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ORIGINAL ARTICLE

Understanding the Experience of stress on initiation of Haemodialysis: A Phenomenological Study

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ABSTRACT

Background: Research evidence on stress among chronic kidney disease/end stage renal disease patients in India is sparse. Experience of stress is a subjective phenomenon. Hence qualitative research methodology helps to gain real insight about factors that cause stress among haemodialysis patients. The objective of this study was to understand the stressors experienced by patients on initiation of haemodialysis treatment.

Methods: A phenomenological approach was used to gain insight into the lived experience of stressors experienced by patients' on haemodialysis treatment. The study was conducted in outpatient haemodialysis units of two private hospitals in Bangalore, India. Participants of the study consisted of six males and four females who were on haemodialysis for between 2 months to 36 months. Individual semi-structured interviews were conducted with all participants. All interviews were audio-taped and transcribed verbatim.

Results: Content analysis was used to analyze the data. Three main themes emerged namely 'Physical stressors', 'psychological stressors' and 'Socioeconomic stressors'. Pain, tiredness and loss of appetite were the predominant physical stressors reported by participants. Shock and depression on diagnosis and initiation of dialysis, difficulty adhering to prescribed therapeutic regimen, feeling of being burden on family, fear of complications and uncertainty about life were the psychological stressors reported by participants. A range of socioeconomic stressors were reported by the participants which included; Loss of employment, financial problems, loss of ability to perform activities of daily living and limited social life.

Conclusion: Findings of this study can be utilized to design a pre-haemodialysis preparatory program which can be implemented for stage-4 chronic kidney disease patients to prepare them for haemodialysis.

Keywords: Stressors; Haemodialysis; lived in experience.

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Introduction

An Indian population-based study determined the crude and age-adjusted end stage renal disease (ESRD) incidence rates at 151 and 232 per million population, respectively (Modi & Jha, 2011). If validated in other parts of this region, it would mean that about 220,000-275,000 new patients need renal replacement therapy(RRT) every year in this part of the world. It is estimated that there are about 55,000 patients on dialysis in India, and the dialysis population is growing at the rate of 10-20% annually. Management of renal failure, despite medical advances, places an extreme psychosocial burden upon patients and their families (Cukor et al., 2007; Gil- landers, Wild, Deighan, & Gillanders, 2008). Patients experience reduced quality of life compared to the healthy population, with vitality, physical and social functioning being of particular concern (Klang & Clyne, 1997; Cleary & Drennan, 2005). Prevalence of depression and anxiety amongst all patients with end-stage renal failure are between 20% and 30%, rising to over 40% in haemodialysis patients (Cukor et al., 2007; Cukor et al., 2008). Financial burden due to high cost of haemodialysis treatment is a major concern for Indian patients in absence of medical insurance facility (Ballal HS, 2009). Difficulties are especially likely to occur during the transition onto haemodialysis (Harwood, Sontrop, Wilson, Spittal, & Locking-Cusolito, 2009).

Studies done in other countries report several stressors identified in haemodialysis patients (Harwood et al., 2009; Burnette & Kickett, 2009; Ekelund & An- dersson, 2007; Gurklis & Menke, 1995). Research evidence on stress among chronic kidney disease/end stage renal disease patients in India is sparse. A study by Udaykumar TR reported that haemodialysis patients' experience more stress as compared to patients' on peritoneal dialysis, (Udaykumar TR, 2003). Experience of stress is a subjective phenomenon. Hence qualitative research methodology may help to gain real insight in understanding stressors experienced by haemodialysis patients. Thus qualitative approach (phenomenology) was adopted to understand stressors experienced by patients on haemodialysis.

Aim of the study

The aim of this study was to address the ques-

tion 'What are the stressors experienced by chronic kidney disease patients on initiation of haemodialysis?

Methodology

Research approach: A phenomenological approach was used to gain insight into the lived experience of stressors experienced by patients' on hemodialysis treatment.

Setting: The study was conducted in outpatient hemodialysis units of two private hospitals in Bangalore. Both the hospitals provided concessions in dialysis charges or free treatment to selected few patients who were too poor to bear the cost of dialysis treatment.

