Original Article

Factors Influencing Scales of Burden, Coping Mechanisms, and Quality of Life in Caregivers of Hemodialysis Patients in Andhra Pradesh, India

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Abstract

Background: Evaluation of factors influencing scales of burden, coping mechanisms, and quality of life (QOL) in caregivers of hemodialysis (HD) patients may lead to the revision of interventions aimed at the betterment of QOL of caregivers of HD patients. In this study, we investigated the influence of demographic, social, and clinical variables on burden, coping mechanisms, and QOL in caregivers of HD patients. **Methods:** In this prospective study, 150 caregivers of HD patients were recruited. Assessment of burden, coping strategies, and QOL were made by the Zarit Burden Interview, Revised Ways of Coping, and Short Form-36 QOL. The role of age, gender, and social and clinical variables on these constructs was investigated using multivariate analysis of variance. **Results:** The mean age was 43.86 ± 1.11 years. Males outnumbered females. Most were Hindu, married, primary school educated, unemployed, spouses, caring the patients, and suffering from chronic diseases for <5 years. In multivariate analysis of variance, effect of age on physical functioning (PF), general health (GH), and physical component summary (PCS) score ($P < 0.01$); gender on burden, distancing, seeking social support, role limitation due to emotional problem, and pain ($P < 0.05$); role limitations due to physical health, energy/fatigue (EF), emotional well-being, PCS, and mental component summary (MCS) score ($P < 0.01$); religion on PF ($P < 0.05$); marital status on burden and GH ($P < 0.05$); PF and PCS ($P < 0.01$); relationship of caregiver with the patient on PCS ($P < 0.05$); EF and MCS ($P < 0.01$); and presence of chronic diseases on GH and social functioning ($P < 0.01$) were observed. **Conclusion:** The role of demographic, social, and clinical variables should be taken into consideration while initiating therapies for reducing the burden and improving the QOL of caregivers.

Keywords: Burden, caregivers, clinical variables, coping strategies, demography, hemodialysis, quality of life, social variables

INTRODUCTION

The prevalence of chronic kidney disease (CKD) ranges from <1% to 17% worldwide.[1] An age-adjusted prevalence of 226 million of ESRD cases was reported in India with annual approximate addition of 220,000 cases.[2] Hemodialysis (HD), peritoneal dialysis, and renal transplantation are three modes of renal replacement therapies used for management of the fifth stage of CKD. Among them, HD is the dominant modality practiced in India with an estimated population of 120,000.[3]

Frequent dialysis and associated comorbidities cause disability in HD patients and increase dependency on caregivers.[4] Caregiving involves physical activity, emotional pressure, social restrictions, and economic demands which increase burden among caregivers and further aggravated by functional and cognitive impairments which lead to increased stress, depression,[5,6] increased use of medication, and reduced quality of life (QOL).

Earlier studies investigated burden/QOL/coping[7-12] in caregivers of HD patients. Most of the earlier studies reported the influence of one or two demographic/social/clinical

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variables on burden/coping/QOL in a caregiver population of HD patients in foreign countries. It is not known whether demographic/social/clinical variables have an influence on burden/coping/QOL in Indian caregiver population. It was observed that status of burden/coping/QOL changes with culture.[13-16] Available interventions directed to reduce burden among caregivers are based on the assessment of burden and its association with coping and QOL without regard to the influence of demographic/social and clinical variables on these constructs. Information on the influence of demographic/social/clinical variables may pave the way for revising intervention strategies by taking into account these variables. We studied the influence of demographic (age, gender, marital status, and religion), social (education, occupation, and relationship with the patients), and clinical (duration of caregiving, presence/duration of treatment receiving for chronic diseases) on burden/coping/QOL. It was hypothesized that the demographic/social/clinical variables may not affect constructs of burden/coping/QOL in caregivers of HD patients in Indian population.

