SUMMARY

The advances in the field of transplantation and medicine have revolutionised life for patients suffering from end stage organ failure. As a result, new years are added with excellent quality of life for these unfortunate patients. The commonest transplant in India is kidney, which is done for patients suffering from end stage kidney failure. These patients could also live with maintenance dialysis; however, quality of life and expenses for maintenance dialysis prohibit this option for Indian patients. Hence kidney transplantation is the only realistic chance for living a good quality and fuller length of life for the patients. The source of donor kidneys could be cadaver or voluntary living donors. Though legal problems of obtaining kidney from cadaver have been solved, there are several logistic problems as yet unsolved for cadaver donor to become generally available to our patients. It is therefore in our country living donors are the main source of kidneys. The live donors have to undergo major surgery
without any benefits to themselves. The results of live closely related well matched donor transplantation are much superior to that of unrelated donor transplant. This unique situation puts lot of psychological stress on the potential donors specially if they are family members, or are related to the patients. Also, there are complex legal, ethical and social problems in accepting unrelated donor. Thus, the family members of the patients are torned between fear of undergoing major surgery and need to save a dearone.

This dilemma in a setting of interpersonal, family & social relationships creates severe pressures & strain. The present study was therefore undertaken with the aim to study the psychological correlates of kidney donation. Several medical studies have shown that the donors do not have adverse prognosis after surgery in terms of their physical well-being (Starzl, 1987, Terasaki, et al., 1995, Recio, et al.,1996). However there are not many studies specially in India regarding the psychological impact of kidney donation.
(A) MATERIAL & METHODS

The following hypotheses were proposed:

1. That self-motivated donors would show better self-acceptance, lesser anxiety, better marital relationship as well as better mental health status in comparison to other self-motivated donors.

2. That those donors who have received counselling would show better self-acceptance, lesser anxiety, better marital relationship as well as better mental health status in comparison to those who have not received counselling.

3. The female donors would show better self-acceptance, lesser anxiety, better marital relationship as well as better mental health status in comparison to the male donors.

4. Those donors who are young would show lower self-acceptance, more anxiety, lower marital relationships well as lower mental health status in comparison to those who are old.

The psycho-physical reactions were studied in terms of:

1. Self-acceptance
2. Anxiety
3. Marital relationship
4. Mental health status
The study was divided into 3 stages of the process of kidney donation, i.e.

1. At the time of registration, i.e. at the time of volunteering as a kidney donor.
2. Prior to kidney donation operation.
3. Three months after kidney donation.

The sample of the study comprised 60 kidney donors coming from Gujarat & neighbouring states of India, in the age group of 18 & above, both males and females who had registered themselves as kidney donors at Muljibhai Patel Urological Hospital, Nadiad, Gujarat. A control group of 60 matched family members of patients who did not actually donate kidney was used for comparison purposes.

The data was collected by personal interviews, questionnaire: open & closed ended questions.

In order to study psychological correlates of kidney donation, the following psychological tools were used:

1. SAI (Kakkar's Self Acceptance Inventory, 1984)
2. CA (Comprehensive Anxiety Test, 1992)
3. MAQ (Marital Adjustment Questionnaire, 1987)
4. MHC (Mental Health Check List, 1992)
All the above tests were administered one after the other during the three stages of kidney donation, i.e. at the time of registration, prior to the operation and three months after kidney donation.

(B) RESULTS:

PART I

(a) **Comparison of kidney donors and control group : Self Acceptance**

Kidney donors did not show any significant difference in self acceptance in comparison to the control group as a result of kidney donation at any of the three stages of kidney donation.

(b) **Comparison of kidney donors and control group : Anxiety**

Kidney donors experienced greater anxiety than the control group at the time of registration.

(c) **Comparison of kidney donors and control group : Marital relationship**

Kidney donors did not show any adverse effect on their marital relationship in comparison to the control group as a result of kidney donation at any of the three stages of kidney donation.
(d) **Comparison of kidney donors and control group: Mental Health Status**

Kidney donors did not show poorer mental health status in comparison to the control group as a result of kidney donation at any of the three stages of kidney donation.

**PART – II**

(a) **Comparison of self motivated and other than self motivated kidney donors: Self acceptance**

Self motivated donors did not show any significant difference in self acceptance in comparison to the other than self motivated donors as a result of kidney donation at any of the three stages of kidney donation.

