Section: Internal Medicine

Original Research Article

DEPRESSION AND PSYCHOSOCIAL BURDEN AMONG CAREGIVERS OF PATIENTS WITH CHRONIC KIDNEY DISEASE

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Received : *02/06/2025*
Received in revised form : *16/07/2025*
Accepted : *03/08/2025*

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DOI: 10.70034/ijmedph.2025.3.262

Source of Support: Nil,
Conflict of Interest: None declared

Int J Med Pub Health
2025; 15 (3); 1417-1424

ABSTRACT

Background: Chronic Kidney Disease (CKD) presents a growing global health burden, affecting not only patients but also their informal caregivers. These caregivers often face considerable psychological challenges, yet their mental health remains underrecognized in routine clinical care. The objective is to evaluate the prevalence and severity of depression and psychosocial burden among primary caregivers of CKD patients and to analyze associated demographic and clinical factors.

Materials and Methods: A cross-sectional analytical study was conducted among 418 caregivers of CKD patients attending a tertiary care teaching hospital. Data were collected using a structured questionnaire, including socio-demographic information and the Hospital Anxiety and Depression Scale (HADS). Statistical analysis was performed using SPSS software.

Results: The prevalence of abnormal depression and anxiety scores among caregivers was 74.2% and 80.4%, respectively. Depression and anxiety were significantly associated with longer duration of patient treatment (>3 years), older patient age, and lower socioeconomic status. The study highlights the substantial psychological toll experienced by caregivers, which intensifies over time and remains largely unaddressed.

Conclusion: CKD caregivers experience high levels of depression and anxiety, exacerbated by prolonged caregiving and financial stress. These findings underscore the necessity of integrating mental health screening and early psychological support into nephrology care frameworks to improve outcomes for both patients and their caregivers.

Keywords: Chronic Kidney Disease, Caregiver Burden, Depression, Anxiety, HADS, Mental Health, Hemodialysis, Cross-sectional Study.

INTRODUCTION

According to the Global Burden of Disease, CKD is one of the top 20 causes of mortality and is quickly gaining public health relevance.[1] It imposes a significant socioeconomic, physical, and mental strain on its sufferers and caretakers.[2]

Caregiving has significant implications for the patient's long-term well-being, as carers play a critical role in preserving the benefits of rehabilitation, which are maximised when the family is healthy and compassionate.[3]

The majority of patients with severe CKD, particularly those receiving renal replacement therapy (RRT) such hemodialysis (HD) and peritoneal dialysis, typically get support from others for their ability to lead a nocturnal lifestyle. People who are heavily active in monitoring and assisting cases during the period of sickness complaint are known as caregivers.[4]

Caregivers of CKD patients play an important part in their care, including medicine administration, special diet preparation, transportation to the hospital to maintain clinic attendance, dialysis treatments, and personal care.[5]

These people are referred to be informal carers since the majority of them are family members or close friends. These caregivers are more likely to suffer from stress, hopelessness, anxiety, and a worse quality of life as a result of caring for and supporting their loved ones.[6]

CKD caregivers frequently experience deterioration in family connections, stress, and social isolation. Because most renal teams do not completely engage these caregivers in their management plan, the psychological needs of these caregivers are frequently disregarded and unsatisfied by the health personnel caring for these CKD patients. These circumstances may have a negative impact on the overall outcome of CKD patients.[7]

Most of the existing studies focuses on the burden of the patients suffering from CKD while this study focuses on the burden of the caregivers in a hospital to assess their psychosocial well being and quality of life. The aim of this study is to examine the relationship between caregiver burden and depression in spouses and caregivers of CKD patients and to clarify the role of anxiety, quality of life, and demographic factors in this relationship. In particular, we investigated whether caregiver burden depends on the above parameters.

Aims & Objectives

- To assess the psychosocial burden and depression in primary caregivers of patients diagnosed with chronic kidney disease.
- To study about the relationship between the severity of depression of caregivers and their attitude towards the disease.
- To create awareness about the level of depression undergone by the caretakers of CKD patients so as to make them undergo counselling at early stage of their depression

MATERIALS AND METHODS

Type of Study: Cross sectional analytical study

Study Design: Cross sectional study involving the caregivers of CKD patients as cases.

