of the questionnaire was 0.704, indicating an acceptable level of reliability and internal consistency (Field, 2020). The third part of the questionnaire contained 11 statements to collect data on respondents' awareness of the issue. For each statement, three answers were offered: "True", "False", and "I don't know". In the analysis, "I don't know" was counted as a false answer. In this part of the questionnaire, respondents' answers were converted into scores (ranging from 0 to 11), with scores ≤5 indicating insufficient awareness, scores between 6 and 8 indicating sufficient awareness, and scores between 9 and 11 indicating good awareness.

Research sample and data collection

The study focused on Slovenian residents as the target population. The study was conducted on a representative random sample of 784 individuals (Taherdoost, 2017). The representative sample was determined based on population data from the Statistical Office of the Republic of Slovenia with a confidence level of 95% and a margin of error of 5%. The online questionnaire, which was accompanied by a statement of the purpose of the study and an informed consent form, was available from 10 to 30 November 2022. The questionnaire was distributed through various channels such as family, friends, work colleagues, social media, and through the snowball collection method. Each respondent consented to participate in the study by clicking on an embedded link and completing the electronic survey, which was prepared and administered using the 1KA One Click Survey (1ka.si; https://www.1ka.si/d/en) web survey software. The data provided by respondents when answering the questions were collected on the 1ka.si server and managed by a researcher via a password-protected 1KA account. Anonymity was ensured during data collection by not tracking or collecting data that could reveal the identity of respondents (*e.g.*, IP addresses, names, surnames, email addresses).

Ethical considerations

The study complied with the principles of the Declaration of Helsinki-Tokyo (World Medical Association, 2013) and received approval from the Ethics Committee of the University of Primorska (Ethics Committee No.: 4264-19-6/23). Informed consent was obtained from participants who completed and submitted the questionnaire. The informed consent included a disclaimer stating that participation in the study was anonymous and voluntary and could be revoked at any time.

Data analysis

The empirical data obtained were processed and statistically analysed using IBM SPSS version 25 (SPSS Inc., Chicago, Illinois, USA). Descriptive statistics, including frequencies, percentages, skewness, kurtosis, means, and standard deviations, were used to describe and summarise the data. Given the normal distribution of the data, the independent sample *T* test and ANOVA parametric tests were used to detect statistically significant differences among the groups. Pearson's correlation coefficient was used to examine correlations. The threshold for statistical significance was set at $p < 0.05$.

Results

A total of 784 respondents participated in the study. Their average age was 33.02 years (SD = 12.11; age range: 17–74 years). Participants' demographics and other characteristics are presented in Table 1.

Table 1. Participants' demographic data

Variables	*n* (%)
Gender	
Female	677 (86.4)
Male	102 (13.0)
Other	5 (0.6)
Age (years)	
<30	389 (49.6)
30–49	301 (38.4)
>50	94 (12.0)
Work sector	
Health and social care	147 (18.8)
Other work sector	359 (45.8)
Non-workers (pupils, students, and retirees)	278 (35.4)
Education	
≤Higher secondary	281 (35.8)
≥Undergraduate degree	503 (64.2)

Note: n = 784.

The results show that the respondents in our research sample held a positive attitude towards organ donation after brain death (mean = 84.79; SD = 10.65). Only 4.7% of respondents expressed a negative or very negative perception towards this issue. In this part of the questionnaire, the majority of respondents agreed with the statement that "organ donation is a way to help other people" (mean = 3.74; SD = 0.456) and disagreed with the statement that "removing organs is disrespectful to the deceased" (mean = 1.52; SD = 0.684).

However, the level of awareness on this topic was relatively low (mean = 6.20; SD = 2.38). In fact, 35.8% of respondents gave incorrect answers to more than 6 of the total 11 questions on this topic. Almost half (48%) of all respondents showed a sufficient level of awareness (6 to 8 correct answers), and 15.5% showed a good level of awareness (9 to 11 correct answers) regarding organ donation after brain death.

The percentage of correct answers for each statement in the section on awareness is presented in Table 2. The vast majority of respondents were aware that a donated organ cannot be transplanted to just any recipient, but must be matched to the donor's blood type and other tissue characteristics (86.1% of correct answers). Incidentally, despite Christianity being the most widespread religion in Slovenia, the vast majority of respondents incorrectly stated that Christianity opposes organ donation after brain death (27.7% answered correctly).

