

Obstacles to the deceased donor transplantation in Pakistan

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ABSTRACT

Introduction Transplantation in many Asian countries is moulded by socioeconomic, religious, cultural and health indicators. In most Asian countries, the living-related donation is the common most organ donation. Due to the limited deceased organ donation, live donor programmes flourished in many Asian countries. Another apparent reason for this tremendous growth of living-related programmes in Asian countries is their larger serving population. Several centres from Asia, including Pakistan and India from Southeast Asia and Egypt in Middle East Asia, on the one hand, have recently emerged as leading living donor transplant programmes. On the other hand, a few Asian countries, including Iran and China, have established some of the world's largest deceased donor programmes.

Discussion In Pakistan, thousands of patients die from end-stage organ failure annually, seeking organ transplants for survival. The exact statics are not available, but over 50 000 people are estimated to die each year as a result of end-stage organ failure without getting a transplant, about 15 000–18 000 from kidney failure, and 10 000 from liver failure and the National Centre for Health Statistics labelled organ failure as a leading cause of death. Despite all these efforts, the knowledge of organ donation among Pakistani people was determined to be around 60%. In Pakistan, the lack of deceased organ donation programmes and the unwillingness of people to deceased organ donation contributes to an increased demand for living organ donation and patients continue to rely on living donors. We discuss various obstacles to deceased organ donation comprising various challenges that form a unique combination, including religious, economic, social, demographic and political factors.

Conclusion: Every single effort should be made to initiate and establish multiple deceased donor programmes in Pakistan. Developing the deceased donor programmes in the country will be vital to counter the countrywide increasing organ shortage. The mainstay transplant activities like organ procurement and distribution systems need to be adequately developed. It will help achieve national self-sufficiency and decrease living donors' burden. With education, the behaviour of healthcare professionals and common people can be changed and a positive attitude toward deceased organ donation can be obtained. As healthcare professionals, we should come forward and take responsibility by enrolling ourselves in deceased donors' registration. Public awareness, medical community interest and government support are essential

in initiating and establishing deceased donor programmes in Pakistan.

INTRODUCTION

Transplantation in many Asian countries is moulded by socioeconomic, religious, cultural and health indicators. In most Asian countries, the living-related donation is the common most organ donation.¹ Due to the limited deceased organ donation, live donor programmes flourished in many Asian countries.² Another apparent reason for this tremendous growth of living-related programmes in Asian countries is their larger serving population.³ Several centres from Asia, including Pakistan and India from Southeast Asia and Egypt in Middle East Asia, on the one hand, have recently emerged as leading living donor transplant programmes.^{4,5} On the other hand, a few Asian countries, including Iran and China, have established some of the world's largest deceased donor programmes.⁴

In Pakistan, thousands of patients die from end-stage organ failure annually, seeking organ transplants for survival.⁶ The exact statics are not available; however, the annual need for various organs in Pakistan is: kidneys 25 000, livers 100 000, hearts 7000, pancreas 2000 and lungs 2000. The living organ donation programmes in the country have failed to cover the growing burden of end-stage diseases.^{7,8} In Pakistan, the National Centre for Health Statistics labelled organ failure as a leading cause of death.⁹

Due to this grave situation, an ordinance was passed in 2007, allowing deceased organ donation in Pakistan.¹⁰ Over time, the Transplantation Society of Pakistan was also founded to promote and address the various aspects of deceased organ donation by conducting awareness conferences and seminars.¹¹ Despite all these efforts, the knowledge of organ donation among Pakistani people was determined to be around 60%.¹² In Pakistan, the lack of deceased organ donation programmes and the unwillingness of people to deceased organ

donation contributes to an increased demand for living organ donation.⁶

One decade ago after the first successful deceased donor liver transplant in Pakistan, patients still rely on living donors only. Developing the deceased donor programmes in the country will be vital to counter the countrywide increasing organ shortage.⁶ Unfortunately, after 15 years of authorisation of the deceased organ donation law, no single active donor transplant programme is in place in the country. The gradual shift from living to deceased donor transplantation will be only possible if constant and effective efforts are put in place for deceased organ donation development. In the future, deceased donor transplantation may replace living donor transplantation and become Pakistan's predominant form of transplantation.

