

The Factors Influencing Organ Donation and the Transplantation of Organs: A Systematic Review of the Qualitative and Quantitative Literature

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DOI: <https://doi.org/10.52403/ijhsr.20240947>

ABSTRACT

Background - Organ donation and organ transplantation refer to a medical treatment approach that involves substituting a diseased or damaged organ or tissue in the human body with a healthy one. Progress in surgical techniques, immunology, and medical science has facilitated the advancement of transplant procedures. Nowadays, a wide range of organs, organ parts, and tissues can be successfully transplanted. Depending on the part of the body in question, the organs that are donated can come from a deceased donor or from a living person. Factors that influence the individual in a positive direction in terms of donating their organs have been presented in previous studies as the socio-economic status of informants, education level, being young, gender, donation to family members and social support.

Aim - of this study is to synthesize qualitative and quantitative research on individuals' attitudes and decisions regarding organ donation, as well as the factors influencing these matters.

Materials and Methods - A systematic search was conducted on the PubMed, Embase, CINAHL, and Web of Science databases for qualitative and quantitative literature regarding factors influencing an individual to donate their organs to other individuals. An inductive thematic analysis was conducted to generate themes and supporting subthemes. Fifteen studies were included.

Results - The three main themes were: socioeconomic and cultural factors, dissatisfaction with, and mistrust of the healthcare system. Unspecified donors demonstrated a deep sense of different factors that influenced the individual to donate their organs to other individuals. Religious factors, fear and prejudices, gender differences, the influence of family members and not being treated well by healthcare professionals were only a few of the factors that were stated in the present study.

Conclusion - The results of the present study show that there were many different factors that influenced an individual to decide whether to donate organs. Even though the individuals belong to different religions, come from different cultures, look at family relationships differently and have different degrees of knowledge, the opinions and factors that influence their decision regarding organ donation are the same. Healthcare should work more actively to inform and increase knowledge and consciousness about organ donation among people who are prospective donors. This can mean more information in several different languages, as well as where different religions stand on organ donation.

Key words: Organ donation, transplantation, influence, factors, decision, review.

