
ORIGINAL ARTICLE**A Qualitative Research on the Experience of Haemodialysis in South Karnataka:
Lived Experience of Persons undergoing Haemodialysis**

Blessy Prabha Valsaraj^{1*}, Shripathy M. Bhat², Ravindra Prabhu³, Dinesh N.⁴

¹Department of Psychiatric Nursing, Manipal College of Nursing Manipal, Manipal University, Manipal - 576104 (Karnataka) India, ²Department of Psychiatry, ³Department of Nephrology, Kasturba Medical College, Manipal University, Manipal - 576104, (Karnataka), India, ⁴Clinical Psychology Department, Manipal School of Allied Health Science, Manipal University, Manipal - 576104, (Karnataka), India.

Abstract:

Background: Any chronic illness puts a person and family at risk of long term suffering, financial depletion and burden on the caregiver. When it comes to chronic kidney disease (CKD), the sufferers have to be dependent on maintenance dialysis weekly twice or thrice that demands a lot of time and finances. Apart from that, they face physical symptoms of fatigue, anaemia, nausea, muscle cramps, fluctuating blood pressure and many other symptoms. They are asked to maintain a strict dietary, fluid and medication regimen in order to support the kidneys. **Aims and Objectives:** The current study aimed at exploring the lived experience of persons undergoing haemodialysis. **Material and Methods:** The study was conducted among ten patients undergoing maintenance dialysis who were diagnosed as having chronic kidney failure from the dialysis unit of Kasturba Hospital, which is a tertiary health care centre in South Karnataka. A qualitative approach with phenomenological research design was adopted. Data was obtained through interviews using a background proforma and semi-structured interview schedule. The data was analysed using Husserl's method. The transcripts were coded and analysed for common categories and themes were derived out of them. **Results:** The themes emerged at the end of the study were mental agony, physical limitations, coping, financial burden, lack of support, feelings towards the machine and dialysis, search for hope and betterment, spiritual coping, marital relationship and sexuality and uncertainty and fear of tomorrow. **Conclusions:** The

authors conclude that the individual's life is centred on negatively oriented cognitions that can be modified with theoretically oriented interventions like cognitive behaviour therapy.

Keywords: Chronic kidney disease, Lived experience, People undergoing haemodialysis

Introduction:

Chronic kidney disease (CKD) is a worldwide health problem. According to World health organization Global burden of disease project, diseases of the kidney and urinary tract contribute to global burden with approximately 850,000 deaths every year and 115,010,107 disability adjusted life years. CKD is the 12th leading cause of death and 17th cause of disability [1].

The individual with CKD faces many physiological and cognitive problems due to metabolic abnormalities, toxic condition from organ failure and major lifestyle changes brought about by ongoing haemodialysis treatment and related complications. Maintaining quality of life, adjusting to haemodialysis and coping with chronic depression and hopelessness are common concerns of individuals with CKD. The treatment regimen demands may be overwhelming for a debilitated patient and further reduce the role functioning within the family. Also severe fluid

and dietary restrictions further increase discomfort and frustration with the disease [2].

Haemodialysis patients experience a sense of loss. Loss may be understood as a trauma connected with being deprived of a considerable external or internal value. Losses refer to professional and social position. The reduced financial status is a very significant problem which often leads to further losses: the necessity to change the lifestyle or habits, or resignation from hobbies [3].

The therapy for CKD is expensive and life-long. [4]. In India, care for kidney disease is available only at the higher-level hospitals. A shortage in the number of publicly funded specialized hospitals forces patients to seek care in expensive private hospitals. A vast majority do not have access to health insurance, and hence have to fund treatment from their resources [5].

The situations of Udupi and nearby districts in Karnataka are not different. Though there are a few Government hospitals offering the haemodialysis with a subsidised cost, the patients are not satisfied with care due to compromised treatment conditions such as lack of nephrologists, dialysis nurses and technicians, reduced duration of dialysis and non-availability of consultation and emergency care. As of now, the cost of single dialysis in a private hospital ranges from ₹1000 to ₹2000 and hence a person requires ₹9000 to ₹18000 for one month's dialysis alone whereas they are in need of additional medications. Majority of the patients cannot afford the cost of Injection Erythropoietin (₹1450 per single dose, for one month ₹26100), which they have to take in order to maintain normal haemoglobin level. Other medications cost minimum ₹3000 for a month and the travel and other expenses vary depend on the mode of travel, distance and need for accompanying person.

