

# Young People's Views of Organ Donation and Transplantation as Seen by High-School and University Students in Sweden

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## ABSTRACT

**Introduction:** Organ donation and transplantation of organs are one of the most effective ways to save lives and improve the quality of life for people with end-stage organ failure. Despite its increasing availability from the technological standpoint, the gap between the number of people waiting for transplantation and the number of donors is widening every year all over the world.

**Aim:** To explore and elucidate high school and university students' attitudes, knowledge and willingness regarding organ donation and transplantation.

**Methods:** Data were collected from March 2018 to September 2019 through three focus group interviews using open-ended questions, following an interview guide and qualitative content analysis according to Graneheim and Lundman and about twenty-five adult students.

**Results:** The analysis of the interviews resulted in three main categories: "Knowledge of organ donation", "Being informed about organ donation" and "Willingness to be a donor", including a number of subcategories. Interest in organ donation of all the students was at an extremely low level and they were critical and emphasized that their school offered very little or no education about organ donation. The extremely low level of knowledge was also found about a donor card, who can donate their organs and who can receive organs from other people.

**Conclusion:** In order to overcome young people's low level of knowledge about organ donation, structured and well-considered educational programs, which provide knowledge, information and education about prejudice relating to organ donation and transplantation should be prepared for all. More programs about organ donation must be available in different media and on the Internet.

**Key words:** Students, organ donation, transplantation, experiences, knowledge and qualitative research.

## INTRODUCTION

Organ donation (OD) is one of the most effective ways to save lives and

improve the quality of life for people with end-stage organ failure. Despite its increasing availability from the

technological standpoint, the gap between the number of people waiting for transplantation and the number of donors is widening every year all over the world. [1] The end result regarding OD depends on the final decision of people directly linked to the health-care system. [2] In the end, in the process of OD and the transplantation of organs, it is the individual who decides whether or not one's organs will be donated to others. However, for young people it may be an abstract concept. There are many uncertainties, ambiguities and misconceptions. Statistical data, unfortunately, tell us that, no matter how much we do, it is still not enough to help all the patients for whom the only salvation is transplantation. [3] The number of organ donors in Europe differs between countries. In Sweden, there were 17.6 per million populations(pmp) in 2015, which was considerably fewer than the number reported in many other European countries. Spain and Croatia have the most donors (pmp) of all European countries, with 34.0 and 39.2 donors, respectively. [4,5] Previous studies of OD have mostly focused on the adult population, who are assumed to be able to take a stand, sign an organ donor card, or enter their names in a donor registry. These studies have shown that there are complex interactions of factors that influence public attitudes toward deceased OD. They include race, ethnicity, sex [6] and the age of the individuals, [7-9] where those who have higher levels of educational attainment and income, [7,10,11] on average, including a greater knowledge of OD, are more likely to have positive attitudes towards deceased OD. [11] Additionally, psychosocial characteristics appear to be associated with OD attitudes, as individuals with altruistic tendencies are more likely to find deceased OD acceptable. [12] Young people are an important target group for organ donation, because they are at a key stage in their development in terms of human values, and a positive attitude towards OD instilled in the younger population will last throughout their lives.

In addition, young people may promote discussion and educate their family members about OD. [13] However, little knowledge and information is available today about the way young people, including teenagers, perceive the issues of OD and transplantation. In Sweden, there are few studies describing the experiences and decisions of young individuals regarding OD and organ transplantation. [14,15]

### **Aim**

The aim of the present study was to explore and elucidate high school and university students' attitudes, knowledge and willingness regarding OD and transplantation.

