A STUDY TO ASSESS THE BURDEN AND TREATMENT SEEKING BEHAVIOUR IN CKD PATIENTS ATTENDING THE NEPHROLOGY OPD IN AIIMS, JODHPUR

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Master of Science in Nursing

Medical Surgical Nursing (Nephro-Urology Nursing)

By

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DECLARATION BY CANDIDATE

I hereby declare that the thesis entitled- “A study to assess the Burden and Treatment seeking Behaviour in CKD Patients attending the Nephrology OPD in AIIMS, Jodhpur” has been prepared by me under the guidance of Dr. Ashok Kumar, Associate Professor (Medical-Surgical Nursing), College of Nursing, AIIMS, Jodhpur, Dr. Nitin Kumar Bajpai, Associate Professor, Department of Nephrology, AIIMS, Jodhpur and Mr. Nipin Kalal, Assistant Professor (Medical-Surgical Nursing), College of Nursing, AIIMS, Jodhpur. No part of this thesis has formed the basis for the award of any degree previously.

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LIST OF ABBREVIATIONS USED

Abbreviation	Elaborated form
AIIMS	All India Institute of Medical Sciences
CKD	Chronic Kidney Disease
df	Degree of freedom
f	Frequency
%	Percentage
N	Number of CKD patients in study
OPD	Out Patient Department
SD	Standard Deviation
S. No.	Serial Number
X^2	Chi-square test

ABSTRACT

INTRODUCTION- CKD is a debilitating condition accountable for high morbidity and is a overall burden on society and government. Due to costs of CKD and complexity of its treatment care is facilitate to very few patients in India. CKD is related to its increasing incidence and prevalence, poor outcomes, and high cost of treatment. CKD is a global threat to health for the developing countries due to expensive and life-long therapy. In India ~90% patients can't afford the treatment cost. Incidence of CKD has doubled in last 15 years. It is seen that early detection can improve prognosis, and screening is a tool for early detection.

OBJECTIVE- The main objective of the study was to assess the Burden and Treatment seeking Behaviour in CKD patients.

METHOD- A Descriptive survey study was conducted on CKD Patients attending Nephrology OPD of AIIMS Jodhpur. Total of 220 CKD Patients were included through the Non-probability Convenient sampling technique, and a self-structured tool was used for data collection. Data was collected in Nephrology OPD of AIIMS, Jodhpur in a period of 3 months.

RESULT- It was found that 33.6% CKD patients were in age group of 50-65 years, 58.6% were male, 75.5% were married, nearly two-third of CKD patients were Hindu and 38.6% CKD patients were having primary education and about 37.3% were diagnosed CKD since 2-3 years. Majority of CKD patients were having Hypertension as comorbidity. More than half of CKD patients had moderate level of burden. CKD patients had highest burden in emotional domain (Mean %= 65.47). Majority of CKD patients 'feel muscle

cramps' in level of burden. More than half of CKD patients (63.2%) had fair level of treatment seeking behaviour. CKD patients had highest treatment seeking behaviour in personal domain (Mean %= 70.58). There was significant association of age, gender, religion, education, duration of disease with burden in CKD patients. There was also significant association of age, gender, marital status, occupation, education, duration of disease with treatment seeking behaviour in CKD patients.

CONCLUSION –This study concludes that majority of CKD Patients had moderate level of Burden and fair level of treatment seeking behaviour. It was found that there was a significant association of age, religion, education, duration of disease with Burden in CKD Patients. There was also significant association of age, gender, marital status, occupation, education, duration of disease with treatment seeking behaviour in CKD Patients. The health care seeking behaviour of CKD Patients drive them to come for treatment.

KEYWORDS – Burden; CKD; Treatment seeking Behaviour

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CHAPTER-I

INTRODUCTION

CHAPTER I: INTRODUCTION

"THE GREATEST WEALTH IS HEALTH."

Publius Vergilius Maro

BACKGROUND OF THE STUDY

Kidney is the main organ of the urinary system which plays an important role to regulate the volume and composition of ECF (Extra Cellular Fluid) and waste products from the body. It regulates the body electrolytes, controlling the acid-base balance and it also performs endocrine functions. The abnormalities of kidneys and lower urinary tract is common and can occur at any age with varying degree of severity. In Kidney diseases, damage to the nephrons occur quickly, or gradually, causing them to lose their filtering capacity. Only after years or even decades the damage becomes apparent.[1]

Chronic Kidney Disease (CKD) is a condition that's characterized by slowly or gradual loss of kidney functions over the time.[2] CKD describes that abnormal structure and function of kidney present for more than three months including kidney damage and Glomerular Filtration Rate (GFR) is less than 60ml/min/1.73m^2.[3] Wastes can build up in excessive level in blood, if kidney disease gets worse. The problems can occur over a long period of time.[2] CKD is common disease mainly associated with aging but now-a-days younger population also start to face it. Hypertension and Diabetes mellitus are the most common cause of development of CKD.[4] Early detection and treatment can prevent to development of advance stage of CKD. If CKD developed into advanced stage of diseases i.e., End-Stage Kidney Disease (ESRD), it can

results to kidney failure that requires Dialysis or other alternative that's renal transplantation to maintain the quality of life.[2]

CKD is a global health problem and now recognized as a common condition associated with increased risk of cardiovascular disease and chronic kidney failure. In United States the incidence and prevalence of kidney failure increased from 1988 to 2004 by using dialysis and transplantation modalities because of increasing prevalence of Hypertension and Diabetes.[5] CKD, increases with age, and affects one person total of 10 in general population, and only 4 per 100,000 will advanced into ESRD (End Stage Renal Disease).[6]

Approximately 37 million American adults developed CKD and many more are at increased risk of developing CKD.[2] It is found that between the ages of 65-74 years; about one in five men and one in four women has some extent of CKD. CKD is prominent in south Asian population such as those from Pakistan and Sri Lanka and black people as compared to the general population. The rationale for this involvement is the high prevalence of Diabetes in South Asian people and higher prevalence of Hypertension in African population.[4] According to 3rd NHANES III (National Health and Nutrition Examination Survey) data, among patients older than 70 years, the prevalence of CKD was 37.8%. Age is an independent predictor of CKD, besides hypertension and diabetes mellitus.[5] In India, the prevalence of CKD was observed to be 17.2% with about~ 6% having CKD Stage 3 or worse.[7]

CKD classified into five stages based on the level of kidney function or their estimated Glomerular filtration rate (eGFR).

Stage 1: Mild kidney damage with kidney normal function with GFR> 90

Stage 2: Mild loss of kidney function with GFR 89-60

Stage 3: Moderate loss of kidney function with GFR 59-30

Stage 4: Severe loss of kidney function with GFR 29-15

Stage 5: Kidney failure with GFR <15[8]

The most common causes for developing CKD is hypertension and diabetes mellitus. Others can include autoimmune diseases (lupus nephritis), polycystic kidney disease, high cholesterol level, glomerulonephritis, chronic obstruction of urinary tract etc. In the early stages of CKD, symptoms are not visible. As the disease worsen, the symptoms can include excessive tiredness, loss of appetite, swelling of feet and ankles, dysnea, hematuria etc.[9]

Management of CKD depends on their underlying causes. The treatment of CKD should be started as early as diagnosed. The sooner the treatment of CKD, better will be the disease prognosis or to improve health and prevent comorbidities (hypertension, diabetes mellitus, cardiovascular disease etc.) associated with CKD. The main modalities in CKD to control the high blood pressure and reduce the blood sugar level. In advanced stages of CKD involves the dialysis and renal transplantation to maintain the quality of life.[10]

Early treatment in CKD, appropriate interventions may slow down its progression, completely halt the progression of the disease, or even reverse the disease process altogether. Many patients with CKD present late to the physician due to lack of awareness, the need to pay out-of-pocket for health care, resource poor settings, traditional beliefs about the cause and nature of the disease, and shortage of specialist combine to lead to inappropriate

treatment seeking behaviour that can lead to late presentation to the physician.[11]

World kidney day is celebrated on every second Thursday of March since 2006 to create an awareness of threat CKD leads to human life and healthy life style changes to reduce the risk factors of CKD. The International Federation of Kidney Foundations (IFKF) and the International Society of Nephrology (ISN) jointly decided to celebrate the World Kidney Day. “Kidney health for everyone everywhere” was the theme for World Kidney Day 2020.[12]

Treatment seeking behaviour is the action undertaken by individuals in response to the symptoms experienced. It involves specific steps and what is done and why it is done. There are various studies shown that when and where to seek health care is influenced by several factors involving the individual’s educational and economic status, belief about the cause and nature of diseases, past experiences with health care services as well as perception about the quality and efficiency of health care services. For an individual, the desired treatment seeking behaviour is respond to an episode of illness by first seeking help from a physician. Treatment seeking Behaviour varies within the community and between communities and can be improved by demographic, socio-economic, emotional, financial and physical factors.[13]

Among the CKD Patients, late presentation to the Nephrologist can be associated with higher CKD- related morbidity, higher burden of other comorbid disease conditions, duration of hospitalization increase, greater coverall cost of care, and higher all-cause mortality.[13]

NEED

According to Global Burden of Disease (GBD) 2015, about 1.2 million deaths, 19 million DALYs (Disability- adjusted life-years) and approximately 18 million years of life lost due to cardiovascular diseases which were directly related to decreased Glomerular filtration rate (GFR). Approximately 5-10 million people die from renal disease annually. CKD is related to huge financial burden. Around 2.62 million patients received dialysis modality globally and need for this was predicted to double by 2030. According to GBD, in the list of total number of death globally in 1990 the CKD was ranked at 27th position, but rose to ranked at 18th in 2010.[14] CKD affecting more or less 13% of United States population as a major health problem. Prevalence of CKD patients will continue to rise, showing the elderly CKD patients and also rise the numbers of diabetes and hypertension patients.[13] The mortality rate of CKD increased from 1990 to 2017 up to 41.5%, rising from 17th leading cause of death to 12th. Approximately 1.2 million people died from kidney disease in 2017.[15]

According to the study, prevalence of CKD in India was found to be about 17.5%, International Society of Nephrology's kidney disease data study center reported the prevalence of CKD in different Indian areas ranges from <1% to 13%.[16]

In India, the renal failure contributes substantially to adult premature death before 70 years of age and represents a growing cause of death.[8] It changes in life style and urbanization results in obesity, HTN and diabetes which is directly associated with the increased risk of CKD. CKD is a global threat to health for the developing countries due to expensive and life-long therapy. The

NKF stated that about 10% population globally are affected by CKD, making it one of most prevalent chronic disease.[8] In India ~90% patients can't afford the treatment cost. Incidence of CKD has doubled in last 15 years.[9]

CKD is a debilitating condition accountable for high morbidity and is a financial burden on society and government. Due to costs of CKD and complexity of its treatment care is facilitate to very few patients in India. So, all the adults more than 40 years of age should be advised to have regular check-ups with blood sugar, blood pressure and serum cholesterol levels.[12]

These data showed to the need for the implementation of appropriate treatment seeking behaviour and health promotion information about CKD and its associated comorbidities. Therefore, health care professionals will have to more involved in not only treating the patient's symptoms, but also promoting and educating patients, caregivers as well as the general public on the consequences of CKD.

During the clinical practice found that the patients were identified with CKD had physical, psychological, financial and family burden and also inappropriate treatment seeking behaviour. The reason behind that the patients were not aware about the disease condition and how to prevent the associated comorbidities. So that the researcher decided to assess the burden and treatment seeking behaviour of CKD patients. From the available literature revealed that CKD is debilitating condition responsible for high morbidity and mortality and inappropriate treatment Seeking behaviour leads to delay in presentation to health care facilities where specialized care can be given.

