

## **Chapter I**

### **Introduction**

Chronic disease of the kidney is a cardinal reason of mortality & morbidity worldwide. CKD has been emerging as a fast expanding global problem related to health in all the nations. Currently, the CKD's global prevalence is estimated to be ranging from 8 to 16% which is expected to increase in the future.<sup>1</sup> The burden of the disease has been increased globally by a considerable percentage of 41.5% from 1990 to 2017.<sup>2</sup> World Health Organization in 2020 has ranked CKD as the tenth major cause of death in their bulletin.<sup>3</sup> It is predicted that the incidence of CKD will rise further & can become the fifth leading cause of years of life lost by 2040.<sup>4</sup> Approximately 15% of adult population in US or 37 million people are guesstimated to have CKD.<sup>5</sup> The number of patients receiving renal replacement therapy surpasses two and a half million and is expected to double by 2030.<sup>6</sup> The prevalence of CKD ranges variably from 4% to 17% in India with broad regional differentiation as seen from previous studies. CKD is now the 12th most prevailing cause of mortality and the 17th biggest cause of disability.<sup>6</sup> The terminal stage of CKD is represented by end stage renal disease. The treatment of ESRD involves costly therapy like dialysis & renal replacement therapy (RRT). Approximately 152 people/million population are affected by end stage of kidney disease. After considering mean of the mentioned figure, then approximately 220,000 patients require kidney transplantation in India. In opposition to this 7500 kidney transplantations are carried out in India at around 250 centres for kidney transplant.<sup>7</sup> According to National Organ and Tissue

Transplant Organization 5,486 kidney transplants were done in India and 792 kidney transplants in Delhi in the year 2020.<sup>8</sup>

Kidney transplantation has been the favoured choice of therapy for patients diagnosed with end stage renal disease due to the reason of better quality of life & survival after transplantation compared with dialysis.<sup>8-9</sup> In India, at present 90342 individuals are listed for kidney transplantation on the waiting list.<sup>8</sup> After USA, India has the 2<sup>nd</sup> largest living kidney transplantation programme in numbers. It has evolved in the last 45 years.<sup>10</sup>

With advancements in preservation of organ, better surgical techniques, and effective immunosuppressive therapy, the expectancy after kidney transplantation has greatly improved.<sup>11</sup> These patients can now be more holistically assessed in terms any comorbidities, modification of life style, their compliance to therapy and effects on quality of life.

Infections are notably the majority of complications after kidney transplantation in the recipients. Infections have been categorized in three time periods after the kidney transplantation- post transplant infections in the early phase, infections at the height of immunosuppression & late onset infections. The infections that take place in the first thirty days after transplantation are known as early post transplant infections.<sup>12</sup> These infections comprise mainly post-surgical infections (approximately 98%), pneumonias, bacteremias, infections of urinary tract and colitis. The infections that occur in the second phase after transplant are commonly opportunistic infections which are the ones that reanimate from inactive infection present in the recipient. These may include viral infections like

CMV(Cytomegalovirus), varicella zoster, herpes simplex, hepatitis B & C, tuberculosis etc.<sup>13-14</sup>

The third category which are late-onset infections present from six months to twelve months after transplant are mostly community acquired, like CAP (community-acquired pneumonia), viral infections of respiratory tract, and urinary tract.<sup>15-19</sup>

As described by the major kidney registries from USA and New Zealand/ Australia, there has been a drop down in the incidence rate of acute rejection which was more than 50% during the 1970s to 10%–20% in the current age.<sup>20-22</sup> Looking at the low rejection rate, Acute Rejection is being examined as secondary outcome rather than primary outcome in research studies of clinical trials. In India, as per the studies the acute rejection rate varies from 17%-28%.<sup>23-24</sup>

Another recurrent complication in recipients of kidney transplant is new-onset diabetes mellitus after transplantation (NODAT). It is commonly linked to infections or disorders of metabolism & may consequently lead to various conditions like diabetic kidney disorder with nephrotic syndrome, impairment in functioning of kidney or even untimely loss of the graft. The reported incidences of NODAT lies from 7% to 30% in the first year after transplantation of kidney.<sup>25-28</sup> New-onset diabetes mellitus after transplantation can lead to occurrence and worsening in major adverse cardiovascular events (MACE). MACE has been the prime cause of morbidity and mortality in the recipients of kidney transplantation.<sup>29-32</sup>