## **METHODS**

### **Data collection**

The study was designed as a qualitative study using data from focus group interviews, [16] with individuals with origins from Bosnia and Herzegovina, Macedonia, and Kosovo. The inclusion criteria were participants who were students, aged between 18 and 25 years. All informants were adults and were 18 years or older at the time of the interviews. Forty students were invited to participate in the study and twenty-five agreed. The participants were 6 girls and 19 boys, aged 18 to 25 years (mean 21.5 years). All the students were born in Sweden, apart from three who came to Sweden as four- to five-year-old children. The interviews and all communication were carried out in Bosnian and Swedish. The information relating to the study that was given to the informants included its voluntary nature and the fact that they could withdraw at any time without having to motivate their decision. All the individuals provided signed informed consent before the interviews. The demographic and clinical characteristics of the informants are shown in Table 1. Data were collected by the first author through group interviews, following an interview guide inspired by Kvale. [17] The interviews

were performed from March 2018 to September 2019. The opening questions were “What do you know about organ donation?” and “Would you consider donating your own organs or organs of a member of your family?”. 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 contact with the individuals was arranged in collaboration with a key person in a Bosnian and Herzegovina association, in the western part of Sweden. Individuals who fulfilled the inclusion criteria were asked to participate in the study. When the key person had recruited enough participants, the first author of the study was contacted and the interview was arranged. Printed information about the aim and background of the study was distributed to the participating students and it was repeated to them orally before the interview. The interviews were carried out in groups at the Bosnian youth association. The participating students were encouraged to speak freely, using their own words, and the interviewer encouraged the individuals to respond to the questions as comprehensively as possible. The interviewer only interrupted to ask questions or to follow up on the information given. The interviews lasted between 75 and 110 minutes, were taped and transcribed verbatim.

### Ethical Consideration

Since there was 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. [18] The World Medical Association Declaration of Helsinki [19] was followed carefully. The informants' identities were protected, i.e. their names and personal identity numbers were not stated in the recordings or any publications.

### Statistical analysis

The qualitative content analysis method, in accordance with Graneheim and Lundman, [20] was chosen for the analysis

and interpretation of the collected data. A manifest analysis of the text was performed. The transcripts were read carefully in order to identify the informants' 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, related 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. The codes that addressed similar issues were then grouped together, resulting in subcategories. Subcategories that focused on the same problem were brought together, in order to create more extensive concepts, which addressed an obvious issue. [20] The results are presented with direct quotations from the interviews. Table 2.

**Table 1. Characteristics of the study population**

Characteristic	Number of participants
Sex	
Male	19
Female	6
Total	25
Educational level	
High school	17
University	8
Total	25
Age (years)	
18-20	17
≥ 20	8
Total	25
Parents' countries of birth	
Bosnia and Herzegovina	12
Macedonia	9
Kosovo	4
Total	25
Religion	
Islam	22
Christian Orthodox	1
Other	2
Total	25
Country of birth	
Sweden	22
Other	3
Total	25

## RESULTS

The analysis of the text resulted in three main categories and nine subcategories, based on how the participating students described their view

regarding OD in Sweden. The categories, presented in Table 3, together with the subcategories, are

**Table 2. Illustration of the analysis process in various stages**

Stage	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 analyzed text links the categories that appeared and emerged from the text.
VII	Direct quotes Presentation of results with direct quotes from the interviews

**Table 3. Overview of categories, subcategories and theme**

Theme	Categories	Subcategories
<i>The organ donation and transplantation – from the students point of views.</i>	Knowledge of organ donation	Knowledge of the donation process The school as the source of knowledge of organ donation Possession of donor cards
	Being informed about organ donation	<i>Parents as students source about organ donation</i> The school as a source of information Information through media of various kinds
	Willingness to be a donor	Unconditional organ donation Priorities in organ donation Only live donation of organs

### Knowledge of organ donation

The knowledge of and interest in OD of all the informants was at an extremely low level. Most of the respondents who were interviewed in this study experienced and understood the subject of OD very seriously, while some respondents, mostly the younger ones, had no knowledge of the concept of OD. However, none of the informants knew how to define OD and did not know which organs they could donate. The ignorance of OD was seen in their ignorance of the process of OD, the kind of donations that are possible, the donor or

recipient body, donor cards and who can possess a donor card. Many respondents mentioned school as the main source of knowledge about OD and said that all knowledge should be acquired at school, even that relating to OD.

