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Assessment of burden and coping strategies adopted by family members of the patients suffering from End Stage Renal Disease (ESRD) in selected haemodialysis unit, West Bengal

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Abstract
A descriptive study evaluated the burden on family members caring for patients with End-Stage Renal Disease (ESRD) and the coping strategies they use. The study's goals were to assess the level of burden experienced by family members, identify coping mechanisms used, determine the correlation between burden and coping strategies and explore associations with specific demographic variables. In this study data were collected from 100 samples using Zarit Burden Interview and Brief COPE scale via purposive sampling technique. Findings of this study results were most families had income up to Rs.1000, caregiving duration mostly 6-12 months, 67% of family members experienced moderate to severe burden, problem-focused coping was most common, burden associated with age, family income, and caregiving duration and a negative correlation present between burden and coping abilities. Findings of the study have implications for nursing services, education, administration, and future research. The study could be replicated with a larger sample in different settings.

Keywords: Burden, Coping Strategies, ESRD Patients, Hemodialysis Unit and Family Members.

Introduction

End-stage renal disease (ESRD), which is the fifth stage of chronic kidney disease (CKD), necessitates treatment with dialysis or a kidney transplant. It's a growing global health issue with varying prevalence rates. In India, ESRD incidence is 152 per million, often caused by diabetic kidney disease. Hemodialysis is the main treatment [1].

ESRD impacts all aspects of patients' and families' lives. Stress leads to social isolation, job loss, dependence on social security, and reduced physical activity. Hemodialysis places a burden on patients and their families, leading to lifestyle changes, depression, anxiety, declining physical health, social isolation, and financial strain. Family members support patients, affecting their physical, social, and emotional well-being [2, 3].

Caring for ESRD patients is stressful, impacting family members' physical and psychological health. Family members often feel unprepared but obligated to care for loved ones. Caregivers experience declining mental and physical health reduced social activities, and financial issues. Providing coping skills, support, and information can improve caregivers' quality of life [4, 5, 6, 7].

Family members face transitions from wellness to illness, influenced by personality traits, attachment, culture, and religion. These factors affect how caregivers cope with stress and manage responsibilities [8, 9].

Need of the study

Patients with ESRD need lifelong dialysis, typically two to three times a week. This ongoing treatment is taxing for both patients and their families, requiring significant contributions from family members. ESRD patients face increased risks of physical, cognitive, and emotional decline due to factors like dialysis duration, age, cardiovascular risks, and metabolic issues. Hemodialysis (HD) treatment for ESRD brings a burden of ongoing medical needs and treatment time. Management of symptoms and complexities of ESRD while aiming for patient rehabilitation is crucial [10].

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ESRD patients often rely on family caregivers for daily living and medical needs like medication management, transportation to dialysis, personal hygiene, and diet maintenance. In India, family members typically provide unpaid care and emotional support due to cultural values. These caregivers experience stress, depression, restlessness, and reduced quality of life. The burden is multidimensional, affecting financial status, time, physical health, social life, and emotional well-being [11].

Coping strategies help family members manage stress and adapt to caregiving challenges. These include problem-focused (addressing the problem directly), emotion-focused (managing emotional responses), and avoidance-oriented strategies. Problem-focused coping is associated with better mental health outcomes [12]. The study aimed to understand the burden on family members of ESRD patients on dialysis and identify their coping strategies.

Materials and Methods

Objectives

1. To assess burden among family members of the patients suffering from ESRD.
2. To determine coping strategies adopted by family members of the patients
3. Suffering from ESRD.
4. To find out relation between burden and coping strategies.
5. To identify association between burden and selected demographic variable.
6. To identify association between coping strategies and selected demographic
7. Variable.

Purpose of the study

The purpose of this study is to assess burden and identify coping strategies of family members of the patients with ESRD.

Delimitation of the study

The study is delimited to-

- The family members of ESRD patients in selected haemodialysis unit.
- The family members of ESRD patients who are diagnosed with this problem from last 6 months.

Assumptions

The study assume that-

- Family members may be main supportive person to take care of ESRD patients.
- Family members of ESRD patients may face many difficulties or adverse events that affect the lives of the family members.
- Family members of ESRD patients may use some kind of coping strategies to manage their burden.

