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RESEARCH ARTICLE

PERCEIVED ILLNESS INTRUSION AND FACTORS ASSOCIATED WITH PATIENTS ONHEMODIALYSIS IN ATERTIARY CARE HOSPITAL

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Abstract

Background/Purpose*:* Dialysis is a medical procedure that is very nerve-wracking as it interferes with the day-to-day activities of the patients suffering from kidney disease. Our study is aimed at finding the association between illness intrusion among patients on dialysis, the effect of duration of dialysis, and patient demographics.

Materials/Methods*:* A cross-sectional study was conducted on 60 Chronic Kidney Disease patients who were on maintenance hemodialysis in RajaRajeswari Medical College and Hospital, tertiary care center in Bangalore, Karnataka for a period of two months. The patients were interviewed using a pre-tested and semi-structured interview schedule. Data was entered and analysed using Tableau software. The results were visualized in percentages and proportions.

Results*:* Out of 60 patients, 42 patients were males and 95% of total patients were married. 61.7% were from urban areas and the majority (81.7%) of the patients funded their dialysis through their own/family income and 75% reported an intrusion in the area of work.

Conclusion*:* A high percentage of people were from urban areas and very few from rural areas. Therefore, setting up Nephrology units in government hospitals would reduce the economic burden on the patient.

Categories: Nephrology, Epidemiology/Public Health.

Introduction:-

Chronic Kidney disease is becoming one of the most prevalent diseases worldwide. Kidney failure is one of the best diseases to manage as we have dialysis, which can replace kidney function. Dialysis is done when the person's kidney is no longer capable of removing enough waste substances and fluid from the blood in order to keep the person healthy. The major causes of kidney disease are obesity, diabetes, and hypertension [1]. The prevalence of chronic kidney disease is close to 800 per million population, and the incidence of end-stage renal disease is 150-200 per million population [2]. In 2010, an estimated 2.3-7.1 million people with end-stage kidney disease died without access to chronic dialysis [3]. Dialysis patients take the most medications compared to any other chronically ill patients, therefore the adherence to the lifestyle patterns,strict dietary intake, and regular visits to the hospital are essential in these patients [4]. The dependency upon the treatment, monetary burden, physical changes within the patient, and the fear of death among thepatients ends up in depression and anxiety [5]. Social epidemiology shows

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that stress like poverty and discrimination influence the patients psychologically [6]. Social support may be a major issue that may influenceon the results of those patients because it features a positive impact on their lives [6]. Enhanced support from their family, friends, and significant others can improve their lifestyle and life expectancy [4].

Materials And Methods:-

A cross-sectional study was conducted on patients who were on maintenance hemodialysis in Rajarajeswari Medical College and Hospital, a tertiary care hospital in Bangalore, Karnataka for a period of two months.

About 60 patients of chronic kidney disease on Hemodialysis were taken up for the study after obtaining informed consent. Included patients who were willing to participate, stable & who had completed at least two months of Hemodialysis. The subjects were interviewed using a pre-tested and semi-structured interview schedule covering demographics, the expenditure for dialysis & social activities affected due to dialysis.

The subjects were asked to rate their perceived illness intrusion regarding work, hobbies, social activities,and relationships with friends on a 4-point scale ranging from 1 (not applicable), 2 (not at all), 3 (to some extent), 4 (to a great extent). As most of the patients were accompanied by a relative, they were also involved in the study during the interview. Data was entered and analysed using Tableau software. The results were visualized in percentages and proportions.

Results:-

Among the 60 subjects, the majority of the study subjects were in the age group of 51 - 70 years (65%) [
Figure1]. 70% of the subjects were males and 30% are females. Hindus accounted for 90%, followed by Muslims (6.7%) and Christians (3.3%). 65% of the patients had their education till 10th grade [Table 1]. The majority were married (57 patients) accounting for 95%. Most of the subjects came for Dialysis from urban areas (62%). A total of 33 patients belonged to a nuclear family (55%) and 26 patients to a joint family (45%).