### Knowledge of the donation process

The majority of the respondents in this study did not know how to define OD. They needed to be educated and taught about OD, the procedure for OD, the decision to be an organ donor and to sign a donor card. The reasons for their ignorance varied. Some of them had never thought about it, for some it

was because they were young, they believed that it was the job of other people to teach them and it was not their obligation to seek knowledge and information about it.

*"In our fast-paced lives, where everything has to be planned and 'served on a plate', it would be good for information and everything else about organ donations to be more readily available, so we wouldn't have to search for information about it."*

### **The school as the source of knowledge of organ donation**

All the participants agreed that schools were responsible for educating students on various issues and that the school is the institution responsible for communicating knowledge about OD. All the respondents were critical and emphasized that their high school offered very little or no education about OD or some other important topics. The subjects, both young and older, stressed that they had rarely talked about OD and the little they had learned was only the result of one of the students asking something about the subject in school.

*"How are we going to know anything about organ donation when no one ever talks about it? I will finish college in three years and my knowledge of organ donation is exactly zero."*

### **Possession of donor cards**

The same situation and the extremely low level of knowledge were also found when it came to the issue of holding donor cards. The majority of respondents did not know what a donor card is, whether they can or cannot hold one, who can donate their organs and who can receive organs from other people, if they must be a person of legal age to be a donor and whether they needed to ask their parents about donating their organs and holding a donor card. None of the subjects in this study had a donor card, but half of them were interested in acquiring one.

*"I think we once talked in school about organ donation, but I have no idea about donor cards."*

*"I am very busy... I can't keep up with my work at university and think about donor cards at the same time. I have no idea."*

*"I think you can have a donor card even if you don't want to be an organ donor... I don't know... I'm not sure."*

### **Being informed about organ donation**

When it comes to obtaining information about OD, the subjects in this study were slightly better informed than their actual knowledge about the same topic. The respondents explained that, in the case of OD, they could be informed by their parents, friends, relatives, someone who has had some experience of ODs, as well as through the internet and media of various other kinds.

The students also expressed their dissatisfaction regarding the information provided by their school about ODs. All the students were critical of their school; they all expressed an interest in obtaining information from their school about OD. All the informants needed more information about OD.

### **Parents as informants about organ donation**

Some of the students had talked with their parents about OD. Some of them had been given information and some not. The reason for this was their parents' low level of interest on the one hand, or their lack of knowledge of OD on the other.

Some respondents had not spoken to their parents because the parents' level of education was very low and they already imagined the answer to their question.

*"The information that I get from my parents is superficial and I don't know if it is true..., I don't know whether I can rely on it."*

*"My parents are illiterate and at this point I have never spoken with them about this."*

### **The school as a source of information**

Students criticized their school again. Information and the provision of information about OD from their school were perceived as insufficient. Information was not even available in Swedish and there was no question of other languages. The respondents indicated that no informative



meeting with students on the topic of OD had ever been held. The students also pointed out that most of them wanted to be informed about OD by their school as an institution.

*"Some important topics, such as the administration of organ donation, have never been explained at our school."*

*"I think it's the duty of schools to inform us about such an important topic... Receiving information does not mean that I would immediately become an organ donor tomorrow."*

### **Information through media of various kinds**

All the participants in this study indicated that one of the main ways of acquiring knowledge and information about OD is through the media. Most of them watched Swedish television, listened to Swedish radio and regularly used the internet. Some of the participants, even during the interview, visited some sites on the internet and quickly became informed about the topic of OD. The joy on their faces showed what makes the majority of the respondents happy – the internet.

