

# UNDERSTANDING THE ATTITUDES AND FACTORS INFLUENCING ORGAN DONATION DECISIONS AMONG UNIVERSITY STUDENTS IN PAKISTAN: A QUALITATIVE STUDY

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## Abstract

**Purpose:** The main purpose of this study was to identify factors that were important in posthumous organ donation decisions in a developing country such as Pakistan.

**Methodology:** A qualitative study was conducted with 50 semi-structured interviews among students of one public and one private university in Lahore (Pakistan) to understand their attitudes and factors influencing their decisions on posthumous organ donations. Purposive sampling technique was used in this study. The interview questions focused on the level of knowledge, motivation and overall attitude towards the posthumous organ donation decision of the respondents.

**Main Findings:** There was a lack of general knowledge among university students in Pakistan. Most of the students had a positive attitude for posthumous organ donation yet moral norms are very influential in the decision-making process for organ donation after death. Those who were willing were reluctant because of the influence of family and friends. Religion was also another significant norm factor for prohibiting them to be an organ donor after death.

**Implications/Applications:** The present study provided a way in the advancement of knowledge towards an understanding of the attitude, moral norms along with social and family influence for not only intention to donate but also signing the donor card. The findings of the study are useful for the government, policymakers and the organizations in Pakistan in their efforts to increase awareness and organ donation rates in the country.

**Novelty/Originality:** The present research was exploratory and the intention for this research was to explore the underlying behavioral and normative beliefs which may inhibit or encourage organ donation among university students. Such qualitative studies are relatively uncommon in transplant literature.

**Keywords:** Organ Donation, Pakistan, Attitudes, Willingness to Donate, Willingness to Sign Donor Card, Qualitative Study.

## INTRODUCTION

Due to the advancement in transplantation techniques, transplant immunology and ways to preserve organs, tissues, and organ transplantation is now a well-accepted treatment for patients suffering from organ failure (Kocaay et al., 2015). With the developments in the field of medicine and the success of transplantations, there is increasing awareness for the world's population to contribute to these life-saving practices for their citizens. Nevertheless, the awareness regarding organ donation has increased around the world, there is still a large gap between the supply of organs needed to fulfill the demand for organs (Siminoff, Traino, and Genderson, 2015). In a survey conducted by the European Commission to determine public opinion towards organ donation and transplantation, approximately 31% of the respondents were unwilling to donate their organs (Kocaay et al., 2015).

In Asia, countries are trying hard to meet the increasing demand for transplantation of failed organs by encouraging posthumous donors (Jafarey and Nagral, 2014). Unfortunately, these efforts have yet to achieve huge successes (Silva and Frontera, 2015). While the number of potential donors has surged, the actual behavior for donation is still very low. To address the difference between availability and demand of the organs, there is a need to study the attitudes of people towards posthumous organ donation and identify factors that will encourage organ donation (Manzano and Pawson, 2014).

Apart from socio-demographic characteristics, there are certain factors that can influence a person's attitude toward posthumous organ donation, including a person's knowledge (Feeley, 2007), values (Miller, 2001), and the influence of significant others (Stephenson et al., 2008). Because of the increasing demand and the low supply of organs, researchers have been urged to find ways to address this gap (Manzari, Mohammadi, Shearbuff, Azizi, and Khaleghi, 2012). To remove psychosocial and structural barriers, it is very important to understand the role of certain beliefs that can help to make a positive intention towards posthumous organ donation. Previous research has observed that whilst the young and

educated persons are mostly willing to donate organs ([Skumanich and Kintsfather, 1996](#)), they are reluctant to sign the donor card. Hence, there is a need to examine the factors which inhibit or encourage organ donation among youth.

