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RESEARCH ARTICLE

Assessment of Anxiety and Burden on Caregivers for Haemodialysis Patients in Southern Punjab, Pakistan

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SUMMARY

The aim of this work was to assess anxiety and depression experienced by unpaid caregivers of chronic hemodialysis patients suffering from end-stage renal failure (ESRF). The evaluation of factors influencing anxiety and depression and caregiving burden was performed. In the present study, non-paid primary caregivers (218 study participants) of patients with ESRF receiving hemodialysis, who were providing care (minimum 6 months and up to 5 years) were interviewed by using the Aga Khan University Anxiety and Depression Scale (AKUADS) and the carer's burden of peritoneal dialysis patients (CSCDP) questionnaire. According to the scoring of AKUADS, 90.4% of caregivers were found to be experiencing significant anxiety and depression. From the assessment of demographic factors collected using the AKUAD scale, it was found that the female was more in number (44%), wedded (72.01%), with a mean life span of 38.5 ± 2 (standard error) years, and have monthly income below average. The main relationships of caregivers with patients were life partners (38%) and parents (18.2%). The highest depression levels were found in mothers as attendants (67%), caregivers of age less than 30 years (22 %), and caregivers of elderly patients (87%). The outcome of this study has revealed a need to plan policies to support unpaid caregivers as well as patients.

Key Words: *Caregiver, anxiety, depression, hemodialysis, objective burden, subjective burden*

Pakistan, Güney Pencap'ta Hemodiyaliz Hastalarının Bakıcılarındaki Kaygı ve Yükün Değerlendirilmesi

ÖZ

Bu çalışmada, son dönem böbrek yetmezliğinden (SDBY) muzdarip kronik hemodiyaliz hastalarının ücretsiz bakıcılarının yaşadığı anksiyete ve depresyonu değerlendirmek amaçlanmıştır. Anksiyete, depresyon ve bakım verme yükünü etkileyen faktörlerin değerlendirilmesi yapıldı. Bu çalışmada, hemodiyaliz alan SDBY'li hastalara bakım veren (en az 6 ay ve 5 yıla kadar) ücretsiz birincil bakıcılarıyla (218 çalışma katılımcısı) Agha Khan Üniversitesi Anksiyete ve Depresyon Ölçeği (AKÜADÖ) ve periton diyalizi hastalarının bakıcılarının yükü (PDHBY) anketi kullanılarak görüşüldü. AKÜADÖ puanlamasına göre, bakım verenlerin %90.4'ünün önemli düzeyde anksiyete ve depresyon yaşadığı belirlendi. AKUAD ölçeği kullanılarak toplanan demografik faktörlerden, kadın cinsiyetin sayıca daha fazla olduğu (%44), %72.01'inin evli olduğu, ortalama ömrü 38.5 ± 2 (standart hata) yıl olduğu ve aylık gelirinin ortalamanın altında olduğu belirlendi. Bakım verenlerin hastalarla temel ilişkileri hayat arkadaşları (%38) ve ebeveynleri (%18.2) ile olmuştur. En yüksek depresyon düzeyi refakatçi annelerde (%67), 30 yaşından küçük bakım verenlerde (%22) ve yaşlı hasta bakıcılarında (%87) bulunmuştur. Bu çalışmanın sonucu, hastaların yanı sıra ücretsiz bakıcıları desteklemek için politikaların planlanması ihtiyacını ortaya çıkarmıştır.

Anahtar Kelimeler: *Bakıcı, anksiyete, depresyon, hemodiyaliz, nesnel yük, öznel yük*

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INTRODUCTION

Prevalence of anxiety and depression among patients undergoing hemodialysis (HD) and their caregivers (CGs) are common psychiatric disorders (Bussotti and Sommaruga, 2018). Several factors contribute to triggering anxiety and depression in HD patients such as co-morbidities, frequent hospitalizations, chronic pain, sleep disturbances, chronic inflammation, increased fatigue, decreased sexual functioning, restrictions in diet and fluids, and dependency on health professionals are common psychiatric disorders their CGs (Zalai, et al., 2012).

A disease not only affects the patient but also affects the life of CGs in various aspects such as their social activities, professional activities, etc. (Zalai, et al., 2012). Dialysis therapy imposes several restrictions on caregivers' life such as decreased physical function, fatigue, social isolation, difficulties in relationships, and feelings of disappointment (Zalai, et al., 2012). Therefore, the prevalence of anxiety and depression among caregivers is reported by various previous studies (Heidari, et al. 2012, Loh, et al. 2017). Caregivers have to face versatile tasks and challenges while providing care to HD patients like patient transport-related issues and getting periodic appointments from doctors following the Medication regimen, coping with emergencies, dressing, symptomatic relief, and cooking customized food for patients as per recommendations.