METHODS

Ethical clearance for the study was obtained from the institutional human ethics committee (IEC No. 564). Details of inclusion and exclusion criteria used for recruitment of caregivers, instruments used, internal and test–retest reliability of instruments, and derivation of final scores were described in our earlier study.[17]

Our earlier study on 100 caregivers of patients undergoing HD showed that the mean and standard deviation of burden score were 31.05 and 5.86, respectively.[18] Assuming $\alpha = 0.05$ and $\beta = 0.2$ and null hypothesis value of 29.7, the calculated sample size was 150. In this prospective study, we recruited a total of 150 individuals using a purposive sampling technique. Data were collected using a questionnaire containing two sections. The first section contained details on demographic, social, and clinical variables, whereas the second section contained instruments such as Zarit Burden Interview, Revised Ways of Coping, and Short Form-36.

Statistical analysis

Continuous variables are presented as the mean and standard error of mean and discrete variables as frequencies and percentages. The averages of groups were compared using *t*-test and one-way analysis of variance. The relationship between variables was investigated by Spearman's rank correlation analyses. An association of dependent and independent variables was examined by regression analysis. The influence of demographic/social/clinical variables on burden/coping/QOL as well as interactions between them was investigated by employing the two-way multivariate analysis of variance (MANOVA). *Post hoc* analysis was performed to investigate the significant difference of means between groups using Tukey's test. Statistical analyses were performed with IBM Statistical Package for the Social Sciences for Windows, version 20.0 (IBM Corp., Armonk, New York, USA).

RESULTS

The demographic, social, and clinical characteristics of caregivers are presented in Table 1. The mean age was 43.86 ± 1.11 years. Males outnumbered females (72.66% vs. 27.33%). Most were Hindu, married, primary school educated, unemployed, spouses, caring the patients, and suffering from chronic diseases for <5 years. Caregivers were in care for an average of 2.30 ± 0.21 years while undergoing treatment for the chronic diseases for an average of 1.89 ± 0.49 years.

Table 1: Demographic, social, and clinical characteristics of caregivers of hemodialysis patients

Variable	Total (*n*=150)
Age (years) (mean±SEM)	43.86±1.11
Religion	
Hindu	136 (90.66)
Muslim	9 (6.00)
Christian	5 (3.33)
Marital status	
Unmarried	16 (10.66)
Married	134 (89.33)
Education	
Illiterate	29 (19.33)
Primary	42 (28.00)
Secondary	25 (16.66)
Intermediate	16 (10.66)
Graduate	24 (16.00)
Post-graduate	14 (9.33)
Occupation	
Unemployee	95 (63.33)
Private employee	22 (14.66)
Government employee	6 (4.00)
Labor	20 (13.33)
Pensioner	7 (4.66)
Relationship with patient	
Spouse	87 (58.00)
Children	38 (25.33)
In-laws	4 (2.66)
Parents	9 (6.00)
Relative	12 (8.00)
Presence of number of chronic diseases	
No illness	113 (75.33)
One disease	33 (22.00)
Two or more diseases	4 (2.66)
Duration of caregiving (years) (mean±SEM)	2.30±0.21
Duration of caregiving (years)	
0- 5	132 (88.00)
6- 10	17 (11.33)
11- 15	1 (0.66)
Duration of treatment for chronic diseases (years) (Mean±SEM)	1.89 ± 0.49
Duration of treatment for chronic disease (years)	
0- 5	133 (88.66)
6- 10	11 (7.33)
11- 15	6 (4.00)

Parenthesis indicates percentage. SEM: Standard error of mean

The mean burden score and level of burden and average of coping variables and QOL subscales in caregivers are given in Table 2. The mean burden score was 38.29 ± 1.35. Seeking social support (SSS) was found to be the dominant coping mechanisms adapted by the caregivers. Role limitations due to physical health (RLDPH) and role limitations due to emotional problem (RLDEP) were found to be the compromised subscales of QOL.