The majority of the study subjects were undergoing dialysis either for a duration of less than a year or for more than 3 years, accounting for 36.7% and 31.7% respectively [

Table **2**]. The majority (58%) was undergoing dialysis thrice weekly. A good number of people (58%) were spending less than 15000 INR (approx. 199.60 USD/ 176.53 EUR). And the people who went through dialysis for more than 2 years are spending more than 15000 INR (approx. 199.60 USD/ 176.53 EUR) per year for their dialysis [
Figure **2**].

The subjects were asked the reason for not opting for renal transplantation, 28 (47%) stated lack of money being the reason and 14 (23%) stated lack of donors [Table 3]. The majority of the subjects, 49 (82%) arranged money for dialysis from their own / family income. Few of them arranged money by selling their property or by going into debt [

Table 4]. The relatives were asked about their attitude towards the patient, 39 (65%) felt it was their responsibility to take care and 2 (3%) of them felt it as a financial burden [Table 5].

In our study, 75% reported illness intrusion in the area of work of which 33% had felt the intrusion to some extent and 42% felt the intrusion to a great extent. With respect to hobbies, 87% reported that they didn't have any hobbies. The majority (71%) of the patients reported that the relationship with friends and family was not affected. Regarding social activities, 13% reported that dialysis didn't interfere with their social life and 28% felt that dialysis interfered to some extent and 57% felt the interference to a considerable extent [

Figure 3].

Figure1:- Age distribution of the patients.

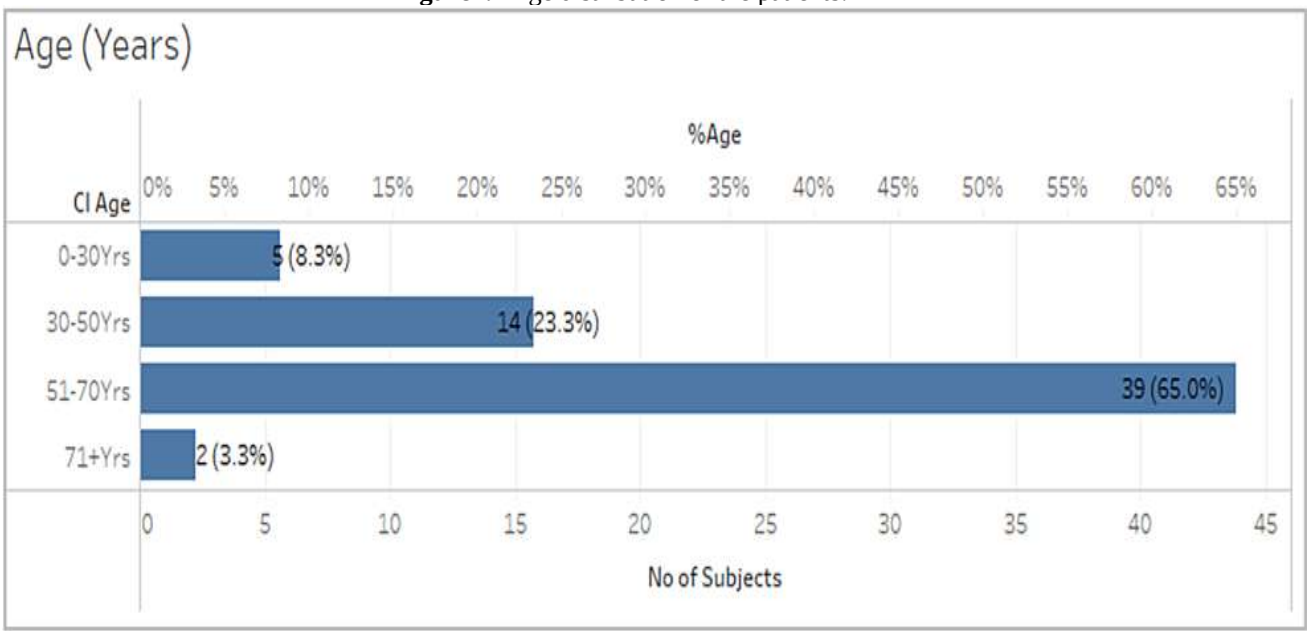

Figure 2:- Average amount spent.