Most of the persons undergoing dialysis travel a long distance but sometimes unable to access public transportation because of strict dialysis schedule or extreme fatigue which adds to the expenses. Many are unable to go for work because of fatigue and dialysis schedules. In the midst of multitude of problems, some of them are eager to talk and many others are withdrawn with the negative thinking that 'what is the use of talking.' It is essential for the health professionals especially for the dialysis nurses to understand their perception towards the illness and treatment as a whole in order to plan appropriate intervention to help them, adapt and cope with CKD.

Material and Methods:

A qualitative research approach with Husserlian phenomenological design was adopted for the study, It's being a systematic, empirical inquiry into meaning [6]. Phenomenology was best suited to the study as the goal of it was to understand how people experience the phenomena of CKD and dialysis.

Setting: The study was carried out in the dialysis unit of Kasturba Hospital, a multispecialty tertiary care centre in South Karnataka.

Sample and Sampling Technique: Persons diagnosed with CKD and undergoing maintenance haemodialysis were selected for the study. Participants were recruited based on purposive sampling and total 18 subjects met the criteria for study, but data saturation with regard to most of the research questions were obtained by ten respondents.

Inclusion Criteria: The patients those who were diagnosed with CKD, completed minimum one year of maintenance dialysis, consented to participate in the study and shared their experience related to illness were included for the study.

Exclusion Criteria: Those who had fatigue and blood pressure alterations during dialysis, delirious and blind were excluded from the study.

Instruments: Information such as age, gender, education, past occupation, current occupation if any, marital status, and information about CKD like duration of period after starting dialysis, duration of kidney disease, type of onset of kidney disease and presence of other illness was collected on a semi-structured interview schedule. The schedule had a total of ten questions. The instruments were validated by giving to five experts and all the items had 100% agreement and hence no modification was done and the items were translated to Kannada and back translated to English by language experts to establish language validity. Ethical clearance from the Institutional Ethics Committee, permission from HOI and informed consent from the participants were sought before the data collection process. The need for audio-recording the conversation was explained in the informed consent.

Data were collected for a period of one year from December 2011 to December 2012 and the respondents were interviewed twice during the data collection period. The interview time was fixed on the basis of the preference of the participants. Most of them preferred the interviews to be carried out while they were undergoing dialysis. During pre-dialysis waiting period, they were engaged with billing, buying medicines or socializing with others and post-dialysis they felt too tired and 'drained' to stay back in the hospital. Hence the time they were in the dialysis was found most suitable for the interview [7]. The initial 30 minutes were avoided as the needling

procedure would interfere with the confidentiality and thus the interviews were carried out after the initial half an hour for one and a half hours out of the five hours of haemodialysis. Even though the interview was pre-scheduled with consent, further freedom was given to the participant to stop or post-pone the interview at any time. The primary researcher who collected the data being known to the respondents for the past few years, all of them were keen in sharing their experience, hence there was no break in the interview process. Each interview took around 50 to 60 minutes.

Data Analysis: It was done based on Husserl's method of analysis.

Step 1- Bracketing: The researcher reflected her own understanding about the situation, to remain objective, as well as to confront the data in its pure form.

Step 2- Intuiting: As a second step, researcher remained open to the meanings attributed by the persons undergoing haemodialysis towards the phenomenon and became totally immersed in it.

Step 3- Analysing: Interviews were recorded with the consent of the participants and transcribed into sheets and coded. Subject names also coded using alphabets in order to maintain anonymity. Significant statements were extracted, common categories were formulated and themes were derived out of them. The transcripts along with the themes were subjected to 'member checking' in order to clarify whether the participants meant same thing.