Study Population: The study participants are caregivers of CKD patients, (selected from in patient or outpatient facilities of the Department of Medicine or General Medicine and Department of Nephrology and Hemodialysis unit) for atleast one month who gives informed consent.

Study area: Tertiary care teaching hospital

Inclusion Criteria

All the first degree caregivers of CKD patients in the family who accompany the patients for various modalities of treatment.

Exclusion Criteria

Caregivers who don’t give valid written consent will be excluded.

Sample Size: 418

$$\frac{Z\ (1-\alpha/2)2pq}{D2} = \frac{(1.96)2x75.5x23.5}{(4.18)2}$$

Z(1−α/2)- Standard normal variate for level of significance, at 5% type I error it is 1.96

d – Absolute error or precision (d=4.18)

p – Expected proportion in population based on previous studies (p=75.5)

q – 100- p (q=23.5)

Methods

- Data is collected using a questionnaire consisting of socio-demographic status, a scale to measure the amount of depression the caregiver faces and the effect of this depression on the care provided to the patients of CKD. The collection of data was of interview type.
- Details of the patients are retrieved from the hospital records viz., renal parameters, Complete blood count, Serum levels of minerals and Ultrasonogram of Abdomen and pelvis.

Informed Consent: Written informed consent was obtained from the study population preceding the study.

Statistical Analysis: The data was analysed using SPSS software. Socio-demographic data are expressed in frequency and percentage.

Conflict of Interest: nil

Confidentiality of the study subjects: is maintained.

RESULTS

Table 1: Age groups: mean 47 ± 3

Age Groups	Number of People	Percentage of People
35–44	124	29.67%
45–54	144	34.55%
55–65	150	35.88%

2.Gender: M = 67.5%, F = 32.5%

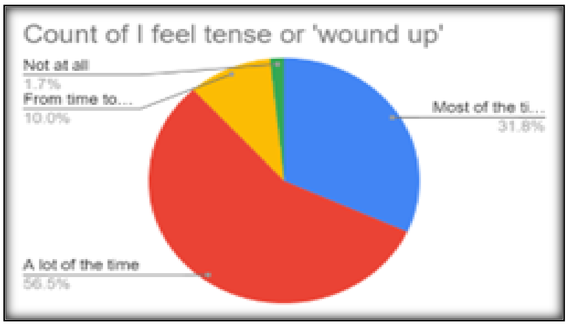
3.Socioeconomic status

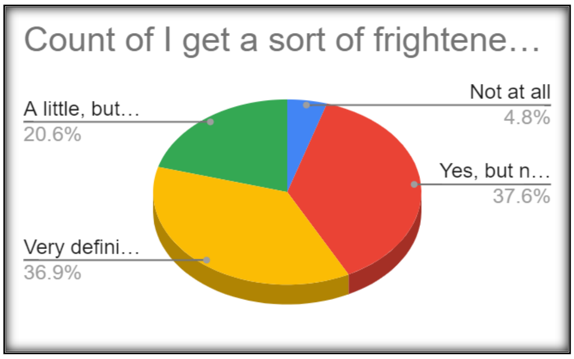
4.Analysis by HADS scoring

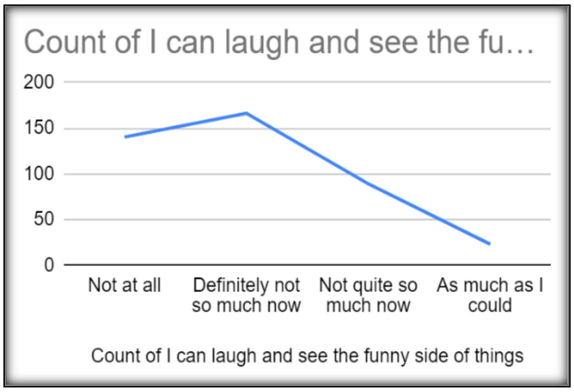
Socio-economic Status	Number	Percentage (%)
Upper Middle Class	130	31.1%
Middle Class	146	34.9%
Lower Middle Class	142	33.9%

