

LIVED EXPERIENCES OF CKD PATIENTS UNDERGOING HEMODIALYSIS AT AIIMS, JODHPUR

A thesis submitted to the

All India Institute of Medical Sciences, Jodhpur

In partial fulfillment of the requirement for the degree

Master of Science in Nursing

(Nephro-Urology Nursing)

By

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[2021]

DECLARATION BY THE CANDIDATE

I declare that the thesis entitled “Lived experiences of CKD patients undergoing hemodialysis at AIIMS, Jodhpur.” has been prepared by me under the guidance of Dr. Ashok Kumar, Associate Professor, College of Nursing, AIIMS Jodhpur, Mrs. Vandna Pandey, Assistant Professor, College of Nursing, AIIMS Jodhpur and Dr. Nitin Kumar Bajpai, Associate Professor, Department of Nephrology, AIIMS Jodhpur. No part of this thesis has formed the basis for the award of any degree previously.

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LIST OF ABBREVIATION USED

CKD= Chronic Kidney Disease

HD= Hemodialysis

ESRD/ ESKD= End stage renal (kidney) disease

ABSTRACT

Background: There are several issues in India which contribute to high prevalence of CKD. It is estimated that about 60% to 70% of CKD cases in India are due to diabetes and hypertension. . Hemodialysis is the most common treatment modality for the end-stage chronic kidney disease in the world.. The patient with CKD undergoing hemodialysis faces many problems due to metabolic abnormalities, toxic condition and electrolyte imbalance from renal impairment and changes in lifestyle.

Purpose: The study aimed to explore the lived experiences of CKD patients undergoing hemodialysis.

Method: This study used a phenomenological approach and a interview guide. The study included patients who were undergoing hemodialysis at AIIMS Jodhpur or at other hospital of Jodhpur and were coming for regular follow up at Nephrology OPD, AIIMS, Jodhpur. Non-probability convenience sampling was used in the study. Sample selection criteria included: patients with CKD undergoing hemodialysis since 3 months or more, more than 18 years, speaks hindi or english language. Data saturation reached after taking 12 interview. Data analysed by using thematic analysis with the help of scientific software ATLAS ti.9.

Result: The following theme emerged from the data: uncertainty with life, dependence, lifestyle changes, coping and support and satisfaction with care.

Conclusion: The researcher hope that findings from the study increases understanding of health care providers about the lived experiences of CKD patients on hemodialysis. It provides greater understanding to nurses and other health care providers in identifying the change in practice to provide better care to patients.

Keywords: CKD, phenomenological, hemodialysis, lived experiences

TABLE OF CONTENTS

Sr. No.	Title	Page No.
I	INTRODUCTION	
	• Back ground	1-4
	• Need	5-7
	• Aim	8
	• Statement of problem	8
	• Objectives	8
	• Operational definition	8-9
	• Delimitation	9
II	REVIEW OF LITERATURE	10-15
III	RESEARCH METHODOLOGY	
	• Methodology Flow chart	16
	• Research approach	17
	• Research Design	17
	• Variables under study	17-18
	• Study setting	18
	• Sampling Process	18-19
	• Description of tool	20
	• Ethical consideration	20-21
	• Validity of tool	21
	• Pilot study	21
	• Data collection procedure	21-22
	• Rigor	22-24
	• Plan for data analysis	24
	• Summary	24-25
IV	ANALYSIS AND INTERPRETATION	
	• Result	26-28
	• Major findings	28-48
	• Discussion	51-56
V	SUMMARY CONCLUSION AND RECOMMENDATION	
	• Summary	57-58
	• Limitations of the study	58
	• Implications	59-60
	• Recommendations	60
	• Conclusion	60-61
	REFERENCES	62-65
	APPENDICES	66-106

LIST OF TABLES

Table no.	Title	Page no.
1.	Frequency & percentage distribution of CKD patients undergoing hemodialysis as per demographic variable	27-28
2.	Themes and subthemes of the study	33

LIST OF FIGURES

Figure no.	Title	Page no.
1.	Schematic presentation of research methodology	16

LIST OF APPENDICES

Appendix-I: Ethical clearance certificate

Appendix-IIa: Consent form (Hindi)

Appendix- IIb: Consent form (English)

Appendix-IIIa: Participant information sheet (English)

Appendix-IIIb: Participant information sheet (Hindi)

Appendix-IVa: Demographic variable (English)

Appendix-IVb: Demographic variable (Hindi)

Appendix-IVc: Interview guide (English)

Appendix-IVd: Interview guide (Hindi)

Appendix- V: Letter for opinion and suggestion from experts for content validity
of tool

Appendix- VI: List of experts validated interview guide

Appendix- VII: Bracketing

Appendix- VIII: List of experts validated themes and subthemes

Appendix- IX: Transcript of the interview

Chapter I-

Introduction

INTRODUCTION

BACKGROUND OF THE STUDY

Chronic illness puts patients as well as their family at risk of suffering for long period of time.¹ As each individual have unique personality so their perception regarding particular situations will also differ. Whatever information shared by patient is not only health history in fact it is patient's feelings and his perception of his illness.²

The kidney is the vital organ of human body which removes waste and excess water and control the pH of the blood so its proper functioning is very essential for life. Chronic kidney disease refers to the damage occurred to kidney or a decrease in the glomerular filtration rate (GFR) which lasts for 3 or more months. If it remains untreated it can result in end stage kidney disease/ renal disease (ESKD), which is the last stage of renal failure.³

According to the Global burden of disease 2015 study there were 1.2 million people died from kidney failure, there is 32% increase in the mortality rate of CKD since 2005. In 2010, it is estimated that 2.3–7.1 million people with end stage renal disease died because of no access to maintenance dialysis. Additionally, each year, around 1.7 million people died from AKI. Overall, it is estimated that 5-10 million people die annually from kidney disease worldwide.⁴

It is found that kidney disease is associated with a tremendous burden on economic. In 2010, 2.62 million people received dialysis worldwide and the need for dialysis was projected by 2030. Worldwide important risk factors for kidney disease include diarrhoeal disease, HIV infection, low birth weight, malaria and preterm births.⁴

It is estimated that 1 in 10 persons in the general population have some form of chronic kidney disease. According to statistics of 2017 of India indicate that 1 in every . In India every year there are 175,000 fresh cases of (stage 4 CKD) and they require maintenance dialysis or renal transplantation for their survival.⁵

There are several issues in India which contribute to high prevalence of CKD. It is estimated that about 60% to 70% of CKD cases in India are due to diabetes and hypertension.⁵ Other causes of CKD are glomerulonephritis and pyelonephritis, polycystic, hereditary or congenital disorders of kidney and renal cancers.³ Data from United Nations Children's Emergency Fund show that vitamin A deficiency and other nutritional issues during pregnancy may leads to decrease in kidney volume at birth and decrease in GFR.⁶

In early stages of CKD, there can be significant damage to the kidneys without signs or symptoms. Symptoms of CKD begin with the creatinine level increases in the body. Patients of CKD exhibit a number of signs and symptoms.

The severity of these signs and symptoms depends on the degree of renal impairment, presence of any other co-morbidity and age of the patient. The most common problems which occur due to CKD are anemia, fluid retention, electrolyte imbalance, metabolic acidosis, hypertension and alteration in calcium and phosphorus level.³

As the patient reaches to the stage of ESRD, the last stage of CKD the point at which kidneys can no longer perform adequately leads to various problems in patients.⁷ The patient will have metabolic disturbance such as waste product accumulation, altered carbohydrate metabolism, elevated triglycerides level. Electrolyte and acid-base imbalances occur in the patients due to accumulation of various waste products in the body. The most common death which occurs in CKD patients is related to cardiovascular disease such as hypertension, heart failure, coronary artery disease and peripheral artery disease. The burden of disease causes various psychologic problems in patient such as anxiety, depression.⁸ So, CKD causes various problem in daily life of patients.

In order to prolong life and improve daily life, patients with ESRD require renal replacement therapy which includes dialysis and renal transplantation⁷. Hemodialysis is the most common treatment modality for the end-stage chronic kidney disease in the world. The majority of patients with chronic kidney disease are undergoing maintenance hemodialysis. The patient with CKD undergoing

hemodialysis faces many problems due to metabolic abnormalities, toxic condition and electrolyte imbalance from renal impairment and changes in lifestyle as well as they have to cope with severe restrictions such as strict adherence to dialysis and medication regimens, dietary and fluid limitations, and minimal physical activities.³

The various problems and restriction on hemodialysis patients leads to a sense of loss. Loss occur as they are being deprived of internal and external value. Their professional and social position is lost due to disease condition as well as financial status is also depleted which leads to unable fulfill personal and family demands. CKD treatment is lifelong which causes financial burdern on patient. The treatment is provided only at higher level hospital in India. Most of the patient donnot have knowledge regarding health insurance and they pay with their own resources.¹

According to study conducted by Chiarania, Chantira CKD patient on hemodialysis faces various problems in their daily life.They stated that patients are facing lifes's limitation due to decrease in physical activity, a narrowed social life. They have to deal with emotional changes such as anger, guilt, depression, unhappiness. They were also facing problems related to uncertainty as they were uncertain about their life. They were having feelings of dependent on medical technology to live a better life.⁷

NEED AND SIGNIFICANCE

Chronic kidney disease (CKD) is a major health problem in the underdeveloped and developing countries of Southeast Asia. In fact, a massive and unmet need exists for dialysis in these developing nations. Not only the large numbers of persons needing dialysis but the resources available for treatment are also insufficient⁷. Worldwide 10% of population is affected by chronic kidney disease (CKD), and millions die each year because of lack of access to reasonable treatment. According to the Global Burden of Disease study 2010, chronic kidney disease was ranked 27th in the list of causes of total number of deaths worldwide in 1990, but rose to 18th in 2010.⁹

Developing countries with population of over 600 million people, cannot afford renal replacement which is resulting in the death of over 1 million people annually from untreated kidney failure. In countries such as India and Pakistan less than 10% of all patients receive renal replacement therapy.¹⁰ In India 2, 00,000 new patients need dialysis treatment every year. But unfortunately only 10 to 20% of them get proper treatment. The remaining are either not diagnosed or unable to continue proper treatment. Statistics suggest that there should be almost 20, 00,000 people on dialysis in India today. The reality is that there are only about 1, 00, 000.⁹

Hemodialysis (HD) was introduced in India in 1962, transplantation was introduced in 1971, and peritoneal dialysis (PD) was introduced in 1991. HD is the most common treatment modality followed by renal transplantation, and PD is

at 3rd position. India is estimated to have about 120,000 patients on HD. The habitual cost of a session of HD is approximately \$9–\$45 (without costs for allotted space and machines).¹¹

According to the study conducted by Dr. Prashant C Dheerendra ,17% of Indians have some form of chronic kidney disease. One third of the above people have advanced stages of the disease. Kidney disease leads to tremendous economic burden. High-income countries typically spend more than 2–3% of their annual health-care budget on the treatment of end-stage kidney disease.¹²

CKD causes various changes in person life. Not only the initial changes in the lifestyle which comes due to the diagnosis of CKD, but also they faces ongoing changes in the life because of maintenance hemodialysis which results in alterations in their diet, fluid, medication and forms of treatment.³ Hemodialysis also increases the economic burden on the patients due to expensive treatment modalities. These changes make patient more depressed and stressed.⁷

Liang-Jen Wang et al. states that for the patients with ESKD hemodialysis can be life-saving treatment although it has adverse affects over patients' mental status. They found depression is the most common psychological problem in CKD patients. Anxiety, feelings of fatigue, and decrease in quality of life are also significant psychological problems and these problems can be interrelated.¹³

It has been observed that there is high prevalence of severe psychological distress in patients with advanced CKD. It has ill impact on CKD outcomes. There are some structured psychotherapies like cognitive behavioral therapy which can be beneficiary for treating depression in this population.⁷

The experiences of patients with chronic kidney disease (CKD) have been studied in number of qualitative studies, which translate subjective experiences the patients into objective quantified data. Though, there are only some qualitative studies which examine the experiences of CKD patients undergoing hemodialysis, their life situation and expressing their experiences within the context of health care professional and caregiver's perspective.

Many patients with CKD undergoing hemodialysis experience intense helplessness before they adjust to the change in their life. The detailed explorations of patient's experience will give the evidence specific areas of life which have more problems. So it is essential for health care provider to understand the perception of participants towards their illness and treatment modalities in order to develop a plan of appropriate interventions.⁷

There are very less studies conducted in India related to experience of hemodialysis patients. As well as the experience of CKD patients undergoing hemodialysis is still unexplored in Rajasthan. As this disease in which the

suffering of the patient is endless, researchers felt a need to conduct a study to explore the experience of CKD patients undergoing hemodialysis

AIM OF THE STUDY

The aim of study is to reveal the meaning and concept the experiences of CKD patients undergoing hemodialysis.

STATEMENT OF PROBLEM

Lived experiences of CKD patients undergoing hemodialysis at AIIMS, Jodhpur.

OBJECTIVE

- To explore the lived experiences of CKD patients undergoing hemodialysis.

OPERATIONAL DEFINITIONS

Health care nursing has specific terminologies. These are the list of items which has been used in research study will help the readers to understand it better.

- **Lived experiences-** It refers to a representation of the experiences of CKD patients who are undergoing hemodialysis for more than 3 months by taking interview with the help of semistructured questionnarie.

- **CKD patients-** It refers to those patients who have been diagnosed with CKD and are undergoing hemodialysis for more than 3 months in hemodialysis unit or other hospital and coming for regular follow up at nephrology OPD of AIIMS, Jodhpur.
- **Hemodialysis-** A medical procedure to remove fluid and waste products from the blood and to correct electrolyte imbalances.

DELIMITATION

The study is limited to-

- CKD patients undergoing hemodialysis for more than 3 months.
- The patients who are undergoing hemodialysis either at AIIMS Jodhpur or at other hospital of Jodhpur and are coming for regular follow up at Nephrology OPD, AIIMS, Jodhpur.

SUMMARY

This chapter discussed the background of the study, explained why it is important to conduct study, problem statement, aims and objectives of the study, operational definitions used in the study and delimitations of the study.

Chapter II-
Review of
Literature

REVIEW OF LITERATURE

Review of literature was done to assess in-depth information regarding the lived experiences of CKD patients undergoing hemodialysis and further exploring the research questions, design and the research methodology.

Valsaraj BP et al. conducted a study in the south Karnataka on the experience of haemodialysis. The study was performed in Kasturba hospital which is a tertiary health care centre in South Karnataka. Ten patients were taken through purposive sampling who were undergoing maintenance dialysis. Researcher found out following themes at the end of the study which were physical limitation, mental agony, coping, lack of support, financial burden, lack of support, feelings towards machine and dialysis, spiritual coping, search for hope and betterment, marital relationship, sexuality, fear of tomorrow and uncertainty.¹

A study was conducted in hemodialysis unit of Thailand by Chiarania, Chantria. The study included 26 patients who were undergoing hemodialysis. Interview was taken for 26 patient from which they find out various problems. The first problem was facing life's limitation. They were having uncertainty in their life. They were having feelings of dependence on various medical technology. They after exploring the lived experience of patients undergoing hemodialysis researcher concluded that it is essential for health care provider to understand

their perception towards the illness and treatment modalities in order to develop a plan of appropriate interventions.⁷

A phenomenological study was conducted by Nahid Shahgholian et al. to assess the lived experiences of patients undergoing hemodialysis with the concept of care. Seventeen patients were taken through purposive sampling who were undergoing hemodialysis. Colaizzi's method was used for data analysis. Results of the study showed that according to participant's concepts of care is empathy, companionship in every needs, social support and good quality dialysis. So these aspects have to be used as basis in planning the care for the patients undergoing hemodialysis by the healthcare team.¹⁴

Robab Sahaf et al. carried out a qualitative study to assess uncertainty; the overbearing lived experience of the elderly people undergoing hemodialysis. One of the most important findings in the main study which they found was "uncertainty", about their future. The elderly patients who are undergoing hemodialysis they have an uncertain position regarding their future life because of short life expectancy. They are afraid of their future and cannot plan their lives properly like others. Providing proper education and sufficient knowledge about disease, treatment and complications by gerontology specialist can reduce their uncertainty regarding future.¹⁵

A thematic synthesis was conducted by Claire Reid et al. to assess the experiences of adults living with hemodialysis. They included seventeen studies involving 576 patients in the thematic synthesis. They developed four analytic themes from those 17 studies. Those themes were like dialysis dependent self in this patient stated their feeling as change in their personality which occur due to dialysis. A restricted life related to physical and emotional factors. Patients also stated some strategies that helped them to regain energy which lead to third theme i.e. regaining control. The last theme was relationships with health professionals. They synthesized a framework on the basis of these themes which can be used to improve patients' experiences of hemodialysis care through application of effective interventions. Focusing on specific interventions helps to established good relationships between patients and health care professionals.¹⁶

In order to find out the direct costs of medical care among hospitalized chronic kidney disease (CKD) with type 2 diabetic patients a study was conducted by K. Satyavani. They divided patients into five groups according to severity of chronic kidney disease. At the end of the study on the basis of results of the study they concluded that the total researcher founds that expenditure for the medical care in two years was significantly higher for hemodialysis rather than renal transplantation. As the direct health-care costs on hospital admissions for treating CKD are considerably higher so to develop a protocol on a cost-effective strategy is essential.¹⁷

