PERCEIVED BURDEN AMONG CAREGIVER OF END STAGE RENAL DISEASE PATIENT UNDERGOING HEMODIALYSIS AT NATIONAL KIDNEY CENTRE, KATHMANDU, NEPAL

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ABSTRACT

Background: Caregiver burden is the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member. This study aims to assess the perceived burden among the caregiver of end stage renal disease patient undergoing hemodialysis. **Methods:** A cross-sectional study was commenced in 296 caregiver of end stage renal disease (ESRD) patient undergoing hemodialysis. The Zarit Burden Interview was used to assess the perceived burden among caregivers attending Kidney Centre using convenient sampling technique maintaining their privacy of data. Data was analysed by means of SPSS version 20 using descriptive as well as inferential statistics. **Results:** Majority of caregivers were ≥35 years, 52.4%, employed 55.7%, married 78.4%, existing health problem 84.5% and were spouse 41.9% of the patient. Similarly, the majority of 51.4% patients were ≥44 years, 63.5% male, 58.1% unemployed, 82.8% married, almost all 91.9% had comorbidity and 56.4% had dialysis done for ≥ 24 months. Around one third 34.5% had little or no burden while remaining 65.5% had perceived burden ranging from mild to severe level. The caregiver level of burden is statistically significant with caregiver age (p=0.018), caregiver existing health problem (p=0.027), relationship with patient (p=0.031), patient age (p=0.040), patient sex (p=0.024), and patient comorbidity (p=0.003). **Conclusion:** The majority of caregiver had perceived mild to severe level of burden. There should be counselling and support system from concerned authority to alleviate caregiver burden.

KEYWORDS: Burden, Caregiver, ESRD patient, Hemodialysis, Zarit Burden Interview, Perceived Burden.

INTRODUCTION

Caregiver burden is the perception of stress and fatigue caused by the sustained effort required in caring for persons with chronic illness or other conditions with special needs for care. Caregiver burden can be defined as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member. Zarit and colleagues defined caregiver burden as "the extent to which caregivers perceive the adverse effect that caregiving has on their emotional, physical health, social life, and financial consequences that impairs one's ability to provide care." [1-3]

Caregivers can be unpaid family members or friends or paid caregivers. Informal or unpaid caregivers are the backbone of long-term care provided in people's homes.

As the population ages and disability worsens, it is critical to understand the physical and mental health burden on caregivers, the range of tasks caregivers may perform, and the societal and economic impacts of long-term chronic diseases or disability.[4]

Worldwide, 349 million people are estimated to be care-dependent, of whom 18 million (5%) are children aged under the age of 15 years, and 101 million (29%) are older people 60 years of age and over. Care-dependence is defined as the need for frequent human help or care beyond that habitually required by a healthy adult. In older people, coexisting chronic diseases (multimorbidity) is frequently associated with the need for health and social care. In most countries, care for older people is provided by informal caregivers (including spouses, adult offspring and other relatives or

friends), and the majority of primary caregivers are women.[5,6]

According to study report of 44 states among community-dwelling adults 45 years of age and older caregiver in 2015-2017 through the Behavioral Risk Factor Surveillance System 22.3% of adults reported providing care or assistance to a friend or family member in the past 30 days. 24.4% of adults aged 45 to 64 years are caregivers compared to 18.8% of adults aged 65 years and older. One in four (25.4%) women are caregivers compared to one in five (18.9%) men. Caregiving can be emotionally and physically demanding. Over half (53%) of caregivers indicated that a decline in their health compromises their ability to provide care. 14.5% and 17.6% of caregivers reported experiencing 14 or more mentally and physically unhealthy days respectively in the past month.[7]

On the other hand, one has to remember that the long-term burden on caregivers, especially the volunteers and unpaid ones, participating in this procedure may lead to the development of a burnout syndrome. This phenomenon may develop both in patients and their caregivers.[8]

A cross sectional study among relatives of ESRD undergoing haemodialysis using Zarit Burden Inventory showed high burden of caring perceived in 52%. Another hospital-based study in UP-PGH Medical Centre revealed burden was significantly correlated with location of patient and the presence of illness among caregivers. Similarly, descriptive correlational study conducted in caregivers to haemodialysis patients presented that 23.5% with high levels of burden, 49% average levels of burden and 27.5% low levels of burden.[9-11]

The current study conducted among caregivers aimed to assess the socio demographic profile and their perceived burden of caregivers' while caring the haemodialysis patients.

