



Original Research Article

ASSESS THE KNOWLEDGE, PERCEPTION, LEVEL OF SATISFACTION AND QUALITY OF LIFE OF BENEFICIARIES UTILISING SERVICES OF PRADHAN MANTRI NATIONAL DIALYSIS PROGRAM (PMNDP)

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ABSTRACT

Background: In India, about 2.2 Lakh new patients of End Stage Renal Disease (ESRD) get added each year which results in additional demand for 3.4 Crore dialysis sessions every year. In the 2016 Union Budget, the Government of India announced the National Dialysis Programme, Pradhan Mantri National Dialysis Program (PMNDP) is supported by National Health Mission (NHM) and is providing free-of-cost haemodialysis services to BPL patients and Ayushman card holder. **Objective:** To assess the knowledge, perception, level of satisfaction and the quality of life of beneficiaries utilising services of PMNDP.

Materials and Methods: A cross-sectional study, for one-year in Indore and Ujjain division. Sources of data collection were patients. Predesigned and pre tested questionnaire (based on KDQOL- SF Scale) to assess the quality of life of beneficiaries utilizing services of PMNDP.

Results: Responses were collected from 240 patients undergoing dialysis at district hospitals. Majority of the beneficiaries (67.5%) had good perception regarding their own-health status after the dialysis. On physical activities (43.3%) perceived little limitation, and (29.2%) had no limitation during dialysis. We found that (38.8%) felt isolated, irritable, confused, difficulty in concentration, 62.7% perceived no problems and 37.3% had little problems in the sleeping habits during dialysis.

Conclusion: While assessing the quality of life of beneficiaries in selected dialysis centres involved in PMNDP, we found that everyone was satisfied from the PMNDP programme as the expenditure was nil. But some of them felt some kind of mental health issues like depression, irritation and difficulty in concentration due to their nephropathy problems and their quality of life seemed to be affected.

Keywords: Haemodialysis, Knowledge, level of satisfaction of beneficiaries.

INTRODUCTION

End Stage Renal Disease (ESRD) is a result of several NCDs. According to Global Burden of Disease study, chronic kidney disease was the 9th leading cause of death in India¹. In India, about 2.2 Lakh new patients of End Stage Renal Disease

(ESRD) get added each year which results in additional demand for 3.4 Crore dialysis sessions every year. The major constraints in receiving appropriate treatment includes high cost in private sectors, Centres located in Metro cities & Medical colleges. Most families have to undertake frequent trips, and often cover long distances to access

dialysis services incurring heavy travel costs and loss of wages for the patient and family members accompanying the patient². This leads to financial catastrophe for families, therefore, both in terms of provision of this important lifesaving procedure and for reducing impoverishment on account of out-of-pocket expenditure for patients, a Dialysis program is required².

To resolve the issues of ESRD patients like financial constraints, low service accessibility and prolonged dependency for survival on Dialysis, Ministry of Health & Family Welfare (MoHFW), Government of India launched Pradhan Mantri National Dialysis Program (PMNDP) in 2016.1 Pradhan Mantri National Dialysis Program (PMNDP) is supported by National Health Mission (NHM) and is providing free-of-cost haemodialysis services to BPL patients and Ayushman card holder. The first phase of this programme envisaged the setting up the haemodialysis (HD) centres in all districts, which is being implemented.

Aims and Objectives

To assess the knowledge, perception and level of satisfaction with quality of life of beneficiaries utilising services of PMNDP.

MATERIAL AND METHODS

This was a cross-sectional study conducted to assess the knowledge, perception and level of satisfaction among beneficiaries utilizing services of PMNDP for a period of one-year in areas of in Indore & Jhabua district of Indore division and Agar & Ratlam of Ujjain division.

Sample size

60 beneficiaries from each district of Indore, Jhabua, Agar, Ratlam involved in PMNDP will be included in the study.