*"Google is the best... Google knows everything... long live Google!"*

*"We have everything on the internet and it's easy to find... but it's difficult to find information when the situation is urgent... knowledge should always be available, especially when it comes to this important topic."*

### **Willingness to be a donor**

The most interesting finding in the present study is that, despite the low level of knowledge and awareness about OD, and regardless of the weak support given by schools as educational institutions, all the informants in this study were in agreement and were willing to donate their organs to others. Most respondents stressed that their organs would be donated unconditionally, but there were respondents who had certain conditions regarding OD. These conditions were priorities for donation, they would

only donate organs while they were still alive and not after death and they wanted to be sure their organs were not abused. Girls showed more interest in and a desire for OD, as well as greater commitment and enthusiasm, than boys.

### **Unconditional organ donation**

All the informants in this study agreed unconditionally to donate their organs to others. During the discussion on preferences for OD, the girls showed more interest and desire for this, but the interest of the boys was also at a high level. The desire of all the participants was to help and this was one way they could try to save one or more lives. Some respondents pointed out that helping others makes them happy and this was the most important thing in life.

*"I want to donate organs regardless of the patient's religious, national or racial affiliation."*

*"I can honour and help save one life..., when someone saves one life, it is as if he saved the whole world."*

### **Priorities in organ donation**

Some informants in this study expressed an interest in planning the selection and priorities in their decision for OD. This group of informants pointed out that their organs should first be donated to a member of their family or friends and then to others who needed it. All the informants in the group that had priorities in OD also pointed out that the likelihood of abuse of authority was lower if they donated within families, where those who donate would be able to monitor the entire process.

*"First family, then everyone else... family is family."*

*"I think it's quite normal to start with the family because it's most important and then everyone else who can be helped and who needs help... of course."*

### **Only live donation of organs**

One feature in this study was that almost all, but mostly the older, informants

stressed that they wanted to donate their bodies unconditionally to other people, but only during the course of their life and not when they die. Older students also asked whether such a thing is possible and whether it is possible to write it on the donor card. The informants also emphasized that, due to their belief in a life after this life, they all wanted to start over again with all their organs in their body. An incomplete body would mean an incomplete next life.

*“All the organs that can be donated, I am more than happy to donate them, but only while I'm alive... not when I die.” and “The next life is the real life... this life is only a station on the way... in the real life, I want to be true and complete.”*

## DISCUSSION

The results of the present study reveal several characteristics relating to the ignorance of high-school and university students regarding the fundamental aspects of OD, such as the definition of OD and the organs they can donate, as well as the donation process. Schools were seen to be a poor source of knowledge and there was little knowledge of donor cards. The reason for the lack of knowledge about OD that the students in this study demonstrated during all the interviews is unknown. It is, however, possible to find the reason in the time in which we live and the fast pace of life experienced by students. The reason may be the insufficient knowledge given by various institutions, such as schools, which was noted by the students in their discussions. The motivation and desire for knowledge of OD and the possession of donor cards would probably be higher if knowledge and information about it were available through different courses offered at school and if students did not have to seek knowledge and information by themselves. However, younger students and university students all acknowledged their lack of knowledge about OD and all of them showed great interest in learning more about OD. The findings of the present study are in line with those of other studies from

European countries. [21-23] All the criticism directed at schools, in terms of the provision of knowledge to students on the issue of OD, was well placed, as evidenced by some earlier studies of the impact of various scientific programs in raising awareness of possessing donor cards, knowledge and awareness of OD, as well as the increased desire of students for OD and transplantation. [24] Another interesting finding in our study was that none of the informants had a donor card, but all the students wanted to have one. The lack of possession of donor cards can be directly linked to the lack of knowledge among students of OD and the poor awareness of students of OD. It may even depend on whether the students were attending university and studying medicine or nursing, or some other subject. In one Turkish study, [25] it depended directly on which university the students were attending and whether they were law or medical students. Some 1.4% of medical students owned a donor card, while none of the law students had one. [25] Other studies also revealed that the percentage of students owning a donor card differs in different countries. In the USA, 80% of students held a donor card, in Brazil, 69.2%, in England, 43%, in Germany, 31.9% and, in Sweden, 22.3%. [26] One English study revealed that 74% of nursing students and 43% of medical students had a donor card. [27] As expected, ignorance of OD stemmed from a lack of information on the topic. The reason for this is perhaps again the pace of life, which is currently very hectic, and maybe the fact that young people do not think much about the possibility of death and OD. The results of the study show that a small number of students had talked about the subject with their parents, while the students whose parents were illiterate had not even begun to talk about the subject. However, a cohesive family environment and family discussion were strong predictors of the willingness of intermediate and high-school students to be organ donors, as reported in a study from Korea. [24] A large number of informants in