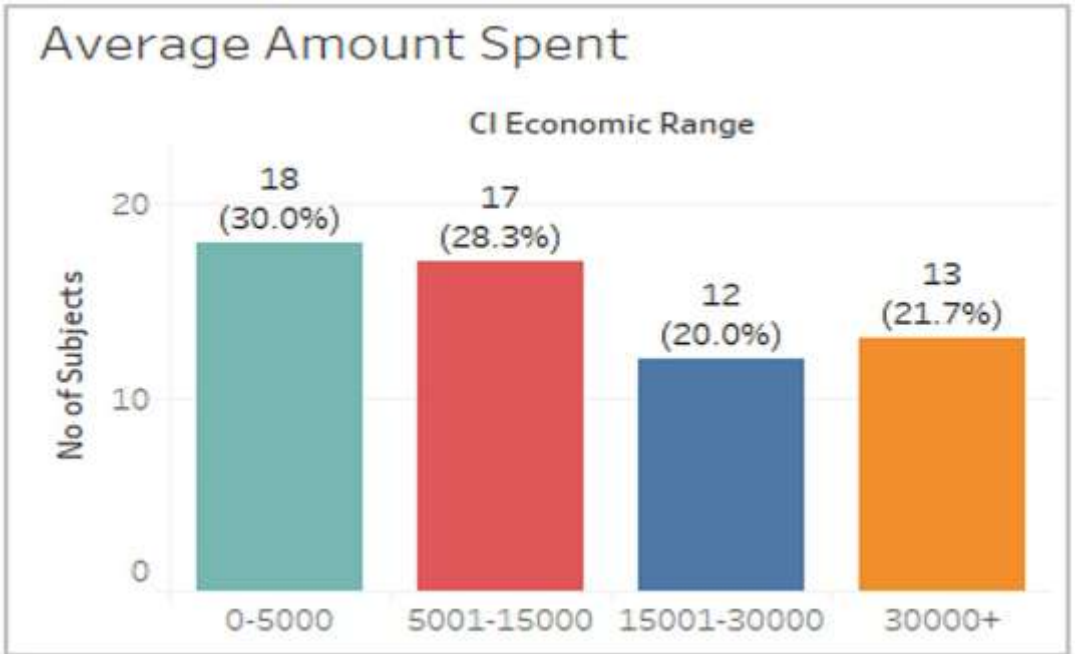

Figure 3:- Perceived illness intrusions in various domains.