Study population	Indore	Jhabua	Agar	Ratlam	Total
Beneficiaries (Patients)	60	60	60	60	240

Sample size calculation formula

$$\text{For beneficiaries } n = \frac{(Z_{\alpha})^2 * (\sigma)^2}{d^2}$$

Z_{α} = confidence level at 95% (standard value of 1.96 $\cong 2$)

$\sigma = 37.82$ = Standard deviation of variable. Value of standard deviation was taken from previously done study. According to KDQOL mean value for the kidney disease targeted scales ranged is 25.26 (work status).

d = absolute error (5%)

$$n = \frac{(2)^2 * (37.82)^2}{(5)^2}$$

$$n = 228 \cong 240$$

$$n = 228 \approx 240$$

It was decided to take 60 patients from each district of dialysis centre.

Inclusion Criteria

Beneficiaries receiving dialysis who give consent.

Exclusion Criteria

Beneficiaries who do not give consent and Serious patients those unable to give consent.

Study tools

Pre-designed and pre tested questionnaire (based on KDQOL- SF Scale)³ to assess the knowledge, perception, level of satisfaction and the quality of life of beneficiaries utilizing services of PMNDP.

Study Method

Interpersonal interview of beneficiaries and where interpersonal interview not possible, the telephonic interview is taken and google form link was send to patients direct.

RESULTS

The present study was conducted in Indore & Jhabua district of Indore division and Agar & Ratlam of Ujjain division for a period of one year (13th December 2020 - 12th December 2021). Sequential sampling method was done. A pre-designed semi-structured questionnaire and KDQOL-SF Scale were used to study, assessment of knowledge, perception and level of satisfaction with quality of life of beneficiaries was done.

In Figure 1 we assess the age and gender wise distribution in which majority of the beneficiaries belong to the age group (76.3%) of 36-65 years and (11%) were below 26 years. There was no difference in distribution of age group among male and female, even though 174 (72.5%) of the study population were males.

In Table 1 we assess the source of knowledge about PMNDP among beneficiaries in which Majority of the beneficiaries (53.3%) got knowledge regarding PMNDP through medical practitioners and rest (35%) got knowledge from health care workers and a few from social workers.

In Table 2 we assess the health status of patients in which majority of the beneficiaries (67.5%) had good perception regarding their own-health status after the dialysis and rest (32.5%) had excellent perception in the last 1 year.

In Table 3 we assess the perception about doing various daily activities in which majority of the beneficiaries (43.3%) perceived only little limitation on various activities, and (29.2%) had no limitation on various activities while (27.5%) perceived lot of limitation on various activities during any day while undergoing dialysis process.

In Table 4 we found that among the beneficiaries (38.8%) felt isolated, irritable, confused, and had difficulty in concentration. Rest (61.2%) had no such problems in the past 4 weeks

In Table 5 while assessing the perception regarding the effect of nephropathy on sleep during dialysis we found that majority of the beneficiaries 62.7% perceived no problems in their sleep habits and rest

37.3% had little problems in the sleeping habits, in the past 4 weeks.

In Table 6 while assessing Perception about health issue we found that majority of the beneficiaries (67.1%) perceived lot of interference with health issues in normal social activities and work while rest (32.9%) had no problems in normal social activities and work.

In Table 7 while assessing the perception regarding social support, majority of the beneficiaries 88.7% were somewhat satisfied with the time spent with their family and friends and their support while 11.3% were very satisfied with the time spent with their family and friends and their support.

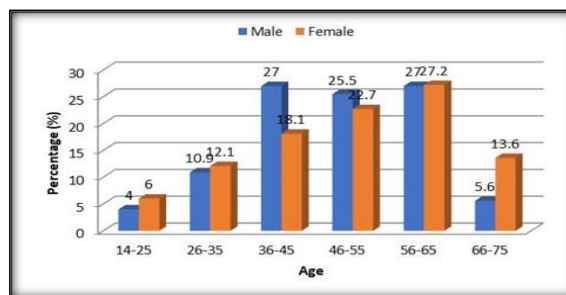


Figure: 1 Age & Gender Distribution among beneficiaries

Assess the quality of life of beneficiaries utilising services of PMNDP by using pre-designed questionnaire KDQOL-SF

Likert's scale is applied in the following table had various range, if anything parameter is zero, not mentioned in the table. [Table 1]

