

APPENDIX – H -1

Data Collection Instrument

Tool to assess the effect of planned teaching on knowledge and practices in relation to selected components of health- related quality of life (HRQoL) in hemodialysis patients. This tool consists of structured interview schedule which has 4 parts

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|-----------------|------------|---|--|
| PART I | Part I-A | : | Demographic Characteristics (16 items) |
| | Part I-B | : | Medical characteristics (16 Items) |
| PART II | Part II-A | : | Knowledge of anatomy and physiology of kidney, kidney disease and its treatment (21 items) |
| | Part II-B | : | Knowledge related to symptoms of hemodialysis patients (selected components of HRQoL) (12 Items) |
| PART III | Part III-A | : | HRQoL related to selected components (12 items) |
| | Part III-B | : | Practices related to selected components of HRQoL (12 Items) |
| PART IV | Part IV | : | Views of patients about instruction manual (10 items) |

Instructions:

1. Part I-A & Part I-B- Place a check mark () against the choice
2. Part II-A, Part II-B & Part III-B - Give 1 mark for the each right answer & 0 for the wrong answer
3. Except in Part II-A, Item No. 2.2, 2.3, 16.1, 17.1, 17.2, 18.2, 18.3, 19.1 all the answers are right answers.
4. Part III-A – The symptoms if present during the past one week to be ranked according to the intensity as perceived by the subjects during pre test and post test.
5. Part III-B - To be administered to only those who are experiencing the particular symptoms during the past one week during pre test or post test.

Structured Interview Schedule

Part-I A

Demographic Characteristics

- | | | | | |
|----|----------------|---|-----|-----------------|
| 1. | Your Name | : | | |
| 2. | Age in years | : | 2.1 | 18 to 39 |
| | | | 2.2 | 40 to 49 |
| | | | 2.3 | 50 to 59 |
| | | | 2.4 | 60 to 69 |
| 3. | Gender | : | 3.1 | Male |
| | | | 3.2 | Female |
| 4. | Marital status | : | 4.1 | Unmarried |
| | | | 4.2 | Married |
| | | | 4.3 | Widowed |
| 5. | Type of Family | : | 5.1 | Nuclear |
| | | | 5.2 | Joint |
| | | | 5.3 | Extended |
| 6. | Care Giver | : | 6.1 | Wife |
| | | | 6.2 | Husband |
| | | | 6.3 | Mother |
| | | | 6.4 | Father |
| | | | 6.5 | Son |
| | | | 6.6 | Daughter-in-law |
| | | | 6.7 | Daughter |
| | | | 6.8 | Any other |

| | | | | |
|-----|-------------------|---|-------|--------------------------|
| 7 | Education : | : | 7.1 | Illiterate |
| | Self | : | 7.2 | Primary |
| | | : | 7.3 | Secondary |
| | | : | 7.4 | Higher Secondary |
| | | : | 7.5 | Graduate/Diploma & above |
| 7.1 | Spouse/Care taker | : | 7.1.1 | Illiterate |
| | | : | 7.1.2 | Primary |
| | | : | 7.1.3 | Secondary |
| | | : | 7.1.4 | Higher Secondary |
| | | : | 7.1.5 | Graduate/Diploma & above |
| 8 | Occupation : | : | 8.1 | Home bound |
| | Self | : | 8.2 | Professional |
| | | : | 8.3 | Clerical |
| | | : | 8.4 | Technical |
| | | : | 8.5 | Business |
| | | : | 8.6 | Laborer |
| | | : | 8.7 | Agriculturist |
| | | : | 8.8 | Student |
| | | : | 8.9 | Unemployed |
| | | : | 8.10 | Retired |
| | | : | 8.11 | Disabled |
| 8.1 | Spouse/Care taker | : | 8.1.1 | Home bound |
| | | : | 8.1.2 | Professional |
| | | : | 8.1.3 | Clerical |
| | | : | 8.1.4 | Technical |
| | | : | 8.1.5 | Business |
| | | : | 8.1.6 | Laborer |

| | | | |
|-----|---|--------|---------------------|
| | : | 8.1.7 | Agriculturist |
| | : | 8.1.8 | Student |
| | : | 8.1.9 | Unemployed |
| | : | 8.1.10 | Retired |
| | : | 8.1.11 | Disabled |
| 9 | Total income per month in Rupees | : | 9.1 <5000 |
| | | : | 9.2 5001-10000 |
| | | : | 9.3 10001-15000 |
| | | : | 9.4 15001-20000 |
| | | : | 9.5 >20001 |
| 10 | Number of family members | : | 10.1 One |
| | | : | 10.2 Two |
| | | : | 10.3 Three |
| | | : | 10.4 Four |
| | | : | 10.5 More than four |
| 11 | Source of payment for hemodialysis | : | 11.1 Self |
| | | : | 11.2 Employer |
| | | : | 11.3 Insurance |
| | | : | 11.4 Charity Trust |
| | | : | 11.5 Pension |
| | | : | 11.6 Parents |
| | | : | 11.7 Other |
| 12 | Place of residence and address | : | 12.1 Suburban |
| | | : | 12.2 Urban |
| | | : | 12.3 Rural |
| 13. | Mode of travel for attending hemodialysis | : | 13.1 Drive self |
| | | : | 13.2 By taxi/auto |

