

## **Human Organ Transplantation: Psychosocial Considerations of Recipients**

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**Abstract:** Transplantation of solid organs saves lives of the many organ failure patients who are left with no other option of treatment, but transplantation, to get over their illness. The method of harvesting the organ from a living or dead person and transplanting it to a different living individual is so complex that the donor, the recipient and their families bear experiences that not only require intensive medical management but also psychosocial care. The article presents review of psychosocial problems with patients in need of organ transplantation.

**Keywords:** Organ, transplantation, psychosocial, considerations of patients.

**Introduction:** Organ transplantation has been a successful therapy for end-stage organ failure. The Transplantation of Human Organs and Tissues Act-1994 permits transplantation of solid organs within the following categories: Living Related Transplantation where organs are obtained from living donors who voluntarily donate organs, primarily, to the relations or near relatives; Living Un-related Transplantation within which organs are donated by living donors to patients apart from near relatives

with the approval of authorization committee for the hospital; Swap Transplantation that involves a paired exchange of organs between two families, who cannot donate organs to their family member due to biological incompatibility or mismatch. Swap transplantation also needs approval from authorization committee; and Deceased Donor Transplantation within which organs are retrieved from brain-stem dead persons who had pledged or expressed the wish for organ donation while alive or whose family has consented for the organ donation upon their death.

### **History of Organ Transplantation in India**

The organ transplantation in the country began around sixty years back. The first successful kidney transplantation was performed at Christian Medical College, Vellore in 1971.<sup>[1]</sup> The first heart and heart-lung transplantation took place in 1994 at AIIMS, New Delhi and Apollo Hospital, Chennai.<sup>[2] [3]</sup> The first successful liver transplantation was done in 1998 in Apollo Hospital, New Delhi<sup>[4]</sup> and first combined pancreas and kidney transplantation was performed in 2004 at AIIMS, New Delhi.<sup>[5]</sup> The first intestine transplantation in 2012 at Medanta Hospital, Gurugram;<sup>[6]</sup> first hand transplantation in 2015 at Amrita Hospital, Kochi;<sup>[7]</sup> and first uterus transplantation in 2017 at Galaxy Hospital, Pune<sup>[8]</sup> are the recent developments in the field of transplantation.

### **Shortage of Organs**

The transplantation scenario in our country presents two important facts. First, the advancement within the field of transplantation has offered opportunity for several terminally ill patients to measure an extended and quality life. Second, the need of organs for transplant has surpassed their availability resulting in the acute organ shortage. Around 220,000 people require kidney transplantation in India.<sup>[9]</sup> Approximately 25,000 patients need liver transplantation annually in India.<sup>[10]</sup> In 2018, 7936 kidney, 1945 liver, 241 heart, 191 lung, 25 pancreas, 14 combined kidney-pancreas and 02 small bowel transplantation surgeries were performed at different transplant centres in the country.

[11]

**Psychosocial Issues**

Mostly, organ transplantation is taken into account as the last option for those terminal patients whose illness can now not be cured by the other medical or surgical intervention. Except renal patients who have option of dialysis, other prospective recipients of heart, lung or liver transplant face two options: probable death due to their disease or the potential life-sustaining intervention of an organ transplant; the critical word here is potential, because it's not uncommon for the recipient's body to reject the donated organ. Hence, when transplant is obtainable as a viable option of treatment, the patient, despite high level of risk, may feel optimistic that he or she will again lead a standard life. Generally, recipients outnumber donors, so criteria should be laid all the way down to determine the suitability of a patient for a transplant.

Patients accepted into a transplant program must meet both the medical and psychosocial criteria for inclusion. The goal of a psychosocial assessment is to gauge the patient's emotional status and network with a view to predicting his or her ability to deal with the transplant program and its subsequent lifetime regimentation of medicines and medical oversight. Also, it's important to spot areas within which the patient may require assistance.<sup>[12]</sup> Specifically, the patient is assessed for previous medical compliance, previous reactions to major stress, education and work history, coping behaviors, existence of mental state, habit, finances, interpersonal relationships, and therefore the integrity of the nuclear family. <sup>[13]</sup> The psychosocial assessment is taken into account critical because of the scarcity of organs and also the have to find patients who are ready to maintain their transplanted organs and who won't defeat the transplantation procedure by neglect, drug use, or noncompliance of their treatment regimen. <sup>[14]</sup>