MATERIALS AND METHODS

A cross sectional study was conducted in Nepal Kidney Centre among caregivers of ESRD patients undergoing hemodialysis.

Study Population

National Kidney Centre was used for data collection. The National Kidney Centre (NKC) is one of the largest dialysis centres of Nepal established in 1997 as one of the member organizations of Health Care Foundation (HECAF) Nepal on a non-profit basis. Study subjects were clarified and written consent was attained from all the Caregivers.

Ethical Consideration

An approval was obtained from Institutional Review Board, Nepalese Army Institute of Health Sciences and permission granted from Nepal Kidney Centre. The informed consent was obtained from the caregiver prior data collection. Privacy was maintained while collecting data. Caregivers were assured about the maintenance of confidentiality of received information.

Caregiver

The caregiver is the patient's family member caring for the patient for more than three months without pay.

Data collection and Tool

All the caregivers coming to this centre from December, 2018 to February, 2019 were included in the study. Sociodemographic details and burden related information was collected using semi-structured questionnaire.

Zarit Burden Inventory

The extent to which caregivers perceive burden was assessed using Zarit Burden Interview.[2] This contains 5-point 22 items Likert scale. The Zarit Burden Interview has the excellent internal consistency; Cronbach's alpha = 0.83 and 0.89 and for test-retest 0.7 reliability.[12] The Cronbach's alpha analyzed in this study was as high as 0.90 after the study. The response for each item is: Never (0), Rarely (1), Sometimes (2), Quite Frequently (3) and Nearly Always (4)

Statistical Analysis

The collected data was cleansed, entered and analysed using SPSS 17 version. Descriptive analysis using mean, standard deviation, and percentage was used; inferential analysis using chi-square test.

RESULTS

The high proportion of the Caregiver 52.4% were age of 35 years and more with high proportion 51.7 were female. Majority 80.1% of the Caregiver resided at Kathmandu; majority 61.8% Caregiver's caste remained Janajati with high proportion 51% had joint family and 51.0% were literate. Among literate Caregiver, high proportion 25.7% had secondary level of education and 55.7% were employed. Majority 78.4% of the Caregiver were married, among 296 Caregiver majority 69.3% had children and among those majority 66.8% had up to 2 children. Most 84.5% of the Caregivers had no personal health problems; high proportion 55.4% had family monthly income ranging from NRs. 10000 to 29999. In high proportion 41.9% were spouse of the patient (Table 1).

Half of the ESRD patients undergoing dialysis 51.4% were 44 years and more and 63.5% were male. High proportion 81.8.7% of ESRD patients were literate. High proportion 58.8% were unemployed and most of them 245(82.8%) were married, among 296 ESRD patient majority 74.7% had children and among those more than half 54.1% had children 3 or more in number. Most of them 91.9% had comorbidity; more than half 56.4% had undergone dialysis for 2 years and more (Table 2).

Regarding the Caregiver's level of perceived burden, nearly always 82.7% Caregivers felt that their social life has suffered because of caring patient. Whilst 8.1% Caregiver nearly always felt embarrass over patient behaviour.

Concerning the level of perceived burden, high proportion of 34.5% had no or little burden and only 11.1% had severe burden felt (Table 3). Age of the Caregiver, Caregiver's existing health problem and relationship with patient has statistically significant association with level of perceived burden (Table 4). Patient's age, sex and comorbidity had statistically significant association with level of perceived burden (Table 5).

