

INTRODUCTION

Chronic kidney disease (CKD) is becoming the foremost health problem in the world and increasing rapidly in low-to middle-income countries. A systematic review showed a high prevalence of CKD in South Asian countries.^{1,2} Study in 12 countries from six world regions: Bangladesh, Bolivia, Bosnia and Herzegovina, China, Egypt, Georgia, India, Iran, Moldova, Mongolia, Nepal, and Nigeria, mentioned that the prevalence of chronic kidney disease was 14.3% in general populations and 36.1% in high-risk populations.³ The prevalence of CKD was 10.6% in Nepal.^{1,4}

Prolong dialysis treatment with CKD affects the patient and his family that leads to caregiver burden.⁵ Objective burden on patients and subjective burden on caregivers leads to lifestyle changes, social isolation, anxiety, depression, financial strain and this also affects physical health. Role strain and personal strain reported in caregivers of hemodialysis patients.⁶ Female caregivers who had an income-generating job and providing care longer than 5 years had a higher burden of care. They had difficulty in maintaining their role in the family and work.⁷

Caregivers of dialysis recipients undergo caring pressure. They had a high level of burden. This pressure harms their quality of life and interrupts caring for patients.^{8,9} The caregiver's personal life becomes unstable and ambiguity raises while caring for a hemodialysis patient.¹⁰ The physical and psychological health is found to be affected while caring for patients with chronic diseases which overall impacts life satisfaction.^{11,12} The core indicator of subjective well-being is general life satisfaction. The lowest level of life satisfaction is seen in the hemodialysis group rather than other chronic diseases.¹³

In a study done in Southern Iran, 72.5% of caregivers had moderate to severe levels of burden in caregivers of patients undergoing hemodialysis patients.⁵ A study conducted in Nepal reported that 49.4% of caregivers had moderate to severe burden with around 17% having severe

burden. Burden increased with increasing age, decreasing education, and decreasing social support. The renal disease affects the life of the patients and their caregivers. Despite the demanding and stressful task of caregivers, they are usually unnoticed in developing countries.¹⁴

Thus, this study aims to assess life satisfaction and burden among caregivers of hemodialysis patients.

MATERIALS AND METHODS

This cross-sectional study was adopted to assess caregiver burden and life satisfaction among caregivers of hemodialysis patients in Bir Hospital, Mahaboudha, and National Kidney Center, Balaju, Kathmandu, Nepal from December 2019 to March 2020. The study started after obtaining approval from the Ethical Review Board of Nepal Health Research Council (Reference Number: 1275), Kathmandu, Nepal. The written informed consent was obtained from the participants before data collection. Caregivers who were engaged in home and hospital setting care for patients living with chronic kidney disease and receiving hemodialysis for at least three months of period, and caregivers who were above 18 years of age were included in the study. The sample size was calculated considering 49.4% prevalence of burden,¹⁴ by using formula of $[(n) = z^2pq/E^2]$, taking 6% allowable error and for finite population using formula of $[n/(1+n/N)]$. The required sample size was 167. According to proportion, 26 caregivers of hemodialysis patients from Bir Hospital and 141 caregivers from National Kidney Center were included in the study.

A structured interview technique was used to collect the data. Zarit Burden Interview-22 (ZBI) was used to assess the level of caregiver burden and the Life Satisfaction Questionnaire (LiSat-11) was used to assess life satisfaction among caregivers.

Zarit Burden Interview-22 (ZBI) is a standard tool containing 22 items that assess different domains of caregivers' life such as Relationships, Emotional wellbeing, Social and family life, Finances, and Loss of control. It is scored on a scale of 0 to 4

where 0 stands for “Never”, 1 for “Rarely”, 2 for “Sometimes”, 3 for “Quite Frequently” and 4 for “Nearly Always”.¹⁵

The total score ranges from 0 to 88. The level of burden was categorized as Little burden (0 - 20); Mild to moderate burden (21 - 40); Moderate to severe burden (41 – 60) and Severe burden (61 – 88).^{16,17} The Nepali version of ZBI was obtained from Malpi Research Trust, France. The reliability of the Zarit Burden Interview-22 tool was 0.851 which was assessed by Cronbach’s alpha.