(b) **Comparison of self motivated and other than self motivated kidney donors: Anxiety**

Self motivated donors did not show any significant difference in anxiety in comparison to the other than self motivated donors at any of the three stages of kidney donation.
(c) **Comparison of self motivated and other than self motivated kidney donors: Marital relationship**

Self motivated donors did not show any significant differences in marital relationship in comparison to the other than self motivated donors as a result of kidney donation at any of the three stages of kidney donation.

(d) **Comparison of self motivated donors and other than self motivated donors: Mental Health Status**

Self motivated donors did not show any significant difference in mental health status in comparison to the other than self motivated donors as a result of kidney donation at any of the three stages of kidney donation.

**PART III**

Out of 60 kidney donors, 30 kidney donors received counselling by a trained social worker who are termed as counselled donors. 30 kidney donors who did not receive counselling by a trained social worker were termed as non-counsellled donors.
(a) **Comparison of counselled kidney donors and non-counselled kidney donors : Self acceptance**

Counselled kidney donors did not show any significant difference in self acceptance in comparison to the non-counselled kidney donors as a result of kidney donation at any of the three stages of kidney donation.

(b) **Comparison of counselled kidney donors and non-counselled kidney donors : Anxiety**

Counselled kidney donors did not show any significant difference in anxiety in comparison to the non-counselled group as a result of kidney donation at the time of registration. However prior to kidney donation and three months after kidney donation, counselled donors showed less anxiety than the non-counselled donors.

(c) **Comparison of counselled and non counselled kidney donors : Marital relationship**

Counselled donors did not show any significant difference in marital relationship in comparison to non-counselled donors as a result of kidney donation at the time of registration and three months after kidney donation. However counselled kidney
donors showed better marital relationship than non counselled kidney donors prior to kidney donation.

(d) **Comparison of counselled & non counselled kidney donors**

: **Mental Health Status**

Mental health of kidney donors remained unchanged as a result of kidney donation at all the three stages of kidney donation inspite of being counselled or non counselled.

**PART IV**

(a) **Comparison of male and female kidney donors : Self acceptance**

Male kidney donors did not show any significant difference in self acceptance in comparison to female kidney donors as a result of kidney donation at any of the three stages of kidney donation.

(b) **Comparison of male and female kidney donors : Anxiety**

Female kidney donors showed more anxiety in comparison to male kidney donors as a result of kidney donation at all the three stages of kidney donation.
(c) **Comparison of male and female kidney donors:**

**Marital relationship**
Marital relationship remained unchanged among male or female kidney donors as a result of kidney donation at all the three stages of kidney donation.

(d) **Comparison of male and female kidney donors:** Mental Health Status
Female kidney donors showed poorer mental health than male kidney donors as a result of kidney donation at all the three stages of kidney donation.

**PART V**

(a) **Comparison of kidney donors according to the age group:**

**Self-acceptance**
There was no significant difference in the self acceptance of kidney donors belonging to Group A (18 years to 35 years), Group B (36 years to 50 years), Group C (51 years and above), as a result of kidney donation at any of the three stages of kidney donation.
(b) **Comparison of kidney donors according to the age group**

*Anxiety*

Kidney donors of all the age groups did not show any significant difference in anxiety at the time of registration. Kidney donors belonging to Group B (36 yrs to 50 yrs) showed more anxiety than the younger kidney donors belonging to Group A (18 yrs to 35 yrs) prior to kidney donation. Kidney donors who were in Group C i.e. 51 yrs & above showed more anxiety in comparison to the Group A (18 yrs to 35 yrs) i.e. younger kidney donors, prior to kidney donation.

Kidney donors belonging to Group B (36 yrs to 51 yrs) showed more anxiety in comparison to the kidney donors belonging to Group A (18 yrs to 35 yrs) i.e. younger kidney donors as a result of kidney donation at the stage of three months after kidney donation.

(c) **Comparison of kidney donors according to the age group**

*Marital relationship*

Marital relationship of kidney donors remained unaffected at all the three stages of kidney donation as a result of age factor.
Comparison of kidney donors according to the age group: Mental Health Status

Kidney donors belonging to Group A (18 years to 35 years) showed better mental health in comparison to Group B (36 years to 50 years) at the stage of three months after kidney donation. Kidney donors belonging to Group C (51 yrs and above) showed poorer mental health in comparison to Group A (18 yrs to 35 yrs) kidney donors as a result of kidney donation at the stage of three months after kidney donation.

