

Gender Differences in the Perception of and Willingness to Participate in Organ Donation - Experiences of Immigrants From Bosnia and Herzegovina Living in Sweden

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Research

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Abstract

Background

Organ donation is a personal choice and many ethical, legal, medical, organisational and social factors are involved. It is possible to transplant some organs from live donors and others only from deceased donors. Nevertheless, the shortage of organs worldwide is a problem. Gender differences may cause decision and willingness to organ donation.

Methods

A total of 60 informants (30 men and 30 women), born in Bosnia and Herzegovina and living in Sweden were available for follow-up. Data was collected by a questionnaire and statistically analysed according to the chi-square test, the D'Agostino-Pearson test for checking normality of continuous data distribution and, based on the distribution of results, Student's t test or the Mann-Whitney test. Statistical significance was defined as $p < 0.05$.

Results

The result showed that significant differences between men and women was highest in the question about definition of transplantation ($p < 0.0001$), information about organ donation ($p < 0.0001$), knowledge about OD ($p < 0.0001$), importance about OD ($p < 0.003$), religious permitting to OD ($p = 0.0001$), religious opposite to OD ($p = 0.0007$), donate to a special person or not ($p = 0.0062$), religion as factor to donate ($p = 0.0007$). It was not better in question about having the donor card ($p < 0.0001$).

Conclusions

Women were found to have more positive attitudes toward organ donation than men. Different socioeconomic factors, cultural beliefs, a higher level of religiousness, a higher level of information and knowledge about organ donation, as well as the ownership of donor cards, may result in a better perception of and willingness to participate organ donation. More knowledge of the religious understanding of organ donations and the reduction in prejudice among respondents would make the awareness and desire for organ donation even greater.

Background

Patients with injured or diseased organs or in whom organs are missing, are given the opportunity for a new life and survival through organ transplants and donation [1]. Organ donation (OD) is a personal choice and many ethical, legal, medical, organisational and social factors are involved [2,3]. It is possible to transplant some organs from live donors and others only from deceased donors. Nevertheless, the shortage of organs worldwide is a problem [4]. In 2018, there were 19.6 people per million (ppm) donated organs in Sweden, which is far fewer than elsewhere. There are vast differences between the numbers of ODs from deceased patients in European countries. The most donors in Europe are found in Spain, 35.0

ppm, and Croatia 39.2 ppm [5,6], while the fewest are found in Bosnia and Herzegovina, 2.0 ppm, and Kosovo, with 1.2 donor ppm [5]. Many reasons and factors affect a person's decision to be an organ donor. Religion plays an important role, as well as race, gender and age [7-12]. In most cases, a better education and higher salaries lead to more organ donations [11,13]. Immunological factors and other non-immunological issues, including the organ size [14] and the donor's age [15] and weight [16], may also be involved. Other more specific factors may also affect a person's stance and decision to donate an organ [17]. There are differences between men and women in this regard. Women are more willing to donate but less willing to receive transplantations [18,19]. There are differences between the sexes regarding OD in the context of heart [20], lung [21], kidney [22] and bone marrow transplants [23]. It is presumed that there are many reasons for these differences. There is a greater need for transplants due to terminal disease in men and they are more prone to hypertension and ischaemic heart disease, which means that their organs cannot be donated. However, women appear to know less about transplantation, but the differences may also be due to the fact that they generally undergo aggressive treatment on a smaller scale and this may be due to the different roles men and women have in society, the economy and culture [24]. The present study aimed to assess gender differences in the perception of and willingness to participate in organ donation among immigrants from Bosnia and Herzegovina living in Sweden.

Methods

Study design

The study was designed as a quantitative study using data from a self-administered questionnaire with participants from Bosnia and Herzegovina living in Sweden.

Participants

A cross-sectional study with a descriptive study design was performed in two cities in the western part of Sweden. The inclusion criterion was participants who were older than 18 years of age, and who were willing to participate. We excluded individuals with cognitive impairment and individuals who were in need of organ transplantation. We asked 72 people to participate in the present study, of which 12 (18%) declined due to lack of time and unwillingness. As a result, our final sample of people was 60 people. The questionnaires and all communication were carried out in Bosnian and in the Bosnian association. The information relating to the study that was given to the participants included its voluntary nature and the fact that they could withdraw at any time without incurring penalties or any loss of access to services. All the participants provided signed informed consent before completing the questionnaires. The demographic and clinical characteristics of the informants are shown in Table 1.