Step 4- Describing: The results are described in the form of sample characteristics, themes and related theoretical descriptions and meanings.

| Themes and sub themes | | |
|-----------------------|--|---|
| Sr. No. | Themes | Sub Themes |
| 1 | Mental agony | • Struggle to accept the illness |
| | | • Guilt for causing or worsening the kidney disease due to ignorance or wrong beliefs |
| 2 | Physical limitations | • Variety of symptoms |
| | | • Actual restriction to the overall activity pattern |
| | | • Life centered on dialysis |
| 3 | Coping | • Difficult to adapt with dietary and fluid restrictions |
| 4 | Financial burden | • Taxing treatment expenses |
| | | • Cannot work for a paying job |
| 5 | Lack of support | • Perceived poor social support |
| | | • Unhappy with the services offered by Government |
| 6 | Feelings towards the machine and dialysis | • Mixed feelings towards dialysis |
| | | • Dependency towards dialysis machine |
| | | • Competency of staff |
| 7 | Search for hope and betterment | • Curious on medical advances |
| | | • Search for treatment alternatives |
| | | • Wish to reduce the dialysis dose |
| | | • Hope for decreased dependency |
| 8 | Spiritual coping | • Acceptance, a spiritual and philosophical process |
| 9 | Marital relationship and sexuality | • Demand lot of marital and family adjustments |
| | | • Diminished sexual interest |
| 10 | Uncertainty and fear of tomorrow | • Loss of hope that 'nothing can improve the condition' |
| | | • Uncertain future |
| | | • Fear of fistula failure |
| | | • Fear about dependency |

The theoretical explanations and formulated meanings of each theme were given below in the form of significant statements and their formulated meanings.

Results:

1. Theme: Mental Agony: Mrs. A, who is 48 years old housewife: “I feel like dying, if I can die just now I would be the happiest person...to live with a chronic illness in my age is like hell... I want to die.”

Mrs. B, a 56 years old housewife: “After knowing the disease, I feel, as if I am dead, my mind is not there with me, no interest to live... I can no longer feel or enjoy anything.”

Mr. C, 60 years old retired clerk: “There is a deep pain in my heart which no one can understand.”

Mr. D, 50 years, who was an accountant earlier: “I neglected my blood pressure and diabetes until I was admitted to ICU where they diagnosed that my kidneys are not working”.

Mrs. B: “First the illness started all of a sudden... vomiting sensation, loss of appetite, tiredness and swelling. I was taken to hospital and they said my kidneys are weak and gave some tablets and sent me home. We thought eating lots of fruits will improve my health, so ate plenty daily..soon my health worsened..only if the doctors had advised me on what to eat or not to eat..expression of despair on the face).”

Mrs. B, Mrs. E (38 years old, who was accountant before the onset of illness) and Mr. F (60 years, recently retired as clerk): “Many told that Ayurveda can cure my illness and I spent a lot for that but after the Ayurveda treatment urine stopped completely”.

Mr. G, 58 years old retired head master: “When one of my kidneys was not functioning well, my daughter who was a student nurse forced me to remove that which I agreed, in another two years I developed problem for the other kidney..everything is written here (touching the forehead,

gloomy expression on the face).”.

Mr. H, 64 years old, who was a business man in the past: “I thought medicines will keep me healthy but those only caused kidney problem” (he continued taking over the counter antibiotics after a chest infection).

Mr. D, Mr. G and Mr. H: “Now what is the use? The damage has already happened..nothing can be done to improve my condition.”

Formulated Meanings:

- Most of them were deeply hurt by the fact that they got this illness.
- Some of them felt bad that their actions or negligence towards the existing illness lead to CKD which could have been avoided. Guilt was prominent content in some of their feelings towards illness, as they didn't understand the nature of the illness in the beginning; their deeds worsened the kidney health drastically.
- Loss of hope that 'nothing can improve their situation' represents negative cognition.

2. Theme: Physical limitations: Mrs. B and Mr. I, (34 years old, unmarried, who was a business man abroad in the past): “Can't do anything on the previous day of dialysis because of swelling and fatigue. “I can't eat anything on the previous day of dialysis, nothing seems to be palatable.”