Life Satisfaction questionnaire (LiSat-11) is a tool that assesses the global item “Life as a whole” and 10 domain-specific items: Vocational situation, Financial situation, Leisure, Contacts with friends and acquaintances, Sexual life, Activities of daily living (ADL), Family life, Partner relationship, Physical/Somatic health, and Psychological health. It is scored on a scale of 1 to 6 where 1 stands for very dissatisfied, 2 for dissatisfied, 3 for rather dissatisfied, 4 for rather satisfied, 5 for satisfied, and 6 for very satisfied. Higher scores indicate a greater level of perceived satisfaction.¹⁸⁻²⁰ Sexual life and partner relationship items were only responded by those who had a partner or who involved in sexual activities. The reliability of the Life Satisfaction questionnaire (LiSat-11) tool was 0.835 which was assessed by Cronbach’s alpha.

Face to face interview lasted for around 20-30 minutes. The collected data were coded, checked, reviewed, and organized daily for completeness. Coded data were entered in Epi data 3.1 and were exported to IBM SPSS version 16. Descriptive statistics (frequency, percentage, mean and standard deviation), Chi-square test and Spearman’s correlation was used for statistical analysis. Statistical significance was considered at $p < 0.05$.

RESULTS

The results showed that the mean age of caregivers was 43.15 ± 14.17 years. The majority of caregivers (42.5%) were middle adults. Out of 167 caregivers, (46.7%) were male and (53.3%) were female. More than two-thirds of the caregivers (69.5%) belonged to a joint family. Majority of the caregivers (85.0%) were married and 77.8% of them had children. Regarding occupational status, only 9.6% of the caregivers were unemployed before diagnosis. However, this figure increased to 40.7% after diagnosis of renal failure was made and 40.1% of them confirmed that it was due to the disease condition. More than half of the caregivers (53.9%) were the spouse of the patient. More than one-third of the caregivers (35.9%) were caring for a period of 6 months to 1 year (Table 1).

Table 1: Socio-demographic characteristics of caregivers

Variables	Frequency	Percentage
Age (in years)		
10-19 (Adolescence)	3	1.8
20-39 (Young adults)	67	40.1
40-59 (Middle Adults)	71	42.5
60-90 (Elderly)	26	15.6
Sex		
Male	78	46.7
Female	89	53.3
Type of family		
Single	51	30.5
Joint	116	69.5
Marital status		
Never married	21	12.6
Married	142	85.0
Divorced	1	0.6
Widow	2	1.2
Cohabiting	1	0.6

Number of children		
No children	37	22.2
One or more than one children	130	77.8
Occupation after diagnosis		
Government employee	5	3.0
Non-government employee/ Self employed	41	24.6
Unemployed	68	40.7
Retired	14	8.4
Homemaker	34	20.3
Agriculture	5	3.0
Relation with patient		
Parent	40	23.9
Grandparent	4	2.4
Spouse	90	53.9
Cousin/Sibling	14	8.4
Son /Daughter	13	7.8
Mother-in-law/Father-in-law	6	3.6
Period of caring		
6 months-1year	60	35.9
1-3 years	49	29.3
3-5 years	25	15.0
More than 5 years	33	19.8

Table 2: Level of burden among caregivers

Level of Burden	Frequency	Percentage
Little or no burden	50	29.9
Mild to moderate	89	53.3
Moderate to severe	22	13.2
Severe burden	6	3.6
Mean Burden Score±S.D.=29.53±1.40		

Table 3: Distribution of burden among caregivers

Domains	Mean	Standard Deviation
Burden in relationship	10.85	4.77
Emotional wellbeing	7.69	4.63
Social and family life	3.60	3.28
Finances	2.42	1.56
Loss of control over ones life	4.97	3.37

This study revealed that the mean burden score among caregivers was 29.53±1.40. More than half of the caregivers (53.3%) fell in mild to moderate categories. Only (3.6%) of the caregivers had a severe burden (Table 2).

Regarding different domains of burden among caregivers, the mean burden in the relationship was reported as 10.85±4.77. Similarly, the mean burden on emotional wellbeing was found to be

7.69±4.63. The mean burden in social and family life was 3.60±3.28. In the same way, the mean burden in finances and loss of control over one's life was 2.42±1.56 and 4.97±3.37 respectively (Table 3).

The results showed that most of the caregivers were satisfied in terms of life as a whole, leisure situation, contacts, sexual life, activities of daily living, family life, partner relationship, physical

health, and psychological health. However, the majority of the caregivers were dissatisfied in regards to their vocational (32.9%) and financial situations (35.9%). The mean life satisfaction score was 36.89±7.03 (Table 4).