Procedure

The study questionnaire was administered by the authors to realise the aim of this study. The questionnaire was in four parts. The first related to the sociodemographic details of the participants, such

as age, gender, educational level, religion, income and marital status. The next part related to the participants' awareness of organ donation, legislation, their opinion of the promotion of organ donation and sources of information about organ donation. The third part related to the participants' knowledge of organ donation, the donation process and holding donor cards, together with their knowledge of the religious attitude to the donation of organs. The last part of the questionnaire related to the participants' willingness to donate their organs. In the last part, the participants were asked to write whether they would donate organs to family members, relatives, neighbours, or to anybody. We first asked a group of 10 individuals to answer the questionnaire. The first author of the study collected the data using face-to-face interviews, in a private room, and those participants were then included in the study population. It took between 10-15 minutes to answer the questionnaire.

Data analysis

Statistical analyses were performed using MedCalc Statistical Software for Windows, version 19.0.3. (MedCalc Software, Mariakerke, Belgium). In the statistical methods in this trial, we used the chi-square test, the D'Agostino-Pearson test for checking normality of continuous data distribution and, based on the distribution of results, Student's t test or the Mann-Whitney test. Statistical significance was defined as $p < 0.05$.

Ethical approval

Since no physical intervention and no information on individual health issues were involved in the study, there was no need to involve the ethical board, according to Swedish law (Swedish Health Care Act) [25]. The World Medical Association Declaration of Helsinki [26] was followed carefully. The healthcare professionals' identities were protected, i.e. their names and personal identity numbers were not stated in the recordings or any publications.

Results

A total of 60 participants, 30 men and 30 women, participated in the present study. The mean age of the men was 41.23 years and the mean age of the women was 40.49 years. The number of illiterate men (6.7%) was higher than that among women (0.0%). The number of women with a high school education was higher than that among men (73% vs. 47%), the women had a higher income than the men (33% vs. 23%) and 90% of all the men were unmarried, while the corresponding figure for women was 60%. All the participants in the present study were Muslims. The majority of the informants in the present study were employed and had an income of between 200,000 and 300,000 SEK (Table 1). The definitions of transplantation, information, knowledge, opinion and important factors for organ donation are presented in Table 2. The answers to the question about the definition of transplantation differ between the women and the men. In 47% of their responses, men stated that transplantation is a medical procedure for the removal of tissue or organs from the body of a deceased person, while, in more than 96% of their responses, women stated that transplantation is a medical procedure for the removal of tissue or organs from the body of a living person ($p < 0.0001$). Our result shows statistically significant differences in the

answers to questions between male and female respondents and the largest difference was seen in the answer to the question about information about organ donation, where 60% of male respondents answered that they did not have sufficient information about organ donation and transplantation, while 73% of the female respondents said the information they had received about organ donation and organ transplantation was above average ($p < 0.0001$). A similar percentage ratio was also found in responses related to the subjective assessment of organ donation and organ transplantation, where female respondents indicated in more than 66% of their responses that they had an excellent knowledge of donation and transplantation, while, in more than 56% of their responses, men responded that they had a poor knowledge of organ donation and organ transplantation ($p < 0.0001$). A similar difference in responses was also noted in the opinions about the importance of organ donation factors, where 37% of men thought that the health of the body's recipient is the most important factor, while 77% of women thought that the most important factor is the kinship of the organ donor ($p = 0.0039$). Our results showed that there is no difference between informants about the implications of organ donation ($p = 1.00$). Their responses regarding the usefulness, support for, risks and religious issues regarding organ donation are presented in (Table 3). Table 3 shows significant differences between the groups in terms of their replies to questions 15 and 19. Question 15 asks whether they believe organ donation is useful and should be promoted, to which 16 men and 27 women replied that they agreed completely, while eight men and two women said that they agreed. Although this is a statistically significant difference, 80% of men and almost 90% of women was still generally in agreement that organ donation is useful and that it should be promoted more. Only five men and one woman selected the reply "I do not agree or disagree" that organ donation is useful ($p=0.0179$). In relation to question 19 about accepting organs from people who are of a different religion, 90% of the women replied positively, but only 63% of the men did so ($p=0.0297$). No statistically significant differences between the groups were registered in the replies to the other questions in Table 3. Responses related to the religious aspects of organ donation are presented in Table 4. In this table, the result of our study showed gender differences in the answers to all the questions. The greatest difference was recorded in the answers about whether their religion permitted organ donation, where 70% of the women and 13% of the men responded that their religion allowed the donation of organs throughout life, regardless of the consequences for the person who makes the donation. To the same question, 50% of men and 10% of women answered that they were not sure whether their religion allowed organ donation ($p = 0.0001$). To the question about religious opposition to organ donation, 50% of men and 93% of women responded that their religion and religion in general did not oppose the donation of organs, while 43% of men and 3% of women indicated that they did not know the answer to this question ($p = 0.0007$). In the question about the reasons why the informants were against organ donation, the answers differed in relation to the different genders, where 67% of men and 37% of women had not thought about organ donation and 13% of men and 60% of women believed that the body should be intact after death ($p = 0.0017$). To question 23, 83% of the women and 40% of the men replied that they would donate their organs to anyone, while 40% of the men and 13% of the women stated that they would donate to their family members ($p=0.0062$). To question 24, 80% of women and 53% of men replied that the person to whom they donate their organs could have a different religious affiliation, but, at the same time, 43% of men and 3% of women indicated that they had not thought about organ donation