Table 2. Percentage of correct answers for each statement in the "awareness" section

Statements (n = 784)	Correct answers *n* (%)
1. (I) A person who is brain dead can still recover.	520 (66.3)
2. (C) Any person who has reached the age of 15 can declare themselves a potential organ donor after death.	235 (30.0)
3. (C) In Slovenia, organ donation and transplantation are regulated by law.	550 (70.2)
4. (C) In a hospital, information about a person's registration in the donor registry can only be accessed by a doctor authorised to do so and only after the person's death.	345 (44.0)
5. (C) Relatives can make the decision to donate the organs of a deceased person, whether or not that person has previously made a decision about organ donation.	234 (29.8)
6. (I) Christian religions oppose organ donation after death.	217 (27.7)
7. (C) It is forbidden to make or receive payment or other material benefits for donated organs.	623 (79.5)
8. (I) Doctors can transplant any donated organ to any recipient, regardless of the donor's blood type and other tissue characteristics.	675 (86.1)
9. (I) Deceased organ donors can only be buried by cremation.	431 (55.0)
10. (C) The patient's quality of life usually improves significantly after an organ transplant.	618 (78.8)
11. (C) In Slovenia, the deceased organ donor's identity cannot be revealed to the organ recipient.	362 (46.2)

Note: C – correct answer; I – Incorrect answer.

Descriptive statistics of the sample population's demographic characteristics in relation to the perception and awareness of organ donation after brain death, along with the associated inferential statistics (independent sample T test and ANOVA), are presented in Table 3. Statistically significant differences in the responses to the part of the questionnaire dealing with public perception of organ donation were observed for all four demographic variables – gender, age group, work sector, and educational level. Female respondents had a more positive perception of organ donation ($t(777) = 2.313$; $p = 0.021$), as did individuals with higher levels of educational attainment ($t(782) = -1.997$; $p = 0.046$), and individuals working in health and social care ($t(504) = -4.450$; $p < 0.001$). Compared to other age groups, the 50+ age group scored the lowest scores (mean = 82.61) in this part of the questionnaire. Regarding respondents' awareness of organ donation after brain death, statistically significant differences were only observed between individual work sectors, with individuals working in health and social care showing higher levels of awareness ($t(499) = -9.242$; $p < 0.001$).

Table 3. Demographic characteristics of the sample population in relation to the sub-domains of awareness and perception – descriptive statistics and differences in perception and awareness

Variable	Perception			Awareness		
	M (SD)	Test value	*p*	M (SD)	Test value	*p*
Gender						
Female	85.14 (10.49)	*t* = 2.313	0.021	6.23 (2.39)	*t* = 0.988	0.323
Male	82.54 (11.07)			5.98 (2.40)		
Age (years)						
<30	84.61 (9.430)	*F* = 3.128	0.044	6.17 (2.425)	*F* = 0.698	0.360
30–49	85.69 (11.129)			6.28 (2.289)		
>50	82.61 (13.349)			6.05 (2.556)		
Work sector						
Health and social care	88.46 (10.42)	*t* = –4.450	<0.001	7.63 (2.05)	*t* = –9.242	<0.001
Other work sector	83.73 (11.02)			5.64 (2.24)		
Education						
≤Higher secondary	83.77 (10.190)	*t* = –1.997	0.046	6.03 (2.326)	*t* = –1.449	0.148
≥Undergraduate degree	85.35 (10.878)			6.29 (2.419)		

Note: F = ANOVA; *t* = independent sample *t*-test; *p* = statistical significance.

Pearson's correlation coefficient was used to ascertain the potential correlation between the general population's awareness levels and perceptions regarding organ donation after brain death. The results showed a positive and weak correlation between the two domains (r_{xy} = 0.36; n = 776; p < 0.001).

Discussion

The aim of our study was to investigate the Slovenian general population's awareness and perceptions of organ donation after brain death. The results of the study revealed a relatively low level of awareness of organ donation after brain death. However, in general, Slovenians demonstrated a positive attitude towards this topic. Similar conclusions have also been reached by numerous studies conducted both in Slovenia and abroad. Berzelak et al. (2019) conducted a comprehensive study on a representative sample of the Slovenian population and identified the discrepancy between people's willingness to donate organs and their actual registration in the donor registry as a major problem in this domain. This phenomenon has also been reported by researchers in Greece (Georgiadou et al., 2012), the Netherlands (Truijens and Exel, 2019), Germany (Uhlig et al., 2015), and Switzerland (Weiss et al., 2017). As a result, experts in the field are constantly searching for factors that influence an individual's attitude towards organ donation (Siegel et al., 2014). According to Kocaay et al. (2015), one's decision to donate organs may be influenced by several factors, including age, gender, level of education, socioeconomic status, as well as one's cultural environment. In addition to these factors, education provided by healthcare professionals directly involved in transplantation activities can also impact the willingness to donate organs (Fan et al., 2022). This can be attributed to the significant role that healthcare professionals play in educating patients and the general public, as their opinions can influence people's attitudes and willingness to donate organs (Shahsavarinia et al., 2016).

