

# Knowledge, Perception and Attitude of Indian Maintenance Hemodialysis Patients toward Renal Transplantation

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## Abstract

**Background:** Chronic Kidney Disease (CKD) is a global health problem and so is the dilemma of choosing the right renal replacement therapy in end-stage renal disease. Renal transplantation undoubtedly improves the quality of life and long-term survival as compared to dialysis, but patients' choice is influenced by their awareness regarding these treatment modalities. **Objectives:** The aim of the present study was to evaluate the knowledge, perceptions and attitude of maintenance hemodialysis (MHD) patients towards transplantation. **Subjects and Methods:** Patients on MHD for more than 3 months duration were included in this questionnaire based cross-sectional study, after a written informed consent. **Results:** A total of 144 patients with a mean age of  $48 \pm 12$  years were included in the study, with 92(63.9%) males and 52(36.2%) females. Most of these had diabetic kidney disease ( $n=58,40.3\%$ ). The source of knowledge regarding transplantation were the treating doctor (76.4%), paramedical staff (9.7%), relatives/friends (11.1%) and social media/other sources (2.8%). Majority of them ( $n=100,69.4\%$ ) were willing to undergo transplantation, but had multiple reasons for continuing hemodialysis, including old age (31.8%), financial constrains (40.9%), fear of post-transplant complications (54.5%), concern for health of the donor after donation (22.7%) and various co-morbidities precluding transplantation (9.1%). Only 41.7% patient was aware of option of diseased donor transplantation, but just 11.1% were enrolled for the same. **Conclusion:** Negative attitude towards transplantation is a potentially modifiable factor and increasing awareness among CKD patients can improve their quality of life, after live or deceased donor transplantation.

**Keywords:** Maintenance hemodialysis, renal transplant, knowledge-attitudes-perception, deceased donor transplantation.

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**Received:** November 2019

**Accepted:** December 2019

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## Introduction

India with only 3% of the world's land area, is harboring 17% of its population, and sprinting fast towards being the most populous nation and also the diabetic capital of the world.<sup>[1]</sup> The incidence of chronic kidney disease (CKD) too is bound to follow suit.<sup>[2]</sup> Management of end stage renal disease not only adds hugely to the expenses for the patient, but also adds to the burden on the health infrastructure, especially if patient has to undergo maintenance hemodialysis.<sup>[1-3]</sup> The biggest challenge in renal transplantation worldwide is the wide gap in the need and availability of donor kidneys, whether live or cadaveric. However often underestimated limiting factor is the paucity of knowledge, misperceptions and negative attitude of patients towards transplantation. We did this study to analyze the knowledge, perceptions and attitude of our maintenance hemodialysis patients towards renal transplantation.

## Subjects and Methods

This cross-sectional observational study was done in a large

tertiary care centre in North India, with 25 bedded, 24 hours functional hemodialysis unit, doing almost 1800-2000 hemodialysis every month (including maintenance and acute dialysis). Only maintenance hemodialysis patients (with more than three months of dialysis vintage) were included in this study after a written informed consent. The study was approved by the institutional ethical committee. All consenting patients were requested to answer a thirty point questionnaire, with respect to the demographic data, literacy, employment, monthly income, etiology of CKD, choice of renal replacement therapy (RRT), hemodialysis vintage and frequency, reasons for their choice, their beliefs and acceptability for renal transplantation. The data was analyzed using percentages of different opinions.

## Results

The total of 183 hemodialysis patients were enrolled for the study, but only 144 patients who answered the questionnaire completely were included in final analysis. The mean age of the cohort was  $48 \pm 12$  years, and it included 92 (63.9%) males and 52 (36.2%) females. Majority of them were

educated, and self-employed or not-working. The diabetic kidney disease (n=58, 40.3%) was the most common etiology for end stage kidney disease (Table-1). Many of them were willing for transplantation (69.4%), but had chosen hemodialysis as initial renal replacement therapy in view of late diagnosis of CKD (11.8%) or urgent need for

RRT when initiated (23.6%) and many were unaware about the option of pre-emptive transplant (60.4%). Some were continuing hemodialysis in view of cost-constrain (39.6%), and many other misconceptions regarding renal transplantation [Table 2-4].