($p = 0.0007$). To question 28, 67% of the men and 30% of the women replied that they did not know anyone who had donated organs, while 43% of the women and 10% of the men indicated that they did know an organ donor and that this person was a relative ($p = 0.0062$). Ownership of a donor card was registered in 67% of women and only 3% of men ($p < 0.0001$). Responses about whether the donor card was an informative or a binding statement differed, where 97% of women and 80% of men indicated that the donor card was an informative statement ($p = 0.0462$).

Discussion

The present study is the first study in Sweden to investigate the relationship between women and men from Bosnia and Herzegovina living in Sweden and their perception and willingness in relation to organ donation. The results in the present study showed that the number of illiterate men was higher than that among women. The number of women with a high school education was higher than that among men, women had higher incomes than men and 90% of all the men were unmarried, while the corresponding figure for women was 60%. This situation was unexpected, and it is not typical of people born in Bosnia and Herzegovina, where men are most frequently highly educated, have a higher income and the ratio between married and unmarried is roughly the same. The reason for this may be that the majority of respondents grew up, graduated and started their first jobs in Sweden and that, apart from the culture from their home country, they also adopted the culture in Sweden. The findings in our study contrast with those in other studies, which showed that men were more educated and informed than women and because of this they had more information and more knowledge about organ donation [27,28]. In the next step of the questionnaire, we looked at gender differences in the definitions of transplantation, information, knowledge, opinion and important factors for organ donation. The present study demonstrated that men and women perceived definitions of organ transplantation differently. Statistically significant differences in being informed and knowing about organ donation were shown in the present study between different genders, where 60% of men answered that they were not sufficiently informed about organ donation, while 73% of women stated their above average satisfaction with information. These findings were comparable with those in another study where the majority of all the informants were adequately informed about organ donation [29]. Knowledge relating to organ donation was higher in women than in men, 66% vs. 56% respectively. Despite gender differences in knowledge about organ donation, this knowledge was high in both men and women. Our findings are in line with those in another study, which showed that 41.5% of all informants had an adequate knowledge of organ donation [29]. Gender differences were also demonstrated in the most important factors relating to organ donation according to the informants, where 37% of the men thought that the health of the body's recipient is the most important factor, while 77% of women thought that the most important factor is the kinship of the organ donor. Our results also revealed gender differences in the description of usefulness and support in the process of organ donation; 16 men and 27 women agreed completely, while eight men and two women agreed that organ donation is a useful thing and needs to be promoted. The social and cultural roles of men and women differ, and they expressed different opinions regarding the usefulness of and support for organ donation. Women generally feel more responsible and act as caregivers and, as a