this study sought help from various media but primarily the internet and Google. A large number of informants also stressed that schools should give information to students about such important, burning issues and that awareness and knowledge of OD was previously at a higher level than is the case today. One study of the effect of an educational program on attitudes towards deceased OD showed that the program, consisting of informative pamphlets and a classroom lecture delivered by a transplant physician, who was himself a kidney transplant recipient, was effective in encouraging medical students to be prepared to sign a donor card, actually to sign a donor card, to discuss deceased OD with their family and to increase their knowledge of OD and transplantation. [28,29] It is important to note that, despite the poor level of knowledge and information about OD and the low level of knowledge and distribution of information from the school and family, the majority of participants wanted to donate their organs unconditionally to other individuals. Some of them wanted to do so without any priorities in their OD and some wanted to begin their OD with members of their families and friends. In many previous studies, it has been shown that students' attitudes supporting transplantation and OD activities in terms of donating organs were less positive. Three in four students mentioned the possibility that psychological discomfort plays an important role in OD and they reported different kinds of discomfort. The majority of students thought that fear and discomfort were the main reason for the lack of OD and transplantation. Difficulties imagining their own death were also reported by the majority of students. [14] This was not, however, the case in our study, where the majority of students were willing to donate their organs, which is in line with another study, where 82% of all students stated that they had thought about donating their organs to others. [28] Probably the most interesting and significant finding in the present study was the occurrence of

prejudice in the majority of the respondents, regardless of their age and level of education. Prejudice as a predictor and as an influence on OD and organ transplantation has been described in previous studies, mostly by adult informants. [30-32]

The prejudice expressed by the informants in our study was the phenomenon where the majority of students wanted to donate their organs to any people in the world, regardless of race, religion and religious affiliation, but they all wanted to donate their organs while they were alive and not in the event of death. The reason for this may be the fact that the majority of students in the study identified themselves as members of one of the two main religions and religion and prejudice go hand in hand when it comes to deciding about the donation and transplantation of organs. On the other hand, the reason for the prejudice in students could possibly be seen in the light of their parents, who were born in other countries but are now living in Sweden. Perhaps their behaviour and cultural heritage contribute to students thinking about OD in this way. The emergence of so-called student prejudice regarding OD should lead us to further consideration and to the conclusion that some cultural, religious and cultural taboos can never be overcome. The present study is one of the first studies in Sweden to investigate students from different educational levels and three different countries in terms of their attitudes, knowledge and willingness regarding OD and organ transplantation.

## **CONCLUSION**

We found that high school and university students expressed insufficient knowledge of and information about OD and organ transplantation. We also found some interesting prejudice among students regarding OD. Structured, well-considered educational programs, which provide knowledge, information and education about prejudice relating to OD and transplantation, should be prepared for all



students and these programs should be run regularly at all educational institutions until university. More programs about OD must be available in different media and on the internet. These programs could motivate students who are unsure of their decision to donate organs and change the opinion of students who have decided not to donate their organs.

**Acknowledgements:** We would like to thank the students who participated in the interviews, without them the conduction of the study would not be possible.

**Author's contribution:** All authors in the present study were included in all steps of preparation of the study. Final proof reading was made by the first author Dr. Ferid Krupic.

**Competing interest:** None to declare.

**Financial support and sponsorship:** No funding was obtained for this study.

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How to cite this article: Krupic F, Grbic K, Senorski EH et.al. Young people's views of organ donation and transplantation as seen by high-school and university students in Sweden. *Int J Health Sci Res*. 2020; 10(8):287-296.

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