OBSTACLES TO DECEASED DONOR TRANSPLANT PROGRAMMES IN PAKISTAN

The various obstacles to deceased organ donation comprise various challenges that form a unique combination, including religious, economic, social, demographic and political factors.

RELIGIOUS

The biggest dilemma is the widespread Muslim belief in the myth that the post-death human body should not get physical harm. Deceased donation is considered an unholy act among Muslims. That is why, deceased organ donation did not gain popularity among Muslims globally.¹³ Pakistan is a major Muslim living country and most Muslim faiths in the country do not encourage deceased organ donation. These religious beliefs are the barriers to deceased organ donation in the country.⁸ Despite the efforts of Islamic scholars globally, the local religious leaders in the community are not an advocator of deceased organs and hence do not promote deceased organ donation which is why the majority of the Muslims in Pakistan are reluctant to deceased organ donation.¹⁴

A historic recommendation was made keeping in view the Fiqha and medical knowledge by the Islamic Jurisprudence Assembly Council in Saudi Arabia in 1988, approving the deceased organ donations.¹⁵ A similar constitution was also passed in Pakistan in 2007, which allows everyone over eighteen years to write a donation statement advance of their death if agree to organ donation, which will be duly signed, by the person and Evaluation Committee, which will verify it and may also assign a hospital recognised by the transplantation monitoring authority. This donation can be revoked by the donor at any time during his or her lifetime.¹⁶

SOCIAL FRAMEWORK

Pakistanis, like other Asians, value family. Majorities of people in Pakistan live in joint families. Although living in joint families is declining with urbanisation in Pakistan,

still people keep close contact with their families. So, it is relatively easier to get a suitable family live donor in Pakistan. It is one of the other significant hurdles to developing deceased donor transplantation in Pakistan, like other neighbouring countries. Similarly, a lack of motivation and a lack of activities in community social support groups have resulted in low awareness among the general population.¹⁷

LIMITED HEALTH RESOURCES AND LACK OF DDLT INFRASTRUCTURE

The infrastructure requirements of living and deceased donor transplant programme initiatives are significantly different. Establishing a living donor transplant programme requires trained staff and a fully equipped multispecialised hospital. However, the deceased donor transplant programmes need substantial shifts in the overall healthcare system and require a core hospital setup with adequate and necessary resources, including well-equipped neurosurgery and cardiac setups. Moreover, the need for emergency/trauma care facilities and intensive care services in hospitals is vital for establishing successful deceased donor transplant programmes in the country.¹⁸

The hurdles to initiating and establishing deceased donor programmes in the country include a lack of healthcare resources and facilities, poorly developed medical infrastructure, low healthcare spending and non-trained medical professionals.^{9 18 19}

In Pakistan, the number of specialised hospitals is limited, and the majority of hospitals lack proper neurosurgery, emergency/trauma care facilities and intensive care units, which make the foundation for deceased organ donation programmes. Many government hospitals practice a good volume of trauma and neurosurgery, but they lack either intensive care units or specialised organ donation units and transplant programmes. Few institutions are offering transplant services and are promoting deceased organ transplantation, but no major success has been achieved to date. Also, no specialised protocol for hospital admission is developed to screen for potential organ donors. Similarly, unmanaged hospital deaths, shortage of ventilators, lack of optimal organ procurement and storage facilities, lack of emergency organ transportation facilities, lack of organ and tissue banks, under-reporting and lack of knowledge regarding deceased organ donation process among the willing organ donors.¹⁸