## LITERATURE REVIEW

Pakistan is one of the most populous Muslim countries in the world with more than two hundred million Muslims ([Pakistan Bureau of Statistics, 2017](#)). It is divided into four provinces namely Punjab, Sindh, Baluchistan and Khyber Pakhtunkhwa with federally administered tribal areas, Islamabad (the capital), Gilgit-Baltistan and Azad Jammu & Kashmir ([Pakistan Tourism Development Corporation, 2017](#)). Punjab is the largest province and the capital of it is Lahore with a population of more than 11 million ([Pakistan Bureau of Statistics, 2017](#)). In Pakistan, the Sindh Institute of Urology & Transplantation (SIUT) is the oldest institute working for posthumous organ donation. Apart from SIUT, there are other organ donation organizations in the country including Shifa International Hospital, Armed Forces Institute of Cardiology, Human Organs Transplant Authority, Transplantation Society of Pakistan, Pakistan Association of Urological Surgeons, Rabwah – blood and eye donation center, Pakistan Eye Bank Society and Al-Shifa Trust Eye Hospital ([Saigol, M. A., 2014](#)). According to SIUT, almost 30,000 people die because of kidney failure and 100,000 because of liver failure in Pakistan each year. Most of the donations in Pakistan are living organ donations being donated either by family members or friends ([Bile et al., 2010](#)). However, the rate of organ donation after death in Pakistan is among the lowest in the world ([Umair, 2017](#)). The greatest challenge in Pakistan is to urge people to donate their organs after death.

It has been assumed that most people consider themselves as being sympathetic and helpful towards other people. However, in the case of posthumous organ donation, the previous literature has found that most people are reluctant to donate their organs after death ([Sanner, 2007](#)). Some of the reasons for such reluctance include a lack of body integrity, distrust of the medical system and denial of family members or close friends ([Russell, Robinson, Thompson, Perryman, and Arriola, 2012](#); [Skumanich and Kintsfather, 1996](#); [Skwirczyńska-Szalbierz, Matoszka, Sepiolo, and Ostrowski, 2014](#)).

The decision to donate one's organ is a difficult decision to make and for this, intention alone is not sufficient. Hence, it is crucial to strengthen the actual behavior towards donation ([Hyde & White, 2009](#); [Stephenson et al., 2008](#)). Even after showing a willingness to donate, a person may face certain barriers that can prevent them from registering as organ donors. While previous studies on donation after death have discovered that individuals have positive attitudes towards the donation behaviors ([Hübner, Mohs, and Petersen, 2014](#); [Khan et al., 2011](#); [McGlade and Pierscionek, 2013](#)), these high rates of positive attitudes have not been converted into actual behavior ([Morgan and Miller, 2002](#); [Murray, Miller, Dayoub, Wakefield, and Homewood, 2013](#); [Potter et al., 2017](#)). In order to understand better a person's intention to be an organ donor, there is a need to use the qualitative approach, which can help to understand the concerns and thoughts of individuals regarding posthumous organ donation. It has been assumed that such broader descriptions are required to understand the beliefs of a person regarding a particular subject ([Irving et al., 2012](#)).

In the case of Pakistan, most of the studies in the field of posthumous organ donation have been done either by medical students or on data taken from patients and their relatives coming to the hospitals ([Khan et al., 2011](#); [Saleem et al., 2009](#)). From these studies, it is difficult to assess the actual attitudes of the general public towards posthumous organ donation and their level of knowledge. These studies were mostly quantitative in nature and due to this, it was difficult to obtain deep insight into a person's reasons for donating/not donating. This present study will be an attempt to fill the gap regarding posthumous organ donation in Pakistan and will help uncover the enacted and socially constructed rather than medically espoused ideas about posthumous organ donation. The results of this study can help tailor future programs for organ donations after death. In addition, the results may be generalized to other developing countries having similar cultural backgrounds.

## OBJECTIVE OF THE STUDY

The main objective of this study was to understand the factors that can help to encourage university students to become organ donors. Importantly, the present study seems to be one of the few studies that considered attitude, social and family influence, moral norms, willingness to donate and then signing a donor card within a non-Western context

## METHODOLOGY

### Design

A qualitative approach was used to uncover factors that would influence the willingness to donate organs after death. For this purpose, the researcher used purposive sampling by using university students. Students are considered ideal for posthumous organ donation as they are healthy individuals and it is expected that if they make a decision to be an organ donor, they will keep it for their lifetime ([Horton & Horton, 1991](#)). In addition, the attitudes and knowledge of university students are important to increase organ donation rates as these individuals can influence their families in aspects of organ donation and transplantation ([Umair, 2017](#)).