To the best of our knowledge, research exploring the effects of anxiety and depression between patients and caregivers in Pakistan is limited. High prevalence of anxiety and depression among CGs of psychiatric patients showed 40.6%, 48 % of stroke patients and cancer patients reported 78% anxiety and depression in Pakistan (Khalid and Kausar 2008, Alvi, et al. 2014, Majeed, et al. 2018). To date, no data regarding any medical strategies adopted to reduce anxiety and depression in CGs were found in Pakistan. According to a study published, caregivers of patients use religious activity to manage stress (Kasi, et al. 2012). Only a few studies were found to assess the burden on HD CGs but no data was available to show both the anxiety and depression burden on HD CGs (Saeed, et al. 2012, Shah, et al. 2017). Thus, the present study aimed to explore the effect of anxiety and depression on CGs of HD patients.

However, the need for awareness and action to address this issue is necessary, requiring a further understanding of mental disorders to facilitate and aid in the development of policies to provide evidence-based support and guidance to unpaid caregivers.

METHODOLOGY

An analytical and descriptive cross-sectional research study was carried out from January 2020 to June 2020 in the dialysis unit of the district headquarters Hospital, in Muzaffargarh, Pakistan. Written legal consent was granted from the ethical committee (no#134P.Practice 2019 dated 26-11-19). All data was gathered through direct dialogues using the local language from the caregivers by one of the authors.

Inclusion Criteria:

Caregivers were enrolled in the study on the following basis:

1. Unpaid caregivers of age from 18 to 60 years
2. Caregivers of both genders were included.
3. Caregivers of patients on dialysis for the last 6 months
4. Caregivers of patients belonging to rural and urban areas were considered for the study.

Verbal consent was taken from caregivers individually Participants were provided with a verbal description of the study purpose and procedure.

Exclusion Criteria

CGs with any previous history of Psychiatry issues, suffering from any chronic disease, Reluctant to answer the questions, or unable to understand the sense of questions, were excluded from the study.

During the present study it was found that most CGs over 60 years were suffering from various chronic diseases such as cardiac diseases, hypertension, and diabetes so to avoid the impact of any anxiety and depression due to their diseases were excluded from the study.

Control Variables

Factors like gender specification of caregiver, life span, community and financial status, kinship with the patient, and duration of care.

Screening Tools

1. **AKUADS:** The Aga Khan University Anxiety and Depression Scale (AKUADS) is used in the present study to assess the prevalence of anxiety and depression among CGs of dialysis patients (Ali, et al. 1998). This scale consists of twenty-five contents which are further subdivided into thirteen contents representing and devoted towards mental and twelve contents representing physical health. These contents evaluate both sides to analyze anxiety and depression. With a cutoff score of 19 points, AKUADS has a specificity of 81%, a sensitivity of 74 %, and a positive predictive value of 63%.
2. **CSCDP:** To investigate the hardships which influence the life of the caregiver, the overload questionnaire for caregivers of patients on peritoneal dialysis (CSCDP) has been used which is developed by J. Teixido et al., particularly for HD patients CGs (Teixidó-Planas, et al. 2006). This screening tool comprises 3 dimensions: the patient's extent of dependence, the carer's subjective overload, and the carer's objective degree of overload. ***Objective*** overload indicates the patient's care requirements affiliated with noticeable caregiving activities. The presence of objective burden shows that the formal back inappropriately alternates with the informal back (Bayen, et al. 2015). ***Subjective*** overload indicates the emotional satisfaction related to the completion of caregiving tasks. The patient's degree of dependency, subjective burden, and objective burden were assessed according to Table 1.

Table 1. CSDP scoring scale to evaluate the degree of dependency, subjective and objective burden

Degree of overload	Patient's degree of dependency	Subjective overload	Objective overload
Slight or none	1-9	1-5	1-7
Mild to moderate	10-17	6-11	8-15
Moderate to severe	18 or more	12 or more	16 or more

Statistical Analysis

Statistical analysis was carried out by using Statistical Package for Social Sciences (SPSS, version 25). Descriptive statistics like mean, standard deviation, and frequencies were calculated for the analysis of collected data. The level of significance was $p < 0.05$.