Participants: A purposive sampling was used to identify and recruit patients aged over 18 years who had started haemodialysis within the previous three years. Selection criteria ensured that the sample reflected the diverse characteristics of the wider haemodialsis patient population with respect to age, gender, marital status, employment status and acute or gradual transition to haemodialysis. Potential participants were excluded if they were judged to be too ill to take part, or if they had significant comorbidity such that their predominant treatment was for another illness. Potential participants were identified and given an information sheet and the opportunity to ask further questions. Written consent was obtained from patients who agreed to participate in the study. Mutually convenient time for an interview was selected. An approval from Hospital Research Ethics Committee for conducting the study was obtained.

Participants of the study consisted of six males and four females who were on haemodialysis for between 2 months to 36 months. The background characteristics of participants are presented in the table 1.

Data collection method

Interviews with participants were conducted using an interview guide. An attempt was made to make interviews informal and conversational. As requested by all patients, interviews were carried out during their dialysis. The interviews covered participants' experiences of daily activities, thoughts, feelings, management of medical regimen and social life. The participants dictated the order and pace of inter-

Table 1. Background characteristics of participants . (n=10) $\,$

Sr no	Gender	Age	Time on Haemodialysis	Marital status	Employment
I	М	32	2 months	Married	Unemployed
2	F	62	II months	Married	Unemployed
3	F	31	3 years	Single	Unemployed
4	М	32	3 years	Single	Unemployed
5	М	57	II months	Married	Unemployed
6	М	36	II months	married	Unemployed
7	М	59	II months	Married	Unemployed
8	F	36	3 years	Married	Unemployed
9	F	24	12 months	Single	Employed
10	М	55	II months	Married	Unemployed

views, which lasted between 30 and 60 minutes. All interviews were audio-taped and transcribed verbatim. After interviewing 10 participants it was observed that no new information was gained and the data saturation had reached.

Data analysis

The interpretive content analysis of the text was undertaken for the purpose of analysing qualitative data. After reading and rereading through the transcribed interviews initial identification of major themes appearing in the data was done. Data analysis continued until no further themes emerged and all relevant text was coded.

Findings and discussion

Analysis of the data resulted in the emergence of three main themes—'Physical stressors, 'psychological stressors' and 'socioeconomic stressors' These themes are presented in the table no.2

Patients who had an acute transition onto haemodialysis reported more psychological stress compared to those whose transition to haemodialysis was gradual. It was also observed that psychological and socioeconomic stressors were more predominantly reported by younger patients.

a) PHYSICAL STRESSORS: Pain, tiredness and loss of

appetite were the predominant physical stressors reported by participants. All the participants reported pain as their major concern. Being pricked with large needles and repeated arterio-venous fistula operations were expressed to be perceived as painful. For example one participant said "I had never seen such big needles! Initially I was very much afraid of needles. (Male, 32yrs). Another explained, "I had to come for operation theatre(for fistula creation) for three times. That was very painful for me...physically...mentally...in every way"(Male, 36yrs).

Tiredness and loss of appetite were among the other most commonly reported stressors. Feeling tired was attributed to dialysis treatment, high creatinine levels and lack of appetite. Many participants reported loss of appetite which was present at the time of diagnosis of chronic kidney disease and which became worst with time. One participant explained, "I can't walk for long distance. I feel tired. Sometimes I even had a fall...that's why I am afraid" (Female, 62yrs). Another said, "Then even with high creatinine....you don't feel like eating sometimes. Just to take medicines forcibly eating...and I have done that forcibly eating thing also" (Female, 31yrs).

Dry and scaly skin is common problem in CKD patients. Itching and swelling were reported as troublesome by a few participants. "See we have the thing like...I used to get itching in the legs...not in hands...in legs...Doctor suggested me to change the soap which has got glycerin. So now it's not

Table 2. Themes . (n=10)

	Definition	Themes		
STRESSORS	Perceived factors	Physical stressors		
EXPERIENCED	that were identified	Pain, Tiredness, Loss of appetite, Itching, Swelling, Muscle cramps.		
BY PATIENTS	stressful on initiation	Psychological stressors		
	of dialysis.	Shock, Depression, Uncertainty about life, Fear of complications, Com-		
		pliance to therapeutic regimen, Feeling of being burden on family.		
		c) Socioeconomic stressors		
		Loss of employment, financial problems, Limited social life, Loss of nor-		
		malcy in life.		

