
Original article

Assessment of the Quality of Life of Caregiver's of Patients Suffering from Chronic Kidney Disease

Gill S. Ajitpal¹, Singh Amandeep², Matreja S. Prithpal², Gupta K. Ashwani², Singh Navtej¹, Khosla P. Prem³ and Prasher K. Pawan⁴

¹Department of Medicine, Gian Sagar Medical College and Hospital, Village Ram Nagar, District Patiala,

²Department of Pharmacology, Gian Sagar Medical College and Hospital, Village Ram Nagar, District

Patiala, ³Department of Pharmacology, Gian Sagar Medical College and Hospital, Village Ram Nagar,

District Patiala, ⁴Department of Medicine (Nephrology), Gian Sagar Medical College and Hospital, Village Ram Nagar, District Patiala, Punjab, India

Abstract

Background. The impact of chronic kidney disease has a profound and pervasive effect on family and friends resulting in psychological strain, social isolation, relationship strains and financial strains from the added responsibilities of managing the patients. Few studies have found a significant burden on the caregivers, but the data from the Indian setup is lacking. Hence, we designed this study to assess the quality of life of caregivers of patients with chronic kidney disease.

Methods. This prospective study was conducted on 68 caregivers of patients suffering from chronic kidney disease. The caregivers were divided into two groups. Group A volunteers were caregivers of patients on haemodialysis, whereas Group B were caregivers of patients not on haemodialysis. The caregivers in both the groups were subjected to Zarit Burden Interview (ZBI) and WHO-QOL-Bref scores.

Results. 68 caregivers were enrolled in the study with an average age of 41.6±15.9 years, and a ZBI score of 30.24±17.15. Group A had 36 caregivers and Group B had 32 caregivers. There was a significantly higher ($p<0.05$) burden in Group A as compared to Group B as evident by ZBI scores. The WHO-QOL-Bref scores in all the 4 domains were significantly higher in Group B which predicts a better quality of life.

Conclusion. Chronic kidney disease takes a toll not only on the patient but also the caregiver of the patients. The amount of burden is more in caregivers of patients on haemodialysis as well as the quality of life is compromised.

Key words: chronic kidney disease, haemodialysis, quality of life, WHO-QOL bref scores, Zarit Bruden Interview

Introduction

Chronic kidney disease is a progressive and irreversible loss of kidney's function; with early diagnosis and proper therapeutic conduct the costs and suffering to patient would be reduced [1]. There are an increasing number of patients with chronic kidney disease receiving home-based care and requiring support from family members [2]. Treatment of chronic kidney disease and complications associated with treatment affect the patient's functional abilities, narrowing their daily activities and, often, the alterations are not detected in conventional clinical and biological evaluations [1]. Patients on dialysis, has to deal everyday with having an incurable illness that forces them to follow a painful and long treatment that causes greater limitations and alterations that reflect on their quality of life. Chronic kidney disease results in alterations in the social interactions and psychological imbalances, in patient, as well as family that accompany him or her [1]. The demand of care giving, especially in managing dialysis has a profound and pervasive effect on family and friends, exact a toll on the physical, social and emotional wellbeing of caregivers [2]. The needs of caregivers' are often neglected and under-prioritized in medical management of chronic kidney disease. The caregivers experience stress from added responsibilities of managing patients' medical treatments, dietary requirements, clinic appointments and psychosocial issues. The caregivers experience depression, anxiety, fatigue, social isolation, relationship strains and financial strains [2].

The study of overload and impact on quality of life of caregivers has become more relevant in chronic diseases such as dementia, Alzheimer's disease, cancer, other pathologies requiring palliative care, rheumatoid arthritis, and gerontology, in recent years and caregiver recovery prog-

Correspondence to:

Matreja Prithpal, Department of Pharmacology, Gian Sagar Medical College and Hospital, Village Ram Nagar, Tehsil Rajpura, District Patiala, Punjab 140601 India;
Phone: +91-1762-507118; Mobile: +91-9855001847; Fax: +91-1762-520024;
Email: drpsmatreja@yahoo.co.in

rams have been implemented. However, these issues have been less studied in caregivers of chronic kidney disease patients [3].

For haemodialysis (HD), the caregiver quality of life has been assessed through questionnaires about partner relationship tests for measuring anxiety, personality, depression, vital satisfaction, and family stress, and health and quality of life questionnaires (*Short Form Health Survey SF-36*) [3].