RESULTS

In the present study, CGs' mean age was 38 years, and 50.5% & 49.5 % were men and women respectively. The most common relationship of CGs to the patient was spouse (36%) followed by daughters (12%). The highest frequency of CGs was between the age of 31-40 years (35.8%) followed by 20-30 years (33.3%), with 41-50 years (17.4%) and 51-60 years (13.3%) being the least. 57.3% of CGs provided full-time care to the patients as patients were fully dependent on them and no other CG was around.

By using **AKUADS**, anxiety and depression were classified into the categories of none, mild, moderate, and severe. To determine anxiety and depression according to the AKUADS scale cut-off score was 20. According to the responses of CGs, it was found that 9.6% had less than 20 scores and 90.4% scored 20 and above. Based on this it can be concluded among 218 CGs 90.4% suffered from anxiety and depression.

The highest levels of depression were found in CGs of age 51-60 years. Based on kinship, severe depression was seen in mothers (67%) and spouses 56.41% as compared to other relations. CGs of patients of age group 61-65 years showed a greater prevalence of anxiety and depression as compared to caregivers of patients of young age. Caregiving time is a prominent predictor of anxiety and depression with the full-time caregivers showing the highest prevalence. The *p*-value was less than 0.05 so it was a statistically significant difference (Table 3). Among 157 married CGs, 31% showed severe depression as compared to unmarried CGs (18%). According to the findings of the current research work, low socioeconomic status is one of the most contributing factors to producing high rates of anxiety and depression in CGs. CGs having a monthly income of \$156 >\$380 experienced higher levels of moderate to severe anxiety and depression in comparison to those earning greater than \$500.

Table 2. Assessment of Anxiety and depression by *AKUADS on basis of CG's demographic characteristics*

Demographic factors	n	Prevalence of anxiety and depression				
		None	**Mild**	**Moderate**	**Severe**	***P*-value**
Kinship						
spouse	78	0	3.80%	39.74%	56.41%	>0.05
mother	18	0	0	33.34%	66.67%	>0.05
father	10	0	0	57.14%	42.85%	>0.05
daughter	27	3.70%	11.11%	48.14%	37.03%	>0.05
son	10	20%	30%	30%	20%	>0.05
other	75	20%	16%	24%	40%	>0.05
Caregiver's age						
21-30 yrs	73	4.10%	47.90%	26%	21.90%	< 0.05
31-40 yrs	78	3.84%	52.56%	30.76%	12.82%	> 0.05
41-50 yrs	38	21.05%	60.52%	15.70%	2.63%	> 0.05
51-60 yrs	29	24.14%	34.48%	17.24%	24.14%	> 0.05
Monthly income						
<\$379	106	1.88%	31.13%	43.39%	23.58%	> 0.05
\$380 ≥ \$500	74	9.45%	35.14%	25.60%	29.72%	< 0.05
> \$500	38	31.57%	26.31%	23.68%	18.42%	> 0.05
Patient age						
20-30 yrs	37	18.90%	45.90%	40.50%	0.00%	> 0.05
31-40 yrs	50	22.00%	44.00%	34.00%	0.00%	> 0.05
41-50 yrs	71	4.22%	49.20%	22.50%	23.90%	> 0.05
51-60 yrs	45	0.00%	31.10%	40.00%	28.80%	< 0.05
61-65 yrs	15	0.00%	0.00%	13.30%	86.00%	< 0.05
Marital status						
Married	157	2.90%	31.20%	35.00%	31.00%	< 0.05
unmarried	61	29.50%	26.20%	26.00%	18.00%	> 0.05
Caregiving time						
Full time (More than 8 hrs	125	4.90%	9.60%	53%	32%	< 0.05
Part-time (3-5 hrs.)	93	16.10%	24.70%	25.80%	33.90%	> 0.05

*$P < 0.05$ implies significance

Table 3. Level of significance of the impact of various variables on the level of depression

Caregiving time	**Part-time CGs n=93**	**Full-time CGs n=125**	***P*-value**
Below moderate and mild depression	73%	19%	$P < 0.05$*
Moderate and above depression	27%	81%	$P < 0.05$*
Patient's age	**CGs of younger age patients (20-50 years) n=158**	**Caregivers of elderly patients n=60**	***P-value***
Below moderate and mild depression	83%	13%	$P < 0.05$*
Moderate and above depression	28%	87%	$P < 0.05$*
Caregiver age	**21-30yrs**	**31-50yrs**	***P-value***
Below moderate and mild depression	21.9%	12.8%	$P < 0.05$*
Above moderate and mild depression	40.50%	56%	$P < 0.05$*

