

## CHAPTER II

### Review of Literature

A substantial review was reviewed pertinent to the topic was done to attain an understanding and gather all related knowledge for building the foundation of the study. The information was availed from various journals, texts, med line search and internet and in depth reading was done by the researcher. The chapter is described in following sections.

**Section I:** Literature review of self care among recipients of kidney transplantation.

**Section II:** Literature review related to psychological symptoms among kidney transplant recipients

**Section III:** Literature review of quality of life in recipients of kidney transplantation

**Section I: Literature review of self care among recipients of kidney transplantation.**

The activities related to self care are of importance as they prevent complications, decrease side effects and improve the outcome of the graft.<sup>32</sup> The lifelong result of kidney transplantation depends on various factors like healthy diet, physical exercise, control of weight, compliance towards the advised behaviours and advices and more importantly optimum adherence to immunosuppressive therapy.<sup>33</sup> The overall compliance to modification of lifestyle has been found suboptimal in Indian setting in the recipients.<sup>66</sup> It has been observed that majority of the recipients

were not aware of the specific fluid requirement and very few were engaged in physical activity. The recipients had a positive attitude for intake of fluid, exercise and diet low in salt but had negative attitude towards low cholesterol diet. Very less percentage of recipients practiced the required self care for intake of fluid and physical activity.<sup>71</sup> The various predictors that have been identified for self management are age of the recipient, sex, dialysis undergone prior to transplant and its duration and the period after transplantation. It is important for nurses to recognize the barriers and predictors which will help in formulating educational interventions.<sup>84</sup> The various barriers identified for self care among the recipients include recipients own physiological and psychological status, system related to health care and socioeconomic status. Based on these specific interventions tailored to patients need can be developed to improve the health status. Been Dahmen MJ et al. (2018) explored the challenges and needs for self management experienced by the recipients of kidney transplantation. The challenges reported by the recipients were modifying activities of life performed daily, following strict medication regime, accepting social consequences and tackling emotional aspect with transplantation. It was seen that the recipients desired adequate knowledge for self care. They also wanted to share their issues related to social life & emotional issues with the nurses and expected a positive feedback from them.<sup>58</sup> In the current scenario, social and emotional issues are not taken care of by the nurses. Interventions focussing on holistic care to improve confidence and motivation are required. A trustworthy relationship with the nurse will help to achieve optimum self care for the recipient. Another study qualitatively appraised the attitudes of healthcare people concerning self-management by renal transplant recipients. Semi structured interviews were used

to collect data on 20 recipients. The identified benefits from self management were preferable quality of life, independence, procreation, and less physical, social and financial issues. It was concluded that the perceptions of health care providers may be of utilization in developing training programmes with regard to self management among recipients of kidney transplantation. The compliance of 110 recipients to the recommended lifestyle changes was evaluated in a descriptive study. A questionnaire was used to assess the same. The findings were that most of the patients visited the outpatient clinic and took immunosuppressive therapy. But the knowledge regarding self control, diet and cancer prophylaxis was deficient. Gordon E et al. (2009) investigated the performance of exercise and intake of fluid as reported by kidney transplant recipients. Mixed design of quantitative and qualitative was used for 82 recipients. One third of the subjects disclosed drinking three litres of fluid each day. Most of them 78% reported to have sedentary activity while the remaining percentage engaged in regular physical activity. They identified the barriers and concluded that the recipients practised optimal self care and there is a need for developing educational interventions.<sup>73</sup> Maasdam L et al. (2021) analysed the impact of self management and health literacy on kidney function, complications and graft failure after transplantation. The sample included 154 patients and Partner in health scale was used. The results revealed that higher education had no influence on graft outcomes. However, higher knowledge of management of symptoms was associated with lower failure of graft.<sup>85</sup> There have been various studies where the interventions have been tested for their effectiveness to improve self care in the recipients of kidney transplantation. Li L et al.,(2020 ) studied effect of transitional care of kidney transplant recipients on their self care ability post discharge. With simple random