INTRODUCTION

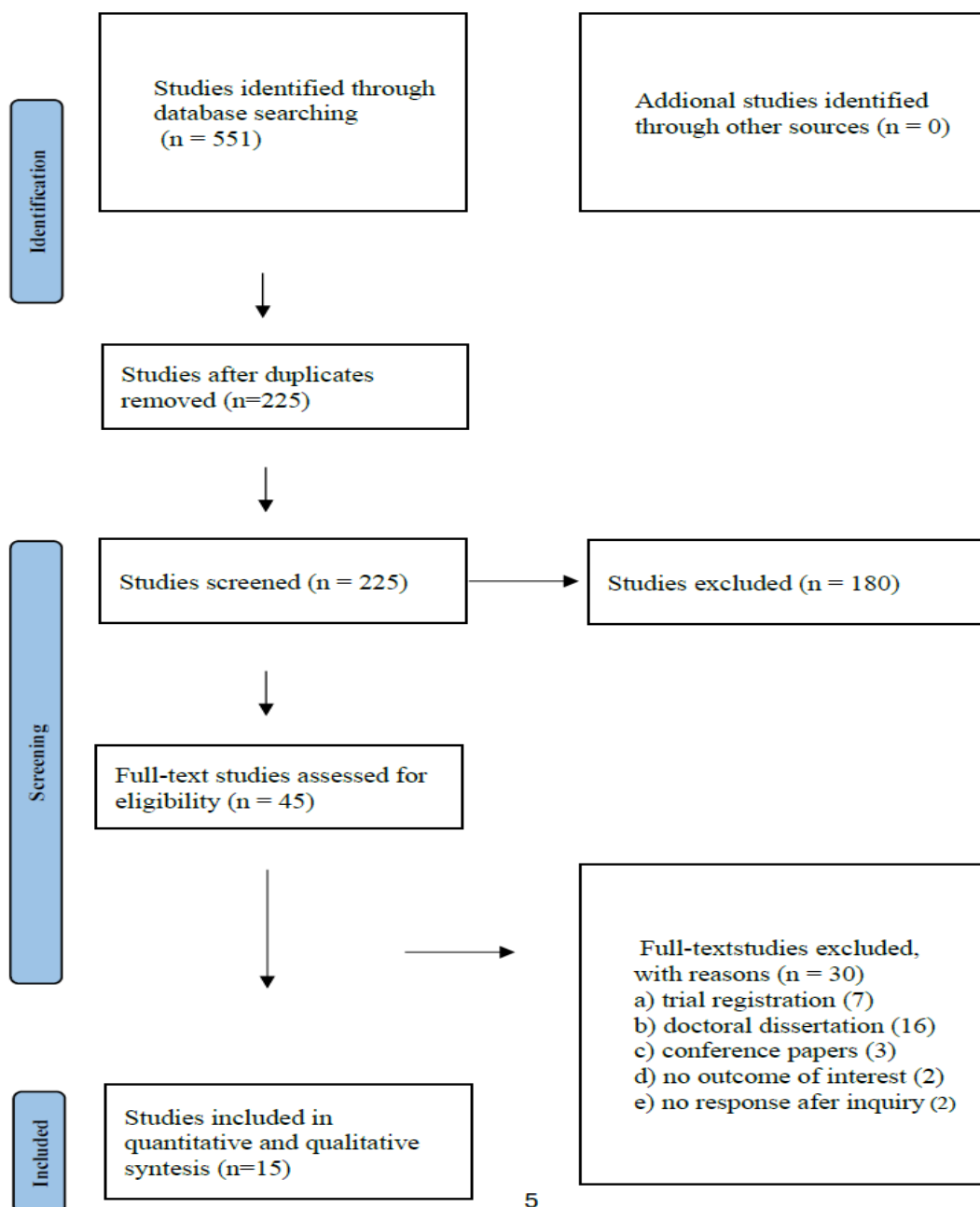
Organ donation (OD) and organ transplantation (TO) refer to a medical treatment approach that involves substituting a diseased or damaged organ or tissue in the human body with a healthy one. Progress in surgical techniques, immunology, and medical science as a whole has facilitated the advancement of transplant procedures. This form of treatment has provided new hope for many patients for whom other treatment options were either not viable or unsuccessful. [1] Regarding these individuals, the question of transplantation is also a question of choosing between life and death, or the quality and length of the patient's life, depending on the abovementioned treatment procedure. The ability to resume an active professional life following a transplant, along with the cost-effectiveness of donations and transplants, are additional benefits of the donation process. [2] Nowadays, a wide range of organs, organ parts, and tissues can be successfully transplanted. Depending on the part of the body in question, the organs that are donated can come from a deceased donor or from a living person. For a transplant to be performed, an adequate number of donors is essential. All persons, regardless of age, can register in the donation register to become an organ donor. In Sweden, approximately 880 organs and 1.450 tissues are transplanted each year, but, unfortunately, at the same time, approximately 60 people die while waiting for a new organ because the need is greater than the supply. [3] The explanation for the current situation lies in

the fact that various factors influence the decision to donate organs, with some factors positively or negatively impacting the final decision. Factors that influence the individual in a positive direction in terms of donating their organs have been presented in previous studies as the socio-economic status of informants, education level, being young, gender, donation to family members and social support. [4-9] Unfortunately, various factors can affect the decision negatively and take the whole process of organ donation in a negative direction. The factors presented as barriers in the decision to donate organs are religious aspects, knowledge and information about organ donation, fear and prejudice, care environment and time, lack of support from the staff and mistrust of healthcare and ethnicity, culture and language. [4, 10-16] Knowledge of factors that can influence decisions relating to organ donation, as well as the experience and behavior of the individual examined in various studies, can be of great importance in the work of healthcare staff when it comes to best responding to and supporting the individuals who are faced with a donation request. The present study therefore aims to synthesize qualitative and quantitative research on the individual's attitudes to and decisions relating to organ donation and the factors that influence these issues.