There is a statistically significant association between the level of burden and marital status (p=0.016), number of children (p=0.012), and annual income (p=0.007). There is no significant association with other socio-demographic

characteristics such as age, education, type of family, and period of caring (Table 5).

A negative correlation was found between burden and life satisfaction among caregivers of hemodialysis patients and was statistically significant (r =-0.441; p value=<0.001). Life satisfaction decreases with an increase in burden (Table 6).

Table 4: Life satisfaction among caregivers of hemodialysis patients

Variables	Very dissatisfied n (%)	Dissatisfied n (%)	Rather dissatisfied n (%)	Rather satisfied n (%)	Satisfied n (%)	Very satisfied n (%)
1. Life as a whole	4(2.4)	23(13.8)	30(18.0)	33(19.8)	72(43.0)	5(3.0)
2. Vocational	6(3.6)	55(32.9)	22(13.2)	31(18.6)	51(30.5)	2(1.2)
3. Financial	20(12.0)	60(35.9)	18(10.8)	33(19.8)	34(20.3)	2(1.2)
4. Leisure	4(2.4)	23(13.8)	20(12.0)	21(12.6)	95(56.8)	4(2.4)
5. Contacts	6(3.6)	17(10.2)	12(7.2)	23(13.8)	105(62.8)	4(2.4)
6. Sexual life (n=147)	5(3.5)	14(9.6)	6(4.0)	21(14.3)	97(65.9)	4(2.7)
7. Activities of daily living	2(1.2)	10(6.0)	16(9.5)	21(12.6)	114(68.3)	4(2.4)
8. Family life	1(0.6)	15(9.0)	8(4.8)	21(12.6)	120(71.8)	2(1.2)
9. Partner relationship (n=147)	2(1.4)	7(4.8)	9(6.2)	17(11.5)	111(75.5)	1(0.6)
10. Physical health	5(3.0)	13(7.8)	9(5.4)	24(14.3)	112(67.1)	4(2.4)
11. Psychological health	2(1.2)	13(7.8)	11(6.5)	27(16.2)	111(66.5)	3(1.8)
Mean Life Satisfaction Score ± S.D.= 36.89±7.03						

Table 5: Association between the level of burden and socio-demographic characteristics of caregivers

Characteristics	Level of Burden		χ ² value	p value
	Little or No Burden n (%)	Mild to Severe Burden n (%)		
Marital status				
Unmarried	13 (7.8)	9 (5.4)	10.265	0.001*
Married	37 (22.2)	108 (64.7)		
Number of children				
No children	18 (10.8)	19 (11.4)	7.931	0.005*
Have Children	32 (19.2)	98 (58.7)		
Annual income				
Sufficient only for less than 6 months	19 (11.4)	75 (44.9)	9.700	0.002*
Sufficient for more than 6 months	31 (18.6)	42 (25.1)		

*p value significant at < 0.05

Table 6: Relationship between burden score and life satisfaction score among caregivers of hemodialysis patients

	Burden	Life satisfaction	p value
Burden	1	-0.441	0.001*
Life satisfaction	-0.441	1	

*p value significant at < 0.05

DISCUSSION

In our study, the mean burden score was 29.53 ± 1.40 . In contrast to this finding, a study conducted in Iran reported the mean caregiver-burden score of 58.5 ± 20.5 out of 96.²¹

The majority of the caregivers (53.3%) were found to have mild to moderate burden. This finding is similar to a study conducted by Chhetri et al. in Nepal (48.78%) and Senmar et al. in Iran (51.9%).^{22,23} Similarly, a study conducted in northern India reported nearly half of caregivers (45.46%) had mild to moderate level of care burden.²⁴ However, the findings contradict with the result reported by Jafari et al.⁸

In the present study, 29.9% of the caregivers had a little burden. Similar to our finding, Mashayekhi et al. had reported 27.5% of the little burden.⁵ In contrast to this finding, studies conducted in Nepal and Turkey had found only 3.7% and 13% of little burden respectively.^{14,16}