| | | | |
|---|---|------|---------------------|
| | : | 13.3 | By public transport |
| | : | 13.4 | By walk |
| 14. Total time spent for dialysis excluding dialysis time (per dialysis) | : | 14.1 | Up to 2 hours |
| | : | 14.2 | 2 to 4 hours |
| | : | 14.3 | 4 to 6 hours |
| | : | 14.4 | 6 to 8 hours |
| | : | 15.5 | More than 8 hours |

Part-I B**Medical Characteristics**

| | | | | |
|----|--|---|-----|-------------------------|
| 1. | Your primary cause of kidney disease | : | 1.1 | Diabetes |
| | | : | 1.2 | Hypertension |
| | | : | 1.3 | Infections |
| | | : | 1.4 | Drugs |
| | | : | 1.5 | Any other |
| 2. | Co-morbid conditions | : | 2.1 | Diabetes |
| | | : | 2.2 | Hypertension |
| | | : | 2.3 | Diabetes & Hypertension |
| | | : | 2.4 | Infections |
| | | : | 2.5 | Any other |
| 3. | Adherence to hemodialysis schedule | : | 3.1 | Once a week |
| | | : | 3.2 | Twice a week |
| | | : | 3.3 | Thrice a week |
| 4. | Length of time on hemodialysis treatment | : | 4.1 | 1 to 6 months |
| | | : | 4.2 | 6 months to 1 years |
| | | : | 4.3 | 1 year to 3 years |
| | | : | 4.4 | 3 to 5 years |
| | | : | 4.5 | > 5 years |
| 5. | Adherence to medications | : | 5.1 | All |
| | | : | 5.2 | Some-specify |
| | | : | 5.3 | Non |
| 6. | Dietary Habits | : | 6.1 | Vegetarian |
| | | : | 6.2 | Non Vegetarian |
| 7. | Hemoglobin | : | 7.1 | < 5 gms |
| | | : | 7.2 | 5.1 to 7 gms |

| | | | |
|---|---|------|------------------|
| | : | 7.3 | 7.1 to 10 gms |
| | : | 7.4 | > 10 gms |
| 8. Blood transfused in last 30 days | : | 8.1 | Yes |
| | : | 8.2 | No |
| 9. Serum Albumin | : | 9.1 | < 4.0 gm/dl |
| | : | 9.2 | > 4.1 gm/dl |
| 10. Inter dialytic weight gain (Median of last 3 readings) | : | 10.1 | < 1.5 kgs |
| | : | 10.2 | 1.6kgs -3 kgs |
| | : | 10.3 | 3.1 kgs -4.5 kgs |
| | : | 10.4 | > 4.6 kgs |
| 11. Rate of blood flow through access/minute | : | 11.1 | < 200ml |
| | : | 11.2 | 201 ml – 300 ml |
| | : | 11.3 | > 301 ml |
| 12. General nutritional status | : | 12.1 | Good |
| | : | 12.2 | Poor |
| 13. Body Mass Index | : | 13.1 | < 18.5 |
| | : | 13.2 | 18.6 – 24.9 |
| | : | 13.3 | > 25 |
| 14. Taking erythropoietin injection | : | 14.1 | Yes |
| | : | 14.2 | No |
| 15. Presence of bleeding | : | 15.1 | Yes |
| | : | 15.2 | No |
| 16. Any hospitalization within 30 days | : | 16.1 | Yes |
| | : | 16.2 | No |

Instructions:

The questions will be read out to you. Please give your answers Yes, No, or Do not know. Please note that more than one answer can be correct .please answer as honestly as possible.

