

REVIEW ARTICLE

BEST COMMUNITY ENGAGEMENT STRATEGIES TO RAISE CULTURE OF ORGAN DONATION IN PAKISTAN USING THE UNIVERSITY PLATFORM

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ABSTRACT

To identify best community engagement strategies, using university platform to raise culture of organ donation in Pakistan.

A comprehensive review was done involving extensive literature review and analysis of public opinions. University-level interactions, focus group discussions and debates were also reviewed to identify factors creating hurdles in ethical organ donation. Efforts for organ donation by various sectors including government and nonprofit organizations were made to develop a strategy to improve ethical, medical, legal and religious knowledge on the holistic process of organ donation. Offering financial incentives to suffering families was identified as a source of motivation to encourage organ donations. In this respect, educated and affluent citizens were found most willing. Such eager individuals/groups can be encouraged to pass on training through various community engagement strategies involving multimedia and street-level campaigns.

Other effective means of invoking encouragement for organ donation can be through the distribution of inspiring real-life stories. Using the quadruple helix model comprising Academia-Healthcare Industry-Government and Community Partnership, advocacy could be boosted and healthcare services can be improved by making state-of-the-art facilities available for organ perfusion. Public recognition for prominent activists / donors can further advance efforts for the cause.

Keywords: Brain death, Deceased donor, Organ tourism, Potential organ donor, Registry.

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INTRODUCTION

‘If you have saved one life, you have saved all humanity’. Al Quran, Verse 5:32

Organ transplantation can save countless lives every year if people could understand the need for donating organs and getting listed as organ donors in their lifetime. Fewer number of willing donors, is a major restrictive factor in increasing transplantation rates in Pakistan.

In this review, we discuss what are the current challenges and potential strategies to expand the pool of organ donors and their registration process.

When one scrutinizes the culture of organ donation and transplantation within Pakistan, there appears a general confusion and lack of knowledge among people. The first response they

give is that they don't want to donate organ/s because they are not sure if it's best for them, or they can live after that, and if religion permits or not.

In Pakistan, the number of hospitals is short, cases are either unreported or people, if willing to donate organ/s, lack the correct knowhow, legalities, or the procedures to do it in the correct manner. Moreover, the occurrence of organ trafficking and the 'lack of knowledge of where your organ is going' mindset, makes the process more difficult¹.

According to a careful estimate by the Sind Institute of Urology & Transplant (SIUT) Pakistan, figure-1 shows the distribution of the reasons for the estimated number of deaths per year.

There is a desperate need to increase the number of donors in order to allow more end stage diseased patients to be transplanted before they die on the waiting-list. Patients with severe

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non reversible brain trauma or death, if medically suitable, can be potential deceased donors and active measures are required to convert them into actual donors successfully².

Deceased V/S Live Organ Donation

Deceased organ donation means operating on a person after brain death and taking out viable organs and keeping them well oxygenated and stored under optimal conditions to be transplanted into another living person/s who are dying from an end stage disease. It is a standard medical procedure and donors are looked at as generous people and honored⁵.

Death from organ failure is on the rise all over the world. People die waiting for a donated organ that can be acceptable through cross match to them. The living organ donation program, despite many medical advancements, has failed to cover the growing burden of end stage diseases. Nearly 80% of organ transplantation all over the world is from deceased donors and proving to be the long term solution in saving lives of patients^{2,3}.

However, this is more prevalent in the Western World where live donor transplant is a rarity due to legal restrictions, affluence of population and better medical and biomedical facilities for tissue banking and preservation of organs donated for life saving purposes.

In Pakistan and the Indo-Pak Subcontinent, it is mostly organ donation from a 'living donor'. It is called 'Direct' if the donation comes from a genetically related living person: mother, father, sibling etc. and 'Indirect' if it comes from a non-genetically related donor who agrees to donate on humanitarian grounds or on payment.

Growing Need of Organ Donation in Pakistan; Demand V/S Supply

The need of organ transplantation can only be truly sensed when you need it or some loved one is in dire need of it. For population at large, people in Pakistan are not thinking about this great humanitarian service. Some of the acceptable forms of organ or tissue donations are

corneal transplants that let the born blind see the shades of life for the first time or let those adults see again who have lost their sight as a result of an accident etc.

Most of the people who have pledged their organs so far in Pakistan are either students, young professionals or members of the medical community.