Operational definition

Burden

In this study burden refers to the problems or stresses faced by family members related to giving care of the patient with ESRD undergoing hemodialysis as measure by Zarit Burden Interview

Coping strategies

In this study coping strategies are refers to the methods of reducing stress related to giving care to the patients with ESRD undergoing hemodialysis as measure by Brief Cope Scale.

Family Member

In these study Family members refers to spouse, parents, siblings, son or daughter who take care of the patients at home.

Research Approach

A descriptive survey approach was used to conduct this study.

Research Design

The research design adopted for the present study is descriptive design.

Variables of the study

Research variables under the study were burden and coping strategies adopted by the family members.

The demographic variables considered for family members included age, gender, marital status, educational status, occupation, monthly income, relationship with patients and duration of care giving to the patient.

The settings of the study

Since the study was intended to collect the data from hemodialysis unit, it was conducted at the hemodialysis unit of Sambhu Nath Pandit Hospital for pilot study and for final study data was collected from hemodialysis unit of IPGME&R, SSKM Hospital and hemodialysis unit at NRS Medical College and Hospital

Population: The population of this study was the family members of the patients with ESRD, attending the Hemodialysis unit in selected hospital.

Sample: In the present study sample consist of family members of the patients with ESRD attending in the selected hemodialysis unit during the data collection period.

Sample size: In the present study, the sample size was 10 in the pilot study and 100 in the final study.

Sampling technique: The sampling techniques adopted for the present study was non-probability purposive sampling.

Sampling Criteria

Inclusion criteria

Those who are-

- Willing to participate in the study.
- Giving care to the patients at more than 6 months.

Exclusion criteria

Those who are

- Not interested during data collection.

Data collection tools and techniques

The most important and a crucial aspect of any investigation is the collection of appropriate information which provides necessary data for the study. Considering the objectives of the study, semi-structured interview schedule for measuring demographic data, Zarit Burden Interview to assess the burden and Brief Cope Scale to assess coping strategies of the family members.

Table 1: data collection tools and techniques

Variable to be measured	Tool	Technique
Demographic variable	Semi-structured interview schedule	Interviewing
Burden	Zarit Burden Interview schedule	Interviewing
Coping strategies	Brief cope scale (4 point likert scale)	Interviewing

Description of the tool

Tool-I Semi-structured Interview schedule on demographic data of family members.

This part was developed to collect information from the family member of the patients with ESRD about demographic data. On the basis of the objectives a semi structured interview schedule was developed on demographic characteristics. There were 8 items such as-age, gender, marital status, education, occupation, monthly income, relationship with the patient and duration of care giving to the patient.

Tool-II - Zarit Burden Interview (ZBI) schedule

This ZBI is composed of 22 items questionnaire develop by Dr. Steven H. Zarit. This is a standard tool to assess burden of the family member. This instruments measures five domain that include the subjective components of the burden. There were a total 22 questions covering some domain which are presented in table 2.

Table 2: Distribution of a number of the items according to domain of the ZBI.

Domains	Number of Items	Question No.
Burden in the relationship	6	1, 8, 11, 14, 18, 20
Emotional Well-being	7	2, 4, 5, 9, 10, 21, 22
Social and family life	4	3, 6, 12, 13
Finance	1	15
Loss of Control over one’s life	4	7, 16, 17, 19

Scoring System

There were 22 items. Scoring was as follows:

- 0 points = Never
- 1 point = Rarely
- 2 points = Sometimes
- 3 points = Quite Frequently
- 4 points = Nearly Always

The total score range is 0-88. Based on this scale, burden is categorized into four levels:

- **Little to no burden:** 0-20
- **Mild to moderate burden:** 21-40
- **Moderate to severe burden:** 41-6
- **Severe burden:** 61-88.

Tool III Standardized Tool- Brief Cope Scale

The Brief COPE Scale, developed by S. Carver, is a standardized instrument designed to evaluate coping strategies. It encompasses 14 coping styles, with each style measuring the extent to which a respondent employs a particular coping method. The scale includes 28 items that cover these 14 coping concepts.