PART-II-A**PRE & POST TEST**

**KNOWLEDGE OF ANATOMY AND PHYSIOLOGY OF KIDNEY,
KIDNEY DISEASE AND ITS TREATMENT**

1. Where the kidneys are situated?
 - 1.1 In the abdomen behind the lower ribs along the spinal column : Yes / No / Do not know
 - 1.2 In the pelvic region : Yes / No / Do not know
 - 1.3 On either side of abdomen : Yes / No / Do not know

2. Parts of the urinary system are
 - 2.1 Kidneys : Yes / No / Do not know
 - 2.2 Ureters : Yes / No / Do not know
 - 2.3 Urinary bladder : Yes / No / Do not know
 - 2.4 Urethra : Yes / No / Do not know

3. What are the functions of kidneys?
 - 3.1 Gets rid of waste products : Yes / No / Do not know
 - 3.2 Balances the body's fluid content : Yes / No / Do not know
 - 3.3 Maintains salt levels : Yes / No / Do not know
 - 3.4 Controls Blood Pressure : Yes / No / Do not know
 - 3.5 Helps to make red blood cells : Yes / No / Do not know
 - 3.6 Maintains healthy bones : Yes / No / Do not know

4. What are the common causes of kidney failure?
 - 4.1 Diabetes : Yes / No / Do not know

- 4.2 High blood pressure : Yes / No / Do not know
- 4.3 Repeated kidney infections : Yes / No / Do not know
- 4.4 Stones in the kidney : Yes / No / Do not know
- 4.5 Hereditary conditions : Yes / No / Do not know
- 4.6 Toxic drugs : Yes / No / Do not know
- 4.7 Toxic substances : Yes / No / Do not know
5. What are the changes in the body when kidney fails?
- 5.1 Kidneys continue to produce urine in small quantities or stops : Yes / No / Do not know
- 5.2 Salt and waste products get collected in the blood : Yes / No / Do not know
- 5.3 All the organs in the body get affected : Yes / No / Do not know
- 5.4 Bone marrow produces less red blood cells : Yes / No / Do not know
6. What are some of the signs and symptoms of early stages of kidney failure?
- 6.1 High blood pressure : Yes / No / Do not know
- 6.2 Blood in urine : Yes / No / Do not know
- 6.3 Foaming urine : Yes / No / Do not know
- 6.4 Puffiness around the eyes : Yes / No / Do not know
- 6.5 Fever : Yes / No / Do not know
7. What are the signs and symptoms present in patient with end stage kidney failure?
- 7.1 Swelling of body : Yes / No / Do not know
- 7.2 Less quantity of urine or no urine : Yes / No / Do not know
- 7.3 Increased BP : Yes / No / Do not know
- 7.4 Nausea and vomiting : Yes / No / Do not know
- 7.5 Tiredness : Yes / No / Do not know
- 7.6 Breathlessness : Yes / No / Do not know
- 7.7 Dry skin : Yes / No / Do not know
- 7.8 Itching of skin : Yes / No / Do not know

8. What are the treatments for chronic kidney disease of end stage kidney failure?
- 8.1 Medicines alone : Yes / No / Do not know
- 8.2 Medicines and special diet : Yes / No / Do not know
- 8.3 Medicine + Special diet + Dialysis : Yes / No / Do not know
- 8.4 Kidney transplantation + medicines : Yes / No / Do not know
9. What are the different types of medicines that H D patients are advised?
- 9.1 Anti hypertensive's : Yes / No / Do not know
- 9.2 phosphate binders : Yes / No / Do not know
- 9.3 Calcium tablets : Yes / No / Do not know
- 9.4 Iron tablets and Epojen injection : Yes / No / Do not know
- 9.5 Alkalysers : Yes / No / Do not know
- 9.6 Vitamins : Yes / No / Do not know
- 9.7 Stool Softeners : Yes / No / Do not know
10. What are the important points to be remembered regarding medicines?
- 10.1 Get instructions about taking of medicines : Yes / No / Do not know
- 10.2 Fix a routine for taking medicines : Yes / No / Do not know
- 10.3 Learn about medicines affected by dialysis and should be taken before or after dialysis : Yes / No / Do not know
- 10.4 Buy medicines from same shop : Yes / No / Do not know
- 10.5 Carry always the list of medicines : Yes / No / Do not know
- 10.6 Never take any other medicines without doctor's order : Yes / No / Do not know
- 10.7 Avoid drugs containing aluminum phosphate, potassium & sodium : Yes / No / Do not know
11. What are the food items allowed in patients on hemodialysis?
- 11.1 Normal to high protein of first class type (*high biological value*) : Yes / No / Do not know

