ORIGINAL ARTICLE

The effect of changing one's country of residence on the decision to become an organ donor: the experience of religious immigrant women living in Sweden

Ferid Krupić[1,2,3,4,5], Sahmir Šadić[5], Svemir Čustović[5], Mahir Jašarević[5], Mirsad Fazlić[5], Kristian Samuelsson[1,2]

[1]Department of Orthopaedics, Institute of Clinical Sciences, The Sahlgrenska Academy, University of Gothenburg, Gothenburg, [2]Department of Orthopaedics, Sahlgrenska University Hospital, Mölndal, [3]Department of Anaesthesiology, Institute of Clinical Sciences, The Sahlgrenska Academy, University of Gothenburg, Gothenburg, [4]Department of Orthopaedics, Sahlgrenska University Hospital Östra, Gothenburg; Sweden, [5]University Clinical Centre Tuzla, Clinic for Orthopaedics and Traumatology, Bosnia and Herzegovina

ABSTRACT

Aim To explore and elucidate women's knowledge of and willingness to take part in organ donation, and to explore if their opinions were changed by coming to Sweden.

Methods The study was designed as a qualitative study using data from interviews with women from Bosnia and Herzegovina, Macedonia, Croatia and Kosovo. The inclusion criteria were women who were immigrants in Sweden and have lived in Sweden for more than 10 years. Five groups including forty-five women were invited to participate in the study and 39 agreed. The women were aged 29 to 73 years (mean 52.5 years).

Results Regarding knowledge and information about organ donation, most women found it very important to be able to talk about such things. However, the knowledge and information about organ donation of almost all the women was at a very low level. None of the women changed their opinion on the organ donation and attitudes from their countries of origin. All women firmly emphasized and explained that by coming to another state they do not become a different person and retain all values they had and with which were born in home country.

Conclusion It is important to study how to find new ways to communicate and work with minorities and vulnerable groups in order to discuss organ donation with all those who could be potential donors in the Swedish health care system.

Key words: organ donation, anthropological aspects, knowledge, gender, immigrants, qualitative research

Corresponding author:
Ferid Krupić
Department of Orthopaedics, Institute of Clinical Sciences, Sahlgrenska Academy, University of Gothenburg,
Göteborgsvägen 31, 431 80 Mölndal, Sweden
Phone: +46 31 342 82 42;
Fax: +46 31 87 85 31;
E-mail: ferid.krupic@gu.se
ORCID ID: http://www.orcid.org/0000-0001- 7082-3414

Original submission:
05 March 2018;
Revised submission:
13 April 2018;
Accepted:
16 April 2018.
doi: 10.17392/953-18

Med Glas (Zenica) 2018; 15(2):192-198

INTRODUCTION

Transplantation of organs is an extremely successful method that saves and improves lives of those suffering from organ failure. Although transplants are more and more accessible in technological terms, there are still many more people in need of new organs than donors, and this difference is increasing from year to year (1). All around the world, many patients do not survive long enough to receive a new organ, and the rate of failure is rising. The success of organ donation (OD) is closely related to decisions made by those immediately involved in health care (2). The statistics show that it is not possible to help everyone who needs a new organ to survive, despite the best efforts of professionals involved (3). There is a large difference between the numbers of potential donors in European countries. In 2016, Sweden had only 18.6 potential donors per million (pmp). This is a much lower figure than in other countries. Croatia has the largest number of potential donors (36 pmp) in Europe, Slovenia has 22, Macedonia 5 and Bosnia and Herzegovina and Kosovo only 1 (4,5). The family of a donor articulated some of the factors related to the willingness to donate organs as: unselfishness and being able to save a life, bodily integrity and dignity, the stance of family members, and mourning and anxiety (6-9). There is, in general, more readiness for live donation to a member of the family in comparison with becoming a donor after death (10–12). Other factors include strong or weak religious, cultural or social and economic convictions (13,14). Research has shown that the factors that mostly affect OD are low age, being female, high social status, education, good understanding of OD, experience of OD and a supportive family (15). No previous studies were found that dealt with gender differences or differences between immigrants and the native population in Sweden.

The aim of this study was to explore and elucidate women's knowledge about and willingness to take part in organ donation and to assess if their opinion was changed by coming to Sweden.

PARTICIPANS AND METHODS

Participants and study design

The study was designed as qualitative research using data from interviews with women from four countries: Bosnia and Herzegovina, Macedonia, Croatia and Kosovo. Data were collected through three focus group interviews (16).

