

MODERATING ROLE OF RELIGIOSITY IN DETERMINING ATTITUDE AND WILLINGNESS TO COMMUNICATE POSTHUMOUS ORGAN DONATION DECISION AMONG UNIVERSITY STUDENTS IN PAKISTAN

SONIA UMAIR

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Thesis Submitted to the School of Graduate Studies, Universiti Putra Malaysia, in Fulfilment of the Requirements for the Degree of Doctor of Philosophy

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Abstract of thesis presented to the Senate of Universiti Putra Malaysia in fulfilment of the requirement for the degree of Doctor of Philosophy

MODERATING ROLE OF RELIGIOSITY IN DETERMINING ATTITUDE AND WILLINGNESS TO COMMUNICATE POSTHUMOUS ORGAN DONATION DECISION AMONG UNIVERSITY STUDENTS IN PAKISTAN

By

SONIA

January 2020

Chairman : Associate Professor Ho Jo Ann, PhD

Faculty : Economics and Management

With the advancement in the field of organ transplantation, a growing number of people are being added to organ transplant waiting lists as it gives them hope to save their lives. Worldwide, there is a huge gap between the demand and supply of available organs and this shortage is the main limiting factor in organ transplantations. The purpose of this study was to explore the antecedents that influenced university students' attitudes and willingness to donate and willingness to communicate the decisions to the families. In addition, the study also examined the moderating role of religiosity between willingness to donate and signing the donor card. Questionnaires were distributed among 450 university students at public and private universities of Lahore, Pakistan. Partial least squares structural equation modelling was used to analyze the direct hypotheses between the proposed constructs (altruism, knowledge, empathy, self-identity, attitude, social norms, moral norms, perceived behavior control, respondent's willingness to donate, willingness to sign a donor card, willingness to communicate) and the moderating effect of religiosity between willingness to donate and signing the donor card. The results confirmed altruism, knowledge, empathy, and self-identity as the antecedents to attitude. This study also found that perceived behavioral control, moral norms, and attitude were antecedents to the willingness to donate organs after death. However, the relationship between social norms and the willingness to donate was not significant. Religiosity moderated the relationship between willingness to donate and signing the donor card, and it strengthened the relationship. The findings of this study provide insight into the factors which influence posthumous organ donation in young adults. The results of this study can be used by the health ministries, NGOs working on posthumous organ donation and the universities to tailor future programs and campaigns. The present study could not assess the actual behavior, and this was the main limitation of the study. Future studies can look in to measure the actual behavior of the respondents by signing the donor card. Also, future studies can take into

consideration the role of personal values in the decision to become an organ donor and trust in the available medical facilities and staff.



Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia sebagai memenuhi keperluan untuk ijazah Doktor Falsafah

PERANAN PENYEDERHANA KEAGAMAAN DALAM MENENTUKAN SIKAP DAN KESEDIAAN MENYAMPAIKAN KEPUTUSAN PENDERMAAN ORGAN SELEPAS KEMATIAN DALAM KALANGAN PELAJAR UNIVERSITI DI PAKISTAN

Oleh

SONIA

Januari 2020

Pengerusi : Profesor Madya Ho Jo Ann, PhD

Fakulti : Ekonomi dan Pengurusan

Kemajuan dalam bidang pemindahan organ telah menyebabkan lebih ramai orang mendaftar di dalam senarai pemindahan organ kerana ianya dapat menyelamatkan hidup mereka. Secara keseluruhannya, terdapat jurang yang besar di antara permintaan dan bekalan organ dan kekurangan inilah yang merupakan halangan terbesar dalam bidang pemindahan organ. Tujuan kajian ini adalah untuk mengkaji faktor-faktor yang mempengaruhi sikap, keinginan dan ketersediaan pelajar universiti untuk menderma dan ketersediaan mereka untuk memberitahu keputusan mereka kepada keluarga mereka. Tambahan pula, kajian ini meletakkan faktor agama sebagai moderasi antara keinginan menderma dan menandatangani kad derma. Soalan kaji selidik telah diedarkan kepada 450 pelajar universti awam dan swasta di Lahore, Pakistan. Partial least squares structural equation modelling (PLS-SEM) telah digunakan dalam menganalisa hipotesis di antara konstruk yang dicadangkan (altruism, pengetahuan, empathy, identiti diri, sikap, norma sosial, norma moral, perilaku tingkah laku, kesanggupan responden dalam menderma, kesanggupan dalam menandatangani kad derma dan kesanggupan dalam komunikasi) dan kesan moderasi ke atas faktor agama di antara kesanggupan untuk menderma dan kesanggupan dalam menandatangani kad derma. Hasil kajian telah mengesahkan bahawa altruism, pengetahuan, emphaty, dan identiti diri sebagai faktor yang mempengaruhi sikap pelajar. Kajian ini juga mendapati kawalan tingkah laku, norma moral dan sikap merupakan faktor yang mempengarhui keinginan untuk menderma organ selepas kematian. Walau bagaimanapun, hubungan antara norma sosial dan keinginan untuk menderma didapati tidak disokong di dalam kajian ini. Peranan moderasi bagi keagamaan di antara keinginan untuk menderma dan menandatangani kad derma ini pula telah menguatkan lagi kajian. Penemuan dalam kajian ini telah memberikan gambaran mengenai faktorfaktor yang mempengaruhi amalan menderma organ selepas kematian di kalangan belia. Hasil kajian ini boleh digunakan oleh kementerian kesihatan, badan bukan

kerajaan dalam bidang pendermaan organ dan universiti dalam merancang program dan merancang kempen berkaitan. Kajian ini tidak dapat menilai sikap sebenar dan ini merupakan halangan utama dalam kajian ini. Kajian akan datang dijangka boleh menilai sikap sebenar responden dalam menandatangani kad derma. Selain itu, kajian seterusnya boleh mempertimbangkan peranan nilai peribadi dalam keputusan untuk menjadi penderma organ dan kepercayaan dalam kemudahan serta kakitangan kesihatan yang tersedia.