## Sampling and Setting

Between November 2018 and January 2019, the researcher along with a research assistant interviewed 50 students from two universities in Lahore: one public and one private university. Both the universities were non-medical universities and had more than 10,000 students in each university. Permission was obtained from the authorities of both the universities before conducting the interviews. Semi-structured interviews were used (Dart, 2010), and the interview questions focused on the level of knowledge, motivation and overall attitude towards the posthumous organ donation decision of the respondents. Each interview took between 30 – 45 minutes. Key questions in the interview are summed up in Table 1.

**Table 1:** Key Questions of the Interview

1. Do you know about brain death and posthumous organ donation?
2. Do you know about posthumous organ donation and law working in Pakistan? What are the laws available in Pakistan?
3. Have you ever considered to be an organ donor? Why? Why not?
4. If you want to be an organ donor, what would be the reaction of the persons who are dear/near to you?
5. Do you feel being an organ donor is morally right? What makes you think so?
6. If ever get a chance, would you like to be an organ donor?

All the interviews were recorded. For the data analysis, all the recordings were transcribed, and the transcripts were later reviewed by the researchers as part of the content analysis. Themes were identified based on the key interview questions in Table 1.

## RESULTS/ ANALYSIS

For this research 50 participants were interviewed: 25 from public and 25 from private universities. 18 of the respondents were females and 32 were males aged between 20-24 years. Regarding basic knowledge, most of the participants were unaware of the concept of brain death. Only 10 (20%) participants knew about brain death. Most of the participants (78%) also did not know which organs could be transplanted. 43 (86%) participants knew that only the liver, kidney, eyes, and heart can be transplanted. 90% of the participants were unaware of any law for organ donation after death in Pakistan and they also did not know any working institute for this purpose. There were 10 participants who told us that they came to know about posthumous organ donation when the famous social worker, Abdul Sattar Edhi, donated his eyes. A participant who knew about posthumous organ donation said:

*“I was unaware that the organs can be donated after death. I only knew that one can donate his one kidney to another person. After the death of Abdul Sattar Edhi, a debate was going on regarding his decision of donating his organs and from there I came to know that a person can donate organs after death. It was a new thing for me. I was surprised initially.... but I liked the idea”.*

From the results of data analysis and reports, five main themes emerged other than knowledge from these interviews. These main themes (1) attitude towards posthumous organ donation, (2) social and family influence, (3) moral norms in posthumous organ donation, (4) willingness to become an organ donor, (5) willingness to sign a donor card.

### Theme 1: Attitude towards posthumous organ donation

40 respondents showed a positive attitude towards organ donation after death, which was a very positive sign. Attitude is known to be one of the first and important components of a person’s intention for being an organ donor (Ralph et al., 2014). People, who show a positive attitude, generally, have a favorable intention for donating an organ after death. In the present study, the participants considered donating organs after death as a helping behavior towards others. An important factor for a positive attitude was to have an empathetic concern about the participants towards people suffering from end-stage diseases. For example, the response of one participant was,

*“It is good if body after death can give life to others, as it will decrease their sufferings and will help them to live a better healthy life”.*

Another consenting participant had the opinion,

*“One should try to be empathetic... as they can also need organs in life. We should think about the illness of the other people who need the organs, and then only we will think about donating organs after death”.*

Those who had a negative attitude were of such opinions appeared to have a general lack of knowledge about posthumous organ donation which seemed to lead to a less favorable attitude towards this donation. For example, one of the respondents told us:

*“I don’t know about this donation, as I feel after death all organs are also dead and cannot be transferred to another person. I only know about kidney donation which mostly relatives can donate. I have read in the newspaper that a person’s close relative donated a kidney”.*

And then he further added,

*"I want the integrity of the body after death. After death, on the day of judgment when I will wake up, I will have no organs. Also, I am not comfortable when I think to cut a dead body and take organs after death. A dead body should be in rest after death".*

An increase in the knowledge about this type of donation can increase the attitude of a person towards the donation.