- 11.2 Energy giving food : Yes / No / Do not know
- 11.3 Fiber rich food : Yes / No / Do not know
12. What are the food items restricted in hemodialysis patients?
- 12.1 Salt& sodium containing food : Yes / No / Do not know
- 12.2 Potassium rich food : Yes / No / Do not know
- 12.3 Phosphorous rich food : Yes / No / Do not know
13. What important points to be remembered regarding diet by hemodialysis patients?
- 13.1 Know the reasons for special diet : Yes / No / Do not know
- 13.2 Talk to your dietitian about creating an eating plan : Yes / No / Do not know
- 13.3 Make a fluid plan including all types of fluid for 24 hours : Yes / No / Do not know
- 13.4 Take protein as advised : Yes / No / Do not know
- 13.5 Take food supplements as advised by doctor : Yes / No / Do not know
- 13.6 Take iron rich food : Yes / No / Do not know
- 13.7 Limit foods that are high in potassium : Yes / No / Do not know
- 13.8 Limit milk and milk products or Replace with nondairy substitutes. : Yes / No / Do not know
- 13.9 Discard liquids from canned fruits and vegetables. : Yes / No / Do not know
- 13.10 Avoid salt substitutes and other seasonings that contain potassium : Yes / No / Do not know
- 13.11 Read labels on “low salt” or “low sodium” packaged foods to be sure ingredients like potassium chloride are not added. : Yes / No / Do not know
- 13.12 Keep an eye on serving size. : Yes / No / Do not know
- 13.13 Leach high potassium vegetables : Yes / No / Do not know

- 13.14 Do not skip dialysis : Yes / No / Do not know
14. What are the types of dialysis?
- 14.1 Hemodialysis : Yes / No / Do not know
- 14.2 Peritoneal dialysis : Yes / No / Do not know
15. How does hemodialysis work
- 15.1 Exchange of blood : Yes / No / Do not know
- 15.2 Removes excess water : Yes / No / Do not know
- 15.3 Balances electrolytes : Yes / No / Do not know
- 15.4 Removes wastes & toxins : Yes / No / Do not know
16. How many times a week hemodialysis should be done for ends stage renal disease patients?
- 16.1 Once a week : Yes / No / Do not know
- 16.2 Twice a week : Yes / No / Do not know
- 16.3 Thrice a week : Yes / No / Do not know
17. What is the normal duration of hemodialysis session?
- 17.1 Four hours : Yes / No / Do not know
- 17.2 Three hours : Yes / No / Do not know
- 17.3 Two hours : Yes / No / Do not know
18. What is the quantity of blood runs through the machine every minute during hemodialysis?
- 18.1 Less than 200 ml : Yes / No / Do not know
- 18.2 201 ml to 300 ml : Yes / No / Do not know
- 18.3 more than 301 ml : Yes / No / Do not know
19. What are the types of access to blood stream for dialysis?
- 19.1 Fistula : Yes / No / Do not know
- 19.2 Graft : Yes / No / Do not know

- 19.3 Perma cath catheter : Yes / No / Do not know
- 19.4 Central venous catheter : Yes / No / Do not know
20. What are the symptoms of the patient when dialysis is not adequate?
- 20.1 Swelling of body : Yes / No / Do not know
- 20.2 Body pain : Yes / No / Do not know
- 20.3 Nausea, vomiting : Yes / No / Do not know
- 20.4 Cramps : Yes / No / Do not know
- 20.5 Itching of the skin : Yes / No / Do not know
- 20.6 High blood pressure : Yes / No / Do not know
- 20.7 Changes in potassium level : Yes / No / Do not know
- 20.8 Breathing difficulty : Yes / No / Do not know
21. What are the blood tests to be done every month when on hemodialysis?
- 21.1 Urea : Yes / No / Do not know
- 21.2 Creatinine : Yes / No / Do not know
- 21.3 Potassium : Yes / No / Do not know
- 21.4 Calcium : Yes / No / Do not know
- 21.5 Phosphorous : Yes / No / Do not know
- 21.6 Albumin : Yes / No / Do not know
- 21.7 Hemoglobin : Yes / No / Do not know
- 21.8 Hepatitis B&C : Yes / No / Do not know
- 21.9 H.I.V. : Yes / No / Do not know

Part-II-B

Knowledge Related to Symptoms/Problems of Hemodialysis Patients

(Health Related Quality of Life)

1. What do you think are the reasons for breathing difficulty in patients on H.D. from the following?
 - 1.1 Excess fluid intake : Yes / No / Do not know
 - 1.2 Intake of salt and salty food : Yes / No / Do not know
 - 1.3 Rise of BP : Yes / No / Do not know
 - 1.4 Excess inter dialytic weight gain : Yes / No / Do not know
 - 1.5 Anemia : Yes / No / Do not know
 - 1.6 Irregular dialysis : Yes / No / Do not know

2. What do you think are the causes of excessive thirst and dry mouth in patients on H.D from the following?
 - 2.1 Restricted fluid intake : Yes / No / Do not know
 - 2.2 More salt intake : Yes / No / Do not know
 - 2.3 More sweet intake : Yes / No / Do not know
 - 2.4 Side effect of some medication : Yes / No / Do not know
 - 2.5 Irregular dialysis : Yes/No/Do not know