Table 1: Source of knowledge about PMNDP among beneficiaries

Source of knowledge	Indore N (%)	Jhabua N (%)	Agar N (%)	Ratlam N (%)	Total N (%)
Medical practitioners	26 (43.3)	31 (51.7)	35 (58.3)	36 (60.0)	128 (53.3)
Relatives	08 (13.3)	03 (5.0)	05 (8.3)	05 (8.3)	21 (8.8)
Social Workers	05 (8.3)	00 (0.0)	01 (1.7)	01 (1.7)	07 (2.9)
Health Care Workers	21 (35.1)	26 (43.3)	19 (31.7)	18 (30.0)	84 (35.0)
Total	60(100.0)	60 (100.0)	60(100.0)	60 (100.0)	240(100.0)

Table 2: Perception of Health status among beneficiaries after getting the dialysis in the last 1 year

Health status of the patients	Indore N (%)	Jhabua N (%)	Agar N (%)	Ratlam N (%)	Total N (%)
Excellent	22 (36.7)	22 (36.7)	35 (40.0)	10 (16.7)	78 (32.5)
Good	38 (63.3)	38 (63.3)	15 (60.0)	50 (83.3)	162 (67.5)
Total	60(100.0)	60 (100.0)	60(100.0)	60 (100.0)	240(100)

Table 3: Perception on problems with work or other regular daily activities as a result of physical health among beneficiaries

Your health now limits by the following activities	No, not limited at all N (%)	Yes, limited a little N (%)	Yes, limited a lot N (%)	Total N (%)
Vigorous activities, such as running, lifting heavy objects	64 (26.7)	114 (47.5)	62 (25.8)	240(100)
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, Climbing of stairs	67 (27.9)	112 (46.7)	61 (25.4)	240(100)
Walking more than mile	67 (27.9)	112 (46.7)	61 (25.4)	240(100)
Walking 500 meters	75 (31.3)	111 (46.3)	54 (22.4)	240(100)
Bathing or dressing yourself	75 (31.3)	111 (46.3)	54 (22.4)	240(100)
Bending, kneeling, or stopping	75 (31.3)	112 (46.7)	53 (22.0)	240(100)
Total	491(29.2)	728 (43.3)	461(27.5)	1680(100)

Table 4: Perception about their own mental health issue among beneficiaries

Mental health issue	True N (%)	False N (%)	Total N (%)
Isolate yourself from people around you	82(34.2)	158(65.8)	240(100)
You act irritable toward those around you	82(34.2)	158(65.8)	240(100)
Difficulty in concentrating or thinking	104(43.4)	136(56.6)	240(100)
Become confused	104(43.4)	136(56.6)	240(100)
Total	372(38.8)	588(61.2)	960(100)

Table 5: Perception regarding the effect of nephropathy on sleep during dialysis among beneficiaries

Sleep disturbance	Yes, a little bit time N (%)	None of time N (%)	Total N (%)
Awaken during night and trouble falling asleep again	82 (34.2)	158(65.8)	240(100)
Get the amount of sleep you need	82 (34.2)	158(65.8)	240(100)
Trouble in staying awake during the day	104 (43.4)	136(56.6)	240(100)
Total	268 (37.3)	452(62.7)	720(100)

Table 6: Perception about health issue which interfered with your normal social activities and work among beneficiaries

Perception about health issue	True N (%)	False N (%)	Total N (%)
My kidney disease interferes too much with my life	173 (72.0)	67 (28.0)	240(100)
Too much of my time is spent dealing with my kidney disease	173 (72.0)	67 (28.0)	240(100)
I feel frustrated dealing with my kidney disease	149 (62.0)	91 (38.0)	240(100)
I feel like a burden on my family	149 (62.0)	91 (38.0)	240(100)
Total	644 (67.1)	316(32.9)	960(100)

Table 7: Perception regarding social support among beneficiaries

Social support	Somewhat satisfied N (%)	Very satisfied N (%)	Total N (%)
The amount of time able to spend with your family and friends	213(88.8)	27(11.2)	240(100)
The support you receive from your family and friends	213(88.8)	27(11.2)	240(100)
Total	426(88.7)	54(11.3)	480(100)