AIM OF STUDY

To assess the Burden and Treatment Seeking Behaviour in CKD Patients.

STATEMENT OF THE PROBLEM

“A study to assess the Burden and Treatment Seeking Behaviour in CKD patients attending the Nephrology OPD in AIIMS, Jodhpur.”

OBJECTIVES

- To assess the Burden among the CKD Patients.
- To assess the Treatment Seeking Behaviour among the CKD Patients.
- To determine the association of Burden and Treatment Seeking Behaviour of CKD Patients with Demographic variables.

HYPOTHESIS

All hypothesis will be tested at 0.05 level of significance.

Null Hypothesis (H_0)-

H_{01}-There is no significant association of Burden with Demographic Variables in CKD patients.

H_{02}- There is no significant association of Treatment seeking Behaviour with Demographic Variables in CKD patients.

Research Hypothesis

H_1 : There is significant association of Burden with Demographic variables in CKD patients.

H_2 : There is significant association of Treatment Seeking Behaviour with Demographic variables in CKD patients.

ASSUMPTIONS

- Patients must be possessing some of the Burden in CKD disease condition.
- Patients must be possessing some of the Treatment Seeking Behaviour in CKD disease condition.

OPERATIONAL DEFINITIONS

- **Burden:** In this study, it defined as the subjective experience of hardship from physical, psychological, emotional and financial effects in CKD patients.
- **Treatment seeking Behaviour:** In this study, it referred as process of remedial actions that CKD patients improved of their perceived disease.
- **Chronic Kidney Disease (CKD):** In this study, CKD is defined as a type of kidney disease in which there is gradual loss of kidney function over a period of months to years, usually more than 6 months.
- **Chronic Kidney Disease (CKD) patients:** In this study, CKD patients refer to the patients age group >18 years develop loss of kidney function, usually more than 6 months.

DELIMITATION

- The study was delimited to patients with CKD diagnosed atleast since 6 months.

SUMMARY OF THE CHAPTER

The chapter describes the background of the study, need, statement of problem, objectives, operational definitions, assumption and delimitation of the study. The next chapter will deal with a review of the literature.

CHAPTER II

REVIEW OF LITERATURE

CHAPTER-II

REVIEW OF LITERATURE

The review of literature was done to assess in depth information regarding the burden, treatment seeking behaviour of CKD, and further exploring the research questions, design the research methodology and explore more about the association of various factors with CKD.

Section 1: Review related to Burden of CKD

Section 2: Review related to Treatment seeking Behaviour of CKD

SECTION 1: REVIEW RELATED TO BURDEN OF CKD

Eric Yuk Fai Wan, Esther Yee Tak Yu, Weng Yee Chin et al. (2019) carried out a study aimed to assess burden of CKD and cardiovascular disease on life expectancy on CKD patients. The result demonstrated that increase in mortality risk and reduction in life expectency was associated with increasing number of comorbidities with CKD. In severe CKD patients burden was high. This study recommends that for reducing mortality and health care cost in case of hypertension, CKD prevention and interventions merits equal to that of cardiovascular disease.[17]

Elliot K. Tannor et al (2019) conducted a study aimed to assess QOL in patients with moderate to advanced CKD. In this study, total sample size was 202 CKD patients in which 118 (58.5%) were males. Mean age was 46.7±16.2

years. The most common cause of CKD was chronic glomerulonephritis that was followed by Diabetes Mellitus and hypertension. The overall mean QOL score was 40.3±15.4. The multiple linear regression showed that low Hb levels and low monthly income were predictive of overall mean QOL.[18]

Olumuyiwa John Fasipe et al (2019) presented a study aimed to create and highlight the awareness about the burden of RRT and associated comorbities among CKD patients. This study was a descriptive, prospective study of about 18-month duration from January 15 to June 2016. The study's result showed that out of 123 CKD patients 82 (66.67%) were males and 41 (33.33%) were females. 86 patients were in CKD stage 5, 15 in CKD stage 4, 19 patients in CKD stage 3, 2 in CKD Stage 2 and left one in CKD stage 1. In these patients, the prevalence of RRT was 56.91%. Most respondents were having two comorbidities with HTN, DM, obesity, heart failure being the most common.[19]

Sabitha Rose Jacob, Rini Raveendran, Suthanthira Kannan (2019) presented a study aimed to find out the causes and comorbidities in CKD through a community based cross sectional design. Interview of CKD patients above 18 years were taken. The study showed that the commonest comorbidities was hypertension, diabetes, cardiovascular disease, malignancies and retinopathy.[20]

Hansani Madushika Abeywickrama et al (2019) conducted a study on QOL and symptom burden among CKDu patients. This was a cross-sectional study included 120 CKDu patients attending the renal clinic. The result showed that about 69.2% were male and mean age of the patients was 61.87, mean GFR was 28.17 (±14.03)mL\min\1.73min^2 and about 70.8% were anemic. The most

experienced Symptom was bone\joint pain. The significant predictor of Heath related Quality of life (HRQOL) was age, whereas Hb level and being a farmer were significant predictor of symptom burden.[21]

Bushra Alshammari et al (2019) conducted a study aimed to explore symptom burden and its management amongst patients receiving HD in addition to caregiver burden. This study was mixed method study consisting of two phases; Phase 1 involves 141 patients convenience sample size involved cross-sectional study. Symptoms will be measured by using CKD-SBI. Also 130 caregivers will covers the ZBI-22 to check the level of burden in caregivers on maintenance HD. Phase 2 is a qualitative descriptive design involving semi-structural interviews of sample size 15 receiving HD. It provides to develop effective interventions to assess and manage symptoms in patients receiving HD.[22]

Hong Li et al (2018) conducted a study on symptom burden amongst patients suffering from ESRD and receiving Dialysis. Total five scales used to assess symptom burden in ESRD patients. Out of five scales, four fail to cover varying symptom attributes. There are several factors that affects the symptom burden level of undergoing Dialysis patients such as demographic Characteristics, psychological factors, and clinical characteristics. The existing studies commonly were cross-sectional and few longitudinal studies amongst undergoing Dialysis Patients. The study concluded that qualitative studies can be performed to enhance understanding of symptom burden experienced by patients that undergoing Dialysis.[23]

Ann M. O'Hare et al (2018) conducted a study aimed to assess emotional impact of illness and care on patients with Advanced Kidney Disease. Total 27 patients with advanced kidney disease between April, 2014 to May, 2016 were recruited. Out of which 10 were receiving centre HD, 5 were PD, and 12 patients had an eGFR ≤20ml\min per 1.73m^2 and had not started dialysis. Semi-structured interviews were conducted. The result showed that 3 themes related to patients emotional experience of care and illness; emotional impact of interactions with individual providers, emotional impact of encounters with the health care system, and emotional impact of meaning-making. To improve care a deeper appreciation of patient's emotional experience may be important.[24]

C H Moideen Kutty Gurukkal, B K Bithun (2018) conducted a study on the comorbidities in CKD patients. The study was a retrospective observational study with 89 CKD consecutive new patients. To cause CKD, the primary causes or comorbidities was diabetic nephropathy, chronic glomerulonephritis and hypertensive nephropathy.[25]

Sameera Senanayake et al (2017) carried out a study aimed to assess the symptom burden and self-perceived severity of symptoms among CKD patients. This is cross-sectional study community based in which randomly 1174 CKD patients selected from 19 medical officers of health areas. The result showed that total 1118 CKD patients having response rate of 95.2%. Total males were 62.7% and mean age was 58.3 years. Stage 4 CKD Patients were in majority and bone\joint pain was the most experienced symptom (87.6%). The most severe symptom was loss of libido. The symptom burden

median score was 35.0 and linear regression showed education up to advanced level, being employed, being dialyzed and comorbities.[26]

Shu Fang Vivienne, Nan-chen Hsieh, Li julin et al (2016) presented a study aimed to find out factors that affects the self-care of CKD patients and also the mediating effects of self-efficacy on knowledge and self-care by using cross-sectional and correlational design. Total 247 samples were taken having CKD through a purposive sampling. The knowledge as well as age both was positively correlated with self-efficacy. The study concluded that self-efficacy between the knowledge and self-care was crucial mediator.[27]

Simon D.S. Fraser, Paul J. Roderick, Carl R. May et al (2015) carried out a study on burden of comorbidities in CKD stage 3 patients. Total of 1741 patients were selected from August 2008 and march 2010 with stage 3. The result showed that hypertension was the common comorbidity burden followed by anemia and pain condition. Treatment burden was independently associated with lower education level. The study concluded that prevalence of high multimorbidity related to greater medication burden and poorer survival.[28]

Hayfa Almutary, Ann Bonner, Clint Douglas (2013) done a literature review aimed to find out the total physical burden in advanced stages of CKD and also to check important instruments to assess for multiple symptoms. The result showed that most common symptoms were fatigue, pain, pruritus and feeling drowsy. For assessing the multiple symptoms the important instruments are inadequate for symptoms dimensions. The study concluded that CKD patients experienced high symptom burden but less is known about

burden of patients with CKD stage 4 and stage 5 receiving the peritoneal dialysis.[29]

William M. McClellan et al (2010) conducted a study on physical and psychological burden of CKD among Older adults. The study aimed to determine the quality of life vary with GFR among older adults. Sample included ages 45 years and older in cohort study having demographic and health information. The result showed that CKD present in about 11.6% of Patients and SF-12 scores are declined from 38.9 TO 35.9 (P=0.0001) as the GFR declined and older CKD Patients experienced an increased prevalence of decreased QOL which cannot be fully explained by other demographic variables.[30]

Khaled Abdel-Kader et al (2009) carried out a study aimed to compare symptoms, depression, and QOL in patients with CKD and those with ESKD. About 90 ESKD and 87 CKD Patients were enrolled. The result showed that there were no differences in complete number of symptoms in DSI score. Whereas, in PHQ-9 scores the proportion is >9 as the median score were similar. In SF-36 physical component summary scores were comparable to mental component summary scores. The study concluded that the low quality of life, prevalence of depression, and burden severity are comparable in patients with advanced CKD and ESKD.[31]

SECTION 2: REVIEW RELATED TO TREATMENT SEEKING BEHAVIOUR OF CKD

Babawale Taslim Bello et al (2017) carried out a study aimed at describing the health care seeking behaviour in CKD patients attending the nephrology outpatient clinic. The study was a cross sectional survey conducted on total 104 adult CKD Patients. Data was collected through structured interviewer-administered questionnaire. About 71.2% patients having appropriate health care seeking behaviour. As compared to appropriate to inappropriate health care seeking behaviour were less likely to see their illness as a medical problem, had a lower mean age, and have below tertiary level education. The study concluded that majority of CKD Patients having appropriate behaviour but there a need for improved health awareness.[12]

Usha Bapatet al (2008) carried out a study on demographics and social factors associated with acceptance of treatment in patients with CKD. This study is a descriptive, total 670 patients with CKD were involved and depend on degree of renal failure, were categorized into dialysis, conservative therapy or transplantation. The patient's mean age was 49.27±16.7 years. About 66.7% were males, 40% were undergraduates, 34% were employed and 70.6% were married. The study showed that negative influencing psycho-social factors for acceptance of treatment were finance(69.3%), logistics (66%), no medical fit donors (13%), lack of social support (17%) and no willing donor (11%).[32]