DISCUSSION

Demographic variables

Age

A significant inverse association of age with physical functioning (PF) (standardized beta (SB) = −0.365, *P* = 0.00), general health (GH) (SB= −0.275, *P* = 0.001), and Physical Component Summary (PCS) score (SB = −0.221, *P* = 0.007) subscales of QOL was observed in univariate regression analysis contributing 12.8%, 6.9%, and 4.2% variation in these variables. In bivariate correlations, a significant inverse association of age with PF (r = −0.468), GH (r = −0.285) (*P* = 0.000), and PCS (r = −0.273, *P* = 0.001) was observed. An inverse association of PCS with age observed in caregivers of HD patients in the present study as observed earlier[8] but in contrast to another study showed a positive association of age with PCS.[19] This may be due to the age difference or cultural factors between ours and participants of another study.[19]

Table 2: Mean burden, coping, and quality of life scores in caregivers of hemodialysis patients

Burden score	
Variables	**Mean±SEM**
Burden score	38.29 ± 1.35
Subscales of ways of coping	
Confrontive coping	2.04 ± 0.03
Distancing	2.02 ± 0.05
Self-controlling	2.05 ± 0.04
Seeking social support	2.58 ± 0.04
Accepting responsibility	1.90 ± 0.07
Escape avoidance	1.16 ± 0.04
Planful problem solving	2.22 ± 0.05
Positive reappraisal	2.41 ± 0.05
Subscales of quality of life	
Physical functioning	71.90 ± 2.05
Role limitation due to physical health	45.33 ± 2.94
Role limitation due to emotional problem	46.00 ± 3.16
Social functioning	74.66 ± 1.78
Energy/fatigue	56.13 ± 1.54
Emotional well-being	60.74 ± 1.34
Pain	68.81 ± 3.88
General health	60.63 ± 1.25
Physical component	61.67 ± 1.69
Mental component	59.38 ± 1.39

SEM: Standard error of mean

Age was divided into two intervals (20–40 and 40–60 years) and entered in two-way MANOVA. A significant effect of age on PF, GH, and PCS was observed which contributed 13.7%, 8.3%, and 6.6% variation in PF, GH, and PCS variables as shown by the partial Et2 values [Table 3]. A significant decrease in mean PF, PCS (*P* = 0.000), and GH (*P* = 0.001) was observed in caregivers of 40–60 against 20–40 years. This observation was consistent in both sexes. The decline in mean PF, GH, and PCS in caregivers of HD patients with age in the present study was also observed in healthy aged individuals, suggesting that it is an aging phenomenon.[20] Lower physical than mental dimension of QOL with aging observed in the present study also reported in healthy older people.[20,21] Lower PF was found to be associated with poor physical performance.[22] Lower mean GH in older than younger caregivers may be due to the significantly higher proportion of chronic diseases in them (84% vs. 16%, *P* = 0.000).

Gender

Gender showed a significant effect on burden, distancing, SSS, RLDPH, RLDEP, energy/fatigue (EF), pain, emotional well-being (EMW), PCS, and Mental Component Summary (MCS) score and contributed 2.6%–7.7% variation in these variables in MANOVA [Table 3]. In bivariate correlation analysis, a significant association of gender with burden (r = −0.213, *P* = 0.009), distancing coping mechanism (r = 0.168, *P* = 0.040), RLDPH (r = 0.225, *P* = 0.006), RLDEP (r = 0.173, *P* = 0.034), pain (r = 0.379), EF (r = 0.288, *P* = 0.000), EMW (r = 0.243, *P* = 0.003), PCS (r = 0.327, *P* = 0.000), and MCS (r = 0.277, *P* = 0.001) was observed. In univariate regression analysis, a significant association of gender with burden score (SB = −0.212, *P* = 0.009), distancing coping (SB = 0.164, *P* = 0.045), SSS (SB=−0.170, *P* = 0.039), RLDPH (SB = 0.225, *P* = 0.006), RLDEP (SB = 0.173, *P* = 0.034), pain (SB = 0.179, *P* = 0.028), EF (SB = 0.272, *P* = 0.001), EMW (SB = 0.253, *P* = 0.002), PCS (SB = 0.262, *P* = 0.001), and MCS (SB = 0.282, *P* = 0.000) contributing 3.9%, 2%, 2.2%, 4.4%, 2.3%, 2.6%, 6.8%, 5.8%, 6.2%, and 7.3% variation in these variables. Significantly higher mean burden (*P* = 0.009) and SSS (*P* = 0.039) in males and in variables such as distancing (*P* = 0.045), RLDPH (*P* = 0.006), RLDEP (*P* = 0.034), pain (*P* = 0.028), EF (*P* = 0.001), EMW (*P* = 0.002), PCS (*P* = 0.00), and MCS (*P* = 0.01), females showed significantly higher mean than opposite gender. Stepwise discriminatory analysis showed that EF subscale of QOL classifies correctly 73% of the caregivers into males and females.