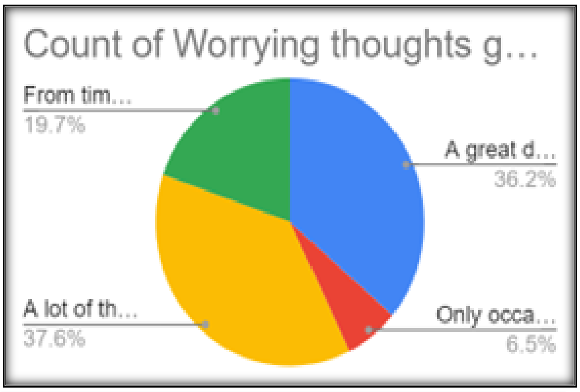
I feel tense or 'wound up'		
Response	**Number**	**Percentage (%)**
Most of the time	133	31.8%
A lot of the time	236	56.5%
From time to time, occasionally	42	10.0%
Not at all	7	1.7%
I still enjoy the things I used to enjoy		
Definitely as much	13	3.1%
Not quite so much	53	12.7%
Only a little	192	45.9
Hardly at all	160	38.3%
I get a sort of frightened feeling as if something awful is about to happen		
Very definitely and quite badly	154	36.9%
Yes,but not too badly	157	37.6%
A little,but it doesn't worry me	86	20.6%
Not at all	20	4.8%
I can laugh and see the funny side of things		
As much as I always could	23	5.5%
Not quite so much now	89	21.3%
Definitely not so much now	166	39.7%
Not at all	140	33.5%
Worrying things go through my mind		
A great deal of the time	151	36.2%
A lot of the time	157	37.6%
From time to time, but not too often	82	19.7%
Only occasionally	27	6.5%
I feel cheerful		
Not at all	138	33.1%
Not often	163	39.1%
Sometimes	87	20.9%
Most of the time	29	7%
I can sit at ease and feel relaxed		
Definitely	7	1.7%
Usually	58	13.9%
Not often	181	43.3%
Not at all	172	41.1%
I feel as if I am slowed down		
Nearly all the time	147	35.2%
Very often	146	34.9%
Sometimes	98	23.4%
Not at all	28	6.7%
I get a sort of frightened feeling like 'butterflies' in the stomach		
Not at all	31	7.4%
Occasionally	82	19.7%
Quite often	188	45.1%
Very often	116	27.8%
I have lost interest in my appearance		
Definitely	139	33.3%
I don't take as much care as I should	138	33%
I may not take quite as much care	93	22.2%
I take just as much care as ever	49	11.7%
I feel restless as I have to be on the move		
Very much indeed	125	29.9%
Quite a lot	176	42.1%
Not very much	92	22%
Not at all	25	6%
I look forward with enjoyment to things		
As much as I ever did	26	6.2%
Rather less than I used to do	79	18.9%
Definitely less than I used to	150	36%
Hardly at all	162	38.8%
I get sudden feeling of panic		
Very often indeed	87	20.8%
Quite often	190	45.5%
Not very often	112	26.8%
Not at all	29	6.9%
I can enjoy a good book or radio or TV program		
Often	33	7.9%
Sometimes	83	19.9%
Not often	173	41.4%
Very seldom	130	31.1%

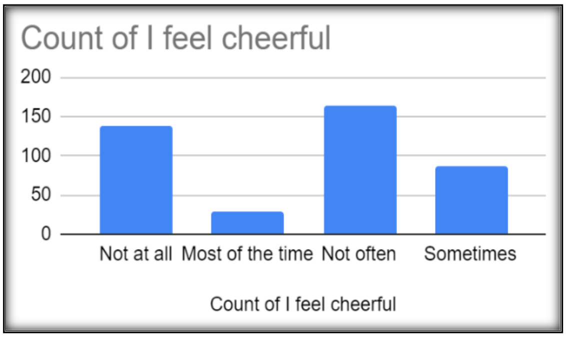
	Anxiety analysis	Depression analysis
Normal	5(1.2%)	16(3.8%)
Borderline abnormal	77(18.4%)	92(22.0%)
Abnormal	336(80.4%)	310(74.2%)