Recently, a few centres in Pakistan have emerged for the provision of living donor services, which includes Pir Abdul Qadir Shah Jeelani Institute of Medical Sciences, Gambat; Shifa International Hospital, Islamabad; Pakistan Kidney & Liver Institute and Research Centre, Lahore; Dow Civil Hospital, Karachi; Sheikh Zayed Hospital, Lahore and Quaid-e-Azam International Hospital, Rawalpindi.²⁰ These hospitals have already established neurosurgery and intensive care units and they can be used to

initiate deceased organ programmes. These institutes having a specialised setup like bone marrow transplant centres/tissue banks can devise programmes to reward donors

EASE OF AVAILABILITY OF INTERNATIONAL LIVING DONOR TRANSPLANTATION WITH NON-RELATIVE DONOR

In Pakistan, close family members and ideally first-degree relatives are given preference to donate to their patients. Extensive and detailed documentation is done before the transplant procedure.²¹ However, neighbouring countries may have less strict policies and regulations.¹⁷ No matter the local rules and policies about transplant tourism, international Living-Donor Liver Transplantation (LDLT) is still a big way to facilitate patients from Pakistan. The patients are offered transplant procedures with non-relative donors in neighbouring countries. The easy availability of this option and the increasing local LDLT programmes may retard the growth and development of Deceased-Donor Liver Transplantation (DDLTL) programmes in the country.²²

Lack of knowledge about the brain death concept

The current status of brain death and deceased organ transplantation in the Islamic world has shown heterogeneous form. There is no consensus among Muslim scholars all around the globe over the brain death concept. The main reasons are confusion regarding the coma state and fear of speeding the death process. In 1986, a resolution was passed in Amman during the third International Islamic Jurists conference, which addressed the brain and cardiac deaths practically the same.²³ In 2000, Iran passed the 'Organ Transplantation and Brain Death Act', which legalised donation after brain death.²⁴ Religion may significantly influence people's behaviour and attitude toward brain death and organ donation.

Lack of education and public awareness and the attitude of healthcare professionals

In Pakistan, as in many other underdeveloped nations, lack of education and ignorance appears to be the primary barriers to deceased donor donation. In 2005, a local study was conducted by Ashraf *et al* regarding the common person's knowledge about organ donation. They reported that around 65% of people had knowledge of organ donation in Pakistan, while 60% were willing to donate their organs. They observed that people's socio-economic status and education adversely affected their knowledge about organ donation. Also, the awareness of organ donation and knowledge that organ donation can save needy people's life was associated with willingness to donate.¹²

Similarly, Khan *et al* also conducted a study to ascertain people's attitudes and knowledge toward organ donation. According to their findings, only 27% of Pakistani citizens were aware of the law regarding organ donation. They advocated for a multi-modal approach to promote awareness in the community toward organ donation with

the involvement of religious scholars, medical professionals, teachers and the media.²⁵

Lack of education and cultural, traditional beliefs and social reasons are among the top reasons for the lack of public awareness regarding deceased donor organ donation in Pakistan, like many other developing countries.^{6,26} One of the other obstacles to developing deceased donor programmes in Pakistan is the attitude of medical staff.²⁷ This thing has been observed in other countries as well.²⁸

Lack of interest of stakeholders, poor economy and lack of legislation

The lack of interest and apathy of the country's stakeholders are also contributing to the delaying establishment of deceased donor programmes in Pakistan. Till now, none of the ruling governments has taken commendable steps for promoting the deceased organ promotion.^{7,9} The other reason for this delay may be the economic downfall of the country and financial constraints as economic instability is the major problem of the country for the last two decades.¹⁸ Moreover, unfortunately, in Pakistan, like most other Islamic countries, the lack of legislation and implementation of the legal verdicts are still not paving the way to deceased donor transplantation. Similarly, geographical remoteness and patient apprehension may contribute to this.¹⁰ The radical shift will be challenging and will require government funding and assistance.

WAY FORWARD TO ESTABLISH A SUCCESSFUL NATIONAL DECEASED DONOR PROGRAMME IN PAKISTAN

The multiple factors for developing successful deceased organ donation, like infrastructure, legislation and community education, need comprehensive development in Pakistan. The mainstay transplant activities like organ procurement and distribution systems need to be adequately developed. The engagement of stakeholders in making and establishing protocols and guidelines is vital for good practices and the development of transplant services.

