ISSN 2795-1952 | eISSN 2976-1107
DOI: https://doi.org/10.3126/mjmms.v4i7.71235

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ORIGINAL RESEARCH Open Access

Burden among Caregiver of End Stage Renal Disease Patient Undergoing Hemodialysis at Tertiary Care Hospital of Nepal

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Received: 22 January 2024
Revised: 15 March 2024
Accepted: 3 April 2024

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Funding details: Self

Citation:
Jha NK, Shrestha K, Tripathi P, Dhimal S, Neupane S, Chapagain S. Burden among caregiver of end stage renal disease patient undergoing hemodialysis at tertiary care hospital of Nepal. MedS.J.Med. Sci.2024;4(7):18-22

Abstract:
Introduction: With a huge number of people being care dependent with most of the caregivers being informal and primarily female, the emotional, physical, social, and financial burden increases for the caregivers. End-stage renal disease (ESRD) is a major cause of elderly patients admitted to hospitals, mostly relying on hemodialysis. Their caregivers are at high risk of having moderate to severe burdens. Zarit's burden scale is a verified 22-item Linkert scale questionnaire that is reliable to measure burden in people who have been caretakers for over a year, have some financial burden, and are a family member.

Materials and Methods: Caretakers of hemodialysis patients (55 in number) were included in the survey at the Nephrology unit of Nobel Medical College and Teaching Hospital. Zarit's Burden scale was weighted against age, sex, religion, education, occupation, family type, marital status, and relationship with the patient, and the severity of the burden was estimated.

Results: 69.1% of the caretakers had moderate to severe burden with more than half (65.5%) of caretakers over 40 years of age. 60% of the caretakers were female. More than 2/3rd (70.9%) of caretakers were the significant other of the patient. A significant relation between age, occupation, and relationship with the patient was found with the level of burden present.

Conclusions: The study reveals the status of caretakers of hemodialysis patients in eastern Nepal. The study reveals differences in caretaker demographics and level of burden being largely affected by age, occupation, and relationship.

Keywords
Burden, Caregiver, End Stage Renal Disease, Hemodialysis, Nepal

INTRODUCTION

National Cancer Institute Dictionary of Cancer Care defines a Caregiver as," A person who gives care to people who need help taking care of themselves. Examples include children, the elderly, or patients who have chronic illnesses or are disabled. Caregivers may be health professionals, family members, friends, social workers, or members of the clergy. They may give care at home or in a hospital or other health care setting" [1]. 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"[2]. Worldwide, 349 million people are estimated to be care-dependent, of whom 18 million (5%) are children under the age of 15 years, and 101 million (29%) are older people 60 years of age and over [3]. 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) are frequently associated with the need for health and social care [4]. 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].

End-stage renal disease (ESRD) is one of the leading causes of hospital admission in elderly patients[6]. The prevalence of new cases of ESKD in Nepal has been found up to 11.36% as per a tertiary care center-based study in Chitwan, Nepal [7]. A study in Nepal has revealed that 43.08% of caregivers had moderate to severe burden while taking care of hemodialysis-requiring ESRD patients [8]. A study in patients receiving hemodialysis in Iran has revealed that, Of 246 participants of the survey, 37.4% of caregivers were experiencing high and very high levels of care burden and 42.7% of them were experiencing a moderate level of care burden [9]. It is imperative that caregivers have multiple types of burdens, including the physical, mental, and financial cost of care [10, 11].

The study conducted at Nobel Medical College, Biratnagar highlights the presence of burden in caregivers of Hemodialysis treatment in ESRD diseases. Only few studies have been conducted around caregiver burdens of ESRD patients undergoing hemodialysis in Nepal [8, 11–13]. No similar studies in eastern Nepal or Province No. 1 have been done, creating a literature gap across the Nepalese hemodialysis burden. This study was conducted to assess the level of burden among caregivers of end-stage renal disease patients undergoing Hemodialysis. The study focuses on finding out the association between the level of burden among caregivers and selected demographic variables (Age, sex, religion, relationship, occupation, and education)

MATERIALS AND METHODS

Study Design and Settings

The descriptive, cross-sectional, hospital-based study was conducted in the Nephrology unit of Nobel Medical College and Teaching Hospital to assess the level of burden among caregivers of end-stage renal disease patients undergoing hemodialysis in Eastern Nepal. It was conducted between October 2022 to January 2023.

Participant, Sample Size, and Sampling Technique

Participants were the caregivers of patients receiving hemodialysis in the background of ESRD. Caregivers willing to participate in the study were included in the study; excluding those with psychiatric illness or with a disability regarding speech and hearing. Cochran's formula was used to calculate the sample size of the study. n=z2pq/d2. z=1.96, p=96.3% for the level of burden in caregivers in the study conducted by Shakya et al [12],q=3.7%, d=5%. n=53. A sample size of 53 was calculated for the study. Purposive, non-probability sampling was used to select the participants.