The present study revealed that 13.2% of the caregivers had moderate to severe burden which is much lower than the study conducted by Mashayekhi et al. (72.5%) and Shakya et al. (49.4%).^{5,14} A study conducted by Nagarathnam et al. reported that the majority of caregivers of hemodialysis patients (40%) had moderate to severe burden.²⁵ Regarding severe burden, other studies conducted in Nepal and Iran showed a nearly equal level of the burden as in our study.^{8,22} There was a significant association between the level of burden and marital status, annual income, and the number of children of the caregivers. A study carried out in Nepal also showed a significant association between the level of burden and marital status, and annual income.¹⁴ Antonaki et al. also reported a significant association with the income of the caregivers.²⁶

However, the findings contradict with the result reported by Menati et al and mentioned that there was no significant relationship between the total burden of care and marital status.²¹

This study found no significant association with age and education which is similar to a study conducted in Turkey and Iran.^{7,21}

The health care providers need to identify the caregiver burden which influences their life satisfaction. This affects providing quality care to patients.

Limitations of the study: The study was limited to only two centers in assessing burden and life satisfaction among caregivers of hemodialysis patients who were residing in Kathmandu valley. Therefore, findings cannot be generalized at the national level. Chronic kidney disease may influence the life satisfaction of patients as well as caregivers. However, the life satisfaction of patients was not assessed in the study.

CONCLUSION

The majority of the caregivers were satisfied in terms of life as a whole, leisure situation, contacts, sexual life, activities of daily living, family life, partner relationship, physical health, and psychological health. Life satisfaction decreases with an increase in burden. More than half of the caregivers fell in mild to moderate burden categories. Only few of the caregivers had a severe burden. There is a statistically significant association between the level of burden and marital status, number of children and annual income.

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REFERENCES

1. Hasan M, Sutradhar I, Gupta RD, Sarker, M. Prevalence of chronic kidney disease in South Asia: A systematic review. *BMC Nephrol.* 2018;19(1):291-291. [[PubMed](#) | [FullText](#) | [DOI](#)]
2. Romanowski K, Clark EG, Levin A, Cook VJ, Johnston JC. Tuberculosis and chronic kidney disease: an emerging global syndemic. *Kidney Int.* 2016;90(1):34-40. [[PubMed](#) | [DOI](#)]
3. Ene-lordache B, Perico N, Bikbov B, Carminati S, Remuzzi A, Perna A, Islam N, Bravo RF, Aleckovic-Halilovic M, Zou H, Zhang L. Chronic kidney disease and cardiovascular risk in six regions of the world (ISN-KDDC): a cross-sectional study. *The Lancet Global Health.* 2016;4(5):e307-19. [[Google Scholar](#) | [Full Text](#)]
4. Sharma SK, Dhakal S, Thapa L, Ghimire A, Tamrakar R, Chaudhary S, et al. Community-based screening for chronic kidney disease, hypertension and diabetes in Dharan. *J Nepal Med Assoc.* 2013;52(189):205-12. [[PubMed](#) | [Full Text](#)]
5. Mashayekhi F, Pilevarzadeh M, Rafati F. The assessment of caregiver burden in caregivers of hemodialysis patients. *Mater Sociomed.* 2015;27(5):333-6. [[PubMed](#) | [Full Text](#)]
6. Bayoumi MM. Subjective burden on family carers of hemodialysis patients. *Open Journal of Nephrology.* 2014;4(2):79–85. [[Full Text](#) | [DOI](#)]
7. Cagan O, Unsal A, Celik N, Yilmaz AT, Culha I, Eren HK. Care Burden of Caregivers of Hemodialysis Patients and Related Factors. *International Journal of Caring Sciences.* 2018;11(1): 279–284. [[Full-Text](#)]
8. Jafari H, Ebrahimi A, Aghaei A, Khatony A. The relationship between care burden and quality of life in caregivers of hemodialysis patients. *BMC Nephrol.* 2018;19(1):321. [[PubMed](#) | [FullText](#) | [DOI](#)]
9. Belasco AG, Sesso R. Burden and quality of life of caregivers for hemodialysis patients. *Am J Kidney Dis.* 2002;39(4):805-12. [[PubMed](#) | [DOI](#)]
10. Ebadi A, Sajadi SA, Moradian ST, Akbari R. Suspended life pattern: A qualitative study on personal life among family caregivers of hemodialysis patients in Iran. *Int Q Community Health Educ.* 2018;38(4):225-232. [[PubMed](#) | [FullText](#) | [DOI](#)]
11. Baumann M, Couffignal S, Le Bihan E, Chau N. Life satisfaction two-years after stroke onset: The effects of gender, sex occupational status, memory function and quality of life among stroke patients (Newsqol) and their family caregivers (Whoqol-Bref) in Luxembourg. *BMC Neurol.* 2012;12:105. [[PubMed](#) | [FullText](#) | [DOI](#)]
12. Segal ME, Schall RR. Life satisfaction and caregiving stress for individuals with stroke and their primary caregivers. *Rehabilitation Psychology.* 1996;41(4):303-320. [[Link](#) | [DOI](#)]
13. Elena MJS, Alvarez MP. Chronic illness: Life satisfaction and adaptive personality styles. *Clin y Salud.* 2014;25(2):85–93. [[Full Text](#)]
14. Shakya D, Tuladhar J, Poudel S. Burden and depression among caregivers of hemodialysis patients. *Palliative Medicine and Care: Open Access.* 2017;4(1):1-6. [[Full Text](#) | [DOI](#)]
15. Pandey S, Sharma C. Perceived burden in caregivers of children with autism spectrum disorder. *J Nepal Health Res Counc.* 2018;16(2):184-189. [[PubMed](#) | [Full Text](#)]
16. Cantekin I, Kavurmaci M, Tan M. An Analysis of caregiver burden of patients with hemodialysis and peritoneal dialysis. *Hemodial Int.* 2016;20(1):94-7. [[PubMed](#) | [FullText](#) | [DOI](#)]
17. Nagarathnam M, Sivakumar V, Latheef SAA. Characteristics of burden, coping strategies, and quality of life: The effect of age, gender, and social variables in caregivers of renal transplanted patients from Southern Andhra Pradesh, India. *Indian J Palliat Care.* 2019;25(3):407-413. [[PubMed](#) | [Full Text](#) | [DOI](#)]
18. Ekstrand E, Lexell J, Brogårdh C. Test-retest reliability of the life satisfaction questionnaire (Lisat-11)