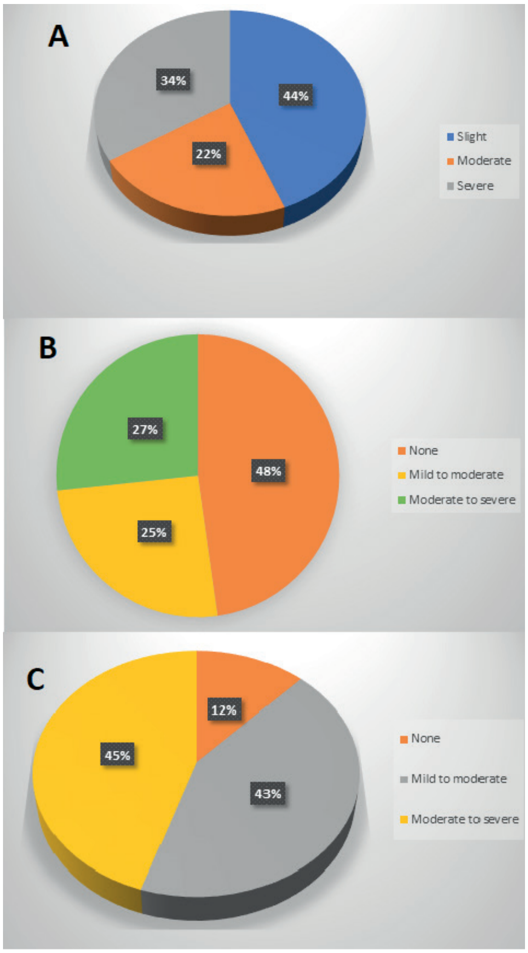

Figure 1. A, B & C represents the prevalence of anxiety and depression due to objective overload, subjective overload & physical dependency of the patient on CGs according to the CSCDP questionnaire respectively

CSCDP: Assessment of burden on CGs by application of the CSDP scale revealed that 80.9 % of them had severe anxiety due to dependence burden. 35.8% of patients showed severe dependency while 36.7% of patients had moderate dependence on their CGs. The dependency of patients on their CGs directly correlates with the health of the patient. In this study, 35.8% and 50% of CGs reported moderate and severe anxiety due to subjective overload, respectively. Mild objective burden was seen in 20.2% (n = 44), moderate objective burden was seen in 35.8% (n = 78) and severe objective burden was seen in 44% (n = 96) CGs. *CSCDP* interview results on different questions are given in Table 4.

In the present study, moderate anxiety, and depression in CGs due to dependence burden was 45%, subjective burden 24%, and objective burden 34%, while severe anxiety and depression in CGs due to dependence burden, subjective burden, and the objective burden was 43%, 24% & 22% respectively. Analysis of anxiety and depression on the base of different burdens is shown in Figures 1A, B & C.

DISCUSSION

A cross-sectional analysis of caregivers of HD patients was conducted and it was determined that a high degree of burden was experienced by CGs causing mental disorders such as clinical anxiety and depression. It must be acknowledged and discussed to alleviate the undue burden and subjective burden on informal caregivers of dialysis patients especially in under progress countries like Pakistan. More studies are needed to develop policies that will support both the patients and their CGs. Caregiving can create enormous burdens on caregivers, causing a decline in their somatic and mental health.

The results of this study highlight the hardships of caregivers for patients with end-stage renal failure on hemodialysis treatment. Both the ailment and its cure have severe effects on the patient and their CGs. Providing long-term care for this chronic disease on daily basis badly influences the caregivers physical, and mental health due to bad standards of living and a reduction in earnings and savings.

In this study, more than 90% of caregivers had clinically significant anxiety and depression. The estimated burden of anxiety and depression is not indifferent from previous work, with rates varying from 27% to 66% (Jafar 2006, Alvi, et al. 2014).

The results of the present study unveil the various aspects of CGs and how their life had changed during these care-providing activities. It was found that CGS was obsessed and oversensitive to their caregiving activities resulting in their bad quality of health and ignorance of their self-care resulting in their mental health issues. Previous studies conducted to assess the burden on CGs also support this fact (Belasco, et al. 2006, Danial, et al. 2016).