Roberta Braun Curtin, Brian A.J. Walters, Dorian Schatell et al (2008) conducted study on self-efficacy and self-management behaviours in patients

with CKD. The study was a cross sectional survey with no intervention involved 174 Patients with CKD completed measures on self-efficacy, physical and mental functioning and self-management. The study aimed to explore the association between the self-efficacy and their self-management behaviour in CKD Patients. The self-management behaviour included- serum creatinine, self-advocacy, communication with caregivers, medication adherence and partnership in care. The result showed that self-efficacy was more dominantly related to self-management behaviour than the demographic variables.[33]

CHAPTER III

METHODOLOGY

CHAPTER III: METHODOLOGY

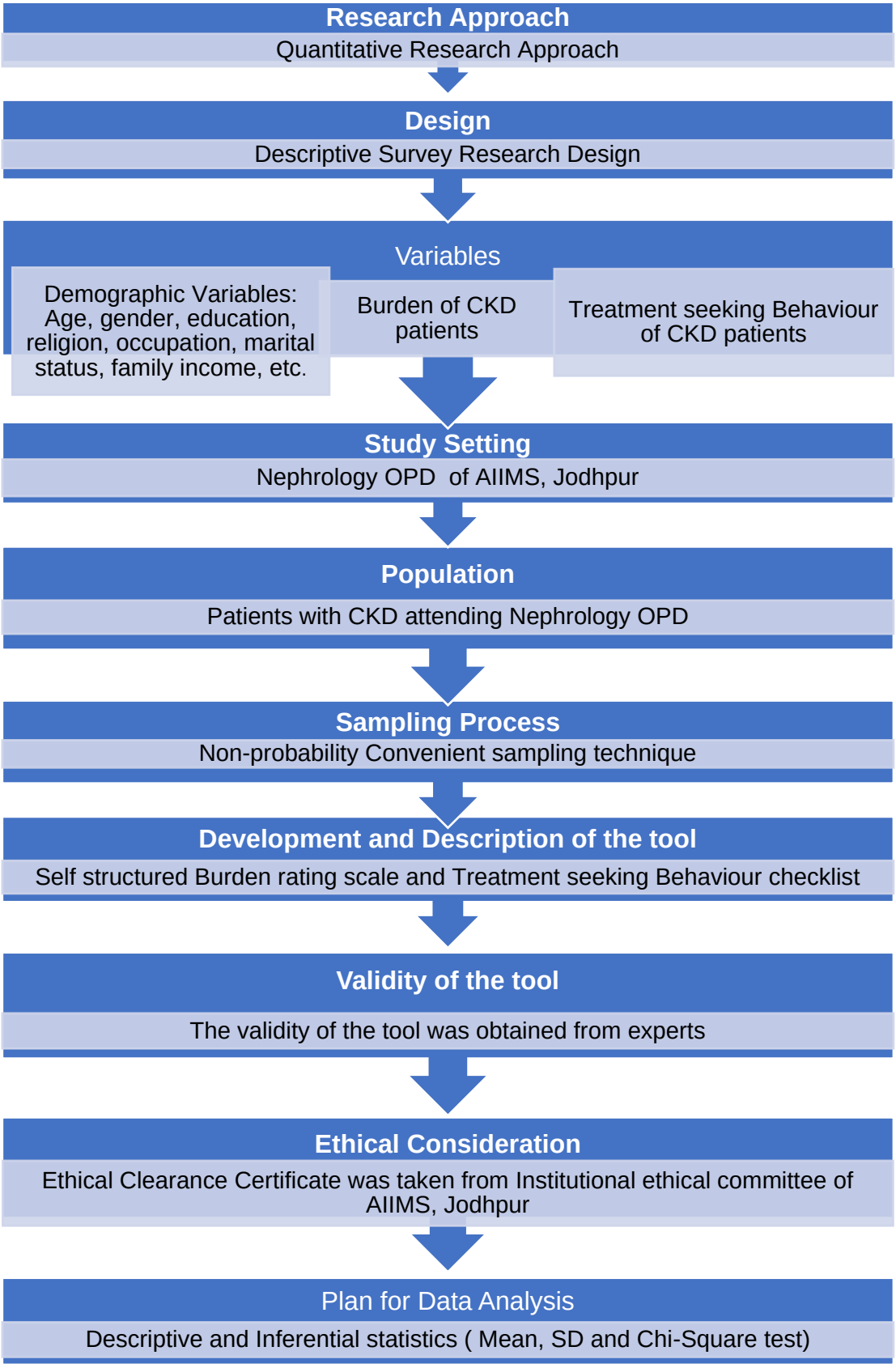

Figure 1 Showing Schematic Presentation of Research Methodology

METHODOLOGY

This chapter deals with the research methodology adopted to conduct the present study. It gives a detailed description of research design, research setting, population, sampling technique, sampling criteria, data collection tool, content validity, ethical consideration, pilot study, reliability, the procedure for data collection and analysis and interpretation.

Research Approach

Quantitative Research Approach

Research Design

Descriptive Survey Research design

Variables

- Demographic variables: Age, Gender, Marital Status, Occupation, Religion Education, Diagnosed CKD since, Income of Family, and Comorbid health Conditions
- Research variables: Burden and Treatment seeking Behaviour of the Patients

Study Setting

The current study was conducted in Nephrology O.P.D of AIIMS, Jodhpur which is a tertiary care hospital. AIIMS Jodhpur is 960 bedded hospital and it is located in second phase of Basni, Jodhpur. The hospital is fully functioning since 2013 and day by day more and more departments and advanced facilities are adding up in current system. At present, all the medical and surgical departments are running their OPDs & IPDs, all the diagnostic tests and operative services to the needies.

Population

Patients with CKD attending Nephrology OPD at AIIMS, Jodhpur

Sample

Patient who were diagnosed with CKD atleast since 6 months and who fulfils the inclusion and exclusion criteria was selected as a sample.

Sampling Technique

Non- Probability Convenient Sampling technique

Sample Selection Criteria

Inclusion criteria

- All the CKD Patients Diagnosed atleast since 6 month.
- Patient age more than 18 years.
- Patients who is able to speak and understand Hindi language.
- Patients who are willing to participate in the study.

Sample Size

The number of people who participate in the study, according to the estimation of prevalence formula. Sample size is calculated by-

$$n = \frac{Z^2 * (P)\ (1-P)}{d^2} = \frac{1.96 * 1.96 * (0.17) * (0.83)}{(0.5)^2}$$

n=216

where,

Z= Z value (e.g. 1.96)

P= percentage picking a choice, expressed as decimal (17%)

(as evidenced by previous research i.e., “prevalence of Chronic Kidney Disease in India- where are we heading?”[35](2015)

d= confidence interval, expressed as decimal (5%)

So, in this study the sample size was 220 and 10% of the total sample was taken in the pilot study and that was 22.

Method of Data Collection

Face-to-face or Telephonic interview method was used for data collection with the help of a self-structured tool. Questions were asked to participants and responses were filled in the questionnaire by the researcher**.**

Development and Description of Tool

A self-structured tool was formulated for the study. It was prepared after a brief review of the Literature including burden and treatment seeking behaviour in CKD patients and expert opinion. The tool was developed in 3 parts, Part A is having Demographic Variables, Part B is a Rating Scale having Burden related questions, and Part C is a checklist related to treatment seeking behavior in CKD Patients **(Appendix-II&III).**

Part A: Demographic Variables

It was having 9 questions related to Demographic Variables which includes age, gender, marital status, occupation, religion, education, diagnosed CKD since, Income of family, and comorbid health conditions.

Part B: Burden related Questions

It was having 18 questions related to level of burden in CKD patients and having 3 options: Never, Sometimes, and Always. It consists of four domains- Physical, Psychological, Emotional, and Financial.

The description of tool as follows:

Domains	Number of items
Physical	1, 2, 3, 4, 5, 6, 7,
Psychological	8, 9, 10, 11, 12,
Emotional	13, 14, 15,
Financial	16, 17, 18
Total	18

Scoring of the tool

There were 18 items in the rating scale which consist of maximum score 54. (minimum Score 18). The score given for ‘Never’ response was 1, for ‘Sometimes’ was 2, and for ‘Always’ response the score was 3.

Interpretation:

The interpretation of tool as follows-

Level of Burden	Score	Weightage of the score
Severe	41-54	75-100%
Moderate	27-40	50-75%
Mild	18-26	34-50%

Part C: Treatment Seeking Behaviour related questions

It was the last part of the tool and had 16 questions related to treatment seeking behaviour in CKD patients. It was having two options: yes and No. It consists of four domains- Personal, Hospital, Family, and Financial.

The description of tool as follows:

Domains	Number of items
Personal	1, 2, 3, 4, 5, 6, 7,
Hospital	8, 9, 10, 11, 12,
Family	13, 14,
Financial	15, 16
Total	16

Scoring of the Tool

It contains 16 items and 3 categories (Good, Fair and Poor behaviour) and the score was given as choosing No (0), and for Yes (1). For item No. 1, 9, 10, 11, 13, and 16 considered as a Negative statement regarding treatment seeking behaviour in CKD Patients. So for the ‘yes’ response the score was 0

whereas, for the 'No' response the score was 1. The maximum possible score is 16 and the minimum possible score is 0.

Interpretation:

The interpretation of tool as follows-

Level of Treatment seeking Behaviour	Score	Weightage of the score
Good	12-16	75-100%
Fair	08-11	50-75%
Poor	≤07	≤50%

Ethical Consideration

Ethical consideration for the current study was

- Ethical approval was taken from the Institutional Ethical Committee of AIIMS, Jodhpur. **(Appendix-1)**
- Certificate reference number-AIIMS/ICE/2020-21/3014
- Written and verbal informed consent was obtained from each study subject involved in the study.
- Confidentiality of the data was maintained and the study subjects were given full autonomy to withdraw from the study at any time.

Validity of the tool

Validity of the tool was established by the opinion of the panel of experts. It included experts in Medical-Surgical Nursing, and Department of Nephrology. After getting their valuable suggestions the necessary modifications were

made in the tool under the guidance of guide. The tool was found to be valid for the study. **(Appendix-V)**

Suggestions for the tool were

- Arrangement of Demographic questions
- Domain wise arrange the questions in the tool

Reliability of the tool

The tool was administered to CKD patients at OPD of AIIMS Jodhpur to check the reliability of tool. Reliability was calculated by Cronbach's alpha in Burden Rating scale and KR-20 method in Treatment Seeking Behaviour checklist. 22 CKD Patients were taken from Nephrology OPD and reliability of Burden rating scale found was 0.92 and for Treatment Seeking Behaviour checklist was 0.72, indicates the tool was reliable to conduct the study.

Pilot Study

Pilot study is basically a trial study carried out before research is finalized to help in defining the research questions or to test the feasibility, reliability, and validity of the proposed study design. The pilot study was carried out in 1st week of October at Nephrology OPD of AIIMS, Jodhpur after taking permission from the institutional ethical committee prior to the data collection with 10% of the total sample size that is 22. The purpose of the study was explained and subjects were assured about confidentiality. Data were collected after taking informed consent through a face to face or telephonic method and finding of the pilot study revealed that study is feasible to conduct.

Procedure for Data Collection

- After taking formal permission, the data was collected for the study.
- Participants were explained regarding the study and assured the confidentiality of information.
- Written and verbal informed consent was taken.
- Face to face or Telephonic interview the patient and record the responses in the tool.
- Approximate time taken to complete the questionnaire was ranging from 15 to 20 minutes from each patient.

Problem faced during the study

- No major problem was faced during the study.