Mrs. B, Mr. G and “I cannot lie down or sleep due to severe breathlessness and will be just waiting when I can get dialysis.” “I feel terribly weak and drained in the next day of dialysis.” Mr. J, 40 years old who was a tailor in the past: “Our week has only three days because rest of the four days are exclusively for the illness.”

Mr. D and Mrs. E: “I can't do anything with my hand, fearing my fistula will fail.” “All are afraid of fistula failure because we see many of those who have trouble with it...It is our lifeline!”

Mrs. A, Mrs. B and Mr. J: “Can't go anywhere because I should not miss dialysis appointment;

getting another appointment is difficult and otherwise also it is tiresome to travel.”

Formulated Meanings:

- The illness causes a variety of symptoms among the individuals.
- There is an actual restriction to the overall activity pattern of the individuals.
- Most of them limit their activities fearing the fistula failure.
- Their life is centered on the dialysis, 'waiting for it and relieving from it'.

3. Theme: Coping: Mrs. A: “In any other illness, people are asked to drink more water, except in kidney failure!” “The worst part about this illness is that you can't drink water as much as you want, how can anyone control thirst..it is an innate feeling that for every human being and animals will have!”

Mrs. E: “I force my friends to drink juice when we go out because I love to drink juice..but now I can't, I feel guilty that why I did not drink enough those times”.

Mr. I: “I was habituated to drink cold drinks every now and then while I was working in Gulf, now I find quitting that as the hardest part in my life.”

Mr. G and Mr. H: “Why to follow diet when I am on dialysis?”

Mr. D: “I am worried that I cannot eat all the foods that I used to enjoy since my childhood.” Mrs. A: “It is impossible for anyone to take food without salt!”

Mr. J: “Do not say this diet to my wife, and then I won't get any food from home from tomorrow!”

Formulated Meaning:

- Dietary and fluid restrictions are perceived as the worst part of the illness by the sufferers.

4. Theme: Financial burden: Mr. J: “There is a cure for all the other illnesses, even for cancer but not for this?! Everything is spent on this disease. How can a common man bear the cost of this

treatment..16000 to 20,000 Rupees for a month? Everything what I have is sold and given to the hospital. There is nothing left for us now. my shop is being sold. How long I can beg in front of others for money?”

Mrs. A and Mr. J: “This is the worst kind of illness and even our enemy should not get this.”

Formulated Meanings:

- The treatment expenses are taxing for the common man, though 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, which becomes difficult because many of them cannot work for a paying job.

5. Theme: Lack of Support: Mr. J: “When you don't have money no one will come near to you.” “Neighbours and relatives stopped talking to us; they are scared that we may ask for money from them.”

Mr. D and Mr. J: “In Goa, dialysis patients are given with 15,000 Rupees, where as we are not getting anything from the Government. Government should consider the suffering of dialysis patients.” “Though a few machines are there in the Government hospitals nobody wants to go there because there are no staff and doctor, lack clean water and procedure, the existing staff have no responsibility, when their duty time gets over they just stop and go.”

Mrs. A and Mr. G: “I haven't attended any social function for the past two years with the fear of facing others.”

Mrs. A, Mr. G and Mr. J: “No one in my locality knows what dialysis is, they ask me 'are you going to hospital' every time they see me outside.” “I won't come out of house, the moment people see me they start asking so many questions and they don't know how much we are going through... They show sorry faces which make me feel still worse.”

Formulated Meanings:

- There is perceived poor social support from the neighbors, relatives and the society at large.
- Most of them are unhappy with the services offered by the dialysis centers in the Government sector.

6. Theme: Feelings towards the Machine and Dialysis

Positive feelings: Mrs. A: “Before starting the dialysis, I was feeling bad to come out of house... every one used to ask me 'are you pregnant' which was a shameful thing for a lady with my age...my children also were big and I couldn't eat or drink anything. After starting the dialysis I feel much better!”