sampling, one hundred KT recipients were enrolled for the study. Transitional care was given to the patients through phone calls, family and outpatient visits and patient's clubs. The tools used were self structured knowledge questionnaire and self care agency scale. The results showed that the patient's knowledge of self care abilities enhanced post intervention.<sup>86</sup> The efficiency of informational program on recipients of renal transplantation to check self efficacy, compliance, knowledge and QOL through a randomized controlled trial was tested. They randomized 159 renal recipients to intervention and control group with 77 recipients in the investigation group and 82 recipients in other group. The intervention had five individualized one to one sessions. The tools used were a knowledge questionnaire and "The General-Self-efficacy Scale". The outcome was measured at 7-8 weeks and six months post transplantation. The findings showed enhancement in the knowledge of recipients in the intervention group and there was difference on compliance amidst the groups.<sup>87</sup> The impact of empowerment intervention through RCT on self care behaviours and empowerment levels of transplant recipients was studied on 122 renal transplant recipients. The sample was randomly allocated to intervention with 56 participants and control with 66 participants. The intervention included six two- hour meetings on self care behaviours. The results showed significant improvement in level of empowerment ( $p=0.023$ ) and self care behaviour (0.009) in the empowerment group.<sup>88</sup> The effect of management of self and self efficacy on QoL in recipients of renal transplantation in a longitudinal, correlational design was assessed. 150 adult transplant recipients were registered for the research and data was collected using self-management scale, self-efficacy scale and SF-36 for assessing of quality of life. It was revealed that recipients with greater self efficacy had better scores on problem

solving and self care behaviour. Self efficacy indirectly affected QoL in reference to mental health domain.<sup>33</sup> A pilot project was carried out to study the usefulness, fidelity and suitability of holistic intervention for recipients of kidney transplantation for self management. The subjects were helped in evolving self regulation skills for self management of illness. There were 60 participants put into two groups. The results showed improved adherence to medication as compared to the other group. There was improvement within experimental group for perceived higher quality of care.<sup>89</sup>

Adherence to immunosuppressive therapy is cardinal in improving the outcome of graft in the recipients of kidney transplantation. It also determines the patient survival & graft survival rates. Nonadherence to immunotherapy is a pivotal risk factor in rejection of graft. The results show females to be more adherent. The barriers identified among recipients in Asian population are lack of knowledge regarding the importance of taking immunosuppressive medications, too many numbers of drugs to be taken, confusion and difficulty in remembering the drug to be taken in a study by Ganjali R et al.<sup>90</sup> A retrospective analysis on compliance to immunosuppression, reduction in dose and discontinuation revealed that poor compliance was related to hypertension, rejection and infections in the recipients. Poor compliance had higher probability of loss of graft that was 50% more than dose reduction and discontinuation of therapy.<sup>44</sup> Zachcial J et al. (2022) found a positive relation among acceptance of illness by the recipient & adherence to medication therapy. Another important factor identified was element of physical & environment quality of life of recipient. It is of utmost importance to identify the factors for better

adherence to prevent loss of the graft and infections.<sup>91</sup> The other reasons identified for non adherence were forgetfulness, not having medication with them as they were away from home, due to their nature of work.<sup>92</sup> There have been other factors identified like cost of medications, complexity in dosage, decision to omit a dose when the patient feels better, side effects of drugs, long duration post transplantation, financial problems, low level of cognition, young age, social isolation and depression. Hu S et al., (2021) explored the effects of anxiety & depression of renal transplant recipients on their self-management capability and clearance rate of creatinine. 88 recipients were enrolled using convenient sampling. It was found in the results that depression was present in 25% of patients, anxiety was present in 12.5% and 34.1% had moderate level of self management. Significant negative effects due to anxiety and depression were seen on the clearance rate of creatinine and psychosocial self-management capability of renal transplant recipients.<sup>93</sup> The relation between medication behaviour self efficacy and knowledge regarding medication and social support of recipients of transplantation was explored in a descriptive study. The sample included of 195 patients post transplantation. The tools used were self efficacy scale and scale for perceived social support. The results revealed a positive association between medication knowledge, social support and with long term medication self efficacy in kidney transplant recipients.<sup>94</sup> Adhikari UR et al., (2018) did a longitudinal study to assess the adherence with lifestyle modifications and recognize the determinants for non adherence. A total of 153 recipients were followed up for one year at three month intervals. The results showed that 64.1% patients were overall compliant. The factors identified to be associated with non compliance were severity of disease, adverse reactions of the drugs and