there" (Female, 24yrs). Muscle cramps were reported by three participants. Excess fluid removal usually resulted in muscle cramps. Some of the participants had perception that 'dialysis machines were not removing water adequately', hence they often requested the health care workers to set the weight loss on machine little higher than what was actually required. One participant said, "I have told them to keep weight loss 3.5kg. I feel some machines are not removing the water adequately. But I am getting little cramps with that. So I asked them to reduce it a little bit" (Female, 36yrs).

b) PSYCHOLOGICAL STRESSORS: There was marked presence of psychological stressors among all participants. Shock and depression on diagnosis and initiation of dialysis, difficulty adhering to prescribed therapeutic regimen, feeling of being burden on family, fear of complications and uncertainty about life were the psychological stressors

Younger participants who did not have prior symptoms of chronic kidney disease expressed that they were shocked to know the diagnosis. Accepting the diagnosis was problem for some wherein others were shocked to such an extent that they could not think anything further. Some participants expressed that they felt as if they 'went blank'. Two of the participants explained, "Reaction was...just blankness in my mind! What is this? What is renal failure...never know...never came across such condition or such patient....so just went blank...something renal failure is something" (Female,31yrs); "But when he said both the kidneys are not working...that was shock of my life!" (Male, 32yrs).

When asked about their first experience of undergoing dialysis majority of the participants whose transition to dialysis was acute reported that they felt very helpless and were shocked to undergo the treatment which they had never heard or seen before. One participant stated, "That was terrible for me...I was...I had not seen any dialysis machine. Dialysis was a new word for me. Then I came to know about this...very painful...Once I landed up onto the bed...next to the dialysis machine...I was really feeling bad and I was looking...what exactly they do"(Male, 32yrs).

Contrary to the experience of younger participants who had acute transition to haemodialysis treatment older patients whose transition to dialysis was gradual were mentally more prepared to accept diagnosis of ESRD and transition to haemodialysis treatment. For example one participant responded, "Because I was already having a problem for past three years...it was known that it will fail one day...because I had already three four problem related to my health, it did not much affect me. I had heart problem, I have BP, I am sugar patient from past 20 years....so these all made my mind matured" (Male, 59yrs).

Uncertainty about outcome of treatment and progression of disease instilled fear of death in minds of most patients on diagnosis of ESRD and initiation of dialysis treatment. One participant stated, "I felt my life may end within that period. Thoughts came like that...fear was very high...fifteen days I did not sleep" (Male, 36yrs). Most participants expressed feelings of uncertainty about their life. Majority were aware that dialysis treatment is not cure for their disease. They

felt helpless to be on dialysis to continue their life. One participant explained, "As a dialysis patient we don't know what is going to happen tomorrow...where is the end but you need to stick on to this....there is no other alternative" (Male, 32yrs). Another stated, "Once you come to this stage....everything will not be in our hands. Whatever the way life goes we have to go like that. We are just trying things...that's all" (Male, 36yrs).

Majority of the participants reported feeling depressed on initiation of dialysis treatment. Loss of employment, long-term nature of treatment with no hope for permanent cure made most of them feel depressed. One participant said "All that time I was quiet busy...so once for all I stopped no...that made me vey tensed and depressed" (Male, 55yrs). Physical changes related to disease and treatment were also attributed to cause depression. "When I wake up in the morning, when I breathe out, it smells very awkward...at that time I feel very....I will be depressed". (Male, 36yrs) One participant even reported suicidal ideation she had during the first few months of her dialysis treatment. "Sometimes I thought of even suicidal attempt...I thought of committing suicide" (Female,31yrs).

Most participants were found to be concerned about complications that would occur due to various reasons. Many were concerned about dialysis and fistula related complications. One stated, "During dialysis anytime suddenly BP will go high and I am diabetic no...even suddenly sometimes it happens...suddenly sugar will go low. Then too much of sweating...some giddiness...immediately they will give treatment.....that way we have to worry" (Male, 55yrs); Another said "It was very frustrating(dialysis treatment).....it will completely remove our energy...something like that I felt"(Male, 32yrs).

Some were found to be constantly concerned about their diet. They wanted to be more careful about their diet to avoid any sort of complications. One participant stated "Now a days also I am very scared to take any-thing...the food. If they allowed me to take a particular food...like nuchal...bittergaurd....they told me I can eat...but that also I am taking very limited amount. One small banana they have allowed me to take but if I take it I feel scared that my potassium will increase" (Female,36yrs).