**Table 1: Baseline characteristics of the patients**

| Baseline characteristics                   | Number of patients | Percentage |
|--|--------------------|------------|
| <b>Gender distribution</b>                 |                    |            |
| Males                                      | 92                 | 63.9%      |
| Females                                    | 52                 | 36.1%      |
| <b>Age distribution (in years)</b>         |                    |            |
| <20  | 4                  | 2.8%       |
| 21-30                                      | 24                 | 16.7%      |
| 31-40                                      | 24                 | 16.7%      |
| 41-50                                      | 32                 | 22.2%      |
| 51-60                                      | 34                 | 23.6%      |
| >60  | 26                 | 18.1%      |
| <b>Marital Status</b>                      |                    |            |
| Married                                    | 108                | 75%        |
| Unmarried                                  | 36                 | 25%        |
| <b>Education</b>                           |                    |            |
| Not studied or studies upto primary school | 24                 | 16.7%      |
| Upto high School                           | 50                 | 34.7%      |
| Upto higher secondary                      | 26                 | 18.1%      |
| Graduation or higher education             | 44                 | 30.6%      |
| <b>Employment</b>                          |                    |            |
| Unemployed                                 | 38                 | 26.4%      |
| Government Employee                        | 20                 | 13.9%      |
| Self-employed                              | 26                 | 18.1%      |
| Private sector Job                         | 20                 | 13.9%      |
| Home-maker by choice (females)             | 40                 | 27.8%      |
| <b>Monthly Income (in Rupees)</b>          |                    |            |
| <20000                                     | 26                 | 18.1%      |
| 20000-40000                                | 50                 | 34.7%      |
| 40000-60000                                | 16                 | 11.1%      |
| >60000                                     | 52                 | 36.11%     |
| <b>Causes of Chronic kidney disease</b>    |                    |            |
| Diabetic Nephropathy                       | 58                 | 40.3%      |
| Hypertensive Nephrosclerosis               | 34                 | 23.6%      |
| Chronic kidney disease                     | 28                 | 19.4%      |
| Chronic interstitial nephritis             | 16                 | 11.1%      |
| Unexplained etiology                       | 8                  | 5.6%       |
| <b>Dialysis Vintage</b>                    |                    |            |
| Less than 1 year                           | 36                 | 25%        |
| 1-3 years                                  | 68                 | 47.2%      |
| 3-5 years                                  | 32                 | 22.2%      |
| More than 5years                           | 8                  | 5.6%       |
| <b>Frequency Of Hemodialysis</b>           |                    |            |
| Once In 10 Days                            | 6                  | 4.2%       |
| Once Weekly                                | 34                 | 23.6%      |
| Twice Weekly                               | 88                 | 61.1%      |
| Thrice Weekly                              | 16                 | 11.1%      |

**Table 2: The details of questionnaire asked to maintenance hemodialysis patients with respect to renal transplantation (SERIES 1-reply in Yes or No)**

| Questionnaire   | Replied as YES | Percentage | Replied as NO | Percentage |
|---|----------------|------------|---------------|------------|
| <b>Knowledge and attitude towards renal transplantation</b> |                |            |               |            |
| Knowledge about option of renal transplant                  | 104            | 72.2%      | 40            | 27.8%      |
| Willingness   | 100            | 69.4%      | 44            | 30.6%      |
| History of previous Transplant                              | 4              | 2.8%       | 140           | 97.2%      |
| Knowledge about option of cadaveric transplant              | 60             | 41.7%      | 84            | 58.3%      |
| Enrolled For cadaveric transplant                           | 16             | 11.1%      | 128           | 88.9%      |