The inclusion criteria were women who were immigrants in Sweden and had lived in Sweden for more than 10 years. Forty-five women, in five groups, were invited to participate in the study and 39 agreed. The women were aged 29 to 73 years (mean 52.5 years). The interviews and all communication were carried out in Bosnian and Swedish (Table 1).

Table 1. Characteristics of the study population

Variables	No (%) of participans
Educational level	
Elementary school	30 (77)
High school/university	5 (14)
Master's	3 (7)
Doctoral/postdoctoral education	1 (2)
Total	**39 (100)**
Age (years)	
20-30	3 (7)
30-39	9 (24)
40-50	13 (33)
51-59	5 (13)
60-70	6 (16)
> 70	3 (7)
Total	**39 (100)**
Lived years in Sweden	
10-20	6 (16)
20-30	25 (65)
30-40	4 (10)
40-50	3 (7)
> 50	1 (2)
Total	**39 (100)**
Employment	
Employed	7 (17)
Unemployed	28 (73)
Pensioner	4 (10)
Total	**39 (100**
Country of Birth	
Bosnia and Herzegovina	19 (50)
Macedonia	7 (17)
Kosovo	9 (23)
Croatia	4 (10)
Total	39 (100)
Religion	
Islam	27 (70)
Christian Orthodox	8 (20)
Catholics	4 (10)
Total	**39 (100)**

All participants were given information relating to the study including its voluntary nature and the fact that they could withdraw at any time without experiencing penalties or loss of access to services. All women provided signed informed consents before the interviews.

Since there was no physical intervention, and no information on individual health issues was in-

volved in the study, there was no need to involve the ethical board, according to Swedish law (19). The World Medical Association Declaration of Helsinki (20) was followed carefully and the informants' identities were protected, i.e. their names and personal identity numbers were not stated in the recordings or any publications.

Methods

Data were collected by the author through group interviews using individualized open-ended questions following an interview guide inspired by Kvale (17). The interviews were performed from September 2017 to February 2018. The opening questions were "*What do you know about organ donation?", "Would you consider donating your own organs or organs of a member of your family?"* and *"Has your opinion on organ donation changed by coming to Sweden?"* The initial questions were supplemented with other short questions such as *"Could you please tell me more about that?"* and *"What do you mean by that?"*. All contacts with the participants were arranged in collaboration with a key person in a Bosnian and Croatian association in the western part of Sweden. Women who fulfilled the inclusion criteria were asked to participate in the study and when the key person had recruited enough participants, the first author of the study was contacted, and the interview was arranged. The interviews were carried out in groups at the Bosnian and Croatian association. They lasted between 60 and 90 minutes, were taped and transcribed verbatim.

Statistical analysis

The qualitative content analysis method, in accordance with Graneheim and Lundman (18), was chosen for the analysis and interpretation of the collected data. A manifest analysis of the text was made and the transcripts were read carefully in order to identify the women's experiences and conceptions. The analysis then proceeded by extracting meaningful units, consisting of one or several words, sentences, or paragraphs, containing aspects related to each other and addressing a specific topic in the material. These meaningful units, connected to each other by their content and context, were then abstracted and grouped together into a condensed meaningful unit with a description close to the original text. The condensed text was further abstracted and labelled with a code. Codes that addressed similar issues were then grouped together resulting in subcategories and subcategories that focused on the same problem and were brought together to create more extensive concepts, which addressed an obvious issue (Table 2). The results were presented with direct quotations from the interviews (Table 3).

Table 2. Illustration of the analysis process in various stages modified from Graneheim & Lundman (18)

Step	Description
I	**Meaning unit** The first step is to identify the words, sentences and paragraph that have the same essential meaning and contain aspects related to each other through their content and context.
II	**Condensed meaning unit description close to the text** Meaning units related to each other through their content and context were then abstracted and grouped together into a condensed meaning unit, with a description close to the original text.
III	**More condensed meaning unit interpretation of the underlying meaning** The condensed text in the meaning unit was further abstracted and interpreted as the underlying meaning and labelled with a code.
IV	**Subcategories** Codes were grouped together based on their relationship and codes that addressed similar issues were grouped together in subcategories.
V	**Categories** Subcategories that focused on the same problem were brought together in order to create more extensive conceptions.
VI	**Theme** Finally, a theme that covers the analysed text links the categories that appeared and emerged from the text.
VII	**Direct quotes** Presentation of results with direct quotes from the interviews.