One of studies where both patients and their caregivers were assessed found that patients were significantly more anxious and depressed but the caregivers also faced financial and disease related problems [4]. Other studies found that caregivers of haemodialysis patients experienced a significant burden and an adverse effect on their quality of life and slightly worse than the population of the same age and gender [5,6].

Despite growing awareness of the influence of chronic kidney disease on health-related quality of life (HRQOL) of patients and their family member's alike, little examination of either HR QOL or caregiver burden among Indian patients caregiver's has occurred. Hence, we designed this study to assess quality of life of caregiver's of patients suffering from chronic kidney disease.

Material and Methods

Procedure

This prospective study was conducted in Gian Sagar Medical College and Hospital, Patiala, India in the Department of Nephrology, Medicine and Pharmacology from November 2010 to February 2011. The study recruited caregiver's of all patients with chronic kidney disease visiting outpatient department as well as those admitted in inpatients department. This study was approved by the Institutional Ethics Committee of the Institution and only those volunteers who gave a written informed consent were included in study.

A total of 120 caregivers were identified as possible recruits in study. Of those caregivers only 68 caregivers participated in study and returned the filled up questionnaire. Family caregivers such as a primary caregiver were identified and recruited for the study. For purposes of the study, "family" was defined as "a unit of two caregivers or more who share bonds, are mutually related through emotional intimacy, and are conscious of being a family" [7]. These caregivers were divided into two groups based on haemodialysis of patients. Subjects in Group A were caregivers of patients who were on haemodialysis whereas; subjects in group B were caregivers of patient's not on haemodialysis.

All subjects were given complete explanations regarding the purpose and requirements of study. Participation was completely voluntary. After permission was granted by subjects, questionnaires were given to the patients caregivers. Response rate among the caregivers was approximately 55%.

Measurement

We collected data on demographic variables, family relationship and duration of the disease.

The Quality of life of caregiver was assessed with help of Zarit Burden Interview and WHOQOL-Bref Scores.

Zarit Burden Interview

Caregiver's burden was measured using Zarit Burden Interview, in English, Hindi and Punjabi translation. The ZBI scale was developed to measure burden among family caregivers of persons and consists of 22 questions with answer varying from 0=never to 4=nearly always. The score values range from 0-21, 21-40, 41-60 and 61-88, a low score indicates little or no burden whereas a high score indicates severe burden [8, 9].

The WHOQOL - Bref

This is a 26-item self-administered generic questionnaire, a short version of WHOQOL -100 scale [10]. It can be analyzed from perspective of either six domains (physical health, psychological health, level of independence, social relationships, environment, & spiritual) or four domains (physical health, psychological health, social relationships, & environment).

Modification of WHOQOL - Bref for impression of caregivers

In order to produce the version of WHOQOL-Bref with which family caregivers rated their impression of the patients' QOL, we used the method of Sainfort *et al.* [11], by giving a new direction to each item. By this modification, caregiver could rate patient as an observer. The modification of WHOQOL-Bref was thus minimal [11,12]. The internal consistency of WHOQOL-Bref, as assessed by Cronbach's alpha coefficient for responses of all caregivers was high (0.89 for the original WHOQOL- Bref, and 0.93 for the caregiver impression version) [12].

Four domains are defined for WHOQOL-BREF, based on its 24 items: domain 1, physical health, is on activities of daily living, dependence on medicinal substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, and work capacity. Domain 2, psychological health, includes bodily image and appearance, negative feelings, positive feelings, self-esteem, spirituality, religion, personal beliefs, thinking, learning, memory, and concentration. Domain 3, social relationships, covers personal relationships, social support, and sexual activity. Domain 4, environment, assesses financial resources, freedom, physical safety and security, health and social care (accessibility and quality), home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation and leisure activities, physical environment (pollution, noise, traffic, and climate), and transport. The raw score of each domain was then transferred to standardized score of 0 to 100, in order to maintain uniformity in scores. Higher

scores mean better quality of life of patients. The QOL index of each domain and their associations with demographic factors were assessed [10,13].