A significant association of gender with burden score observed in the present study was found earlier,[17,18] whereas other studies showed no association in caregivers of HD patients.[7,11,23,24] A higher burden score in male than female caregivers may be due to higher percentage of males (72.66% vs. 27.33%) and higher percentage of illiteracy (25% vs. 2.43%) in males than females and involvement of males in tasks such as transportation and lifting, maintaining hygiene and arranging special diet for patients, attending HD sessions and

Table 3: Influence of demographic, social, and clinical variables on burden, coping, and quality of life scores evaluated by two way multivariate analysis of variance

Variable	*F*	Significance	Partial η^2
Age			
Physical functioning	23.22	0.000	0.137
General health	13.167	0.000	0.083
Physical Component Summary score	10.300	0.002	0.066
Gender			
Burden	6.189	0.014	0.041
Distancing	3.925	0.049	0.026
Seeking social support	4.633	0.033	0.031
Role limitation due to physical health	7.648	0.006	0.050
Role limitation due to emotional problem	4.262	0.041	0.028
Energy/fatigue	11.062	0.001	0.070
Pain	4.167	0.043	0.028
Emotional well-being	10.32	0.002	0.066
Physical Component Summary score	9.426	0.003	0.061
Mental Component Summary score	12.140	0.001	0.077
Religion			
Physical functioning	3.573	0.031	0.047
Marital status			
Burden	4.318	0.039	0.029
General health	3.962	0.048	0.026
Physical Component Summary score	6.784	0.010	0.044
Physical functioning	13.713	0.000	0.086
Relationship of caregiver with the patient			
Energy/fatigue	4.730	0.001	0.120
Mental Component Summary score	3.539	0.009	0.092
Physical Component Summary score	2.771	0.030	0.077
Presence of chronic diseases			
General health	5.754	0.004	0.076
Social functioning	8.658	0.000	0.111

complications, limited and altered daily activities, and looking after the needs of other family members.[17] A significantly higher mean burden score was observed in illiterate against highly educated caregivers (intermediate [10 + 2], graduate, and postgraduate) ($P < 0.05$). Most of the male caregivers in the present were spouses (70%), and in contrast, most of the female caregivers were children (44%) of the patients. Spouses were reported to be more motivated, attached, and stay long hours in providing the care than children.[25] This may also be responsible for higher mean burden in male than female caregivers.

Higher mean distancing in females and SSS in males suggest that female than male caregivers are likely to use distancing, whereas males than females often use SSS mechanisms in coping the caregiving. Distancing is emotion focused, whereas SSS is both problem and emotion-focused coping strategy. The distancing mean score was found to be higher in male than female Jordanian caregivers[11] in contrast to our finding which may be due to cultural factors. Distancing is used to detach from situation or to develop positive attitude on the situation,[26] whereas SSS coping mechanism is employed when responsibility is accepted and attempts were made to manage the situation more of often by the spouse.[11,25] In our study, higher mean SSS among males than females may be due to the higher percentage of them happens to be spouses. Most of the females are children (40%). Compared to spouses, children are not motivated, attached, and stay long hours in caring. This may be the reason that female caregivers in our study are using distancing strategy.