A study was carried out on discussions of the kidney disease trajectory of elderly patients and nephrologists. A focus group interview was conducted by Jane O. Schell et al with 11 nephrologists and 29 patients more than 65 years of age with CKD or undergoing hemodialysis. They have identified six themes which are as follow. The first theme was patients are shocked by their diagnosis. The second theme is patients are uncertain how their disease will progress. The third theme is patient lack preparation for living. The fourth theme is nephrologists struggle to explain illness complexity. The fifth theme is nephrologist manage a disease over which they have little control. The last theme is nephrologists tend to avoid discussions of the future. Therefore it can be concluded that patients and nephrologists go through various challenges to understand and prepare for kidney disease trajectory.¹⁸

A qualitative study was conducted by Linda Kruegar among Hmong patients undergoing hemodialysis and nurse providing care to them. The study findings revealed that nurses use a variety of methods to learn Hmong culture but they felt that there was lack of training for them. They stated that Hmong patients were compliant to their hemodialysis treatment but they were less compliant to their medication regimen and fluid/dietary restrictions. They identified various barriers among patients such as anxiety, family support, transportation, depression and finances. Various cultural challenges were identified by nurses which included fear of treatment, communication, beliefs about illness and treatment.¹⁹

A phenomenological study was conducted with the aim to examine the experiences of patients suffering from Chronic Kidney Disease undergoing hemodialysis. Hagren et al. found out three themes feeling evoked in the care situation, not finding space for living and attempting to manage restricted life. The themes included various sub-themes such as sense of emotional distance, feeling vulnerable, struggling with time consuming care. They concluded that patients feel themselves lifelong dependent on HD machine as well as patients experienced role changes and dependence on treatment and health care providers.²⁰

Interviews were conducted on Jordanian patients with CKD undergoing hemodialysis by Eman Al Nazly et al. with the aim to explore the lived experiences of patients. The researcher used purposive sampling and interviewed nine patients. Researcher used Collazi's framework for analysis which lead to seven themes time wasted, lifestyle changes, family and marital role disruption, symptoms-related suffering, motivators to alleviate stressors, religious commitment and experience of health care providers. They concluded that nurses should know the experience of patients to provide better care to patients.²¹

Nahid Shahgholian et al. conducted a phenomenological study on supporting hemodialysis patients at Al-Zahra Hospital Iran. The study was performed on 17 patients with end-stage renal disease (ESRD) who were undergoing

hemodialysis. They emerged 4 themes (psychological support, accompaniment, social support, and spiritual support) which included 11 sub-themes from patients experience. According to the viewpoint of the participants the concept of support is psychological support, social support, accompanying the patient, and spiritual support. It has to be used in healthcare planning to improve the health and quality of life of these patients along with their adaptation to the disease and its treatment process.²²

A phenomenological study was conducted by Sonali Tarachand Jadhav , Premila Leeb to assess the experience of stress on initiation of hemodialysis. The study was performed in two private hospital of banglore. Total 10 patients were interviewed for the study. They found out that patients were having various physical stressors such as pain, tenderness, loss of appetite, itching, swelling, weakness. Due to burden of disease condition they were facing various psychologic problems problems of shock, depression, uncertainty with life, burden of disease. They were facing various financial problems such as loss of employment, limited social life, loss of normalcy in life.²³

Chapter III-

Methodology

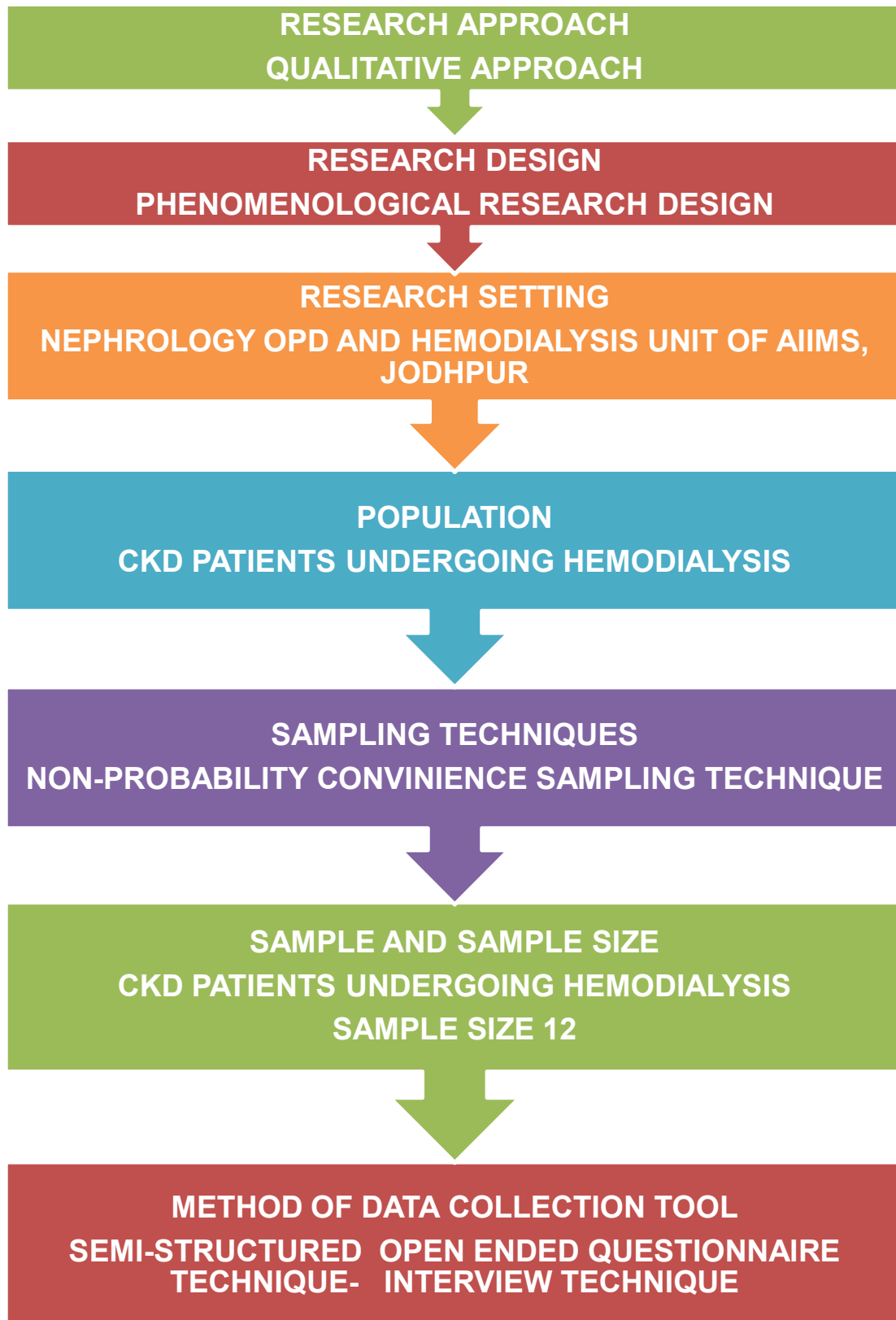


FIGURE 1:- Schematic presentation of research methodology

RESEARCH METHDOLOGY

This chapter presents the method used to conduct this study. It includes research design, study setting, target population, inclusion and exclusion criteria, sample and sampling technique, description of tool, validity of tool, ethical consideration, pilot study, data collection procedure, rigor and plan for data analysis.

RESEARCH APPROACH

The research approach is the overall plan for how to obtain answers to all questions being studied and how to handle some of the difficulties encountered during the research approach. Qualitative research approach was used in present research study.

RESEARCH DESIGN

After considering the objectives of the study, phenomenological research design was used in the study to investigate the phenomenon under study.

VARIABLES

- Demographic variable: Age, Gender, Education, Occupation, Religion, Marital Status, Total Number of Family Members, Family Income, Duration of Illness, Duration of Dialysis, Number of cycle per week and Other Health Associated Problems.

- Research variable: Lived experiences of CKD patients undergoing hemodialysis.

STUDY SETTING

The study was conducted in AIIMS, Jodhpur which is a tertiary care hospital. AIIMS Jodhpur is 960 bedded hospital and it is located in second phase of Basni, Jodhpur. As per the IT cell of AIIMS Jodhpur in 2020 total 2709 patients attended the hemodialysis unit. The area of the study was hemodialysis unit which consists of 8 bed and nephrology OPD of AIIMS, Jodhpur where patient were coming for regular follow up but undergoing hemodialysis at another hospital.

TARGET POPULATION

The patients who are undergoing hemodialysis at AIIMS Jodhpur or at other hospital of Jodhpur and are coming for regular follow up at Nephrology OPD of AIIMS, Jodhpur.

SAMPLING TECHNIQUE

Non -probability convenience sampling technique was used in the study. Non-probability convenience is a type of sampling technique in which researcher collect

data that includes the sample from the population that is close or convenient for researcher.

SAMPLE SELECTION CRITERIA

Study includes:-

- The patients with CKD undergoing hemodialysis since 3 months or more.
- Patients aged more than 18 years.
- Patients who were able to speak and understand Hindi or English.
- Patients who were willing to participate in the study.

SAMPLE SIZE

The sample size for qualitative data is estimated based on data saturation. Data collection was done using interview technique. After taking 10 interview researcher found that there is no new data obtained from the patients. But for safe side researcher included 2 more interviews so that no new data prevail after data collection. So, total sample size is 12 CKD patients undergoing hemodialysis.

METHOD OF DATA COLLECTION

Interview technique was used for data collection with the help of a semi-structured open ended questionnaire to explore the lived experiences of CKD patients undergoing hemodialysis.

DEVELOPMENT AND DESCRIPTION OF TOOLS

A semi-structured open ended questionnaire was formulated for the study. It was prepared after a brief review of the research and non-research literature and opinion of experts.

The semi -structured open ended questionnaire consists of two parts *i.e.* Part 1 and Part 2 (Appendix- IV).

Part 1: It consists of 12 items seeking on background data such as Age, gender, education, occupation, religion, marital status, total number of family members, family income, duration of illness, duration of dialysis, number of cycle per week and other health associated problems.

Part 2: It consists of 8 open ended questions which are based upon the aim of exploring the lived experiences of CKD patients undergoing hemodialysis.

ETHICAL CONSIDERATIONS

Ethical clearance was obtained from the institutional ethical committee, AIIMS Jodhpur.

- Certificate reference number- AIIMS/ICE/2020-21/2097 (**Appendix-I**)
- Written informed consent was obtained from each study patients involved in the study after giving proper explanation of the purpose of the study. They were informed that they can quit from the study at any point of time during the data collection.

- Informed consent was also developed in Hindi language.
- Confidentiality and anonymity of the patients and the data collected was maintained throughout the study.

PILOT STUDY

A pilot study was collected to check the feasibility of the study and data was collected from 3 patients undergoing hemodialysis in AIIMS, Jodhpur and fulfilling the sample collection criteria. The interviews were taken from the patients with the help of interview guide and it was explained that interviews will be audio recorded and used by the researcher for data research purpose only. No changes were made on the interview guide after the pilot study.

VALIDITY OF THE TOOL

The interview guide was validated through panel of experts which included experts from nephrology department, college of nursing AIIMS, Jodhpur and AIIMS Bhubneswar. Total 5 experts validated the interview guide and necessary modifications were done on the basis of suggestion of experts.

DATA COLLECTION PROCEDURE

- Data was collected in the month of October and November 2020. Before the actual data collection, the informed consent was taken and patients

were assured that the information would be kept confidential and it will be used for study purpose only.

- They were informed that the interviews will be audio recorded and will only be used for the research purpose.
- Interview was taken after taking their formal agreement.
- Flexible timings was used for the data collection according to the convenience of the patient.
- The interview was conducted in a calm and quiet place to avoid distraction and to provide comfort to the patients. Each interview took 20-25 minutes.
- The interview was conducted in hindi language.
- The interview was initiated with general and open-ended questions with the help of interview guide.
- The interview was started and audio was recorded when the Patients was ready to speak.
- Field notes were taken by the researcher during the interview. Whenever necessary, follow-up questions were asked to clarify the information.
- Total 12 interviews were taken for data collection.

RIGOR: QUALITATIVE STUDY

Lincoln and Guba (1985) gave four criteria for enhancing the trustworthiness of the data which are as follows: credibility, transferability, dependability and confirmability.²⁴

Credibility refers to the confidence in 'truth' of the data and findings. The findings should be compatible with the experience of the patients. Credibility was maintained by recruiting the participants in the study who were willing to participate and helped to acquire the main phenomenon under the study. It was also maintained by using the **observation, memo writing, interactive and reflective questioning**. Each interview was audio- recorded and using these recordings individual transcription was made which confirmed that all the information was captured accurately. Researcher also made few visits to the area prior to actual interviews to make good relations with patient and make them comfortable to share their experiences.

Transferability refers to applicability of the findings in other context. Thick description of the findings from the patients were stated along with the direct quotations under the theme with patients number and quotation number. This enable the readers to compare the result in context of his/her own setting.

Dependability refers to the stability (reliability) of the data over time and conditions. This means the findings of inquiry can be repeated if were replicated with same (or similar) patients in the same (or similar) context that is consistency of the findings in similar circumstances. The researcher conducted an **audit trial** which included all the raw data and explanation about research process and how themes and subthemes ere extracted from the data were explained to another peer researcher who were familiar with study design and context of the study

setting. In addition, coding and re-coding approach was performed after two weeks of prior coding. Also the **Panel of experts** had consensual agreement on the findings of the study. **(Appendix-VIII)**

Confirmability refers to the extent to which findings of the study are shaped by the response of the patients not by the researcher's personal interest, motivation and bias. Patients were approached after secondary data analysis and they confirmed that the findings were suggestive of the statements they gave during the interview. Audio recordings were checked at various stages of data analysis by the supervisor.

DATA ANALYSIS

Colaizzi's framework (1978) was used in the study to analyse the data. Bracketing **(Appendix- VII)** was done before the data collection through peer review and self review technique of bracketing . Data analysis was done in this study with the help of scientific software called ATLAS.ti 9. Six month student license was purchased and latest ATLAS.ti 9 was used to analyse the data.

SUMMARY OF THE CHAPTER

The chapter described the methodology used in the study which consists of research design, variables, setting, population, sample, sampling technique, data collection, pilot study, procedure for data analysis and plan for data analysis . Total 12 interviews were taken. Rigor of the data was maintained at various

stages of the study by the researcher to enhance the trustworthiness of the data.

The next chapter dealt with the analysis and interpretation of the data.

Chapter IV-
Analysis,
Interpretation and
discussion

ANALYSIS, INTERPRETATION AND DISCUSSION

The objective of the present study is

- To explore the lived experiences of CKD patients undergoing hemodialysis.

The data and finding has been organized and presented in the following sections

Section1: Description of demographic variables of CKD patients undergoing hemodialysis.

Section2: Analysis and interpretation

SECTION 1: Description of demographic variables of the study

**Table 1 : Frequency and percentage distribution of CKD patients
undergoing hemodialysis as per demographic variable**

N= 12			
S.No.	Demographic Variable	F	(%)
Age			
1.	(a) 18-30 years	3	25%
	(b) 31-45 years	4	33.33%
	(c) 45-60 years	2	16.66%
	(d) 60 years and above	3	25%
2.	Gender		
	(a) Male	8	66.66%
	(b) Female	4	33.33%
3.	Education		
	(a) Secondary	5	41.66%
	(b) Graduation or above	7	58.33%
4.	Occupation		
	(a) Homemaker	4	33.33%
	(b) Government employee	1	8.33%
	(c) Business	1	8.33%
	(d) Retired	2	16.66%
	(e) Unemployed	4	33.33%
5.	Religion		
	(a) Hindu	11	91.66%
	(b) Muslim	1	8.33%

Marital status			
6.	(a) Married	9	75%
	(b) Unmarried	2	16.66%
	(c) Divorced	1	8.33%
Number of family members			
7.	(a) <=5	7	58.33%
	(b) > 5	5	41.66%
Monthly income of family			
8.	(a) 20 thousand or below	1	8.33%
	(b) 20-40 thousand	1	8.33%
	(c) 40 thousand or above	10	83.33%
9.	Suffering from CKD		
	(a) 3 months – 1year	1	8.33%
	(b) More than 1 year	11	91.66%
Undergoing hemodialysis			
10.	(a) 3 months – 1 year	5	41.66%
	(b) More than 1 year	6	50%
Cycles in a week			
11.	(a) 2 cycles per week	12	100%
Other associated problem			
12.	(a) Yes	11	91.66%
	(b) No	1	8.33%

Table 1 depicts the distribution of CKD patient undergoing hemodialysis as per demographic variables. It was found out that 33.33% of patient belong to age group of 31-45 years. About 66.66% patients were male. More than half

(58.33%) have studied up to graduation or above. About 33.33% of patients were homemaker and unemployed. Most of patient (91.66%) belong to Hindu religion. About 75% patient were married. More than half (58.33%) patient having more than 5 family members. Mostly patient were having monthly family income above 40 thousand i.e. 83.33%. Results found that 91.66% patients were suffering from CKD for more than one year. Half of the patient i.e. 50% were undergoing hemodialysis for more than 1 year. All patients i.e. 100% were undergoing hemodialysis for 2 days a week. Most of the patient (91.66%) were having associated problems such as diabetes, hypertension, nausea, vomiting, headache, hypotension.

