CHAPTER - 1

INTRODUCTION

Kidneys are paired vital organs situated in the abdomen (FIGURE - 1).

Position of Kidney in Human Body

They are responsible for (a) maintenance of normal chemical composition of body fluids, (b) maintenance of blood pressure, (c) processing vitamin D & its active form, and (d) producing erythropoietin for formation of hemoglobin. Structurally, the kidneys are made up of about a million factional units known as the nephrons. Uniquely, only 20% of the functional capacity of the kidneys is sufficient for good quality of life. This leads to a special situation, i.e.
it is possible for a kidney donor to lead a normal quality of life with one normal kidney.

All living beings have been blessed with immunity, an ability to discern self and non-self. This is essential to fight against invading disease producing germs & cancers, etc. However the same benevolent immunity rejects a transplanted organ as “foreign” unless very closely matched.

Hence, the success of transplantation depends on how closely matched is the donor to the recipient. In most of the developed countries kidneys are obtained for transplantation from brain dead individuals, unfortunate victims of road traffic accidents. Unfortunately this cadaver donor source is not practically available in our country for several reasons.

Considering the above factors in our country, the vast majority of kidney transplantations are done from live donor source, either related or unrelated.
When compared with dialysis, kidney transplantation has greater rehabilitation potential for a patient with end stage renal disease (Blagg et al. 1973). Successful transplantation is often viewed by the patient as the gateway to "personal liberation" and to restoring control over one's life and one's self (Galpin, 1992).

The first successful kidney transplantation clinically was performed by Murray, Merrill and Harrison at Boston on 23rd December-1954. Some initial psychiatric studies have questioned the fundamental willingness to make this type of sacrifice (Brewer, 1970). It has been reported that family pressures originate from internal feelings of guilt or fear of family rejections (Simmons, et al. 1971).

Understanding of the psychological aspects of transplantation has grown rapidly over the past decade (Craven and Rodin, 1992). This increased understanding has resulted in the opportunity to offer informed psychological support as an integral part of transplantation cases.

The course and outcome of severe chronic illness are decisively affected by social, psychological & emotional variables. It is important
to understand the individual & the family as all face a series of adaptive tasks in relation to the illness. Each of the three phases of the illness, i.e. the diagnostic, chronic and end stage poses special tasks and requires different defenses & coping capacities from the patient, family & health care personnel (Mailick, 1979).

It is to be noted that transplantation itself demands cooperation from every possible resource, i.e. (a) adequate funds are required for transplantation & post-operative medicines, specially antirejection drugs, (b) long hospitalisation therefore not able to resume job early, and (c) availability & willingness of live related donor.

Experience tells that two families faced with the same illness stressor can respond in dramatically different ways: one family may mobilize itself constructively with the demands it faces whereas the other family is mobilized by the situation & begins to unravel as demands are placed on it. For example there may be two families where only live related donor source is an unmarried sister. One family may decide that saving the life of the recipient by the best matched donor is of importance, whereas the other family may give weightage to what will happen if the sister is not able to find a suitable match for marriage after donation etc.
While assessing the kidney donors, techniques of case work illustrated by Florence Hollis (1964) are used, namely psychological support, clarification and insight development. As such the live related kidney donors are motivated and encouraged as there is a will to save somebody's life. At the same time insight therapy is utilized to achieving a change in the donor by developing his insight into his/her difficulties & increasing the ability of the ego to deal with difficulties through the emotional experience in the transference situation.

It is a common observation that the married donors are often posed with conflict. If a brother decides to donate his kidney to save his sister's life, his wife may tend to oppose it. Similarly if a married sister is willing to donate her kidney, her husband and her in-laws may refuse permission for doing so. Here we find classical example of psychological ownership of a mate in a closed marriage.

Each individual family comes from a different cultural, religious and educational background which ultimately guides him/her in taking crucial decisions about kidney donation. The family as such contributes an essential ego sustaining function, for it is the intimate
give and take of internal interaction. The family more than any other groups provides the individual with affection, understanding, sympathy and a sense of worth and identity. In the family, adults are expected to fulfill certain commitments and carry role tasks. The major vital roles of the responsible family members contain the dynamic experiences that shake & shape the family. Many other factors play a key role in tackling illness, such as economic background, education & emotional interaction between family members.