**The Waiting Period**

The patient who meets the medical and psychosocial criteria is placed on an organ transplant waiting list. In order to ensure the viability, organs need to be transplanted as early as possible. In cardiac transplantation, the heart has to be transplanted ideally

within a short interval after the retrieval. In the country, most of the transplant centres are situated in big metropolitan cities, therefore, for patients residing at distant places, relocation near the hospital may be required so that the patient is able reach the hospital at a short notice when an organ becomes available. This might cause emotional stress, social disruption and financial burden to the patient and the family because of incurring the expense of maintaining two households, removing children from school, and so forth. The waiting time could even be from some days to weeks to months, looking forward to the organ and availability. Although the sickest are first within the priority for an organ, the sad reality is that too often, patients die before an organ becomes available. Thus, additionally to the strain of waiting and having to position their lives on hold at a moment's notice, the patient and family must accommodate the anomaly of the simplest result while the patient's condition continues to deteriorate, often requiring hospitalization and further life and family disruption. <sup>[15]</sup> The relocation can bring a significant change in the life of caretaker in terms of errands, child rearing, work and social commitments. The waiting stage is "immersion" because the caretaker becomes completely immersed in efforts to keep the patient alive. All cognitive activity is directed towards planning for the patient's welfare; all affective activity would be a reflection of the patient's emotion. The caretaker finds this immersion extremely stressful. <sup>[16]</sup> At this stage, interventions on a component of the healthcare team may involve providing information about the temporary shelters, their locations and rentals; tapping community resources free or subsidized accommodations; orientation and education on hospital and transplant procedures; assessing patients emotional level and social support; and individual and/or family counseling and group therap. <sup>[12][17][18]</sup>

Once an organ has been procured, the patient is admitted to the hospital to await the scheduled transplant. While awaiting the transplant, patients and members of the family experience an honest range of emotions, from relief that the transplant is admittedly and eventually happening, to fear of death and dying. Many patients and their families

believe that each and every medical problem will cease after the transplant has taken place. Initially, patients and members of the family experience a renewed hope because the long wait is over and new life is on the way to begin. However, the actual fact is that a transplant isn't a cure but a treatment for the disease and it comes with many life changes including side effects of lifelong transplant medications, the threat and fear of the likelihood of organ rejection and also the requirement for an extra organ, and thus the haunting memory of the pre-surgical and surgical experience. <sup>[14]</sup>

### **Life after Transplant**

The transplant surgery takes while and also the recovery trajectory is tense and physically demanding. After transplant, the patient is shifted from OT to an ICU. This is often a critical time because the patient is medically unstable and the viability of the transplant is uncertain. Once the organ begins to function and also the patient begins to heal, he or she is moved off the treatment unit to a ward. The family needs thorough support. <sup>[12]</sup> Immediate post-transplant phase brings euphoria or a honeymoon period for the patient and family. The threat of possible death disappears; there don't seem to be any further symptoms of illness and associated feelings of helplessness; and thus the patient feels the advance that the transplanted organ has delivered to his or her body. <sup>[13]</sup> The initiation of lifelong immunosuppressive drugs that serve to stay the body from rejecting the new organ can bring bouts of irritability, paranoia, and depression for the patient, together with other natural reactions to surgery.

Two outcomes are possible at this immediate post-transplant stage: either the patient responds positively to the immunosuppressant drugs and begins to heal or there's a rejection episode. In the event of rejection, the body fights the invasion of a foreign organ (the organ of the donor) and defeats it, rendering the organ inoperable. This will be a serious setback and might even be fatal to the patient. It can mean that another transplant must be considered; heroic medical intervention is initiated to stay the patient viable to

simply accept another organ, should it become available. Needless to mention, the patient and family are devastated at this turn of events.

As the patient begins to emerge from the treatment phase of the transplant experience, support from family is central to his or her emotional well-being. As in many medical situations, family and friend support incorporates a buffering effect on the experience of a critical illness. They assist the patient feel cared for and in some instances, literally help in the hospital because nursing staff is sometimes ineffectual to meet the necessities of the patient. In hospital, the patient is surrounded by medical and para-medical staff that's available round the clock to manage any complexity and ensure his or her safety all the time. Post-transplant discharge from the hospital is extremely emotional time. Family caregivers could even fret about their ability to manage the patient's care reception and other concerns like finances and also the quality of life for recipient and family begin to surface that were not considered when the transplant was discussed. <sup>[19]</sup>