SECTION 2: Analysis and Interpretation

The data was analysed using the Colaizzi's framework (1978). Researcher familiarized herself with the scientific software ATLAS.ti.9. through online tutorials. Qualitative data was analysed into two steps: Data preparation and thematic analysis.

I. Data preparation

Transcription of data

Bracketing was done before the data collection through peer and self-review technique. Interviews were transcribed into verbatim after listening to the audio recorded interviews. Efforts were made to keep the originality of the words

spoken by the patients. Patients were given code so that the anonymity of the patients can be maintained.²⁴⁻²⁶

II. Thematic analysis

The study followed the steps of thematic analysis:

- **Familiarization with the data:** To obtain a deeper insight of the phenomenon, the researcher immersed herself into the data by reading the interview transcripts repeatedly.
- **Identifying the significant statement:** The researcher identified all the statements from the data that have a relevance to the phenomenon under study.
- **Formulating the meaning:** Initially, codes were generated on the basis of different thoughts, ideas and meanings from careful consideration of significant statements. Codebook was generated and was further imported to ATLAS. ti 9 software for the data analysis.
- **Clustering the themes:** The codes were categorized into themes and subthemes on the basis of similarities or relationships among them. Themes were more connected to the research question whereas subthemes were more associated with the group of codes that emerged from the significant statement.
- **Developing an exhaustive description of the phenomenon under study:** Themes, subthemes and codes were reviewed repeatedly and a hierarchical

category was made which is called thematic map analysis. The researcher wrote full and exhaustive description of the phenomenon after the primary data analysis.

- **Producing a fundamental structure:** The findings from the data analysis are so vague that it is necessary to provide a fundamental structure to it. The codes, subthemes and themes were refined through the process of secondary data analysis and the essence of each theme were identified and captured. Themes were finalized and it was reviewed from the various experts.
- **Seeking verification of the fundamental structure:** One of the important aspect of the Colaizzi's framework is confirmation of the findings with the patients. The researcher went back to the patients and confirmed the findings of the study. The patients agreed with findings. Certain modifications were done based on the suggestions of experts and patients.

This section describes the findings of qualitative data which aims to explore the lived experiences of CKD patients on hemodialysis.

Results: Objective of the study was to explore the lived experiences of CKD patients undergoing hemodialysis. Five themes and 14 sub-themes were emerged after the thematic analysis as shown in table 2. The first theme is uncertainty with life which includes subtheme fear of death, fear of treatment. The second theme is dependence which includes subtheme care from family members, adherence to hemodialysis treatment. The third theme is lifestyle

changes which includes subtheme disturbed dietary habits, impaired daily activity, decreased social life, loss of job, difficulty in education, financial burden. The fourth theme is coping and support which includes subtheme appropriate family support, stress relieving activity. The last theme is satisfaction with care which includes subtheme good hospital services and improvement in health condition .

Table 2: Themes and subthemes of the study

S.No.	Themes	Sub-themes
1.	Uncertainty with life	Fear of death Fear related to treatment
2.	Dependence	Care from family member Adherence to hemodialysis treatment
3.	Lifestyle changes	Disturbed dietary habits Impaired daily activity Decreased social life Loss of job Financial burden Difficulty in education
4.	Coping and Support	Appropriate family support Stress relieving activities
5.	Satisfaction with care	Good hospital services Improvement in health condition

Detailed description of themes and sub-themes

Theme I: Uncertainty with life

The patients were uncertain about their life. They were having so many fear regarding their future. The patients were having fear whether they will able to live a long life. They were also scared of hemodialysis as they were having many complication after undergoing dialysis.

Sub-theme 1: Fear of death

The patients were having fear of death whether they will live a long life.

“Job to mai continue dubara kar ni sakti hon. Bas thoda sa darr lgta rehta hai life ko leke ki kab tak thk rahongi mai. Isliye ghar se niklte waqt dialysis ke liye apni beti ko hug karke aati hon ki sab thk rakhna” P1 ¶ 24

“Dar sa bhi lgta hai ki kab kya ho jaye mujhe mai achi jindagi jeena chata hon bas ussi ke liye kidney transplant ka wait bhi kar raha hon mai ki meri life achi ho jaye uske baad.....” P6 ¶ 127

“Bas meko dar lgta rehta hai kab tak jee paon mai abhi to bachon ko bda krna hai abhi kafi life pdi hai aage bas mere bache bde ho jayein settle ho jayein fir koi chinta ni hai bhavishya ki.....” P12 ¶ 265

Sub- theme 2: Fear related to treatment

The patients were having fear related treatment and its complications. They were having fear of dialysis because they had so many complication after undergoing dialysis.

“Aur kya bataoon kuch samajh ni aaraha dialysissss... ek dar hai mere liya jaise hi 3 ghnte pure hote hain headache hota hai mujhe aur vo sehn ni hota mujhse skin puri dry ho jati hai chere pe pimple ho gye baal jhad rahe hain bhot dikkat hain.....”P7 ¶ 164

“Aesi to koi feelings ni hai bas dar lgta hai mujhe dialysis se ek tarike se acha ni lgta mujhe dialysis bhot dikkat hoti hai mujhe sir dard hota hai, weakness hoti hai to acha ni lgta hai mujh..”P10 ¶ 216

“Ab aur to kya btayein bas kabhi kabhi thoda dar lgta hai ki tabiyat kharab na ho jaye vaise dialysis acha hai kyonki uski vajah se abhi thik thak jindagi chal ri hai par iski vajah se kafi dikkat bhi hoti jo ki maine apko btayein hain”P11¶ 248

“Mujhe dar sa lgta hai dialysis se kyonki kafi tabiyat kharab hoti hai jis din dialysis krake mai ghar jata hon.. Bhot weaknes si lgti hai mujhe dialysis krake jab mai ghar jata hon. Halki tabiyat to thk hwi hai par dikkatein bhi bhot aayi hai dialysis ki vajah se”P12 ¶ 258

Theme II: Dependence

Most of the patients had feeling of dependence on various medical technology for living a normal life and they also felt dependent on family members especially the day of dialysis.

Sub- theme 1: Care from family members

Most of the patients were dependent on family members on the day of dialysis for coming to hospital and after they reach home they were not able to perform activity on that day. Also patients who underwent fistula formation require care from others for 1 to 2 months as that hand could not be used for few months for activity

“Jabse fistula bna hai tabse thoda dependent ho gyi hon kyunki left hand se kam krna bilkol mna hai aur pain bhi hai. Phele tha ek aur fistula jo block ho gya to uske baad central line lga di. Central line se bas neck pe dikkat hoti jyada move ni karti hon mai apni neck ko. Abhi filal dikkat ho ri kafi nhane mai, daily ke kam mai. Par abhi corona hai varna kisi maid ko rakh leti kam ke liye. Beti job pe jati hai to uski help leni padti hai. Abhi main dependent ho on hair care ni kar pati hon 4 se 5 mahine ho se.....” P3 ¶ 63

“Aab ek trah se dependent bhi apne damad pe beti pe wahi leke aate hain hume hospital mein, khayal rakhte hain ghar pe meri wife khayal rakhti hain. Jis din dialysis krake jao to us din fistula wala hath to hila ni pate hain bas us din rest hi karte hain.....”P7¶ 43

“Family pe dependent lgta hai mujhe sabse jyada khudh ki personal life jaise mai akle kuch bhi ni kar pata hon..... Aurrrrr sabse bda ki akle main nha bhi ni pta hon.. PERMA cath lga hai to akle nhane mai dikkat hoti hai...” P12 ¶ 156

Sub-theme 2: Adherence to hemodialysis treatment

Most of the patients felt that they were totally dependent on hemodialysis to live a normal life. They felt that HD treatment is too important which could not be ignored. They had felt that their condition improved after undergoing hemodialysis.

“As such to kuch feelings ni hai par hemodialysis jarori hai krana..... Bina kraya to ab jindagi jee ni sakte hain. Ab agar achi life jeeni hai to hemodialysis to krana hi padega. After dialysis even my condition has improved. Phele sans lena mai dikkat hoti thi par ab dialysis ki wajah se acha lgta hai.” P1¶ 11-12

“Acha hai dialysis aur feelings to kya hi ki jarori hai krana ek traikhe se.Nahi krayenge to tabiyat biagd jayegi. Ab to rehna hi hai puri jindagi iske sath. Koi problem ni aari dialysis se sab thk hai....” P2 ¶ 40

“Aesa hai ki dialysis to krana hi hai ab isme to kya hi kar sakte achi life jeeni hai to krana hi padega. Balki dialysis jabse start hwa meri condition improve ho gyi hai phele meko sans mein dikkat hoti , urine mai dikkat ab ye hai ki dialysis krane se sans mein dikkat ni hoti hai mai normal kam kar leti hon....”P3 ¶ 59

“Ni ye to medical advice hai. So it has to be done. Aur to aesi koi feelings ni hai. Bas krana hai ab to life dialysis pe dependent hai issi ke sahare jee sakte hai hum bas.” P4¶ 83

“Par dialysis krana bhi jarrori hai iska bina to tabiyat kharab si lgti hai ab jab tak transplant ni ho jata hai tab tak yahi ek hope hai....” P7 ¶ 149

“Dekho bura to lgta hai kyonki dialysis se bhi kafi dikkat hoti hai par kuch kar ni sakte hai dialysis to krana hi padega agar thk rehna hai tabiyat thk rakhni hai to krna hi padega dialysis to aur to koi option ni hai.... Ab to age bhi ni rahi ki transplant ho jaye isliye ab dialysis se hi life aage chal sakti hai....” P8 ¶ 172

“Aesa to kuch ni hai dialysis bhot jarrori hai filal abhi jewan jeene ke liye nahi krayenge to tabiyat aur kharab ho jayegi isliye krna to hai hi dialysis...” P9 ¶ 195

“Aesa to kuch feelings ni hai par dialysis ek jarrori part ho gya life ka ye krana to jarori hai ab nahi krayenge to tabiyat khrab ho sakti hai isliye krana hi padega dialysis to ab.” P11 ¶ 238

Theme III: Lifestyle changes

Most of patients had faced various changes in their life due to hemodialysis. Various changes such as related to their activity, dietary, social life , financial, education and occupation. They were trying to adopt to these changes.

Sub- theme 1: Disturbed dietary habits

The patients had shown concern towards their changes related to dietary habits which had disturbed their normal life pattern. They described they had restriction on food and water. Water restriction was their major problem.

“Khane mai to normal food kuch bahar ka ni khate hai hum. Bahar ka khana waise bhi hme pasand ni hai itna. Pani pe bhi rok hai sirf 1 litre bola hai peena ka

par kai bar jyada ho jata hai pyas lgti hai to control ni ho pata uski vajah se wajan badh jata hain.” P2 ¶ 46

“Khana sab normal kahti hon bas namak kam aur suagar kam kahti hon. Bas pure din mai 1 litre se jyada ni pee sakti. Kabhi jyada pyas lagti hai to ice cubes kha leti hon thoda thk lgta hain. Pani peena ka bhot man hota kai bar par control krna pdta hain. Weight kai bar badh jata hai mera.” P3 ¶ 62

“Pani kafi dar dar ke peena pdta hai kahin weight gain na ho jaye lag bahg 1 litre pee lete hain. Khane mai bas vahi kam sugar vala namak vala kahana pdta hai . Bahar ka kuch bhi ni kahte hai hum, bas ghar ka hi khana kahte hain....” P4 ¶ 86

“Khane peene mai diet thodi kam ki diet ko divide kiya ki ek sath sabkuch khana ni hai thoda divide krna pdta hai. Pani bhi bas 1 litre peena pdta hai starting mai khubh pyas lgti thi par ab habitual ho gya hai. Lmba chlana hai to habitual hona pdega warna ya 2 saal mai hi nikal lenege” P5 ¶ 107

“Diet mai to kafi changes khane mai jyada namak vala ni khana hai phosphorus aur potassium vala khana ni khana jaise kela ni kha sakte hain.... Aur fir pani bhi jyada ni pee sakte hain jyada peene sa kafi dikkat ho jati hai firr....” P8 ¶ 179

“Han khane mai bas kam oil vala, namak ka khana ye sab hi hai aur pani kam peena hai 1 litre se jyada ni peena hai ye to hai hi dikkat...” P9 ¶ 199

“Sabse jyada dikkat to pani ki lgti hai mujhe.. Khane mai bhi hlka sa hi khao jyada patte dar sabji ni kahte hain jisme jyada potassium ho...” P10 ¶ 218

*“Bhot sare changes hwe jaise aap jyada pani ni pee sakte ho to hmesha dyan se pani peena pdta hai soch soch ke... Khane mai jyda bhar ka ni kha sakte hain aesi sabjiyan ya fruits ni kha sakte jinme potassium jyda ho to sab dekh ke hi khana pdta hai..”***P11 ¶ 240**

“Khane peene mai bhi kafi badlaw aaye hai jaise jyada pani ni pee sakte hain kuch bahar ka khana mai dar sa lgta hai doctor kai sari sabjiyan bhi mna ki hai jisse potassium na bdhe...” **P12 ¶ 260**

Sub-theme 2: Impaired daily activity

The patients felt that due to hemodialysis their daily life activity had been impaired as they felt discomfort on the day of dialysis and fistula present or other vascular access present

“Family pe dependent lgta hai mujhe sabse jyada khudh ki personal life jaise mai akle kuch bhi ni kar pata hon..... Aurrrrr sabse bda ki akle main nha bhi ni pta hon.. PERMA cath lga hai to akle ni nhane mai dikkat hoti hai...” **P7 ¶ 156**

“Han samsayein to khubh hwi dialysis ki wajah se par kya Karen dialysis bhi jarrori hai. Jaise aaj mein dialysis krake jaongi to kuch kaam ni karti hon ghar ka fir next day se thk ho jata hai” **P1 ¶ 14**

“Jis din dialysis krake jao to us din fistula wala hath to hila ni pate hain bas us din rest hi karte hain....” **P2 ¶ 43**

“Bus jis din dialysis krake ghar jati hon to weakness rehti hai, vomiting si aati hai, us din mai daily ke routine work ni kar pati hon, jaise ki roj karti hon.” **P3 ¶ 60**

“Daily life mai to movement mai dikkat ho gyi thi jyada chlte hi thkan hone lgt hai jyada hardwork ni kar sakte hain...” P4 ¶ 106

“Ab to kam ni kar pati hon phele kam kar leti thi sab ab weakness dheere dheere badh hi rahi.” P8 ¶ 176

“Jis din dialysis krake jao pura time weakness lgti rehti hai kuch acha ni lgta pura time rest hi karti hon... Kuch kam ni hota hai us din mujhse..” P11 ¶ 241

Sub-theme 3: Decreased social life

Most of the patients felt that their social life had been completely changed after they had started dialysis. They felt that they had no social life now.

“Meri social life bhot change ho gyi after CKD mai jyada bahar ni jati hon friends se ni mil pati hon, kisi occasion pe ni jati hon. Bahar ka khana bhi avoid karti hon.” P1 ¶ 19

“Bas ek dikkat hai bahar kahi aana jana ni hota hai, social life puri khatam si hogyi ye bimari hone ke badd, dur sa lagta hai ki kahi bahr gye to bimar na pad jaye.” P2 ¶ 44

“Social life to bilkol bhi hi ni rahi hai. Bahar kahin aati jati ni hon, bas ghar mein hi rehti hon. Family occasion mai aana jana sab band ho gya mera” P3 ¶ 65

“Social life mai mujhe travelling ka bhot shauk tha vo bilkol band ho gya kahin aana jana sab band ho gya uska bhot dhukh hai mujhe,.Pichli jindagi se compare Karen to abhi life kharab hai mai phele sportsmen tha par ab kuch ni hai. Mera ek beta Australia mai mai phele gya tha abhi bhi jana ke man par sab plan kharab ho gya” P4 ¶ 87

“Bas bahar kahin ni jata hon mai ghar pe hi rehta hon social life ek dam khatam si ho gyi hai phele jab delhi mai tha tab dost the ab yahan koi dost ni hai bas hum log phone pe hi baat kar leta hain” P6 ¶ 132

“Bahar ja ni sakte khel ni sakte hai doston se ni mil sakte hai” P7 ¶ 153

“Han social life to farak padta hai hi hai social life mai to phele ghumne firne jate the par ab to ja ni pate hain kyonki hafte mai 2 bar dialysis krana hota hai kafo weakness lgta hai to kahin ni jate hainnnn.... Shadi mai jane ho to jata hai par dialysis vale din ni 2 ya 3 day jate hain...” P8 ¶ 178

“Bahar jana vana to kam hi jata hon dar lgta hai kahin tabiyat kharab na ho jaye to iske liye kam hi jata hon bahar mai..... Aur dikkat to yahi hai ki dialysis to krna hi padega kahin pe bhi apko krna hi padega...” P9 ¶ 200

“Takkat ni hai bahar ghumne firne ka kabhi heart ki dhadkan badh jati hai acahank se man to krta hai bahar jana ke par kya Karen jaa ni sakte hain...” P10 ¶ 219

“Aur Social life to khatam si hi lgti hai jaise kahain bahar ni ja sakte kisi occasion pe ni ja sakte hain kisi se mil ni sakte hain to bilkol change si ho gyi haii social life.” P11 ¶ 241

“Kahin bahar ana jana bhi band ho gya hai mera, friends se milna, occasion mai jana sab band ho gya” P12 ¶ 261

Sub-theme 4: Loss of job

The patients felt that they had lost their occupation after they had diagnosed with CKD and started hemodialysis which had bring drastic change in their life.