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To my Parents, for their eternal love and prayers
And
my Husband, for always being my strength

This thesis was submitted to the Senate of the Universiti Putra Malaysia and has been accepted as fulfilment of the requirement for the degree of Doctor of Philosophy. The members of the Supervisory Committee were as follows:

Ho Jo Ann, PhD

Associate Professor Faculty of Economics and Management Universiti Putra Malaysia (Chairman)

Serene Ng Siew Imm, PhD

Associate Professor
Faculty of Economics and Management
Universiti Putra Malaysia
(Member)

Norazlyn Kamal Basha, PhD

Senior Lecturer
Faculty of Economics and Management
Universiti Putra Malaysia
(Member)

ZALILAH MOHD SHARIFF, PhD

Professor and Dean School of Graduate Studies Universiti Putra Malaysia

Date:

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Signature:	
Name of Chairman	
of Supervisory	
Committee:	Associate Professor Dr. Ho Jo Ann
	D M
Signature:	ATTENDED
Name of Member	+100 Tab. (************************************
of Supervisory	
Committee:	Associate Professor Dr. Serene Ng Siew Imm
Signature:	
Name of Member	
of Supervisory	
Committee:	Dr. Norazlyn Kamal Basha

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LIST OF ABBREVIATIONS

SIUT Sindh Institute of Urology & Transplantation

HOTA Human Organs and Transplant Authority

TRA Theory of Reasoned Action

TPB Theory of Planned Behavior

PBC Perceived Behavioral Control

ODWM Organ Donor Willingness Model

WTD Willingness to Donate

WTS Willingness to Sign

SDB Social Desirability Bias

SI Self-Identity

UMT University of Management & Technology

UCP University of Central Punjab

PU Punjab University

FC Forman Christ

SEM Structural Equation Modelling

PLS Partial Least Squares

CFA Confirmatory Factor Analysis

CB Covariance-Based

AVE Average Variance Extract

CR Composite Reliability

HTMT Heterotrait-Monotrait

VIF Variance Inflation Factor

CHAPTER 1

INTRODUCTION

1.1 Introduction

This chapter provides an introduction about organ donation and its current situation in Pakistan. Organ transplantation, which began in the 1930s, is the transfer of any living organ or tissue to any injured or ill person to recover their health or to cure their illness (Robson, Razack, & Dublin, 2010). The advancement in technology contributed towards a new era of anticipation and life to ailing patients when in the 1950s, kidney transplantation was successfully performed (Yilmaz, Yucel, & Dondu, 2017). Although the practice of organ donation encompasses socio-cultural, legal, and ethical challenges, over the past half-century, the field of organ transplantation has emerged as a technologically radical clinical specialty (Bile, Qureshi, Rizvi, Naqvi, Usmani, & Lashari, 2010). Organ transplantation is now considered an efficacious treatment for organ failure across the world (Wenger & Szucs, 2011). In the case of renal failure, kidney transplantation improves patients' quality of life, as it does in the cases of liver, lungs, or heart failure where transplantation is the only possible treatment for most patients (Wenger & Szucs, 2011). In terms of organ donation, an organ donor is a person who donates any part of his body, organ, tissue, or cell (The Transplantation of Human Organs and Tissues Act, 2010). For transplantation, organs can be donated by either a living or deceased donor (Robson et al., 2010). Cadaveric, deceased, or posthumous donations comprise organ donations, i.e. the taking of organs (heart, lungs, kidneys, liver, pancreas) or tissue donations, i.e. the taking of tissues (skin, corneas, tendons, bone) from clinically dead or brain-dead people (Diest, Cardoso, & Niesing, 2003). Brain death is an irreversible and simultaneous loss of brain and brainstem functions (The Transplantation of Human Organs and Tissues Act, 2010).

The medical success of organ transplantation has generated massive demand for organs from patients, as they desire a chance for a better life after treatment. Unfortunately, this increasing demand for organ donors has outstripped the supply of donor availability (Sirois, Sears, & Marhefka, 2005). The greatest challenge for transplants is the huge gap between the number of organs available and the demand for organs (Robinson, Klammer, Perryman, Thompson, & Arriola, 2014). In the United States alone, more than 20,000 transplants were made in 2013 while more than 75,000 patients needing transplants were still on the organ transplant waiting list (Phillipson, Larsen-Truong, Pitts, & Nonu, 2015). In fact, the scarcity of organs is a global issue (Murray, Miller, Dayoub, Wakefield, & Homewood, 2013; Verjee, Haddad, Laws, & Abu-Raddad, 2014; Wilczek-Ruzyczka, Milaniak, Przybyłowski, Wierzbicki, & Sadowski, 2014) as there exists a massive gap between patients waiting transplants and the availability of potential donors (Raghavendra, Karinagannanavar, Khan, & Vandana, 2014). In 2016, the percentage of deceased donations per million people was 35.1% in Spain, 26.0% in USA, 20.8% in UK, 13.2% in Brazil, 8.4% in South Korea, and 6.4% in Chile (Tumin, Tafran, Tang, Chong, Mohd Jaafar, Mohd Satar, & Abdullah, 2016). Despite the fact that India has the

highest number of deaths by road accidents in the world, the posthumous organ donation rate in India was only 0.05% per million people and in Hong Kong, the rate was less than 5% (Raghavendra et al., 2014). Like its neighboring country, the organ donation rate in Pakistan is also detrimentally low. However, in Sri Lanka, posthumous organ donation is very common, and this country even donates over 5,000 eyes to Pakistan each year (The Nation, 2015).

The scarcity of organs for transplantation and the importance of organ donation calls for the encouragement of people to make decisions about posthumous organ donations (Smits, Borne, Dijker, & Ryckman, 2005). In this study, the focus was on posthumous donations (donations from a dead person) only, as it is considered as the most important source of organs (Hyde & White, 2014). Research on this issue has shown that one of the main obstacles to posthumous organ donation is the failure to get the consent of the family (Hammami et al., 2012), notably because many next of kin are hesitant to proceed with organ donation (Newton, 2011). The key reason for this refusal is that most patients either do not register their donation decision or do not communicate their decision with their families (Potter et al., 2017). In the United States, the next of kin had refused to give consent for organ donation in 47% of the eligible cases (Newton, 2011). Though the rate of posthumous organ donation and transplantation varies from country to country, the dearth of organ donors remains a universal issue (Phillipson et al., 2015).