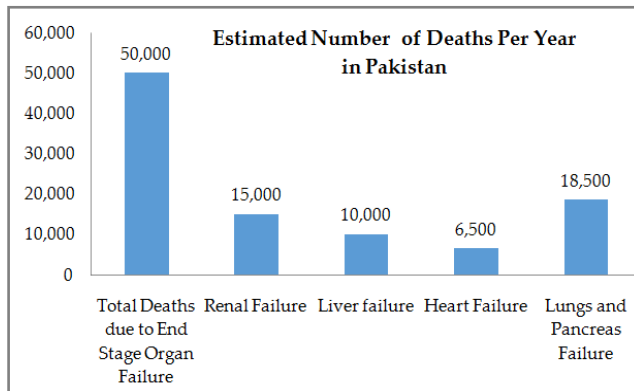


Figure-1: Estimated number of deaths in Pakistan due to various end stage organ failures- Source, Sindh Institute of Urology and Transplantation, Karachi³.

There is enormous potential, as one person can save up to 17 lives. For example, if patients

Table-I: Demand of organ transplantation in Pakistan per year, in numbers.

Demand for Organ Transplant in Pakistan per year, in number.	
Kidneys	25,000
Livers	100,000
Hearts	7,000
Pancreases	2,000
Lungs	2,000

who are declared brain dead when shifted to a ventilator in time, can be converted into actual donors from potential ones. This can save up to 1,014, 428 and 220 people in major cities like Karachi, Lahore and Islamabad respectively. Organs that can be donated include kidneys, heart, liver, lungs, pancreas and intestine. Some tissues that may also be donated include corneas, skin, bone, bone marrow among others. Pakistan has a demand of around as shown in table-I & fig-2.

Hurdles in Promoting the Culture of Organ Donation

According to WHO, out of 63,000 kidney transplants that are conducted every year in the world, 10% donors belong to developing countries who are unrelated to the patients receiving the organ⁴. However, In South-East Asia, and Pakistan, almost all organ donations come from

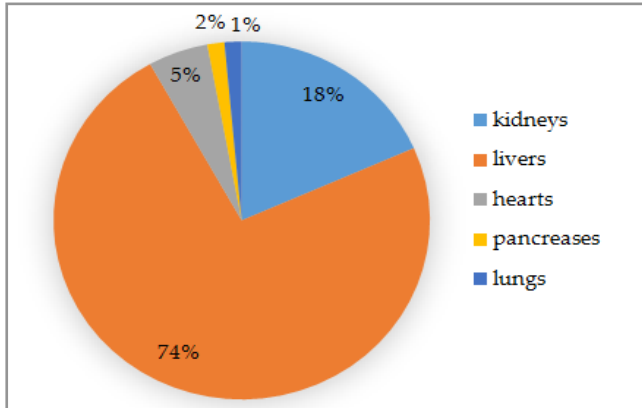


Figure-2: Demand of organ transplantation in percentage.

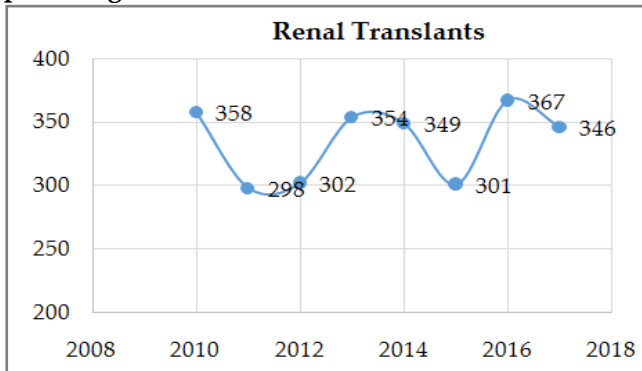


Figure-3: Sindh Institute of Urology and Transplantation, Karachi: (Renal Transplants over the year in SIUT, Karachi Pakistan since 2010 to 2017 (Source SIUT website).

living donors due to lack of systemic listing of donors, organs and tissue banks².

In developed countries, where organs donations are made on humanitarian grounds and organ trade is strictly prohibited, there is a greater number of donors. However, this does not meet the need of organs required to save lives, therefore, organs are imported from developing countries through various channels and means.

This leads to Commercial Organ Trading which is mostly illegal and harms the poor donor.