3. What do you think are the causes of loss of taste & appetite in patients on H.D. from the following?
 - 3.1 Collection of waste products in the body : Yes / No / Do not know
 - 3.2 Side effect of some medication : Yes / No / Do not know
 - 3.3 Dry mouth : Yes / No / Do not know
 - 3.4 Lack of exercise : Yes / No / Do not know
 - 3.5 Anemia : Yes / No / Do not know
 - 3.6 Irregular dialysis : Yes / No / Do not know

4. What do you think are the causes of constipation in H.D. patients from the following?
- 4.1 Restricted fluid intake : Yes / No / Do not know
 - 4.2 Lack of intake of vegetables & fruits : Yes / No / Do not know
 - 4.3 Lack of activities : Yes / No / Do not know
 - 4.4 Absence of exercise : Yes / No / Do not know
 - 4.5 Effect of certain medication (Lophos) : Yes / No / Do not know
 - 4.6 Irregular dialysis : Yes / No / Do not know
5. What do you think are the causes of body pain (Headache, soreness in muscles, Joint pain, back pain) in HD patients from the following?
- 5.1 Swelling of body including fistula site : Yes / No / Do not know
 - 5.2 Changes in B P : Yes / No / Do not know
 - 5.3 Calcium deficiency : Yes / No / Do not know
 - 5.4 Changes in potassium level : Yes / No / Do not know
 - 5.5 Involvement of bone : Yes / No / Do not know
 - 5.6 Aluminum toxicity : Yes / No / Do not know
 - 5.7 Lack of activities & exercises : Yes / No / Do not know
 - 5.8 Lying down most of the time : Yes / No / Do not know
 - 5.9 Anemia : Yes / No / Do not know
 - 5.10 Irregular dialysis : Yes / No / Do not know
6. What do you think are the causes of cramps during and after dialysis?
- 6.1 Rapid removal of excess fluid during H.D. : Yes / No / Do not know
 - 6.2 Rapid change in level of sodium : Yes / No / Do not know
 - 6.3 Low calcium level : Yes / No / Do not know
 - 6.4 Cold extremities : Yes / No / Do not know
 - 6.5 Irregular dialysis : Yes / No / Do not know

7. What do you think are the causes of weakness after dialysis?
- 7.1 Rapid removal of excess fluid during H.D. : Yes / No / Do not know
 - 7.2 Lack of food intake : Yes / No / Do not know
 - 7.3 Changes in blood pressure : Yes / No / Do not know
 - 7.4 Low hemoglobin : Yes / No / Do not know
 - 7.5 Irregular dialysis : Yes / No / Do not know
8. What do you think are the causes of disturbed sleep in HD patients from the following?
- 8.1 Breathlessness due to fluid retention : Yes / No / Do not know
 - 8.2 Body pain : Yes / No / Do not know
 - 8.3 Cramps : Yes / No / Do not know
 - 8.4 Change in blood pressure : Yes / No / Do not know
 - 8.5 Day time sleeping : Yes / No / Do not know
 - 8.6 Lack of exercise : Yes / No / Do not know
 - 8.7 Intake of tea or coffee in the evening : Yes / No / Do not know
 - 8.8 Irregular dialysis : Yes / No / Do not know
9. What do you think are the causes of dryness and itching of the skin in H.D. patients from the following?
- 9.1 Increased level of phosphate : Yes / No / Do not know
 - 9.2 Deposition of urea on the skin : Yes / No / Do not know
 - 9.3 Lack of oil on the skin : Yes / No / Do not know
 - 9.4 Use of strong soap for bath : Yes / No / Do not know
 - 9.5 Use of too much detergents on clothes : Yes / No / Do not know
 - 9.6 Allergy to the dialysate : Yes / No / Do not know
 - 9.7 Irregular dialysis : Yes / No / Do not know

10. What do you think are the causes of restricted mobility in H.D. patients from the following?

- | | | | |
|-------|---|---|------------------------|
| 10.1 | Swelling of body | : | Yes / No / Do not know |
| 10.2 | Fatigue | : | Yes / No / Do not know |
| 10.3 | Body pain | : | Yes / No / Do not know |
| 10.4 | Lack of exercise | : | Yes / No / Do not know |
| 10.5 | Lack of protein in the diet | : | Yes / No / Do not know |
| 10.6 | Lack of control of sodium & potassium in the diet | : | Yes / No / Do not know |
| 10.7 | Fear of worsening of symptoms | : | Yes / No / Do not know |
| 10.8 | Presence of infections | : | Yes / No / Do not know |
| 10.9 | Dizziness & fainting | : | Yes / No / Do not know |
| 10.10 | Restricted by family members | : | Yes / No / Do not know |
| 10.11 | Irregular dialysis | : | Yes / No / Do not know |