The recipients of kidney transplantation need to learn to amalgamate lifestyle modification advice & medication into their day-to-day routines. They also need to

accustom to the changes in social roles and thus can get through with the emotional consequences after transplantation.<sup>32</sup> The recipients have to take a vital part in their care after transplantation through self-management which leads to enhancement of their quality of life.<sup>33-34</sup> From previous research it has been seen that the recipients of kidney transplantation are found to be more compliant to medication as compared to lifestyle modification. It may be due to the reason that the recipients feel medications can alone take care of the graft. Therefore, the assessment of recipients to the recommended lifestyle is of paramount importance.<sup>35</sup>

Nonadherence to immunosuppressive therapy leads to a seven fold rise in failure of the transplant, yet the rate of nonadherence to medication is estimated to exceed 30% in recipients of kidney transplantation.<sup>36-37</sup> Nonadherence to immunosuppressive therapy poses a risk for below par outcomes post transplantation.<sup>33,39-40</sup> Non-adherence to therapy is a major threat for rejection & loss of the allograft among recipients of kidney transplantation..<sup>41-44</sup>

Recent studies have shown that there have been intenserelational, psychological and social changes after kidney transplantation which can affect the patient and his family. The findings from the previous literature have revealed that recipients of kidney transplantation are exposed to mental health disorders which can adversely affect their quality of life.<sup>45-46</sup> The chances of the risk of rejection also get increased due to these disorders. The most common conditions observed as comorbid illness in kidney transplant recipients are depression, anxiety and alteration of the body image.<sup>47-48</sup> These conditions can adversely affect the adherence to immunosuppressive therapy increase the chances for rejection.<sup>49</sup>

In comparison to dialysis, kidney transplantation has better outcome on the quality. However when compared quality of life in relation to health between the recipients and general population, it was found that the recipients had lower QoL for the same demographic characteristics of age & sex.<sup>50-52</sup> Previous studies in literature have reported that the long term QoL of kidney transplant recipients is not at par with healthy controls of the population in general. It has been found that the QoL of the recipients has been adversely influenced by the symptoms of distress, anxiety and depression. The QoL is also affected by graft rejection and infections post transplantation.<sup>53</sup>

### **Background of the study**

The recipient after kidney transplantation has to follow a compounded and continuing self management regimen. This helps to improve the end result of transplantation and reduce the risk of developing infections and related diseases. The various self management measures required by the transplant recipient include regular taking medications for immunosuppression, physical activity, preventing infections, monitoring for adverse effects of drugs, self monitoring, nutritional management, practicing protection from sun and regular follow up of consultations with the specialists.<sup>54</sup> These collective self-management demands are viewed useful for maintenance of sound health and reducing the reappearance of CKD complications.

Self-management is referred to “as managing one or more chronic conditions (e.g. symptoms, treatment, physical and psychosocial consequences, and lifestyle

changes) and integrating them into daily life with the aim of achieving optimal quality of life”.<sup>55</sup>

Self-management is described as “the tasks that individuals must undertake to live with one or more chronic conditions, having the confidence to deal with medical management, role management and emotional management of their conditions”.<sup>56</sup>

The advantage of self management for the recipient at any point of time after the transplantation is that it happens to be personalized and helps to enhance the capability of the recipient to enhance their health condition.<sup>57-59</sup>

The risk factors identified for below par adherence to immunosuppressive therapy are longer time after transplantation, younger age, psychological factors, financial problems, social isolation and less cognition. Despite the clinical significance of strict adherence to immunosuppressive therapy, the transplant recipients experience difficulties with adherence due to many reasons. Therefore self management support has utmost focus on boosting self monitoring and adherence to immunosuppressive therapy.<sup>35,58</sup>

In order to promote best medical and psychosocial outcomes after kidney transplantation the nurses should reinforce management of self after transplantation.<sup>55</sup>

The self management programme should be multicomponent including individualized care designing, psychosocial support, education and other tracking tools.<sup>59</sup> The patients may face a number of challenges after transplantation which might lead to stress in the patients despite advances in transplant technology. The various factors that can affect quality of life are uncertainty about the health in

future, supporting resources & finances, follow up and side effects of medical treatment.<sup>60</sup>

The two most common psychological disorders that can affect the disease process and survival of graft in kidney transplant recipients are anxiety and depression.<sup>61-62</sup>

Anxiety and depression can lead to inadequate individual care, altered quality of life difficulty in integrating the new acquired graft into self management and non compliance to treatment.