Statistical Analysis

The analysis was accomplished using statistical resource software Statistical Package for the Social Sciences (SPSS), applying the instrument's specific syntax, as per instructions. The data was presented as mean±standard deviation. The Student t test for independent samples and one-way analysis of variance (ANOVA) were used to compare the QOL index between caregivers' subgroups and between caregivers of haemodialysis patients and patients not on haemodialysis. Chi-square test was used to analyse non parametric data. A *p* value less than 0.05 was considered statistically significant.

Results

A total of 120 primary caregivers were recruited from November 2010 to February 2011. Out of these 68 caregivers responded to participate in study and signed the written informed consent. Demographic information of caregivers is shown in Table 1. The mean age of caregivers was 41.6±15.9 years. 63 % of caregivers were male and 43% of caregivers were spouses of the patients. The mean ZBI Score was 30.24±17.15.

Table 2 shows the demographic characteristic of caregivers who were divided into two groups. Group A had caregivers of patients who were on haemodialysis, whereas Group B had caregiver's patients not on haemodialysis. The mean age of caregivers, gender, and co-morbid disease of patients was comparable in both groups. There was a statistically significant difference in the ZBI Scores in both groups (34.89±17.39 in group A vs. 25±15.52 in group B).

Table 1. Characteristics of Family caregivers

	Caregivers	
	(n)	%
Mean Age	41.6 ± 15.9	
Men	41.65 ± 16.54	
Women	41.40 ± 14.99	
Sex		
Men	43	63.23
Women	25	36.77
Relation		
Spouse	29	42.65
Others (Parents, Siblings)	39	57.35
ZBI Scores	30.24 ± 17.15	
WHO Scores		
Domain 1	54 ± 12	
Domain 2	54 ± 17	
Domain 3	62 ± 20	
Domain 4	59.3 ± 18.1	

Table 2. Demographic Profile of Caregivers of patients with chronic kidney disease

	Group A	Group B	p value
Number of subjects	n=36	n=32	
Age (years) (Mean ± SD)	40.5 ± 15.2	42.8 ± 16.8	p=0.564*
Sex (M:F)	25:11	18:14	p=0.382#
Co morbid disease (number of patients)			
Hypertension	17	15	p=0.977#
Diabetes	17	11	p=0.408#
Relation with Patients			
Spouse	15	14	
Others	21	18	p=0.862#
ZBI Score (Mean ± SD)	34.89±17.39	25±15.52	p=0.016 ^{cr} *

^{cr}p<0.05 and is significant as compared to other group, *using two-tailed unpaired student 't' test, #using Chi-square test with Yates correction

Burden among Caregivers

Figure 1 shows the range of scores and number of caregivers in both groups. The ZBI score was divided into little or no burden, mild to moderate burden, moderate to severe burden and severe burden in range of 0-20, 21-40, 41-60 and >61 respectively. The ZBI score range in Group A was between 9 and 74, whereas in group B range was between 13 and 76. There were a statistically significant higher number of caregivers in Group A in score ranges

of more than 21, whereas higher number of caregivers in Group B had a score range of less than 21.

Figure 2 shows the WHO-QOL Bref scores in both groups. The raw score of all four domains were analysed viz Physical health, Psychological, Social relationship and environment, raw score of each domain was then transferred to standardized score of 0 to 100. The scores in all the 4 domains were higher in caregivers of patients who were not on haemodialysis. There was a statistically significant higher score in all four domains in group B as compared to group A.

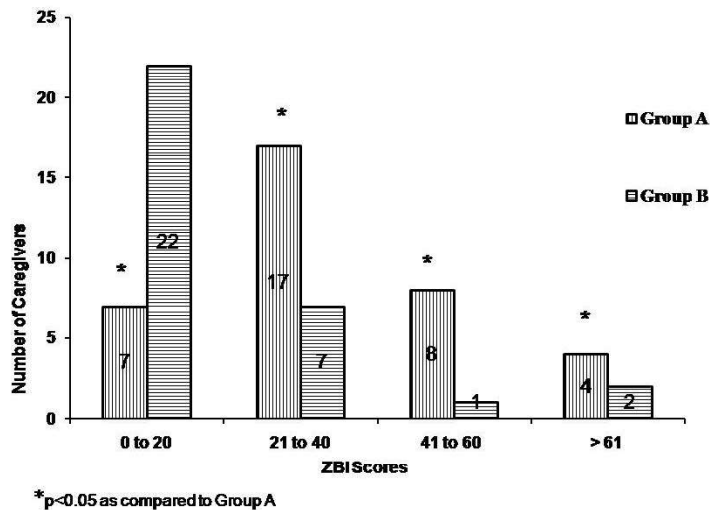


Fig. 1. ZBI scores in both groups

Discussion

The caregivers of patients with chronic kidney disease are required to provide technical care along with managing patient’s medical treatment, dietary requirement, clinic appointments and psychosocial issues resulting in stress on caregiver’s physical, social and emotional wellbeing [2]. The purpose of our study was to assess Quality of li-