MATERIAL AND METHODS

This systematic review was performed in accordance with PRISMA, [17] (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Figure) 1.

Figure 1. PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines



5

Qualitative studies were analyzed to resolve the problem and match the purpose of the study. Since the qualitative method is described as one where people talk about their experiences and the purpose of the study was to highlight various factors that influence people in their decision to be an organ donor, all the authors in the study

therefore felt that studies with a qualitative approach were more appropriate to match the purpose.^[18]

Study selection

Initially, a selection of appropriate studies was made in consultation with an expert at the University Library in Gothenburg.

Following this consultation, two authors of the study (FK, MK) independently conducted the search and selection of studies. The chosen articles focused on individuals' experiences regarding the factors that influenced their decision to donate organs to others.^[19] The inclusion criteria for the studies were as follows: written in English, employing a qualitative approach, being original research, and peer reviewed. The publication period was restricted to studies published between 2005 and 2023.

Literature search strategy

The search terms used to find relevant studies were organ donation, transplantation, factors, decision, informants, qualitative studies, review, systematic and literature. The search terms were separated using the search operator AND. The searches were carried out in PubMed, Medline, CHINAL, Embase. We also searched reference lists of relevant studies and reviews, as well as transplantation journals. We began by reviewing the titles of all the studies, followed by reading the abstracts. Studies whose abstracts appeared to align with the purpose of our research were then selected for a full reading. After this process, we chose the most relevant studies that could contribute to our findings. Out of a total of 551 studies reviewed, 15 were ultimately included in our literature study (Table 1). All the scientific studies that were found to be suitable in presenting results in our study were analyzed according to the five-step model analysis process.^[20] All the authors thoroughly reviewed the selected studies, with particular focus on the results. They identified the main findings in each study, and in the next step, compiled the similarities and differences among these key findings. These similarities and differences were then compared to identify new themes and sub-themes. In the final step, the identified themes and sub-themes were synthesized into a cohesive whole, which was then used as the structure for the

headings in the results section of the new study.

Table 1. Search Terms and Search Results of Databases

Database	Hits
PubMed	255
Cocrane Library	134
Embase	98
AMED	64
Total	551

Search terms used: Factors OR Influence OR Organ Donation OR Transplantation of organs OR socioeconomic OR culturally OR satisfaction OR dissatisfaction OR healthcare OR healthcare system OR religion OR fear OR prejudices OR gender OR healthcare professionals OR family members AND treatment OR quantitative OR qualitative AND patients AND adults OR experiences.

RESULTS

The search strategy initially identified 551 articles from electronic databases, after removing duplicates. Following a review of titles and abstracts, 45 articles were selected for full-text evaluation. Ultimately, 15 articles met the inclusion criteria and were incorporated into the study. Studies were conducted in the United States (3), India (1), Malaysia (1), China (1), Iran (2), Bosnia and Herzegovina (1) and Sweden (6). The articles were published between 2005 and 2023 and the data were largely collected using semi-structured interviews and focus groups. Three main themes emerged from the thematic analysis of the included articles. These were: socioeconomic factors, culture as a factor and mistrust of healthcare. Supporting quotes for individual themes and subthemes can be found in the results section.

Socioeconomic factors

The studies identified that describe socioeconomic factors influencing individuals' decisions to become organ donors highlighted educational level as a predictor of donation, gender as a

significant factor, and the extent of information available about the organ donation process.

Education level

The studies that examined the level of education as a factor in the decision to become an organ donor primarily focused on informants with high school and university education, as well as those without a university degree. The level of education was connected with owning or not owning a donor card, information about organ donation, knowledge of the process and belonging to a certain religion. The closer the country was in relation to where the study was conducted in Europe, the better the results. Information and knowledge about what could be donated, how the donation process works and to whom people could donate their organs was at a very low level among the majority of the informants. Various media were helpful in obtaining a clearer picture of organ donation.