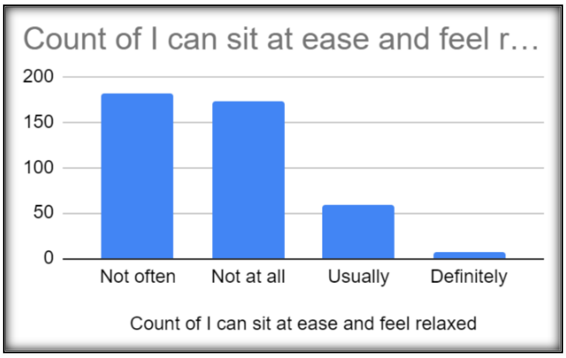


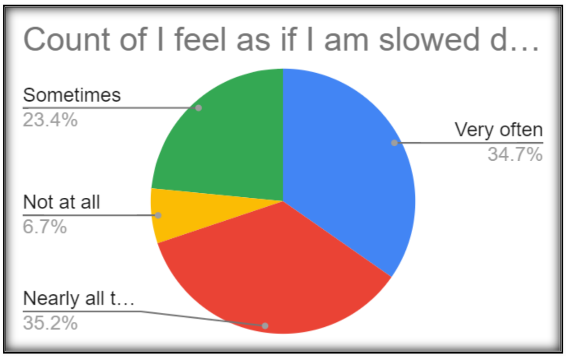


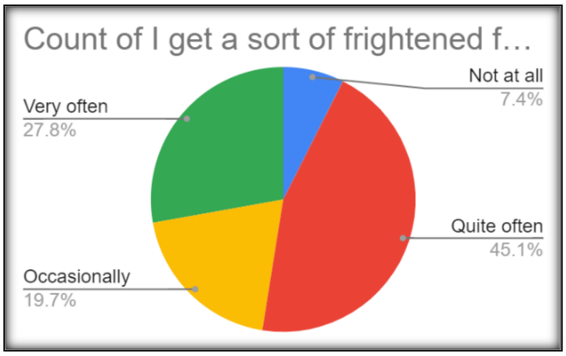


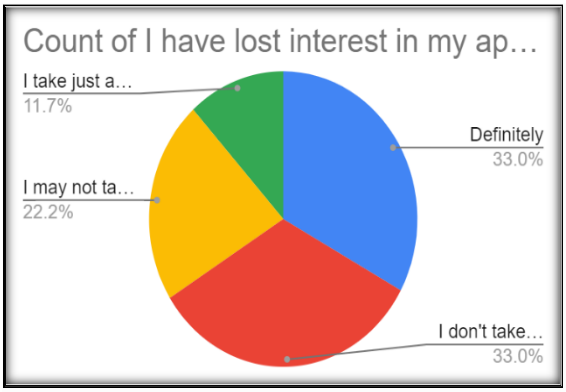


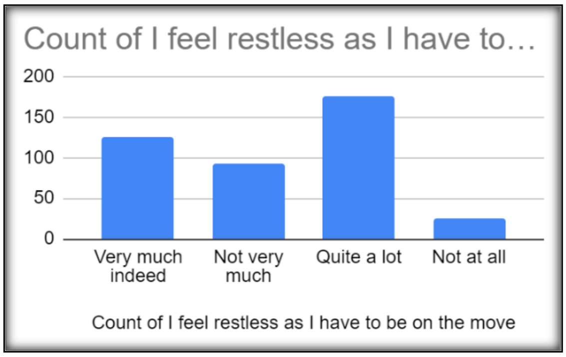


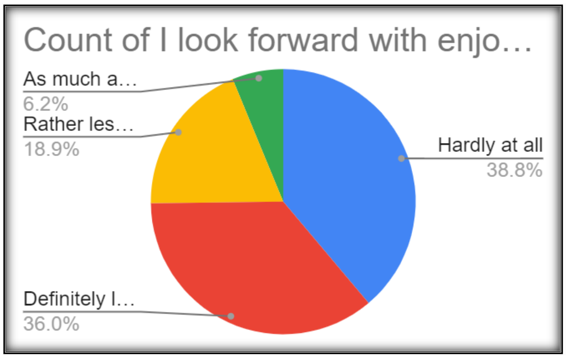


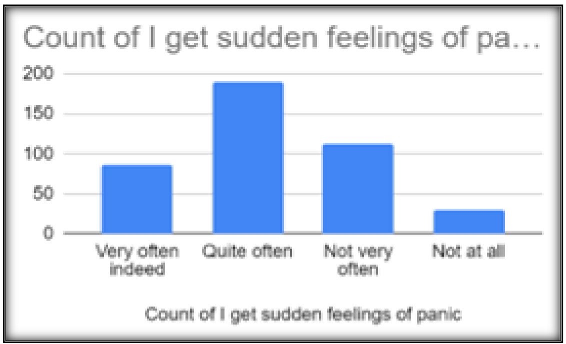


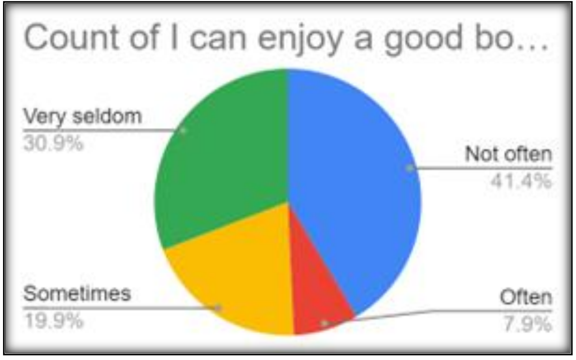












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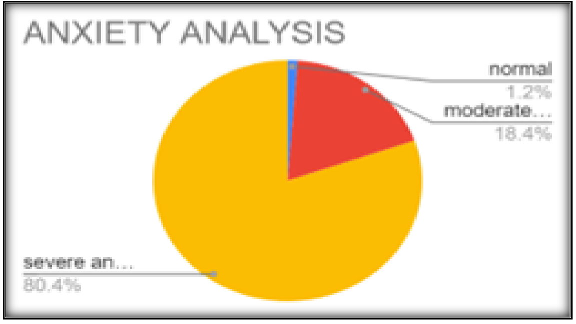
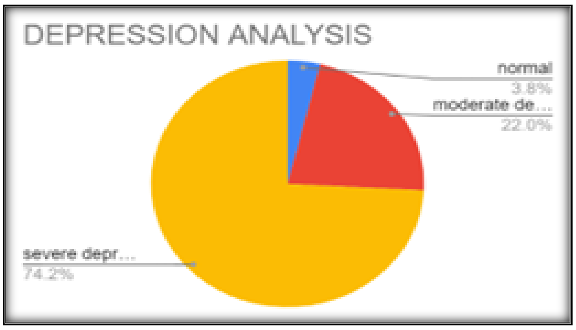




Relationship of duration of treatment with the level of depression

	Less than 3 years	**More than 3 years**
Normal(mild)	4	12
Borderline(moderate)	22	70
Abnormal(severe)	84	226

Relationship of duration of treatment with the level of anxiety

	Less than 3 years	**More than 3 years**
Normal(mild)	3	2
Borderline(moderate)	24	53
Abnormal(severe)	83	253

Thus, both anxiety and depression increase gradually as the age of the patient undergoing the treatment increases. This is represented in the below figure.