- and association between items in individuals with chronic stroke. *J Rehabil Med.* 2018;50(8):713-718. [[PubMed](#) | [FullText](#) | [DOI](#)]
19. Jacobsson L, Lexell J. Life satisfaction 6-15 years after a traumatic brain injury. *J Rehabil Med.* 2013;45(10):1010-5. [[PubMed](#) | [FullText](#) | [DOI](#)]
 20. Fugl-meyer AR, Melin R, Fugl-meyer KS. Life satisfaction in 18- to 64-year-old Swedes : In relation to gender, age, partner and immigrant status. *J Rehabil Med.* 2002;34(5):239-46. [[PubMed](#) | [FullText](#) | [DOI](#)]
 21. Menati L, Torabi Y, Andayeshgar B, Khatony A. The relationship between care burden and coping strategies in caregivers of hemodialysis patients in Kermanshah, Iran. *Psychology research and behavior management.* 2020;13:133. [[Google Scholar](#) | [Full Text](#) | [DOI](#)]
 22. Chhetri SK, Baral R. Caregiver burden among caregivers of patient undergoing hemodialysis in tertiary care center : A descriptive cross-sectional study. *J Nepal Med Assoc.* 2020;58(223):148–152. [[PubMed](#) | [FullText](#) | [DOI](#)]
 23. Senmar M, Rafiei H, Yousefi F, Razaghpoor A, Bokharaei M. Caregiver burden among family caregivers of older patients receiving hemodialysis and its relevant factors. *Journal of Nephro pharmacology.* 2019;8(1):1–5. [[Full Text](#) | [DOI](#)]
 24. Sharma M, Lakhara P, Kumar Sharma S, Jelly P, Sharma R. The burden of caregivers of patients undergoing hemodialysis. *Journal of Holistic Nursing and Midwifery.* 2021;31(2):69-75. [[Google Scholar](#) | [Full Text](#)]
 25. Nagarathnam M, Sivakumar V, Latheef SA. Burden , coping mechanisms , and quality of life among caregivers of hemodialysis and peritoneal dialysis undergoing and renal transplant patients. *Indian J Psychiatry.* 2019;61(4):380-8. [[PubMed](#) | [Full Text](#) | [DOI](#)]
 26. Antonaki E, Xidakis D, Kalogeropoulou M, Linardakis M. Burden and Quality of Life of Caregivers of Chronic Haemodialysis Patients in Heraklion, Crete. *Ellīniko Periodiko tīs Nosīleutikīs Epistīmīs.* 2018;11(3):33-47. [[Researchgate](#)]