RESULTS

The analysis of the text resulted in two main categories and seven subcategories based on how women described their situation regarding OD (Table 3).

Table 3. Overview of the theme, categories and subcategories

Category	Subcategories	Theme
Ignorance about organ donation	Lack of information Indifference towards organ donation Lack of education	The change in the state of residence does not change the decision on the donation
Anthropological aspects in organ donation	Cultural beliefs Religious beliefs The family Views about organ donation in Sweden	

Ignorance about organ donation

Regarding knowledge and information about OD, most women deemed it very important to be able to talk about such things. However, the level of knowledge and information about OD amongst almost all women was very low. Some of them attributed this to a challenging life, some to lack of time and some to education, while other women did not even think about it and were totally uninterested.

Lack of information

The majority of the women blamed their ignorance on insufficient access to information on the donation of organs. They also drew a parallel with their home countries where information about this issue is still scarce.

"I think that a little talk about the donation of organs, providing information, should be offered, without us asking for information."

Indifference towards organ donation

The majority of the women had been preoccupied with other life issues and therefore had not thought about organ donations, either as someone who might need an organ now or as someone who might need an organ in the near future. Most of the respondents also showed a complete lack of interest in OD.

"I do not know anything about it", "as God decides", "I will never be interested in it", "I will think about it when the time comes for it."

Lack of education

One of the important factors that most women in this study highlighted was the education they received about organ donation. They stressed that despite their desire to be informed about organ donation, their educational potential is low which creates problems. A large number of the women came to Sweden at the beginning of the war in the Balkans, and they prioritized other things over education and the continuation of their education.

"When I came to Sweden my life changed completely", "I have prioritized other things rather than school", "It was important to survive, everything else had to wait."

Anthropological aspects of organ donation

The energy shown by these women in their stories about their people, habits and religion was visible throughout all the interviews. In all interviews and in all women, a strong anthropological sense of ethnicity and religious commitment were visible alongside clear evidence of the influence of religion and prejudice, pride and dignity, and great love and loyalty to the state. However, these characteristics negatively affected the possibility of OD in those women. Almost all the interviewed were against the donation of organs, precisely because of the role played by the factors above in their lives.

Cultural beliefs

Most women stated that culture is very important to people and that culture and affiliation with culture remains with people all the time. They also stressed that, regardless of the relative comfort of life in Sweden, all of them had cultural "baggage", which they carried with them day and night.

"I was born far away from here, we don't ever talk about organ donations, as it is in Sweden."

"Culture is something that sucks human beings in and involves your entire life."

Religious beliefs

One of the most important things involved in the decision to donate organs is religion and religious prejudices that most women mentioned in this study. All the women retained their beliefs and religious affiliation when they came to Sweden and these religious preoccupations and beliefs pushed aside other things, such as organ donation. The majority of women have also demonstrated that prejudices can play a role in decisions about organ donation.

"I was religious in my country and I am religious here too." "My religion allows the donation of organs, but I'm not for it." "I heard that if you donate your kidney to someone after death you have problems with urination." There were also opposing opinions: *"I am a Catholic and my religion allows the donation of organs and I will donate my organs after death."*

The family

Family and familial relationships are unexpectedly very important for the women. All the women

stressed that it is very important for a family to consider certain things, and all the women stressed that all possible donations of organs should first occur in the family circle, for a member of the family. Other possibilities were not even considered.

"I would only donate my organs to my family, my son, daughter or husband." "Family is everything for me, if I need I will give my life for them."

Views about organ donation in Sweden

None the women changed their opinions and thinking about organ donation from that of their countries of birth. All women firmly emphasized that by coming to another state you do not become a different person but rather you retain all the values you had before and with which you were born in your home country. The majority of women also emphasized that there are great opportunities for such a life in Sweden.

"I have lived in Sweden for 40 years and I am the same person as when I came to Sweden." "A man does not change by changing state boundaries." "My opinion on the donation of organs is the same as it was 35 years ago." "I do not think enough about the donation of organs, so I cannot change my thinking about it."

The final minutes of discussion with the women were set aside for open discussion where the women could freely express themselves about the topic. Even then, all the women agreed that people do not change overnight, and people do not change by altering their place of residence. All the women agreed that they had retained the views on the donation of organs that they had had in their home countries.