The downside of the commercial organ trade is that the donor suffers and does not get any care after the transplant operation which can prove to be detrimental for his/her own health later on. Malpractices of doctors, lack of good technique, infection prevention and unethical behavior of

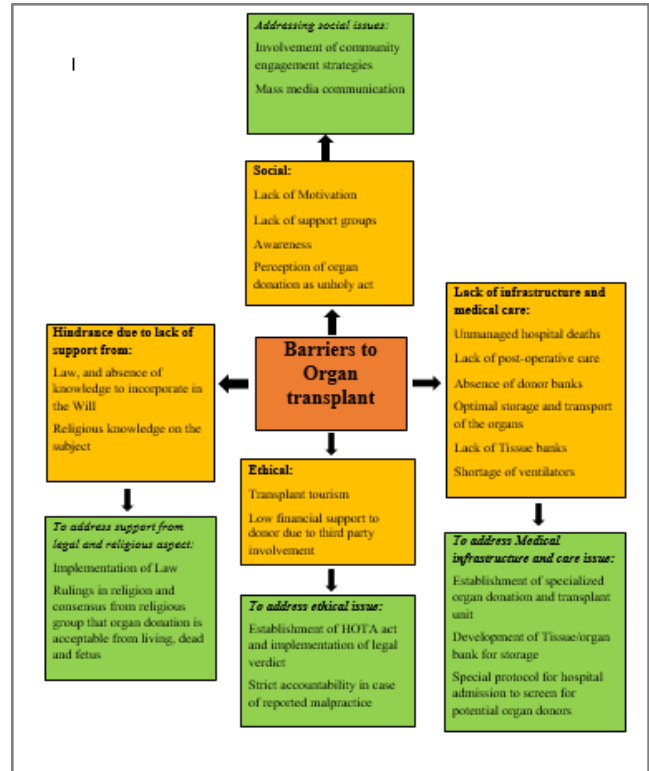


Figure-4: Barriers in organ transplantation.

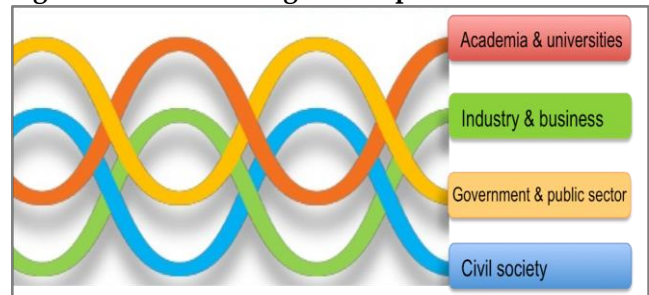


Figure 5: Illustration of Quadruple Helix Model¹⁵.

people involved has put a bad name to this service to humanity⁴.

For instance, for years India had been the favorite spot for availability of cheaper organs obtained by criminal health practitioners for personal gains and sold at high prices while the

donor suffered at the hands of the middle man (transplant tourism) until 1994, when strict laws were implemented there. This provided a golden opportunity for criminals to promote it in

Poor Pakistanis who donate kidneys do it because they are poverty stricken or are “bonded labor”, a system under which they are tied to property owned by landlords⁶.

Table-II: Myths and facts about organ donation in Pakistan.

Myth	Fact
Some potential donors have this perception that the doctors won't try to save them if they are registered donors in order to obtain the organs for transplant	The fact of the matter is that only after all efforts fail to save the patient (accident case or otherwise) and his/her brain death is declared; arrangements are made for organ donation, if deceased is found to be a registered donor.
Another perception is that people can wake up from brain death like they can from long standing coma.	People can recover from comas, but it's highly unlikely to recover from brain death. Brain death: Brain dead are not alive. The brain and brain stem has failed to show any life activity and the change is not reversible. However, spinal reflexes might persist even in brain dead patients. Coma: Comatose-patients are not dead. Their eyes are closed, and they are in a state of depressed consciousness from which they cannot wake up. Unlike Brain Death, brain stem responses, non-purposeful motor responses or spontaneous breathing are still present. They can have variable outcomes: progression to brain death, evolution to a state of chronically depressed consciousness, recovery of consciousness, vegetative state or minimally conscious state patient. Vegetative state: Patients in this state are alive but also have severely impaired consciousness. They may open their eyes instantly. A false impression of consciousness, may be given by eye opening but there is no awareness of the surrounding environment. These patients do not speak or respond to the external stimuli. They do not attend or track objects that are presented to them; body movements are non-purposeful..”
Aging affects donation of organs	In reality it does not.
Donor's body is disfigured	Skilled surgeons perform surgery in most respectful ways and the wounds are closed and body handed over to relatives in a dignified manner. This by no means delays the funeral.
Donors fear that religion (especially Islam) does not allow them to donate.	Organ donation in the eyes of religious groups has become one of the major Biomedical Ethical issue. All major religions support organ donation as a selfless, charitable act and on confirmation of Brain Death, most religions favor organ donation and Islam is one of them. It is based on the ethical belief to serve humanity in any way possible without harming the donor and keeping the dignity of both donors and recipients. Christians generally support the concept of donating in good faith and leave the decision to the individual. The Church of England has stated that organ donation is an act of Christian duty. Jehovah's Witnesses, however do not readily approve of it based on complexity of the procedure and blood transfusion involvement.