To increase the pool of potential donors, it is essential to identify specific factors that facilitate better attitudes towards tissue and organ donation and lead to desirable actual behavior like willingness for signing a donor card or willingness to communicate the decision with family (Phillipson et al., 2015). Thus, the aim of the present study was to explore the attitudes and willingness towards organ donation and transplantation in Pakistan using an organ donation model. Additionally, attitude and willingness to sign a donor card was examined in relation to the willingness to donate organs and to the discussion of such willingness to donate with family.

1.2 Research Questions

The current study proposed the following research questions:

- 1. What are the antecedents that influence an individual's attitude towards posthumous organ donation?
- 2. Do attitude, social norms, moral norms, and perceived behavioral control influence the willingness to donate?
- 3. Does willingness to donate translate into willingness to sign a donor card?
- 4. Does religiosity moderate the relationship between willingness to donate and willingness to sign a donor card?
- 5. Does willingness to sign a donor card lead to willingness to communicate with the potential organ donor's family?

1.3 Research Background

Organ transplantation is a successful method of treatment as it can save the lives of organ recipients. It is a success story of the modern age, and one can look at its positive impacts from different perspectives. For instance, for a donor and his or her relatives, organ transplantation can be living a new life through another person's body, as the donor's organs would be transplanted into another person to save his life. Recipients would get the opportunity to live a healthy life with healthy organs. In the medical field, this advancement helps cure different chronic diseases and ultimately provides a cost-effective solution for a healthy life (Simpson, 2012). Organ donation is an important health issue as its purpose is to improve other people's health and requires significant sacrifice on the donors' part (Park, Smith, & Yun, 2009). Thus, the promotion of effective organ donation can save many lives. The greatest challenge in this area is to reduce the increasing gap between the demand for organ transplantations and the number of organs available for donation.

Posthumous donation is now a well-established source of organs in developed countries for people suffering from end-stage diseases of their vital organs. With the developments in the field of medicine and the success of transplantations, there is increasing awareness among the global population to contribute to these life-saving practices. However, Asian countries' efforts to meet the increasing demand for organ transplantation through deceased donor programs have been unable to achieve huge success (Jafarey & Nagral, 2014). It is particularly noteworthy to consider that even though the number of potential donors has surged, the actual behavior of donation is still very low in this region (Jafarey & Nagral, 2014).

1.3.1 Organ Donation in Pakistan

Pakistan is a populous country with more than 200 million citizens (Pakistan Bureau of Statistics, 2017). It is a predominantly Islamic society, with Muslims comprising over 95% of the population (Pakistan Tourism Development Corporation, 2017). This country has four provinces, namely Punjab, Sindh, Baluchistan, and Khyber Pakhtunkhwa, along with federally administered tribal areas called Islamabad (the capital), Gilgit-Baltistan, and Azad Jammu & Kashmir (Pakistan Tourism Development Corporation, 2017). Punjab is the most densely inhabited province with a population of more than 110 million, wherein Lahore is the capital and most populous city of Punjab with a population of approximately 11 million (Pakistan Bureau of Statistics, 2017). During the years 2015-2016, it was estimated that the number of accidents in Pakistan was 9,100, of which Punjab had the highest number with 3,288 road accidents and 2,053 deaths in those accidents (Pakistan Bureau of Statistics, 2017). Many patients suffering from end-stage diseases could have been saved through organ transplantations from the deceased accident victims. However, Pakistan's posthumous organ donation rate is one of the lowest in the world. As of the year 2018, only five people have donated their organs after death and only three people have donated their corneas after death from the time posthumous organ transplantation started in the country (Transplantation Society of Pakistan, 2018).

Over the last decade, the subject of organ transplantation has received serious attention as a bioethical issue in Pakistan because of the mushrooming trend of transplantations worldwide (Saleem et al., 2009). In Pakistan, the Sindh Institute of Urology and Transplantation (SIUT) is one of the oldest organizations actively operating an organ donation program. Other institutes are the Shifa International Hospital, Human Organs and Transplant Authority (HOTA), Armed Forces Institute of Cardiology, Pakistan Association of Urological Surgeons, Transplantation Society of Pakistan, Rabwah Blood and Eye Donation Center, Al-Shifa Trust Eye Hospital, and Pakistan Eye Bank Society (Saigol, 2014).

Though the actual organ donation rate in Pakistan is not known, it is estimated that this rate is less than 1% per million people (Mirza Naqi Zafar, General Secretary, SIUT, personal communication, April 5, 2017). Indeed, Pakistan has only 1,000 kidney and 100 liver transplants from living donors per year, while cornea donations are also rare. In 2015, only 900 kidney and 139 liver transplantations were performed in Pakistan (Mirza Naqi Zafar, General Secretary, SIUT, personal communication, April 5, 2017). In all these cases, organs were taken from live donors (Mustafa, 2016).

In Pakistan, on average, 16 people are added to an organ waiting list while ten die waiting for an organ every day (Shahid et al., 2016). The SIUT (Sindh Institute of Urology and Transplantation) is where Pakistan's first cadaver kidney transplant was performed in 1995. The kidneys, retrieved from a 14-year-old Dutch girl, were gifted by the Euro Transplant Foundation and were transplanted into a female Pakistani patient (Sindh Institute of Urology & Transplantation, 2013). In October 1998, a 24-year-old Pakistani donated his organs and hence, Pakistan became the ninth Islamic country to perform a cadaver organ transplant (Sindh Institute of Urology & Transplantation, 2013). The only treatment for patients who are suffering from end-stage liver, heart, or pancreas failure is posthumous organ donation, which can save thousands of these patients (Güden, Çetinkaya, & Naçar, 2013).