### **Theme 2: Social and family influence in posthumous organ donation**

The pressures from the family or friends can determine whether a person performs any action with ease. In posthumous organ donation, the norms held by people deemed important to the potential organ donor has been found to have a significant influence on the intention of becoming an actual organ donor (Murray et al., 2013). In the present study, among the 50 participants, 15 respondents described that important individuals in their lives and family members played an important and significant role in their decision-making process. This indicates the importance of social and family influence while making decisions. Among the participants who were not willing to donate had this to say:

*"Organ donation is a good idea, but I think.... my parents will dislike my decision. Also, it is difficult to talk about death issues with the family".*

Another non-consenting participant answered,

*"My friends will never like to discuss this idea. Also, if I want to be an organ donor after death at this young age, my friends will never want me to sign the donor card".*

One of the consenting participants argued,

*"I know about posthumous organ donation and want to be an organ donor. One of my friends has already signed the donor card. He has discussed with me on the importance of this donation and because of him, I am already interested to donate my organs".*

On the other hand, 30 participants believed that being an organ donor was their own choice, and they would not consider the opinion of others. The results indicate that educating the public can advance the social norms for deceased organ donation and can promote family discussions regarding decision making.

### **Theme 3: Moral norms in posthumous organ donation**

An important aspect observed from the interviews was that the moral norms could be an important variable to consider while determining the intention to donate. Moral norms are an individual's perception of moral correctness or incorrectness in performing a specific behavior (Rivis, Sheeran, & Armitage, 2009). Among the interviewees, one participant responded,

*"I am in favor of the posthumous organ donation because, if I donate my organs after death that will endorse my principles".*

Another was of the opinion,

*"One should sign organ donation after death. It would be morally right for me if I donate my organs after death".*

10 of the 50 respondents thought that donating organs after death was morally wrong and went against their principles. One of the non-consenting participants had this to say:

*"I don't think that a person should donate his/her organs, either in his/her lifetime or afterlife. Our life is a gift to us by Allah, and it is our moral obligation to take care of our body. On the day of judgment, we will need to answer about our bodies".*

From the results of other interviews, it was observed that moral norms play an important role in the intention of a specific behavior such as posthumous organ donation.

### **Theme 4: Willingness to donate organs**

Results of previous studies have revealed that individuals who had increased knowledge about organ donation and positive attitudes were the ones who had greater intention to donate organs after death (Feeley, 2007). Having a willingness to donate organs can lead to signing the donor card. Thus, before the actual behavior, it is important to know about the general willingness for certain behaviors. From the interviews conducted, 50% (25) of the participants showed their willingness toward posthumous organ donation. Importantly, this ratio was higher for females (18) as compared to males (7). An important observation was that students from the public university responded more positively compared to those from the private university. The students who were willing to donate were the ones who already had some knowledge about posthumous organ donation.

### Theme 5: Willingness to sign a donor card

In the case of posthumous organ donation, signing a donor card is far more important than showing only willingness to donate (Demir & Kumkale, 2013). Previous studies have argued that people tend to show their willingness to donate but when it comes to signing the organ donor cards, many are reluctant to do so (Morgan & Miller, 2002; Ali et al., 2013; Park, Smith, & Yun, 2009). The results of this study were also consistent with those of previous studies. 80% of the respondents were unaware of the fact that to be an organ donor after death, a person needed to sign an organ donor card during their lifetime. In addition, they were also unaware that family consent for removal of the organs was needed. The interviewees who showed their willingness towards posthumous organ donation were reluctant to sign the organ donor card. Many of them had the same concerns about signing the donor card i.e. they were afraid that it went against Islam. All the interviewed students were Muslims and they were hesitant in signing the donor card as they thought of it as a decision that went against Islam. One of the students was willing to donate but did not want to sign the donor card. This was what he said,

*"I do want to sign the card, but I feel... my religion prohibits me. That's why I am reluctant"*.

Family involvement in the decision-making process was also important. As one of the students said,

*"I am interested in posthumous organ donation and consider it a noble cause, but... I am afraid of the discussion with my family, they will deny my decision"*.

One of the female students reported,

*"Previously, we discussed posthumous organ donation in our home, but my parents were not interested to talk about death (in the home). For my decisions, I highly acknowledge the decision and the opinion of my parents. Even though I feel it is a great cause to save another person's life, yet I am afraid... I'll not consider being an organ donor after my death as it will go against my parents."*