Table 3: Distribution of the number of items according to coping style of the Brief Cope Scale

Coping styles	Total number of items	Question No.
Self-distribution	2	1, 19
Denial	2	3, 8
Substance abuse	2	4, 11
Behavioural disengagements	2	6, 16
Active coping	2	2, 7
Use of informational support	2	10, 23
Positive reframing	2	12, 17
Planning	2	14, 25
Acceptance	2	20, 24
Humour	2	18, 28
Religion	2	22, 27
Emotional support	2	5, 15
Self-blame	2	13, 26
Venting	2	9, 21

Scoring of Brief Cope Scale

Respondents rate items on a 4-point Likert scale:

- 1 = never do
- 2 = do it a few times
- 3 = do it mostly but not always
- 4 = do it always

Each of the 14 scales consists of 2 items. Scores for each scale range from 2 (minimum) to 8 (maximum), with higher scores indicating greater use of that coping strategy. Total scores are calculated by summing items for each scale, resulting in a range of 28-112. Higher total scores indicate a higher degree of coping strategy utilization.

Organization of data and analysis

- **Section I:** Findings related to demographic characteristics of family members by frequency and percentage.

- **Section II:** Findings related to the description of burden of the family members according to obtained score in Zarit Burden Interview.
- **Section III:** Findings related to the description of coping strategies adopted by the family members according to obtained score in Brief Cope Scale.
- **Section IV:** Findings related to relation between burden and coping strategies adopted by the family members by correlation co-efficient.
- **Section V:** Findings related to association between burden and selected demographic variables by chi-square.
- **Section VI:** Findings related to association between coping strategies and selected demographic variable by chi-square.

Section I Findings related to demographic characteristics of family members

Table 4: Frequency and percentage distribution of demographic characteristics, n=100

Demographic characteristics	Frequency	Percentage (%)
Age (yrs.)		
18-33	53	53
34-49	37	37
50-65	10	10
Gender		
Male	45	45
Female	55	55
Transgender	0	0
Marital status		
Married	81	81
Unmarried	17	17
Separated/Divorced	1	1
Widows/Widower	1	1
Educational status		
Primary	3	3
Up to Secondary	22	22
Higher Secondary	32	32
Graduate	31	31
Post Graduate	12	12

Data presented in table 4 shows that majority (53%) of the family members were belong to the age group 18-33 Yrs. and 55% of them were female, majority (81%) of the family members were married and 32% of participant's educational status was up to higher Secondary.

Table 5: Frequency and percentage distribution of demographic characteristics of family members. n=100

Demographic characteristics	Frequency	Percentage (%)
Occupation		
Home maker	33	33
Daily labor	18	18
Service holder	20	20
Business	29	29
Monthly income (Rs.)		
Up to 10000	39	39
10001 - 15000	28	28
Above 15000	33	33
Relationship with patients		
Parents	10	10
Siblings	29	29
Daughter or son	40	40
Spouse	21	21
Duration of care giving to the patient		
7 months to 12 months	81	81
13-24 months	19	19

Data showed in the table 5 shows that majority (33%) of the family members were home maker, 39% of participant's monthly income up to Rs.1000/-, 40% of them were son or daughter in relation with patient and majority (81%) of them giving care to their patients for 7-12 months.

Section II Findings related to the description of burden of the family members according to obtained score in Zarit Burden Interview.

Table 6: Domain wise possible score, obtained score, mean, mean percentage and rank of burden score among family members. n=100

Domain wise burden score of family members	Range of possible score	Range of obtained score	Mean	Mean percentage	Rank
Burden in the relationship	0-24	4-20	13.77	57.7	3
Emotional wellbeing	0-28	2-23	15.64	55.85	4
Social and family life	0-16	1-14	7.84	49	5
Finance	0-4	0-4	2.42	60.5	1
Loss of control over one's life.	0-16	1-16	9.59	59.93	2

Data presented in table 6 shows that mean percentage score(60.5%) was higher in burden related to finance thus it ranked one followed by loss of control over one's life (59.93%), burden in relationship (57.7%), emotional wellbeing (55.85%) and social and family life (49%).

Table 7: Possible score range, obtained score range, Mean, Median and Standard Deviation of burden score among family members. n=100

Variable	Range of possible score	Range of obtained score	Mean	Median	SD
Burden of family members	0-88	11-80	49.49	52	12.26

Data presented in table 7 shows that obtained burden score range from 11 to 80. The calculated mean burden score of family member was 49.49, with median being 52 and SD of 12.26.