“Meri naukri chut gyi dialysis ke karan. Hafte mai do chutti koi ni deta hai. Agar mai jati bhi hon to family members allow ni karte hain ki tabiyat kharab na ho jaye... Meko bhot dukh.....hota is chig ka mai ab apni practice continue ni kar apti hon.” P1¶ 20

“Sabsa bda dikkat ye lgta hai ki meri job chut gyi ab family ka khrcha mai utha ni pata hon ek trah se dependent sa feel hota hai mujhe meri family par” P12 ¶ 261

Sub-theme 5: Difficulty in education

Many patients said that because of hemodialysis their education had discontinued and some of them had diverted their study plans to others which could be done despite having hemodialysis.

“Phele mera goal tha CGL ke liye ye income tax department ke liye job hai par ab mai vo bilkol change ho gya usme medical aur physical fit ho, par vo to ab mai kar ni sakta hon... Normal office job chaeye ab to ...” P10 ¶ 162

“Studies mai to bhot change ho gye hain jyada der betho to problem hoti jyada dhyan ni lag pta hai... Kabhi BP high hota hai to headach hota, kabhi bhi vomiting ho jati hai...” P7 ¶ 154

Sub- theme 6: Financial burden

Patients had also complained about the financial burden they had related to hemodialysis. They had told its very hard for them to fulfil their family financial need.

“Sabsa bda dikkat ye lgta hai ki meri job chut gyi ab family ka khrcha mai utha ni pta hone k trah se dependent sa feel hota hai mujhe meri family par” P12 ¶ 261

“Paison ka dikkat to hai papa hi hai kamane vale vo 60 saal se upar ke hain to ghar karcha bhi chlana pdta hai 16 hjar lag jate hain mahine ke bas soch rahe hain ki idhar udhar se transplant kra lein” P1 ¶ 221

Theme IV: Coping and Support

Most of the patients felt that they had got full family support and were using many coping measures to overcome the stress related to hemodialysis.

Sub-theme 1: Appropriate family support

The patients felt that they got very much support from their family members during disease process and hemodialysis. They described that family members were supporting in their daily work, transportation, emotional support.

“Family se pura support hai mujhe halki mai thoda dependent hon unpe par vo mujhe feel ni hone deta hain” P7 ¶ 135

“Mera husband hai jo hmesha support karte hain sath rehte hain, mera in-laws there ” always.... supportive. Meri daughter hai jiske sath mai full day reh kar apni tension durr kar deti hon.” P1 ¶ 28

“Aur beti damad ka kafi support hai, halki beta ni hai mera idhar par support to use bhi milta hai. Bas sab aesa hi chal raha” P2 ¶ 48

“Meri do beti hain dono hi bhot supportive hai ek to yahi rehti hai mere sath hmesha mujhe leke jana aur lana meri beti hi karti hai. Mera husband bhi bhot supportive hai pura khayal rakhte hain vo.....” P3 ¶ 67

“Family ka pura support hai meri mummy papa mujhe pura support krte hain har chig ma” P7 ¶ 160

“Han family pura support karti hai husband, beta, bahu sab sath dete hain to jyada dikkat ni hoti hai” P8 ¶ 181

“Han family valon ka pura support hai mujhe mera parents, meri wife sab mera bhot khyal rakhte hain.....” P10 ¶ 224

“Family sabse bda support hai hmesha support krte hain mera pura khyal rakhte hain to jyada feel ni hota hai jo bhi dikkaten hai.” P11 ¶ 244

“Han family ka to kafi support hai mujhe, meri wife bhi kafi supportive hai to jyada dikkat to ni hwi mujhe.” P12 ¶ 263

Sub- theme 2: Stress relieving activities

The patients had used various recreational activity to relieve stress related to CKD and hemodiaysis. They had discussed about it as they enagage themselves with family members or finding out some activities.

“Maine ek group bhi join kiya hwa jisme paediatrics realted case discussion hota rehta hai, seminars hote rehte hain to unko attend krke mujhe acha lgta hai as new cases dekhne aur sikhne ko milte hain.” P1 ¶ 22

“Ghar pe rehta hon apni wife ke sath samay bitate hon. Bache hain vo aate rehte hain unke sath khelta hai time bitate hain to thk lgta hai.... TV dekh lete hain din mai bas aesa hi tym kat jata” P2 ¶ 48

“Aesa to kuch khas ni hai TV dekh lete hai, poote kai sath khel lete.” P4 ¶ 89

“Aur jyada kuch ni apne doston se call pe baat kar leta hon, Tv dekh leta hon , movies, web series bas yahi chlta rehta hai...” P6 ¶ 135

“Aur mai job ki taiyar kar raha to padhai karke apna tension durr kar leta hon mai waise aur to alag khas kuch hai ni....” P7 ¶ 160

“Aur baki mai thoda kuch kam kar leti hon, TV vagera dekh leti hon, bachon se baat kar leti hon to jyada tension to hoti ni hai thk sab” P8 ¶ 181

“Kuch ni bas aesa hi ghar pe rehke padhta hon gharvalon se baten karke, TV dekh ke kar leta hon time pass” P10 ¶ 224

“Aur pura din mai ghar pe rekhar bachon ko pdha deta hon, unke sath khel leta hon to time pass ho jata hai mera.. Aur kuch kuch online bhi sikhta rehta hon jisse mai ghar beth ke koi job kar sakon....” P12 ¶ 263

Theme IV: Satisfaction with care

Most of patients were very much satisfied with the care provided by the staff. They felt safe, comfortable during the procedure. They had also stated that good care provided lead to improvement in their condition.

Sub-theme 1: Good hospital services

The patients felt that the care provided were adequate related to their condition and very much satisfied.

“Par life chal ri hai daiysis ki wajah se yahan ka staff bhi bhot acah hai bahot care krata hai bhot kam dikkat hoti hai iski wajah se dialysis mein. Doctor bhi bhot ache hain that’s why my treatment is going well.” P1 ¶ 29

“Doctor aur staff sab ache sahi treatment chal raha badhiya hai sab.” P2 ¶ 52

“Yahan ke doctor staff kafi ache hai to jyada kuch dikkat aayi ni. Proper follow up krate hain, apni koi bhi samasya hum Doctor ko kabhi bta saktein.” P4 ¶ 87

“Staff aur doctors ka behaviour to kafi acha hai idhar hmesha pura khayal rekhtein hain, dialysis ke waqt ek staff to rehta hi hai aur doctors bhi beech mai aake puchte rehte hain” P6 ¶ 139 – 140

Sub- theme 2: Improvement in health condition

The patients felt that after dialysis their condition had been improved so much because of dialysis they were living a normal life.

“After dialysis even my condition has improved. Phele sans lena mai dikkat hoti thi par ab dialysis ki vajah se acha lgta hai.” P1 ¶ 12

“Balki dialysis jabse start hwa meri condition improve ho gyi hai phele meko sans mein dikkat hoti , urine mai dikkat ab ye hai ki dialysis krane se sanse mein dikkat ni hoti hai mai normal kam kar leti hon” P3 ¶ 59

“Kuch ni aesa to bas dialysis chal raha hai krana hi padega jindagi ussi chal ri hai meri to krana jarrori. Aur dialysis ke baad meri tabiyat thk vhi hwi phele se kafi ab meko better feel hota hai phele se par hafte mai 2 baar krana pdta hai bhot weakness si lgti rehti hai mujhe.....” P6 ¶ 129

“Kafi better feel hwa dialysis krane ke baad par uske sath sath kafi sari dikkat bhi aayi hai.. Dialysis acha bhi hai bura bhi hai mera hisab se to..” P9 ¶ 195

DISCUSSION

The current study was conducted to explore the lived experiences of CKD patients undergoing hemodialysis. In this section, discussion about the research findings with the current literature is done.

The findings showed that 66.66% patients were male. More than half (58.33%) have studied up to graduation or above. About 75% patient were married. Results found that 91.66% patients were suffering from CKD for more than one year. Most of the patient (91.66%) were having associated problems such as diabetes, hypertension, nausea, vomiting, headache, hypotension. The present findings can be compared with the study conducted by Nahid Shangolian et al. They found that 53% patients were female. About 23.5% were studied up to college level. More than half of the patients (53%) were married and having diabetes. About 53% were having duration of dialysis for 10- 24 months.

The present study found five themes and 14 subthemes which are discussed below.

In current study it has been reported that patient are having uncertainty with their life. They having fear of death, having fear related to treatment. The findings from this study is similar with the study conducted by Chiarania, Chantira. The found that patients expressed their feelings as they were uncertain about their life. Many patients reported that their HD therapy was going well but they expressed

feelings related to unpredictable future. They expressed things such as they donot know when they will die. They only had wish for better future.⁷

The findings of uncertainty with life can also be compared with the study conducted by Robab Sahaf et al they found that many elderly people having fear of unkown. Patients are frightened of conditions in the dialysis ward . They have fear of death, fear of dialysis and equipment. They stated their feeling as they are scared, don't know what will happen to them on dialysis bed.¹⁵

In the present study, it was found that most of the patients were having feeling of dependence on various medical technology for living a normal life and they also felt dependent on family members especially the day of dialysis which was compared with the study conducted by Chiarania, Chantira. They found out that patients said the they could have died but advance hemodialysis helped them to live a long life. Hemodialysis machine played a important role, as participants stated that they are dependent on the machine and to their caregivers. Participants expressed their feelings by saying that hemodailysis had sperated them from others and even they cannot ignore the treatment. ⁷

The findings of dependence also echo with study conducted by Hagren et al. They found that patients expressed their feelings with hemodilaysis machine a very important aspect of their life which they cannot avoid. Hence, patients were expressing dependence on the health care provider and those who were receiving treatment.²⁰

The findings of impaired physical activity can be compared to study conducted by Chiarania, Chantira. They found out that many patients have many physical limitation which is caused by hemodialysis created role dysfunction, resulting in emotional distress in many patient. Due to physical limitation they are not able to play many roles in life.⁷

The findings of lifestyle also echo with study conducted by Nahid Shahgholian et al. They found out that many patients stated that because of their old age, underlying disease, fatigue and boredom they often need help and support of their family member for their daily activity including health care activities.¹⁴

The patients has shown concern towards their changes related to dietary habits which has disturbed their normal life pattern. The findings also echo with study conducted by Chiarania, Chantira the patients expressed their feeling by saying that ESRD created most stressful events as it created social limitations related to diet and fluid restrictions.⁷

The findings of disturbed dietary habits also echo with the study conducted by Eman Al Nazly et al. They stated that patients reported fluid and food restrictions as a dialysis related stressors and some also repoted that they were adhered to treatment regimen to avoid any kind of side-effects.²¹

Most of the patients feel that their social life has been completely changed after they have started dialysis. They feel that they have no social life now. The findings can be compared with the study conducted by Chiarania, Chantira. The patients stated that they are lonely and missing their friends due to social limitations.⁷

The findings of decreased social life can also be compared with study conducted by Claire Reid et al. They found that various restriction related to dietary, fluid , time spent on dialysis and various symptoms such as fatigue had affected patients social life. This resulted in difficulties maintaining social connections and friendships.¹⁶

Patients has also complained about the financial burden they have related to hemodilaysis. They have told its very hard for them to fulfil their family financial need.The findings of this study echo with study conducted by Valsaraj BP et al.which patient stated that the treatment expenses of hemodialysis is very much for the common man, although most of them get some form of free treatment or concession, the other expenses of travel, food and children's education etc. need to be met. It becomes difficult for them to meet these expenses from their job.¹

The findings of financial burden can also be compared with study conducted by Chariana Chatnia. They stated that CKD has created various problems such as economic hardship, physical limitation and emotional disturbance. Many patients

reported that they need money for their medical treatment. They need money so that they can raise their family members and for personal expenses. Thus, it shows they having economic burdern related to hemodilaysis.⁷

The present findings of financial burden can also be associated with the findings of the study conducted by K. Satyavani et al. They concluded that the total expenditure for the medical care in two years was significantly higher for hemodialysis rather than renal transplantation. As the direct health-care costs on hospital admissions for treating CKD are considerably higher so to develop a protocol on a cost-effective strategy is essential.¹⁷

The patients feel that they have lost their job after they have diagnosed with CKD and started hemodiaysis which has bring drastic change in their life. The findings can be compared with the study conducted by Eman Al Nazly et al. They stated that patients have many physical symptoms which has affected their ability to keep their jobs or necessitated them to switch to another job. Therefore, patients relied on spouses and siblings for help with house work. They were dependent for transportation to and from the dialysis unit.²¹

Nahid shangolian et al. conducted a study whose findings can be associated with the findings of loss of job. They stated their feelings by saying that frequent dialysis, treatment expenses, transporation cost has lead to loss of job. Loss of job has lead to financial bureden on the patients.¹⁴

The findings of support can be associated with the study conducted by Nahid Shahgholian et al. They stated that emotional support provided by family members is an important part of their care.¹⁴

The findings of support can also be associated with study conducted by Chiarania, Chantira. They stated that family members played an important role in substituting missing social activities. Patients expressed their feelings by saying that they enjoy themselves when they spend time with their family members.⁷

The findings of coping can be compared with study Eman Al Nazly et al. stated that patients had continued to draw strength from family members, which they have considered important for helping them deal with their disease.²¹

Most of patients are very much satisfied with the care provided by the staff. They feel safe, comfortable during the procedure. They have also stated that good care provided has improved their condition. The findings can be compared with study conducted by Valsaraj BP et al. They stated that most of them have positive regard for dialysis, knowing that they feel much better after starting the dialysis.¹

The present study can also be compared with the study conducted by Eman Al Nazly et al. They found out in their study that the patients spend their 10- 12 hours in dialysis unit. They are always in contact with health care professionals

especially the nurses working in dialysis unit. The patients expressed their feelings by saying that nurses working there are very supportive. They always tries to make them happy in order to relieve their stress. Many patients also stated that there can be improvement in communication skill related to nutritional education.²¹

SUMMARY

This chapter presented the findings related to experiences of CKD patients undergoing hemodialysis. Total 12 interviews were taken with the help of semi-structured questionnaire. Non- probability convenience sampling was used in the study. Colaizzi's framework (1978) was adopted in the study to analyze the data. Total 5 themes and 14 sub-themes were emerged after the thematic analysis as shown in table 2. The first theme is uncertainty with life which includes subtheme fear of death, fear of treatment. The second theme is dependence which includes subtheme care from family members, adherence to hemodialysis treatment. The third theme is lifestyle changes which includes subtheme disturbed dietary habits, impaired daily activity, decreased social life, loss of job, difficulty in education, financial burden. The fourth theme is coping and support which includes subtheme appropriate family support, stress relieving activity. The last theme is satisfaction with care which includes subtheme good hospital services and improvement in health condition . This chapter described themes and subthemes in detail and rigor was maintained throughout the study. Findings from this study were discussed with the other studies in the discussion section.

Chapter V-

Summary,

conclusion and

recommendations

SUMMARY, CONCLUSION AND RECOMMENDATIONS

SUMMARY

A qualitative phenomenological study was conducted on “Lived experiences of CKD patients undergoing hemodialysis at AIIMS, Jodhpur”. The objective of the study was to explore the lived experiences of CKD patients undergoing hemodialysis. The patient suffering from CKD undergoing hemodialysis at AIIMS or other hospital and coming for regular follow up were sample. Ethical permission were taken from the Institutional ethical committee, AIIMS, Jodhpur. Tool consists of demographic variable data and semi structured interview guide to collect the data through audio recorded interview. Pilot study was conducted using these tools no modification was done after pilot study. Total 12 interviews were taken. Informed consent was given to participants and they informed about aims and objectives of the study and about accessibility of the data. Each interview took 20-25 minutes. The interview were listened and transcribed into verbatim. Colaizzi’s framework was used for data analysis using ATLAS ti. 9 scientific software. Five themes and 14 subthemes were extracted and these were discussed with the findings of other studies. The first theme is uncertainty with life which includes subtheme fear of death, fear of treatment. The second theme is dependence which includes subtheme care from family members, adherence to hemodialysis treatment. The third theme is lifestyle changes which includes subtheme disturbed dietary habits, impaired daily activity, decreased social life, loss of job, difficulty in education, financial burden. The fourth theme

is coping and support which includes subtheme appropriate family support, stress relieving activity. The last theme is satisfaction with care which includes subtheme good hospital services and improvement in health condition .

LIMITATION OF THE STUDY

The limitation of the study can be as only one setting was taken for the data collection. More than one setting can be used for data collection in future.

IMPLICATIONS

The information obtained from the study provide some important implications for nursing practice, nursing education and nursing administration which help the nurses to provide care to CKD patients undergoing hemodialysis.

NURSING PRACTICE

The findings of study revealed that CKD patients undergoing hemodialysis faces various challenges in their daily life. Their experience told many thing about their perception related to hemodialysis. They require effective coping strategies to face these challenges. Nurses should know about these experiences because it will help them to provide better care to patients. Nurses can have interaction with the patient during their diaysis and can ask about their problems they are facing in their daily life. It will lead to a effective communication and nurses will get an idea about patient problems. After understanding patient problem nurses can try

to solve them. They can help the patient to cope up from such problems. They can encourage family members to understand the patient problems and encourage them to provide valuable time to patients.

NURSING EDUCATION

The nursing curriculum may include components about experiences of CKD patients undergoing hemodialysis so that when they become future nurse later on they will try to talk to patients and ask about their experiences. This will help in providing better care to patients.