Some also expressed concern about repeated blood transfusions they had to undergo due to anemia. They feared that blood transfusions would lead to various infections. One participant expressed, "But if we take direct blood it will affect us a lot! Like we get... what to say...pimples...pus...pus formation will occur in

all parts of the body. When I take blood of others even though it is tested also it will show its reaction a lot" (Female, 24yrs).

Adhering to therapeutic prescription of diet, limited fluid intake and medications was found very stressful by most participants. All the participants reported that adhering to limited fluid intake was the most difficult task for them. One participant stated "In this dialysis main thing is food only! Food in the sense water....even in the food or whatever it is, I can control totally but fluid is main. They have given restriction...you should not drink much water...that is really bad!" (Female, 24yrs). For some taking too many oral medications made it more difficult to adhere to limit their fluid intake. Majority exceeded their prescribed fluid limit as they needed more water to swallow the medicines. One participant explained, "It's very difficult! We have to take tablets three times. Tablets will be around 10tablets...7-8 tab- lets...that alone will consume 1 litter water. Rest of the things...it's very difficult to handle within that limit. In my case I drink more water. Most of the times I cross the limit" (Male, 36 yrs). Others found it difficult to adhere to prescribed diet and fluid intake when they had to attend family functions and social gatherings. One participant explained "When I go out with friends or cousins will come to my house, going for parties or functions....we can't control ourselves. Like especially when I am with my friends, I can't tell them right...see I can't have this....I can't have that...only for me. That I can't do. So I will be like normal....like them only....that Ι will never be et"(Female, 24yrs). Some also reported physical problems they had to face due to limited fluid intake. One participant stated, "Without water so many problems I am facing...like no sleep in the night.... second thing motion is very difficult". (Male, 57yrs)

After fluid intake dietary restriction was reported as the most difficult to follow by many participants. Salt restriction especially was found to be more stressful by majority participants. Participants expressed, "Eating less salt is miserable...adjusting for this type of diet is hard and bit difficult...even now I feel hard for diet...Sometimes I have to quarrel with my wife" (Male, 59yrs); "I can't have food without salt. Only that is the problem, till now I am unable to come out of it" (Female, 24yrs). Giving up favorite food items was also stressful for some participants "The main thing is potato...I love potato...potato...tomato...it hurts...my favorite dish is non-veg. But that also should be avoided. It hurts like anything...you can't imagine and explain the thing.....it is beyond explanation. It brings tears in my eyes" (Male, 36yrs).

A few participants found it stressful to take too many medicines for a long duration. One participant was concerned about chemicals used in medicines and thought that these would probably further cause more damage to the kidney. "Very difficult!!! Swallowing everyday so many tablets I am very much...very difficult...For last 4-5 years I am taking so many tablets. I am fed up of taking tablets now...very much fed up" (Male, 57yrs).

All the participants reported the feelings of being burden on their family members. Majority had to give up their employment due to time demands of dialysis treatment. Financial dependency on family due to unemployed status was reported as a stressor by these participants. Participants expressed this as,"Because like...I was not dependent on my family for anytime. After I completed my graduation I started working .But suddenly when it happened like this...I used to feel like...now I have become very much dependent on my family" (Female, 24yrs); "I do not want to give any trouble...further problems to my family also...simply unnecessarily....Simply whatever the doctors are telling...medicines and all restrictions I will follow.....If I don't follow then automatically the problem will come. I will have to get admitted in hospital...people will have to come...because of me they should not be put in trouble. Already they suffered too much" (Male, 55yrs); "My mother my father when I was in St. Johns (hospital) in the beginning like when I used to go for dialysis, never they were able to attend parties functions...many things they were unable to do because of me" (Female, 24yrs). Some others perceived themselves as obstacle in life of their family members who took care of them. They felt guilty for the sacrifices family members had to make to take care of them. One participant expressed, "Second thing is she (sister) is not getting married...because of me...A sister at home with dialysis who will take care...if she gets married and goes away. That is a bit difficult thing....so its directly or indirectly its upon me! I have been just like a curse" (Female, 31yrs).

C) SOCIOECONOMIC STRESSORS: A range of socioeconomic stressors were reported by the participants which included; Loss of employment, financial problems, loss of ability to perform activities of daily living and limited social life.

