Socio Economic Rehabilitation of Solid Organ Transplant Recipients

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INTRODUCTION

Socio Economic Rehabilitation is an important outcome parameter in successful organ transplant recipients particularly in developing countries with low income patients who have to depend on extraneous sources to fund the operation costs.[1] It is an undisputed fact that the quality of life of a successful transplant recipient is much better than that of a patient on dialysis or poorly treated end stage renal failure patient. But often ethical questions are raised about the need for popularising such costly treatment protocols needing scarce public funding when basic public health issues like nutrition deficiencies, incomplete immunisation coverage, outbreak of communicable diseases keep occurring.[2]

Financing a transplant raises many concerns for patients and their families. The first step is developing a financial strategy figuring out how much money the insurance will bear. Most patients use a combination of sources. Most patients use the insurance coverage for the transplant procedure and other sources like savings and private funding for the medical and nonmedical costs of pre and post-transplantation. In this planning social workers can provide their advice.[3] In developing countries the health insurance coverage is very poor with large sections vulnerable to the huge catastrophic expenses involved.[1,12]

Kerala experience

In the initial years the recipient patient and their families had to depend on social groupings to collect money for them from philanthropists to fund the evaluation procedures and the surgical procedures. Now many State Governments provide funding for hemodialysis and the transplant procedure to help these hapless families. The Kerala State Government has conceived the Karunya Benevolent Fund raised from the sale of Karunya lottery tickets to exclusively fund the treatment expenses of several chronic illnesses like cancer, burns, organ failure and transplantation. Karunya Benevolent Fund provides financial assistance to underprivileged patients suffering from serious ailments like cancer, hemophilia, serious kidney and cardiac aliments and for palliative care.[4] The scheme operated by the Finance Department allots money based on recommendations from the treating physicians and is operable in Government hospitals and selected private hospitals. The scheme allots assistance for both dialysis and renal transplant procedures in the form of allotments directly paid at the service point and not as money which could be misused. It is observed that this financial help has lifted a huge burden off the recipient family. Private enquiries have revealed that often other sources are not needed if the procedures take place in Government centres. Thus these families do not have to refuse transplant for financial reasons. In addition funds are available from the Chief Minister's Fund, the local Member of Parliament's Fund, and the local Member of Legislative Assembly's Fund and from the Local Self Government institutions.

Patient Assistance Program of the American Transplant Foundation offers two types of grants, one for the living donors and one for transplant recipients.[5] The program is designed to provide lifesaving monetary assistance for the most vulnerable patients with significant financial hardship. This aims to provide support so that they will not be in financial hardship after giving the Gift of Life. The program provides emergency financial assistance grants to transplant recipients and living donors regardless of their legal status and is the only program available nationwide in USA.

The US Federal Government provides financial help for treatment of kidney failure. In 1972 the US Congress passed a law that allows most people with kidney

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failure coverage by Medicare. In 2011 the average cost to Medicare per person was $88,000 for hemodialysis, $71,000 for peritoneal dialysis and $33,000 for the transplant procedure.[6]

Several other organisations provide financial help for the patients. National Kidney Foundation helps dialysis patients and offers assistance to kidney transplant or dialysis patients with outpatient medications and other expenses.[7] The Bone Marrow Foundation's Lifeline Fund provides financial assistance to help cover the costs of transplant related expenses. The program also leverages social media to allow others to learn about the needs of children and adults undergoing a transplant and make a direct contribution to their care.[8] American Liver Foundation has released an exhaustive document American Liver Foundation Support Guide for facilitating medications, transportation and transplant assistance.[9] This also helps to connect to other organisations that either have financial assistance programs or connect patients to other resources so they can access affordable care.

Post-Transplant Scenario

Several studies have been done to measure the full range of costs and benefits of these therapies to the individual recipients, their families and the society at large. This call to examine quality of life is due to the increasing prevalence of more types of transplantation which has become possible with better transplantation technology and immunosuppression. Increasingly psychosocial, psychiatric and ethical aspects are being considered.[10,11]

In a developed country, successful kidney transplantation is associated with considerable improvements in survival and quality of life, positive psychosocial outcome as well as significant cost savings when compared with dialysis. Serious global inequities in access to transplantation exist internationally. For most low and middle income countries, transplantation programs face many challenges due to the lack of infrastructure, financial constraints and lack of adequate cadaveric donor programs. Similarly, survival can also be compromised by the affordability of immunosuppressive drugs, malnutrition and recurrent infections. In India the per capita income was Rs 38,037 per annum in 2010-11 and hence only a few can afford transplant in the absence of financial assistance. A significant number of ESRD patients in India either fail to initiate dialysis, die or discontinue renal replacement therapy due to financial disability. Long term positive impact of renal transplantation is only seen in the higher social class of patients in India.[1]

One time funding support for transplant surgery had adverse impact on socioeconomic rehabilitation. This may partly be because of very high indirect costs, related to transplant like cost of dialysis during the long waiting period, cost of travel, food and accommodation for the patients and donor family members. The high cost of immunosuppressive drugs adds to significant out of pocket expenses. Loss of job, financial debt, less participation in social functions and outlook towards transplant were also different based on the social class. Financial support from different sources spread over the period from the pre-procedure workup, for the transplant procedure and for postoperative care is needed in addition to social backup and psychological support to withstand these difficult times.

Very few studies are available regarding the socioeconomic status of patients with failed renal transplantation procedures but it is likely to be worse compared to those with successful transplants. There is obviously the grim situation of the patients being back on dialysis, increasing debt, loss of livelihood, need for fresh transplantation in the near future and the threat of a psychologically depressing bleak future needing counseling.

CONCLUSIONS

Pre-transplant social strata have a significant on post-transplant socioeconomic rehabilitation. When offering transplant to underprivileged population, decision should not be taken based on emotional basis but after a careful informed decision taking into consideration the expenses and the need for continuous funding sources. 25% patients have a history of poor compliance to immunosuppressive drugs due to financial difficulties thus endangering the long term graft survival. Low public spending compounds this difficulty. Added to this is the nonavailability of health insurance for large sections especially the rural population. Xu et al identified three key preconditions for household catastrophic health expenditure in a multi-country analysis- availability of health services on payment, lack of health insurance and one time funding only being available.[12] Several Southern States like Tamil Nadu, Kerala have started a private public participatory model for sharing resources, with resultant increasing reach for the transplant services.[13,14]

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END NOTE

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