result, they are much more likely to donate their organs than men. In many countries, the traditional role of women also includes looking after family members when they are ill [30,31]. Religious aspects of donation were described differently according to gender. The women had more knowledge of their religion's permissive attitude towards organ donation (70% vs 13%) and the majority of women (93%) knew that their religion did not oppose the donation of organs. In the question about reasons why the informants were against organ donation, the answers differed between the genders. In response to this question, 67% of men and 37% of women stated that they did not think about organ donation and 13% of men and 60% of women believed that the body should be intact after death. In other studies, men were found to refuse to donate their bodies after death more often than women [32], as men were more worried about their physical integrity, believing that desecrating their bodies would bring them misfortune [33]. This is a significant factor in people's attitude towards organ donation [34]. Gender differences were also demonstrated in the question about the person to whom the informants would donate their organs, where 83% of women and 40% men indicated that they would donate their organs to anyone, while 40% of men and 13% of women would donate to their family members. Motherhood may also give women a sense of duty to volunteer for organ donation to save their spouse, children and other family members. The findings in our study are in line with those in another study which shows that sisters, mothers and wives more frequently donate their living organs to children, brothers, fathers and husbands [30,35]. There is a very interesting study of organ donation between wives and husbands. This study showed that more than 30% of eligible wives were willing to donate their organs to their husbands, while only 7% of husbands were willing to donate their organs to their wives [36]. Moreover, 80% of women and 53% of men were willing to donate to people with other religious affiliations and 43% of men and 3% of women responded that they did not think about donating organs at all. The majority of the women did not know anyone who had donated their organs. The results of the present study also revealed gender differences in the ownership of donor cards. In our study, 66% of the women owned a donor card, while only one of the men owned a donor card. The majority of the women (96%) thought that the donor card was of an informative nature. The findings in our study are in line with those in previous studies, which showed that women were more willing to sign a donor card and donate their organs [32,37]. Other previous studies from low-income and under-developed countries reported results that are contrary to our findings [28,39]. It is difficult to give a specific reason for the stronger response of women to organ donation than that of men. We believe that women are more motivated, because altruism is more pronounced in them, as well as the desire to help a close family member or a person outside the family survive. We must also not forget motherhood and care for the family, which in most cases is found in the mother and in the mother's arms.

Study limitations

To the best of our knowledge, this is the first study of its kind in western Sweden. However, the study has some limitations, such as its cross-sectional design and the small sample. This makes it difficult to generalise the findings of our study. The other limitation in the present study may be that the first author of the study has the same ethnicity as the informants, and this may have influenced the informants' answers.

Conclusion

The results of the present study have succeeded in demonstrating gender differences in the perception of and willingness to participate in organ donation. Women were found to have more positive attitudes toward organ donation than men. Different socioeconomic factors, cultural beliefs, a higher level of religiousness, a higher level of information and knowledge about organ donation, as well as the ownership of donor cards, may result in a better perception of and willingness to participate organ donation. More knowledge of the religious understanding of organ donations and the reduction in prejudice among respondents would make the awareness and desire for organ donation even greater. We suggest that healthcare professionals and governmental and non-governmental departments should take the initiative actively to motivate people to give their consent to organ donation to a greater extent.

Abbreviations

OD – Organ donation

Ppm – people per million

SEK – Swedish kronas

Declarations

Ethics approval and consent to participate

All participants were verbally informed of the design and nature of the study and that their identities would be protected. They gave permission to record the questionnaire, and later, the material was locked in a safe. The participants received written information in which it was made clear that their participation was voluntary and that they could withdraw from the study without any repercussions to their clinical follow-ups. The patients were asked to sign a written consent form.

Consent for publication

Not applicable.

Availability of data and materials

No additional data are available due to the importance of confidentiality.

Competing interests

The authors declare that they have no competing interests. None of the authors have any financial or other potential conflict of interest.

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Author contributions

FK and EHS were involved in the conception and design of the work. FK did the statistical analysis of data. FK drafted the article and all authors revised it critically for important intellectual content. All authors gave final approval of the version to be published.

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Tables

Table 1. Demographic characteristics of the informants

Variable	Male (n,%)		Female (n,%)	
Age (years)				
< 25	2	6.7	2	6.7
25-40	2	6.7	9	30.0
41-55	8	26.7	13	43.3
56-70	16	53.3	5	16.7
> 70	2	6.7	1	3.3
Gender	30	100	30	100
Education				
Illiterate	2	6.7	0	0.0
Primary school	13	43.3	8	26.7
High school	14	46.7	22	73.3
Degree/above	1	3.3	0	0.0
Marital status				
Unmarried	27	90.0	24	60.0
Married	3	10.0	6	40.0
Religion				
Muslim	30	100	30	100
Other	0	0	0	0
Employment				
Employed	19	63.3	24	80.0
Unemployed	0	0.0	3	10.0
Retired	10	33.3	1	3.3
Other	1	3.3	2	6.7
Income (SEK)				
< 100,000	11	36.7	5	16.7
100k-200k	5	16.7	6	20.0
201k-300k	6	20.0	8	26.7

301k-500k	7	23.3	10	33.3
> 500,000	1	3.3	1	3.3

Table 2. Definition of transplantation, information, knowledge, opinion and important factors related to organ donation.