DISCUSSION

In this study caregiver were assessed for their perceived burden in caring of ESRD patients undergoing hemodialysis. The study shows 52.4% of Caregiver were of age 35 years and more, 80.1% residing in same town (Kathmandu), 51% had joint family, 51% were literate and many of them 78.4% were married and 69.3% with children. More than half 55.4% had monthly income ranging from NRs. 10,000 to 29,999, most of them 84.5% had no health problems and spouse 41.9 % remained as a caregiver to patient. These findings are supported by hospital-based study done in UP-PGH Medical Centre which shows majority of Caregivers were in the age group of 41-60 and >60 years being 40% and 43% respectively. Similarly, another study reveals high proportion of 68.6% and 62% were female among caregiver. Female caregiver 71.2% were again present in similar study with consistent finding.[13] Supporting this study spouse 62% remains the caregiver. In contrary to this study, caregivers are more unemployed 74.5% and illiterate 51% in two different studies.[9,14]

Table 1: Sociodemographic Characteristics of Caregivers n=296.

VARIABLES	FREQUENCY	PERCENT
Age (yrs.)		
< 35	141	47.6
≥ 35	155	52.4
Median: 35; IQR(Q_3-Q_1): 47-27 Min:15; Max:80		
Sex		
Male	143	48.3
Female	153	51.7
Address		
Kathmandu	237	80.1
Other than Kathmandu	59	19.9
Caste		
Janajati	183	61.8
Brahmin/Chhetri	95	32.1
Dalit	18	6.1
Family Structure		
Nuclear	145	49.0
Joint	151	51.0
Education Status		
Illiterate	7	2.4
Literate	289	97.6
Education		
Basic education	62	20.9
Primary level (5-8 grade)	21	7.1
Secondary level (9-10 grade)	76	25.7
Higher Secondary level (11-12 grade)	69	23.3
More than higher secondary (>12 grade)	61	20.6
Occupation		
Employed	165	55.7
Unemployed	131	44.3
Marital Status		
Unmarried	64	21.6
Married	232	78.4
Children		
Yes	205	69.3
No	91	30.7
No. of Children (n=205)		
Up to 2	137	66.8

More than 2	68	33.2
Median:2; IQR (Q3-Q1): 3-2; Min:1; Max:6		
Health Problems		
Yes	46	15.5
No	250	84.5
Family Income (NRs. monthly)		
<10000	57	19.3
10000 to 29999	164	55.4
≥ 30000	75	25.3
Caregiver Relation with Patient		
Spouse	124	41.9
Son/Daughter/Son-in-law/Daughter-in-law	30	10.1
Parents	85	28.7
Others (Cousin, friend etc)	57	19.3

Concerning the patient's socio-demographic profile, more than half 51.5% patients were 44 and more years of age, 63.5% were male, most of them 81.8% were literate and 82.8% were married with 74.7% had children, 58.1% were unemployed. Maximum of them 91.9% had comorbidity and 56.4% had undergone hemodialysis for more than 24 months, shortest 3 and longest duration being 144 months.

Table 2: Sociodemographic Characteristics of ESRD Patients undergoing Hemodialysis n=296.

VARIABLES	FREQUENCY	PERCENT
Age (completed years)		
<44	144	48.6
≥ 44	152	51.4
Median:44; IQR(Q3-Q1):60-30.25; Min:15; Max:84		
Sex		
Male	188	63.5
Female	108	36.5
Education		
Illiterate	54	18.2
Literate	242	81.8
Occupation		
Employed	124	41.9
Unemployed	172	58.1
Marital Status		
Unmarried	51	17.2
Married	245	82.8
Children		
Yes	221	74.7
No	75	25.3
Number of Children		
< 3	102	45.9
≥ 3	120	54.1
Comorbidity		
Yes	272	91.9
No	24	8.1
Dialysis Duration (months)		
< 24	129	43.6
≥ 24	167	56.4
Median: 24; IQR(Q3-Q1):36-12; Min: 3; Max: 144		

This study findings are supported by another study in which patient 56.1% were male, 66.7% married, most of them 74.5% unemployed, presence of comorbidity being hypertension 33.3% and Diabetes 49%. Inconsistent findings were found on education status 51% remaining illiterate.[14]

Table 3: Level of Perceived Burden among Caregivers n=296.