“I was unaware that the organs can be donated after death. I only knew that one can donate one kidney to another person. After the death of Abdul Sattar Edhi, there was a debate about his decision to donate his organs and that’s how I found out that a person can donate organs after death. It was a new thing for me. I was surprised initially... but I liked the idea.” [21]

The majority of the students in another study criticized the school system as being responsible for the lack of basic education on organ donation. Ignorance of organ donation depended on the level of information and the ownership of donor cards.

“How are we supposed to know anything about organ donation when no one ever talks about it? I shall finish college in three years and my knowledge of organ donation is exactly zero.” [22]

“I think we talked once about organ donation in school, but I have no idea about donor cards.” [22]

Another study showed that the level of education did not always follow the expected decision relating to organ donation. In the study in which informants with and without a university education and from two different countries were compared, it emerged that only 2% of the informants with a university education wanted to own a donor card and that more than 50% of them did not think that organ donation was necessary. [23]

Gender aspects

Gender differences in organ donation decisions were noted in areas such as the definition of organ donation and transplantation, the level of information and knowledge about organ donation, the perceived importance of donation, religious beliefs, and the possession of a donor card. Female gender and higher income were predictors of a positive view of organ donation. [24]

Other studies involving religious women and immigrants living in Sweden indicate that their information and knowledge about organ donation were significantly limited. The women in these studies attributed this to a lack of time, the absence of any formal education on the subject, and a general lack of interest.

“I often find myself in the company of older people and we discuss organ donation. They talk about things that neither religion nor science states and which are simply untrue.” [25]

“Everything you need can be found on the internet... Google is the best.” [25]

“All the information is available on radio and television... and there is also the internet.” [25]

“I think that a little talk about the donation of organs, providing information, should be offered, without us asking for information.” [26]

“I don’t know anything about it”, “as God decides”, “I will never be interested in it”, “I will think about it when the time comes.” [26]

In a similar study of immigrants who are religious and live in Sweden, the authors concluded that gender, age or religious affiliation did not play a role and were not factors in the decision-making about organ donation. In contrast, having information, knowledge and religious education in organ donation helped many in the study when they needed to decide whether to donate their organs.

Cultural factors

Cultural factors influencing informants' decisions regarding organ donation included various religious aspects, which were reflected in differing behaviors when faced with making such decisions. Additionally, language barriers played a significant role, as religion, language, and culture are deeply interconnected.

Religious aspects

The studies reviewed in our research indicate that religious aspects significantly influenced the decision to donate organs. These aspects were shaped by the informants' self-assessed level of religiosity, their religious knowledge, their religion's stance on organ donation, beliefs about ownership of one's body, and concerns related to fear and prejudice. Additionally, the decision to donate was often influenced by a preference to prioritize donating organs to family members before considering others. Increased information and knowledge about organ donation were found to be a factor that influenced organ donation in a positive direction.

"The real-next life – that's life. My body must be buried complete for real life." [27]

"What if there are complications and you die//uff ... no ..., never, not on your life." [27]

"A man from my family said that, if you donate an eye or parts of the eye, in the next life you will not be able to see." [27]

"I could imagine donating them to my kids ... if I dare ..., I don't know ... maybe." [27]

Priorities in decisions

When it came to different priorities in terms of organ donation and which were linked to religious informants, they themselves estimated this in such a way that they wanted to donate first to their family members, then to close relatives and finally to their friends. Informants also wrote in this study that they would prefer not to donate their organs to any person they had never met and did not know.^[28]

Increased religious knowledge

Increased knowledge of and about religion proved positive in the decision to donate one's organs to others. Generally, religion as such is a factor that "slows down" the decision to be an organ donor, but, with the right education and increased knowledge of religion, religious images of organ donation and influence from the media and society, this image can be turned in a positive direction.

"When I compare myself then and today... I am a different person in terms of religion and religiosity." [29]

"I never thought about donating organs and religion, I didn't know much about it, but I know now and now I would definitely donate my organs to others." [29]

"I'm happy to have met you, I'm happy to know how I can help others, I'm happy because I will be able to donate my body, thank you." [29]

Increased knowledge of and information about organ donation reduced fear and removed prejudices among prospective organ donors.