NURSING RESEARCH

The study findings can be helpful in giving information for future nurse researchers who want to explore the area of experiences of CKD patients undergoing hemodialysis.

NURSING ADMINISTRATION

The findings of the present study indicated that there is lack of proper staff for counseling and educational services for hemodialysis patient who can address the emotional and psychological concerns timely. The hospital administration should arrange such staff or nursing personnel can be given responsibility for providing counseling services to hemodialysis patients. They can also provide

inservice educational programmes regarding this problem for nurses to provide quality care to patients.

RECOMMENDATION FOR FUTURE RESEARCH

On the basis of findings of the study, it was recommended that:

- A similar study can be conducted in the other hemodialysis of rajasthan so that more diverse sample can be included.
- A mixed method study can be conducted so both quantitative and qualitative data can be obtained related to CKD patients.
- A similar study can be conducted by taking consideration for taking more than one study setting.

CONCLUSION

The purpose of this qualitative phenomenological research was to explore the lived experiences of CKD patients undergoing hemodialysis. The data was collected by using interview technique. Data was collected by face to face interview. Total 12 interviews were conducted. Thematic analysis suggested by Colaizzi (1978) was used in the research. Total 5 main themes and 14 subthemes were formed. The first theme is uncertainty with life which includes subtheme fear of death, fear of treatment. The second theme is dependence which includes subtheme care from family members, adherence to hemodialysis

treatment. The third theme is lifestyle changes which includes subtheme disturbed dietary habits, impaired daily activity, decreased social life, loss of job, difficulty in education, financial burden. The fourth theme is coping and support which includes subtheme appropriate family support, stress relieving activity. The last theme is satisfaction with care which includes subtheme good hospital services and improvement in health condition.

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APPENDICES

APPENDIX- I

10/5/2020

5.jpeg



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

No. AIIMS/IEC/2020/ 3078

Date: 01/06/2020

ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number: AIIMS/IEC/2020-21/ 2037

Project title: "Lived experiences of CKD patients undergoing haemodialysis at AIIMS Jodhpur"

Nature of Project: Research Project Submitted for Expedited Review
Submitted as: Student Research Project, as a part of Academic Programme
Investigator: Babli
Supervisor: Dr. Ashok Kumar
Co-Supervisor: Dr. Nitin Kumar Bajpai & Mrs. Vandna Pandey

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
Institutional Ethics Committee
AIIMS, Jodhpur

Basni Phase-2, Jodhpur, Rajasthan-342005, Website: www.aiimsjodhpur.edu.in, Phone: 0291-2740741 Extn. 3109
Email: ethicscommittee@aiimsjodhpur.edu.in

APPENDIX-IIa

सूचित सहमति प्रपत्र (हिंदी)

परियोजना का शीर्षक: टो एक्सप्लोर लिब् एएक्सपेरैसेस ऑफ सीकेडी पेशेंट्स उंडरगोइंग हेमोडायलिसिस

प्रधान अन्वेषक का नाम: बबली (M.Sc. नर्सिंग)

नमूना पहचान संख्या:

मैं _____ पुत्री/पुत्र _____ निवासी

“टो एक्सप्लोर लिब् एएक्सपेरैसेस ऑफ सीकेडी पेशेंट्स उंडरगोइंग हेमोडायलिसिस” 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 व्यक्ति या नियामक अधिकारियों से देखी जा सकती है। मैं इन व्यक्तियों को अपने रिकॉर्ड तक पहुंचने की अनुमति देता/ देती हूं।

दिनांक: _____

स्थान: _____

हस्ताक्षर

यह प्रमाणित करने के लिए कि मेरी उपस्थिति में उपरोक्त सहमति प्राप्त हुई है।

दिनांक: _____

स्थान: _____

प्रमुख अन्वेषक के हस्ताक्षर

साक्षी 1

साक्षी 2

हस्ताक्षर

नाम: _____

हस्ताक्षर

नाम: _____

APPENDIX-IIb

Informed consent form (English)

Title of the project : Lived experiences of CKD patients undergoing hemodialysis at AIIMS, jodhpur.

Name of the Principal Investigator: Babli (M.Sc. Nursing)

Sample Identification No.

I _____ D/o, S/o _____
_____ R/o _____

_____ give my full, free, voluntary consent to be a part of the study “Lived experiences of CKD patients undergoing hemodialysis at 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 questions.

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 and any of my records may be looked at by responsible individual from AIIMS, Jodhpur, Rajasthan or from regulatory authorities. I give permission for these individuals to have access to my records.

Date: _____

Place: _____ Signature

This to certify that the above consent has been obtained in my presence.

Date: _____

Place: _____ Signature of Principal Investigator

Witness 1

Witness 2

Signature

Signature

Name: _____

Name: _____

APPENDIX-IIIa

Participant Information Sheet

Part-I

1. Purpose of the research study: The aim of study is to reveal the meaning and concept the experiences of CKD patients undergoing hemodialysis.
2. Study procedure to be followed: To explore the lived experiences of CKD patients undergoing hemodialysis
3. Benefits from the study: To reveal the meaning and concept the experiences of CKD patients undergoing hemodialysis.
4. Risk of the study: None
5. Complication of the study: None
6. Confidentiality: Data collected from the participants shall not be allowed shared with anyone except the study investigator.
7. Rights of the participants: Participants would have the freedom to share their data and to continue or leave the study if they desire so at any point of time.

Participant Signature:

Participant Name:

Name:

Part 2:

Investigator's word

I have explained the purpose, procedure, benefits, and harms of the study in details to the participants. All the information regarding study has been disclosed and enough opportunity for asking questions regarding the study was given to study participant.

Principal Investigator Signature

Witness signature

Name:

Name:

Date:

Date:

APPENDIX-IIIb

प्रतिभागी जानकारी

भाग-1

1. अध्ययन का उद्देश्य : ऐम ऑफ थिस स्टडी इस टो रिवील मीनिंग एंड कॉन्सेप्ट ऑफ सीकेडी पेशेंट्स उंडरगोइंग हेमोडायलिसिस
2. अध्ययन प्रक्रिया: टो एक्सप्लोर लिव्ड एएक्सपेरिंसेस ऑफ सीकेडी पेशेंट्स उंडरगोइंग हेमोडायलिसिस
3. अध्ययन से लाभ : टो रिवील मीनिंग एंड कॉन्सेप्ट ऑफ सीकेडी पेशेंट्स उंडरगोइंग हेमोडायलिसिस
4. अध्ययन का खतरा: कोई नहीं
5. अध्ययन की जटिलता : कोई नहीं
6. गोपनीयता : प्रतिभागी से एकत्र किये गये आंकड़ों का अध्ययन अन्वेषक को छोड़कर किसी के साथ साझा नहीं किया
7. प्रतिभागी के अधिकार : प्रतिभागियों को अपने आंकड़ों को साझा करने ,जारी रखने या अध्ययन छोड़ने के लिए किसी भी समय के किसी भी बिंदु पर स्वतंत्र होंगे

प्रतिभागी हस्ताक्षर :

प्रतिभागी नाम :

दिनांक :

भाग 2:

अन्वेषक के शब्द :

मैंने प्रतिभागियों को अध्ययन के उद्देश्य ,प्रक्रिया ,लाभ और नुकसान के बारे में विस्तार से बताया है। अध्ययन के बारे में समस्त जानकारी का खुलासा किया गया है और अध्ययन के बारे में प्रश्न पूछने के लिए पर्याप्त अवसर अध्ययन प्रतिभागी को दिया गया था।

प्रधान अन्वेषक हस्ताक्षर

गवाह हस्ताक्षर

नाम :

नाम :

तिथि:

तिथि:

APPENDIX-IVa

TOOL FOR DATA COLLECTION (ENGLISH)

PART- 1

Demographic variables

1. Age -
2. Gender -
3. Education -
4. Occupation -
5. Religion -
6. Marital Status -
7. Total Number of Family Members -
8. Monthly income of family -
9. How long you are suffering from Chronic Kidney Disease?
.....
10. From how long you are undergoing hemodialysis?
.....
11. How many cycles you underwent in a week?
.....
12. What other health associated problems you are having and from
how long it is there?
.....

APPENDIX-IVb

डाटा संकलन हेतु उपकरण/स्रोत (हिंदी)

भाग -1 (जनसांख्यिकीय-प्रपत्र)

कृपया नीचे दिए गए प्रश्नों को पढ़ें और उपलब्ध कराए गए स्थान को भरें

1. आयु -
2. लिंग -
3. शिक्षा -
4. व्यवसाय -
5. धर्म -
6. वैवाहिक स्थिति -.....
7. परिवार के सदस्यों की कुल संख्या -
8. परिवार की मासिक आय -
9. आप कब से बहुकालीन गुर्दा रोग से पीड़ित हैं?
.....
10. आप कब से हीमोडायलिसिस करवा रहे हैं?
.....
11. आप हफ्ते में कितने साइकिल्स कराते हैं?
.....
12. आपको कौन सी अन्य स्वास्थ्य संबंधी समस्याएं हैं और यह कितने समय से है?
.....

APPENDIX-IVc

PART - 2

TOOL TO EXPLORE THE LIVED EXPERIENCES OF CKD PATIENTS UNDERGOING HEMODIALYSIS

Open ended questionnaire for In-Depth Interview

Introduction: (2 minutes)

I wish you good Morning. Thank you for participating in my Research. I am Babli, M.Sc. Nursing student from College of Nursing, AIIMS, Jodhpur. As a Part of my academic research program, I am conducting this Interview. No information will be shared to any person except for research purpose. The Questions will be open-ended questions. The answers will be recorded in audio tape recorder.

Objectives: (1 Minute)

The purpose of the study is to explore the lived experiences of patients with Chronic Kidney Disease undergoing hemodialysis.

Questions:

1. How long you are suffering from Chronic Kidney Disease?
2. What was your first reaction when you were diagnosed with Chronic Kidney Disease?
3. How did you feel when you get to know that you have to live on maintenance hemodialysis?
4. Now what feelings you have towards hemodialysis?
5. Which are the problems you are facing due to hemodialysis in your daily life?
6. What are the support and coping measures you are taking to solve those problems?
7. What do you think about your future?
8. Is there anything else you would like to say about your experience as person on hemodialysis?

Thanking session :Thank you so much for spending your valuable time. I assure that these interviews and your suggestions will help in providing adequate support and care for patients with CKD who are undergoing hemodialysis.

APPENDIX-IVd

भाग – 2

टो एक्सप्लोर लिब्ड एएक्सपेरैसेस ऑफ सीकेडी पेशेंट्स उंडरगोइंग हेमोडायलिसिस को जानने के लिए उपकरण
विस्तार साक्षात्कार के लिए खुली प्रश्नावली

परिचय: (2 मिनट)

मैं आपको सुप्रभात शुभकामनाएं देती हूँ। हमारे शोध में भाग लेने के लिए धन्यवाद। मैं बबली कॉलेज ऑफ नर्सिंग, एम्स, जोधपुर से एम.एससी नर्सिंग क छात्रा हूँ। मेरे शैक्षणिक अनुसंधान कार्यक्रम के एक भाग के रूप में, मैं इस साक्षात्कार का संचालन कर रही हूँ। विस्तार साक्षात्कार के लिए प्रश्न खुली प्रश्नावली होंगे। उत्तर ऑडियो टेप रिकॉर्डर में दर्ज किए जाएंगे।

उद्देश्य: (1 मिनट)

अध्ययन का उद्देश्य टो एक्सप्लोर लिब्ड एएक्सपेरैसेस ऑफ सीकेडी पेशेंट्स उंडरगोइंग हेमोडायलिसिस
प्रश्न:

1. आप कबसे सीकेडी से पीड़ित हैं?
2. जब आपको बहुकालीन गुर्दा रोग का पता चला था तब आपकी पहली प्रतिक्रिया क्या थी?
3. जब आपको यह पता चला कि आपको जीवन भर के लिए हीमोडायलिसिस पर रहना तब आप कैसा महसूस कर रहे थे?
4. अब हीमोडायलिसिस के प्रति आपके क्या विचार हैं?
5. आपको हीमोडायलिसिस के कारण अपन दैनिक जीवन में किन समस्याओं का सामना करना पड़ रहा है?
6. इन समस्याओं को हल करने के लिए आप कौंसे उपाए और सहयोग अपनाते हैं?
7. आपके भविष्य के बारे में आपके क्या विचार हैं?
8. और कुछ जो आप साझा करना चाहते हैं?

धन्यवाद सत्र

अपना बहुमूल्य समय बिताने के लिए आपका बहुत-बहुत धन्यवाद। मैं विश्वास दिलाती हूँ कि ये साक्षात्कार और आपके सुझाव हीमोडायलिसिस से गुजरने वाले बहुकालीन गुर्दा रोग के रोगियों के लिए पर्याप्त सहायता और देखभाल प्रदान करने में मदद करेंगे

APPENDIX-V

A LETTER REQUESTING EXPERTS FOR CONTENT VALIDITY

From:

Babli

M.Sc. (NURSING) 1st Year

College of Nursing, AIIMS, Jodhpur

To

.....

Subject: Expert opinion on validity of interview guide/schedule

Respected Ma'am/ Sir

I Babli student of M.Sc (Nursing) 1st year College of Nursing, AIIMS, Jodhpur, have selected the following topic for research project:

“ Lived experiences of CKD patients undergoing hemodialysis at AIIMS, Jodhpur”

The objectives of following study are:

- To explore the lived experiences of CKD patients undergoing hemodialysis.

I request you to kindly go through the interview questions 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 suggestions.

Thanking you in anticipation.

Yours sincerely

Babli

APPENDIX -VI

List of experts validated interview schedule

Name of experts	Designation
1. Dr. Manish Chaturvedi	Additional professor Department of Nephrology AIIMS, Jodpur
2. Mr. Anand L.	Assistant professor College of Nursing AIIMS, Bhubhneswar
3. Mrs. Nadiya Krishnan	Assistant professor College of Nursing AIIMS, Bhubhneswar
4. Mr. Nipin Kalal	Assistant professor College of Nursing AIIMS, Jodhpur
5. Mrs. Nimrata Rana	Assistant professor College of Nursing AIIMS, Jodhpur

APPENDIX-VII

BRACKETING

The bracketing is done before data analysis so that there is **no preconceived notions** which may affect the result of my study.

Method of bracketing used for this study is by **peer review** with my classmates and **writing memos**. **Writing memos** is a process where researcher writes whatever comes to his mind, just writing it down.

Researcher personally thinks that hemodialysis leads to various problems in the life of patients. Patients life totally changes after starting with hemodialysis.

Patients faces various problems related to physical problem, family, social and financial. Following are my preconceived notions which I am writing it down on the paper.

- Treatment related fear
- Burden on family members
- Having various physical problems
- Sexual problems
- Cost related to hemodialysis
- Restriction on fluid, diet and social life
- Stress related to disease condition
- Decreased self-esteem.

Researcher is also a registered nurse and working in the nephrology unit as a student posted for clinical posting as a part of academic requirement. I don't have experience as an independent staff. I am working under supervision of staff working in hemodialysis unit.

I hope that this will not affect my study results and I will be completing my thesis successfully.

Babli

Dated : 1st September 2020

APPENDIX-VIII

List of experts validated thematic analysis

Name of experts	Designation
1. Mrs. Gomathi A.	Associate Professor College of nursing AIIMS, Jodpur
2. Mrs. Mamta	Assistant Professor College of Nursing AIIMS, Bhubhneswar
3. Mr. Nipin Kalal	Assistant Professor College of Nursing AIIMS, Jodhpur
4. Mrs. Nimrata Rana	Assistant Professor College of Nursing AIIMS, Jodhpur
5. Mr. Ashish Parihar	Assistant Professor College of Nursing AIIMS, Jodhpur

APPENDIX-IX

Transcript of the interview

Subject Code-Res_1

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Mere ko 1.5 saal ho gya kidney ki problem shuru hwa uske baad mera dialysis start hwa. Mere symptom shuru hwa..... the jab mujhe phela baby hwa 2003 mein. Meko bhot high B.P. and sugar ho gya tha. Sugar to thk ho gya delivery ke baad par mera B.P. high raha. Fir 2015 mein suddenly meko ek din maal mein chest pain hwa, sans ne le pa ri thi mein. To meko pass k ek hospital mein admit kra diya. Then unhone bola ki apka angiography hoga. To jab angiography kraya to pta chla meri renal arteries stenosed thi. To unhone mujhe medicine di BP normal hwa 140/80 fir meko discharge kar diya. Us time mera creatinine 3 tha. Doctor ne kha thoda increase hoga fir normal ho jayega par normal ni hwa bdta raha. Mein routine checkup krati rehti thi fir mera urea bhi badh gya to maine AIIMS mein dikhaya to Doctor ne meko bola ki apko dialysis krana padega kyonki apki kidney thk se kam ni kar ri.....

To aesa mera kidney ka problem start hwa..

Interviewer: Jab apko pta chla apko CKD hai apki kya pratikiya thi?

Interviewee: Phele to bhot bur lga mujhe..... Ek dam se shock s alga. Aesa lga ki mere sath hi aesa kyon hwa. Ek dam se stress agya ki ab life kaisi chalegi. Fir doctor se batchit ki unhone kaha itna stress ni lena hai. Par fir bhi thoda sa tension tha.

Meri Job chut gyi thi I was not able to work.