The greatest challenge in Pakistan is to stimulate people to sign organ donor cards. In this country, there is a general lack of knowledge and awareness about posthumous organ donation (Shahid et al., 2016). Even those who are aware of organ donation have different levels of knowledge and views regarding posthumous organ donation (Saleem et al., 2009). People in Pakistan are mostly unaware of the importance of signing a donor and discussing it with family (Umair, 2017). In order to gain a better understanding and more current perspective of this issue, the researcher conducted some interviews on the locals to obtain the general views on the issue. Since it was only to obtain a general understanding of the issue, convenience sampling was used to select. During these interviews, it was observed that at times, people were willing to donate but did not know about organ donation or the types of organs that could be donated after death.

"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".

(Asad Ejaz, Student, Department of Business & Economics, The University of Lahore, Lahore, Personal Communication, January 3, 2017).

Additionally, fears related to religious permissibility and family denial were other reasons for a lack of potential donors (Saleem et al., 2009). Even though there were fatwas from Islamic scholars in favor of posthumous organ donation, misunderstandings still existed regarding this matter in Pakistan (Dawn, 2016). There were people who considered donating their organs after death a noble cause.

"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".

(Ali Raza, Student, Department of Education, University of the Punjab, Lahore, Personal Communication, January 7, 2017).

Also, there were people, who were willing to donate but had the fear of Islamic prohibition.

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

(Ayesha Khan, Student, Department of Education, University of Management & Technology. Lahore, Personal Communication, January 23, 2017).

Thus, to increase the supply of organs, it is vital to increase knowledge and awareness about posthumous organ donation, permissibility in religion, and the process and benefits of becoming an organ donor. This is particularly needed in Pakistan, a country with one of the lowest organ donation rates in the world.

1.4 Problem Statement

In 2016, it was reported in the well-known Pakistani newspaper "Dawn" that only five individuals had donated their organs at the time (Dawn, 2016). Although this donation rate had increased to eight people by 2018 (Transplantation Society of Pakistan, 2018), Pakistan has still been unable to change society's mindset regarding organ donation. Deprivation of healthcare facilities, little to no awareness of organ donation, and the religious uncertainties related to organ donation have caused the perception that

Pakistani people are not aware of the serious health complications that can be resolved through transplantation (Zubair, 2012). According to the Sindh Institute of Urology in Pakistan, 30,000 people die of renal failure and 100,000 suffer from liver failure each year (Mustafa, 2016). From this number, approximately 50,000 people lose their lives due to irreversible organ failure and this is increasing at a rate of five percent annually (Shahid, Arshad, Munir, Aleem, & Imam, 2016). In most cases, patients can be saved if there are organs available for transplantation.

The issue of organ donation makes a tangible impact on the number of lives that can be saved, yet limited research has been conducted on organ donation in Pakistan. Very few studies have been published in the last few years within the Pakistan context, e.g., research undertaken by Ashraf et al. (2005), Badrolhisam & Zakaria (2012), Khan et al. (2011) and Saleem et al. (2009). It is noteworthy that most of the work in this area was performed on medical students or patients only (Ali, Qureshi, Jilani, & Zehra, 2013; Khan et al., 2011; Saleem et al., 2009; Shahid et al., 2016). In addition, living donors, blood donors, and deceased donors were not separated into different categories in these studies (Saleem et al., 2009). There is a need for such distinction because these types of donations are not only different from each other, but the number of organs is more limited for live donations compared to posthumous donations.

Though work on organ donation has been undertaken in developed countries in the 21st century, there is still a gap between the demand and supply of organs needed for transplantation. Previous studies on donation after death have discovered that individuals have positive attitudes toward donation behaviors (Ashkenazi, Steinberg, & Cohen, 2018; Hübner, Mohs, & Petersen, 2014; Khan et al., 2011; McGlade & Pierscionek, 2013). However, these positive attitudes have not been converted into actual behavior (Morgan & Miller, 2002; Murray et al., 2013; Potter et al., 2017). Hence, a much-debated question is whether more individuals with a positive attitude towards posthumous organ donation would increase the number of actual organ donors. This discrepancy between attitude and behavior has been documented as a problem in prosocial or voluntary donation domains (Anker, Feeley, & Kim, 2010). Importantly, in developing countries, transplantation mainly depends on living organ donors, who contribute about 85% to 100% of transplantations (Robson et al., 2010). Phillipson et al. (2015) argued that to increase the posthumous organ donation rate, it is necessary to identify not only factors that help form positive attitudes towards posthumous organ donation, but also factors that increase the donation behavior and discussion with families. This study addressed this gap by exploring various antecedents of both the attitude for organ donation as well as the willingness for its actual behavior, which is signing a donor card.

In studies on organ donation, the attitude has been considered an important component of the willingness to donate (Gauher et al., 2013; Hill, 2016; Ralph et al., 2016). Many social science theories, including the Theory of Reasoned Action (TRA) and Theory of Planned Behavior (TPB), assert that attitude towards an objective will contour behavior towards it (Kopfman & Smith, 1996; Morgan & Miller, 2001). Hence, in organ donation, researchers usually, first measure the attitude towards willingness.

Statistically, attitude is found to be a strong predictor of a person's willingness, which leads to actual behavior towards donating organs (Kopfman & Smith, 1996; Morgan & Cannon, 2003; Morgan, Stephenson, Harrison, Afifi, & Long, 2008). When examining respondents' attitudes, previous research on posthumous organ donation has limited the study of antecedents to knowledge and altruism (Yilmaz et al., 2017; Lafaye & Kreis, 2013; Morgan, 2004; Wu, Tang, & Yogo, 2013). However, these antecedents may be insufficient to explain attitudes, which could impede the determination of behavior in organ donation.