All participants highlighted financial problem as the most stressful factor. Cost of dialysis treatment, medications and transportation charges was perceived to be huge financial burden by participants. Loss of employment further complicated the financial problems.

Participants expressed their difficulties as, "Before I was doing business, by the time everything adjusted then there were no expenses. Now I have stopped working and expenses have increased. Hospital expenses are more...medicines...that insulin costs 500 Rs it comes for a week only...plus the tablets also....plus the dialysis cost....it's difficult!" (Male, 55yrs); "Per dialysis we used to pay 900 Rs. weekly thrice it was and in a month... it is very costly. A middle class family....really they can't spend so much money. Nobody will have so much of savings also" (Female,24yrs.)

Younger patients were more concerned about loss of employment and financial dependency on others. One participant stated, "When I quit the company I was having this disease. Now I am not able to take that much stress....the work pressure was too much that you need to be physically available every time and the dialysis is one obstacle where every time you need to stick onto the machine...right next to it"(Male, 32yrs). Some constantly worried to meet the expenses of their treatment. Some others did not want to start with treatment due to lack of finances. Some participants expressed this as "But I do not go by auto. Auto fare will come up to 70-80Rs. If I save that money it can be used to buy my tablets....so I go by bus only" (Female, 36yrs); "The doctor told to start dialysis...then I started. What to do like that I was...I didn't want to start it...because it takes money also n owe don't have so much money!" (Female, 62yrs)

Most participants wished to start working again and be financially independent. As dialysis treatment demanded time, most participants verbalized difficulty finding jobs that permitted for flexible work timings. One participant stated, "My first and foremost thing is to get a good job. That should have much flexible timings...once we become economically independent then no other problems will arise" (Male, 32yrs). Some others who wished to work again reported lack of family support. One participant stated, "From past 15 days I was coaxing my husband that I want to do MA in English. But he says ...don't take risk...why you want to do all this...I said....I want to work as a teacher...but he is not allowing me to do that" (Female, 36yrs). Although renal transplant was perceived as best option, lack of finances made it difficult to go for transplantation. Uncertainty about successful transplant also made them unsure to spend on this treatment modality. "The transplant is the best thing....but it depends on financial probabilities of your family and the success rate of transplant being successfully done" (Male, 32yrs).

Participants did not want to be talked about as 'different' or 'diseased person' among their social circle. Answering questions asked by people related to disease or treatment was frustrating for most of them. One participant stated, "I didn't want people to see me in some other way....some other way means...obviously they can show their sympathy for me...she is a kidney failure patient...she is that...she cannot do this...that. They start showing much care or whatever it is....I don't want that to happen"(Female,24yrs). Most felt that presence of neck vein catheter made them look and feel awkward to go out in public as they had to answer peoples queries related to the catheter. Most chose to avoid going out when neck vein catheter was present. One of the participant stated, "That time the catheter here....near neck....I used to feel very bad! It's not good at all! I can't go out, I can't go to anybody's house or I can't roam...you can see it right? Someone can see it. I used to tie a scarf, but I never liked. It was there almost three months. I never went out" (Female, 24yrs). Avoiding social contact was perceived as solution by younger participants. Most felt that friends, relatives looked at them negatively. For example one participant stated, "The thing is I avoid all the things. My social life is zero now. I won't entertain any meetings with the friends won't go out to meet anybody. Before when we are normal they treat us like very important. After you get this disease the treatment they give you is entirely different" (Male, 36 yrs). Some expressed that their social life was limited to meeting and interacting with dialysis department staff as they spent most of their time in the dialysis unit. One stated, "So social life in the sense going for dialysis, getting dialysis done, speaking to the dialysis staff, sisters...all...this is the social life! Outside I don't have anybody" (Female, 31yrs).

Inability to perform day to day self-care activities gave rise to feelings of dependency on significant others. Feeling of loss of normalcy was expressed by most participants. For example one participant stated, "In my house we heat water on stove for bath. So in a vessel we keep water. So sometimes I will take it off from the stove. But my mother she will stop me. Every day she will scold me...never she will allow me to do that. So that one I feel very bad. Because every day morning calling her and saying...Please do this for me....that I feel very bad!" (Female, 24yrs). Physical inability to pursue work related activities, hobbies and social activities that were enjoyed once was found troublesome by many. For example some participants stated, "My main hobby was trekking....very often...once in three months at least...Another thing is swimming and rafting. Right now everything is paralyzed"(Male,36yrs;); "Before I used to cook, keep everything ready, then go to school; from school to Geeta classes, lectures like that I will attend and after coming, I used to do my work, all household work. But now to go for one place also is very difficult" (Female, 62yrs).