Data collection procedure and study variables

A face-to-face interview was conducted after receiving consent from the participants. Standard tool burden was assessed using the Zarit Burden Interview[2]. Zarit's Burden Scale is a reliable scale to identify the burden of caregivers who have been looking after the patient for more than 1 year, are family members and have some form of financial burden[14]. This contains 5- point 22 items Likert scale[15]. The 22-item Linkert scale allows scoring from 0 to 4 for every item in the scale. The range is given below: Total score range: 0 to 88 0-21: no to mild burden; 21-40: mild to moderate burden; 41-60: moderate to severe burden; and ≥ 61: severe burden

The Zarit Burden Interview has excellent internal consistency; Cronbach's alpha = 0.83 and 0.89 and for test-retest 0.7 reliability [14]. The level of Burden in the caregiver was calculated based on the Zarit Burden Interview and was weighted against age, sex, religion, education, occupation, family type, marital status, and relationship of the caregiver with patients. The age, sex, duration of illness, and duration of hemodialysis were evaluated for the patient.

Statistical analysis and data management

Collected data was entered in EpiData and analyzed using SPSS version 22 software. Frequency and percentage for patients and caregivers were calculated based on socio-demographic variables. Chi-square tests and p-value was calculated for the test of independence and association between burden and caregiver's socio-demographics.

Ethical Consideration

Data was collected after ethical clearance from IRC of Nobel Medical College and Teaching Hospital (Ref-

NMCTH 714/2022). Written consent was collected from the caregiver and patient before collection of the data.

RESULTS

Patient Profiles:

The patients receiving hemodialysis for ESRD of various socio-demographic characteristics. Nearly 3/4th (74.5%) of patients were above 50 years of age. More than 2/3rd (69.1%) of patients were male. Duration of illness was fairly distributed with 45.5% receiving hemodialysis within 1 year of illness. 61.8% of the population was in treatment for more than a year. Further details are included in Table 1.

Caregiver Profiles:

More than half (65.5%) of caregivers were 40 or above

Table 1|Patients socio-demographic characteristics

Characteristics	Frequency	Percentage
Age		
<50 year	14	25.5
≥ 50year	41	74.5
Sex		
Male	38	69.1
Female	17	30.9
Duration of Illness		
<1 year	25	45.5
≥ 1year	30	54.5
Duration of Hemodialysis		
<1 year	21	38.2
≥ 1year	34	61.8

40 years of age. With a male-to-female ratio of caregivers at 2:3. 65.5% of the caregivers were Hindu. Nearly half (47.3%) of caregivers were illiterate. More than 4/5th of caregivers (81.8%) were married. 70.9% of caregivers belonged to joint families and were mostly either housemakers (32.7%) or in service (30.9%). Most of the caregivers were spouses of patients (70.9%). More details on the socio-demographics of caregivers are in Table 2.

Table 3|Level of Burden among Caregivers (n=55)

Level of Burden	Frequency	Percentage
Little or no burden (0-20)	13	23.6
Mild to moderate burden	3	5.5
Moderate to severe (41-	38	69.1
Severe (61-88)	1	1.8

As per Zarit Burden Scale, more than 3/4th (76.4%) of caregivers has mild to severe burden with 69.1% having moderate to severe burden. Only one caregiver had a severe burden as per the scale. The level of burden is detailed in Table 3.

Table 2|Caregivers Socio-demographic

Characteristics	Frequency	Percentage
Age		
<40 year	19	34.5
≥ 40year	36	65.5
Sex		
Male	22	40.0
Female	33	60.0
Religion		
Hindu	36	65.5
Muslim	6	10.9
Buddhism	5	9.1
Christian	8	14.5
Education		
Illiterate	26	47.3
Basic (1-8)	16	29.1
Secondary (9-12)	9	16.4
University (above 12)	4	7.3
Marital Status		
Married	45	81.8
Unmarried	10	18.2
Type of family		
Nuclear	10	18.2
Joint	39	70.9
Extended	6	10.9
Occupation		
Housemaker	18	32.7
Farmer	8	14.5
Service	17	30.9
Business	12	21.8
Relation with Patients		
Child	8	14.5
Parent	3	5.5
Sibling	5	9.1
Spouse	39	70.9

A significant relationship between age and presence of burden was found among caregivers($p=0.039$). Similarly strong association between occupation and burden ($p=0.009$) & relationship with patients and burden ($p<0.0001$) was elucidated. No significant relation between education, religion and sex was found with level of burden. More details can be found in Table 4.