There is also a need for legislation aiding the development of the deceased donor programme. The deceased donor donation is a good alternative and has the best potential to expand the donor pool; however, there is a problem with its acceptance. Further changes in the legal framework may be helpful. One of the few proposals will be an amendment in transplantation laws, like moving toward presumed consent instead of informed consent may be more beneficial for developing deceased donor programmes.

Similarly, the healthcare professionals' knowledge and attitudes play a critical role in establishing a successful programme. Similarly, improving the education system by inclusion of organ transplant related bioethical issues in high schools, college and university curricula is the key to developing a strong foundation for deceased organ donation awareness over the upcoming years in



Pakistan. Similarly, educating the people through art, dramas, theatre, electronic messaging and social media campaigns with motivational videos, adverts, vlogs and blogs will improve the knowledge of people regarding deceased organ donation.

The next step would be redefining the 'concept of death', as it is the most controversial and debatable topic regarding religious and legislative perspectives. Local consensus on the definition of brain death and the correct meaning of cardiac and brain death is needed.

In countries like Pakistan with undeveloped deceased donor transplant programmes, Islamic scholars' support and guidance should be achieved to increase public awareness in a religion-dominating country like Pakistan. Organ donation should be promoted keeping in view the Islamic faith. This can be performed nicely in light of given Islamic fatwas, and Quran teachings as The Quran verses 'Whosoever saves the life of one person, it would be as if he/she saved the life of all mankind'. Local campaigns at mosques to provide information to the public are recommended.

Religious scholars, medical professionals, government officials, social activists and influential social media activists in the country should highlight the benefits of deceased organ donation. They should play their role in the active campaign regarding deceased donor awareness in the general public and the medical community. To increase awareness regarding deceased organ donation and transplantation, investment in the current organ donation models, action through governmental legislation and active use of media and technology are the keys. The transplant community must launch an ongoing public education campaign to change public opinion about organ donation and gain wider social acceptability. Achieving the national self-sufficient deceased donor programmes does require government support and commitment, medical professionals' active involvement and community efforts.

Moreover, epidemiologic studies should be conducted on the spectrum of liver and kidney diseases presenting for transplantation. Prevention measures planning will lessen the overall disease burden on the transplant waiting list. Furthermore, there is a much need for a central national transplant registry to provide necessary information on disease aetiology, patients' socio-demographics, risk factors, treatment modalities and outcomes.

It will be a more practical way to start deceased donation programmes in the country in larger multispecialised hospitals actively performing living donor transplantation and practicing a large volume of neurosurgery and trauma surgery.

Also, as healthcare professionals, we should come forward and take responsibility by enrolling ourselves in deceased donors' registration. We should set an example for others. This action will significantly impact and serve as a motivational source for the public.

Moreover, research scholars and medical students should also play an integral role in this regard. No one

can neglect their role in increasing awareness campaigns. These measures and efforts can decrease Pakistan's broad deceased organ donation gap. In addition, sports persons, film stars and other celebrities can attract people especially young potential donors through vigorous campaigning.

In short, deceased donor transplantation establishment in the country needs government support along with the support of healthcare professional associations, civil society organisations, media and religious leaders. A better understanding is also needed regarding 'brain death'. The provision of healthcare infrastructure, and legislation regarding organ donation along with the participation of the community, academia and industry, can share the burden and bring improvement in society as well as in healthcare systems.

CONCLUSION

Every single effort should be made to initiate and establish multiple deceased donor programmes in Pakistan. The role of the government, education department, healthcare industry and community in advocacy and support of deceased organ transplantation development in Pakistan is vital. It is the government's responsibility to provide infrastructure, bring improvement in the healthcare system, provide affordable healthcare, and provide legislation regarding organ donation. Public awareness through education and community/social and religious organisations' involvement can change domestic understanding, and people's behaviour and can propagate voluntary organ transplant donors' registration. At last, the goal cannot be achieved without the active participation and interest of the medical community.

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