Our study sought to identify the differences in awareness of organ donation after brain death across different demographic groups. The results only revealed statistically significant differences between different work sectors, with higher awareness levels observed among individuals working in health and social care. In contrast, the results of other studies (Dasgupta et al., 2014; Khan et al., 2011; Saleem et al., 2009) suggest that awareness of organ donation after brain death also increases with the level of educational attainment.

One of the aims of our study was to determine whether demographic characteristics are associated with the general population's perception of the topic under discussion. A slightly greater inclination towards organ donation after brain death was observed among women, individuals with higher educational attainment, health and social care workers, and individuals under 50 years of age (Table 3). These findings are consistent with international studies that have investigated attitudes towards organ donation after brain death in relation to sociodemographic data. These studies (Georgiadou et al., 2012; Weiss et al., 2017) have demonstrated that women, individuals with higher educational attainment, and younger populations are slightly more favourably inclined towards the topic. Berzelak et al. (2019) also observed this feature among Slovenian residents, noting that although the differences were not significant, they were crucial in shaping the guidelines for creating various campaigns and promoting related topics.

Finally, our aim was to examine the potential association between the awareness of organ donation after brain death and the perceptions thereof. While we identified a positive correlation between these two variables, international opinions on this matter are extremely divided. Murakami et al. (2020) demonstrated an association between higher levels of awareness of organ donation and the inclination to donate organs. Nevertheless, heightened awareness of the topic was not associated with the decision to register in the donor registry. Conversely, several studies have demonstrated that higher awareness of organ donation is associated with more favourable perceptions of organ donation after brain death (Dasgupta et al., 2014; Fan et al., 2022; Fontana et al., 2017; Uhlig et al., 2015) and with actual registration as an organ donor (Figueroa et al., 2013). However, other studies (Chung et al., 2015; Ibrahim and Randhawa, 2017; Marck et al., 2012; Ríos et al., 2015) do not observe such correlations in their studies. It is important to note that comparing these results on attitudes towards organ donation after brain death is a challenging task as not all studies used the same questionnaire. The inconsistencies between the results may also be influenced by the different cultural and social backgrounds against which the studies were conducted, as well as by their inherent characteristics – values,

norms, religious beliefs, and respondents' trust in the reliability of responsible institutions. It should also be emphasised that the decision to register as a donor should be influenced by three key areas of knowledge: understanding the concept of brain death, the method of transplant organ allocation, and knowing the stories of organ recipients (Rasiah et al., 2016).

In terms of possible limitations of our study, it is important to note that we did not include information on the respondents' place of residence, which leaves us uncertain of whether we adequately represented the residents of all statistical regions. Secondly, our research sample included only a limited number of respondents over the age of 65, which limits our exploration of older adults' perceptions of the topic. Future studies may benefit from including information on respondents' religious affiliation as demographic data, and on exploring its correlation with their awareness and perceptions of organ donation after brain death. It would also be worthwhile to extend the quantitative research method to include respondents' willingness to register in the donor registry, a factor that cannot be gleaned from the results of the scale used in this study. Despite these limitations, this study is one of the first to identify the factors associated with the general public's perception and awareness of organ donation after brain death in Slovenia, and thus provides a solid basis for further research in this area.

Conclusion

Our study has shown that the Slovenian population generally supports organ donation after brain death, despite a relatively low level of awareness of the topic. The importance of continuous education, directed at both the general public and healthcare practitioners, cannot be overstated in order to emphasise the importance of organ donation after brain death. Healthcare professionals play a pivotal role in promoting willingness to donate organs, which can ultimately lead to a higher number of registrations in the donor registry. Therefore, in order to gain the trust of the general public, it is essential that information on this topic is provided by experienced professionals working in the field of transplantation medicine. The task of raising awareness on such subjects is a great responsibility and underlines the importance of reliability and credibility in our efforts.

Ethical aspects and conflict of interest

The authors have no conflict of interest to declare.

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