**Table 3: The details of questionnaire asked to maintenance hemodialysis patients with respect to renal transplantation (SERIES 2- multiple answers allowed)**

| Questionnaire  | Number of patients | Percentage |
|--|--------------------|------------|
| <b>Reason for opting hemodialysis as renal replacement therapy</b>       |                    |            |
| Late diagnosis of CKD (in ESRD)  | 17                 | 11.8%      |
| Had urgent requirement of renal replacement therapy when initiated       | 34                 | 23.6%      |
| Was not given proper counselling for option of pre-emptive transplant    | 87                 | 60.4%      |
| Easy availability of hemodialysis facility                               | 89                 | 61.8%      |
| Unavailability of suitable donor   | 78                 | 54.2%      |
| History of renal transplant failure in family and friends                | 15                 | 10.4%      |
| High cost of renal transplantation                                       | 57                 | 39.6%      |
| Poor medical condition requiring optimization before transplant          | 28                 | 19.4%      |
| <b>Source of Information regarding renal transplant</b>                  |                    |            |
| Doctor   | 110                | 76.4%      |
| Paramedical Staff  | 14                 | 9.7%       |
| Relatives and Friends  | 16                 | 11.1%      |
| Social media and other sources   | 4                  | 2.8%       |
| <b>Reason for willingness</b>  |                    |            |
| To avoid hemodialysis  | 92                 | 92%        |
| To increase quality of life  | 64                 | 64%        |
| Recommended by doctor  | 6                  | 6%         |
| To live longer   | 40                 | 40%        |
| <b>Donor Choice for renal transplant</b>                                 |                    |            |
| Live donor   | 38                 | 38%        |
| Cadaveric  | 84                 | 84 %       |
| <b>Choice of donor in willing patients in case of live related donor</b> |                    |            |
| Parents  | 26                 | 26 %       |
| Siblings   | 12                 | 12 %       |
| Spouse   | 72                 | 72 %       |
| Children   | 0                  | 0.0%       |
| Close relative   | 2                  | 2%         |
| Answered more than one of these  | 10                 | 10%        |
| <b>Reason for reluctance for renal transplant (n=44)</b>                 |                    |            |
| Older age of patient   | 14                 | 31.8%      |
| Fear of poorer prognosis after transplant                                | 24                 | 54.5%      |
| Financial constrains   | 18                 | 40.9%      |
| Concern for donor's health   | 10                 | 22.7%      |
| Medically Unfit for transplant   | 4                  | 9.1%       |

**Table 4: The Information and Perception of maintenance hemodialysis patients with respect to renal transplantation (SERIES 3- reply as agree, disagree or don't know; answers quoted in percentages)**

|   | Agree  | Disagree | Don't know |
|---|--------|----------|------------|
| Seen successful transplant outcomes   | 58.3 % | 26.3 %   | 15.4 %     |
| Seen many failed renal transplants  | 36.2 % | 52.7 %   | 11.1 %     |
| Received insufficient information   | 44.6 % | 52.7 %   | 2.7 %      |
| Transplant better option than hemodialysis                                    | 59.8 % | 29.1 %   | 11.1 %     |
| Fear of graft rejection within 1 Year   | 8.3 %  | 59.8 %   | 31.9 %     |
| Transplant causes more trouble  | 23.7 % | 65.2 %   | 11.1 %     |
| Afraid of transplant surgery  | 13.8 % | 79.3 %   | 6.9 %      |
| Concerned about cost of the medical therapy post-transplant                   | 11.1 % | 86.1 %   | 2.8 %      |
| Health after 1 year on Hemodialysis is better than after renal transplant     | 38.8 % | 61.2 %   | 0.0%       |
| Health after 1 Year after transplant is better than remaining on hemodialysis | 44.5 % | 11 %     | 44.5%      |

## Discussion

Developing countries like India face unique challenges in management of CKD, like region specific etiologies (for example CKD of undifferentiated etiology), diagnosis in advanced stage, paucity of awareness regarding the disease and its treatment modalities and wide discrepancies in health care opportunities and affordability.<sup>[1]</sup> Our study shows that the understanding about renal transplantation was very poor in Indian maintenance hemodialysis patients. Sadly only 72% of our patients had knowledge about transplant as a modality for renal replacement therapy, lesser than the West-African MHD patients from Cote