Mrs. E: “My life was miserable until I agreed to start with the dialysis, could not eat anything at all, extreme weakness, abdominal swelling and vomiting like sensation...but I did not want the dialysis to begin as I was scared. and I knew once I start, there is no going back. Then gradually, tried Ayurveda and the urine completely stopped...and then fistula was created. Life suddenly turned positive again once after starting dialysis, there wasn't anything bad as I feared...I became as energetic and thought I can do everything as before.”

Mrs. A, Mr. D and Mrs. E: “The machine has become a central part of life...it is like I am connected to this, wherever I go, I have to rush to this machine for keeping me alive!”

“It is hard to believe that this machine takes away all the unwanted.”

Preferences with Machine: Mr. D: “The moment I get into the dialysis unit, I will first look for this machine, I am not comfortable in any other machines, if I get that side, I cannot complete the five hours, I will develop cramps and they have to stop immediately.”

Preferences with Dialysis Staff: Mr. G: “I prefer that staff only”

Mr. H: “The staffs here are like angels, they work tirelessly to keep us alive.”

Negative Feelings towards Dialysis: Mr. I: “It is horrible to be tied to a machine for five long hours... time just stay still...nothing can be done, can't move or sleep...why can't they reduce the time to three or four hours?”

Mr. C: “Machine takes away some of our blood and something good from body also. that is why I feel so drained and tired after dialysis...that whole day and the next day are wasted because I just want to lie down...lethargic and unable to do anything.”

Mr. I: “Dialysis makes us so thirsty and nothing can quench my thirst afterwards, the moment I reach home, I gulp litres of cool water and lie down and will not eat anything later that day.”

Mr. I and Mr. C: “Is there anything that can be done in order to get rid of this dialysis?”

Formulated Meanings:

- Most of them have positive regard for dialysis, knowing that they feel much better after starting the dialysis.
- Some of them get bored due to the long hours of dialysis.
- Some of them prefer the same dialysis machine; it could be that they feel their body is adapted well with that machine due to the long association.
- The preferences of staff were seen with them. All of them feel the experience of the staff matters, and some felt certain staff was gentle while inserting the needle while compared with others, some of them felt the staff need to be really strong in order to hold the needled area tight to stop the bleeding soon after the needle removal. Thus competency of staff is an important criterion that determines patient preferences.

7. Theme: Search for Hope and Betterment:

Mr. F and Mr. H: "Is there any machine that can be put inside the body or is there any other possible treatment? "When they are going to invent artificial kidney?"

Mrs. E: Till two years everything was okay. I could come to dialysis and go back alone by riding my two wheelers, and later again I started growing weaker and weaker...(trying her level best to conceal the emotion) (she needs assistance to get in and out of the car and wheel chair). If only I can manage to come and go alone that is enough for me!"

Mr. I: "Whether I can get cured with Ayurveda treatment?"

Mr. C: "If I maintain the diet that you advice can I reduce the dialysis to once per week?"

Mr. H: "Tell if I do the exercise, whether I can reduce my dialysis to weekly one?"

Formulated Meanings:

- Most of the men are curious to know about the medical advances in the direction of kidney replacement.
- Many of them are in search for alternative medicines to get cure from the illness.
- Some of them just want to reduce the duration and frequency of the dialysis.
- Many of them hope for a better health and thus decreased dependency.

8. Theme: Spirituality: Mr. J: "It's all happening because of the God, why has he put this much of trouble into my life? Why hasn't he got ears and eyes? I am going to ask him why he has made a mess out of my life...yes I am going to give him tight when I meet him. I just wanted to live peacefully and independently without giving any trouble to others and now those both are not possible..?"

Formulated Meaning:

- Reason for the suffering is being sought through spiritual and philosophical processes

9. Theme: Marital Relationship and Sexuality:

Mr. J: "My wife is also fed up with my illness... How long any one can bear this burden!"

Mr. H: "I cannot enjoy sex anymore because I feel all discomfort after it. an itching sensation all over the body".

Mr. J: "We engaged in sex, the next minute we had to rush to hospital because of severe breathlessness."