CONCLUSION

(1) Self motivated donors did not show better self acceptance, lesser anxiety, better marital relationship as well as better mental health status in comparison to other than self motivated donors. The present study thus fails to support the proposed hypothesis. In a setting of kidney transplantation while the donors are being selected, altruistic, voluntary and ethical consideration form an important aspect of the donor selection process. The proposed donor's ability to give an informed consent to undergo this major surgery without any pressure or coercion is an essential precondition while
selecting a donor. If a prospective donor, whether self motivated or other, shows reluctance, direct or implied it is a definite reason for his being rejected as a donor. Hence the donors who show excessive anxiety, reluctance or fear are automatically rejected. In this study also all such prospective kidney donors were systematically excluded. It seems therefore that the sample was preselected by the circumstances and hence the related hypothesis could not be confirmed.

(2) Counselling donors showed lesser anxiety than noncounselled donors prior to kidney donation and three months after kidney donation. Counselling donors showed better marital relationship prior to kidney donation. However counselled donors did not show better self acceptance and better mental health status. The above results support the hypothesis. Counselling thus seems to reduce the fears related to kidney donation among kidney donors. Counselling helps improve the understanding of one’s health and potentials in actually helping a dearone by donating an organ. A sense of global fulfillment seems to have been experienced by the kidney donors.

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The female kidney donors showed more anxiety and poor mental health status compared to the male kidney donors. The female donors did not show better marital relationship and better self acceptance compared to male donors. Fear of high tech gadgets and medical technology must have contributed to their more anxiety and poor mental health scores, possibly because of their lower educational levels. They might have felt a compulsion to donate because of our (Indian) family and social circumstances where females are looked upon (required to), to save the breadwinning males at any cost. To support this fact kidney transplantations done at a centre where present study was conducted, 53% among donors were females whereas 84% recipients were males. Based on this experience it could be argued that females in the prevailing social circumstances are bound to experience greater fear and insecurity about well being of themselves and of the recipient. This tendency probably gets reflected in increased anxiety and poor mental health among female donors contrary to our expectations.

Contrary to expectations the results showed that the middle aged and older donors showed more anxiety than the younger
kidney donors. Younger donors showed better mental health than older kidney donors. This seems to be probably because the older persons i.e. kidney donors belonging to Group ‘C’ (51 years and above), needed longer time to heal following surgery compared to youngsters. This may have lead to fear of physical disability and a spectre of dependence for the older persons. The middle aged Group ‘B’ (36 years to 50 years) also showed higher anxiety compared to youngsters is probably a reflection of “middle life crisis”, worry regarding completing responsibilities, financial settlement etc.

To sum up, the study thus shows that there is hardly any particular consistent adverse negative effect of kidney donation on kidney donors as far as self acceptance, anxiety, marital relationship and mental health status is concerned, irrespective of their being self or other than self-motivated, counselled or non-counselled, males or females and old or young.

**An Action Programme for the management of kidney donations**

Due to advances in medical sciences organ transplantations for patients suffering from end stage disease of vital organs is a reality today. However like in most scientific advances this has lead to
special social psychological problems related to transplantations. The commonest organ source for transplantation all over the world is from cadaver (brain dead individuals); in fact this is the only source for unpaired organs. The commonest cadaver is from roadside accident victims who have suffered serious brain injury. This has lead to special requirement of grief counselling and psychological management of the bereaved next of kin. Though the legal problems of taking organs from the cadaver in our country have been sorted out with the advent of The Human Organ Transplantation Act of 1994, there exist several logistic problems for this becoming a common reality in our country. All over India about 300 (Shroff, 1998) cadaver kidney transplantations are carried out at various centers. The kidneys being paired vital organs offer an alternative of taking one kidney for the transplantation from a living voluntary donor source. It is well established medically that closely related donor kidneys have better chance of acceptance and hence have better long-term survival. Through numbers of medical studies (Prandini, et al.,1987; Beekman et al.,1994; Manorajan R., et al.,1999) it has been established that donating a kidney though involves a major surgery for the individual, at some risk to life, has no long-term adverse effect on longevity or functional physical capacity of the donor. This fact leads to severe psychological stress to family members of the patient
suffering from end stage renal disease (ESRD) especially in our country because alternative treatment like cadaver donor kidney transplantation, maintenance haemodialysis (MHD), continuous ambulatory peritoneal dialysis (CAPD) are not generally available due to various reasons. There is also paucity of scientific studies into the immediate and long term psychological effects to kidney donors, their families and friends. The present study addresses this lacunae. I feel that to donate one’s kidney is a very personal decision, however it is the responsibility of the team, in fact society at large, to make sure that these noble human beings, who at a considerable personal risk are trying to save another human being from the door step of death to return him/her as useful individual to the society, that their physical, psychological and spiritual health is safe guarded.