Plan for Data Analysis

- The data analysis was conducted to reduce, organize and give meaning to the data.
- Data coding was done and entered into Microsoft Excel 2010 and all entries were checked for any error. **(Appendix: IX)**
- The analysis was done by using SPSS version 20. Descriptive statistics like frequency, percentage and inferential statistics like X^2 was used for the analysis of the data.
- Data were interpreted and depicted with the help of tables, charts, bar graphs, etc.
- Level of significance was taken as <0.05.

Summary of the Chapter-

The Chapter described the research, approach, design, variables, setting, population, sample, sampling techniques, tools used for data collection, pilot study procedure for data collection, and plan for data analysis. The next chapter dealt with the analysis and interpretation of the data.

CHAPTER IV

ANALYSIS, INTERPRETATION, AND DISCUSSION

CHAPTER IV

ANALYSIS, INTERPRETATION, AND DISCUSSION

This chapter presents the analysis and results of the recent study. The data collected were first coded and entered in the master data sheet.

The objectives of the present study are:

- To assess the Burden among the CKD patients.
- To assess the Treatment seeking Behaviour among the CKD Patients.
- To determine the association of Burden and Treatment seeking Behaviour of CKD Patients with Demographic variables.

The data and finding had been organized and presented under the following sections-

Section1- Description of Demographic variables of CKD Patients

Section2- Frequency and Percentage of Level of Burden in CKD Patients

Section3- Domain wise Mean, SD and Mean % of Burden in CKD Patients

Section 4- Item wise Mean and SD of level of Burden in CKD Patients

Section 5- Frequency and Percentage of Level of Treatment seeking Behaviour in CKD Patients

Section 6- Domain wise Mean, SD and Mean % of Treatment seeking Behaviour in CKD Patients

Section 7- Item wise Mean and SD of level of Treatment seeking Behaviour in CKD Patients

Section 8- Association of Burden with Demographic Variables

Section 9: Association of Treatment seeking Behaviour with Demographic Variables

SECTION 1. DESCRIPTION OF DEMOGRAPHIC VARIABLES OF THE CKD PATIENTS

Table 1: Frequency and Percentage distribution of CKD Patients as per Demographic Variables

N=220

S. NO.	Demographic Variables	f	%
1.	**Age**		
	a) 18-35 years	40	18.2
	b) 35-50 years	62	28.2
	c) 50-65 years	74	33.6
	d) 65 years and above	44	20
2.	**Gender**		
	a) Male	129	58.6
	b) Female	91	41.4
3.	**Marital Status**		
	a) Married	166	75.5
	b) Unmarried	19	8.6
	c) Widow/ Widower\Separated	35	15.9
4.	**Occupation**		
	a) Unemployed	54	24.5
	b) Government Job	41	18.6
	c) Private Job	43	19.5
	d) Business	29	13.2
	e)Others	53	24.1
5.	**Religion**		
	a) Hindu	142	64.5
	b) Muslim	76	34.5
	c) Sikh	03	0.9
6.	**Education**		
	a) Illiterate	50	22.7
	b) Primary	85	38.6
	c) Secondary	54	24.5
	d) Graduation and above	31	14.1

7.	**Diagnosed CKD since**		
	a) 6 month-1 year	14	6.4
	b) 1-2 year	69	31.4
	c) 2-3 year	82	37.3
	d) 3-4 year	55	25
8.	**Income of Family**		
	a) ≥52,734	49	22.3
	b) 26,355-52,733	46	20.9
	c)19,759-26,354	62	28.2
	d)13,161-19,758	40	18.2
	e) 7,887-13,160	22	10
	f) 2,641-7,886	01	0.5
9.	**Comorbid Health Conditions***		
	a)Yes	220	100
	b) No	0	0
	• Diabetes	35	15.9
	• Hypertension	171	77.8
	• Neurological Disorders	15	6.9
	• Asthma/COPD	13	5.9
	• Peripheral Vascular Disease	06	2.8
	• Musculoskeletal Disorders	07	3.2
	• Heart Disease	26	11.9
	• Others	17	7.8

**Comorbid Health conditions having multiple response.*

Table 1 depicts the frequency and percentage distribution of CKD patients as per demographic variables. It is found that 33.6% CKD patients falling in the age groups of 50-65 years followed by 35-50 years age group which was 28.2%, About 20% patients of the total population were in the age group of 65 years and above, only 18.2% patients were 18-35 years of age. About 58.6% patients were males followed by 41.4% females. 75.5% CKD patients had married followed by 15.9% widowed\separated patients and 8.6% patients had unmarried. The 24.5% patients were unemployed followed by 24.1% were in others occupation, 19.5% patients were doing private job, nearly 18.6% were doing government job

and about 13.2% CKD patients were doing Business. The 64.5% patients were Hindu in religion followed by 34.5% Muslim patients and only 0.9% patients were Sikh. About 38.6% CKD patients were having primary education followed by 24.5% were having secondary education, nearly 22.7% patients were Illiterate and 14.1% patients were graduation and above. About 37.3% CKD patients were diagnosed disease by 2-3 years duration followed by 31.4% patients come under 1-2 years of disease duration, nearly 25% were 3-4 years of disease duration and about 6.4% were diagnosed disease since 6 month-1 year.

Result depicts that 28.2% patients were having family income 19,759-26,354 followed by 22.3% were ≥52,734, about 20.9% and 18.2% were having 26,335-52,733 and 13,161-19,758 respectively, and about 10% of patients were falls in category of 7,887-13,160 followed by 0.5% patients were in 2,641-7,886 category. The most common co-morbidities found in CKD Patients were Hypertension in 77.8%, Diabetes mellitus in 15.9%, Heart disease in 11.9%, others disease in 7.8%, neurological disorders in 6.9%, Asthma\COPD in 5.9%, musculoskeletal in 3.2% and Peripheral vascular disease in 2.8%.

SECTION 2. FREQUENCY AND PERCENTAGE OF LEVEL OF BURDEN IN THE CKD PATIENTS

Table 2. Frequency and Percentage of level of Burden in CKD Patients

N=220

S. NO.	Level of Burden	f	%	Mean ± SD
1.	Mild (18-26)	63	28.6	
2.	Moderate (27-40)	133	60.5	30.70 ± 10.11
3.	Severe (41-54)	24	10.9	

The maximum score was 54 and minimum score was 18.

Table 2 depicts the frequency and percentage of level of burden in CKD patients. It is found that 60.5% CKD patients were having moderate level of burden followed by 28.6% mild level of burden and about 10.9% CKD patients were having severe level of burden. The overall mean of level of burden was 30.70. Hence, majority of CKD patients were having moderate level of burden.

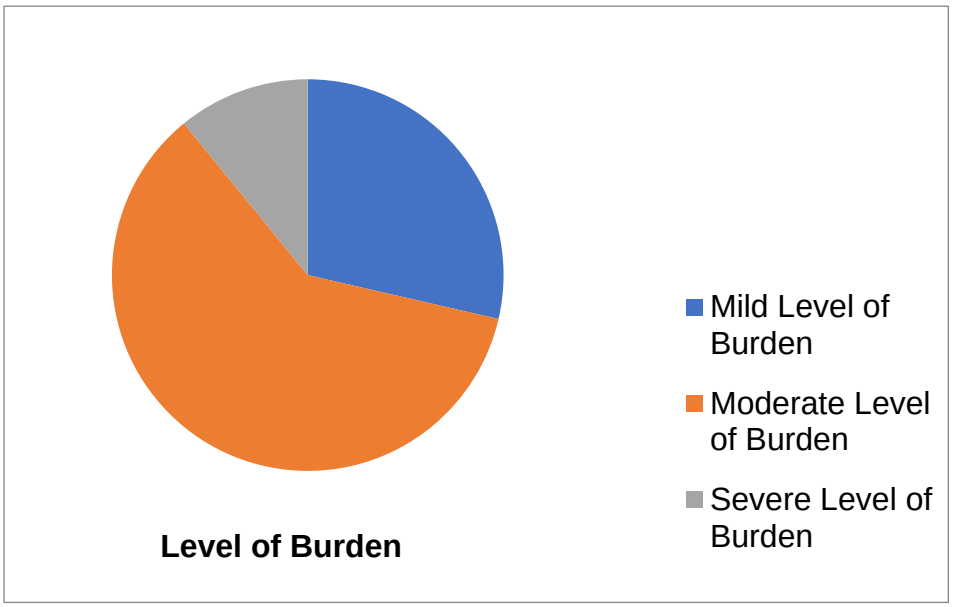

Figure 2 Showing Pie chart for Level of Burden in CKD Patients

SECTION 3: DOMAIN WISE MEAN, SD AND MEAN % OF BURDEN IN CKD PATIENTS

TABLE 3: Domain wise Mean, SD and Mean % of Burden in CKD Patients

N=220

S. NO.	Domain	Mean ±S.D.	Mean %
1	Physical	13.75 ±4.33	65.47
2	Psychological	6.86 ±2.61	45.74
3	Emotional	6.01 ±1.7	66.78
4	Financial	4.06 ±1.47	45.12

Number of items in each Domain; Physical- 7, Psychological- 5, Emotional- 3, Financial-3

Table 3 depicts domain wise mean and mean % of burden in CKD patients. It is found that CKD patients had highest burden in emotional domain (Mean %= 66.78) followed by physical domain (Mean %= 65.47). CKD patients had lowest burden in financial domain (Mean %= 45.12) followed by psychological domain (Mean %= 45.74). Hence, majority of the CKD patients had highest burden in emotional domain.

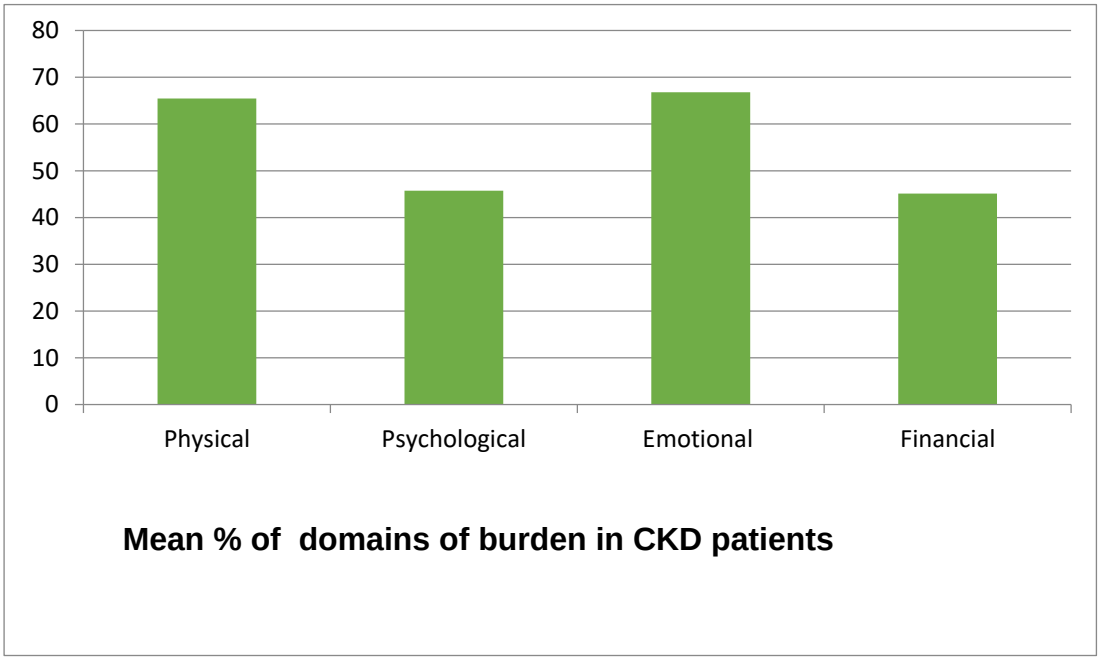

Figure 3 Showing bar graph of Mean % of domains of burden in CKD patients.

