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Assessment Of Psychological Wellbeing, Coping Strategies, Resilience And Social Support Of Family Members Of Chronic Kidney Disease (CKD) Patients Receiving Hemodialysis (HD) At Selected Hospitals In Kolkata, West Bengal.

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Abstract:
Background: *Chronic disease has psychological impact on patient's family members. The family is the first party responsible for care for the health of its members and it is important to know the different means it uses to deal with a stressful situation. With this view a descriptive study was conducted to assess psychological wellbeing, coping strategies, resilience, social support and relationship among those variables.*
Materials and Methods: *The conceptual framework was based on "Sr. Callistra Roy's Adaptation model". Data were collected from 200 family members who are directly involved in patient care attending Hemodialysis department at four multispecialty hospitals in Kolkata by purposive sampling technique with the help of structured demographic proforma, Ryff's Psychological wellbeing scale, Brief COPE scale, Brief Resilience Scale, Multi-dimensional Scale of perceived Social Support. Data were collected by interviewing and paper-pencil method.*
Results: *Findings revealed that most of the (46.5%) family members had moderate psychological wellbeing. The findings showed that emotion-focused and problem-focused coping strategies were mostly used whereas dysfunctional coping strategies were used less frequently. But in dysfunctional coping strategies self-distraction ranked highest (mean score = 7.18). Majority (70%) of the family members were developed moderate resilience and maximum (75%) respondents had high social support. A statistically significant co-relation was found between psychological well-being and different categories of coping strategies, resilience ($t=3.997$, $p<0.001$), social support ($t=6.12$, $p<0.001$)), also between resilience and social support ($t=5.089$, $p<0.001$). There was significant association between psychological wellbeing and the duration of dialysis, educational level and monthly income respectively.*
Conclusion: *The study was concluded with few recommendations to replicate on different populations and can be implicated in the field of nursing education, nursing practice, nursing administration and nursing research.*
Key Word*: Chronic kidney disease, Hemodialysis, psychological wellbeing, coping strategies, resilience and social support*

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I. INTRODUCTION

Kidney disease is defined as end-stage when a patient's glomerular filtration rate has fallen to <15 ml/min/1.73 m2 [1]. Mortality associated with end-stage kidney disease (ESKD) is high [2]. The appearance of a chronic disease within the family causes family members to experience a series of transformations, but their responses depend on the profile of the ill person, such as age and sex, on ways of coping, and on the family's beliefs etc. [3]. The individual and family alike can use coping strategies so as to control the stress, and the way that these choose these is determined by resources - both internal and external - including responsibility, health, support, beliefs, material resources and social skills [4]. The family is the first party responsible for care for the health of its members, and it is important to know the different means that it uses to deal with a stressful situation. Thus, this study's objective was to identify the coping strategies used most by the family members of patients with chronic kidney disease receiving hemodialysis.

The term "resilience" has been defined in a variety of ways, including the ability to bounce back or recover from stress, to adapt to stressful circumstances, to not become ill despite significant adversity, and to function above the norm in spite of stress or adversity (Carver,1998; Tusaie & Dyer, 2004). In addition, the measures that have been developed to assess "resilience" have not focused on these qualities but on the factors and resources that make them possible (Ahern, Kiehl, Sole & Byers, 2006) [5]. Positive social support (family or friends) plays an important role in one's ability to make healthier choices. Social support means being able to access people that a person can rely upon if needed. The support of family and friends during a crisis has long been seen to have a positive emotional effect on people and has a physical benefit as well. Research conducted at Brigham Young University and the University of North Carolina showed that people who did not have strong social support were 50% more likely to die from illness than those who had such support [6]. Finally, family, friends and co-workers can also provide practical support, such as rides to the doctor or pharmacy, going to the supermarket, and offering childcare during health care visits and motivate to take steps to be more active and get back to previous condition more quickly [7]. **Alnazly EK and Samara NA (2014)** conducted a qualitative study on "The Burdens on Caregivers of patients above 65 Years Old Receiving Haemodialysis: A Qualitative Study". The majority of caregivers reported social isolation, health problems and little time for self-care[2]. **Magda M. Bayoumi (2014)** conducted a study on "Subjective Burden on Family Carers of Haemodialysis Patients". The total burden scores were moderately to severely for all caregivers. The total caregiver's burden was significantly positively correlated with the patients' age ($r = 0.461$) and negatively correlated with patients' level of education ($r = -0.290$) [8]. **Wicks N.M, Milstead . Jean. E et al. (2016)** conducted a study on "Subject Burden and Quality of Life in Family Caregivers of Patients with End-stage renal disease" The results showed that QOL of caregiver was significantly related to caregiver burden and caregiver self-rated health. Caregiver burden did not differ by type of dialysis (CAPD, incenter hemodialysis, etc.) or employment status [9]. **White Y and Grenyer. F. S. B (2009)** conducted a study to investigate the biopsychosocial impact of end-stage renal disease on dialysis patients and their partners. This study gives a unique perspective on the negative impact which dialysis can have on couples[10]. So, on the basis of intense literature search it can be said that several studies were conducted on caregiver burden of family members of CKD patients getting dialysis and its effect on their quality of life. Some studies were conducted on use of coping strategies to get rid of their altered psychological condition, resilience and role of social support on quality of life. Most of those studies were related to other chronic disease. Very few studies had all these variables simultaneously and also relation among these variables. Because of these reasons the researcher decided to conduct a study on psychological wellbeing, coping strategies, resilience and social support of family members of CKD patients getting haemodialysis.