For younger participants disease and dialysis treatment halted future life plans. One participant stated, "I was just preparing for my MA literature exams and suddenly I had this swelling in February. I stopped those MA literature preparations. Then I came this way...dialysis way... I gave it up...it was very horrible!" (Female, 31yrs).

Discussion

Our findings offer interesting insights into stressors experienced by ESRD patients' on initiation of haemodialysis. However, the limitations of the study include the small purposive sample. Hence generalisation of the findings to the larger population of patients may not be possible. However, the primary aim of the study was not to generalize the findings, but to develop an in-depth account of participants' stressors on initiation of haemodialysis therapy.

It was observed that participants experienced physical, psychological and socioeconomic stressors on initiation of haemodialysis. Findings of this study suggest that psychological and socioeconomic stressors were predominantly expressed by the participants. Findings of study by Auer J et.al. also report that psychological stressors were predominant in these patients (Auer J et.al., 1990).

Like the findings of our study, the literature highlights prevalence of fatigue that ranges from 60% to as high as 97% in patients on long-term renal replacement therapy (Chang, Hung, Huang, Wu, & Tsai, 2001; Murtagh, Addington- Hall, & Higginson, 2007; Weisbord et al., 2005). Findings of a qualitative investigation conducted by Theofilou et.al. reported that fatigue typically reported post and during dialysis interfered with daily activities and mobility (Theofilou, Synodinou, & Panagiotaki, 2013). Weisbord et al. reported that dry skin (72%), feeling tired or lack of energy (69%), itching (54%) were the most commonly reported symptoms by dialysis patients which led to significant reduction in health related quality of life among these patients (Weisbord et al., 2005)

Psychological stressors reported in our study are in agreement with many other studies that have reported depression, helplessness, uncertainty about prognosis in haemodialysis patients as stressors. (Harwood, Locking- Cusolito, Spittal, Wilson, & White, 2005; Burnette & Kickett, 2009; Ashby et al., 2005; Tagay, Kribben, Ho- henstein, Mewes, & Senf,

2007). In addition to these, our study identified compliance to diet and fluid limitation as one of the major psychological stressor. Patients were anxious, constantly worried and were not effectively able to cope with these limitations. Feeling of being burden on family members was another important psychological stressor identified by our study.

Findings of our study draw attention to economic burden and social disconnect experienced by patients during transition to hemodialysis. Similarly Udaykumar et al.reported that patients on haemodialsis had higher scores in the "socio-economic aspect" of stress (75.87 \pm 6.48) as compared to peritoneal dialysis patients (39.0 \pm 5.57, P<0.001) (Udaykumar TR, 2003).

Differences in experience of stress by younger vs. older patients and acute vs. gradual transition to haemodialysis are important to be considered while designing patient preparation programs. Study also helps to bring out the real and imaginary fears of patients during transition to dialysis. Patients often are more depressed and are in need of psychological support during their transition to dialysis. Suicidal risk is high among depressed hemodialysis patients(Sachan Rekha, Gupta Pooja, Patel ML, Chaudhary Shipra, & Agarwal Reshu, 2012). It is important for nurses to understand the thoughts and feelings of patients on transition to haemodialysis, in order to provide needed information and counselling for these patients. Across several developmental and lifespan transitions, as discussed by Mahler & Kulik, (1998) and Rosenkoetter & Garris, (2001) preparation has been identified as reducing psychological distress and improving general wellbeing. Good-quality education and counselling has central significance during patient preparation for treatment in chronic illnesses.

Conclusion

This study has identified stressors experienced by chronic kidney disease patients on initiation of haemodialysis in Indian context. Study's findings illustrate physical, psychological and socioeconomic stressors experienced by patients. These findings can be utilized to design a pre-haemodialysis preparatory program which can be implemented for stage-4 chronic kidney disease patients to prepare them for haemodialysis .

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