SECTION 4: ITEM WISE MEAN AND SD OF LEVEL OF BURDEN IN CKD PATIENTS

Table 4: Item wise Mean and SD of level of Burden in CKD Patients

N=220

Level of Burden	Mean ±SD
Do you-	
1) have Anorexia	1.87± .65
2) feel excessive Tiredness	2.4± .57
3) have difficulty in Sleeping	1.79± .62
4) have bone/joint pain	2.29± .72
5) have Pruritus	1.49± .60
6) feel muscle cramps	2.43± .55
7) have difficulty in keeping legs straight	1.45± .62
8) feel anxious about the disease condition	1.66± .57
9) feel that this disease cursed by God	1.16± .45
10) suffer from low self-esteem	1.35± .55
11) have experienced depressive thoughts or feeling	1.52± .58
12) have fear of death	1.15± .46
13) feel sad	2.05± .53
14) like to share your feelings with someone	2.35± .57
15) have episodes of emotional outburst	1.61± .60
16) think the cost of treatment is high	1.54± .55
17) borrow money for your treatment.	1.31± .49
18) cut down expenses on recreational activities.	1.21± .43

Table 4 depicts the item wise mean and SD of level of burden in CKD patients. It is found that highest burden in CKD patients were having ‘feel muscle cramps’ with the mean i.e., 2.43, followed by ‘feel excessive tiredness’ with mean i.e., 2.4 and next frequent burden was ‘like to share feelings with someone’ with the mean i.e., 2.35. The lowest burden in CKD patients were having ‘fear of death’ with the mean i.e., 1.15, followed by ‘feel that the disease cursed by God’ with mean i.e., 1.16 and next lowest burden was ‘cut down expenses on recreational activities’ with mean i.e., 1.21. Hence, the most frequent level of burden in CKD patients had ‘feel muscle cramps’ and least level of burden had ‘fear of death’.

SECTION 5. FREQUENCY AND PERCENTAGE OF LEVEL OF TREATMENT SEEKING BEHAVIOUR IN CKD PATIENTS

TABLE 5. Frequency and Percentage of Level of Treatment seeking Behaviour in CKD Patients

N=220

S. No.	Level of Treatment seeking Behaviour	f	%	Mean ± SD
1	Good (12-16)	56	25.5	
2	Fair (8-11)	139	63.2	10.08 ± 6.35
3	Poor (≤7)	25	11.4	

The maximum score was 16 and minimum score was 0.

Table 5 depicts the frequency and percentage of level of treatment seeking behaviour in CKD patients. It is found that 63.2% of CKD patients were having fair level of treatment seeking behaviour followed by 25.5% good level of treatment seeking behaviour and about 11.4% CKD patients were having poor level of treatment seeking behaviour. The overall mean of level of treatment seeking behaviour was 10.08. Hence, majority of CKD patients were having fair level of treatment seeking behaviour.

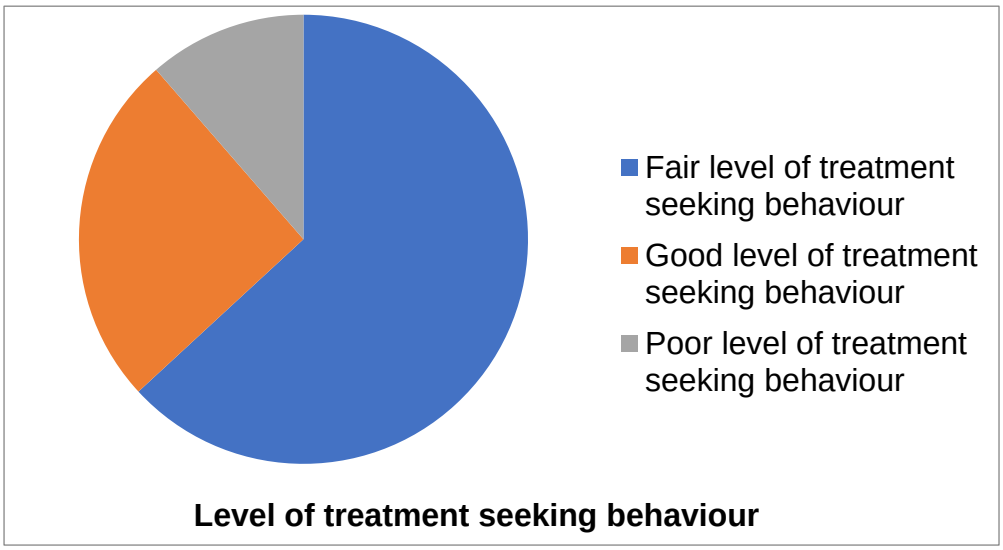

Figure 4 Showing Pie chart for Level of Treatment seeking Behaviour in CKD Patients

SECTION 6: DOMAIN WISE MEAN, SD AND MEAN % OF TREATMENT SEEKING BEHAVIOUR IN CKD PATIENTS

TABLE 6: Domain wise Mean, SD and Mean % of Treatment seeking Behaviour in CKD Patients

N=220

S. NO.	Domain	Mean ±S.D.	Mean %
1	Personal	4.94±2.87	70.58
2	Hospital	3.43±1.78	68.8
3	Family	0.57±0.88	29
4	Financial	1.13±0.82	57

Number of items in each Domain; Personal- 7, Hospital- 5, Family- 2, and Financial- 2

Table 6 depicts the domain wise mean and mean % of treatment seeking behaviour in CKD patients. It is found that CKD patients had highest treatment seeking behaviour in personal domain (Mean %= 70.58) followed by hospital domain (Mean %= 68.8). CKD patients had lowest treatment seeking behaviour in family domain (Mean %= 29) followed by financial domain (Mean %= 57). Hence, the most affected treatment seeking behaviour domain was personal domain in CKD patients.

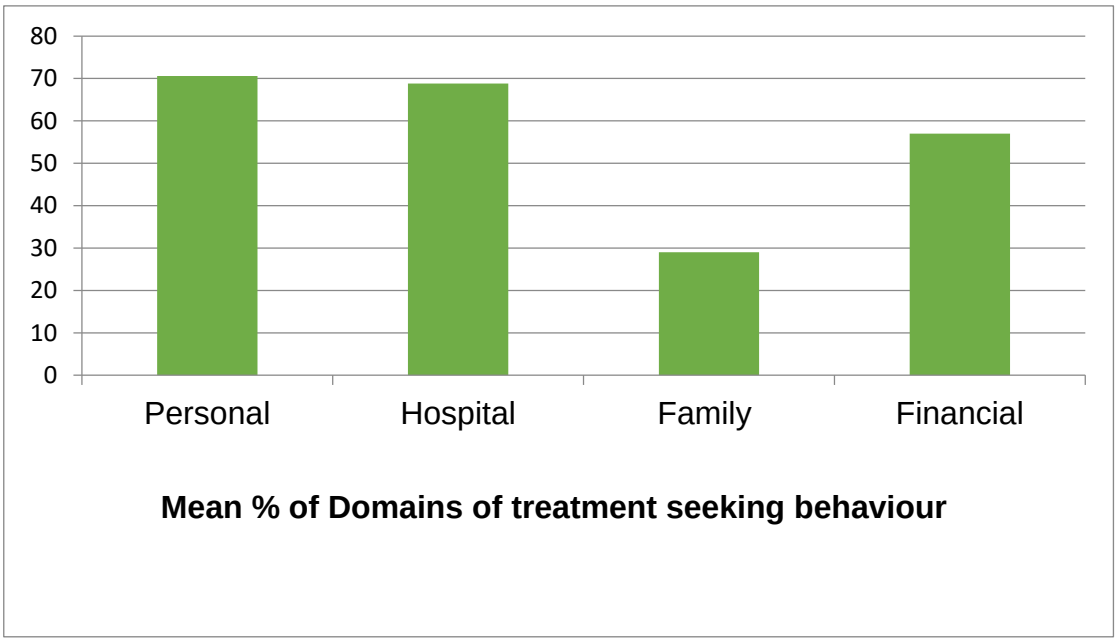

Figure 5 Showing bar graph of Mean % of treatment seeking behaviour in CKD patients

SECTION 7: ITEM WISE MEAN AND SD OF LEVEL OF TREATMENT SEEKING BEHAVIOUR IN CKD PATIENTS

Table 7: Item wise Mean and SD of Level of Treatment seeking Behaviour in CKD Patients

N=220

Level of Treatment seeking Behaviour	Mean ±SD
Do you-	
1. take home remedies to manage common ailments related to present disease.	0.46± .50
2. know about the treatment period and disease severity. (Sign and Symptoms).	0.53± .50
3. receiving treatment on right time as prescribed by Physician, when visited to health care centre.	0.87± .32
4. think usage of health services is beneficial to you.	0.86± .33
5. follow Diet regimen as prescribed by Physician.	0.63± .48
6. have faith in prescribed treatment as compare to traditional healer.	0.92± .26
7. think visiting hospital to receive treatment limit Activities of Daily Living.	0.64± .48
8. think health care provider values your respect and dignity and their behaviour is appropriate.	0.96± .18
9. think distance from residence to health care facility restricts you to seek treatment.	0.30± .46
10. have concern regarding confidentiality of your health information which affects you to seek treatment.	0.81± .39
11. influenced by advertisement and mass media about	0.41± .49

medications and do self-treatment.	
12. think the quality and spending time of received health services is acceptable.	0.92± .26
13.depend on family members during hospital visits.	0.36± .48
14. feel rejected or affect the relationship with family members because of disease condition.	0.20± .40
15. think cost of services affects your life style and living standards of family members.	0.30± .45
16. purchase medications without doctor's prescription.	0.83± .37

Table 7 depicts the item wise mean and SD of level of treatment seeking Behaviour in CKD patients. It is found that highest level of treatment seeking behaviour in CKD patients were 'think that health care provider values respect and dignity and their behaviour is appropriate' with the mean i.e., 0.64 followed by 'have faith in prescribed treatment as compare to traditional healer and think the quality and spending time of received health services is acceptable' with the same mean i.e., 0.92 and next level of treatment seeking behaviour was 'receiving treatment on right time as prescribed by physician, when visited to health care centre' with the mean i.e., 0.87. Whereas, the lowest level of treatment seeking behaviour in CKD patients were 'feel rejected or affect the relationship with family members because of disease condition' with the mean i.e., 0.20 followed by 'think distance from residence to health care facililty restricts to seek treatment' and 'think cost of services affects the life style and living standards of family members' with the same mean i.e., 0.30 and next lowest level of treatment seeking behaviour were 'depend on family members

during hospital visits' with the mean i.e., 0.36. Hence, the most frequent level of treatment seeking behaviour in CKD patients was 'think that health care provider values respect and dignity and their behaviour is appropriate' and least level of treatment seeking behaviour was 'feel rejected or affect the relationship with family members because of disease condition'.