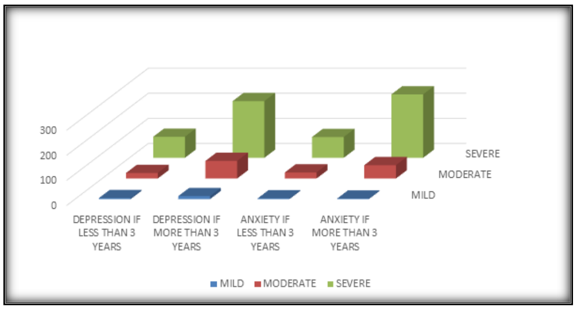
Relationship of depression according to age group of the patients

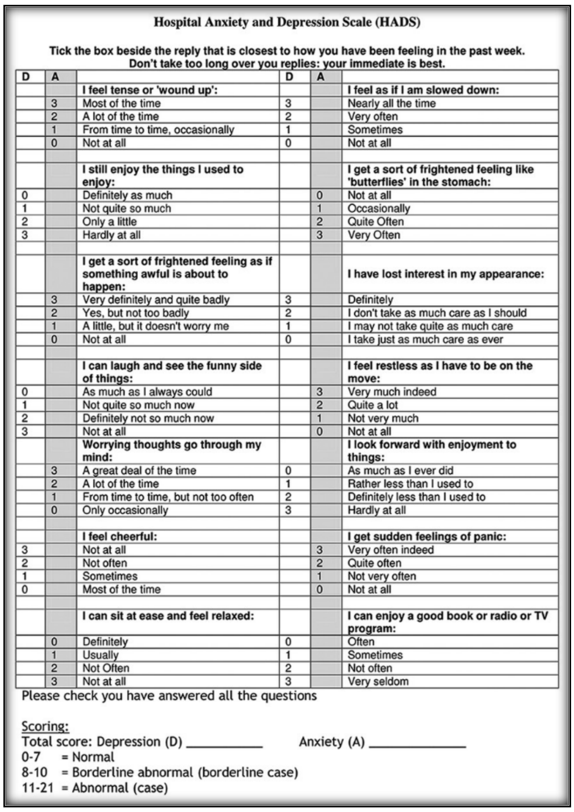
	0-7(Mild)	8-10(Moderate)	11-21(Severe)
35-44	5	8	3
45-54	27	29	36
55-65	98	92	120

Relationship of anxiety according to age group of the patients

	0-7(Mild)	8-10(Moderate)	11-21(Severe)
35-44	2	1	2
45-54	25	20	32
55-65	103	108	125

The level of depression and anxiety both increase as the age group of the patient increases. This signifies that the age of the patient is related directly to the level of depression of their caregivers.





Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			**I feel as if I am slowed down:**
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			**I get a sort of frightened feeling like 'butterflies' in the stomach:**
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			**I have lost interest in my appearance:**
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			**I feel restless as I have to be on the move:**
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			**I look forward with enjoyment to things:**
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			**I get sudden feelings of panic:**
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			**I can enjoy a good book or radio or TV program:**
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:
Total score: Depression (D) __________ Anxiety (A) ____________
0-7 = Normal
8-10 = Borderline abnormal (borderline case)
11-21 = Abnormal (case)

DISCUSSION

This study was a cross-sectional questionnaire-based study. The questionnaire used is HADS scaling system,[17] along with demographic and patients details and the severity of illness depending on the duration of treatment taken. A convenience sampling method was implemented in this study.

To summarize, this study clearly pointed out that the caregivers of patients with CKD undergo depression and psychosocial stress much more than the normal people. Also, their awareness about this depression is very poor which must be look forward into as a serious issue.

In the Gulf, renal disorders are quite common and are becoming more prevalent. It has been reported that patients with renal illness experience increased rates of depression, as well as carers who experience emotional stress.[18] It may be deduced that the high prevalence of renal illnesses in the Kingdom may also reflect a high prevalence of the depression that is connected with these diseases, but the therapy of the kidney disease is given far more attention than the depression that is related to it. This investigation investigates the frequency of depression in caregivers. Depression should be given the same consideration as renal illness since both conditions are equally devastating. It is ranked as the second most debilitating and expensive condition in the world.[19]

Among the caregivers almost everyone was found to have depression as CKD is a debilitating disease and thus no cure or reversal can occur at any stage of the disease. This leads to increased depression among the patients and also the caregivers as a lifelong problem which cannot be reverted back. The risk of depression among the caregivers was found to be more than four times higher than in general population.[20]

