DOI: https://doi.org/10.53350/pjmhs22167308

ORIGINAL ARTICLE

Depression in Primary Caretakers of Maintenance Hemodialysis Patients

NATASHA KHATRI[1], KIRAN NASIR[2], RUQAYA QURESHI[3], MURTAZA DHROLIA[4], AASIM AHMAD[5]
[1]Resident Physician, [2]Associate Professor, [3]Assistant Professor, [4,5]Professors, Department of Nephrology, The Kidney Centre, Karachi Sindh Pakistan
Correspondence to: Natasha Khatri, Email: natasha.khatri90@outlook.com, Cell: 0336-0652667

ABSTRACT

Objective: To assess the frequency of depression among the primary caretakers of maintenance hemodialysis (MHD) patients at our center and its association with different factors.

Study Design: Prospective cross-sectional study.

Place and Duration of Study: The Kidney Centre Postgraduate Training Institute Karachi, Pakistan from 1st July 2021 to 31st December 2021.

Methodology: One hundred and eighty-five data were collected using two questionnaires, one for demographic data and other was Beck Depression Inventory (BDI-II) for assessment of depression, filled by the primary investigator and caretaker respectively. BD-II is a self-reporting questionnaire that consists of 21 questions and is used globally for measuring the severity of depression.

Results: There were 123 (66.5%) males and 62 (33.5%) females. The mean age was 44.8±12.4 years. Hypertension was the most prevalent comorbid in 56 (30.3%) followed by diabetes mellitus in 32 (17.3%). The most common relationship was children of the patient in 59 (31.9%), whereas the second most common relationship was a spouse in 54 (29.2%). We found that 99 (53.5%) of our study participants had minimal depression, while none had severe depression. Variables like education, work status, monthly income, number of earning people, years on hemodialysis, comorbid conditions, and relationship with the patients were significantly associated with the degree of depression ($P<0.05$).

Conclusion: The participants were suffering from minimal depression. We also found a positive association of depression in caretakers with multiple study variables. These findings will help physicians identify depression in caretakers of maintenance hemodialysis patients and identify those who need a referral to a psychiatrist/psychologist for proper treatment.

Keywords: Depression, Primary Caretaker, maintenance, Hemodialysis

INTRODUCTION

End-stage renal disease (ESRD) is increasing, especially in elderly patients who require special care.[1] Patients requiring maintenance hemodialysis (MHD) for ESRD undergoes physical, psychological, financial, and social difficulties.[2] They require support from their caretaker, which causes an increased burden on the caretaker.[3] MHD affects the lifestyle of both patient and the caretaker.[4] Home dialysis therapy, with peritoneal dialysis (PD) or hemodialysis (HD), is associated with a better standard of life and better well-being for dialysis patients but with a greater obligation on the caretaker.[5,6]

Depression is the most common psychiatric disorder among MHD patients and their caretakers. The burden has increased on the caretakers with a rise in the number of patients requiring MHD. Depression affects family members and affects the dynamics within the family.[7] Medications and their adverse effects, immobility and associated fatigue, malaise, inability to work, sexual dysfunction, fear of death, and dependency on a machine for life, adversely affect the quality of life of patients undergoing MHD and leads to depression.[8]

A caretaker is defined as person who takes care of a patient with chronic illness. An informal caretaker takes care of the patient's somatic, mental, and monetary necessities without getting a salary. They can be family members or friends, whereas formal caretakers are paid and designated professionally. Important obligations of caretakers of MHD patients are to timely give medicines, look after their diet, and bring their patients for clinic follow-ups and their routine MHD while maintaining their lifestyle.[9,10]

Chronically ill patients like ESRD on MHD are usually married and in mid to elderly age groups. Their caretakers are mostly spouses of similar age groups;[11] most of them have an illness, lack community links, and are restricted financially. Such obligation of caretaking can lead them to sadness, unsatisfactory well-being, and stress that subsequently affect their standard of life, which becomes inferior to the general population. It is similar to the caretakers of other chronic illnesses, and hence they are sometimes referred to as hidden patients.[12,13]

Many factors increase stress and depression in caretakers, including a low level of education, increased caretaker's age, level of patient's caring capability, associated comorbid conditions like ischemic heart disease (IHD), disturbed office hours in those working, taking time off, losing job, retirement, financial situation of the family, having children, and comorbidities.[14]

The Pakistani population lives in a close family network. In most families, close relatives (parents, children, siblings, spouses) are expected to take care of the chronically ill person, as most families cannot afford formal caretakers. The prevalence of depression in caretakers of MHD patients was found to be 33.4% in a study done in Pakistan, which was associated with low financial status, unemployment, and marital status.[8]

Mental and physical support systems for caretakers of chronic diseases like ESRD are lacking in our country as the problem is not highlighted well. The mental well-being of caretakers of MHD patients may be missed, and their necessities overlooked, leading to depression. The purpose of this study is to evaluate the frequency of depression among the caretakers of MHD patients at our centre and look for factors associated with it. This will help in timely referral, diagnosis, and management of depression in caretakers by a psychologist.