The present study has demonstrated that there is no immediate or medium term adverse psychological effect of kidney donation. It is therefore essential to develop a very comprehensive program to remove the chances of having any negative impact after donating one’s kidney.
EDUCATION ASPECT:

1. In the present study it was found that majority of kidney donors had no information about what is the function of kidney or what is kidney donation. Only after he/she is required to donate their kidney that they came to know about kidney function, its failure etc. Therefore health awareness at all levels of population needs to be highlighted.

2. Specific trained personnel, preferably with medical social work or psychology background should be a part of transplant team responsible for undertaking individual, family & community education program.

3. The trained personnel should also be responsible for making every effort to start a cadaver donation programme by making the public aware of brain death criteria and becoming an important cog in the wheel of developing such a programme which will ultimately result in less need for living donation.

4. Public education should also be aimed at educating the public in preventing diseases which lead to organ failure such as diabetes, hypertension, smoking, alcoholism, over the counter medication, diet etc.
COMMUNITY SUPPORT ASPECT:

5 All kidney donors should get priority status at various levels as they have donated their vital organ for somebody else's benefit in situation of life and death.

6 Greater efforts by transplant programs and by society at large to honour and support donors post-transplant are desirable.

7 Hospitals, community groups, social clubs appreciate this sacrifice regularly during their meetings. These can be arranged as felicitation functions (like felicitating toppers in 10th or 12th Std.). This way an awareness would be made and people will not hesitate to donate their kidney in case of need.

8 Travel expenses and necessary help to get reservations for traveling to the follow-up centre for check-ups should be made available.

9 Government & society's support for employment to the kidney donors is strongly recommended.
10. Personnel departments of various Govt. & other organisations should be made aware that these people are completely capable of living and doing all normal functions expected of their age & sex.

PSYCHOLOGICAL ASPECT:

11. An atmosphere of openness and no pressure to be built by support personnel so that kidney donor feels free to approach team members for clarification of doubts. This will help in reducing anxiety prior to operation and also after operation.

12. Married donors should be encouraged to discuss issues of personal concerns like effect of kidney donation on sexual relationship, emotional concerns, child bearing and planning for follow-up expenses.

13. Immediately after operation till discharge, counsellor’s support is to be made available to kidney donor so that donor feels he is cared for and kidney donor’s psychological well-being also becomes priority.
LIFE STYLE ASPECT:

14 The kidney donor is motivated to contact the medical social worker if he feels that a particular event or incidence is emotionally upsetting because he has donated kidney.

15 The kidney donor should be advised to seek help if he experiences some adverse effect on his physical and mental health any time.

16 During follow-up visits if the kidney donor fails to get cooperation from employer regarding leave etc. necessary efforts should be done to clarify matter with the employer.

HEALTH CARE ASPECT:

17 Insurance companies should be encouraged to insure donors after nephrectomy with proof of "normal" functions of the remaining kidney.

18 It is recommended that insurance companies should not increase premiums prior to donor nephrectomy.
REHABILITATION ASPECT:

19 To appreciate the sacrifice of the kidney donor & to improve the quality of life, rehabilitation of the kidney donor must be emphasised. Multidisciplinary team consultations along with vocational programs should be easily accessible to all kidney donors.

FURTHER RESEARCH

1 Long term study to ascertain the psychological impact of kidney donation should be done.

2 The impact of recipient outcome on donor's psychological well-being needs to be studied.

3 The present study is single centre experience. Hence a multicentric study is recommended to ascertain the present study's findings in a larger context.