Table 8: Range of possible score, obtained score, frequency and percentage distribution of family members according to level of burden. n=100

Level of burden	Range of Possible score	Range of obtained score	Frequency	Percentage (%)
Severe burden	61-88	69-100	13	13
Moderate to severe burden	41-60	47-68	67	67
Mild to moderate burden	21-40	24-46	16	16
Little or no burden	0-20	0-20	4	4

Minimum score - 0
Maximum score - 88

Data presented in table 8 shows that 67% family members had moderate to severe burden and 13% family members had severe burden.

Section III Findings related to the description of coping strategies adopted by the family members according to obtained score in Brief Cope Scale.

Table 9: Domain wise obtained score, Mean, and Mean percentage and rank of different coping strategies used by family members. n=100

Coping scale	Mean	Mean%	Rank
Active coping	4.90	61.25	5
Use of informational support	5.03	62.88	3
Positive reframing	4.09	51.13	9
Planning	5.01	62.63	4
Emotional support	4.34	54.25	6
Venting	4.31	53.88	7
Humour	2.12	26.50	13
Acceptance	5.44	68.00	2
Religion	6.73	84.13	1
Self-blame	2.91	36.38	12
Self-distraction	4.13	51.63	8
Denial	3.20	40.00	11
Substance abuse	2.07	25.88	14
Behavioural disengagement	3.89	48.63	10

Maximum score of each scale-8
Minimum score in each scale -2

Data presented in the table 9 shows maximum use of coping strategies was religion, ranked 1st, followed by acceptance (68%), use of informational support (62.88%), planning (62.63%), active coping (61.25%) and although mean percentage score (25.88%) was least and rank was 14 related to substance abuse but it also use as coping strategies.

Table 10: Broad domain wise mean, mean percentages and rank of coping strategies used by family members. n=100

Broad domain wise coping Strategies	Range of obtained score	Range of possible score	Mean	Mean% score	Rank
Problem focused coping	10-32	8-32	19.30	60.31	1
Emotion focused coping	15-47	12-48	25.85	53.85	2
Avoidant coping	8-20	8-32	13.29	41.53	3

Minimum score - 28
Maximum score - 112

Data presented in table 10 shows that among the coping strategies used by family members, problem focused coping, rank-1 followed by emotion focused coping (53.85%), avoidant coping (41.53%).

Section IV To find out relation between burden and coping strategies.

H_0 There is no significant relationship between burden and coping strategies used by family members of ESRD patients at 0.05 level of significance.

Table 11: Relationship between burden and coping strategies adopted by family members of the patients. n=100

Variables	**Correlation coefficient ('r')**	**'t' value**
Burden among family members		
Coping strategies adopted by family members	-0.04	0.38

t (98)=1.99, p>0.05

Data presented in table 11 shows that there was a negative correlation (-0.04) between burden of the family members and coping strategies adopted by family members which was not statistically significant as the computed 't' value (0.38) less than table (1.99) at 0.05 level of significance. So, null hypothesis accepted. This indicated there were no significant relationship between burden and coping strategies.

Section V: Findings related to association between burden of the family members of the patients and selected demographic variable.

Table 12: Chi square value showing association between burdens of the family members of patients with the selected demographic variables. n = 100

Variables	**Burden of the family members Median=52**		**Value of χ^2**
	<Median	**≥Median**	
Age (in yrs.)			
<35 yrs.	34	20	9.16*
≥35 yrs.	15	31	
Occupation			
Employed	12	8	1.2
Others	37	43	
Monthly Income			
Up to Rs.10000	25	14	5.84*
Above Rs.10000	24	37	
Duration of care giving to patients			
Up to 1 Yr.	35	46	5.7*
Above 1 Yr.	14	5	

χ^2 (df_1) =3.84, p<0.05, *****- Significant

Data presented in table 12 showed that the chi square values computed between burden of the family members with selected variables like age, family income and duration of care giving were significantly associate with burden of the family members at 0.05 level of significance.

Section VI Findings to identify association between coping strategies adopted by family members and selected demographic variable.