Level of Burden	Frequency	Percent
Little or No (0-20)	102	34.5
Mild to Moderate (21-40)	95	32.1
Moderate to Severe (41-60)	66	22.3
Severe (61-88)	33	11.1

Mean Score±SD:31.8±19.6; Median: 3; Min:0; Max:82

Regarding level of perceived burden, the result revealed that little or no burden remains 34.5% while severe burden being 11.1% among caregiver. These findings are not supported by another study which has 49% caregivers had medium burden and 23.5% had severe burden.[14] Similarly 52% of high burden was reported in caregivers study conducted in a hemodialysis unit of a tertiary care hospital.[9] While studying on caregiver, one more study showed partially consistent finding in which 47.5% caregiver had mild to moderate burden and only 3.3% had little or no burden.[15]

Table 4: Association between Level of Perceived Burden with Selected Variables among Caregiver n=296.

Variables	Level of Perceived Burden				χ^2	p-value
	Little or No n (%)	Mild to Moderate n (%)	Moderate to Severe n (%)	Severe n (%)		
Age (completed years)					10.021	**0.018**
< 35	58 (19.6)	76 (25.7)	48 (16.2)	19 (6.4)		
≥ 35	44 (14.9)	13 (4.4)	13 (4.4)	10 (3.4)		
Sex					4.198	0.241
Male	44 (14.8)	46 (15.5)	32 (10.8)	21 (7.0)		
Female	58 (19.6)	49 (16.5)	34 (11.4)	12 (4.05)		
Caste					1.470*	0.967
Brahmin/Chhetri	36 (12.1)	29 (9.7)	21 (7.0)	9 (3.0)		
Dalit	6 (2.0)	7 (2.3)	3 (1.0)	2 (0.6)		
Janajati	60 (20.2)	59 (19.9)	42 (14.2)	22 (7.4)		
Address					3.012	0.390
Kathmandu	84 (28.4)	73 (24.7)	56 (18.9)	24 (25.0)		
Outside Kathmandu	18 (6.1)	22 (7.4)	10 (3.4)	9 (3.0)		
Educational Status					4.808*	0.088
Illiterate	0 (0.0)	3 (1.0)	2 (0.7)	2 (0.7)		
Literate	102 (34.5)	92 (31.1)	64(21.6)	31(10.5)		
Occupation					6.413	0.093
Employed	62 (21.0)	52 (17.6)	29 (9.8)	22 (7.4)		
Unemployed	40 (13.5)	43 (14.5)	37 (12.5)	11 (3.7)		
Family Structure					5.139	0.162
Nuclear	58 (19.6)	46 (15.5)	26 (8.8)	15 (5.0)		
Joint	44 (14.8)	49 (16.5)	40 (13.5)	18 (6.0)		
Marital Status					0.898	0.826
Unmarried	20 (6.7)	23 (7.7)	15 (5.0)	6 (2.0)		
Married	82 (27.7)	72 (24.3)	51 (17.2)	27 (9.1)		
No. of children (n=205)					1.287	0.732
Up to 2	49 (23.9)	44 (21.4)	28 (13.6)	16 (7.8)		
More than 2	23 (11.2)	18 (8.7)	17 (8.2)	10 (4.8)		
Monthly Income (NRs.)					3.896	0.691
<10000	16 (9.7)	22 (7.4)	13 (4.4)	6 (2.0)		
10000 to 29999	55 (8.7)	50 (10.1)	40 (8.1)	19 (4.0)		
>30000	31 (6.0)	23 (6.7)	13 (5.4)	8 (2.3)		
Existing Health Problem					9.155	**0.027**
Yes	10 (3.4)	13 (4.4)	13 (4.4)	10 (3.4)		
No	92 (31.0)	82 (27.7)	53 (17.9)	23 (7.7)		
Relationship with Patient					8.877	**0.031**
Spouse/Parents	63 (21.3)	77 (26.0)	46 (15.5)	23 (7.8)		
Others	39 (13.2)	18 (6.1)	20 (6.8)	10 (3.4)		

***Fisher's Exact Test; 0.05 level of significance*

Age of the Caregiver, Caregiver's existing health problem and relationship with patient has statistically significant association with caregiver's perceived level of burden. Caregiver's sex, caste, address, educational status, occupation, family structure, marital status, no. of children, and monthly income has no statistically significant relationship with perceived level of burden.