Variables	Male (n,%)		Female (n,%)		p value
A transplantation is a:					
Medical procedure between a deceased and a sick person	14	46.7	1	3.3	< 0.0001
Medical procedure between a living and a sick person	7	23.3	29	96.7	
Medical procedure between a living or a deceased person to a sick person	7	23.3	0	0.0	
Medical procedure without reason	14	46.7	1	3.3	
I have heard about organ donation					
Yes	28	93.3	28	93.3	1.000
No	2	6.7	2	6.7	
The most important factors for organ donation are:					
The age of the recipient	9	30.0	3	10.0	0.0039
The relationship with the donor	9	30.0	23	76.7	
Health condition	11	36.7	4	13.3	
Religious affiliation	1	3.3	0	0.0	
My knowledge regarding organ donation is:					
Poor	17	56.7	1	3.3	<0.0001
Good	11	36.7	9	30.0	
Excellent	2	6.7	20	66.7	
My opinion about the information I have received about organ donation is that it is:					
Insufficient	18	60.0	1	3.3	<0.0001
Satisfactory	11	36.7	7	23.3	
Above average	1	3.3	22	73.3	

Table 3. Usefulness, support, risks and religious issues regarding organ donation

Variable	Male (n,%)		Female (n, %)		p value
Organ donation is useful					
I completely agree	16	53.3	27	90.0	0.0179
I agree	8	26.7	2	6.7	
I neither agree nor disagree	5	16.7	1	3.3	
I disagree	1	3.3	0	0.0	
I completely disagree	0	0.0	0	0.0	
I support organ donation					
Yes	26	86.7	27	90.0	0.1341
No	1	3.3	3	10.0	
I don't know	3	10.0	0	0.0	
I would agree to an organ transplant if my life were in danger					
Yes	22	73.3	27	90.0	0.1299
No	2	6.7	2	6.7	
I don't know	6	20.0	1	3.3	
I would accept organs from a person of another religion					
Yes	19	63.3	27	90.0	0.0297
No	3	10.0	2	6.7	
I don't know	8	26.7	1	3.3	
I would donate organs to a person of another religion					
Yes	21	70.0	27	90.0	0.0724
No	2	6.7	2	6.7	
I don't know	7	23.3	1	3.3	

Table 4. Religious aspects of organ donation

Variable	Male (n,%)		Female (n,%)		p value
Organ donation is against my religion					
Yes	2	6.7	1	3.3	0.0007
No	15	50.0	28	93.3	
I don't know	13	43.3	1	3.3	
The reasons why I am against organ donation					
Fear of manipulation	5	16.7	1	3.3	0.0017
Untouched body after death	4	13.3	18	60.0	
Religious beliefs	1	3.3	0	0.0	
I have not thought about donation.	20	66.7	11	36.7	
I would donate my organs to				%	0.0062
Family	12	40.0	4	13.3	
Friends	2	6.7	0	0.0	
Anybody	12	40.0	25	83.3	
I won't donate	4	13.3	1	3.3	
Religious aspects of the donation				%	0.0007
Same religion	1	3.3	5	16.7	
Other religion	16	53.3	24	80.0	
I don't know	13	43.3	1	3.3	
Does your religion permit organ donations?					
Yes, regardless of the consequences	4	13.3	21	70.0	0.0001
Yes, if I can survive without the organ	8	26.7	6	20.0	
Yes, after death	1	3.3	0	0.0	
No, not allowed	2	6.7	0	0.0	
I am not sure	15	50.0	3	10.0	
Do you know anyone who has donated organs?					
Relatives	3	10.0	13	43.3	0.0026
Friends	5	16.7	1	3.3	

Acquaintances	2	6.7	5	16.7	
I don't know anyone who has donated	0	0.0	2	6.7	
I don't know	20	66.7	9	30.0	
Do you own a donation card?					
Yes	1	3.3	20	66.7	<0.0001
No	29	96.7	10	33.3	
What is the character of a donor card?					
Informative	24	80	29	96.7	0.0462
Binding	6	20	1	3.3	