SECTION 8. ASSOCIATION OF BURDEN OF CKD PATIENTS WITH DEMOGRAPHIC VARIABLES

TABLE 8. Association of Burden of CKD Patients with Demographic Variables

N=220

S.NO.	Demographic Variables	Burden			X^2	df	P value
		Mild	Moderate	Severe			
1.	**Age**						
	a)18-35 years	25	13	02			
	b) 35-50 years	24	33	05	42.9	6	0.00*
	c) 50-65 years	11	53	10			
	d) 65 years and above	03	34	07			
2.	**Gender**						
	a)Male	38	78	13	0.27	2	0.87NS
	b) Female	25	55	11			
3.	**Marital Status**						
	a) Married	50	100	16			
	b) Unmarried	08	10	01	7.65	4	0.10NS
	c) Widow/ Widower\Separated	05	23	07			
4.	**Occupation**						
	a) Unemployed	10	35	09			
	b) Government Job	16	23	02			
	c) Private Job	17	23	03	19.27	8	0.10NS
	d) Business	03	19	07			
	e) Others	17	33	03			
5.	**Religion**						
	a) Hindu	46	79	17			
	b) Muslim	15	54	07	10.09	4	0.03*
	c) Sikh	02	00	00			
6.	**Education**						
	a) Illiterate	07	33	10			
	b) Primary	18	60	07	24.14	6	0.00*
	c) Secondary	22	26	06			
	d) Graduation and above	16	14	01			

7.	**Diagnosed CKD since**						
	a) 6 month-1 year	08	06	00			
	b) 1-2 year	32	31	06	28.3	6	0.00*
	c) 2-3 year	17	56	09			
	d) 3-4 year	06	40	09			
8.	**Income of Family**						
	a) ≥52,734	08	34	07			
	b)26,355-52,733	13	28	05			
	c) 19,759-26,354	22	31	09	11.29	10	0.33NS
	d) 13,161-19,758	14	23	03			
	e) 7,887-13,160	06	16	00			
	f)2,641-7,886	00	01	00			

**Significant (p<0.05), NS-Non significant (p>0.05)*

Table 8 depicts the association of burden with demographic variables in CKD patients. It is found that there was significant association of age, religion, education, duration of disease with burden in CKD patients. There was no significant association of gender, marital status, occupation, income of family with burden of CKD patients. Thus, research hypothesis H_1 was partially accepted.

SECTION 9. ASSOCIATION OF TREATMENT SEEKING BEHAVIOUR OF CKD PATIENTS WITH DEMOGRAPHIC VARIABLES

TABLE 9. Association of Treatment seeking Behaviour of CKD Patients with Demographic Variables

N=220

S. No.	Demographic Variables	Treatment Seeking Behaviour			X^2	df	P value
		Good	Fair	Poor			
1.	**Age**						
	a)18-35 years	21	19	00			
	b) 35-50 years	21	40	01	42.41	6	0.00*
	c) 50-65 years	10	50	14			
	d) 65 years and above	4	30	10			
2.	**Gender**						
	a)Male	42	67	20	17.12	2	0.00*
	b) Female	14	72	05			
3.	**Marital Status**						
	a) Married	42	106	18			
	b) Unmarried	09	10	00	10.17	4	0.03*
	c) Widow/ Widower\Separated	05	23	07			
4.	**Occupation**						
	a) Unemployed	09	38	07			
	b) Government Job	15	24	02	16.02	8	0.04*
	c) Private Job	17	22	04			
	d) Business	07	16	06			
	e) Others	08	39	06			
5.	**Religion**						
	a) Hindu	38	87	17			
	b) Muslim	16	52	08	7.036	4	0.134NS
	c) Sikh	02	00	00			
6.	**Education**						
	a) Illiterate	05	33	12			
	b) Primary	16	59	10	42.01	6	0.00*
	c) Secondary	15	37	02			
	d) Graduation and above	20	10	01			

7.	**Diagnosed CKD since**						
	a) 6 month-1 year	10	04	00			
	b)1-2 year	21	45	03	26.79	6	0.00*
	c) 2-3 year	18	52	12			
	d) 3-4 year	07	38	10			
8.	**Income of Family**						
	a) ≥52,734	13	30	06			
	b) 26,355-52,733	13	28	05			
	c) 19,759-26,354	15	42	05	3.22	10	0.97NS
	d) 13,161-19,758	11	24	05			
	e) 7,887-13,160	04	14	04			
	f) 2,641-7,886	00	01	00			

Significant (p<0.05), NS-Non Significant(p>0.05)*

Table 9 depicts the association of treatment seeking behaviour with demographic variables. It is found that there was significant association of age, gender, marital status, occupation, education, duration of Disease with treatment seeking behaviour. There was no significant association of income of family, religion with treatment seeking behaviour of CKD patients. Thus, research hypothesis H_2 was partially accepted.

MAJOR FINDINGS OF STUDY

The study findings showed that approximately one-third of CKD patients (33.6%) were of 50 to 65 years of age. More than half of them (58.6%) were male and about 75.5% were married. 24.5% CKD patients were unemployed and approximately two-third (64.5%) of them were Hindu. More than One-third of CKD patients (38.6%) had primary education and 37.3% were diagnosed CKD since 2-3 years. About 77.8% CKD patients had hypertension as comorbidity in CKD patients.

More than half of CKD patients were having moderate level of burden (60.5%). Majority of CKD patients had highest burden in emotional domain (Mean %= 65.47). Out of total CKD patients majority of patients had level of burden 'feels muscle cramps' (mean=2.43). More than half of CKD patients (63.2%) were having fair level of treatment seeking behaviour. Majority of CKD patients had highest treatment seeking behaviour in personal domain (mean %=70.58). Out of total CKD patients, majority of CKD patients think that 'health care provider values the respect and dignity and their behaviour is appropriate' in treatment seeking behaviour.

There was significant association of age, religion, education, duration of disease with burden in CKD patients and thus, H_1 Hypothesis was partially accepted. There was significant association of age, gender, marital status, occupation, education, duration of disease with treatment seeking behaviour in CKD patients and thus, H_2 hypothesis was partially accepted.

DISCUSSION

A review of literature globally reveals considerable variation in the reporting of burden and poor treatment seeking behaviour prevalence across studies. Now a days CKD is leading cause of Dialysis and renal transplantation worldwide. Globally CKD is increased due to comorbidities like Hypertension and Diabetes mellitus of the population. The current study was conducted to assess the burden and treatment seeking behaviour of the CKD patients. In this section, discussion about the research findings from quantitative study with the current literature available is done. It is organized and discussed as follows: burden and treatment seeking behaviour of CKD patients.

The study findings shows that the 60.5% CKD patients were having moderate level of burden, 28.6% were having mild level of burden and 10.9% had severe level of burden. Majority of the CKD patients 63.2% had fair level of treatment seeking behaviour, 25.5% were having good level of treatment seeking behaviour and 11.4% were having poor level of treatment seeking behaviour. In this study, burden and treatment seeking behaviour was significantly associated with the demographic variables. A similar study conducted by Babawale Taslim et al[12] (2017) revealed that majority of CKD patients (71.2%) having appropriate health care behaviour.

In the current study, findings shows that the most common level of burden in CKD patients were having ‘muscle cramps’ followed by ‘feeling excessive tiredness’. A study conducted by Hansani Madhushika Abeywickrama et al[21] (2019) revealed that the most common level of physical burden was bone\joint pain. Another study conducted by Sameera Sannayanka et al[26] (2017) revealed that majority of

patients were having bone\joint pain as most experienced symptom and the most severe symptom was loss of libido. A similar study conducted by Hayfa Almutary[29] et al (2013) showed that majority of CKD patients were having common symptoms such as fatigue, pain, feeling drowsy and pruritus.

The current study findings showed that most common comorbidity related to CKD was hypertension (77.8%) and Diabetes mellitus (15.9%). A similar study conducted by Olumuyiwa John Fasipe et al[19] (2019) showed that majority of CKD patients were having two comorbidities such as hypertension and diabetes mellitus. Another study conducted by C H Moideen Kutty Gurukkal et al[25] (2018) revealed that the comorbidities that causes CKD was diabetic nephropathy, chronic glomerulonephritis and hypertensive nephropathy. A study conducted by Simmon D. S. Fraser et al[28] (2015) revealed that hypertension was the most common comorbidity found in CKD patients.

In the present study reveals that there is statistical significant association of level of burden with demographic variables like age, religion, education and duration of disease. Statistical significant association of level of treatment seeking behaviour with demographic variables like age, gender, marital status, occupation, education, duration of disease regarding regarding CKD. A similar study conducted by Usha Bapatet et al[32] (2008) revealed that gender, marital status and occupation were significantly associated with acceptance of their treatment.

SUMMARY OF THE CHAPTER

The chapter presents the data analysis, interpretation, and discussion of the data collected to assess the Burden and Treatment seeking Behaviour in CKD Patients. Descriptive and inferential statistics were used for data analysis and frequency percentage and chi-square were calculated. Chapter V presents a summary and conclusion.

CHAPTER V

SUMMARY, CONCLUSION AND RECOMMENDATIONS

CHAPTER IV

SUMMARY CONCLUSION AND RECOMMENDATIONS

The chapter gives a brief account of the present study including the conclusion from the findings, limitations, implications of the study and recommendations for future research.

Summary

CKD has progressively emerged as a major public health problem worldwide, with adverse physical, psychological, emotional and financial outcomes. CKD is develop over a long period of time includes damaging of kidney that causes functional limitation and disability to the patients. CKD usually doesn't causes any symptoms until it reached to advanced stage. The assessment of Burden and Treatment seeking Behaviour in CKD patients plays a vital role in patient's experience and clinical management of the disease. This descriptive survey study was conducted to assess Burden and Treatment seeking Behaviour in CKD patients attending nephrology OPD of AIIMS, Jodhpur Rajasthan. Total of 220 CKD patients of age group above 18 years included in this study. Samples were taken through a non-probability convenient sampling technique and data was collected through face to face or telephonic interview method. Burden and Treatment seeking Behaviour in CKD patients were assessed.

The objectives of the study were:

a. To assess the Burden among the CKD Patients.
b. To assess the Treatment seeking Behaviour among the CKD Patients.

c. To determine the association of burden and treatment seeking behaviour of CKD Patients with Demographic variables.

The research approach was a quantitative research approach and design used was a Descriptive survey research design. The demographic variables were: age, gender, marital status, occupation, religion, education, diagnosed CKD since, income of family and comorbid health conditions, and other variables were burden and treatment seeking behaviour in CKD patients.

Data were collected through face to face or telephonic interview the patients and recorded the responses in the tool and analyzed with the use of descriptive statistics. It is found that approximately one-third of the CKD patients (33.6%) were in age group of 50-65 years, 58.6% were male, 75.5% were married, nearly two-third (64.5%) of CKD patients were Hindu and 38.6% CKD patients were having primary education and about 37.3% were diagnosed CKD since 2-3 years. Majority of CKD patients (77.8%) were having hypertension as comorbidity.

In the Burden, more than half of CKD patients (60.5%) had moderate level of burden. Majority of CKD patients had highest burden in emotional domain (Mean %= 65.47). Out of total CKD patients majority of patients were having level of burden ‘feels muscle cramps’ (mean=2.43). More than half of CKD patients (63.2%) had fair level of treatment seeking behaviour. Majority of CKD patients had highest treatment seeking behaviour in personal domain (mean %=70.58). Out of total CKD patients, majority of CKD patients think that ‘health care provider values the respect and dignity and their behaviour is appropriate’ in treatment seeking behaviour.

There was significant association of age, religion, education, duration of disease with burden in CKD patients and thus, H_1 Hypothesis was partially accepted. There was also significant association of age, gender, marital status, occupation, education, duration of disease with treatment seeking behaviour and thus, H_2 Hypothesis was partially accepted.