fe of caregivers of patients with chronic kidney disease. Our study showed that there was moderate burden on caregivers of patients as per Zarit Burden Interview and Quality of life of caregivers was also compromised as per WHO-QOL Bref Score. The amount of burden was significantly more on caregivers whose patients were on haemodialysis and quality of life was significantly better in caregivers whose patients were not on haemodialysis.

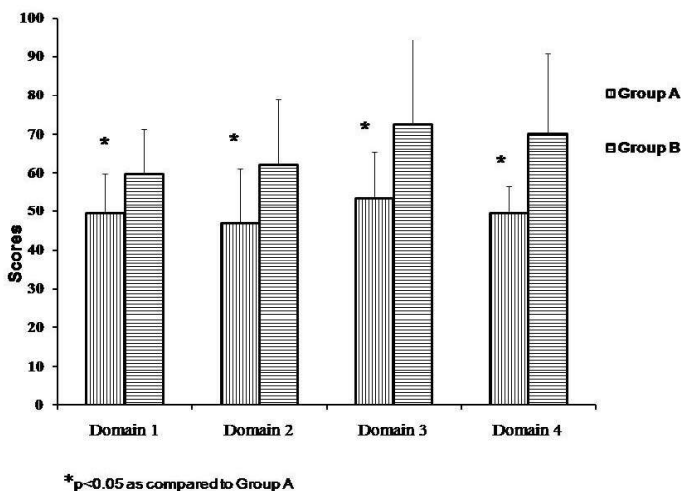


Fig. 2. WHO-QOL Bref scores in both groups

Few studies done earlier have shown a negative impact on life of patients and their partners manifesting mostly as psychological symptoms. These studies showed that ca-

regivers were less optimistic, less confrontative, had pervasive sadness, resentment, guilt and loss. The caregiver had low efficiency in handling various aspect of partner’s situation whereas other study showed a better ability of partner

to cope with life style adjustment [14-16]. The results of our study are in concordance with these studies where not only the spouse but other primary caregivers had moderate burden as well as compromised quality of life.

Other studies done to assess quality of life of caregivers of patients on haemodialysis have shown that these caregivers had a slightly worse QOL as compared to general population [6]. The caregivers of haemodialysis patients had a significant burden and an adverse effect on quality of life, and social support and psychological intervention could improve the outcome as was observed in another study [5]. The results of our study are in agreement with studies where quality of life was adversely affected in caregivers who had patients who were on haemodialysis.

Most of the studies to assess quality of life enrolled patients as well as caregivers of patients suffering from chronic kidney disease, or undergoing haemodialysis, or continuous ambulatory peritoneal dialysis. These studies found that patient as well as caregivers had a significant poor quality of life and moderate to severe burden [5,6,14-16]. The focus of all these studies was on well being of patients and its effect on quality of life of caregivers. Our study is quiet different in this aspect from these studies as in our study the main focus is on caregivers and their outlook to aspect of life which shows that caregivers entity is as important as patients.

Most of the studies done to assess quality of life have been done on patients suffering from chronic kidney disease with caregiver's aspect being taken care as a part of the study. Our study is a unique as we are only taking into account amount of burden and quality of life of caregivers of patients suffering from chronic kidney disease. There are a few limitations in our study firstly, number of volunteers enrolled in our study is limited and secondly, some psychological intervention could be given to caregivers and their quality of life could be assessed after it.

Conclusion

To conclude we studied quality of life of caregivers of patients who were suffering from chronic kidney disease. We found that in Indian set up where the social system is very strong caregivers of patients with chronic kidney disease had a moderate amount of burden and compromised quality of life. The burden was significantly more in caregivers of patients who were on haemodialysis and these caregivers had a poor quality of life as compared to caregivers of patients who were not on haemodialysis.

Conflict of interest statement. None declared.

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