Interviewer: Aapko kaise lga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Meko dialysis ke bare mai thoda bhot phele se pta tha as I am a doctor. But jab pta chla ki..... Mujhe bhi krana hai to phele thoda dar lg apar fir

nhai kyonki dialysis bhot jarori hai krana. Ab to jab tak krana hai jab tak ki kidney transplant na ho jaye. Name to register kra rakha hai.

Interviewer: Aab hemodialysis ke prati aapki kya bahnayein hain?

Interviewee: As such to kuch feelings ni hai par hemodialysis jarori hai krana.....

Bina kraya to ab jindagi jee ni sakte hain. Ab agar achi life jeeni hai to hemodialysis to krana hi padega. After dialysis even my condition has improved. Phele sans lena mai dikkat hoti thi par ab dialysis ki wajah se acha lgta hai.

Interviewer: Aapke dainik jewan main hemodialysis ke karan kaun si samsayein ho rahi hain?

Interviewee: Han samsayein to khubh hwi dialysis ki wajah se par kya Karen dialysis bhi jarrori hai. Jaise aaj mein dialysis krake jaongi to kuch kaam ni karti hon ghar ka fir next day se thk ho jata hai..... Ghar ke sab kam kar leti hon cooking vagera.....

Meri diet mai bhi kuch changes ni hai because I do not get weight gain. Doctor has told me to take regular fluid and diet intake.

Meri shadi shuda jindagi mai bhi kuch change ni hwa sab normal hai.....

Financial problem bhi ni hai my husband is good earning to kabhi dikkat hi ni hwi paion ki wajah se daialysis mein.....

Aane jane mai bhi koi dikkat ni hoti bas corona ke tho gya to thoda dar lgta infection baki kuch dikkat nahi hai.....

Meri social life bhot change ho gyi after CKD mai jyada bahar ni jati hon friends se ni mil pati hon, kisi occasion pe ni jati hon. Bahar ka khana bhi avoid karti hon.

Meri naukri chut gyi dialysis ke karan. Hafte mai do chutti koi ni deta hai. Agar mai jati bhi hon to family members allow ni karte hain ki tabiyat kharab na ho jaye..... Meko bhot dukh.....hota is chig ka mai ab apni practice continue ni kar apti hon.

Interviewer: In samasyon ko hal karne ke liye aap konse upaye aur sahyog apnate hain?

Interviewee: Mera husband hai jo hmesha support karte hain sath rehte hain, mera in-laws there are always..... supportive. Meri daughter hai jiske sath mai full day reh kar apni tension durr kar deti hon. Usko pdhati hon, uske sath khubh batein karti hon, uske sath khalti hon aur din nikal jata hai..... Maine ek group bhi join kiya hwa jisme paediatrics realted case discussion hota rehta hai, seminars hote rehte hain to unko attend krke mujhe acha lgta hai as new cases dekhne aur sikhne ko milte hain.

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: As such to koi plans ni hai bas yahi beti ka khayal rakhna usko bda hote dekhna hai. Job to mai continue dubara kar ni sakti hon. Bas thoda sa darr lgta rehta hai life ko leke ki kab tak thk rahongi mai. Isliye ghar se niklte waqt dialysis ke liye apni beti ko hug karke aati hon ki sab thk rakhna.....

Baghwan pe hai vishwas ki meko vo thk rakhega. Mera bas ye hai ki baghwan itni life de de ki mai apni beti ki graduation and marriage kra don tab tak mujhe kuch na ho. Mera bina meri beti kaise reh payegi abhi to vo kafi choti hai..... Independent ho jaye fir I will not have any fear.

Interviewer: Aap hemodialysis par apne anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Dialysis ke bare mai as ab to ye bhot advance hogya hai actually mere father ko CKD tha jab mai sirf 12 saal kit hi. To mera father army mai the in 1991. Us time facility ni the ki dialysis ki. From jodhpur he has to go to pune for dialysis aur tab sirf peritoneal dialysis hoti thi. Fir 1991 mai to vo admit hwe the hospital mai to unka hb sirf 3 tha aur anasraca tha pura body mein.....

Next day raat mai bola ki blood donate krenge mummy ko us time Ram mandir aur babri masjid ki wajah se karfew lga hwa tha to meri mummy blood donate ni kar apyi. Aur army hospital main aesa hota hai ki nurses hi sambhal leti hai patient ko to unhone raat mai blood ne lgaya mera father ko. Next day jab hum gye to mere father ward mai ni the bola ki X- ray krwane bheja hwa. X-ray room mai bhot halchal thi aur X-ray ke time mera father ko table pe hi cardiac arrest aa gya aur unki death ho gyi.....

Bhot bur alga us time to mai bhot choti thi pta bhi nit ha ki dialysis hota kya hai. Ab wahi dialysis mera sath ho raha kabhi socha nit ah ki aesa hoga. Par life chal ri hai daiysis ki wajah se yahan ka staff bhi bhot acah hai bahot care krata hai

bhot kam dikkat hoti hai iski wajah se dialysis mein. Doctor bhi bhot ache hain
that's why my treatment is going well.

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Mujhe lagbhag 5 saal ho gya is bimari se gujarte hwe. Mujhe heart ka problem phele se hi tha bypass surgery hwa tha mujhe to mai ICU mai admit tha us time. Mai karibib karib behosh ho gya tha Allahabad mai kafi..... ilaj hwa par thk ni hwa to mere damad ne boal ki PGI lucknow chalo wahan dikhate hain. Wahan test vagera kraya to pta chla ki meri kidney thk se kam ni kar ri hain. One month tak mai vahan ICU mai raha. Urine mai koi dikkat nit ha par mera phele prostate ka bhi surgery hwa tha.

Interviewer: Jab apko pheli bar pta chla apko CKD hai apki kya pratikiya thi?

Interviewee: Ab pratikiya to kya hi par bur lga ki aesa mera kidney kharab ho gya. Mai karib char se panch din behosh tha ICU Allahabad mai fir mujhe wahan se PGI shift kar diya fir jab hosh aaya to maine nurse se pucha mai khan hon to nurse ne bola aap PGI mai hain santoshti hwi ki achi jgha hi hon..... To ek dam se suddenly mujhe pta chla ki mere kidney kharab ho gyi hai to react bhi ni kar paya. Ab to accept kar liya chal raha hai sahi ilaj ho raha.

Interviewer: Aapko kais alga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Dialysis ke bare mai pta tha ki hota hai ye jinki kidney kharab ho jati wok rate hain, Halaki mera damad khudh doctor hai to jo bhi sawal aye puch liya tha ki kaisa, kya hoga, kya sab dhyan rakhna. Aur fir doctor bhi ache hain yahan kai, nursing staff to aesi koi dikkat ni hwi.....

Mai phele allahabd mein rehta tha fir mai shift ho gya yahan jodhpur kyonki damad beti rehti hain. Ek kiraya ka makan le liya main mai aur meri wife sath mei rehta. Hmare yahan beti ke ghar ka pani tak nip eta to beti ke ghar to ni reh sakta tha mai. Beta delhi mai job karta to ek trah se yahan aaya to damad beti ka support mil gya mujhe. Ab bas chal raha dialysis satisfy hon main dialysis aur kidney transplant ka to koi vicahr hi ni hai ek to meri age ho gyi hai bas yahi hai ki dialysis thk thak chlta raha koi preshan na aaye.

Interviewer: Aap hemodialysis ke prati apki kya bahvnayein hain

Interviewee: Acha hai dialysis aur feelings to kya hi ki jarori hai krana ek traie se. Nahi krayenge to tabiyat biagd jayegi. Ab to rehna hi his puri jindagi iske sath. Koi problem ni aari dialysis se sab thk hai.....

Interviewer: Aapke dainik jewan main hemodialysis ke karan kaun kaun se samasayein ho rahi hain?

Interviewee: Samasayein to kya hi ab hafte mai do bar hi hota dialysis ab dialysis ek ya do din phele pani jyada ho jata body nein chla ni jata thoda sa chalte hi sanas phull jati hai fir jab dialysis hota tabhi thoda acha lgta hai,

Aab ek trah se dependent bhi apne damad pe beti pe wahi leke aate hain hume hospital mein, khayal rakhte hain ghar pe meri wife khayal rakhti hain. Jis din dialysis krake jao to us din fistula wala hath to hila ni pate hain bas us din rest hi karte hain.....

Shaadi shuda jindagi mai to kya hi badlwa ab to age ho gyi sab sahi hai wife bhot sath deti hai mera. Aur koi dikkat ni financial wagera sab badhiya meri pension aati hai achi, beta bhi naukri krta hai to aesa koi dikkat ni hai, Bas ek dikkat hai bahar kahi aana jana ni hota hai, social life puri khatam si hogyi ye bimari hone ke badd, dur sa lagta hai ki kahi bahr gye to bimar na pad jaye.

Aur mai to phele hi retired ho gya tha 9 months phele kidney ka problem start hwe to job se to koi bhi unstaisfaction ni hai.....

Khane mai to normal food kuch bahar ka ni khate hai hum. Bahar ka khana waise bhi hme pasand ni hai itna. Panipe bhi rok hai sirf 1 litre bola hai peena ka par kai bar jyada ho jata hai pyas lgti hai to control ni ho pata uski vajah se wajan badh jata hain.

Interviewer: In samasyon ko hal karne ke liye aap konse upaye aur sahyog apnate hain?

Interviewee: Ghar pe rehta hon apni wife ke sath samay bitate hon. Bache hain vo aate rehte hain unke sath khelta hai time bitate hain to thk lgta hai..... TV dekh lete hain din mai bas aesa hi tym kat jata. Aur beti damad ka kafi support hai, halki beta ni hai mera idhar par support to use bhi milta hai. Bas sab aesa hi chal raha..... Stress to kuch ni hai sab bache settled hain ghar hai apna Allahabad koi rehta ni hai.

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: Kuch ni hai vichar ab life sab khatm koi charm ni reh gya life mai ab kamre se bahar hi nikalta mai aur meri wife mast hain bachen kabhi phone kar leta hai puch leta hain. Sab khatam ho gya hai kuch ni sochte jaisa chal raha usme satisfy hai.

Interviewer: Aap hemodialysis par apna anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Kuch ni aesa to dialysis must hai krane jarori hai iska bina to jee ni sakte hain aur kya bateyen bas krana padega dialysis. Doctor aur staff sab ache sahi treatment chal raha badhiya hai sab.

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Mujhe 3 saal se CKD hai, shuru aesa hwa tha ki mera urine kam, swelling ho gyi thi firsans mai dikkat ho gyi thi. Meko BP ki problem jab mera first baby tha tabse start ho gyi thi, sugar ka bhi dikkat hai 7 saal se, thyroid ka bhi problem hai. Yahipn par hi pta chla mera kidney mai bhi kuch dikkat hai fir Doctor ne mera treatment bhi chalo kar doya tha.

Interviewer: Jab aapko pta chal apko CKD hai apki kya pratikiya thi?

Interviewee: Bura laga sablog disturb hwe mai bhi, family bhi disturb hwi. Par fir dheere adjust kiya maine, family ne bhi. Phele to mai medicine par hi thi, fir Ahmdebad gyi thi apni daughter ke pass wahan suddenly meri tabiyat kharab ho gyi . Mujhe hospital mein admit kraya gya fir wahan se mera dialysis shuru hwa. Fir uske baad mein yahan aagyi fir tabse yahin par hon meri beti hai doctor uske sath hi rehti hon idhar.

Interviewer: Aapko kais alga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Aesa tha ki dialysis to krana hi hai ab isme to kya hi kar sakte achi life jeeni hai to krana hi padega. Balki dialysis jabse start hwa meri condition improve ho gyi hai phele meko sans mein dikkat hoti , urine mai dikkat ab ye hai ki dialysis krane se sanse mein dikkat ni hoti hai mai normal kam kar leti hon.....

Ab urine bhi din mai 2 ya 3 bar aa hi jata hai aur aesi kuch dikkat ni hai life mai thk chal raha sab. Bus jis din dialysis krake ghar jati hon to weakness rehti hai, vomiting si aati hai, us din mai daily ke routine work ni kar pati hon, jaise ki roj karti hon.

Interviewer: Aapke dainik main hemodialysis ke karan kaun kaun se samasayein ho rahi hain?

Interviewee: Dainik jeewan mai to aesa jyada badlaw ni aaya. Mein apna routine work khudh karti hon. Khana sab normal kahti hon bas namak kam aur suagar kam kahti hon. Bas pure din mai 1 litre se jyada ni pee sakti. Kabhi jyada pyas lagti hai to ice cubes kha leti hon thoda thk lgta hain. Pani peena ka bhot man hota kai bar par control krna pdta hain. Weight kai bar badh jata hai mera. Family ke upar to aesa kuch dependent ni hai main apne kam khudh kar leti hon.

.....

Jabse fistula bna hai tabse thoda dependent ho gyi hon kyonki left hand se kam krna bilkol mna hai aur pain bhi hai. Phele tha ek aur fistula jo block ho gya to uske baad central line lga di. Central line se bas neck pe dikkat hoti jyada move ni karti hon mai apni neck ko. Abhi filal dikkat ho ri kafi nhane mai, daily ke kam mai. Par abhi corona hai varna kisi maid ko rakh leti kam ke liye. Beti job pe jati hai to uski help leni padti hai. Abhi main dependent ho on hair care ni kar pati hon 4 se 5 mahine ho se.....

Aane jane mai bhi kuch dikkat nahi hai daughter aati hai meri vo mujhe le aati fir chod deti hai ghar.

Social life to bilkol bhi hi ni rahi hai. Bahar kahin aati jati ni hon, bas ghar mein hi rehti hon. Family occasion mai aana jana sab band ho gya mera.

Interviewer: In samasyon ko hal karne ke liye aap konse upaye aur sahyog apnate hain?

Interviewee: Jaise pani ki pyas lgti hai to mai ice cubes kah leti hon, thoda kam kar leti hon. Baal vaal bnane ke liya beti ki help le leti hon. Ghar ka kam ke liye maid rkh leti hon. Bas aesi hi samasyon ko hal kar leti hon.

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: Vicahar to kya hi hai ab to umar ho chli hai family mai sab thk hai bas kat jaye jindagi jyada tabiyat kharab na ho. Aur to kuch future plans ni hai mera.

Interviewer: Aap hemodialysis par apna anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Aap puchiya bta denge par waise koi dikkat ni hai mujhe. Acha treatment hai iccha ho to kidney transplant krao varna ni krao. Life ko leke kya dar aab aaye hai to jana to hai hi meri soch hai. Jyada sochenge to depression mai jayenge isse acha hasi kushi se rahe aur ache se rahein

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Mujhe 2017 mai pta lga aur creatinine bda us waqt mai delhi tha mera bda beta delhi tha phele wahan dikhaya tah wahan mujhe admit kiya..... Aur dialysis krate hwe mujhe 6 months ho gye hain. Maine kisi aur hospital mai dialysis ni kraya yahin start kiya tha dialysis krna mmmmmmm.....

Hafte mai do bar krata hon mai dialysis. Dialysis ki wajah se sirf weakness aaati hai mujhe aur to koi dikkat ni bas ek bar vomiting aayi thi.....

Mujhe hypertension and diabetes hai kariben 2006 se us time stent lgaya tha. Aur diabetes to shuru se hi hai after 45. Jab maine regular test kraya tha to creatinine bda hwa tha urine ya aur koi dikkat ni thi.

Interviewer: Jab apko pta chla apko CKD hai apki kya pratikiya thi?

Interviewee: Bhot bura lga tha. Kafi changes hwe life mai travel band ho gya mmmmmmmmm. Aur to kuch ni.....

Interviewer: Aapko kaise lga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Bur alga par kya kar sakte hain krana to padega hi bina kraye to ni reh sakte hain..... Ye ek jarrori part ho gya hai life ka ab to..... Life kafi change ho gyi hai dialysis ke baad se ek dam. Aur us ke according ab rehna sikh gye hain hum.....

Interviewer: Aab hemodialysis ke prati aapki kya bahnayein hain?

Interviewee: Ni ye to medical advice hai. So it has to be done. Aur to aesi koi feelings ni hai. Bas krana hai ab to life dialysis pe dependent hai issi ke sahare jee sakte hai hum bas.

Interviewer: Aapke dainik jewan main hemodialysis ke karan kaun si samsayein ho rahi hain?

Interviewee: Bahar niklna band ho gya. Jyada kahin ja ni sakte. Travelling band ho gyi meri. Mujhe hospital bhi beta hi leke aata hai gadhi mai. Han fistula wali side soo nahi ahypertension ki.

Pani kafi dar dar ke peena pdta hai kahin weight gain na ho jaye lag bahg 1 litre pee lete hain. Khane mai bas vahi kam sugar vala namak vala kahana pdta hai . Bahar ka kuch bhi ni kahte hai hum, bas ghar ka hi khana kahte hain.....

Social life mai mujhe travelling ka bhot shauk tha vo bilkol band ho gya kahin aana jana sab band ho gya uska bhot dhukh hai mujhe,.Pichli jindagi se compare Karen to abhi life kharab hai mai phele sportsmen tha par ab kuch ni hai. Mera ek beta Australia mai mai phele gya tha abhi bhi jana ke man par sab plan kharab ho gya. Dar lgta hai kahin gye aur tabiyat na kharab ho jaye.

Interviewer: In samasyon ko hal karne ke liye aap konse upaye aur sahyog apnate hain?

Interviewee: Aesa to kuch khas ni hai TV dekh lete hai, poote kai sath khel lete. Aaj kal to band hai corona ki wajah se warna bahar ghum leta the thoda. Beta aur wife se baatchit kar leta hai man khush rehta hai.