"I had heard that, when a kidney is donated, it isn't possible to urinate after death. That's ridiculous. I'm now convinced that it's nonsense." [29]

Dissatisfaction with and mistrust of the healthcare system

Dissatisfaction with and reduced trust in the healthcare system expressed itself in the form of prospective donors not being satisfied with the premises, with the treatment by the staff and the fact that the

staff avoided information about the organ donation process. All this caused prospective organ donors to lose motivation, energy and the will to donate their organs.

Dissatisfaction with healthcare professionals

Prospective organ donors who expressed dissatisfaction with the healthcare staff also gave negative responses and were not willing to donate their organs to others in need. Informants mentioned that this was local, that they were not treated correctly and that the staff were not qualified for their jobs.

“Well, we were just saying how it’s more or less IHS doctors here, but maybe if it was in [large city named] or any other place, I would definitely trust the doctors.” ^[30]

“A lot of the healthcare we get up here isn’t up to standard, I believe, because of the tight budget ...” ^[30,31]

“The nurses talked to him as if he was wide awake.” ^[32]

Fear related to healthcare system

People who were asked about donating their organs to others, where the question was linked to the healthcare system in the country in which they live, answered that they were afraid of possible errors that could occur during the surgical process, that they could be disabled after the operation and that they could “inherit” any diseases from the person to whom they donate their organs.

“I was always afraid that something bad would happen to me during the surgery. Honestly, I was not sure, but I had no other choice.” ^[31]

“Because if someone spotted me in the hospital, he would find out that I was a donor. There was no privacy at all in the hospital.” ^[31]

Care environment

The importance of space where the donation process takes place, according to prospective donors, plays a very important role. Moreover, people who are more or less

connected to organ donation also mentioned that it was important to have a room that is not connected to the intensive care unit, where they could rest.

“It’s important to have a room where you can cry undisturbed.” ^[32-35]

DISCUSSION

This study aims to synthesize both qualitative and quantitative research on individuals' attitudes and decision-making processes regarding organ donation, as well as the factors that influence these decisions. Based on this, a literature review of qualitative and quantitative articles was chosen as the method. A literature review was chosen, as it provides an image of the state of knowledge in a certain area.^[20] The qualitative articles were chosen because they aim to deepen knowledge of people's experiences and experiences of a certain phenomenon – in this case, the donation process.^[18] An empirical method with data in the form of interviews could have been chosen to match the purpose and this might have been regarded as more credible, as the result would have consisted of information from a primary source. However, the authors opted out of this option, as an empirical study with data collection in the form of interviews takes a long time to complete and that time was not thought to be within the predetermined time frame of the course. The result of the present study showed that three main themes emerged from the thematic analysis of the included articles. These were: socioeconomic factors, which were characterized by education level as a predictor of donation, gender as a factor related to organ donation, as well as the level of information about organ donation. It is nothing new that increased knowledge, education and information about any matter increases knowledge about the matter in question. In our case, it is a question of increased knowledge and regular education in school, as well as more information via various media, increasing the percentage and willingness of people to donate their organs to family members or to other

parties.^[36, 37] In previously published studies and regarding gender as a factor in the decision to donate one's organs to others, we found that women, in comparison to men, are more willing to donate their organs to others and to sign a donor card. The reason for this could perhaps be sought in the fact that all mothers who give birth and create another life perhaps have more understanding about this in comparison to men.^[38-40] Culture is a factor, characterized by different behaviors by informants in situations where they needed to make decisions about organ donation, as well as different language situations, because religion, language and culture go hand in hand. The results in all the studies that were read in the results section of the present study show that the majority of informants in these studies rated themselves as religious and deeply religious Muslim or Christian individuals. Every registered religion in the world allows organ donation and is against it only when it comes to taking someone's organ and selling it and making money from this. In this case, organ donation is prohibited. However, despite the fact that all religions are in favor of allowing religious individuals to donate their organs, the majority of informants in studies are against donating their organs to others. It was clear that some people did not want to hear a word of this at all, some may think and take time and think about it, while a small number of them would consider donating their organs to their next of kin.^[41-45] Calling yourself religious, interpreting religion in your own way and not knowing the fact that every major religion allows organ donation is not acceptable. This issue could perhaps be raised at a higher level and among all the religious leaders in some major religions with the main tasks of educating, informing and training each person in their group and highlighting the importance of donating their organs to help themselves in this way and others who are in need of organ donation. In the special Chinese culture, and in relation to prejudices, people believed that registering the donor card as healthy