d'Ivoire (97.3%) and Nigeria (75%),<sup>[4,5]</sup> however they were better informed than the Saudi Arabian (39%) and Bangladesh CKD cohorts (30%, 34%).<sup>[6-8]</sup> Consequently lesser number of our patients (69.4%) were willing for transplant than the Cote d'Ivoire cohort (78.3%),<sup>[4]</sup> Saudi-Arabians had comparable willingness (69%) as they also feared their old age (61%) and surgical complications (26%), whereas Chinese feared transplantation the most with only 46.4% willing for transplant.<sup>[9]</sup> Even the high income country like Hungary had no different experience, with only 71% of their MHD patient willing for transplant.<sup>[10]</sup> The main motivations for the Cote d'Ivoire cohort was the desire to stop dialysis (52.4%) and the quest

for a better quality of life (41.1%).<sup>[4]</sup> The concern about high cost of transplant compared to hemodialysis, were common to many.<sup>[4,5]</sup> Another common deterring factor in our study as well as in worldwide meta-analysis,<sup>[11]</sup> was the concern for family donor's health, whereas many of these wished to undergo transplantation if deceased donor kidney was available. Unfortunately deceased donor program has not yet kick-started in our state, and we refer our patients to get enrolled at a nearby union territory central government premium institute, where the whole process is very lengthy and painstaking, and consequently only 11% of our patients were enrolled for the same, and these too were on waiting list for years. North Indian population unlike their southern counterparts have lesser enthusiasm for diseased organ donation, primarily because of superstitions and lack of awareness. Other regions in the world too have their own set of unique challenges, like religious misbeliefs affect deceased donations in Islamic population,<sup>[12,13]</sup> racial bias affecting African Americans ESRD population,<sup>[14,15]</sup> and bias affected females and old aged MHD patients.<sup>[14-16]</sup> The pain and uncertainties of patient on deceased donor waiting list is heartbreaking.<sup>[11]</sup>

Similar challenges have been reported from Morocco<sup>[12]</sup> where although 71% believed transplant will give them better life, but only 41% were willing for it, and a mere 12% were noted on the transplant list. 61.4% lacked adequate information, 56.8% thought life is impossible with only one kidney, 50.6% estimated transplant to be more expensive as 52.3% belonged to low economic status.<sup>[12]</sup> Eligibility analysis in another large Moroccan cohort reported old age and cardiovascular comorbidities as major deterrent factor for transplantation.<sup>[17]</sup>

This study is a small effort intended to sensitize the transplant physicians and surgeons in India and across the world regarding the lack of awareness of ESRD patients regarding renal transplantation as the standard of care renal replacement therapy. Like all others studies, this too had its limitations. It was a single centre study with a small cohort of MHD patients, and region based limitations like no deceased donor program in our state. A multicenter, multiregional study can better compare the regional, religious and socioeconomic impacts on live and deceased renal transplant.

A dedicated team based renal replacement therapy counselling should be in place, helping patients in early CKD to plan their renal replacement therapy well in advance before ESRD, with option of pre-emptive transplant highlighted to them. Transplant counselling should be group based with active participation of transplanted patients and their donors. This can help CKD patients in choosing suitable RRT, and alleviate their fears and misconceptions and hence negative attitude towards renal transplantation. Also potentially modifiable is the superstitions and misbeliefs of the society and raising awareness towards deceased organ donation.

## Conclusion

There is a paucity of knowledge regarding renal

transplantation, among the chronic kidney disease patient on maintenance hemodialysis, leading to their negative attitude towards transplant. A little more effort by the health care team can alleviate their fears and misconceptions and help in improving their quality of life after a living or deceased donor transplantation.

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**How to cite this article:** Kaur S, Sharma D, Chahal HS, Sethi S, Sohal PMS, Makkar V. Knowledge, Perception and Attitude of Indian Maintenance Hemodialysis Patients toward Renal Transplantation. *Asian J. Med. Res.* 2019;8(4):MC13-MC17.  
DOI: [dx.doi.org/10.21276/ajmr.2019.8.4.MC4](https://doi.org/10.21276/ajmr.2019.8.4.MC4)

**Source of Support:** Nil, **Conflict of Interest:** None declared.