Significantly higher mean RLDPH, RLDEP, pain, EF, EMW, PCS, and MCS in female than male caregivers were observed in contrast to other studies done on general populations[20-22,27,28] and caregivers of renal transplanted patients[25] which showed lower mean in QOL subscales in female against male caregivers. Higher mean in subscales of QOL in female than male caregivers when compared to other studies[20-22,25,27,28] may be due to the lower burden score, cultural factors, and sample size differences and suggest better QOL than male caregivers. Higher mean RLDPH, RLDEP, pain, EF, EMW, PCS, and MCS in female than male caregivers suggest that they have no limitations in daily activities and have full of energy and calm.[29] In those studies which reported lower mean in subscales of QOL in female when compared to male caregivers had not investigated burden score or its levels.[20-22,27,28] In Spearman's rank correlation analysis, a significant inverse association of burden score with RLDPH (*r* = −0.625), RLDEP (*r* = 0.523), EF (*r* = −0.488), EMW (*r* = −0.425), PCS (r = 0.598), MCS (*r* = −0.579, *P* = 0.000), and pain (*r* = −0.172, *P* = 0.035) was observed and the significance was consistent when analyzed gender wise also though there is a little variation in correlation coefficient values.

Social and clinical variables

Religion

In MANOVA, a significant association of religion with PF was observed contributing 4.7% variation [Table 3]. Christians showed a higher mean PF followed by Muslims and Hindus. No statistically significant difference was observed between the religious groups when analyzed in one way ANOVA. Earlier studies done on caregivers of HD patients showed no association of religion with PF.[8,19,30] In univariate regression analysis, religion was significantly associated with PF (SB = 0.170, *P* = 0.038) contributing 2.2% variation in PF. It is interesting to note that religion was the only variable found to be associated with PF when investigated in Spearman's rank correlation (*r* = 0.193, *P* = 0.018).

Marital status

A statistically significant association of marital status with burden score, PF, GH, and PCS was observed in MANOVA contributing 2.9%, 8.6%, 2.6%, and 4.4% in these variables [Table 3]. In bivariate correlation analysis, a significant association of marital status with burden score (*r* = 0.172, *P* = 0.035), PF (*r* = −0.319, *P* = 0.000), and PCS (*r* = −0.257, *P* = 0.002) was observed. A significant association of marital status with burden score (SB = 0.169, *P* = 0.039), PF (SB = −0.267, *P* = 0.001), and PCS (SB = −0.206, *P* = 0.011) contributing 2.2%, 6.5%, and 3.6% variation in these variables was observed in univariate regression analysis. Significantly higher mean burden score (*P* = 0.039) and lower mean PF and PCS score (*P* = 0.01) were observed in married against unmarried caregivers. Mean GH though lower in married when compared to unmarried caregivers but was not statistically significant. In caregivers of renal transplant patients, marital status was found to be the significant predictor of burden.[25] Higher mean caregiver burden in married against unmarried may be due to the higher percent of lower level educated in the former than in the latter group. A higher mean burden score was observed in low-educated (primary educated) than high-educated (intermediate (10 + 2) caregivers ($P < 0.05$) in *post hoc* analysis, followed by one-way ANOVA. The lower mean PF and PCS may be due to the higher caregiver burden in married than unmarried caregivers. The burden score showed a significant inverse association with PF (*r* = −0.376 and PCS (*r* = −0.598) (*P* = 0.000) in Spearman's rank correlation analysis. One-way ANOVA analysis showed decreasing mean PF (F = 7.281) and PCS (F = 19.03) (*P* = 0.000) with an increase in the severity of burden.