Pakistan which was a much less regulated environment leading to a boom in 'transplant tourism' there.

Pakistan and developing countries are notorious for “transplant tourism” and according to conservative estimates, up to 1,500 transplant

tourists visit Pakistan every year, second only to their neighbor, China. On an average recipient patients pay up to USD 40,000 to Clinics in Pakistan while the poor donor gets only USD 1500 to 2000⁵.

Hence, legitimacy and ethics are the two major dilemmas faced today in promoting organ donation widely. It is important to ensure that the vulnerable population is not exploited and punished, while also ensuring that the needy ones get the organs for transplants they require legally and under required medical supervision⁵.

Due to uncertain means of declaration of death, Organ transplantation also poses a bioethical issue for strong debate in Pakistan, the Muslim world in particular and world over in general³.

Keeping the above in view, in developing countries like Pakistan, the best option is deceased organ donation-the "*gift of life*". This practice needed close monitoring through legislation but there was no law to protect the donors and prevent unethical organ trade in the country until in July 2007, when media reports created hype regarding the issue as at least 10 hospitals in Lahore, Pakistan, were found involved in the black marketing of human organs. Therefore, the Supreme Court of Pakistan, gave out a ruling as a result of which the "Transplantation of Human Organs and Tissues Bill 2007" was passed in the National Assembly, to regulate the illegal, unethical organ trade in the country.

Organ Transplantation Bill 2007

The bill passed in 2007 proposes a number of strict measures; restricting organ donation only to above eighteen years, close blood relatives and put a ban on donations by those who are not genetically related to the recipients. All donations have to be evaluated by a committee of medical experts that would ensure that the donation is fully voluntary. Additionally, the bill proposes 10-years in jail for anyone guilty of trading of organs for money on a commercial basis⁶.

This led to some control on organ trafficking, however, growing demand led to a surge in black marketing of organs and people still had concerns about the religious connotations of donation. When the Federal Shariat Court (Religious Court) dismissed the allegations to the bill in 2008 and the law was amicably passed by the houses of Parliament, opposition to organ donation by some religious groups faded away.

Further, the Supreme Court ruled in favor of regulating and carefully tracking organ donations and subsequent transplantations in March, 2010. It took serious action against the traffickers, and Human Organ Transplant Authority (HOTA) was established and soon 450 cases of organ trade were captured in the villages of Punjab. Since then, HOTA Federally and its branches provincially keep checking organic trafficking strictly⁷.

Myths and Facts About Organ Donation in Pakistan

One of the key factors that is a major barrier to organ donation is high prevalence of myths. Some of the common myths are listed in table-II.

Recent Developments in Pakistan

Pakistan has been striving to develop the infrastructure for successful organ donation from both live and deceased donors. The lack of infrastructure is the biggest hurdle after formulation of the law and clarity from the shariyah court (the religious law and ruling). Organ donation has been legally practiced in prominent Muslim countries like Saudi Arabia, Iran, Lebanon, Malaysia, Bangladesh and now Pakistan.

The Islamic Fiqah Council, held in the fourth conference in Jeddah, Kingdom of Saudi Arabia, stamped approval on tissue and organ donation, drawing roots to the medical research and fiqahi that one person can be benefited from the body parts of other living or dead person⁸.

In recent years, Pakistan has emerged as a safe, reliable and ethical environment for organ donation. In this regard, following centers in different regions of the country are providing services of organ transplantation:

- SIUT, Karachi
- AFBMTC, Rawalpindi
- Transplant unit, Shifa International Hospital, Islamabad (Successfully conducted 650 living donor liver transplants)
- Agha Khan, Karachi
- Doctor's hospital and Medical Center, Lahore
- Pakistan Kidney and Liver Transplant Institute (PKLI), Lahore

Strategy for Community Penetration to Promote Organ Donation

Every child should be given the freedom to live with an aspiration and a firm belief that "I can save lives even after I am gone". This can be achieved with the help of mass media by the depiction of organ donors as national heroes and bearers of honor, eventually increasing the number of potential donors in the deceased donor registry program.

Key Strategies to Embed The Culture of Organ Donation in Pakistan Include

1. Efforts to Increase Knowledge:

A prominent indication from the study by Saleem *et al* (2009), states that knowledge regarding the donation of organs has a significant correlation with level of education ($p=0.00$). Second indication was correlation with socio economic status ($p=0.038$). Both of the factors were found to be independent predictors of organ donation. Another factor that was found to be the independent predictor was the realization that donation of organ is acceptable in religion (p -value <0.05)⁹.