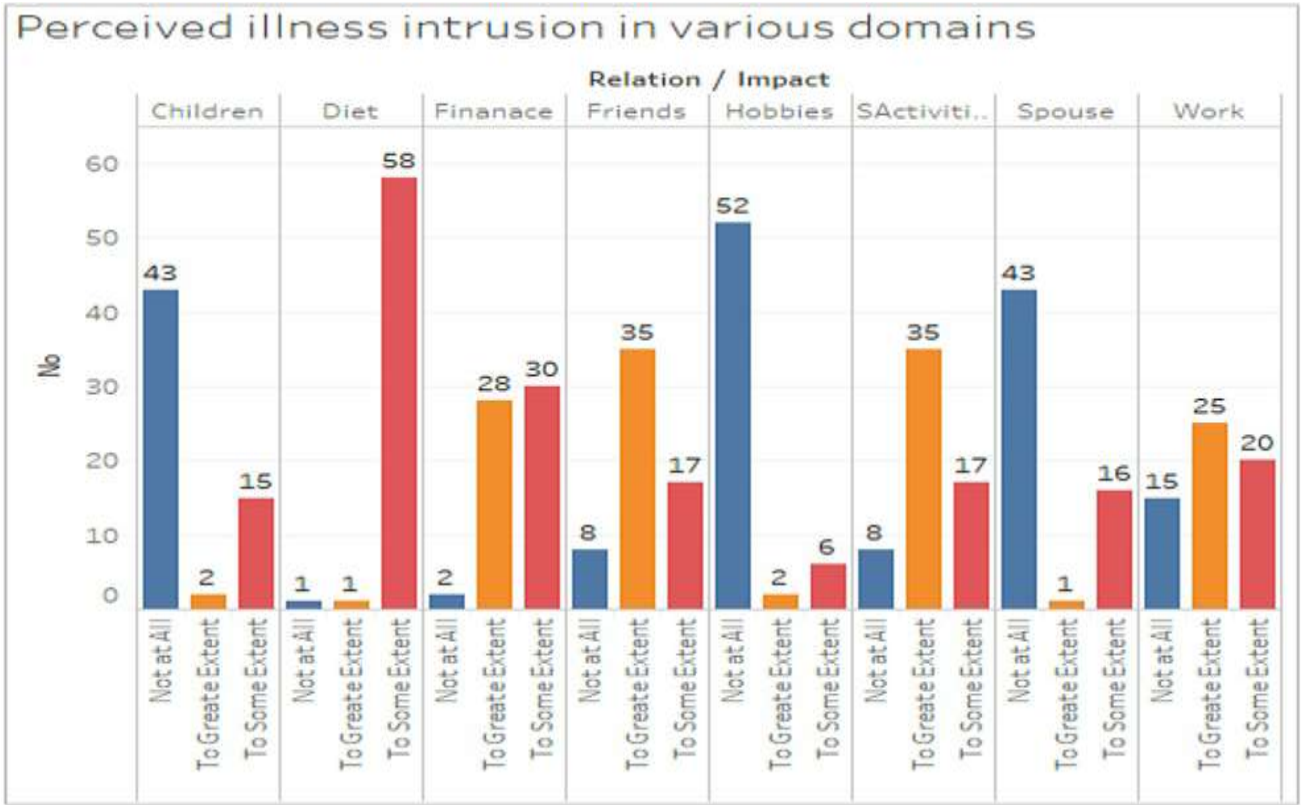

Table 1:- Educational status of the patients.

Highest Education	Number of patients	% of total patients
Did not receive any education	15	25.00%
Below 10th grade	9	15.00%
10th grade	15	25.00%
12th grade	8	13.30%
Graduate	13	21.70%

Table 2:- Duration of dialysis.

Duration	Number of patients	% of total patients
Less than 1 year	22	36.70%
1 year to 2 years	10	16.70%
2 years to 3 years	9	15.00%
More than 3 years	19	31.70%

Table 3:- Reason for not choosing dialysis.

Reason for not choosing dialysis	Number of patients	% of total patients
Age factor	2	3.30%
Fear	3	5.00%
Lack of donor	14	23.30%
Lack of money	28	46.70%
Not aware	6	10.00%
Denial by the relatives to donate	7	11.70%

Table 4:- Source of Money for dialysis.

Source of Money	Number of patients	% of total patients
Debt	7	11.70%
Insurance	1	1.70%
Own / Family Income	49	81.70%
Sale of property	3	5.00%

Table 5:- Relative attitude of the caregiver.