LIMITATIONS OF THE STUDY

- No intervention was provided.
- The study was confined to a single hospital setting, among CKD patients attending nephrology OPD of AIIMS, Jodhpur.
- Samples may not be completely honest with their responses.
- One-time data collection which limit generalizability of the study finding.
- Follow up was not done for the patients who were having severe burden and poor treatment seeking behaviour.

IMPLICATION

Nursing is an art and science. It is based upon the current knowledge i.e., frequently changing with discoveries, ideas, techniques, methodologies and motivations. When nurses integrate the science and art of nursing in their practice, the quality of care provided to patients is at the level of excellence that benefits innumerable clients. The finding of the study has implications on nursing practices, nursing administrations, nursing research and general public.

- **The implication in nursing-** The nurses consists of a wide part and the main resourceful people in health care system, the majority of CKD

patients can approach and consult with the nurses for their different kinds of health care needs. Nurses are also available at a different level of health care delivery system. This study mainly focuses on burden and treatment seeking behaviour in CKD patients, as we found that majority of patients were having moderate level of burden and fair level of treatment seeking behaviour in their disease condition, so the nurses should educate the patients regarding burden and treatment seeking behaviour and can teach them to go for regular follow-up.

Community health nurses are working in field areas in communities, schools and are in contact with the majority of the general population. Majority of general population are suffering from Diabetes Mellitus and Hypertension, which can be a leading cause for developing CKD. So, the community Health nurses can implement screening and educational programs in community for the better improvement and wide implications of these programs. Nurses can also perform role play or awareness programs to develop awareness regarding the CKD.

- **The implication in practice-**This study showed that patients are at their borderline risk for developing severe level of burden and poor level of treatment seeking behaviour in CKD. So, every health care professional should give health education and promote awareness programs related to reducing burden and promoting good treatment seeking behaviour in CKD patients and advise every patients for regular follow up. More and more awareness program should be conducted by the nurses because now a day it is major burden on the

society. It will aid up in improvisation of knowledge of patients regarding CKD.

- **The implication in education-** The student nurses of today are the nursing officers, educators, administrators, supervisors of future; this study has implications in nursing education as well. The nursing education should emphasis on the importance of health education by the student nurses. New innovative ways should be taught to them. Nursing education should emphasis on more on preparing prospective nurse to impart the information on CKD and how to decrease its severity.
- **Nursing administration-** The concept of extended and expanded role of the nurse offers many opportunities for a nurse administrator to improve the quality of life of middle and older age population. The nurse administrator should co-ordinate her work along with the preventive, curative and rehabilitative aspect of care. The nurse administrator at various levels of health care delivery system should focus their attention to make public aware about some awareness programs related to decreasing Burden and promoting treatment seeking behaviour among CKD Patients. Nurse administrators can ensure periodic in-service programs to keep the nursing fraternity updated on the various treatment modalities and advances in CKD prevention and treatment.
- **Nursing research-** One of main aims of research is to contribute knowledge to the body of nursing to expand and broaden the scope of nursing. This is possible only if nurses are taking initiative to conduct

further research. Research should be done to find the preventive measures to decrease burden and improve treatment seeking behaviour in CKD patients as it is most common problem now a days. More studies can be done on a larger population and can be performed in different settings also.

- **General public-** General public can also use the data to avoid and reduce the burden and treatment seeking behaviour in their disease condition and screening can be done to identify comorbidity that further leads to develop CKD.

RECOMMENDATIONS

On the basis of findings of study, it is recommended that

- A study can be replicated on a larger sample of CKD patients, in different setting for making broad generalization.
- Separate study can be performed on Burden and Treatment seeking Behaviour in CKD patients.
- A study can be conducted for the future research to seek systematic research and intervention to establish a better understanding of disease and prevention.
- Some wide programs can be launched for screening of comorbidities related to CKD and awareness programs too.
- A similar study can be done using some teaching strategies i.e.self-instructional module, Information booklet, computer assisted instructions and video films on preventive aspects of developing CKD.

CONCLUSION

CKD is most common disease all across the world and mainly in developing and underdeveloped countries. In India also, CKD most common disease in middle and old age population, but now a days younger population also start to face it. The present study was a descriptive study to assess burden and treatment seeking behaviour of CKD patients. The current study showed that 60.5% of CKD patients had moderate level of burden and 63.2% of them had fair level of treatment seeking treatment. There was significant association of burden and treatment seeking behaviour with demographic variables. Patients with all stages of CKD experience overall Burden that can be; physical, psychological, emotional and financial burden warranting rigorous measure to relieve Burden and to improve the well-being of CKD patients. High disease burden and poor treatment seeking behaviour among CKD patients is a major health problem in India. Unacceptable burden and treatment seeking behaviour among CKD patients should be brought to notice of health care providers caring for CKD patients and health policymakers.

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APPENDICES

APPENDIX-I

अखिल भारतीय आयुर्विज्ञान संस्थान, जोधपुर
All India Institute of Medical Sciences, Jodhpur
संस्थागत नैतिकता समिति
Institutional Ethics Committee

No. AIIMS/IEC/2020/ 3095 **Date: 01/06/2020**

ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number: **AIIMS/IEC/2020-21/**3014

Project title: **"A study to assess the burden and treatment seeking behaviour in CKD Patients attending nephrology OPD in AIIMS, Jodhpur"**

Nature of Project:	**Research Project Submitted for Expedited Review**
Submitted as:	**Student Research Project, as a part of Academic Programme**
Investigator:	**Bindiya**
Supervisor:	**Dr. Ashok Kumar**
Co-Supervisor:	**Mr. Nipin Kalal & Dr. Nitin Bajpai**

Institutional Ethics Committee after thorough consideration accorded its approval on above project.

The investigator may therefore commence the research from the date of this certificate, using the reference number indicated above.

Please note that the AIIMS IEC must be informed immediately of:

- Any material change in the conditions or undertakings mentioned in the document.
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research.

The Principal Investigator must report to the AIIMS IEC in the prescribed format, where applicable, bi-annually, and at the end of the project, in respect of ethical compliance.

AIIMS IEC retains the right to withdraw or amend this if:

- Any unethical principle or practices are revealed or suspected
- Relevant information has been withheld or misrepresented

AIIMS IEC shall have an access to any information or data at any time during the course or after completion of the project.

Please Note that this approval will be rectified whenever it is possible to hold a meeting in person of the Institutional Ethics Committee. It is possible that the PI may be asked to give more clarifications or the Institutional Ethics Committee may withhold the project. The Institutional Ethics Committee is adopting this procedure due to COVID-19 (Corona Virus) situation.

If the Institutional Ethics Committee does not get back to you, this means your project has been cleared by the IEC.

On behalf of Ethics Committee, I wish you success in your research.

Dr. Praveen Sharma
Member Secretary

Member secretary
Institutional Ethics Committee
AIIMS,Jodhpur

APPENDIX-II

TOOL FOR DATA COLLECTION

(IN HINDI)

भाग **1 :** <u>जन सांख्यिकीय परफॉर्मा</u>

कुट **-** संख्या**: -**_____

निर्देश**:** कृपया प्रश्नों को ध्यान से पढ़ें और उचित उत्तर दें।

जन सांख्यिकीय डेटा

1. आयु

ए। **18-35** वर्ष

ख। **35-50** वर्ष

सी। **50-65** वर्ष

घ। **65-80** वर्ष

2. लिंग

ए। पुरुष

ख। महिला

3. वैवाहिक स्थिति

ए। विवाहित

ख।अविवाहित

सी। विधवा **/ विधुर / अलग**

4. व्यवसाय

ए। **बेरोज़गार**

ख। सरकारी नौकरी

सी। निजी नौकरी

घ। **व्यापार**

इ। अन्य

5. धर्म

ए। हिंदू

ख। मुसलमान

सी। सिख

घ। ईसाई

6. शिक्षा

ए। निरक्षर

बी। प्राथमिक

सी। माध्यमिक

d। स्नातक और ऊपर

7. ज्ञात **CKD** कब से

ए। 6 महीने -1 साल

ख। 1-2 साल

सी। 2-3 साल

घ। 3-4 साल

8. **परिवार की आय**

ए। ≥52,734

ख। 26,355-52,733

सी। 19,759-26,354

घ। 13,161-19,758

इ। 7,887-13,160

च। 2,641-7,886

जी। ≤2,640

9. **कोमोबिटिज स्वास्थ्य की स्थिति**

ए। मधुमेह

बी। उच्च रक्तचाप

सी। मस्तिष्क संबंधी विकार

डी। अस्थमा / COPD

इ। बाह्य संवहनी बीमारी

च। वात रोग

जी। दिल की बीमारी

ज। अन्य

भाग 2 : CKD रोगियों में बोझ के आकलन के लिए रेटिंग पैमाना

इस पैमाने को रोग के संबंध में बोझ के आकलन के बारे में जानकारी प्राप्त करने के लिए डिज़ाइन किया गया है। कृपया निम्न कॉलम में अंकित करें:

मानदंड	कभी-नहीँ	कभी-कभी	हमेशा
शारीरिक			
□ क्या आप-			
• भूख नहीं लगती है			
• अत्यधिक थकान महसूस करना			
• नींद आने में कठिनाई होना			
• हड्डी / जोड़ों का दर्द हो			
• **खुजली है**			
• **आपको मांसपेशियों में ऐंठन महसूस होती है**			
• **पैर सीधे रखने में कठिनाई होती है**			
मनोवैज्ञानिक			
□ क्या आप-			
• अपनी बीमारी की स्थिति के बारे में चिंतित महसूस करें			
• **आपको लगता है कि यह बीमारी भगवान द्वारा श्रापित है**			
• **कम आत्मसम्मान से पीड़ित हैं**			
• अवसादग्रस्त विचार या भावना का अनुभव किया है			
• **मृत्यु का भय है**			
भावनात्मक			
□ क्या आप-			

• इस बीमारी से दुखी हैं			
• **अपनी भावनाओं को किसी के साथ साझा करना पसंद करते हैं**			
• भावनात्मक प्रकोप से पीड़ितहैं			
वित्तीय			
□ क्या आप-			
• लगता है कि आपके उपचार की लागत अधिक है			
• **अपने इलाज के लिए पैसे उधार लेते हैं।**			
• **मनोरंजक गतिविधियों पर खर्चों में कटौती करते हैं।**			

<u>भाग -3: उपचार से संबंधित व्यवहार आकलन करने के लिए चेकलिस्ट</u>

<u>निर्देश-</u>

यह चेकलिस्ट बीमारी की स्थिति के बारे में व्यवहार की मांग के उपचार के मूल्यांकन के बारे में जानकारी प्राप्त करने के लिए डिज़ाइन की गई है। कृपया निम्नलिखित के रूप में उपयुक्त कॉलम में चिह्नित करें (√):

मानदंड	**नहीं**	**हाँ**
निजी		
क्या आप-		
1. वर्तमान बीमारी से संबंधित सामान्य बीमारियों का प्रबंधन करने के लिए घरेलू उपचार करते हैं।		
2. इलाज की अवधि और बीमारी की गंभीरता के बारे में जानते हैं। (संकेत और लक्षण)।		
3. जब आप स्वास्थ्य देखभाल केंद्र में जाते हैं, तो चिकित्सक द्वारा निर्धारित समय पर उपचार प्राप्त करते हैं।		
4. लगता है कि स्वास्थ्य सेवाओं का उपयोग आपके लिए फायदेमंद है।		
5. डाइट रेजिमेंट फॉलो करते हैं जैसा कि फिजिशियन द्वारा बताया गया है।		
6. पारंपरिक उपचारकर्ता की तुलना में निर्धारित उपचार में विश्वास है।		
7. लगता है कि अस्पताल में जाकर दैनिक जीवनयापन की गतिविधियां सीमित हो जाती हैं		