can be a bad omen. Some informants who were believers in Buddhism believed in metempsychosis. They therefore insisted on keeping their body intact after death. Overwhelmingly, the imperfect regulatory system and mistrust made many families refuse to register a donor card, despite their strong desire to donate their organs.^[33,46] This was one of the biases not shown in any of the previously published studies; mistrust of healthcare, donors not being satisfied with the premises, with the treatment by the healthcare professionals and the fact that the staff avoided information about the organ donation process. Finally, the results of the present study show that informants in the previously presented studies and who have been interviewed in our study show a very high level of dissatisfaction with the healthcare system, with the healthcare staff and with the appearance and the possibility of staying in premises that are planned for organ donors and their families. The findings of our study align with previous research, which highlights that one of the most significant concerns for individuals considering organ donation for themselves or their relatives is the treatment they receive from healthcare staff. This encompasses the staff's sensitivity to the emotional toll on individuals who have lost a loved one who may be a potential donor, the effectiveness of communication with prospective donors, and the often-distressing experience associated with the organ donation process. The relatives also mentioned the ignorance of the healthcare staff regarding the grieving process and the fact that their ignorance was very painful. This contributed to relatives refusing to donate their organs because the fear of exposing their organs to more suffering was ever-present.^[46] Other things that informants in the previous study mentioned that influenced their decision to be prospective organ donors included a great deal of ignorance on the part of the healthcare staff regarding the grieving process. Those informants mention that the staff were not aware of the different phases of the grieving

process and that they did not think much about people who were in the grieving process. If the staff do not take this into account, there is a risk that the entire process will be interrupted, and the grieving process will be incomplete.^[46-48] In today's global healthcare where modernization in every aspect takes more and more space in society and in our lives, the consequences of all this are that the number of healthcare professionals is declining, information about various things is becoming scarce and this then increases both stress among the professionals and patient dissatisfaction. The big question is: do we dare to have more dissatisfied patients and prospective organ donors, who are our first employers and people who are willing to donate their organs and prolong the lives of others?

CONCLUSION

The results of this study indicate that a variety of factors influence an individual's decision to donate organs. These factors are closely linked to the individual's socioeconomic and cultural background, as well as issues that lead potential donors to feel dissatisfaction with the healthcare system and its staff. Even though the individuals in the present study belong to different religions, come from different cultures, look at family relationships in a different way and have different degrees of knowledge, the opinions and factors that influence their decisions relating to organ donation are the same. It is important that these individuals receive support in terms of their stance. Health and medical care should work more actively to inform and increase knowledge relating to the subject of organ donation among people who are prospective organ donors. This may involve more information in several different languages and information regarding where different religions stand on organ donation. More research on the subject is needed so that the staff in health and medical care are informed about the difficulties individuals have when they need to make a decision about donating their organs.

Declaration by Authors

Ethical Approval: Not Applicable.

Acknowledgement: Nil.

Conflict Of Interest Statement: Nil.

Funding: Nil

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How to cite this article: Ferid Krupić, Melissa Krupić, Emina Dervišević, Svemir Čustović, Edna Supur, Lutvo Sporišević. The factors influencing organ donation and the transplantation of organs: a systematic review of the qualitative and quantitative literature. *Int J Health Sci Res.* 2024; 14(9):368-378. DOI: <https://doi.org/10.52403/ijhsr.20240947>