comorbidities.<sup>66</sup> A research was done to evaluate knowledge, adherence to treatment and QOL of recipients. A sum total of 244 recipients were registered and amongst them 45.5% patients were found to be adherent to regimen. It was revealed in the results that recipients with better QoL were highly expected to follow the medication regimen ( $p < 0.05$ ). They concluded that more than 50% of recipients were non adherent to medication regimen.<sup>90</sup> The attitudes of recipients of kidney transplantation in relation to adherence to medication, and its relation with clinical results were studied descriptively. 113 kidney recipients after six weeks of transplantation participated in the survey. The results showed no association of attitude with self reported non adherence to therapy. The non adherence was found to be related with a reduction of two year survival of the graft.<sup>95</sup> Different methods have been used to measure adherence like self report, electronic monitoring, observation of strips of tablets and maintenance of diary. Out of all these methods electronic monitoring for adherences is the best method as an objective measure.<sup>96-99</sup> A randomized controlled study of TAKE-IT intervention in recipients of kidney transplant was conducted to check adherence. The intervention was a multicomponent intervention for promotion of adherence to medication. Adherence to medication was recorded electronically. Study subjects in the experiment group had consequently higher odds of taking medication or taking medication at or near the time than the control group. The multicomponent TAKE-IT intervention significantly improved medication adherence. They concluded that graft outcomes can be improved with better adherence to therapy.<sup>100</sup> Garcia MF et al., (2015) evaluated the effect of an educational and behavioural approach among kidney transplant recipients on treatment adherence in a randomized study. 111 transplant

recipients were split into control and treatment group. The component of intervention was weekly thirty minutes education sessions on drugs and behavioural changes. The adherence to treatment was tested after three months by ITAS questionnaire. The results displayed a significant disparity in nonadherence rates among groups. The short term adherence was improved after the intervention in experimental group.<sup>101</sup> The outcome of pharmaceutical intensified programme on 74 kidney transplant recipients was studied applying a sequential control group design. The patients of experimental group were given a supplementary pharmaceutical care and instructions by an exclusive pharmacist. The adherence to immunosuppressive therapy was observed for one year by a medication event checking system, drug holiday (DH) incident and pill count (PC). Morisky questionnaire was used for self-reporting. The results revealed that the experimental group showed significant results for adherence to medication, pill count and drug holiday.<sup>102</sup>

**Summary:** There have been studies done with some forms of intervention like transitional care, tailored intervention, empowerment support group, self management support intervention on kidney transplant recipients. These interventions were found to be effective in improving patient's knowledge, self care ability, self efficacy and self care behaviours. They have suggested that team caring for transplant patients should integrate strategies incorporating the various components of care. The interventions have found to be practicable and admissible by professionals of health care and the receiver of transplantation. The barriers to self care were also identified like restricting fluid during dialysis period and deficient



knowledge related to self care. These barriers can also help in formulating the intervention.

The studies related to adherence to immunosuppressive therapy have shown that more than 50% of the recipients were not adherent to the therapy. There have been various barriers identified for nonadherence like concurrent use of many immunosuppressive drugs, confusion in medication taking, lack of knowledge of immunosuppressive medications, and difficulty in remembering medication taking. The intervention studies were found to be effective in improving the adherence and graft survival of the recipients.

## **Section II: Literature review related to psychological symptoms among kidney transplant recipients**

The clinical management of post transplant patients focuses on the management of the graft while the significance of wholeness between mind and body is being neglected. Psychological symptoms like stress, poor coping & negative emotions can adversely affect the recovery and health outcomes of the kidney transplant recipient.<sup>103-104</sup> The personality of the recipient can also affect the response to the graft and its long term outcome.<sup>61</sup> The physiological and psychological stressors of the recipient can have repercussions on quality of life among the recipients. Therefore, it becomes important to evaluate and monitor the recipient for any psychological and emotional disorder. Jana AK et al., (2014) highlighted the existence of anxiety & depression in kidney transplant recipients. They also assessed its relationship with quality of life. 105 patients were chosen in the cross sectional study. The tools used were HADS for depression and anxiety and WHO QoL scale.