11. What do you think are the causes of dialysis access failure?

- | | | | |
|------|---------------------------------------|---|------------------------|
| 11.1 | Low blood pressure | : | Yes / No / Do not know |
| 11.2 | Bleeding from the puncture site | : | Yes / No / Do not know |
| 11.3 | Clot formation in the vascular access | : | Yes / No / Do not know |
| 11.4 | Swelling of the affected hand | : | Yes / No / Do not know |
| 11.5 | Infection at the puncture site | : | Yes / No / Do not know |

12. What do you think are the causes of sexual dysfunction in HD patients?

- | | | | |
|------|--|---|------------------------|
| 12.1 | Changes in hormones | : | Yes / No / Do not know |
| 12.2 | High B.P. or Low B.P. | : | Yes / No / Do not know |
| 12.3 | Tiredness | : | Yes / No / Do not know |
| 12.4 | Anemia | : | Yes / No / Do not know |
| 12.5 | Effect of medicines used for high B.P. | : | Yes / No / Do not know |
| 12.6 | Fear and ignorance of spouse | : | Yes / No / Do not know |
| 12.7 | Lack of exercise | : | Yes / No / Do not know |
| 12.8 | Irregular dialysis | : | Yes / No / Do not know |

PART-III-A

Assessment of symptoms/problems of Hemodialysis Patients or HRQoL related to selected components

Many patients on hemodialysis have symptoms/problems due to the disease and treatment. Do you have these symptoms/problems? If so please rate them according to the key given below.

- | | | | |
|-----|--------------------------------------|------------|--|
| 0 | = | Not at All | |
| 1 | = | Somewhat | |
| 2 | = | Moderately | |
| 3 | = | Very Much | |
| 1. | Breathing difficulty | : | Not at All/Somewhat/Moderately/Very Much |
| 2. | Excessive thirst and dry mouth | : | Not at All/Somewhat/Moderately/Very Much |
| 3. | Loss of taste & appetite | : | Not at All/Somewhat/Moderately/Very Much |
| 4. | Constipation | : | Not at All/Somewhat/Moderately/Very Much |
| 5. | Body pain | : | Not at All/Somewhat/Moderately/Very Much |
| 6. | Cramps after dialysis | : | Not at All/Somewhat/Moderately/Very Much |
| 7. | Weakness after dialysis | : | Not at All/Somewhat/Moderately/Very Much |
| 8. | Disturbed sleep | : | Not at All/Somewhat/Moderately/Very Much |
| 9. | Dry skin & itching of skin | : | Not at All/Somewhat/Moderately/Very Much |
| 10. | Restricted mobility | : | Not at All/Somewhat/Moderately/Very Much |
| 11. | Clotting or problem with access site | : | Not at All/Somewhat/Moderately/Very Much |
| 12. | Sexual dysfunction | : | Not at All/Somewhat/Moderately/Very Much |

Part III – B

Practices related to symptoms/problems in Hemodialysis Patients

(Health related quality of life)

1. What do you think can be done to manage breathing difficulty in H.D. patients?
 - 1.1 Prepare a fluid plan for 24 hours and follow that : Yes / No / Do not know
 - 1.2 Calculate all types of fluid : Yes / No / Do not know
 - 1.3 Limit salt & salty food items : Yes / No / Do not know
 - 1.4 Take adequate protein : Yes / No / Do not know
 - 1.5 Take medicines to control BP : Yes / No / Do not know
 - 1.3 Take iron rich food, iron tablets erythropoietin : Yes / No / Do not know
 - 1.7 Check weight daily : Yes / No / Do not know
 - 1.8 Regular dialysis : Yes / No / Do not know

2. What do you think can be done to manage excessive thirst in H.D. patients?
 - 2.1 Follow fluid plan to have fluid available throughout 24 hours : Yes / No / Do not know
 - 2.2 Drink water as allowed after retaining in the mouth for some time : Yes / No / Do not know
 - 2.3 Use small cup to drink water : Yes / No / Do not know
 - 2.4 Suck Lemon (if permitted) : Yes / No / Do not know
 - 2.5 Suck chewing gum : Yes / No / Do not know
 - 2.6 Suck ice cube : Yes / No / Do not know
 - 2.7 Rinse or spray mouth with cold water : Yes / No / Do not know
 - 2.8 Avoid salty food items : Yes / No / Do not know
 - 2.9 Check the label of food items for sodium and salt : Yes / No / Do not know
 - 2.10 Regular dialysis : Yes / No / Do not know