In assessing a donor's suitability to donate issues other than physical fitness, like emotional stability and motivation to donate are of great significance. The physical evaluation therefore is undertaken only after the psychological assessment and counselling to the family and the donor is done by a trained person who is an essential part of any transplantation team. The training includes acquiring skills and knowledge of principles of human growth & behaviour and personality development. A trained social worker with medical and psychiatric specialization is ideally suited to undertake this responsibility of assessing donors before physical evaluation.
It is of primary importance at the time of evaluation that the potential donor is allowed to meet the counsellor alone (Howard, 1998). The counsellor who possesses skills of social casework establishes rapport with the donor. The atmosphere is set for openness, i.e. honesty in self-disclosure, questions and answers and education. The counsellor allows the donor to ventilate his/her feelings, giving opportunity for free expression, listening to the reactions and creating a general sense of comfort and "no-pressure". The interview is directed towards clarifying doubts, accepting fear and to find out if there is ambivalence towards the decision of kidney donation and also identifying factors responsible for his consenting/offering to be a donor. This will help to understand the level of motivation, the barriers and emotional strength & weakness, the family members who are supportive and those who are opposed to his/her decision of kidney donation. It is also essential to know what is the financial background of the donor, i.e. whether the income will be lost during the check-up or the job remains secure, or whether he/she will get the sanctioned leave when the investigations are going on. These issues once discussed with the social worker, the donor receives information and also receives assistance in planning. This helps in co-ordination during investigations and towards actual decision of donating kidney.
"Illness & suffering have, since time immemorial, been matters of grave concern to all those who came in contact with them. The value attached to human life, the desire to prolong it and or alleviate suffering have through the centuries inspired the quest for ever more effective means of disease control & prevention (Field, 1967). In treating end stage renal disease patients, the following statements by Minna Field seem to be very apt: "like a pebble thrown into water, illness causes ever expanding circles, affecting not only the person who is ill but his family which is called upon to meet many of the emotional and physical costs of the illness, his close relatives & his friends".

When the patient is told about the diagnosis of end stage chronic renal failure, many of our patients due to lack of education are unaware of what is the kidney. Therefore, the patient and his family members are explained about his present medical condition and treatment alternatives. The treatment alternatives are maintenance haemodialysis life-long, live-related donor kidney transplantation and lastly palliative or conservative treatment. The patient & his family members need to have discussions and counselling sessions with the treating doctor and the social worker. If the patient decides to undergo kidney transplantation then the search for a donor within the
family begins. The social worker calls a family meeting of the patient, potential donors and their spouses. All those family members are explained about kidney function and kidney donor selection and rejection criteria. The kidney donors are explained about (1) short-term surgical risks: about the scar, catheter, and hospitalisation.

THE KIDNEY DONOR (FIGURE - 2)

(2) long-term risk of impaired renal function & hypertension, (3) loss of time and money, (4) other treatment alternatives like dialysis always possible for the recipient, (5) kidney transplant may not solve all health problems of the patient, (6) transplanted kidney may not function. After understanding these risks all donors who are physically fit i.e. without diseases like hypertension, diabetes, heart
problem, kidney stone disease, jaundice or major psychological illness are selected after medical tests. Serially the medical tests are carried out over a period of 7 to 10 days. If there is more than one willing donor in the family, the more closely-matched donor is selected after the special test of “HLA” typing. The final test is renal angiography. Once a suitable donor is found then all necessary statutory & medical formalities are completed and the kidney transplantation is planned (FIGURE 3 & 4).

The patient & the donor are explained about the follow-up check-ups after transplant surgery. All this is said to have a tremendous impact on marital relationships. It has been noted that at times a relationship
seems to get strained, or else a strong bond of mutual understanding is created. At times there is a lot of anxiety & pressure while taking such a crucial decision. Among the donors, sexual behaviour may also get adversely affected due to unnecessary fear and ignorance if not properly counselled.

Social work in medical care concerns with illness. The central characteristic of medical social work is its direct concern with illness and its medical treatment and with any consequent adjustment in the lives of patients and their families. The patient is faced with the constant encounters with the problems of physical pain and mental anguish which form a major feature of the work. Therefore, the present study is undertaken to focus on and enhance the understanding of psychological effects of kidney donation on kidney donors. At the time when an individual is faced with health problem, that too of serious chronic life-threatening illness, both the patient and his family members undergo tremendous stresses which in most cases may have an impact on their daily routine and affect their interpersonal relationships. With this background, the present research has been undertaken.