It was seen in the results that 8.57% participants presented with syndromal depression and anxiety.<sup>47</sup> The symptoms of depression and its correlated factors were explored among the receivers of kidney transplantation. It was a descriptive study done on 287 recipients. The findings showed that depressive symptoms were reported in the recipients greater than the general population. They concluded that depression should be evaluated as routine examination in the follow up of the recipients.<sup>105</sup> A descriptive research was conducted to determine quality of life & manifestations of mental ill health in recipients after kidney transplantation. The study enrolled 118 transplant recipients. The results exhibited that severity of anxiety, depression & stress changed after kidney transplantation. Post transplantation the quality of life of patients showed a satisfactory level of daily functioning. The various factors related with quality of life were found to be pain, vitality, occupational status, physical functioning, social activity and sleep quality.<sup>106</sup> A pilot project on adolescent receivers of kidney transplantation was done to assess the presence of psychological distress, nonadherence and find association between psychological distress and medication adherence. Two interviews were conducted at a time gap of 12 months on 22 adolescents. In the initial interview it was found that 36.4% of participants had symptoms of anxiety & depression. The non adherence to medication was 13.6% and 50% nonadherence for visit to clinic. In the consequent second interview the medication non adherence remained the same while the nonadherence for clinics was decreased. The study revealed through predictive analysis that anger was associated with high risk for medication nonadherence.<sup>107</sup> Arpaslan B et al., (2004) assessed in a descriptive study the mental health disorders in the kidney transplantation recipients. The sample consisted of twenty male and

twenty female recipients. The results showed that half of the patients had psychiatric diagnosis. 25% of patients had major depression. It was reported that percentage of psychiatric disorders was high in kidney transplant recipients ( $P = .003$ ). The symptoms of depression present in the recipients of kidney transplantation were studied in a descriptive design on 131 recipients using convenience method of sampling. Majority of the patients exhibited symptoms of depression. The related factors discovered to be affecting depression were age, marital status, self-efficacy & self care behaviour of recipient.<sup>108</sup> Another study evaluated the relation of QOL and depression with compliance to pharmacological therapy in liver and kidney transplant donee. The research included 86 patients of kidney transplantation and 50 recipients of liver transplant. The results conveyed that the physical functional status of recipient was firmly correlated with non adherence in recipients of kidney transplantation. Low openness scores were associated with 91% more nonadherent in kidney recipients. Increasing age was related to adherence in liver transplant recipients.<sup>109</sup> Salehi Z et al., (2015) analysed the influence of continuing care on anxiety, stress & depression among kidney transplant receivers in Iran. The trial involved 80 participants randomly assigned into two groups. The outcome was assessed by DASS 21. Continuous care was given to the experimental group for a period of three months and ordinary care was given to the other group. The findings exhibited that the intervention of continuous care lessened the mean total score for anxiety, stress and depression significantly.<sup>110</sup> A prospective RCT was carried out to ascertain the efficiency of mindfulness based stress reduction intervention to decrease the manifestation of anxiety & depression among the transplant recipients. The MBSR intervention included a meditation training programme of teaching,

health information and an active control by peer group. The outcome was assessed at eight weeks, after a period of six months and one year. The outcome showed that the intervention decreased anxiety symptoms ( $p < 0.02$ ) at one year. The within group findings showed that there was an enhancement in quality of life at first time point of eight weeks for all the outcome variables and the gains of the intervention were continued at one year after transplantation.<sup>103</sup> Baines Let al.,(2004) evaluated individual versus group psychotherapy on the recipients of kidney transplantation on depression utilizing Beck's depression inventory. The research was done on 82 recipients and they received 12 week individual or group psychotherapy. Both the therapies showed improvement but significant improvement was seen in the subjects who received individual therapy than the group therapy ( $p = 0.01$ ).<sup>104</sup> Therefore individual therapy alongwith family member should be practices to reduce psychological and emotional stress.

**Summary:** It has been seen from the previous studies that psychological symptoms of stress, anxiety, depression and anger were present among the kidney transplant recipients. These symptoms have been discovered to be correlated with higher infections, more number of hospitalizations, degraded quality of life and nonadherence to immunosuppressive therapy. Various interventions have been conducted like continuous care model and mindfulness-based stress reduction to decrease the psychological symptoms among the recipients and have found to be effective.