II. MATERIAL AND METHODS

The descriptive study was conducted on family members of CKD patients receiving Hemodialysis in Dialysis unit of Ruby General Hospital, Medica Superspeciality Hospital, Fortis Hospital and Kidney Institute and Peerless Hospitex Hospital and Research Center Limited from November 2016 to December 2016. A total 200 study participants were included in this study.

Research design: Descriptive survey research design.

Study location: The study was conducted in Dialysis unit of Ruby General Hospital, Medica Superspeciality Hospital, Fortis Hospital and Kidney Institute and Peerless Hospitex Hospital and Research Center tertiary level hospital.

Study Duration: November 2016 to December 2016

Research approach: Survey research approach.

Research Variables: Psychological wellbeing, coping strategies, Resilience, social support**,** demographic variables. **Settings:** Dialysis unit of selected hospitals in Kolkata.

Population: Family members of CKD patients receiving Hemodialysis.

Sample size: 200.

Sample size calculation: The sample size was calculated with percentage of caregiver burden as 72.8% based on previous studies (Fatemeh Mashayekhi et al, 2015) and confidence interval 90%. The estimated sample size was calculated as 207.

Subjects and selection method: non-probability purposive sampling technique was used. Parents, grandparents, spouses, siblings, children, grandchildren of CKD patients receiving Hemodialysis (HD) at selected Hospitals in Kolkata, West Bengal who were directly involved in patient care and fill-filled inclusion and exclusion criteria.

Reliability of the tools: Cronbach's alpha of tool II, III, IV, V was 0.71, 0.81, 0.72, 0.83 respectively. So, the tools were found reliable.

Inclusion criteria:

1. Family members of CKD patients who were on treatment of Hemodialysis within 2 yrs.
2. The family members who were available and were willing to participate in the study.
3. The family members who could read, write, understand and comprehend Bengali and English language.

Exclusion criteria: Those had given Incomplete data were excluded from the study.

Procedure methodology:

The data collection procedure was started after getting permission from Institutional Ethics committee and the concerned tertiary care hospitals.

The investigator introduced her and explained the purpose of the study. The concerned HOD were explained regarding the procedure.

Informed consent was taken from the participants and asked the participants to complete the tool-I, demographic proforma and tool-II, Ryff" s psychological wellbeing scale, tool III Brief COPE scale, tool IV Brief Resilience scale and tool V Multidimensional Scale of Perceived Social Support considering inclusion and exclusion criteria.

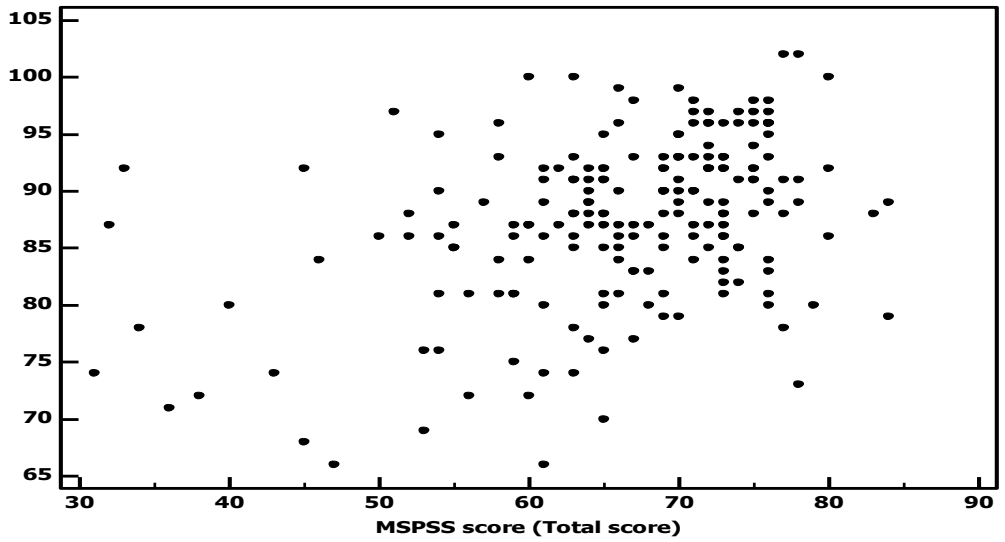
Interviewing and Paper & Pencil techniques were used in data collection. After completing a specific code was assigned and further analysis was done among 200 respondents.