DISCUSSION

Perception regarding various physical activities and daily routine activities

In our study, majority of the beneficiaries (43.3%) felt only minimal restrictions on a various physical activity, whereas (29.2%) experienced none and 27.5% felt significant restrictions on a various physical activity while undergoing dialysis. Similarly in a study of Dąbrowska-Bender, M., Dykowska et al (2018),^[4] showed that the parameter having the biggest negative impact on the QoL of patients receiving haemodialysis was an impeded possibility to continue work or studies and a change of life plans. Also, study done by Dziubek, W, Kowalska et al (2013),^[5] based on a 6-month observation of 28 patients, a significant reduction in QoL, in particular in physical activity and in everyday activities with depression and anxiety was observed.

Perception regarding mental health

In our study, majority of the beneficiaries (38.8%) reported felt isolated, irritable, confused, and had difficulty in concentration, whereas the remaining (61.2%) reported no such problems as compared to the previous four weeks. Similarly, in a study done by Moya Ruiz, M.A., et al (2017),^[6] showed that regarding the variables of sadness and nervousness, 54.5% were sad, and 59.1% were nervous. Garcia-Llana, H., Remor, E. and Selgas, R., (2013),^[7] showed that the modality of dialysis does not differentially affect the emotional state or specific adherence to drugs, but it is nevertheless related to their overall adherence to treatment and to their QOL.

Perception regarding Sleep

In our study, majority of beneficiaries (62.7%) reported no issues with their rest and sleep patterns. 37.3% reported having minor sleep-related issues over the previous 4 weeks. Similar results were obtained in the study of Shibata, S., Tsutou, A. and Shiotani, H., (2014),^[8] that sleep disorders are prevalent in HD patients with nearly 60% of patients suffering from disturbed sleep. Also, in the study of Iliescu, E.A., Coo, H., McMurray et al (2003),^[9]

showed that Poor sleep is common in dialysis patients.

Perception regarding social activities

In our study, majority of the beneficiaries (67.1%) felt that health issues frequently interfered with typical social and professional activities, while the remainder (32.9%) had no difficulty at all as compared to the previous 4 weeks. Majority of the beneficiaries (88.7%) reported that they were moderately satisfied with the time they spent with their family and had their support, while 11.3% were extremely satisfied. Similarly in a study done by Gerogianni, S., Babatsikou et al (2016),^[10] a significant reduction of QoL of patients was observed in their normal and social activities 41.7% (n=40) agreed that renal failure affected negatively the quality of their life while 45.3% (n=43) used to spend too much time trying to cope with nephropathy. 32.7% (n=32) reported a lot satisfaction from the time they spend with family and friends while a 68.3% (n = 67) were feeling that were burden to their family because of nephropathy. Also, in the study of Msc, R.N. and Babatsikou, F.P. et al (2014),^[11] concluded that Chronic kidney failure is associated with long-term effects on social life of patients and providing social support, support of the family and support of the friendly environment in patients with CRF is associated with reduction in depressive symptoms, positive perception of their illness.

Satisfaction of beneficiaries

In our study, all the beneficiaries expressed satisfaction regarding the skills and behaviour of the staff involved in PMNDP as well as the facilities at the dialysis centres. For follow-up, everyone received frequent calls from the health staff. Those who participated in the study had no complaints about the PMNDP staff at all. In order to help the patients, all of the staff members offered them encouragement and full support. 100% of the participants in the study took their medications as per the prescription by their doctors on a regular basis. Similar study done by Elias, M.A., Van Damme, W. and Wouters, E., et al (2022),^[12] a qualitative multiperspective study done on south India conclude that the need for comprehensive

management practices, including diet counselling and psychosocial support. While there are comprehensive guidelines on the establishment and management of dialysis services, more policy attention needs to be on effective implementation of these, to ensure better accessibility and quality of existing services.

CONCLUSION

While assessing the awareness and perception among beneficiaries, we found that majority of them continued their work with their kidney problems and few switched off their work. Majority of them suffered nephropathy due to diabetes and hypertension and some due to other kidney disorder and very few suffered due to drug abuse. Majority of them got knowledge about PMNDP through medical practitioners and some from health care workers and a few from social workers & relatives.