Researchers have argued that the attitude of a person is related to altruistic values (Mostafa, 2010) and knowledge (Saleem et al., 2009). Yet, in determining the attitude of a person in terms of organ donation, variables other than knowledge and altruism need to be investigated (Hyde & White, 2009). To deal with this issue, this study attempted to fill this gap by studying additional predictors, namely self-identity and empathy, of the attitude towards willingness to donate and willingness to sign an organ donor card. Empathetic concerns towards a person in need of an organ can help develop a positive attitude towards donating (Falomir-Pichastor, Berent, & Pereira, 2013). Also, self-identity can contribute to a positive attitude towards performing a particular role within society (Masser, White, Hyde, & Terry, 2008). It has been observed that attitude can indeed be influenced by empathy and self-identity (Hyde & White, 2009; Skumanich & Kintsfather, 1996; Steele et al., 2008; Wilczek-Ruzyczka et al., 2014). Thus, the present study argued that both these variables are important antecedents in determining the attitude of a person towards organ donation willingness and are valuable additions to the organ donation model. However, the influence of empathy and self-identity on the attitude to become a posthumous organ donor has not been investigated in previous organ donation models.

In earlier organ donation models by Horton & Horton (1990), Kopfman & Smith (1996), and Morgan (2004), little attention was given to the effect of moral norms and perception of control on respondents' willingness to donate (Kashif, Sarifuddin, & Hassan, 2015). Omitting moral norms and control behavior from organ donation models may prevent researchers from fully understanding the reluctance of individuals to donate. This is because organ donation carries significant moral and ethical obligations (Simpson, 2012) and is also a decision-making process not completely under an individual's volitional control (Hasbullah, Jumaat, Mad, & Salleh, 2014). However, in most studies on posthumous organ donation, only social norms have been considered an important component in determining the willingness of a person (Stephenson et al., 2008; Wakefield, Watts, Homewood, Meiser, & Siminoff, 2010), along with attitude.

To address this issue, in addition to attitude and social norms, moral norms and perceived behavioral control (PBC) were studied in relation to the willingness for organ donation. Moral norms address a person's concern to help needy people while perceived behavioral control refers to the influence of factors beyond a person's control (Ajzen & Madden, 1986). The application of moral norms and perceived behavioral control to the issue of organ donation has been confirmed in studies that

found both to be noteworthy predictors of willingness to donate blood (Hyde & White, 2009). There is also evidence to support including moral norms and perceived behavioral control in the analysis of behavioral willingness in the organ donation context (Giles, McClenahan, Cairns, & Mallet, 2004; Hasbullah et al., 2014; Rivis, Sheeran, & Armitage, 2009). However, limited work has been undertaken to examine the collective effect of perceived behavior control, moral norms, and social norms on the willingness towards donation (Kashif et al., 2015). This study addressed this limitation by including perceived behavior control and moral norms along with attitude and social norms in the model to measure the willingness for posthumous organ donation.

Many previous studies measured respondents' attitude towards organ donation instead of their willingness to become an organ donor (Balwani et al., 2015; Coad, Carter, & Ling, 2013; Nordfalk, Olejaz, Jensen, Skovgaard, & Hoeyer, 2016; Saleem et al., 2009). According to Morgan & Miller (2002), willingness towards behavior, i.e. becoming an organ donor, is highly important and needs to be studied further. Only by increasing the willingness towards actual behavior of the public, the gap between availability and demand for organs can be reduced. Statistically, attitude is considered as a strong predictor of a person's willingness, which leads to the behavior of donating organs (Kopfman & Smith, 1996; Morgan & Cannon, 2003; Morgan et al., 2008). According to previous studies, many individuals showed positive attitudes towards organ donation, yet very few of them were actually willing to become donors (Murray et al., 2013; Range & Brazda, 2015; Stephenson et al., 2008). The present study attempted to address the aforementioned limitation by examining the relationship between attitude, willingness to donate, and subsequently willingness to sign an organ donor card.

Studies on posthumous organ donation have shown that the relationship between willingness to donate and willingness to sign an organ donor card is inconsistent (Morgan & Cannon, 2003; Morgan et al., 2008). Though people may be willing to donate, they are reluctant to show a willingness to sign donor cards (Demir & Kumkale, 2013). Because of this discrepancy, the gap between demand and supply of organs is expanding (Hübner & Lippke, 2014; Miller, 2001; Tumin et al., 2016). The present study aimed to address this issue by testing the moderating effect of religiosity on the relationship between willingness to donate and the willingness to sign organ donor cards for posthumous organ donation.

Religiosity is taken as a moderator as religion is one of the most important drivers of human behavior that can be used to motivate people towards organ donation (Stephenson et al., 2008). Religious associations play an exceptionally important role in determining psychological and social practices (Ysseldyk, Matheson, & Anisman, 2010). Researchers have shown a keen interest in donation behavior for decades, yet there are still discrepancies in their findings, which highlights the need to understand the impact of religiosity on donation behavior. Previous findings on charity work suggest that there is more to religious belief than just its direct impact on the donation (Teah, Lwin, & Cheah, 2014).

According to Ranganathan and Henley (2008), if a person has strong religious beliefs, he or she would be more involved in charity work, which would increase donations. In the case of organ donation, the religious beliefs of the major religions, including Islam, Hinduism, Sikhism, Buddhism, and Christianity have been studied and importantly, none of the religions are against organ donation (Randhawa & Neuberger, 2016). In the case of Islam, even though there are several verdicts in favor of organ donation, Muslims still have doubts about the exact status of organ donation in Islam. There is a need to publicize these verdicts for the understanding of the public (Transplantation Society of Pakistan, 2018).

Studies on the role of religion in the willingness to donate organs are still unclear in the literature (Robinson et al. 2014). In the case of Pakistan, it has been observed that people have mixed religious opinions related to organ donation after death (Umair, 2017). According to Faltynek (2013) and Stephenson et al., (2008), one of the primary reasons for the lack of available organ donors was that people perceived donation to be against their religious beliefs; hence the need is to include such beliefs into explanatory models on posthumous donation willingness (Robinson et al. 2012). Specifically, within the perspective of Pakistan, where religion has a great influence in determining opinions, religiosity can be a critically important variable in organ donation behavior (Saleem et al., 2009).