3. What do you think can be done to manage loss of taste & appetite in H.D patients?
- 3.1 Take frequent mouth wash : Yes / No / Do not know
- 3.2 Suck lemon (if permitted) : Yes / No / Do not know
- 3.3 Use more spices (mustard, pepper) while cooking : Yes / No / Do not know
- 3.4 Use of vinegar in cooking : Yes / No / Do not know
- 3.5 Keep mouth moist by frequent rinsing : Yes / No / Do not know
- 3.6 Take small frequent meals : Yes / No / Do not know
- 3.7 Add more sugar if not a diabetic : Yes / No / Do not know
- 3.8 Eat essential food items first : Yes / No / Do not know
- 3.9 Use food supplements as advised : Yes / No / Do not know
- 3.10 Regular moderate exercise : Yes / No / Do not know
- 3.11 Regular dialysis : Yes / No / Do not know
4. What do you think can be done to manage constipation in H.D. patients?
- 4.1 Take more leafy vegetable (after draining the water) and fruits like guava, apple, pineapple, papaya and pear : Yes / No / Do not know
- 4.2 Do exercise - yoga, walking, swimming : Yes / No / Do not know
- 4.3 Regular schedule time for passing motion : Yes / No / Do not know
- 4.4 Take medicines (stool softeners) as prescribed : Yes / No / Do not know
- 4.5 Regular dialysis : Yes / No / Do not know
5. What do you think can be done to manage body pain in H.D. patients?
- 5.1 Restrict fluid to avoid water retention : Yes / No / Do not know
- 5.2 Take calcium supplement : Yes / No / Do not know
- 5.3 Take Vitamin D supplement : Yes / No / Do not know

- 5.4 Apply anesthetic cream on the fistula site before dialysis : Yes / No / Do not know
- 5.5 Avoid strenuous work : Yes / No / Do not know
- 5.6 Control blood pressure : Yes / No / Do not know
- 5.7 Treat anemia by diet & medications : Yes / No / Do not know
- 5.8 Learn about activities & exercises permitted : Yes / No / Do not know
- 5.9 Regular exercise for about 30 minutes : Yes / No / Do not know
- 5.10 Regular dialysis : Yes / No / Do not know
6. What do you think can be done to manage cramps during and after dialysis
- 6.1 Follow fluid plan strictly to avoid excess ultra filtration process : Yes / No / Do not know
- 6.2 Follow diet plan strictly (to avoid potassium changes) : Yes / No / Do not know
- 6.3 Keep the extremities warm by using socks, hot water bag etc. : Yes / No / Do not know
- 6.4 Follow all the medications : Yes / No / Do not know
- 6.5 Report any symptoms promptly : Yes / No / Do not know
- 6.6 Avoid walking bare foot indoors : Yes / No / Do not know
- 6.7 Regular dialysis : Yes / No / Do not know
7. What do you think can be done to manage weakness after dialysis?
- 7.1 Avoid excess rapid fluid removal by limiting weight gain between dialysis sessions : Yes / No / Do not know
- 7.2 Have regular meals during dialysis : Yes / No / Do not know
- 7.3 Take rest following dialysis : Yes / No / Do not know
- 7.4 Take all medications as prescribed : Yes / No / Do not know
- 7.5 Take iron rich food : Yes / No / Do not know
- 7.6 Avoid exertion : Yes / No / Do not know
- 7.7 Regular dialysis : Yes / No / Do not know

8. What do you think can be done to manage disturbed sleep in H.D. patients?
- 8.1 Avoid day time sleeping except for a nap : Yes / No / Do not know
- 8.2 Take regular exercise : Yes / No / Do not know
- 8.3 Take medicines for blood pressure Phosphates as prescribed : Yes / No / Do not know
- 8.4 Take calcium supplements : Yes / No / Do not know
- 8.5 Avoid tea/coffee in the evenings : Yes / No / Do not know
- 8.6 Restrict fluid intake : Yes / No / Do not know
- 8.7 Take warm milk before bed time : Yes / No / Do not know
- 8.8 Regular dialysis : Yes / No / Do not know
9. What do you think can be done to manage dryness and itching of the skin in H.D. patients?
- 9.1 Use of medication (phosphorus binders) : Yes / No / Do not know
- 9.2 Use mild soaps : Yes / No / Do not know
- 9.3 Use oil on the skin : Yes / No / Do not know
- 9.4 Avoid prolonged hot bath : Yes / No / Do not know
- 9.5 Do not rub alcohol or any chemical producing scent on the skin : Yes / No / Do not know
- 9.6 Use only soft cotton fabrics for under clothing and avoid wool and rough polyesters : Yes / No / Do not know
- 9.7 Use as little detergent as possible : Yes / No / Do not know
- 9.8 Regular dialysis : Yes / No / Do not know
10. What do you think can be done to manage restricted mobility in H.D. patients?
- 10.1 Restrict fluid and salt intake to avoid Swelling : Yes / No / Do not know
- 10.2 Check weight regularly : Yes / No / Do not know
- 10.3 Rest adequately to prevent fatigue : Yes / No / Do not know
- 10.4 Learn about activities & exercises permitted : Yes / No / Do not know