### THEORETICAL & PRACTICAL IMPLICATIONS

The findings of this study have provided some key theoretical and practical implications. In order to provide a better understanding of this issue and to add insights into the existing literature, a qualitative study was conducted for this study. It has been observed that the data which is obtained based on human experiences is sometimes more compelling than quantitative data (Anderson, 2010). Also, the qualitative approach is broad and open-ended, which helps the participants to talk about the matters important to them (Choy, 2014) and aids understanding of the driving factors for a certain issue. The present research was exploratory and the intention for this research was to explore the underlying behavioral and normative beliefs which may inhibit or encourage organ donation among university students. These findings, while preliminary in nature, have important implications for developing our understanding of the factors which can influence organ donation intention and provide a basis for the development of theoretical frameworks in organ donation intention. The study helped to unearthed deeply held beliefs that could be the main drivers for making the decision to be an organ donor. Such qualitative studies are relatively uncommon in transplant literature. Previous literature on organ donation urged to have such qualitative studies, that could explore certain motivating or demotivating beliefs about organ donation (Krespi et al., 2017; Murray et al., 2013; Russell et al., 2012).

The present study lays the foundation to explore some initial factors that are important in the posthumous organ donation decision, especially in a developing country such as Pakistan. In addition, conducting the interviews helped to provide an in-depth understanding of this issue. One of the issues that emerged from this study relates specifically to the general lack of knowledge about the posthumous donation, its process and what happens after signing the donor card. Previous studies in other parts of the world have observed that a high level of knowledge leads towards high intention to donate (Feeley, 2007; Kocaay et al., 2015; Melku et al., 2016). Thus, education in this field can play a crucial role to increase the posthumous organ donation rate. Previous research in the field of posthumous organ donation has observed religion as one of the obstacles for donation (Faltynek, 2014; Randhawa & Neuberger, 2016; Robinson, Klammer, Perryman, Thompson, & Arriola, 2014). Hence, in Muslim countries like Pakistan, religious scholars may need to educate and guide people towards the permissibility of donation of the organs after death. An important aspect that previously has not been taken into consideration in Pakistan was the role of social influence and moral norms. Pakistan is a country where the concept of family and relatives and the discussions and results of these discussions are influential over decisions is very strong, these social and moral norms are very important. These factors can be very significant and need to consider while making any campaign for promoting posthumous organ donation. Another significant result was to get consent for signing a donor card. Presently only eight persons have donated their organs after death in Pakistan. The results of our study have revealed that people are not only willing to donate but are also willing to sign the organ donor card, which is very encouraging. These findings are different from the findings of some other studies (Miller, 2001; Umair, 2017), where it has been observed that people are willing to donate but not willing to sign the donor card. A little more work, devotion, and guidance for this cause can create a big difference. The government, policymakers and the organizations working for this issue needs to work on root levels, as at present many there are many potential donors around the country who have never been approached.

## CONCLUSION

At a global level, there is a serious need to bridge the gap between demand and available supply of organs. In Pakistan, like in many other countries, the need for organs calls for a national-level communication strategy that increases the awareness, knowledge, and willingness of people to donate organs posthumously. This will help increase the organ donor rate and ultimately prolong the lives of people through organ transplantations. The present study was an attempt to answer this call by examining certain factors that can motivate people particularly university students for becoming organ donors. The results of the present research significantly contribute to the identification of key areas to be focused on to increase donation rates. As mentioned earlier, in Pakistan, there is limited knowledge about posthumous organ donation and not only family involvement, but religious beliefs are one of the major barriers to this sensitive issue. There is a need to educate our community. When the community will better understand the concept of posthumous organ donation, this will direct the overall behavior and beliefs and will help to increase the rate of a posthumous organ donor in Pakistan.

## LIMITATIONS & STUDY FORWARDS

There were certain limitations to this research. Initially, it was very difficult to talk about an issue as it is a taboo issue in Pakistani society. Another important limitation was due to some ethical issues, donor cards were not get signed by those who were willing to do so. This study provided a broader conceptualization of certain motivating and demotivating factors towards organ donation after death. Exploring these concepts in detail is necessary. Thus, future studies can use the findings of this study to develop a theoretical model for understanding the quantitative effect of these factors on organ donation after death.

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## AUTHOR CONTRIBUTION

Study conception and design were developed by Jo-Ann Ho and Sonia Umair. Data collection and analysis were performed by Sonia Umair and Umair Waqas. The first draft of the manuscript was written by Sonia Umair. Review and editing were done by Jo-Ann Ho, Norazlyn Kamal Basha, and Serene Siew-Imm Ng. All authors read and approved the final manuscript.

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