There can be various complications of medications after kidney transplantation which can adversely affect the quality of life of recipients.<sup>63-64</sup> Quality of life remains an important measure in defining health outcomes in recipients of kidney transplantation.

Self management support helps to empower the recipients, enhance their lifestyle and adherence and ultimately boost their health related quality of life.<sup>65</sup> Following self care management in accordance with medical indications, the kidney transplant recipient can have a satisfactory quality of life. This indicates that more productive and multicomponent approach is required to empower the recipients for self care.

### **Rationale of the study**

Recent study findings have revealed that the kidney transplant recipients' knowledge, practices related to infection control and self-care are inadequate. The compliance with the recommended lifestyle after transplantation has been found suboptimal in Indian population.<sup>66</sup> There has been a gap in the knowledge related to complications due to infections after kidney transplantation.<sup>67-68</sup> The kidney transplant recipients are

likely to be more compliant to medications than modifications in the lifestyle which can further lead to occurrence of complications.<sup>69</sup>

It has been reported that there has been a lack in instructions related to diet. So proper guidance needs to be provided and emphasis should be given on the importance to follow the diet. There has also been a low frequency of practising exercise by the recipients.<sup>70</sup> Therefore, tailored regimes related to exercise can be planned to improve the compliance to their physical activity.<sup>71</sup> It has been reported that the recipients do not adhere to modifications in lifestyle.<sup>72-73</sup> Nurses have an essential role to identify nonadherence and devise different methods to support the recipients. The repercussion of lack in knowledge can be mortal and it is also one of the major hurdle to successful kidney transplantation. Therefore rationalized programs for recipients are essential.<sup>74-75</sup> The implementation of the educational program will help in making improvements in their knowledge, reported practice of infection control, and self-care skills. Therefore educational programme with follow up is required to improve compliance among kidney transplant recipients.

A predominant issue for patients in post transplant phase is deficit knowledge about immunosuppressive therapy.<sup>44,76</sup> So effective educational strategy need to be investigated as an approach to improve the knowledge and preparation for the challenges that happen in post transplant period.

Since there is no specific method to improve adherence to therapy among kidney transplant recipients, the intervention has to be developed based on the factors influencing adherence to therapy. So, a combination of cognitive, affective and



behavioural interventions can be used by nurses to promote adherence to therapy and self care.

Anxiety, depression and stress after surgery can affect the recovery of the recipient and ultimately hamper the prognosis.<sup>77-78</sup> These can also adversely decrease the ability of self-management.<sup>79</sup> Negative emotions and psychological symptoms can also affect their quality of life.<sup>70,80</sup> Self management is vital for chronic disease to reduce the complications and improve the quality of life of the recipients.<sup>34,81-82</sup>

The recipients of kidney transplantation need to be made aware of depression and should be educated for its early identification and treatment. Screening can early detect depression and will help to provide prompt social and psychological support for kidney transplant recipients. Interventional studies with longitudinal assessment could provide better understanding of depression and its management.

However as per the literature review and to the best of researcher's knowledge there is no such study conducted on effectiveness of self care management programme including education and behaviour therapy for kidney transplant recipients in India, though a sound knowledge of management of self in patients with kidney transplant is vital to boost quality of life & compliance to immunosuppressive therapy. So, this study is undertaken to evaluate the efficacy of nurse led self care management programme on self care behaviour, their psychological symptoms & quality of life among recipients of kidney transplantation. The intervention in the present study would help in better recovery, avoid graft rejection and prevent complications in kidney transplant recipients.

## **Research statement**

“A study on effectiveness of nurse led intervention on self care behaviour, psychological symptoms and quality of life among kidney transplant recipients in a selected tertiary care hospital of New Delhi”.

## **Aim of study**

To evaluate the effectiveness of nurse led intervention on self care behaviour, psychological symptoms and QOL among kidney transplant recipients in a selected tertiary care hospital of New Delhi.

## **Research question**

Is nurse led intervention helpful in improving self care behaviour, psychological symptoms and QOL of recipients of kidney transplant?