Previous studies have argued on the direct influence of religiosity towards organ donation (Robinson et al., 2014; Randhawa, 2012; Stephenson et al., 2008). However, according to Teah et al. (2014), limited research has been undertaken on the indirect impact of religiosity on motivation to donate. Hence, it can be argued that religiosity may act as a moderator between the willingness to donate and to sign a donor card, whereby it may strengthen this relationship. This study aimed to tie the gap between religiosity and its relationship with willingness to donate and willingness to sign a donor card by investigating the moderating effects of religiosity on this relationship.

Another great barrier to organ donation is the denial of family consensus at the time of the donation (Breitkopf, 2006; Man & Wu, 2008; Marck et al., 2016; Morgan, 2004). It has been observed that the views of family members regarding organ donation play a significant role in the willingness to donate. There exists a positive relationship between willingness to sign a donor card and willingness to communicate the decision to the family (Horton & Horton, 1990). To increase the general knowledge about organ donation and to reduce the myths regarding this topic, it is vital to increase the willingness of individuals to talk to their family members about organ donation. This can be important in reducing the opposing attitudes of family members about the willingness of a person to donate his/her organs (Morgan, 2004). Previously, willingness towards communication with family was not researched in the models presented by Horton & Horton (1990) or Kopfman & Smith (1996). Several studies have examined the antecedents to willingness to sign a donor card, including attitude, knowledge, and social norms (Besser et al.; Feeley & Servoss, 2005; Gazibara et al., 2015; Hübner & Lippke, 2014).

Noticeably, there have been studies carried out on family communication about posthumous organ donation (Marck et al., 2015; Miller, 2001; Trompeta, Cooper, Ascher, Kools, Kennedy, & Chen, 2012; Volz, Wenger, & Szucs, 2011), yet very little research has systematically explored the factors associated with a person's willingness to communicate with his or her family. It is important to consider family communication in posthumous organ donation cases as the actual donation decision is made by family members under extremely difficult circumstances. Apart from this, discussion with one's family can be a significant factor in increasing awareness and knowledge about organ donation, addressing the misconceptions about the process and ultimately, increasing the number of organ donors (Morse et al., 2009). It can be assumed that an individual's discussion about their willingness to donate with their family may possibly be the most important factor in turning willingness into actual behavior (Morse et al., 2009).

Based on these gaps in the literature, multiple variables like knowledge, attitude, altruism, and social norms were considered to have significant relationships with the willingness to behave. These variables were pooled into a theoretical model of willingness towards organ donation and willingness to communicate this decision to family members. It is this model that formed the basis of the present study. Therefore, the focus of the current research was on the willingness to sign an organ donor card and then, the willingness to discuss with family.

1.5 Research Objectives

The general objective of the study was to examine the factors that would encourage organ donation amongst individuals. Specifically, this study planned to:

- Examine the influence of knowledge, altruism, self-identity and empathy on the university student's attitude towards posthumous organ donation.
- Explore if attitude, social norms, moral norms, and PBC would influence the university student's willingness to donate.
- Determine if willingness to donate has a significant impact towards willingness to sign a donor card.
- Confirm if the relationship between willingness to donate and willingness to sign a donor card would be strengthened with higher religiosity
- Determine if willingness to sign a donor card has a significant influence on a university's student's willingness to communicate with the family.

1.6 Scope of the Study

This section describes the parameters of the research, including the subject areas of investigation, the underlying theories of the framework, and the constructs that were included in the study. The scope of the sample population for this study is also explained.

The research framework for this study applied theories from the fields of management and psychology. The main objective of the study was to examine the factors that can encourage organ donation amongst individuals. For this purpose, the TPB, simulation theory, and identity theory were used in the research. Based on the research objectives and variables chosen, survey questionnaires were distributed to the respondents. The justifications for applying these theories and concepts are elaborated in Chapter Three, while the measurement tools used in the survey are explained in Chapter Four.

The current study focused on posthumous organ donation for several reasons. First, living donors are usually close relatives of the recipient (Shaw, 2010). Second, with the advancement in drugs, living donors are becoming less necessary, so there is weaker justification for improved success rates being the basis for preferring a living related donor (Horton & Horton, 1991). Most importantly, many types of organ transplants can only be performed through posthumous organ donations. It is for this reason that posthumous organ donation is now considered crucial for transplantation (Kocaay, Celik, Eker, Oksuz, Akyol, & Tuzuner, 2015).

This study involved attitude and behavioral willingness towards posthumous organ donation in Pakistan. To this end, the perception of university students was assessed to examine the relationship between attitude and willingness and then, between willingness to donate and willingness to become an organ donor, with religiosity as a moderating variable. The sample population was derived from the young students of four public and private universities in Lahore, Punjab who were above 18 and less than 35 years of age. This is because of the reason that adults above 18 and less than or equal to 35 are considered as young adults (Petry, 2002). The reason for choosing Lahore was that it is considered the largest city and the most advanced district of Punjab with an expected population of more than 11 million (Mazhar & Jamal, 2009).

There is a growing tendency across the social sciences to use students as a sample in research studies, as this increases response rates, is time-saving, and lowers costs (Bryman, 2015). There are many reasons to use students in present study. For instance, it has been observed from previous research that young adults (aged and better-educated people are the ones most prone to donations (Skumanich & Kintsfather, 1996). Thus, it was important to examine the factors that encourage them to donate organs after death. The students' population was also ideal for this research as a donor needs to be a healthy young adult with healthy organs, and if he/she signs a donor card at this stage, it is expected that he/she will continue with this attitude and willingness throughout his/her lifetime (Horton & Horton, 1991; Wong & Chow, 2017). Students are also considered to be more open to new ideas and information and, in the future, may become opinionated leaders who shape the attitudes of others on such important issues (Feeley, 2007).

1.7 Significance of the Study

This study is a significant effort in advancing the academic literature and contributing to the alleviation of problems faced by practitioners. The findings of the study will not only help health administration in Pakistan but will also be useful for other developing countries sharing sociocultural and economic similarities.