DISCUSSION

This is the first study in Sweden regarding the attitudes of immigrant women from four countries to the donation of organs, and the things that have affected their attitudes since they came to Sweden. The study has shown various features of the participants. Information about organ donation, cultural background, religion, and prejudice were the issues that affect a person's attitude to OD. Most subjects were interested in learning more about OD, but the information available was insufficient. The interviewed women said that they were not interested in OD because they did not know much about it, and they were not highly educated. This supports our earlier studies, when we interviewed non-Swedish nationals from a variety of backgrounds (21). They also stated that the scarcity of information given by medical staff has had the greatest effect on their attitude to OD (21). Other research interviewed both males and females comparing their replies. This showed that women are more active in seeking information for themselves and others. They are key in providing information for their family, which may also affect others (22). It has been shown many times that the relationship between knowledge, information and attitudes to OD is very important (23,24). We also demonstrated in this study that culture and religion, including religious beliefs and prejudices, are also significant in relation to organ donation in the families of the women we interviewed. They showed strong affiliation with their culture and religious beliefs, pride and dignity, but also affection and commitment to the country they were now living in. They were all practical believers who expressed their beliefs openly. This is in accordance with other research showing that these factors, in addition to linguistic barriers, race, and gender are important in deciding about OD (21,25,26). Some women in this research stated that they would not donate their organs because they believed their bodies belong to God, and that He should decide on matters of life and death. These beliefs are very important in decision-making regarding OD, as was also shown in another study (27). Religious beliefs were a very strong predictor of whether participants in the study would be willing to donate their organs to people outside their family. In another study we conducted, both genders provided the same results, even though they were from different countries (21). However, research in India (28) has shown that males and females decide differently about OD and that men are more likely to be donors. This may be due to the higher level of education of men in that country, or because men tend to watch television more often than women so they receive more information about OD (28).

Our main interest in the present study was to learn if moving to a different country could affect a person's attitude to organ donation as there have been few such studies around the world. None of the women in our research altered their opinion about OD having changed their country of residence. Although they did mention that they had greater opportunities in Sweden, they stated very

clearly that people do not change when they move to a different country, but they take their up-bringing and culture with them. Although there are differences around the world in relation to organ donation, some things are the same. There is a need for donations in every country, and the need is growing. This includes all races and ethnicities. Sometimes the differences in terms of willingness to donation are due to economics, and social prejudice. Unfortunately, the races that need donations most are often those who are least willing to be donors. A great deal of work needs to be done to educate these groups and promote organ donation to help meet the need. Furthermore, although many individual believers think otherwise, all the major religions have a positive stance towards organ donation and have published statements to this effect (29). People, and in this case women, who have come to Sweden from other countries are unwilling to adapt to the local culture, which includes the decision to donate their organs.

In conclusion, this study shows that the availability of information about OD, and cultural background are significant factors for women who have moved to Sweden from other countries. They could be organ donors but their cultural background often influences their decision. Medical staff must understand the gender-related differences in the context of OD, and that native-born Swedes and immigrants have different attitudes to OD because a person's attitudes and up-bringing do not change simply because they have changed their country of residence. Moreover, in talking with immigrants as patients, it is necessary to keep the language and procedure simple. It is important to study how to find new ways to communicate and work with minorities and vulnerable groups, to discuss organ donation with all who could be potential donors in the Swedish health care system.

FUNDING

No specific funding was received for this study.

TRANSPARENCY DECLARATIONS

Competing interest: none to declare.