There are several areas of potential psychosocial problems in post-transplant adjustment for the patient: problems related to the organ, self-concept, illness, family and job, finance, and ability to cope. <sup>[13]</sup> Organ-related problems include feeling like a different person, feeling unworthy of the donated organ, and feeling guilty at being alive at the cost of a donor's life. Changes in physical appearance because of the side effects of the immunosuppressant medications (swelling, hair growth, weight gain) and loss of self-esteem are common. Possibility of organ rejection may escalate level of anxiety and depressive symptoms. Strict following of the medical regimen and acceptance of one's chronic medical condition are the illness-related concerns. Family-related problems revolve around communication in asserting and redefining roles and standing, and job related concerns revolve around productivity, performance, and finding and maintaining employment. Finances are often strained by unaccounted and uninsured medical expenses with the escalating costs of medication. Coping capacity is affected to the extent that patients and families find it difficult to handle stress, reduced social contacts, and

disabled social interaction. Of course, some recipients will handle many of these areas easily, whereas for other recipients it will be more difficult. <sup>[13]</sup>

Intervention through individual and family counseling sessions in which feelings are validated, and shared among family members, shall be initiated. Support groups for post transplant recipients and their families may offer an ideal platform for the discussion of these and other transplant-related concerns. Empathy, emotional support, encouragement, faith and hope should be major elements of psychosocial intervention at this stage. <sup>[17]</sup> The intervention may require intensive casework; marital counseling; reinforcing coping strategies; highlighting personal strengths; environmental manipulation; advocacy; and referral services.

**Conclusion:** Organ transplantation is quite new in India as compared to several other western countries. Many strides have been made in different parts of the country for the development of this therapy in the management of organ failure patients. The demand of organs surpasses the availability. The process of transplantation goes through several phases. At every stage, the patients and their families come across several psychosocial hardships that impede their functioning. The active management of these social and psychological issues results in better transplant outcome.

### References

- [1] Singh NP and Kumar A. Kidney transplantation in India: Challenges and future recommendation. *MAMC J Medical Sciences* 2016; 2: 12-17.
- [2] Venugopal P. The first successful heart transplant in India. *Natl Med J India* 1994; 7: 213-15.
- [3] Sundar et al. Lung transplant: The Indian experience and suggested guidelines – Part 1 selection of the donor and recipient. *Journal of the Practice of Cardiovascular Sciences* 2018; 4(2): 88-95.

- [4] Narasimhan G. Living donor liver transplantation in India. *Hepatobiliary Surg Nutri* 2016; 5(2): 127-32.
- [5] Guleria et al. The first successful simultaneous pancreas-kidney transplant in India. *Natl Med J India* 2005; 18(1): 18-19.
- [6] Soin et al. India's first successful intestinal transplant: The road traveled and the lessons learnt. *Indian J Gastroenterol* 2014; 33(2): 104-13.
- [7] Iyer et al. First two bilateral hand transplantations in India (Part 1): From vision to reality. *Indian J Plast Surg* 2017; 50(2): 148–152.
- [8] Srinivasan S. Uterus transplants in India: yawning regulatory gaps. *Indian Journal of Medical Ethics* 2017; 2: 135-37.
- [9] Shroff S. Current trends in kidney transplantation in India. *Indian J Urol.* 2016; 32(3): 173–174.
- [10] Soin AS. Liver transplant scene in India. *MAMC J Med Sci* 2016; 2(1): 6-11.
- [11] Global Observatory on Donation and Transplantation. (2018, <http://www.transplant-observatory.org/> accessed on 25 June 2020).
- [12] Bright, M. (1994). Social work practice with organ transplant patients. In: M. Holosko & P. Taylor (Eds.), *Social work practice in health care settings* 2nd ed. Toronto: Canadian Scholars' Press, 1994 pp 441–452.
- [13] Dhooper, S. *Social work and transplantation of human organs*. Westport, CT: Praeger, 1994, p74-75.
- [14] Zilberfein F, Hutson C, Snyder S et al. Social work practice with pre- and post-liver transplant patients: A retrospective self-study. *Social Work in Health Care* 2001; 33(3/4): 91–104.
- [15] Bohnengel A. Coping with kidney transplantation. *Perspectives* 1983; 5: 5–16.
- [16] Mishel MM and Mardaugh CL. Family adjustment to heart transplantation: Redesigning the dream. *Nursing Research* 1987; 36(6): 332-38.

- [17] Suszycki et al. Social workers' responsibilities in heart transplantation programs. *Progress in Cardiovascular Diseases* 1990; 23(1): 35-48.
- [18] Christopherson LK. Cardiac transplant: A psychological perspective. *Circulation* 1987; 75(1): 57-62.
- [19] Jones J. and Egan M. The transplant experience of liver recipients: Ethical issues and practice implications. *Social Work in Health Care* 2000; 31(2): 65-88.

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