1.7.1 Theoretical Significance

First, this study is significant as it adds the TPB as a basis to previous organ donation models which have used the TRA (Morgan, 2004). The TPB is an extension of the TRA and helps in understanding the positive or negative evaluations of organ donation. It has been used to the prediction of a range of behaviors in the altruistic and health domains including blood donation (Godin, et al., 2005; Kashif et al., 2015; Hyde et al., 2013; Yean et al., 2015). However, in these studies, TPB accounted for 30% to 40% of the variance to predict behaviors. While standard TPB model can provide an initial assessment of person's behavioral intention and/or behavior towards organ donation after death, in order to account for the remaining unexplained variance, other additional variables can also be included if they capture a significant variance in intention or behavior after taking theory's current variables into account (Ajzen, 1991). This study is significant as it not only studied the standard TPB components (attitude, subjective norms, PBC) but also suggested other social and personal components that may impact a person's willingness to become an organ donor.

By using TPB, this study extended the Organ Donor Willingness Model (Morgan, 2004) into a comprehensive model by examining and incorporating different factors associated with attitude, willingness to donate organs, and willingness to sign an organ donor card, into the model. The proposed research framework extended previous work in the field of posthumous organ donation by complementing the recommendations of previous researchers and integrating multiple perspectives into the subject (Robinson et al., 2014; Marck et al., 2016; Teah et al., 2014; Range and Brazda, 2015; Kashif et al., 2015; Shahid et al., 2016). The details of the model development are explained in Chapters Two and Three.

The third significance of the study is the identification of valuable antecedents to the attitude in the organ donation model. In particular, self-identity from identity theory and empathy using simulation theory were examined in relation to attitude. Identity theory helps to understand the identity confirming behaviors (Terry et al., 1999). Within a TPB model, self-identity is expected to be a significant predictor of a positive attitude (Hyde & white, 2009). Self-identity has been considered an important influencer of individual behavior (Conner & Armitage, 1998) and has been found to independently predict willingness as well. Referring to previous research on blood donation attitudes, Giles et al. (2004) argued that people are more willing to give blood if they consider donating blood an important part of their self-identity. In the case of organ donation, when a person considers organ donation an important part of his/her self-concept, there are more chances that he/she will perform donation-like activities,

including organ donation (Hyde & White, 2009). Conner and Armitage (1998) claimed that, when coupled with a strong self-identity, attitude becomes even stronger due to attitudinal consistency.

It has also been noted that feeling distressed or sad for another is distinct from feeling personally distressed or sad at witnessing another's difficulty (Batson & Ahmad, 2009), which is usually when a person imagines the other person's feeling in that situation and reacts accordingly. This phenomenon comes from simulation theory, known as empathy and has a positive effect on charity and prosocial behavior (Fajardo, 2012). Simulation refers to a person's decision-making process to think about others and to develop empathetic concerns for those in need of help (Goldman, 1992). It has been observed that one of the motivators of helping behavior is the desire to relieve personal distress or sadness caused by perceiving another's pain (Webb, Green, & Brashear, 2000). Within TPB, empathy can act as an additional predictor of a positive attitude for helping behaviors (Li, 2016). Researchers have argued empathy and selfidentity as important variables to be considered in organ donation behavior (Morgan et al., 2008; Hyde & White, 2009). However, the role of empathy and self-identity were not examined in the previous organ donation models (Horton & Horton, 1990; Kopfman & Smith, 1996, Morgan, 2004). The present study examined the role of empathy and self-identity towards positive attitude for posthumous organ donation.

Another significance of the study is that it incorporates moral norms and perceived behavioral control, in addition to attitude and social norms, into the organ donation model (Morgan, 2004) to provide an understanding of the willingness for posthumous organ donation. Both moral norms and perceived behavioral control, working in parallel with attitudes and social norms, may have important influences on the willingness to perform behaviors that have a moral or ethical aspect (Conner & Armitage, 1998; Hyde & White, 2009, 2010). It is thus important to include an assessment of moral norms and perceived control within an organ donation context.

The fifth significance of this study is that it investigates the moderating effect of religiosity on the willingness to donate and willingness to sign a donor card, particularly in a predominantly Muslim community. Because religiosity is a key aspect of an individual's decision making, it is critical to understand its role in posthumous organ donation. As mentioned earlier, the relationship between willingness to donate and the willingness to sign a donor card is inconsistent. Hence, this study, in accordance with the suggestion of Teah et al. (2014), incorporated religiosity in the examination of the relationship between willingness to donate and to sign a donor card. By discovering the moderating effect of religiosity, the organ donation literature is extended in relation to establishing boundary conditions that strengthen this relationship.

1.7.2 Practical Significance

To encourage organ donation among the Pakistan population, research on the attitudes and willingness towards organ donation and transplantation is vital to design culturally appropriate promotional and educational programs (Saleem et al., 2009). It is important to identify influential factors that can communicate the need for organs and effectively aid in increasing the donation rate in Pakistan. As mentioned earlier in this chapter, there are several barriers to organ donation that discourage a community from donating their organs.

This study is significant as it has practical value in addition to the theoretical value. By providing empirical evidence, the current study gives an insight into the factors that influence the attitudes of Pakistani people regarding organ donation and transplantation. Indeed, past researchers stressed the need to motivate the Pakistan population to donate organs after death (Khan et al., 2011). Shahid et al. (2016) also urged for more research as well as awareness programs to increase the posthumous organ donation rate in Pakistan. Hence, the present study aimed to study the factors needed to boost the organ donation rate for transplantation in Pakistan.

It is expected that the current study will help governmental and non-governmental organizations, especially the Health Ministry of Pakistan and the NGOs working for organ transplantation in Pakistan, to better understand the role of antecedents to attitude and willingness to communicate the organ donation decision of a person. The key antecedents included were self-identity, empathy, moral norms, and perceived behavioral control. Also, in the present study, the researcher desired to determine the role of religiosity in motivating Pakistani people to be organ donors. This information can support the tailoring of targeted future programs and campaigns that promote people's knowledge and understanding regarding organ donation after death in religion.