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: Future plans to kuch ni hai phele mai high court mai vakalat krta tha fir ye bimar ke wajah se administrative ka kam krne lga ab to vo bhi chut gya to aesa kuch hai ni bavishya ko leke.

Interviewer: Aap hemodialysis par apna anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Kya bateyein ab to dialysis to chal hi raha hai..... Bhot kharab baat hai ek trah se har hafte krana pdta hai. Beech mai yahn kuch construction chal raha tha to maine socho thk hai badhiya hai acha hai lekin mai jab kuch din baad aaya dekha to pta chal 4.5 kg badh gya mera. Aur fir dialysis krya us din to kafi dikkat hwi mujhe.

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Meko hwe 8 saal 7 mahine. Mujhe 872 dialysis ho chuke hai 8 saal se. Mai week mai 2 bar aata hon dialysis ke liye. Meko phle BP thi us time check krya to 272 ho rkha tha BP baki aur koi dikkat nit hi mujhe routine test krane ke baad pta chla ki meri dono kidney kharab ho gyi hain. Mera urine dhere dhere kam ho gya tha. Bas vahi check kraya to BP jyada nikla aur kidney khrab nikli phele to kuch bhi nit ha suddenly hwa ye. Phele pta ni ha mujhe mera BP itna high hai. Phele jab check kraya to pta chla ki 272 hai tab mai khudh hi gya tha hospital check krane bas thoda ajeeb sa lag raha tha. Phir jab check kraya to declare kar diya ki kidney kharab hai.

Interviewer: Jab apko pta chla apko CKD hai apki kya pratikiya thi?

Interviewee: Hhehehee maine to bhot normaly liya tha ab jo ho gya uska to kya kar sakte hain tension li ni to thk hai ab chal raha haiOption sab ajma liya kidney transplant sara kuch kar liya. Actually ghar se to koi mila ni donor sabse chota to mai hi hon kisiko BP ki problem hai kisi ko sugar ki bimari. Accidental vale main nam register kraya hai par abhi tak kisi mai bhi number ni aaya..... Hopefully yahan start hwa par Corona beech mai aagya Yahan 4 transplant hwe sare badhiya hwe abhi tak to start ho jata. Par ye corona 1 saal kha jayega abhi to sardiyon mai pta chalega ki ye kitna fail raha abhi to garmi chal rii mai hi dekha hai iska natak.....

Interviewer: Aapko kaise lga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Actually mai 1 saal tablet pe the mera creatinine bhi kam tha par fir baad mai bdta gya fir uske baad control ni hwa . Dialysis ke patient to phele se dekh liya the maine to easy way mai bta diya ye dialysis hai iska procedure sab bta diya tha to jyada tension ni li. Mai jyada tension ni leta hon miane normally hi liya tha. Ab dialysis to krana hi padega jab tak koi donor ni mil jata hai tab tak to dialysis par hi dependent hai. To jyada sochna kya bas ache se care karo time se dialysis krao kuch dikkat ni aaati hai....

Do mahina tak to even maine apni family ko btaya bhi nit ha unko tension ni deni thi mujhe isliyeeee....

Interviewer: Aab hemodialysis ke prati aapki kya bahnayein hain?

Interviewee: Bahnayei to vahi mujhse to thk lgta hai dialysis jyada kuch dikkat hoti ni hai ek trah se mai adjust kar chuka hon dialysis to thk hai sahi chal raha....

Interviewer: Aapke dainik jewan main hemodialysis ke karan kaun si samsayein ho rahi hain?

Interviewee: Daily life mai to movement mai dikkat ho gyi thi jyada chlne hi thkan hone lgt hai jyada hardwork ni kar sakte hain..... Mai apna sara kam khudh krta hon mujhe dependent feel ni hota hai...

Khane peene mai diet thodi kam ki diet ko divide kiya ki ek sath sabkuch khana ni hai thoda divide krna pdta hai. Pani bhi bas 1 litre peena pdta hai starting mai khubh pyas lgti thi par ab habitual ho gya hai. Lmba chlana hai to habitual hona pdega warna ya 2 saal mai hi nikal lenge.

Social life mai to jyada kuch change ni chle jate hai occasion mai bas jyada activity ni krte hai thoda thoda sa kuch kam kar leta hain. Jyada sardiyan mai dikkat hoti hai jyada sardi lgti hai fir vo ek bar tolerate honi band ho jaye to sehn ni hoti hai fir. Islie sardi mai thoda bach ke rehna pdta hai.....

Hheheeeeeee dhera dhera sambal jata hai isme main chig hai patient ki vo apne apko kaise cover krta hai matlab tablet kaise leni hai admi chup chap se le le agar nil eta hai to fir dikkat hoti hai.

Ab jaise hi dialysis start ho ga to mai need lunga 2 ya 3 ghnte aur last ke 1 ghnte mai neend khul jati hai kyonki BP high ho jata hai. Itna saal ho gye mujhe abhi vomiting ni hoti hai. Kuch log aate hai bina khaye piya to unko aati ahi vomiting. Mai to even khudh drive krke jata hon ghar. Mujhe aesi koi thkan ni lgti hai jab mai dialysis krake ghar jata hon ye sab mental game hai

Interviewer: In samasyon ko hal karne ke liye aap konse upaye aur sahyog apnate hain?

Interviewee: Han ghar se pura support hai mujhe sab help krte hai. Jls ghar mai paise hota hai sab set rehta hai ab mere sare bhai set hai to kam chl rha hai aur mai khudh kam krta hon beth ke. Bas physical kuch ni par kar leta hon mai khudh apna kam.

Mai jyada tension leta ni hon apna ghar pe rehna family ke sath time bitana apna job ka kam karna sab kar leta hon isliye koi dikkat ni hai mujhe.

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: Vichar to kya bas tabiyat thk rhe, mai aesa thk thak kam karta hon. Kidney transplant mai number aa jaye to aur bhi badhiya rehega. Apne bachon

ko bda kar don shadi vadi ho jaye to thoda relax ho jaonga aur to kuch vichar hai ni filal lkoi mujhe.

Interviewer: Aap hemodialysis par apna anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Patient bas apne apko sambhal le to Imba chalega. Abhi India mai sabse jyada dialysis ke patient Bangalore mai hain usko 25 saal ho gye vo to motivation speech bhi deta hai mai kafi jeeno se mila hon.. Dar to niaklna pdega agar vo nikala to kahatm samjho admi.... Family valon ko dar hai thoda bhot to ab mere kai bar BP 240 or 260 chla jata hai ab mai usko normal leta hon to thk ho jata varna hyper lon to badh jata hai..... Ghabrat sabse bda factor hai.....

Hahahhaahahah han meko aesi kuch khas dkkat ni hai mai to kai logon ko chedta rehta hon beech mai rote hai vo beech mai unko samjahta hon ki usko apni normal working kit rah lo to vo easy ho jayega.. Ab agar lamba chlna hai to procedure follow krna padega. Doctor staffs itna ache hai idhar kabhi bhi call kar lo OPD aa jao to dikkat sunte hai aur ache se solve bhi krte hai hai. Dialysis ke time bhi vo og dsab chog ka dhayn rakhte hain .. Koi bhi dikkat aaye tabhi ki tabhi solve kar deta hai use....

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Muje kidney ka dikkat hwe 1 saal ho gya hai. Aur dialysis ko 1 saal ho gya. Mujhe suddenly bhukh lagni kam ho gyi thi aur weekness ho gyi thi. Iske baad mai doctor ke pass gya check kraya to mera hemoglobin 5.8 tha mera uske baad mai yahan jodhpur aa gya mera chachu idhar nursing staff lge hwe hain phele mai delhi mai admit raha 6 din vahan treatment chla mera vahan to pta chla kidney mai dikkat hai to 2 ya 3 dialysis hwe idhar fir mai idhar hi aa gya tha yahan par test vagera hwa mera fistula bna mera. Aur abhi mujhe transplant ke liye bola gya hai.....

Interviewer: Jab apko pta chla apko CKD hai apki kya pratikiya thi?

Interviewee: Kaisa lagna sab thk hai ab bura lga tha mujhe bhot pdhai kar raha tha mai B- tech second year mai tha mai.... Open se kuch man ni kiya mera padhne ka. Fir abhi yahan jodhpur mai hi hain...

Interviewer: Aapko kaise lga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Mujhe shock lga ki ek dam se ye kya ho gya achi life chal ri thi meri college jata tha mai padhai kar raha tha mai fir acahnak se ye sab ho gya to sab change ho gya Delhi se jodhpur aagya chacha ke pass friends change ho gye sab change ho gya.....

Bhot bura lgta hai ki mai padh ni pta ho ab padhai khatam karke mujhe job mai lagna tha ab vo bhi ni ho paaa rha hai mujhse.... Aur bhot choti umar ye ho jaye to bhot bura lgta hai abhi to puri life padi thi mere liye.. Dar sa bhi lgta hai ki kab kya ho jaye mujhe mai achi jindagi jeena chata hon bas ussi ke liye kidney transplant ka wait bhi kar raha hon mai ki meri life achi ho jaye uske baad.....

Interviewer: Aab hemodialysis ke prati aapki kya bahnayein hain?

Interviewee: Kuch ni aesa to bas dialysis chal raha hai krana hi padega jindagi ussi chal ri hai meri to krana jarrori. Aur dialysis ke baad meri tabiyat thk vhi hwi phele se kafi ab meko better feel hota hai phele se par hafte mai 2 baar krana pdta hai bhot weakness si lgti rehti hai mujhe.....

Interviewer: Aapke dainik jewan main hemodialysis ke karan kaun si samsayein ho rahi hain?

Interviewee: Aur kuch dikkat ni hai dialysis chal raha hai mai apna kam khudh kar leta hon jyada kuch dikkat ni hai mujhe. Bas dialysis krane aao tohachu ya mummy aate hain muje leke mai khudh se ni aaata hon...

Bas bahar kahin ni jata hon mai ghar pe hi rehta hon social life ek dam khatam si ho gyi hai phele jab delhi mai tha tab dost the ab yahan koi dost ni hai bas hum log phone pe hi baat kar leta hain....Financial problem to kuch ni hai.

Khane mai to bas normal khana khata hon bahar ka ni khta hai jyada phosphorus vale food mna kiya hwe mujhe bas. Pani mai normal hi peeta hon aesi koi rok tok ni hai mujhe.....

Interviewer: In samasyon ko hal karne ke liye aap konse upaye aur sahyog apnate hain?

Interviewee: Family se pura support hai mujhe halki mai thoda dependent hon unpe par vo mujhe feel ni hone deta hain..... Aur jyada kuch ni apne doston se call pe baat kar leta hon, Tv dekh leta hon , movies, web series bas yahi chltta rehta hai...

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: Future plan to bas yahi hai ki mai apni pdhai continue karon.....Han ye hai ghar pe bethe computer ka course kar lo college to ni ja paonga ab mai... Kidney transplant ke liye soch hwa hai mummy hai donor par bas vahi abhi corona ki vajah se ho ni paaa raha hai transplant...Sara test ho rakhe hai mere hain bas wait hi hai kyonki next number mera hi hai.....

Interviewer: Aap hemodialysis par apna anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Aur to kuch ni hai bas dialysis chal raha hai koi dikkat ni hai bas yahi hai aur sab thk hi hai.....

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Mujhe ek 1 saal ho gya kidney ka dikkat hwe phele mujhe headache hwa fir swelling hwa mujhe chere pe fir pairon main hwe. Fir ulti sir dard bechahini.....

Phele mai jaipur mai tha vahan pe 5 din admit kiya tha creatinine kafi badh gya tha vahan muje PERMA cath dla tha... Fir mai yahan admit hwa tha aur yahn pe biopsy hwa tha mera uske baad se 21 march ko mujhe discharge kar diya tha.....

Interviewer: Jab apko pta chla apko CKD hai apki kya pratikiya thi?

Interviewee: Pura change ho gya life ek dam se mera jab mai yahn se discharge next day hi lockdown ho gya tha sab ghar mai beth gye the. Normal hi life mai to....

Bur alga tha kafi mujhe phele starting mai bola gya mujhe ki 6 months treatment denge ye hope thi ki recovery ho jaye fir 6 month gujar gye doctor ne bola ki improvement ni hai to dialysis start kar diya aur bola kidney transplant ke liye abhi transplant ke liye wait kar raha hon.

Interviewer: Aapko kaise lga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Bur lga kyonki dialysis krate hain tab puri life change si ho jati hai aur puri jindagi krana to ek bhot bda challenge sa hai apne mai..... Par dialysis krana bhi jarrori hai iska bina to tabiyat kharab si lgti hai ab jab tak transplant ni ho jata hai tab tak yahi ek hope hai.....

Interviewer: Aab hemodialysis ke prati aapki kya bahnayein hain?

Interviewee: Bahnayein to kya hi hai bas chal raha hai dialysis

Interviewer: Aapke dainik jewan main hemodialysis ke karan kaun si samsayein ho rahi hain?

Interviewee: Daily activities to puri change hi ho gyi hai mmmmmmmmmmmmmmmmm
gahr pe cafefully rehna pdta hai desk se durr rehna kisi se jyada baat ni kar sakte
hain . Pani jyada ni pee sakte hain.. Bahar ja ni sakte khel ni sakte hai doston se
ni mil sakte hai....

Studies mai to bhot change ho gye hain jyada der betho to problem hoti jyada dhyan ni lga pta hai... Kabhi BP high hota hai to headach hota, kabhi bhi vomiting ho jati hai.....

Mai job ke liye taiyari kar raha ho nab ghar bethe bethe... Friends se milne mai problem hoti hai kahin ja ni pta hon bahar akle mai... Kahin bhi jaon to family members sath jate hain.. Friends k esath bahar ghumne bilkol band hai... Family occasion pe jana bhi bilkol band hai apne ghar pe hi rehta hon....

Family pe dependent lgta hai mujhe sabse jyada khudh ki personal life jaise mai akle kuch bhi ni kar pata hon..... Aurrrrr sabse bda ki akle main ha bhi ni pta hon.. PERMA cath lga hai to akle ni nhane mai dikkat hoti hai...

Chalne firne mai bhi dikkat hoti hai jyada chal ni pta hon urine bhi dheere dheere band ho gya hai.. Phele aata tha mujhe 1ya 1.5 litre ab to bilkol band ho gya hai....

Shadi shuda jindagi mai bhot change aaye mai married tha meri kidney khrab hone ki baad meri wife ne mujhe divorce de diya 2 saal ho gye mujhe..... Sexual problem mai mujhe normal hai par kabhi kabhi BP padh jyada hai.....

Interviewer: : In samasyon ko hal karne ke liye aap konse upaye aur sahyog apnate hain?

Interviewee: Family ka pura support hai meri mummy papa mujhe pura support krte hain har chig mai.... Aur mai job ki taiyar kar raha to padhai karke apna tension durr kar leta hon mai waise aur to alag khas kuch hai ni....

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: Phele mera goal tha CGL ke liye ye income tax department ke liye job hai par ab mai ab vo bilkol change ho gya usme medical aur physical fit ho par vo to ab mai kar ni sakta hon... Normal office job chaeye ab to Aur bas transplant ka wait hai ab to future mai aur to kuch plan hai ni aur future ka...

Interviewer: Aap hemodialysis par apna anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Aur kya bataoon kuch samajh ni aaraha dialyisssss..... ek dra hai mere liya jaise hi 3 ghnte pure hote hain headache hota hai muhe aur vo sehen ni hota mujhse skin puri dry ho jati hai chere pe pimple ho gye baal jhad rahe hain bhot dikkat hain..... Meko problem dialysis ke din hi hoti hai fir to thk ho jata hai. Diet mai apne pasand ka kuch kha ni sakte jyada pani ni peee sakte hain bas kafi change ho jati hai life dialysis ke bad mmmmmmm.....

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Mujhe 7 se 8 saal ho gya kidney ka problem hwe. Mujhe dialysis krate hwe 4 saal ho gye hain. Hafte mai 2 bar krati hon mai dialysis. Meko BP ki dikkat thi bhot hifh rehta tha mera BP to ek bar test kraya to pta chla ki aesa kidney mai dikkat ho gyi hai fir 3 saal mai medicine par rahi fir tabiyat kharab hone lgi to dialysis start kra diya mujhe.....

Interviewer: Jab apko pta chla apko CKD hai apki kya pratikiya thi?

Interviewee: Kuch koi khas ni kyonki meko 20 saal se BP high rehta tha baki sugar vagera kuch problem ni thi...Par creatinine dheere dheere badh raha tha fir kai doctor ne kha ki dialysis pe to jarror jaoge kyonki ye chronic hai to jab dialysis shuru hwa to us trah to mind se prepare thi mai halki doctor kehta tha 5 pe raha to creatinine itna raha to dialysis pe ni jaoge fir craetinine ek dam se 7 se bahar badhne lga to fir dialysis start kar diya.....

Interviewer: Aapko kaise lga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Dekho bura to lgta hai kyonki dialysis se bhi kafi dikkat hoti hai par kuch kar ni sakte hai dialysis to krana hi padega agar thk rehna hai tabiyat thk rakhni hai to krna hi padega dialysis to aur to koi option ni hai..... Ab to age bhi ni rahi ki transplant ho jaye isliye ab dialysis se hi life aage chal sakti hai.....

Interviewer: Aab hemodialysis ke prati aapki kya bahnayein hain?