Statistical analysis:

Analysis and interpretation of the data were done based on the objectives of the study. The obtained data were analyzed using descriptive and inferential statistics and SPSS software (version 17.0) [Illinois, Chicago: SPSS Inc, 2008] and MedCalc (version 11.6) [Mariakerke, Belgium: MedCalc software 2011]. The statistical test employed were range, mean, median, standard deviation, frequency, percentage, r-value, t-value and chi square test. The levels $p<0.05$, $p<0.001$, $p<0.01$ were considered as significant.

III. RESULTS

Findings related to demographic data of subjects: Majority (41%) of the family members belonged to the age group 41-60 years, 52.5% of the respondents were female, 59% of the family members of patients with CKD were their spouse, 63% patients of the respondents were getting dialysis for 1 yr. to 2 years, 93% belonged to Hindu community, 45.5%) were graduate, 56% were retired persons and housewives, 39.5% had a monthly family income of ≤ 20,000 rupees, 57.5% belonged to nuclear family, 55% of respondents were having other financial source in terms of insurance or Mediclaim. **Findings related to level of psychological wellbeing of family members:** High, moderate, low psychological wellbeing were evident in 23%, 49%, 28% family members. Findings related to coping strategies adopted by the family members: The rank order of coping strategies showed that the patients used most frequently emotion focused coping strategies that include acceptance, positive reframing, emotional support, humor, turning to religion. Self-distraction is only one type of dysfunctional coping strategy which ranked highest but others, that are venting, self-blame, behavioral disengagement, denial and substance use were used less frequently (mean score venting, self-blame, behavioral disengagement, denial and substance use). **Findings related to resilience of the family members**: 70%, 15.5%, 14.5% respondents had moderate, low and high resilience respectively**. Findings related to social support perceived by the family members:** 78.5%, 19.5%, 2% respondents were having high, moderate and low social support respectively. **Findings related to relationship between level of psychological wellbeing and different coping strategies, resilience and social support:** A statistically significant co-relation was found between psychological wellbeing and problem-focused coping strategies ($r = 0.35$, $t = 5.28$, $p<0.001$), emotion-focused coping strategies ($r = 0.43$, $t = 6.78$, $p<0.001$), resilience ($r = 0.25$, $t = 3.4$, $p<0.001$)**,** social support ($r = 0.4$, $t = 6.12$, $p<0.001$) [fig 2] respectively. A statistically significant co-relation was found between psychological wellbeing and social support from significant others ($r = 0.398$, $t = 6.1$, $p<0.001$) [fig 3], family ($r = 0.36$, $t = 5.43$, $p<0.001$) [fig 4]**,** friends ($r = 0.20$, $t = 2.73$, $p<0.01$) respectively.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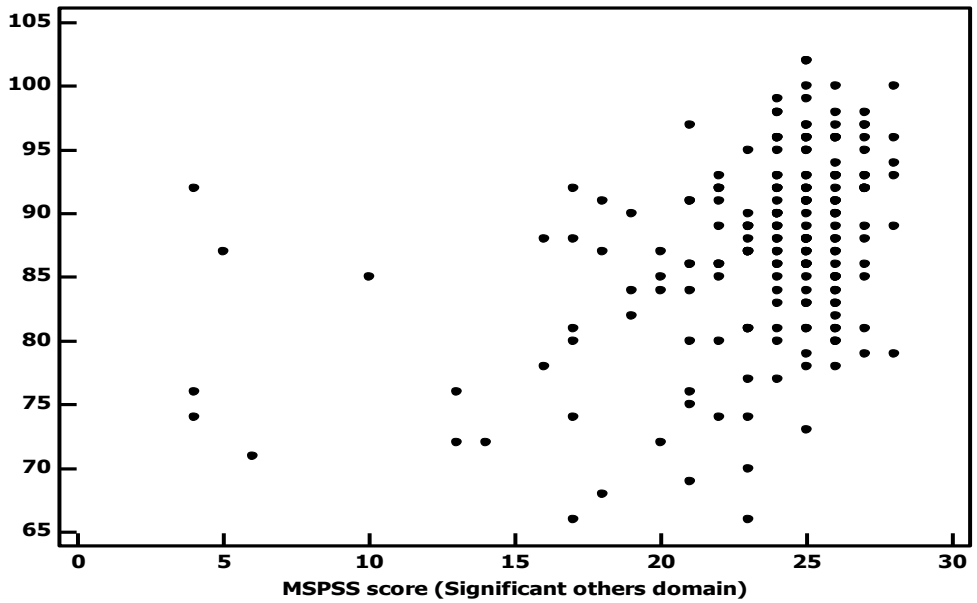
MSPSS score (Total score)