REFERENCES

1. Levitt M. Could the organ shortage ever be met? Life Sci Soc Policy 2015; 11:6.
2. Council of Europe. International figures on organ donation and transplantation. Transplant Newsletter , 2012.
3. Wilow K. Författningshandbok, Stockholm, Sweden: Liber, 2013 (in Swedish).
4. Anonimus. Report of the Madrid Consultation Part 1: European and universal challenges in organ donation and transplantation, searching for global solutions. Transplantation 2011; 91:539-566.
5. Citerio G, Cypel M, Dobb GJ, Dominiquez-Gil B, Frontera JA, Greer DM, Manara AR, Shemie SD, Smith M, Valenza F, Wijdicks EF. Organ donation in adults: a critical care perspective. Intensive Care Med 2016; 42:305-15.
6. Rodrigue JR, Cornell DL, Howard RJ. Relationship of exposure to organ donation information to attitudes, beliefs, and donation decision of next of kin. Prog Transplant 2009; 19:173-9.
7. Irving MJ, Jan S, Tong A, Wong G, Craig JC, Chadban S, Rose J, Cass A, Allen RD, Howard K. What factors influence people's decisions to register for organ donation? The results of a nominal group study. Transplant Intern 2014; 27:617-24.
8. Irving MJ, Tong A, Jan S, Cass A, Chadban S, Allen RD, Craig JC, Wong G, Howard K. Community attitudes to deceased organ donation: a focus group study. Transplantation 2012; 93:1064-69.
9. Gauher ST, Khehar R, Rajput G, Hayat A, Bakshi B, Chawla H, Cox BM, Warrens AN. The factors that influence attitudes toward organ donation for transplantation among UK university students of India and Pakistani descent. Clin Transplant 2013; 27:359-67.
10. Boulware LE, Ratner LE, Cooper LA, Sosa JA, LaVeist TA, Powe NR. Understanding disparities in donor-behavior: race and gender differencesin willingness to donate blood and cadaveric organs. Med Care 2002; 40:85-95.
11. Conesa C, Rıos Zambudio A, Ramırez P, Canteras M, del Mar Rodrıguez M, Parrilla P. Socio-personal profile of teenagers opposed to organ donation. Nephrol Dial Transplant 2004; 19:1269-75.
12. El-Shoubaki H, Bener A. Public knowledge and attitudes toward organ donation and transplantation: a cross-cultural study. Transplant Proc 1993; 2005:1997.
13. Padela AI, Rasheed S, Waren GJW, Choi H, Mathur AK. Factors associated with positive attitudes toward organ donation in Arab Americans. Clin Transplant 2011; 25:800-8.
14. Lopez JS, Valentın MO, Scandroglio B, Coll E, Martın MJ, Sagredo E, Martınez JM, Serna E, Matesanz R. Factors related to attitudes toward organ donation after death in the immigrant population in Spain. Clin Transplant 2012; 26:200-11.
15. Wakefield CE, Watts KJ, Homewood J, Meiser B, Siminoff LA. Attitudes toward organ donation and donor behavior: A review of the international literature. Prog Transplant 2010; 20:380-91.

16. McLafferty I. Focus group interviews as a data collecting strategy. J Adv Nurs 2004; 48:187-94.
17. Kvale S. Den kvalitativa forsknings intervjun. (The qualitative research interview). Lund, Sweden: Studentliteratur, 1997.
18. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trust worthiness. Nurse Educ Today 2004; 24:105-12.
19. Swedish Health Care Act. The Act concerning the ethical review of research involving humans. http://www.epn.se/eng/start/2003_460.apsx. (16 June 2015).
20. The World Medical Association Declaration of Helsinki. Code of Ethics 1964 (revised). Edinburgh: World Medical Association, 2005.
21. Krupic F, Sayed-Noor AS, Fatahi N. The impact of knowledge and religion on organ donation as seen by immigrants in Sweden. Scand J Caring Sci 2017; 31:687-94.
22. Dodd-McCue D, Tartaglia A, Cowherd R. The role of women in the donation consent decision: building on previous research. Prog Transplant 2007; 17:209-14.
23. Bratton C, Chavin K, Baliga P. Racial disparities in organ donation and why. Curr Opin Organ Transplant 2011; 16:243-9.
24. Alvaro EM, Siegel JT, Turcotte D, Lisha N, Crano WD, Dominick A. Living kindey donation among Hispanics: a qualitative examination of barriers and opportunities. Prog Transplant 2008; 18:243-50.
25. Alkhawari FS, Stimson GV, Warrens AN. Attitudes toward transplantation in U.K. Muslim Indo-Asians in west London. Am J Transplant 2005; 5:1326-31.
26. Sadic S, Sadic J, Krupic R, Fatahi N, Krupic F. The influence of information and religion on organ donation, as seen by school teachers in Bosnia and Herzegovina. Mater Socio Med 2016; 28:373-7.
27. Irving MJ, Tong A, Jan S, Cass A, Rose J, Chadban S, Allen RD, Craig JC, Wong G, Howard K. Factors that influence the decision to be an organ donor: a systematic review of the qualitative literature. Nephrol Dial Transplant 2012; 27:2526-33.
28. Poreddi V, Sunitha TS, Thimmaiah R, Math SB. Gender differences in perceptions and attitudes of general population towards organ donation: an Indian perspective. Saudi J Kidney Dis Transpl 2017;28:599-8.
29. Da Silva IRF, Frontera JA. Worldwide barriers to organ donation. JAMA Neurol 2015; 72:112-1.