Formulated Meanings:

- The marital relationship goes through a testing period during the chronic illness. As per the observation of the researchers most of the wives adapt well and take care of their husband in the best possible ways by accompanying, buying medicines and snacks etc. Some of the wives on the other hand find their husbands adamant after the onset of illness.
- Family needs to make a lot of adjustments.
- Diminished sexual interest after the onset of illness.
- Most of them are reluctant to talk about the relationship and sexuality.

10. Theme: Uncertainty and Fear of Tomorrow:

Mr. C: "I do not know what is going to happen tomorrow." "I just want to come alone for treatment as no one is there to accompany me for these long hours that too two days in a week."

Mr. J: "Any one problem anyone can manage, so many problems keep coming on your way... I am sure no one can bear it... how long it can go like this?"

Mr. J: "I have paid 2000 rupees and applied for Kidney transplant. Now two years are over, nothing has happened. .by the time they decide to transplant who knows I am there or not?"

Mr. C: "We cannot do any job. .what happens if the fistula breaks.. Isn't this our lifeline (looking at the direction of fistula)?"

Formulated Meaning:

- Most of them are uncertain about their health,

future dependency level.

- They are unsure of the possibility of kidney transplant.
- Fear of fistula breakage keeps them away from activity.

Discussion:

The themes emerged at the end of the present study were sense of deep pain and loss of hope, physical limitations, restriction, financial burden, lack of support, feelings towards the machine, search for hope and betterment, spirituality, marital relationship and sexuality and uncertainty and fear of tomorrow. A phenomenological study among dialysis patients at Madurai, emerged with similar themes. [8].

A meta synthesis of 240 dialysis patients out of ten phenomenological studies has come up with four major themes such as: having a physical shackle in life, feeling of mental and emotional distress, relying on a haemodialysis machine and dealing with problems [9]. Another review has identified a total of 28 qualitative studies that explored perceptions, experiences and meaning of persons undergoing dialysis, through electronic and hand search and the researcher summarized ten major themes out of those findings such as uncertainty, haemodialysis and the dialysis machine: dependency Issues, normality and lifestyle, meaning of Illness, emotions, physical effects, relationships: families and healthcare providers, body image, suffering and spirituality [10].

The current study has found that feelings of guilt and loss of hope were closely associated with lack of sufficient knowledge with regard to prevention and management of kidney disorder. Similar findings have been reported by Sheiba in her dissertation [8]. Clarkson and Robinson have also highlighted sub-themes on health management and education that identified gaps in the healthcare service wherein subjects were lacking adequate information on health care that worsened health [11].

Financial constraints have been verbalized by

many of the participants in the present study. In India 90% patients cannot afford the cost [4]. Care for kidney disease is available only at the higher-level hospitals. There is no formal referral system; patients can go to any hospital, including to referral hospitals anywhere in the country. A shortage in the number of publicly funded specialized hospitals forces patients to seek care in private hospitals which makes the treatment expensive. A vast majority do not have access to health insurance, and hence have to fund treatment from their resources [5]. The financial and broader social effects have been studied by previous researchers [12, 13].

'Feelings towards the machine and dialysis' has evolved as one of the prominent themes in the present study. Patients on haemodialysis often refer to the impact of the machine and how it tends to dominate their whole experience [14]. The machine is also seen to be controlling the body, and the body being separated from the self, with the feeling that the patient has lost control over it [15]. On the other hand, the machine may paradoxically in many cases be seen as a lifeline with the purpose of sustaining life [16]. Patients therefore regard it as crucial to keep the same machine, since they look upon it as part of them and their lives.

Spirituality is considered as basic in coming in terms with the illness in the present study. Walton and Molzahan have explored spirituality among persons undergoing haemodialysis through a grounded theory approach and have found that spirituality is linked with confronting mortality, reframing, adjusting with dialysis and facing challenges [17].

Present study has brought out the experience of diminished interest in sexuality and lack of free disclosure of sexual matters among the people undergoing haemodialysis. This report is at par with a descriptive narrative literature review carried out by Stewart who has identified that sexual dysfunction has been common in patients

on haemodialysis. The majority of studies reviewed have indicated a physiological effect in men (78%). Fewer studies have reported the effect on self- concept (66%), intimate relationship (21%), or family/social roles (less than 1%). Further in line with the present study, that report has also revealed minimal patient expression of sexual dysfunction to health care providers [18].