### **Section III: Literature review associated to quality of life in recipients of kidney transplantation**

A leading important indicator of medical treatment is quality of life among recipients of renal transplantation. However the complex management after transplantation which includes multi drug therapy and modifications in the lifestyle can negatively impact the quality of life.<sup>111</sup> The HRQOL is found to be affected by sociodemographic, clinical, psychosocial and lifestyle characteristics.<sup>112</sup> Hwang et al, (2021) explored the linkage of various factors with HRQOL on patients who had received kidney transplantation. The investigation was done on 163 transplant recipients and data was collected through self report survey. The finding showed a positive correlation of HRQOL with social support, post traumatic growth, perceived health status, self determination of the recipient. They suggested to developing a system that would help the recipients in returning back to work.<sup>113</sup> HRQL of patients after renal transplant was studied cross sectionally by Das RC et al (2014). The sample comprised of twenty recipients and twenty donors of kidney transplantation. The data was collected at two weeks before the surgery and six months post surgery in the follow up. The mean sum total of quality of life of recipients & donors had significantly improved ( $p < 0.05$ ) before and after the transplantation.<sup>114</sup> A longitudinal study to recognize the elements associated with health related QOL of recipients of kidney transplantation was conducted in five transplant centres of France. The Multivariate linear regression model was used for analysis. The results revealed that sociodemographic & clinical variables were related with low health related QoL. The new variables related with poor QOL among recipients identified were poor social support & treatment with antidepressants.<sup>115</sup> The association of

HRQoL and kidney function in recipients of kidney transplant was studied and clinical measures were investigated which were linked to aspects of quality of life. The study was conducted at Ahmadabad with 54 kidney transplant recipients. The replies were summarized and grouped in two categories of physical and mental section. The findings revealed that scores of mental health were better in males than females. No distinctive difference was seen between mental & physical component outcome of the recipients.<sup>116</sup> The quality of life related to health and their associations with regard to kidney function in patients of kidney transplantation was explored by Gautam R et. al, (2018). The sample included 54 participants who had completed three months after transplantation were involved in the study and SF-36 scale was used. The results exhibited that male had significantly higher scores for mental health than females ( $p < 0.05$ ). Age had no effect on physical or mental component score. The time duration after transplantation was significantly associated with less score on vitality scale.<sup>117</sup> The experiences of kidney transplant recipients were analysed who participated in tailored education based programme in the post transplantation period. Twelve patients were included in this explorative qualitative design. Interviews that were semi structured were conducted. It was revealed in the results that the subjects found the education programme to be individualized pertaining to their needs.<sup>118</sup> Raiesifar A et al., (2014) explored the effect of continuing care through randomized controlled study comprising of 90 kidney transplant patients on their quality of life. The model was adopted and applied to participants in two groups. The treatment group with their family members received sessions on awareness of diseases and need of follow up. KTQ-25 was used to appraise quality of life. The intervention resulted in difference in the two groups which was significant

for quality of life.<sup>119</sup> A quasi experimental research was evaluated to check the impact of educating the patient intervention of the strategies to cope, knowledge, quality of life & self efficacy in recipients. Data was collected on 50 patients after transplantation. The results showed enhancement in each and every component of quality of life & self efficacy post education intervention. The subjects also reported improved knowledge and positive coping after the intervention. They concluded that continuous education can be beneficial for the transplant recipients.<sup>120</sup> Another RCT evaluated the outcome of self management program for participants with kidney transplantation in Iran. The self management program for chronic illness was the intervention for the experimental group whereas the training session on diet was given to control group. As a result of the intervention, there was a positive effect of the programme on quality of life in recipients of patients with transplant.<sup>121</sup> Aghakhani N et al., (2021) studied the efficacy of education programme on self care on QOL of 59 recipients of kidney transplantation in a single blind RCT. The intervention was a bedside self care education programme through three sessions. The control group was given the standard care. The results revealed difference between the groups which was significant after the intervention on quality of life of the recipients ( $p < 0.001$ ). The conclusion was that the self care intervention programme was an effectual method to enhance the comprehension and skills of the recipients.<sup>122</sup> Personalized approach is desirable in optimizing quality of life in care after the transplant. The various types of interventions that have been found beneficial in improving quality of life are psycho educational, self management and cognitive behaviour therapy. Combined interventions of lifestyle and self management also seem promising for the recipients.

**Summary:** The numerous research studies have indicated that quality of life gets improved following the kidney transplantation in contrast to the pre transplantation period. But the quality of life remains lower when matched with individuals of general public. The quality of life gets affected with passing time due to various factors like infections, worries for rejection of graft, changes in physical and social function and side effects of the immunosuppressive therapy. So, various studies were conducted to enhance quality of life through interventions of education programme, continuing care programme and self management programme. These interventions were discovered to be productive in boosting the dimensions of quality of life.