- 10.5 Do household works like chopping vegetables & cleaning : Yes / No / Do not know
- 10.6 Try walking, cycling & swimming : Yes / No / Do not know
- 10.7 Regular exercises for 30 minutes, 3 times a week : Yes / No / Do not know
- 10.8 Stop exercise if symptoms like chest pain, increased heart rate, breathlessness, cramps, fainting, nausea develops : Yes / No / Do not know
- 10.9 Do not exercise if there is fever or increased blood pressure : Yes / No / Do not know
- 10.1 Include family members/care takers in planning activities : Yes / No / Do not know
- 10.1 Discuss with doctor/nurse regarding activities & exercise : Yes / No / Do not know
- 10.1 Take adequate first class proteins to maintain albumin level : Yes / No / Do not know
- 10.1 Take calcium and vitamin D supplements as prescribed : Yes / No / Do not know
- 10.1 Prevent infections by following all precautions : Yes / No / Do not know
- 10.1 Educate spouse, family members about the disease : Yes / No / Do not know
- 10.1 Regular dialysis : Yes / No / Do not know
11. What do you think can be done to manage problems with dialysis access site?
- 11.1 Check for “thrill” every day while rising and before going to bed : Yes / No / Do not know
- 11.2 Keep pressure dressing at least for four hours after dialysis : Yes / No / Do not know
- 11.3 Do not allow checking of BP on the affected hand : Yes / No / Do not know

- 11.4 Do not allow blood collection from the affected hand : Yes / No / Do not know
- 11.5 Protect the access site from any injury : Yes / No / Do not know
- 11.6 No tight wrist watch or jewelry on the affected hand : Yes / No / Do not know
- 11.7 No tight band or clothing on the affected hand : Yes / No / Do not know
- 11.8 No heavy activity with the affected hand : Yes / No / Do not know
- 11.9 Do not sleep on the affected arm or keep it bent for long period : Yes / No / Do not know
- 11.10 Exercise the fistula by squeezing small ball in the hand in case of fistula every day : Yes / No / Do not know
- 11.11 Inform doctor/nurse if swelling, increased warmth, bleeding or pain are noticed : Yes / No / Do not know
- 11.12 Check blood pressure & avoid low blood pressure : Yes / No / Do not know
12. What do you think can be done to manage sexual dysfunction?
- 12.1 Control blood pressure : Yes / No / Do not know
- 12.2 Treat anemia : Yes / No / Do not know
- 12.3 Maintain physical intimacy with the spouse as before dialysis : Yes / No / Do not know
- 12.4 Avoid tension on access site during contact : Yes / No / Do not know
- 12.5 Follow birth control measures as advised : Yes / No / Do not know
- 12.6 Report to the physician so that drug may be changed : Yes / No / Do not know
- 12.7 Educate spouse about the disease : Yes / No / Do not know
- 12.8 Regular exercise : Yes / No / Do not know
- 12.9 Regular dialysis : Yes / No / Do not know

Part -IV

Views of hemodialysis patients about the Instruction Manual

| Sr. No. | Views | 0 | 1 | 2 | 3 | 4 |
|---------|--|------------------|-------|------------|----------|-------------------|
| 1 | Language of the manual is simple to understand | : Strongly Agree | Agree | No Opinion | Disagree | Strongly Disagree |
| 2 | The Content of the Manual is adequate, covering all the symptoms | : Strongly Agree | Agree | No Opinion | Disagree | Strongly Disagree |
| 3. | The Content of the Manual is written in logical sequence | : Strongly Agree | Agree | No Opinion | Disagree | Strongly Disagree |
| 4. | The pictures help in understanding the content | : Strongly Agree | Agree | No Opinion | Disagree | Strongly Disagree |
| 5 | The Manual is referred to when ever there are any doubts | : Strongly Agree | Agree | No Opinion | Disagree | Strongly Disagree |
| 6. | The size of the Manual is easy to handle | : Strongly Agree | Agree | No Opinion | Disagree | Strongly Disagree |
| 7. | The manual is interesting to read | : Strongly Agree | Agree | No Opinion | Disagree | Strongly Disagree |
| 8. | The suggestions/advice regarding the symptoms given in the Manual are easy to follow in daily life | : Strongly Agree | Agree | No Opinion | Disagree | Strongly Disagree |
| 9 | Review part of the Manual helps in remembering important points | : Strongly Agree | Agree | No Opinion | Disagree | Strongly Disagree |
| 10 | Will recommend the Manual to other Hemodialysis patients | : Strongly Agree | Agree | No Opinion | Disagree | Strongly Disagree |