Interviewee: Phele jab creatinine badh gya to khana peena sab chut gya tha aur darte rehte the fir dialysis shuru hwa to fir normal ho gya tha.... To dialysis ki wajah se kafi relief mila meko mere symptoms mai acha feel hone lga kyonki jaise creatinine badh raha tha tabiyat kharab hoti ja ri thi par ab better hai.....

Interviewer: Aapke dainik jewan main hemodialysis ke karan kaun si samsayein ho rahi hain?

Interviewee: Ab to kam ni kar pati hon phele kam kar leti thi sab ab weakness dheere dheere badh hi rahi.

Family ke upar to itna dependent to ni lgta hai kyonki apna kam to mai kar leti hon baki bahu hai vo khana vana bna leti hai..... Family mai to koi dikkat ni hai sab thk hai

Han social life to farak padta hai hi hai social life mai to phele ghumne firne jate the par ab to ja ni pate hain kyonki hafte mai 2 bar dialysis krana hota hai kafo weakness lgta hai to kahin ni jate hainnnn..... Shadi mai jane ho to jata hai par dialysis vale din ni 2 ya 3 day jate hain.....

Diet mai to kafi changes khane mai jyada namak vala ni khana hai phosphorus aur potassium vala khana ni khana jaise kela ni kha sakte hain... Aur fir pani bhi jyada ni pee sakte hain jyada peene sa kafi dikkat ho jati hai firr.....

Interviewer: In samasyaon ko hal karne ke liya aap kya

Interviewee: Han family pura support karti hai husband, beta, bahu sab sath dete hain to jyada dikkat ni hoti hai..... Aur baki mai thoda kuch kam kar leti hon, TV vagera dekh leti hon, bachon se baat kar leti hon to jyada tension to hoti ni hai thk sab.... Tension lungi to mera hi tabiyat kharab hoga BP badh jayega isliye shant hi rehti hon mai.....

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: Future plans to kuch ni hai transplant vagera to kuch ni hai kyonki vo hi ni sakta is age mai to par phele bhi kabhi socha ni hai.... Isliye koi specific plans to ni hai mera sab thk hai aur sab bache settled hai to kya hi plans karne hainnnnnnnn.....

Interviewer: Aap hemodialysis par apna anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Heheee matlab dialysis ki koi achi chig ni lgti humko kyonki band jate hain kahin ja ni sakte hai bde age mai to kya dekh li sari jindagi ache se bitati ab kya krna je eke to matlab jeene ki waise koi badhiya iccha ni hai ab sari icchyein matlab bachpan se smooth life jeeyen hai to kuch dekhne ki kuch karne ki koi iccha ni hai.... Job krene ke liye to mere husband allow ni krte the aur meri saas thodi budhi thi to mai job pe jati to kuch kam unhe bhi krna hi padta isliye ni ki job mere husband us tim engineer college mai professor the to sab kuch ache se chal raha tha.... Bas bachon ko pdhai vadhai main help karti thin a meri koi iccha ni thi job krne ki.....

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Mujhe kidney ka dikakt 2010 se hai.. Phele mujhe bukhar aaya tha to maine ayurveda valon se typhoid ki dwai li to meri kidney kharab ho gyi thi...Fir ahmedabad gye vahan admit hwe fir dialysis start kiya par 4 ya 5 saal dwaii bhi li fir tabiyat kharab hwi to dialysis start ho gya....

Interviewer: Jab apko pta chla apko CKD hai apki kya pratikiya thi?

Interviewee: Kya hi bas bhot bura lga mujhe tension mai aagya thoda ki ye kaise ho gya family valon ko bhi bur alga dikkat hwi kafi fir dheere dheere adjust kiya situation se....

Interviewer: Aapko kaise lga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Lgna to kya tha bas kuch kar to sakte hai ni dialysis to krana hi padega to bas kra rahe hain dialysis chal raha haiiiii.....

Interviewer: Aab hemodialysis ke prati aapki kya bahnayein hain?

Interviewee: Aesa to kuch ni hai dialysis bhot jarrori hai filal abhi jewan jeene ke liye nahi krayenge to tabiyat aur kharab ho jayegi isliye krna to hai hi dialysis.....Kafi better feel hwa dialysis krane ke baad par uske sath sath kafi sari dikkat bhi aayi hai.. Dialysis acha bhi hai bura bhi hai mera hisab se to...

Interviewer: Aapke dainik jewan main hemodialysis ke karan kaun si samsayein ho rahi hain?

Interviewee: Dikkat hai fistula vali vahi sabse bdi dikkat hai..... Wekness ata rehta hai jis din dialysis krake jate hain, sir dard krta rehta hai bas....

Han ghar ka to sara kam kar leta hon bas sharir sahi rehta hai to koi kar leta hain.. Phele ghar valon ki jarrort ni padti par ab padne lgi ahi kam vagera ke liye.....

Han khane mai bas kam oil vala, namak ka khana ye sab hi hai aur pani kam peena hai 1 litre se jyada ni peena hai ye to hai hi dikkat....

Bahar jana vana to kam hi jata hon dar lgta hai kahin tabiyat kharab na ho jaye to iske liye kam hi jata hon bahar mai.... Aur dikkat to yahi hai ki dialysis to krna hi padega kahin pe bhi apko krna hi padega.....

Interviewer: In samasyaon ko hal karne ke liya aap kya

Interviewee: Bas aesa hi kam pani pee liya, medicine time pe li to jyada dikkat hoti ni hai baki family valen hai ache se khayal rakhte hain mera..... Bas jyda tension leni bhi kyon ab to jo ho gya bas uske sath adjust karo au aage badho bas yahi kar sakte hain..

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: Future ko leke ab kya hi sochna bachon ki shadi ho gyi hai mai abhi bhi job to kar rahi halki dusri job hai par ach ahai kuch to kam kar rha hon bas yahi hai ki tabiyat thk rehe jab tak jindagi hai ache se jiyon mai.....

Interviewer: Aap hemodialysis par apna anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Dialysis to yahi hai ki sovidha mil jave na to kahin pe bhi karwa sakta hai ussi centre pe dhudh ke jao jaise abhi mai beech mai bimar ho gya to dusre hospital valon ne mna kar diya to fir AIIMS aaye kyonki dialysis krana to jarrori hai.....

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Shayad 10 months ho gye sir dard hwa mujhe, BP badh gya achanak se mera fir test kraya to dekha kidney thk se kam ni kar ri kuch medicine li arram ni mila to fir dialysis start karwana pda....

Interviewer: Jab apko pta chla apko CKD hai apki kya pratikiya thi?

Interviewee: Bhot jyada bura lga mujhe mai bas abhi 12th pass krene hi vala tha corona aagya fir mujhe kidney ka dikkat ho gya to bhot jyada bura lga mujhe us waqt....

Interviewer: Aapko kaise lga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Phele to medicine leni start ki doctor ne kha agar aram ni mila to dialysis start krenge par aaram ni mila to dialysis shuru kar diya.... Han puri jindagi to rehna pad sakta isliye mai to transplant ka wait kar raha hon kyonki muje dialysis pasand ni hai bilkol bhi transplant ho jaye to roj roj ki taklif se aaram mile

Interviewer: Aab hemodialysis ke prati aapki kya bahnayein hain?

Interviewee: Aesi to koi feelings ni hai bas dar lgta hai mujhe dialysis se ek tarike se acha ni lgta mujhe dialysis bhot dikkat hoti hai mujhe sir dard hota hai, weakness hoti ahai to acha ni lgta hai mujhe.... Par thoda relief bhi milta jis din pani bahar nikal dete hain.

Interviewer: Aapke dainik jewan main hemodialysis ke karan kaun si samsayein ho rahi hain?

Interviewee: Dialysis ke din bhot kamjori lgti thi hai sir dard sa rehta us din mai rest karta hon pure din.. Sabse jyada dikkat to pani ki lgti hai mujhe.. Khane mai bhi hlka sa hi khao jyada patte dar sabji ni kahte hain jisme jyada potassium ho...

Takkt ni hai bahar ghumne firne ka kabhi heart ki dhadkan badh jati hai acahank se man to krta hai bahar jana ke par kya Karen jaa ni sakte hain....

Kisi kam mai kisi ki koi jarrot ni pdti hai par fir bhi dpendent ho gya hon ghar valon pe meko aesa lgta hai jaise mai phele tha 85 kg ka ab mai 56 kg ka ho gya hon mai football or cricket player tha to ab kuch ni kar pata hon...

Paison ka dikkat to hai papa hi hai kamane vale vo 60 saal se upar ke hain to ghar karcha bhi chlana pdta hai 16 hjar lag jate hain mahine ke bas soch rahe hain ki idhar udhar se transplant kra lenn....Meri shari mai bhot takkat thi akle mai main Gaye to utha liya tha.....

Shadi shuda jindagi mai to koi dikkat ni hai 4 saal ho gye shadi hwe meri wife abhi pregnant hai abhi to koi dikkat ni hai mujhe meri wife 9 month mai... Waise madam mere bache ko to koi dikkat to ni hogi na jabse bacha hwa hai meko aur tension ho gyi hai ki bache ko to kuch hoga nii.....Waise biwi ko mna kiya tha par vo boli kuch ni hoga baghwan sab thk rakhegi

Interviewer: In samasyaon ko hal karne ke liya aap kya

Interviewee: Kuch ni bas aesa hi ghar pe rehke padhta hon gharvalon se baten karke, TV dekh ke kar leta hon time pass. Han family valon ka pura support hai mujhe mera parents, meri wife sab mera bhot khyal rakte hain....

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: Abhi to teacher ne diya hai 1 mahina ka time ki soch ke btao ki kya krna hai mai soch raha hon ki ghar bethe koi course ho to vo kar leta hon taki padhai n ark jaye meri... Aur transplant ke liya socha hwa hai name register kraya hwa hai dekho ab kab hota hai transplant

Interviewer: Aap hemodialysis par apna anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Aesa kuch alag ni hai bas dialysis thk thak chltta rahe koi dikkat ni ho aur jaldi se transplant ho to roj roj ki dikkat na ho aur to alag kuch ni hai.....

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Mere ko 2 saal ho gye kidney ki problem shuru hwe. Aur 1 saal se mai dialysis kra ri hon. Mujhe dikkat start hwe thi 2 saal phele meko BP tha phele se 20 years se. Meko sans lene mai dikkat hone lagi thi maine test kraya to pta chla ki mera cratinine bdha hwa tha.... Fir 1 saal maine medicine li to creatinine fir bhi badh rha tha to mujhe dialysis pe jana pda.

Interviewer: Jab apko pta chla apko CKD hai apki kya pratikiya thi?

Interviewee: Mujhe kafi bura lga tha us time. BP ka dikkat to tha hi par ya ni pta tha kidney aesa kharab ho jayega. Kafi stress aagya tha ek dam se fir doctor ne batchit ki unhone kha ki jyada stress mat lijiye aap. Dialysis krke aap ek normal life jee sakte hain.

Interviewer: Aapko kaise lga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Mai 1 saal se medicine pe thi to ek trah se doctor ne btaya tha ki agar creatinine aesa hi bdhta rha to dialysis pe jana pad sakta hai to mai ek trah se prepare thi mai ki dialysis pe jana pad sakta hai to jyda kuch lga ni bas aab ek trah se dialysis pe dependent rehna padega ab.

Interviewer: Aab hemodialysis ke prati aapki kya bahnayein hain?

Interviewee: Aesa to kuch feelings ni hai par dialysis ek jarrori part ho gya life ka ye krana to jarori hai ab nahi krayenge to tabiyat khrab ho sakti hai isliye krana hi padega dialysis to ab.

Interviewer: Aapke dainik jewan main hemodialysis ke karan kaun si samsayein ho rahi hain?

Interviewee: Daily life mai to kafi sare changes aaye hi hain. Bhot sare changes hwe jaise aap jyada pani ni pee sakte ho to hmesha dyan se pani peena pdta hai soch soch ke..... Khane mai jyda bhar ka ni kha sakte hain aesi sabjiyan ya fruits ni kha sakte jinme potassium jyda ho to sab dekh ke hi khana pdta hai..

Jis din dialysis krake jao pura time weakness lgti rehti hai kuch acha ni lgta pura time rest hi karti hon mai..

Social life to khatam si hi lgti hai jaise kahain bahar ni ja sakte kisi occasion pe ni ja sakte hain kisi se mil ni sakte hain to bilkol change si ho gyi hai social life.

Shadi shuda jindagi mai to kuch change ni hai mere husband bhot supportive bhot khayal rakhte hai mere har taklif mai sath dete hain.

Interviewer: In samasyaon ko hal karne ke liya aap kya

Interviewee: Family sabse bda support hai hmesha support krte hain mera pura khyal rakhte hain to jyada feel ni hota hai jo bhi dikkaten hai. Aur jyda kuch chinta hai na waise bachon ki shadi ho gyi hai sab settled hai apni life mai to sab thk chal raha hai.

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: Aesa to kuch vicahr ni hai bas thk thak life chalti rehe jyda kuch dikkat ni aaye dialysis mai aur to kuch ni hai vichar mere.

Interviewer: Aap hemodialysis par apna anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Ab aur to kya btayein bas kabhi kabhi thoda dar lgta hai ki tabiyat kharab na ho jaye vaise dialysis acha hai kyonki uski vajah se abhi thk thak jindagi chal ri hai par iski vajah se kafi dikkaten bhi hoti jo ki maine apko btayein hain. Bas ye dikkatein kam ho jayen to badhiya hai dialysis aur logon ko jyada darna nahi chaeye dialysis se.

Interviewer: Aap kabse CKD se pidite hain?

Interviewee: Mmmmmmm mujhe 3 saal ho gye kidney ki problem hwe.. Mai teen saal se dialysis kra raha hon..Mujhe phele se hi sugar aur BP ka problem tha..Fir meri tabiyat thodi si kharab hone lgi thi to aesa hi routine test kraya to pta chala ki kidney thk se kam ni kar ri hai meri...Fir mera dialysis start hone lga....

Interviewer: Jab apko pta chla apko CKD hai apki kya pratikiya thi?

Interviewee: Bhot bura lga mujhe. Kafi changes aane lge life mai, life bilkol badal si gyi meri... Mai job krta tha tha vo chut gyi meri... Ab family ka pura responsibility papa pe aagya to bhot bura lga mujhe.....

Interviewer: Aapko kaise lga jab apko pta chla ki apko puri jindagi hemodialysis krana padega?

Interviewee: Dialysis ke bare mai phele se thoda bhot pta tha ki hota kya kyon krate hain par jab khudh ke sath hwa to thoda aalag sa lga. Aur lagna to kya tha ab dialysis jarrori hai krana nahi krayenege to ek achi life to jee ni payenge.

Interviewer: Aab hemodialysis ke prati aapki kya bahnayein hain?

Interviewee: Mujhe dar sa lgta hai dialysis se kyonki kafi tabiyat kharab hoti hai jis din dialysis krake mai ghar jata hon.. Bhot weaknes si lgti hai mujhe dialysis krake jab mai ghar jata hon. Halki tabiyat to thk hwi hai par dikkatein bhi bhot aayi hai dialysis ki vajah se

Interviewer: Aapke dainik jewan main hemodialysis ke karan kaun si samsayein ho rahi hain?

Interviewee: Danik jeewan mai to khubh sare badlav aaye hain dialysis ki vajah se jis din mai dialysis krake jata hon to weakness si rehti hai mujhe, BP kam ho jata hai. Us din mai pura rest krta hon jyada kuch kam ni karta hon... Khane peene mai bhi kafi badlav aaye hai jaise jyada pani ni pee sakte hain kuch bahar ka khana mai dar sa lgta hai doctor kai sari sabjiyan bhi mna ki hai jisse potassium na bdhe.....

Sabsa bda dikkat ye lgta hai ki meri job chut gyi ab family ka khrcha mai utha ni pta hone k trah se dependent sa feel hota hai mujhe meri family par.... Kahin bahar ana jana bhi band ho gya hai mera, friends se milna, occasion mai jana

sab band ho gya.... Han paion ka dikkat bhi hai kyonki meri to job chut gyi hai ab sara khrcha father hi uthate hai mere to thoda financial problem bhi hai.....

Interviewer: In samasyaon ko hal karne ke liya aap kya

Interviewee: Han family ka to kafi support hai mujhe, meri wife bhi kafi supportive hai to jyada dikkat to ni hwi mujhe.. Aur pura din mai ghar pe rekhar bachon ko pdha deta hon, unke sath khel leta hon to time pass ho jata hai mera.. Aur kuch kuch online bhi sikhta rehta hon jisse mai ghar beth ke koi job kar sakon....

Interviewer: Aapke kya vichar hai ab apne bhavishya ko lekar?

Interviewee: Ab vichar to kya bas koi job mil jaye jo ki mai aaram se ghar pe beth ke kar lon jyada kahin bahr na jana pade aur mai kuch kma bhi lon taki meko kisis pe dependent na hona pade... Aur sabse badhiya hoga agar kidney transplant ho jaye fir to kafi sari dikkatein solve ho jayenge....

Interviewer: Aap hemodialysis par apna anubhav ke bare mein kuch aur kahana chaate hain?

Interviewee: Aesa to kuch khas ni dialysis acha bhi hai bura bhi hai, dono hi hai mere liye to na krao to bhi dikkat krao to bhi dikkat to bas life chal ri hai aese hi bas ache se chlti rahi aage bhi bas aur to kuch ni hai jiiiii.....