It is also expected that the results of the present study would help to adopt a comprehensive approach towards public policy design that may aid in designing strategies or promotional materials for awareness towards posthumous organ donation and transplantation. As policymakers may need to know about the feelings and beliefs that are important to increase people's willingness towards organ donation after death and their willingness to discuss the decision with the family. The results of this study can help to arrange campaigns and social events. For example, if this study found that self-identity and empathy were significant, the government can have policies to make donor's identities visible in campaigns and to promote the concept of being empathetic towards the person in need of an organ. The targeted campaigns and events can be useful in educating the people towards not only increasing their willingness for signing the donor cards but also to communicate their willingness to be organ donors with their families.

Importantly, the study set out to determine the willingness to donate among university students in Pakistan. Knowing the factors that encourage donation aids universities in designing well-directed campaigns that promote the concept of becoming potential organ donors among students. Therefore, this study is significant in filling the practical gap regarding students' willingness to donate and willingness to sign donor cards in Pakistan.

The above-mentioned justifications explain the significance and contributions of this study. The proposed framework contributes towards the advancement of the literature by extending existing models on posthumous organ donation through additional variables recommended by previous researchers. Hence, the findings of the study would fill the research gaps and solve the research problems suggested by the previous researchers. The present study is also relevant to the needs of policymakers and organizations working for posthumous organ donation.

1.8 Definition of Terms

This section provides definitions of the key variables in this study.

Attitude: Attitude is, "The degree to which a person evaluates or appraises the behavior in question to be favorable or unfavorable, captured in a dimension of pleasant or not pleasant, good or bad, harmful or beneficial, or like or dislike" (Hasbullah et al., 2014, p.143).

Knowledge: Knowledge in organ donation is, "an understanding of facts about organ donation, and how accurate or inaccurate the facts are" (Kopfman & Smith, 1996, p.35).

Altruism: Altruism is, "a personal trait of being helpful and taking care of the welfare of others" (Smith et al., 2013, p.117).

Empathy: Empathy is defined as, "being cognitively aware of another person's internal states and/or putting oneself in the place of another and experiencing his or her feelings, or one's ability to experience and understand another person's affective or psychological state" (Paniculangara & He, 2012, p.251).

Self-identity: Self-identity is defined as, "the extent to which a person perceives himself or herself as performing a particular role within society" (Masser et al., 2008, p.222).

Social norms: Social norms are defined as, "an individual's perception of the social pressure to perform or not to perform the target behavior" (Yean, Johari, & Sukery, 2015, p.144).

Moral Norms: Moral norms can be defined as, "one's own socially determined and socially validated values attached to a particular behavior" (Conner & Armitage, 1998, p.1441).

Perceived Behavioral Control (PBC): PBC is defined as, "the perceived belief of easiness or difficultness in performing a certain behavior" (Hasbullah et al., 2014, p.143).

Religiosity: Religiosity is defined as, "one's relationship with a particular faith, tradition or doctrine about a divine other or supernatural power" (Wong, Rew, & Slaikeu, 2006, p.163).

1.9 Organization of the Thesis

This thesis is organized into six chapters. Chapter One introduces organ transplantation and donation, followed by an explanation of the concept of posthumous organ donation worldwide and in Pakistan. In addition, the research problem is discussed, and research questions and objectives are formulated. The chapter further elaborates on the research significance and scope and provides the operational definitions used in the study.

Chapter Two outlines the theoretical concept of the study. It starts with an explanation of organ donation and the process of posthumous organ donation. Then, the approaches adopted in posthumous organ donation are discussed, including its theoretical and model bases. The various factors influencing donor behavior and willingness to donate are reviewed. Barriers in posthumous organ donation are then acknowledged and finally, gaps in the literature are identified.

Chapter Three explains the research framework and hypothesis development for the present study. The overarching theory is introduced, followed by a discussion of the variables' relationships and the development of the research hypotheses.

Chapter Four discusses the methodology utilized in the study. The chapter explains the research philosophy, research design, questionnaire design and administration, pilot test, data collection and, finally, the data analysis strategy for the study.

Chapter Five provides the results of the statistical analysis and, finally, Chapter Six discusses the findings, and implications of the present study, as well as limitations and suggestions for future research.

1.10 Chapter Summary

This introductory chapter discussed the background of the study pertaining to organ donation. This chapter explained the problems, both theoretical and practical, that influenced the research objectives. The findings of this study are anticipated to have theoretical and practical contributions in extending the academic literature, particularly in identifying the specific attitudes and norms that lead to organ donation decision-making behavior. In the next chapter, the relevant literature on the important aspects of organ donation is discussed, as these provide the foundation for the present study.

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BIODATA OF STUDENT

Sonia Umair is an academician, researcher, and mother of two. From the University of Management and Technology Lahore, she completed her BBIT and MBA (Human Resources Management) with distinction. She has also received "Ahmed Dawood Gold Medal", which is awarded annually to an outstanding participant of the year. She has been lecturing undergraduate and graduate students of business management since 2011. She has worked as a research collaborator on a project funded by "The Sumitomo Foundation" from 2019 to 2020. Sonia is currently involved in several scholarly projects and publications. She seeks to continue research across the domain of business management and its multi-faceted social implications on society. Her areas of interest are corporate social responsibility, organizational behavior, and business ethics.

LIST OF PUBLICATIONS

Journal Article

Published

Umair, S., Ho, J. A., Basha, N. K., Ng, S. S. I., & Waqas, U. (2020) Understanding the attitudes and factors influencing organ donation decisions among university students in pakistan: a qualitative study. *Humanities and Social Science Reviews*, 8(1), 52-59.

Accepted

Role of Empathy and Knowledge Towards Attitude and Willingness for Posthumous Organ Donation: An Empirical Study Among University Students of Pakistan. (Saudi Journal of Kidney Diseases and Transplantation).

Conference Proceedings

Ho, J. A, Umair, S. (2020). A Comparative study between Japan and Malaysia: Attitude and willingness to donate. 4th International Online Conference on Recent Advancements in Interdisciplinary Research (4th ICRAIR-2020), Malaysia.



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