Moreover, a study done on awareness of medical students about organ donation reveals that about 50% of the students lacked the knowledge and awareness on organ donation. Large cohorts of the study participants were unaware of the religious rulings and national laws on the subject¹⁴.

Therefore, major investment needs to be done by increasing awareness on the subject.

2. Symposia and Seminars:

It has been observed through media campaigns, drives, research and studies that organizing symposia can address the doubts and questions young potential donors have at university level. Universities can provide a platform for discussion of practical problems of transplantation including ethical, medical, legal and social aspects.

3. Inclusion of Organ Transplant Related Bioethical Issues in High School, College, University Curriculum:

It's imperative to include such educational material at least at high school level and university level through academic teaching, dramas, art and theatre etc. to promote the registry of potential donors and develop the culture of organ donation in the country.

4. Mass Media Interventions:

Media, especially Social Media is proving to impress and engage people of all ages and walks of life. Hence, is an ideal tool to promote organ donation.

Using a theatre drama, a motivational video, adverts, vlogs and blogs, can bring a substantial change.

In addition, vigorous campaigning, involving film stars, cricketers and other celebrities can be a huge attraction for young potential donors as proved by some of the SIUT organ donation drives².

By showcasing successful donations in the past, bringing light to the thousands of lives, saved and enriched by donors, we can inspire heroes in the future. A great example can be the symbol of humanity, Mr Abdul Sattar Edhi, a renowned philanthropist and corneal donor in Pakistan, whose love for mankind extended beyond his worldly life. Others are inspired by international celebrities like Lady Diana who was also an organ donor.

One of the registered deceased donors said: "You die knowing you could help save someone's life"¹⁰⁻¹⁵.

5. Promote Deceased Donor Program:

There are so many who wish to donate but their families are unaware of the fact. Consequently, in case of accidental deaths or otherwise the decision lies in the hands of the family, and yet another potential donor is lost.

Nearly all institutions / hospitals offering transplants and management of complications, promote Deceased Organ Transplant but very few have been successful in attaining reasonable registrations, and finally using those organs for successful transplants. Universities like NUMS and the like, that have a specialized institute like Bone Marrow Transplant Center/Tissue Banks, can actually devise programs to reward donors or engage medical students in such surgeries and post-operative wards to promote donor registration¹⁶⁻²⁰.

Through Universities, if this preposition is floated and projection of successful cases like Edhi, are highlighted in the youth, it can increase enthusiasm and serve the cause.

Liaising with active organizations working for organ transplantation and helping in collaborative efforts for establishing programs by agencies, scientists, physicians and health personnel can enhance the ethical practices of organs donation.

6. Care of Living Donor:

Mostly, living donor is at loss and not provided ample support after organ donation, therefore, potential donors become skeptical. To remove this apprehension, upgraded medical facilities can be provided by university-government-industrial linkage²¹⁻²⁴.

7. Post-operative And Transplant Rejection Complications:

This is one of the major demoralizing factors in transplant stories. Which can be overcome through connection of Industry and government by investing in infrastructure development. Research universities like NUMS along with its specialty institutions can be a perfect nurturing ground to cultivate the concept of Organ

Transplant in Pakistan for a mutually benefitting situation for all.

Future Plans

Our first part of research revealed through this literature review that university involvement is an important milestone in removing barriers and spreading awareness on the subject which can later lead to tapping into involvement of industry to improve infrastructure. When youngsters, well-informed about the importance of this critical issue, will become a part of the dynamics of the health care industry, they will be stakeholders and advocates of organ donation and will eventually remove the barriers.

Later, university platform will be used as primary productive forum for implementing key strategies to embed the culture of organ donation among the local populace. Tools / metrics will be devised to quantify change in perception/attitudes toward organ donation at the provincial and university levels.

CONCLUSION

The above mentioned strategies can be unified into a single framework- 'the quadruple helix model', which comprises of Academia, Government, Industry (Health Care) & Community, for advocacy / support that can directly influence domestic understanding in favor of organ donations.

This can play a role in changing behavior/s and propagating voluntary registration as organ transplant donors as well as bringing improvement in the healthcare system to make it conducive to maximize use of the deceased donor organs, as most of them go wasted because of lack of availability of ventilators to brain dead donors.

Although it is the government's responsibility to provide infrastructure, affordable health-care, and legislation regarding organ donation; participation of community, academia and industry, can share the burden and bring improvement in society as well as in health care systems.

CONFLICT OF INTEREST

This study has no conflict of interest to be declared by any author.

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