While assessing the quality of life of beneficiaries in selected dialysis centres involved in PMNDP, we found that everyone was satisfied from the PMNDP programme as the expenditure was nil. But some of them felt some kind of mental health issues like depression, irritation and difficulty in concentration due to their nephropathy problems. We also found that some of them felt sleep disturbances and had physical health issues. They also had certain personal and social issues on account of their nephropathy and their quality of life seemed to be affected.

The study highlights the need for more financial and personnel investments in ESKD care in India so as to ensure optimal care for the growing patient population. In our study we concluded that all facilities of infrastructure, human resources, equipment's, drugs, diagnostic services were available in all selected districts and few facilities was unavailable in Jhabua and Agar districts as per guideline of PMNDP.

Ethical consideration

Ethical approval was obtained from the Institutional Ethics Committee before commencing the study. Informed consent was obtained from all participants, ensuring their privacy, confidentiality, and voluntary participation. Measures were taken to maintain data security and protect participant identities throughout

the study. The research was given ethical clearance by the Institutional Committees of M.G.M. Medical College & M.Y. Hospital, Indore (M.P.) (DCGI Reg No. ECR/397/Inst/MP2013/RR-20) On 25TH Jan 2021.

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REFERENCES

1. Pradhan Mantri national dialysis programme guidelines for establishing peritoneal dialysis services 2019.
2. Khanna U. The economics of dialysis in India. *Indian J Nephrol.* 2009 Jan;19(1):1-4. doi: 10.4103/0971-4065.50671. PMID: 20352002; PMCID: PMC2845186.
3. Kidney Disease Quality of Life Instrument (KDQOL), https://www.rand.org/health-care/surveys_tools/kdqol.html
4. Dąbrowska-Bender, M., Dykowska, G., Żuk, W., Milewska, M. and Staniszewska, A., 2018. The impact on quality of life of dialysis patients with renal insufficiency. Patient preference and adherence, pp.577-583
5. Dziubek, W., Kowalska, J., Kuszal, M., Rogowski, Ł., Gołębiowski, T., Nikifur, M., Szczepańska-Gieracha, J., Zembroń-Łacny, A., Klinger, M. and Woźniewski, M., 2016. The level of anxiety and depression in dialysis patients undertaking regular physical exercise training-a preliminary study. *Kidney and Blood Pressure Research*, 41(1), pp.86-98.
6. Moya Ruiz, M.A., 2017. Study of the emotional state of patients on hemodialysis. *Enfermería Nefrológica*, 20(1), pp.48-56.
7. García-Llana, H., Remor, E. and Selgas, R., 2013. Adherence to treatment, emotional state and quality of life in patients with end-stage renal disease undergoing dialysis. *Psicothema*, 25(1), pp.79-86.
8. Shibata, S., Tsutou, A. and Shiotani, H., 2014. Relation between sleep quality and daily physical activity in hemodialysis outpatients. *Kobe J Med Sci*, 59(5), pp. E161-E166.
9. Iliescu, E.A., Coe, H., McMurray, M.H., Meers, C.L., Quinn, M.M., Singer, M.A. and Hopman, W.M., 2003. Quality of sleep and health-related quality of life in haemodialysis patients. *Nephrology Dialysis Transplantation*, 18(1), pp.126-132.
10. Gerogianni, S., Babatsikou, F., Gerogianni, G., Koutis, C., Panagiotou, M. and Psimenou, E., 2016. Social life of patients undergoing haemodialysis. *International Journal of Caring Sciences*, 9(1), p.122.
11. Msc, R.N. and Babatsikou, F.P., 2014. Social aspects of chronic renal failure in patients undergoing haemodialysis. *International journal of caring sciences*, 7(3), p.740.
12. Elias, M.A., Van Damme, W. and Wouters, E., 2022. Accessibility and quality of haemodialysis services in an urban setting in South India: a qualitative multiperspective study. *BMJ open*, 12(2), p. e052525.