Numerous studies have shown that the causes of depression in CKD patients include the reaction to the diagnosis, the type of lifelong treatment the patient will receive, and the consequences of these long-term treatments, such as reduced quality of life, job loss, and financial burden on the patient and family.[21-23] The effects of depression, which is known to be a disabling condition, exacerbate these reactions. The incapacity of the depressed individual to carry out daily tasks, including as thinking, eating, sleeping, and working, becomes even more apparent. The symptoms might include exhaustion, despondency, restlessness, headaches, and even suicidal thoughts.[24] Also, it's been clearly observed in our study that the lower middle class undergo a bit more of a depression than those from other class due to their additional stress relating to the cost of treatment for their beloved ones.

Most of the time, the patient and family are more concerned with medication adherence than they are with recognizing the importance of depressive symptoms. There may be a treatment gap for depression in CKD patients. Only 16% of HD patients with depression were receiving therapy, according to Watnick et al. In order to improve other negative outcomes, such as inadequate nutritional status and treatment compliance related to CKD, treating depression in CKD patients is crucial. The depression of CKD patients in turn leads to an increased level of depression for their caregivers.[25]

When compared to those without depression, patients on chronic HD are twice as likely to pass away or need hospitalization within a year, and they run the risk of a 30% increase in both total hospital days and number of hospitalizations.[26] Couples who have CKD may experience stress in their traditional marital roles. The patient's capacity to work might be impaired, which would further change the relationship roles. Additionally, the patient's unhappy feelings could be tied to their marriage. The spouses who take on the role of caretakers may feel depressed or hostile. Sexual dysfunction may ultimately alter the dynamics of the partnership.[27,28]

The ability to comply with therapy and provide for the family's financial requirements might be severely impacted by financial stress. But research examining the connection between survival and Socio-economic status in CKD patients have revealed that greater Socio-economic status was linked to better survival, independent of race.[29] The caregivers have a variety of challenges, such as changes to their sleep patterns, health, social lives, and holiday preparations. At least three days a week are spent on dialysis for both patients and caretakers, which limits their social life and makes them feel dependent on the dialysis Centre.[30] Consequently, they are forced to drastically alter their way of life.[31]

Caregivers miss days of work and more likely to quit or retire early.[32] Despite the stress that caregivers endure, they have not been given the management they need to prevent depression and other side effects of the caregiving load. Patients' and caregivers' depression have been overlooked and given less attention than the patients' CKD treatment. The death rate of carers who encountered these challenges was found to be greater than that of the control groups who did not provide care.

The number of subjects with anxiety in 418 caregivers are 336 members who are 80.4% who undergo anxiety symptoms as per the HADS scale. Also, around 77 members who undergo mild to moderate anxiety features comes to 18.4%. The number of depressive individuals in the 418 volunteers seems to be 310 members who are around 74.2% and mild to moderate depression with 92 members who come as 22%. This almost proves that the level of depression and anxiety among the relatives of patients with CKD are found to be higher than the normal people.

Also this study has clearly pointed out that the depression and anxiety level increases if the duration of treatment taken by them is more than 3 years as the caregivers are prone to accompany them for the whole duration thus leading to affection in their normal day to day activites than those who accompany patients of recently diagnosed CKD patients. The study also stated out that the level of anxiety and depression increase according to the age group of patients undergoing Hemodialysis.

Implications: This study provided benefit in analyzing and educating the caregivers about the depression they are facing while they are taking extensive care of their relatives and accompanying them for hemodialysis frequently.

This makes the doctors and other health care workers to care about the relatives of CKD patients while assessing their depression scale using a similar scale like HADS even during the time of diagnosis to prevent them getting frustrated in accompanying their relatives so as it doesn't affect their personal life, economic conditions and their social life. This makes the doctors to take care of the caregivers and give proper psychiatric counselling in an early stage of their depression thus reducing further upcomings in their life.

CONCLUSION

Patients with CKD and those who care for them need to be made aware of the high frequency of depression among themselves, the circumstances that make it more likely to occur, as well as the effects it can have on their marital, social, and economic situations.

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