DISCUSSION

It was noted that most of the caregivers had some sort of level of burden, regardless of age, sex, religion, education, occupation, or relationship with the patient. Caregivers of older age (>40 years) were found 65.5% against 39.6% only above 40 in a research conducted by

Table 4|Association between Level of Burden with Selected Variables among Caregivers (n=55)

Characteristics	No Burden		Moderate to severe burden		Chi-square	P-value
	Frequency	Percentage	Frequency	Percentage		
Age						
<40year	8	42.1	11	57.9	4.241	0.039
≥ 40year	6	16.7	30	83.3		
Sex						
Male	8	36.4	14	63.6	2.300	0.129
Female	6	18.2	27	81.8		
Religion						
Hindu	12	33.3	24	66.7	3.409	0.065
Non-Hindu	2	10.5	17	89.5		
Education						
Can read and write	7	24.1	22	75.9	0.056	0.813
Can't read and write	7	26.9	19	73.1		
Occupation						
Housemaker	0	0	18	100.0	9.321	0.009
Employment	7	41.2	10	58.8		
Others	7	35.0	13	65.0		
Relation with Patients						
Child	7	50.0	1	2.4	20.120	<0.0001
Parent/sibling	0	0	8	19.5		
Spouse	7	50	32	78.0		

Shakya et al[12] at Human Organ Transplant Center, Kathmandu, Nepal. Our study was much closer to the study by Chhetri et al, conducted at Chitwan Medical College with 56.08% of caregivers being older than 40 years[8] and to study by Maharjan et al at Bir Hospital and National Kidney Center with 58.1% of caregivers above 40 years of age[13].

This figure might be suggestive of differences in caregiving practices across the nation. Most of the caregivers were female (60%) comparable to a previous study by Chhetri et al at 57.72% [8], Maharjan et al (53.3%)[13], Shakya et al (56.1%)[12] Sharma et al (57%)[16] expressing the fact that women are more willing to provide care and carry the burden of caregiving. Unlike studies conducted in Nepal, showing nearly half of caregivers from either nuclear or joint family[8, 16], our study has shown almost 3/4th of families are joint similar to Maharjan et al [13].

Our study revealed 76.4% of caregivers had some level of burden in similar to Maharjan et al(70.1%)[13], significantly higher than Indian surveys like Sharma et al (60.9%) [16], Joseph et al (60.9%)[10] and Nagarathnam et al (66.67%) [17], but lower than in other surveys conducted at Nepal such as Shakya et al (96.3%)[12] and Chhetri et al 95.23% [8]. Abou 69.1% of caregivers have moderate to severe burden, which was comparatively higher than studies conducted in Nepal such as Maharjan et al (13.2%)[13], Chhetri et al (43.08%) [8], Shakya et al (49.4%)[12]. These researches were more consistent with Indian researches respectively Joseph et al (52.94%)[10],Sharma et al(13.63%) [16]. Our study revealed that age had significant relation with burden in caregivers, relating aging population have higher burden compared to younger people, similar to study conducted by Joseph et al in Sikkim[10] and Shakya et al at Human Transplant Center[12]. Caregiver burden was significantly higher for spouse compared to parents or siblings. 70.9% of caregivers were spouses of patient, higher compared to other studies in Nepal[8,12,13]. The study reveals the increased burden in the caregivers with their patient in ESRD in the circumstance of needing hemodialysis. The study explores the association between multiple socio-demographic variables like age, sex, relationships, occupation, religion and education to the burden of caregivers.

Limitation of the study: The study is one setting-based study, and thus cannot be generalized to all the population of the nation.

CONCLUSION

Most of the caregivers of ESRD patients requiring hemodialysis had some degree of burden, either financial, emotional, or mental. A significant association between age, sex, and spouses with burden level was noticed. Differences in gender and age distribution recommend the societal construct and sense of responsibility respectively.

ADDITIONAL INFORMATION AND DECLARATIONS

Acknowledgments: We are grateful to all the patients and caretakers for their support. We are also thankful to the Nephrology unit of Nobel Medical College for their support during the data collection procedure.

Author Contributions: Concept and design: NKJ, KS, PT, SN; literature review: NKJ, KS, PT, SD, SN, SC; data collection: NKJ, PT, SD, SN, SC; data analysis: NKJ, PT, SD, SC; manuscript draft: NKJ, KS, SD, SN, SC. All authors contributed to the analysis, review and write up of the final manuscript, interpretation of results, and revision of the manuscripts

Declaration of conflict: The authors declare no conflict of interest.

Funding: No funding was received for this study.

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