Fig: 2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MSPSS score (Significant others domain)

Fig 3

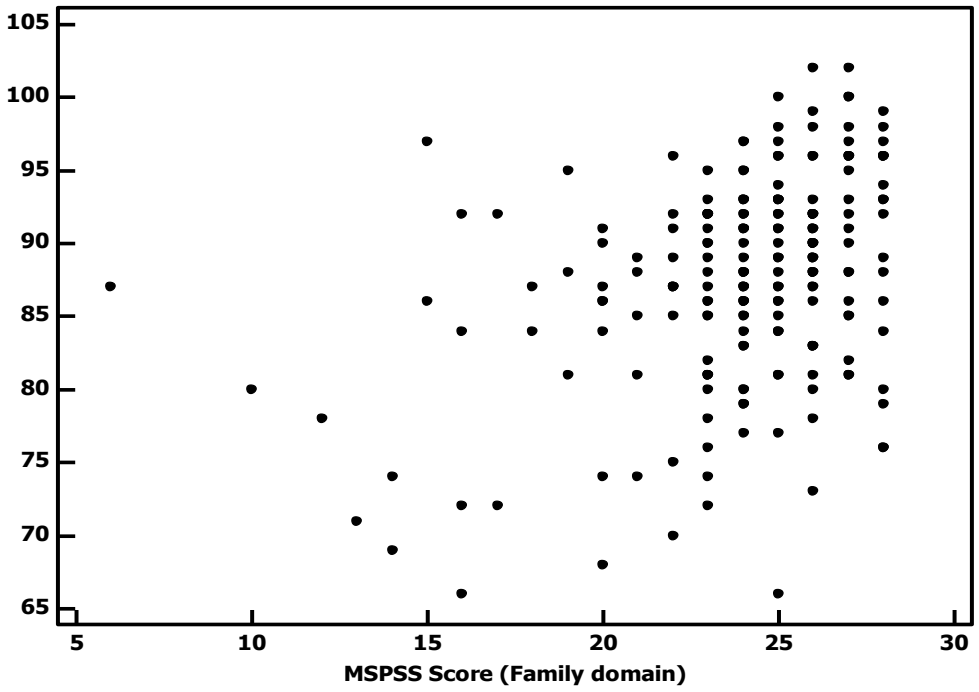

Fig 4

Other findings:

- There was a statistically significant co-relation between resilience and social support (r = 0.34, t = 5.09, p<0.001) [fig 5].
- Psychological wellbeing of respondents was dependent on their patient 's duration of dialysis (χ^2=4.28*, p<0.05), family member 's educational level (χ^2=21.86***, p<0.001) and monthly family income (χ^2= 5.05*, p<0.05) [Table 1].