The present findings have revealed that most of them were uncertain about their future. A study conducted in US at two Wincosin hospital dialysis units on the experience of a specific migrant population called Hmong group has revealed that they felt profound sadness, weakness and uncertainty. They have described feelings of fatigue and inability to participate in family, social, and clan activities. This has also contributed to their sadness. Feelings of uncertainty and fear related to life, death, dialysis and future and regarding kidney transplant have been identified [19].

Many other researchers also have identified that uncertainty is inevitable and present at the forefront of the patient's mind during illness. Patients have to live with the uncertainty of not knowing when or whether something may go wrong or with the possibility of debility as the illness advances [13, 14, 20-22]. Uncertainty also is associated with waiting for a transplant, life is put on hold and so created uncertainty [23].

Considering the strong reality oriented negative cognitions and life situations, sound long term psychological interventions could be planned by professionals. Anxiety and depression are common psychiatric conditions in CKD and they predict morbidity, mortality, and poor quality of life [24, 25]. The administrators can appoint psychiatric nurses, exercise therapists and dieticians in the dialysis unit. Inspirational materials should be distributed to the patients to read and also displayed through visual media. Thus they can be constantly motivated to cope up with major life change.

Researchers have found that persons undergoing

haemodialysis are deeply engrossed with their meaning, experiences and perceptions of illness that may not be modified with casual teaching. The adaptive behavioural change requires planned, theoretically oriented therapy such as Cognitive Behaviour Therapy (CBT). CBT aims to help patients identify dysfunctional cognitions, test them against reality and alter them, thereby improving their emotional well-being, coping behaviour and physical health. People can be assisted to develop more realistic, self-helping beliefs by using CBT, which could enable them to cope more effectively with diet and fluid restrictions inherent in the haemodialysis treatment regimen [26]. CBT can be tailor made to meet the requirements of persons undergoing haemodialysis by incorporating sessions on modification of negative cognition, plan for improved adherence to diet, fluid, dialysis and drugs, relaxation, exercise and improvement of sleep. Private and public sector health care delivery systems should make dialysis acceptable and affordable to the common man. Large community based awareness programmes would help the people to build knowledge on CKD, which would bring two-fold positive outcomes first by preventing the occurrences of CKD and second by developing positive attitude towards the people suffering with CKD.

Conclusion:

From the ten themes: feelings, expressions and narratives emerged such as mental agony, physical limitations, coping, financial burden, lack of support, feelings towards the machine and dialysis, search for hope and betterment, spiritual coping, marital relationship and sexuality and uncertainty and fear of tomorrow. The detailed explorations of patients' experience gave the evidence that the patients are affected in most of their life areas and they are in need of professional help for developing adaptive mechanisms to cope with the burden of chronic kidney failure.

References:

1. World Health Organisation. Burden of disease project: [http://www.3.who_int/whosis/menu.cfm?path=evidence,burden & language](http://www.3.who_int/whosis/menu.cfm?path=evidence,burden%26amp;language) accessed on September 2006.
2. Barry PD. Psychosocial Nursing, care of physically ill patients and their families. Philadelphia: Lippincott, 1996.
3. Lubkin IM. Chronic illness: Impact and interventions. Boston, Jones & Bartlett, 1998.
4. Lysaght MJ. Maintenance dialysis population dynamics: current trends and long-term implications. *J Am Soc Nephrol* 2002; 13 (Suppl 1):S37-40.
5. Jha V, Chugh KS. Dialysis in developing countries: Priorities and obstacles. *Nephrology* 1996; 2: 65-71.
6. Shank G. Qualitative research: a personal skills approach. New Jersey: Merrill Prentice Hall, 2002.
7. Cukor D, Halen NV, Asher DR, Coplan JD, Weedon J, Wyka KE, Saggi SJ, Kimmel PL. Psychosocial Intervention Improves Depression, Quality of Life, and Fluid Adherence in Hemodialysis. *J Am Soc Nephrol* 25:2014.
8. Sheiba D. A qualitative analysis of the impact of end stage renal disease on the lived experience of dialysis patients and their spouses from a selected hospital Madurai. Unpublished dissertation, Manipal University, 2002.
9. Bayhakki, Hatthakit U. Lived experiences of patients on hemodialysis: a meta-synthesis. *Nephrol Nurs J* 2012; 39(4):295-304; quiz 305.
10. Hurst H. Qualitative Study to Explore the Experiences of Patients with Encapsulating Peritoneal Sclerosis. (PhD thesis) University of Manchester 2011.
11. Clarkson KA, Robinson K. Life on dialysis: a lived experience. *Nephrol Nurs J* 2010; 37(1):29-35.
12. Gerhardt U. Qualitative researches on chronic illness the issue and the story. *Soc Sci Med* 1990; 30(11):1149-1159.
13. Kutner NG. Social worlds and identity in end stage renal disease. In: Research in the Sociology of Health Care. Roth J, Conrad P. (Eds) Greenwich, London, JAI Press Inc. 1987.
14. Kaba E, Bellou P, Andrea S, Kytritsi E, Gerogianne G, Zetta S, Swigart V. Problems experienced by haemodialysis patients in Greece. *Br J Nurs* 2007; 16(14):868-872.
15. Giles S. Struggles between the body and machine: the paradox of living with a home haemodialysis machine. *Soc Work Health Care* 2005; 41(2):19-35.
16. Hagren B, Pettersen IM, Severinsson E, Lützén K, Clyne N. Maintenance Haemodialysis Patients' Experience of their Life Situation. *J Clin Nurs* 2005; 14(3):294-300.
17. Walton J, Molzahan AE. Finding a balance: a grounded theory study of spirituality in hemodialysis patients. *Nephrol Nurs J* 2002; 29(5):447-56; discussion 457.
18. Stewart M. Narrative literature review: sexual dysfunction in the patient on haemodialysis. *Nephrol Nurs J* 2006; 33(6):631-641; quiz 642.
19. Krueger L. Experiences of Hmong patients on dialysis and the nurses working with them. *Nephrol Nurs J* 2009; 36(4):379-387.
20. Gregory DM, Way CY, Hutchinson TA, Barrett BJ, Parfrey PS. Patients' perceptions of their experiences with ESRD and haemodialysis treatment. *Qual Health Res* 1998; 8(6):764-783.
21. Keeping LM, English LM, Fleming-Courts N. Informal and incidental learning with patients who use continuous ambulatory peritoneal dialysis. *Nephrol Nurs J* 2001; 28(3):313-4, 319-323.
22. King N, Carroll C, Newton P, Dornan T. "You can't cure it so you have to endure it": the experience of adaptation to diabetic renal disease. *Qual Health Res* 2002; 12(3):329-346.
23. Moran A, Scott P, Derbyshire P. Waiting for a kidney transplant: patients' experiences of haemodialysis therapy. *J Adv Nurs* 2011; 67(3):501-509.
24. Kimmel PL, Thamer M, Richard CM, Ray NF. Psychiatric illness in patients with end stage renal disease. *Am J of Med* 1998; 105(3):214-221.
25. Dogan E, Erkoc R, Eryonucu B, Sayarliogu H, Agargun MY. Relation between depression, some laboratory parameters and quality of life in haemodialysis patients. *Ren Fail* 2005; 27(6):695-699.
26. Sharp J, Wild MR, Gumley AI, Deighan CJ. A cognitive behavioural group approach to enhance adherence to haemodialysis fluid restrictions: a randomized controlled trial. *American J of Kidney Dis* 2005; 45(6):1046-1057.

*Author for Correspondence: Blessy Prabha Valsaraj, Associate Professor, Dept. of Psychiatric Nursing, Manipal College of Nursing, Manipal University, Manipal, Udipi, Karnataka - 576104.
Cell: 9945193662 Email: blessy.v@manipal.edu