अस्पताल		
8. लगता है कि स्वास्थ्य देखभाल प्रदाता आपके सम्मान और सम्मान को महत्व देता है और उनका व्यवहार उचित है।		
9. लगता है कि स्वास्थ्य देखभाल की सुविधा के लिए निवास से दूरी आपको उपचार लेने के लिए प्रतिबंधित करती है।		
10. अपनी स्वास्थ्य जानकारी की गोपनीयता के बारे में चिंता है जो आपको उपचार लेने के लिए प्रभावित करती है।		
11. दवाओं के बारे में विज्ञापन और मास मीडिया से प्रभावित हैं और स्वयं उपचार करते हैं।		
12. लगता है कि प्राप्त स्वास्थ्य सेवाओं की गुणवत्ता और खर्च का समय स्वीकार्य है।		
परिवार		
13. अस्पताल के दौरे के दौरान परिवार के सदस्यों पर निर्भर हैं।		
14. जब तक आप बीमारी की स्थिति के लिए परिवार के सदस्यों के साथ रिश्ते को अस्वीकार या प्रभावित महसूस करते हैं।		
वित्तीय		
15. लगता है कि सेवाओं की लागत आपकी जीवन शैली और परिवार के सदस्यों के जीवन स्तर को प्रभावित करती है।		
16. डॉक्टर के पर्चे के बिना दवाएं खरीदते हैं।		

APPENDIX – III

TOOL FOR DATA COLLECTION

(TOOL IN ENGLISH)

PART A: Demographic Performa

Code no: -_____

Instructions: Please read the questions carefully and give the appropriate answer.

Demographic Data

1. **Age**
   a. 18-35 years
   b. 35-50 years
   c. 50-65 years
   d. 65 years and above

2. **Gender**
   a. Male
   b. Female

3. **Marital Status**
   a. Married
   b. Unmarried
   c. Widow/ Widower\Separated

4. **Occupation**
   a. Unemployed
   b. Government Job
   c. Private Job
   d. Business
   e. Others

5. **Religion**
   a. Hindu
   b. Muslim
   c. Sikh
   d. Christian

6. **Education**
   a. Illiterate

b. Primary
c. Secondary
d. Graduation and above

7. **Diagnosed CKD Since**
   a. 6 month-1 year
   b. 1-2 year
   c. 2-3 year
   d. 3-4 year

8. **Income of Family**
   a. ≥52,734
   b. 26,355-52,733
   c. 19,759-26,354
   d. 13,161-19,758
   e. 7,887-13,160
   f. 2,641-7,886
   g. ≤2,640

9**. Comorbid Health Conditions**
   a. Diabetes
   b. Hypertension
   c. Neurological Disorders
   d. Asthma/COPD
   e. Peripheral Vascular Disease
   f. Musculoskeletal Disorders
   g. Heart Disease
   h. Others

PART B: Rating scale for assessing Burden of CKD Patients

This scale is designed to get information about the assessment of burden regarding the disease condition. Please mark (√) in the appropriate column as following:

Domains	**Never**	**Sometimes**	**Always**
Physical			
Do you-			
• Have Anorexia			
• Feel excessive Tiredness			
• Have difficulty in Sleeping			
• Have bone/joint pain			
• Have Pruritus			
• Feel muscle cramps			
• Have difficulty in keeping legs straight			
Psychological			
Do you-			
• Feel anxious about the disease condition			
• Feel that this disease cursed by God			
• Suffer from low self-esteem			
• Have experienced depressive thoughts or feeling			
• Have fear of death			
Emotional			
Do you-			
• Feel sad			
• Like to share your feelings with someone			

• Have episodes of emotional outburst			
Financial			
Do you-			
• think the cost of treatment is high			
• borrow money for your treatment.			
• Cut down expenses on recreational activities.			

PART-3: Checklist for assessing treatment seeking behaviour of CKD Patients

Instructions

This checklist is designed to get information about the assessment of treatment seeking behaviour regarding the disease condition. Please mark (√) in the appropriate column as following:

Domains	**No (0)**	**Yes (1)**
Personal		
Do you-		
1. take home remedies to manage common ailments related to present disease.		
2. Know about the treatment period and disease severity. (Sign and Symptoms).		
3. receiving treatment on right time as prescribed by Physician, when visited to health care centre.		
4. think usage of health services is beneficial to you.		
5. follow Diet regimen as prescribed by Physician.		
6. have faith in prescribed treatment as compare to traditional healer.		
7. think visiting hospital to receive treatment limit Activities of Daily Living.		
Hospital		
8. think health care provider values your respect and dignity and their behaviour is appropriate.		
9. think distance from residence to health care facility restricts you to seek treatment.		

10. have concern regarding confidentiality of your health information which affects you to seek treatment.		
11. influenced by advertisement and mass media about medications and do self treatment.		
12. think the quality and spending time of received health services is acceptable.		
Family		
13. depend on family members during hospital visits.		
14. feel rejected or affect the relationship with family members for disease condition.		
Financial		
15. think cost of services affects your life style and living standards of family members.		
16. purchase medications without doctor's prescription.		

APPENDIX – IV

DEMOGRAPHIC VARIABLES CODING

S. No.	CONTENT	CODING
1.	**Age**	
	a. 18-35 years	1
	b. 35-50 years	2
	c. 50-65 years	3
	d. 65 years and above	4
2.	**Gender**	
	a. Male	1
	b. Female	2
3.	**Marital Status**	
	a. Married	1
	b. Unmarried	2
	c. Widow/ Widower\Separated	3
4.	**Occupation**	
	a. Unemployed	1
	b. Government Job	2
	c. Private Job	3
	d. Business	4
	e. Others, specify	5
5.	**Religion**	
	a. Hindu	1
	b. Muslim	2
	c. Sikh	3
	d. Christian	4
6.	**Education**	

	a. Illiterate	1
	b. Primary	2
	c. Secondary	3
	d. Graduation and above	4
7.	**Diagnosed CKD Since**	
	a. 6 month-1 year	1
	b. 1-2 year	2
	c. 2-3 year	3
	d. 3-4 year	4
8.	**Income of Family**	
	a. ≥52,734	1
	b. 26,355-52,733	2
	c. 19,759-26,354	3
	d. 13,161-19,758	4
	e. 7,887-13,160	5
	f. 2,641-7,886	6
	g. ≤2,640	7
9.	**Comorbid Health Conditions**	
	a. Diabetes	1
	b. Hypertension	2
	c. Neurological Disorders	3
	d. Asthma/COPD	4
	e. Peripheral Vascular Disease	5
	f. Musculoskeletal Disorders	6
	g. Heart Disease	7
	h. Others	8

APPENDIX – V

LIST OF EXPERTS FOR TOOL VALIDATION

Mrs. Vandna Pandey

Assistant Professor

College of Nursing

AIIMS, Jodhpur

Mrs. Nimarta Rana

Assistant Professor

College of Nursing

AIIMS, Jodhpur

Mr. Maneesh Sharma

Assistant Professor

College of Nursing

AIIMS, Rishikesh

Dr. C. Vasantha Kalyani

Associate Professor

College of Nursing

AIIMS, Rishikesh

Ms Milan Tirwa

Associate Professor

College of Nursing

AIIMS, New Delhi

Ms. Rakhi Mishra

Assistant Professor

College of Nursing

AIIMS, Rishikesh

APPENDIX – VI

INFORMED CONSENT FORM HINDI

सूचित सहमति प्रपत्र **(**हिंदी**)**

परियोजना का शीर्षक: **"अ स्टडी टू असेस द बरडन एंड ट्रीटमेंट सीकिंग बिहेवियर इन सीकेडी पेंशेंटस अटेंडिंग नेफरोलौजी ओपीडी इन एम्स जोधपुर|"**

प्रधान अन्वेषक का नाम: **बिंदिया** (M.Sc. नर्सिंग)

नमूना पहचान संख्या **:**

मैं _____पुत्र**/पत्नी**_____निवासी _____ **"अ स्टडी टू असेस द बरडन एंड ट्रीटमेंट सीकिंग बिहेवियर इन सीकेडी पेंशेंटस अटेंडिंग नेफरोलौजी ओपीडी इन एम्स जोधपुर|"** नामक अध्ययन जिसकी प्रक्रिया और प्रकृति मुझे मेरी भाषा में समझा दी गई है। मैं इस अध्ययन का एक हिस्सा बनने के लिए अपनी पूरी, स्वतंत्र, स्वैच्छिक सहमति देता/ देती हूं। मैं समझता / समझती हूं कि मेरी भागीदारी स्वैच्छिक है और मुझे बिना कोई कारण बताए किसी भी समय अध्ययन से बाहर निकलने के अपने अधिकार के बारे में पता है। मैं समझता / समझती हूं कि मेरे और मेरे किसी भी रिकॉर्ड की जानकारी एम्स, जोधपुर, राजस्थान के जिम्मेदार व्यक्तिया नियामक अधिकारियों से देखी जा सकती है। मैं इन व्यक्तियों को अपने रिकॉर्ड तक पहुंचने की अनुमति देता/ देती हूं।

दिनांक: _____ _____

स्थान: _____ हस्ताक्षर

APPENDIX – VII

INFORMED CONSENT FORM ENGLISH

Title of the project: -**"A study to assess the burden and treatment seeking behaviour in CKD Patients attending the nephrology OPD of AIIMS, jodhpur".**

Name of principle investigator: - **Ms Bindiya (MSc. Nursing) Mob. 7494894645**

Participant Identification No.: -

I, _____D/O or W/O_____R/O_____P

Give me full, free, voluntary consent to be a part of the study **"A study to assess the burden and treatment seeking behaviour in CKD Patients attending the nephrology OPD of AIIMS, jodhpur"** the procedure and nature of which has been explained to me in my own language to my full satisfaction. I confirm that I have had the opportunity to ask question.

I understand that my participation is voluntary and I am aware of my right to opt out of the study at any time without giving any reason.

I understand that the information collected about me, may be looked at by responsible individual from All India Institute of Medical Sciences, Jodhpur, Rajasthan. I give permission for these individual to have access to my records.

Date: - _____

Place: - _____ Signature

APPENDIX – VIII

A LETTER REQUESTING EXPERTS FOR CONTENT VALIDITY

From:

Bindiya

M.Sc. Nursing 1st year

College of Nursing

AIIMS, Jodhpur

To,

Subject: Expert Opinion on Validity of self-structured tool.

Respected Sir/Madam,

I Bindiya student of M.Sc. Nursing 1st year, (Batch-2019) College of Nursing, AIIMS, Jodhpur, Rajasthan (Raj.) have undertaken the following topic for research project: "A Study to assess the burden and treatment seeking behaviour in CKD Patients attending Nephrology OPD in AIIMS, Jodhpur". under the supervision of Dr. Ashok Kumar, Associate Professor, College of Nursing, AIIMS Jodhpur.

Objectives of the study are:

1. To assess the burden among the CKD Patients.
2. To assess the treatment seeking behaviour among the CKD Patients.
3. To determine the association of burden and treatment seeking behaviour of CKD Patients with demographic variables.

I request you to kindly go through the tool and give your opinion for any modification and improvement needed. Your esteemed opinion and critical comments will provide the required direction and contribute immensely to the quality and content of my final research.

Looking forward to your expert guidance and suggestion.

Thanking you in anticipation.

Yours Sincerely

Bindiya

M.Sc.Nursing