**Objectives:** The objectives of the study were-

Primary Objectives:

1. To determine the effectiveness of nurse led intervention on self care behaviour of kidney transplant recipients.
2. To determine the effectiveness of nurse led intervention on psychological symptoms of kidney transplant recipients.
3. To determine the effectiveness of nurse led intervention on quality of life of kidney transplant recipients.

Secondary Objectives:

1. To find the correlation between pretest self care behavior &

psychological symptoms of kidney transplant recipients.

2. To find correlation between pretest self care behaviour & quality of life in kidney transplant recipients.
3. To find correlation between pretest psychological symptoms & quality of life in kidney transplant recipients.

## **Hypothesis**

1. H<sub>1</sub> There would be statistical significant improvement in self care behaviour of kidney transplant recipients receiving nurse led intervention compared to the control group as assessed by Self care practice scale and MGL adherence scale at  $p < 0.05$ .
2. H<sub>2</sub> There would be statistical significant decrease in psychological symptoms of kidney transplant recipients receiving nurse led intervention compared to control group as assessed by DASS 21 at  $p < 0.05$ .
3. H<sub>3</sub> There would be statistical significant improvement in quality of life of kidney transplant recipients receiving nurse led intervention compared to control group as assessed by WHOQOL- BREF at  $p < 0.05$ .

## **Operational definition of terms:**

1. **Effectiveness:** Effectiveness refers to an extent nurse led intervention is effective in increasing self care behaviour scores & quality of life scores and decreasing psychological symptom scores in recipients of kidney transplantation.

2. **Self care behaviour:** Self care behaviour refers to self care practices and adherence to taking immunosuppressive therapy by recipients of kidney transplantation as measured with self care practice scale and Morisky Green Levine adherence scale.
  - (i) **Self care practice:** These are the activities performed by kidney transplant recipients in order to improve well being as assessed by self care practice scale.
  - (ii) **Adherence to immunosuppressive therapy:** It is defined as the expanse to which kidney transplant recipients follow prescribed instructions of medication as measured by Morisky Green and Levine adherence scale.
3. **Psychological symptoms:** Psychological symptoms refer to anxiety, stress & depression experienced by recipients of kidney transplantation as measured by Depression Anxiety Stress Scale (DASS-21).
4. **Quality of life:** It refers to kidney transplant recipient's physical health, psychological health, personal beliefs, relationship with others in society and relationship to the environment as measured by WHOQOL-BREF.
5. **Nurse led intervention:** Refers to self care management programme prepared by investigator for empowering patients with kidney transplant for self management after transplantation at home. It comprised of formal health education, relaxation therapy, counselling and telephonic reinforcement.
6. **Kidney transplant recipient** – Refers to a patient with last stage of kidney disease who has been transplanted a compatible kidney from a matched donor and has completed 3 months after transplant.

**Assumptions:** The study assumes that -

1. Subjects will be true representative of the population.
2. Subjects will adhere to the nurse led self care management programme.

### **Delimitations**

The study was delimited to kidney transplant recipients only who visited Transplant clinic at AIIMS New Delhi, and who had completed 3 months after kidney transplantation.

### **Conceptual framework**

The framework for organization of concepts in this study was based on Dorothea Orem's Self care deficit, supportive educative system theory.<sup>83</sup> According to this theory nursing is required when the individual is incapable of practicing continuous and effective self care and needs help.

The components included were:

**Self care:** This component of self care applies to the activities which are initiated by the individuals and carried out for themselves for maintaining their existence and health and welfare.

**Self care agency:** It implies the individual person's capability to take part in care of the self. It is affected by certain key factors. In this study self care agency applies to the kidney transplant recipient's ability to care for self after transplantation which is