The results of the percent study showed more time CGs spend with their patient, increased the degree of burden on CGs. These findings were also reported by Evans *et al.,* and Morton *et al.*(Evans, et al. 1985, Morton, et al. 2010).

Our study enlightens that CGs of bedridden patients and old age were suffering more depression as compared to patients who were not fully dependent on their CGs for common household activities.

This study revealed that the financial condition and marital status of CGs played a vital role in the development of anxiety and depression as lack of finances increased their stress level resulting in a lack of resources to facilitate that patient and CGs.

Further, patients under expectations from their care providers overwhelmed them, for being fully responsible for patient health and all tasks. These results are also consistent with the findings of the previous study (Ando, et al. 2015). The high prevalence of anxiety and depression among CGs in developing countries could be explained on basis of various contributing reasons such as underprivileged health facilities compared to other developed countries, lack of financial resources, and lack of training for CGs. Caregiving can create enormous burdens on caregivers, causing a decline in their somatic and mental health. Many interventions need to be considered to ease this overload like betterment in patient's condition and standards of living, caregivers' appreciation at community levels, coping plans, gratitude and appreciation of mutual relationship issues, and psychosocial backup.

CONCLUSION

It was determined that the high degree of anxiety and depression experienced by the CGs affected their physical and psychological health. There is an immense need to recognize and address this issue. Various strategies are needed to reduce this burden to enhance CGs' quality of life.

Limitations

The present study was carried out in one of the hospitals of southern Punjab. If multiple dialysis units were involved in the study, it would have been more interesting, and the results could have been more reliable as well as generalizable. The time-bound nature of the study prevented detailed exploration.

Table 4. Response of CGs according to the CSDSP questionnaire

Questions asked from CGs	CGs response			
	Never %	Sometimes %	Mostly %	Always %
1. Does the patient go out frequently?	29	44	19	8
2. Does the patient do any housekeeping tasks?	69.7	17.4	4.1	4.6
3. Does the patient need help with personal cleanliness?	61.9	18.3	11.9	3.2
4. Does the patient need help take his/her food?	52.3	41.3	2.8	3.7
5. Can the patient be left alone for 2-3 hrs. per day?	28.5	31.8	17.5	22.2
6. Can the patient be left alone all night long?	34.4	33	18.8	13.8
7. Does the patient seek help to solve problems associated with dialysis?				
8. CGs must give up all personal hobbies due to the patient's burden	0.9	13.8	75.2	10.1
9. CGs having sleeping troubles	10.5	15.6	32.6	41.3
10. CGs are tired day by day due to the patient burden	11.5	38.1	25.2	24.9
11. CGs feel depressed when thinking about peritoneal dialysis daily	2.8	27.9	31.2	38.1
12. CGs feel that life is not worth living	3.6	52.8	38.1	5.5
13. Do CGs react negatively to the stress and pressure of providing care to the patient?	27.1	68.0	3.2	1.7
14. CGs feel overwhelmed because they have the responsibility of the patient's dialysis appointments	5.0	74.0	17.9	3.1
15. I do not feel like going out or having fun	46	34	11	9
16. CGs do not look to the future with much hope	52	23	12	13
17. CGs get irritated when the patient does not do things correctly or makes mistakes	44	28	18	10
18. CGs are not able to show affection	82	12	5	1
19. CGs feel anguished having to face other problems	38	44	10	8
20. To what extent does helping with dialysis impact CGs working life	11	44	28	17
21. Do CGs have to modify their holidays due to caregiving activities?	9	42	34	15
22. Does care of the patient impact CGs family life?	15	38	18	14
23. To what extent has CGs social life been altered or affected?	16	44	23	17
24. To what extent have CGs had to modify or adapt their hobbies for helping with the care of the patients and hospital appointments?	16.5	21.1	45.0	17.4
25. Do you feel CGs health has been affected?	16.5	31.7	47.2	4.6
26. Are CGs family members being affected?	14.2	17.0	60.1	8.7
27. Do CGs feel completely responsible for the health and well-being of the patient?	25.2	43.6	12.9	18.3
28. To what extent have CGs readapted or modified their schedule to accommodate the caregiving duties?	8.7	20.2	49.1	22.0

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

AUTHOR CONTRIBUTION STATEMENT

Research hypothesis (HR, MN). Experimentation and data collection (MN, ZR). Draft of the text (RS, BA) Interpretation of the data and use of software (HR), Text reviewed (AK). Statistical analysis (HR, MN). Writing, review & editing (HR, SN,)

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