Patient's age, sex and comorbidity had statistically significant association with level of perceived burden. Whilst patient's education status, occupation, marital status, children and no. of children, and dialysis duration has no statistically significant relationship with caregiver's perceived level of burden.

Table 5: Association between Level of Perceived Burden and Patient related Variables n=296.

Patient's Variables	Level of Perceived Burden				χ^2	p-value
	Little or No n (%)	Mild to Moderate n (%)	Moderate to Severe n (%)	Severe n (%)		
Age (completed years)						
< 44	59(19.9)	43(14.5)	32(10.8)	10(3.4)	8.334	**0.040**
≥ 44	43(14.5)	52(17.6)	34(11.4)	23(7.8)		
Sex						
Male	73 (24.6)	63 (21.2)	37 (12.5)	15 (5.0)	9.404	**0.024**
Female	29 (9.7)	32 (10.8)	29 (9.7)	18 (6.0)		
Education Status						
Illiterate	12 (4.0)	21 (7.0)	12 (4.0)	9 (3.0)	5.624	0.131
Literate	90 (30.4)	74 (25.0)	54 (18.2)	24 (8.1)		
Occupation						
Employed	48(16.2)	40(13.5)	24(8.1)	12(4.1)	2.363	0.500
Unemployed	54(18.9)	55(18.6)	42(14.2)	21(7.1)		
Marital Status						
Unmarried	24 (8.1)	9 (3.0)	12 (4.0)	6 (2.0)	6.909	0.075
Married	78 (26.3)	86 (29.0)	54 (18.2)	27 (9.1)		
Median:24; IQR (Q3-Q1):36-12; Min:3; Max: 144						
Children						
Yes	67(22.6)	76(25.7)	51(17.2)	27(9.1)	6.906	0.075
No	35(11.8)	19(6.4)	15(5.1)	6(2.0)		
No. of children (n=221)						
< 3	36(12.2)	34(11.5)	22(7.4)	10(3.4)	2.409	0.492
≥ 3	32(10.8)	42(14.2)	29(9.8)	17(5.7)		
Dialysis Duration						
<24 months	39(13.1)	38(12.8)	34(11.4)	18(6.1)	4.984	0.173
≥ 24 months	63(21.3)	57(19.3)	32(10.8)	15(5.1)		
Comorbidity						
Yes	99 (33.4)	90 (30.4)	56 (18.9)	27 (9.1)	13.576*	**0.003**
No	3 (1.0)	5 (1.6)	10 (3.3)	6 (2.0)		

=*Fisher's Exact Test; 0.05 level of significance*

This finding is partially supported by a descriptive cross-sectional study of Central India which reveals that caregiver burden was not associated with occupational status but was significantly associated with caregiver's education.[16] inconsistent findings were found in study done among caregiver of dialysis patients which showed that caregivers belonging to low socio class had moderate to severe burden (p<0.001).[17] Caregiver burden was associated with patient age (p=0.007, r=0.376) which is consistent with this study while the level of education of the caregivers was also found to be related to the caregiver burden (z=-2.373, p=0.018) which is not consistent with this study.[18] the caregiver relation to patient spouse/partner had association with the caregiver's perceived level of burden (p=0.003) which is consistent with this study.[19]

CONCLUSION

Based on the findings, it is concluded that though the high proportion of caregiver has no or little burden but two third of the caregiver perceived burden levelling from mild to severe. The level of caregiver's burden is influenced by the independent variables such as caregiver age, existing health problem, and relation with patient. Likewise, the level of caregiver's burden is predisposed by the patient age, sex and presence of comorbidity.

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