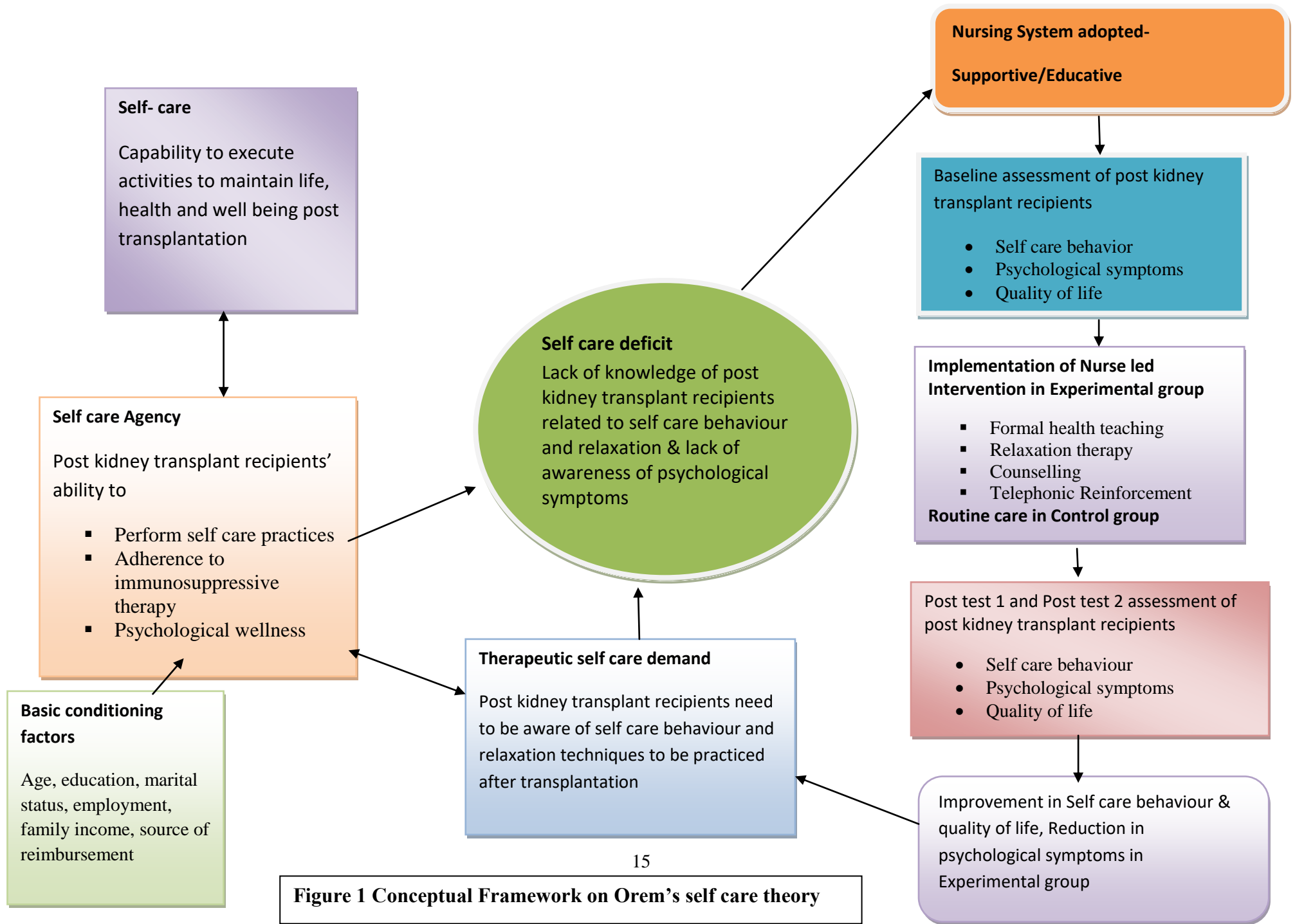
affected by age of the recipients, their educational status, marital status, income of family and source of reimbursement.

**Self care requisites:** These are the requirements that can be interpreted as actions aimed with regard to the foundation of self-care. It refers to the need of the post kidney transplant recipients to learn about self care behaviour and relaxation techniques and perform them during post kidney transplantation period for enhancing their quality of life and reducing psychological symptoms.

**Therapeutic Self care demands:** Self care demands mean "totality of self care actions to be performed for some duration in order to meet self care requisites by using valid methods and related sets of operations and actions". In the present study kidney transplant recipients are required to do self care activities, relaxation therapy and take medications.

**Self care deficit:** It is inability of post kidney transplant patients to perform self care effectively because of lack of knowledge about self care behavior and relaxation method.

**Nursing System:** This system starts when patient's treatment related self care demand is more than which he has. The researcher has adopted supportive educative system of nursing to educate, counsel and reinforce regarding management of self among patients who had undergone kidney transplantation to boost their self care behaviour, quality of life and reduce the psychological symptoms.



**Figure 1 Conceptual Framework on Orem's self care theory**