Table 13: Chi square value showing association between coping strategies adopted by family members of the patients with the selected demographic variables. n=100

Variables	**Coping strategies of the family members Median=58**		**Value of χ^2**
	<Median	**≥Median**	
Age (in yrs.)			
<35 yrs.	28	26	0.38
≥35 yrs.	21	25	
Occupation			
Employed	11	9	0.36
Others	38	42	
Monthly Income			
Up to Rs.10000	24	15	4.02^*
Above Rs.10000	25	36	
Duration of care giving to the patients			
Up to 1 Yr.	38	43	0.74
Above 1 Yr.	11	8	

x^2df(1)=3.84, p<0.05, *- Significant

Data presented in table 13 showed that the chi square values computed between coping strategies of the family members with selected variable like monthly income was only significantly associated with coping strategies of the family members at 0.05 level of significance.

Results

Findings related to demographic characteristics of family members:

- Majority (55%) of the respondents were females.
- Majority (53%) of respondents belonged to the age group 18-33 year.
- Maximum respondents (32%) completed Higher Secondary education.
- Maximum respondents (33%) were home maker.
- Monthly income maximum (39%) of the subjects ranged up to Rs.10000.
- Majority (81%) respondents were married.
- Maximum (40%) respondents were son or daughter in relation with patient.
- Majority (81%) respondents were giving care to the patients for 7-12 months.

Findings related to the burden of family members

Mean of total burden score was 49.49 with median 52 and a standard deviation of 12.26 (Maximum obtained score 80 and minimum obtained score 11).

Majority (67%) of the respondents had moderate to severe level of burden.

Maximum calculated mean percentage score (60.5%) of burden was present in the domain of finance with rank -1

Findings related to coping strategies adopted by family members

Majority of respondents used problem focused approach (mean percentage 60.13%) as coping strategies.

Majority (84.13%) of family members use religion as coping strategy.

Mean of total coping strategies score was 58.17 with median 58 and a standard deviation of 9.34.

Findings related to the Correlation between burden and coping strategies

A negative correlation (r= -0.04) was found between burden experience and coping strategies adopted by family members.

Findings related to association between burden and selected demographic variables

Statistically significant associations were found between burden and:

- Age of respondents (Chi-square value = 9.16)
- Occupation of family members (Chi-square value = 5.84)
- Relationship of family members with ESRD patients (Chi-square value = 7.44)
- Duration of caregiving to the patient (Chi-square value = 5.7)
- No statistically significant association was found between burden score and certain demographic variables like occupation.

Findings related to association between coping strategies and selected demographic variables

Chi square value (4.02) showed a statistically significant association between coping strategies and income of the respondents.

No statistically significant association was found between burden score and selected demographic variables like age, occupation, relationship with the family members and duration of care giving to the client.

Discussion

Discussion related to major variable

- Data analysis from the present study showed:
- Majority (67%) of family members experienced moderate to severe burden.
- Maximum burden was related to finance (mean percentage score 60.5%).
- Most family members (84.13%) used religion as a coping style.
- Problem-focused approaches were commonly used coping strategies (mean percentage 60.13%).

Findings were supported by similar studies i.e.

Elkafrawy L *et al.* (2019) [2] found moderate burden in 44% of caregivers and severe burden in 3.3%.

Menati L *et al.* (2020) [11] reported high care burden in 86% of caregivers, with avoidance being a common coping strategy.

A negative correlation between burden and coping was found but wasn't statistically significant. Chi-square values showed significant associations between burden and variables like age, occupation, and duration of caregiving. These findings align with Sharma B. *et al.* (2015) [13].

Conclusion

The present study revealed that majority of family members of ESRD patients experienced the moderate to severe burden. The findings also highlighted that there was a few demographic characteristics which had a significant impact on the burden experienced by family members.

In the present study it was observed that majority of the family members were used religion as coping strategies i.e. family members try to find comfort in religion or spiritual beliefs and believed in puja, prayer or meditation. They used problem focused approaches as coping strategies to manage their burden. In this present research study, it was observed that family member’s burden found to be increased with increasing age of the family members. It was also observed that coping of the family members found to be decreased with the increase of burden.

Family relationship is very important for understanding, helping, sharing and caring the patients. So, there is a high need for proving psychological education to the family members of ESRD patients for improving coping abilities thus they can reduce their burden of care and enhancing the efficacy of care for their loved ones.

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