n=200

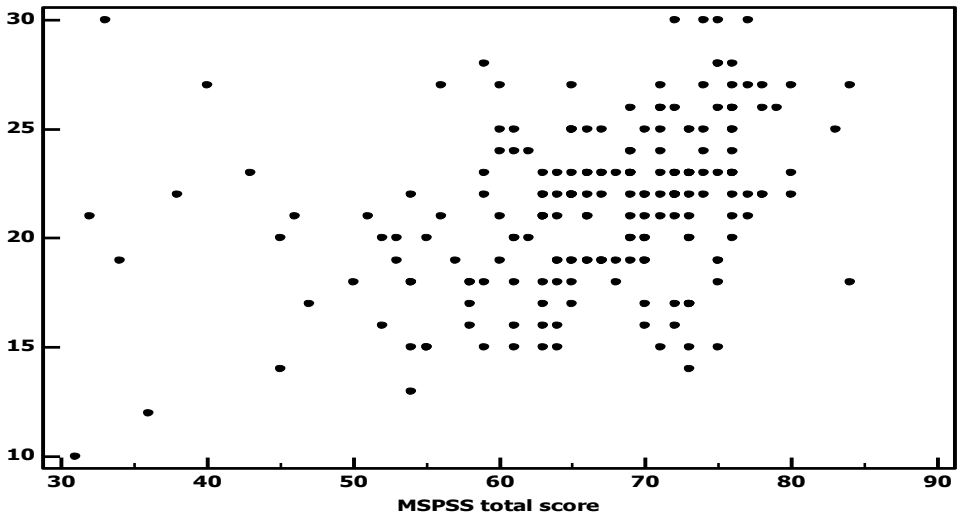

Fig 5

Table 1 n=200

Selected variables	Psychological wellbeing		X^2
	< Median	≥ Median	
Duration of dialysis of patient			
< 1 yr.,	27	47	4.28*
1 yr. to 2 yrs.	65	61	
Education			
<Higher-secondary	32	8	21.86***

≥Higher-secondary	62	98	
Monthly income			
≤30,000	62	63	5.05*
>30,000	25	50	

$\chi 2$ df (1) = 3.84, $p>0.05$; $\chi 2$ df (1) = 10.83, $p<0.001$

IV. DISCUSSION

The findings of the present study revealed that majority (41%) of the family members of CKD patients belonged to the age group 41-60 years and maximum (52.5%) respondents were female. Among the respondent's majority that is 59% of the family members of patients with CKD were their spouse. Most of the (55%) families were having other financial source in terms of health insurance or Mediclaim. The findings were consistent with the study conducted by **Marques FRB, Botelho MR, Marcon SS, Pupulim JSL (2014)**[11]**.** In the present study high wellbeing was evident only in 23% family members, 49% respondents were having moderate wellbeing, where as 28% were experienced low psychological wellbeing. The findings of the study were consistent with the research study conducted by **Dunn SA, Lewis SL, Bonner P** (1994) on spouses of Continuous Ambulatory Peritoneal Dialysis (CAPD) patients. The result revealed that 21% of the spouses perceived high Quality of Life, whereas 55% moderate and 24% fair to poor respectively[12]. In the present study maximum respondents had used self-distraction to divert mind from stressful situation. Next acceptance was used as emotion focused coping most frequently. The study findings were supported by **Marques FRB, Botelho MR, Marcon SS, Pupulim JSL (2014)**[11]. They stated in their study that the strategy used most was escape-avoidance. The second most-used strategy was social support, an emotion-focused coping. The families use coping strategies of different intensities. In the present study more than half that is 70% respondents had moderate resilience, and 14.5% respondents had high resilience where as 15.5% had low resilience. The study findings were consistent with the study conducted by **West C, Buettner P, Stewart L, Foster K and Usher K (2012).** In their study resilience score was above average for the family members [13]. In the present study there was a statistically significant co-relation between psychological wellbeing and social support ($r = 0.4$, $t = 6.12$, $p<0.001$). This finding was supported by the study conducted by **Alvarez UF, Valdes C, Estebanze C, Rebolo P** (2004). The findings revealed that lower mental component summary (MCS) score was associated with lower functional social support of the caregiver[14]. In the present study there was a statistically significant co-relation between resilience and social support ($r = 0.34$, $t = 5.09$, $p<0.001$). This finding was consistent with the finding done by **Greeff A and Thiel C (2012).** The result indicated that family resilience was fostered by the family's internal strength and the experience of social support [15]. In the present study duration of dialysis and monthly income affects psychological wellbeing of the family members. The findings were consistent with the study conducted by **Dunn SA, Lewis SL, Bonner P N (2012).** They stated in their study, titled "Quality of life for spouses of CAPD patients" that Quality of Life is influenced by income and was positively correlated with years on dialysis[12].

V. CONCLUSION

The study findings revealed that most family members are having good quality psychological wellbeing, coping strategies, resilience, social support. Their patients' duration of dialysis and their own educational status, financial condition influences their psychological wellbeing. Psychological wellbeing is positively correlated with resilience, different categories of coping strategies and their perceived social support from family, friend and significant others group. They used different kinds of coping strategies to get rid of their tension but in different level. Most of the family members avoid dysfunctional coping strategies such as denial, self-blaming and substance use. Also, their resilience is related with degree of social support they received.

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