Relationship of caregiver with the patient

QOL subscales such EF, PCS, and MCS were significantly associated with relationship with the patient in MANOVA contributing 12%, 9.2%, and 7.7% variation in these variables. A significant association of relationship with the patient was associated with PCS (*r* = 0.336, *P* = 0.00) and MCS (*r* = 0.175, *P* = 0.032) in bivariate correlation analysis. In univariate regression analysis, relationship with the patient was significantly associated with PCS (SB = 0.214, *P* = 0.008) contributing 3.9% variation. In *post hoc* analysis, spouse showed a significantly lower mean EF than son-daughter-in-law (*P* = 0.008). A significantly lower mean EF was observed in children (son/daughter) than son/daughter-in-law (*P* = 0.040). Parents showed a significantly lower mean EF than son/daughter-in-law (*P* = 0.001) and relatives (*P* = 0.014). These observations suggest that primary relatives (spouse, children, and parents) showed a lower mean EF against son/daughter-in-law and other relatives. A significantly lower mean PCS was observed in spouses against children (*P* = 0.001), son/daughter-in-law, and other relatives (*P* = 0.016). Parents showed a significantly lower mean PCS than children (*P* = 0.019), son/daughter-in-law (*P* = 0.016), and other relatives (*P* = 0.020) in *post hoc* analysis. Spouses (*P* = 0.006), children (*P* = 0.032), and parents (*P* = 0.001) showed a significantly lower mean MCS than son/daughter-in-law, whereas parents of the patients showed a significantly lower mean MCS than other relatives (*P* = 0.025). In three subscales of QOL (EF, PCS, and MCS), primary care relatives (spouses, children, and parents) showed significantly lower QOL scores than son/daughter-in-law and other relatives. Lower EF, PCS, and MCS in caregivers suggest experiencing of tiredness and worn-out and suffering from nervousness and depression.[31] Lower mean EF, PCS, and MCS may be due higher percentage of male (72%), married (89%), and lesser educated (up to 10 + 2 only) (50%) caregivers who had shown a higher burden score resulting in lower EF, PCS, and MCS. Burden score was significantly associated with EF (*r* = −0.488) PCS (*r* = −0.598), and MCS (*r* = −0.579) (*P* = 0.000) in bivariate correlation analysis.

Presence of chronic diseases in caregivers

In MANOVA, the presence of chronic diseases was significantly associated with GH and SF contributing 7.6% and 11.1% variation in these variables [Table 3]. In one-way ANOVA, mean GH (F = 10.657, *P* = 0.000) and SF (F = 5.432, *P* = 0.005) significantly decreased with an increase in the number of chronic diseases. A significant relationship of the presence of chronic diseases with GH (*r* = −0.310, *P* = 0.00) and SF (*r* = −0.220, *P* = 0.007) in bivariate correlation analysis was observed. In univariate regression analysis, the presence of chronic diseases was significantly associated with GH (SB= −0.356, *P* = 0.00) and SF (SB= −0.258, *P* = 0.001) contributing 12.1% and 6% variation in GH and SF variables. In this study, 25% of the caregivers had 1 or more chronic diseases which may have resulted in lower GH and SF. Lower SF and GH in caregivers suggest that caregivers are experiencing difficulties in daily activities due to emotional and physical problems which may have led them to perceive poor health and anticipating that it gets worsened with time.[31]

This is a single-center study and, to generalize results of our study on caregivers of HD patients, requires the collection and analysis of the data from multiple centers and multicultural settings. We have no control on the responses of the respondents on questionnaire items or their state of mind. We have collected data from the caregivers when they were waiting outside the dialysis unit when the modality sessions were running for their patients. We have documented the responses of the caregivers for all the items of three instruments at the same time period. We have no idea whether the collection of responses on all the items of three instruments has any effect in their responses.

CONCLUSION

The results of the present study suggest that demographic, social, and clinical variables contribute 2.6%–13.7% variation in burden, coping strategies, and QOL of caregivers. Based on our observations, we propose that the variable which contributes a higher quantum of variation among demographic, social, and clinical variables on the burden, coping, and QOL constructs should be taken into consideration while designing the interventions in reducing the burden and improving the QOL of caregivers of HD patients. Effect of age on QOL; gender and marital status on burden score; gender on coping strategies; gender, religion, marital status, relationship of caregiver with the patient and presence of chronic diseases on QOL indicate that demographic factors (age and gender) independently on QOL and coping strategies and in combination, with the demographic, social, and clinical variables influences the burden and QOL scores.

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Conflicts of interest

There are no conflicts of interest.

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