Relative attitude	Number of patients	% of total patients
Felt more of a financial burden	2	3.30%
Felt more affectionate/ understanding	7	1.70%
No change in attitude	3	5.00%
Felt more of a physical burden	9	15.00%
Felt that it is their responsibility	39	65.00%

Discussion:-

The ongoing treatment regimen for chronic kidney disease, involving frequent dialysis sessions, can significantly disrupt the daily lives of patients. This disruption extends across multiple dimensions, including social, psychological, economic, and relational aspects. As the duration of dialysis increases, there is a noticeable decline in the quality of life experienced by individuals undergoing this treatment. [9,10]

In our study, a striking majority (95%) of the participants were male, a pattern similarly observed in a study by Bhatti AN et al., where 77% of subjects were also male. This gender discrepancy might be attributed to societal treatment-seeking behaviours, which may inadvertently disadvantage females. Additionally, the considerable financial burden associated with lifelong treatment could be contributing to this skewed representation.[9,10]

Urban representation was evident among 62% of our study's subjects, paralleling findings from a study conducted by Bapat U et al., where 86% hailed from urban areas. The concentration of dialysis centers primarily within the private sector and urban regions in India could explain this trend. The geographical limitation of these facilities may hinder rural residents from accessing treatment due to both financial constraints and distance. [7, 8]

Examining the duration of dialysis, a majority (53%) of participants in our study underwent treatment for a span of 2 to 24 months. This pattern echoes results from Bapat U et al., where a significant proportion (80%) fell within the 2 to 30-month range. This suggests that prolonged maintenance hemodialysis may correlate with reduced survival prospects.[7]

Frequency of dialysis sessions also emerged as an important variable. In our study, a substantial portion (58%) underwent dialysis thrice weekly. This aligns with the findings of Bapat U et al., where a majority (56%) followed the same frequency. [7, 9]

Employment-related disruption due to illness was reported by 75% of our participants. This corresponds closely with results from Bapat U et al., where 70% faced interference in their work due to illness. Pursuits outside of work, such as hobbies, appeared to be limited, with 87% reporting a lack of hobbies in our study. This is consistent with Bapat U et al., where the majority (50%) shared a similar sentiment. Encouragingly, a substantial number of participants (71%) felt that their relationships with family and friends remained unaffected. This finding mirrors results from Bapat U et al., where a majority (79%) reported minimal interference of illness in their interpersonal relationships. [7] Regarding social activities, a minority (13%) noted that dialysis had an impact on their social life in our study. In contrast, Bapat U et al. reported that 50% of subjects did not experience such interference. [5]

In summary, chronic kidney disease patients undergoing regular dialysis experience multifaceted challenges that extend beyond medical aspects. Factors such as gender distribution, urban-rural divide, treatment duration, and social implications collectively contribute to the complex landscape of their quality of life.

Conclusions:-

In our study, we found that the majority of the patients were married male patients with a lesser academic qualification from the urban areas. Nephrology units should be started in each government district or at least at the regional level, which makes it possible for the people from the rural areas to utilize the facilities from the cost point of view as well as the distance. Educating and counselling the subjects on hemodialysis to socialise and engaging themselves in light physical and spiritual activities with an active lifestyle is important. As there are fewer studies in this regard, more studies need to be carried out towards the social and economic aspects of the people on hemodialysis.

Additional Information

Disclosures

Human subjects: Consent was obtained or waived by all participants in this study. Institutional Ethics Committee, Rajarajeswari Medical College and Hospital issued approval RRMCH-IEC/14/2017-18. Subject: Approval of Research Proposal by the Institutional Ethics Committee. The IEC meeting at RRMCH was held on 24.05.2018. The Committee has gone through the study material submitted and presented by you forresearch protocol "Perceived Illness Intrusion and Factors Associated with Patients on Hemodialysis in a Tertiary Care Hospital" after detailed deliberations, the committee accords its APPROVAL for the said research protocol. You are required to inform to IEC of the following. 1. Any amendments to protocol. 2. Discontinuation of research project, mentioning the reasons for the same. 3. Any adverse events to be informed to IEC. 4. After completion of the above research project, principal Investigator is required to submit a brief summary of the results obtained to the IEC. Animal subjects: All authors have confirmed that this study did not involve animal subjects or tissue. Conflicts of interest: In compliance with the ICMJE uniform disclosure form, all authors declare the following: Payment/services info: This research was funded by ICMR under Short Term Studentship #2018-03440. Financial relationships: All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work. Other relationships: All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

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