MATERIALS AND METHODS

This prospective cross-sectional study was done at The Kidney Centre Postgraduate Training Institute Karachi, Pakistan (TKC-PGTI) from 1st July 2021 to 31st December 2021 after approval from the hospital ethical review committee (TKC-ERC reference No. 97-NEPH-072020). A total of 185 caretakers of MHD patients at our center were recruited for this study. Participants included in this study were those who gave written informed consent, are between the ages of 18- 85 years, who were able to comprehend in Urdu or English, who were not a member of the medical or healthcare team of the hospital, and are not providing care to any other chronic patient at home. Those who had previous treatment for depression, cognitive dysfunction, psychiatric or neurological disorder, drug or alcohol abuse, and those who were unwilling to participate, were excluded. Confidentiality was ensured throughout the study. Each participant was interviewed separately after taking written informed consent. Participants were given full authority to refuse to participate or withdraw from the study.

Two research questionnaires were used. One questionnaire was pre designed by the study investigators for collection of demographic data. Other was Beck Depression Inventory (BDI-II) for depression scoring. The questionnaire for demographic data was filled by the primary investigator (PI) by directly inquiring from

the participants, including; age, sex, occupation, socio-economic status, marital status, number of children, co-morbid conditions, and relationship with the patient. The participants filled BDI-II while they waited outside the hemodialysis hall for the completion of their patient's MHD session.

The frequency of Depression was evaluated by using BDI-II. The Urdu version was adapted and validated. This questionnaire consisted of 21 questions, total score consisted of 63, out of which 0-13 for minimal; 14-19 for mild; 20-28 for moderate; 29-63 for severe depression. There were 5-point Response Scale (0-4 Likert Response Scale): 0 for Not at all; 1 for Very seldom; 2 for Sometimes; 3 for Most of the time; 4 for All of the time. A score of >21 was highly suggestive of clinical depression. BDI-II was given to the participants. PI explained the questionnaire and filled the questionnaire with a verbal inquiry for participants that could not read or write. The PI checked the questionnaire for any missing variables after being filled by the participants.

Data was entered and analyzed using SPSS-21. Chi-square or Fisher's exact test established the association of parameters with the level of depression as appropriate. P-value of ≤0.05 was considered significant.

RESULTS

There were 123 (66.5%) males and 62 (33.5%) females. The mean age was 44.8±12.4 years. One hundred and forty-two (76.8%) were married, 69 (37.3%) were graduates, 79 (42.7%) were doing an office job, 84 (45.4%) belonged to an income group of <50,000 PKR, and 99 (53.5%) had only one earning family member. Hypertension (HTN) was the most prevalent comorbid in our study participants 56 (30.3%) followed by diabetes mellitus (DM) 32 (17.3%) [Table1].

The most common relationship was found to be children of their patient in 59 (31.9%) whereas the second most common relationship was spouse in 54 (29.2%) [Fig. 1]. According to the categories of BDI-II questionnaire, 99 (53.5%) of our study participants had minimal depression while none of the participants had severe depression (Fig. 2).

Variables like gender, age and marital status of the participants were not significantly associated with the level of depression, whereas, education, work status, monthly income, number of earning individuals in the family, years on MHD, comorbid conditions and relationship with the patient was found to be significantly associated with the degree of depression (P<0.05). The graduate or a higher than graduate-level education participants had minimal depression 73 (73.7%) compared to other levels of education. Similarly, work status had a profound impact on the level of depression. Most of the participants who were doing an outdoor job (fieldwork) had minor and moderate depression [23 (43.4%) and 13 (39.4%) respectively] as compared to other types of jobs, while 66 (66.7%) of office workers (indoor job) had minimal depression. We found that participants had minor to moderate depression [minor depression 46 (86.8%), moderate depression 32 (97%)] in the income group of < 50,000 PKR, whereas 52 (52.5%) had minimal depression in the income group of >100,000 PKR. The participants who had only one earning family member in their house were moderately depressed 29 (87.9%), as compared to those with three and more earning people in the family. Among all moderately depressed participants, the majority were taking care of their patients for more than 5 years 22 (66.7%). The percentage of moderate depression among DM participants was higher than minimal and minor depression (36.4% v/s 13.1% and 13.2%), respectively, although 86 (86.9%) of the nondiabetic participants had minimal depression. Similar observations were found among participants with HTN and ischemic heart disease (IHD). Relationship with the patient was strongly associated with levels of depression. Majority of the participants 39 (39.4%) were children of their patients in the minimal depression group, whereas 16 (48.5%) of the participants were the parent of their patients in the moderate depression group. (Table 2).

DISCUSSION

Depression not only affects the patient but their caretaker as well. We found that majority of our study population had minimal depression, whereas none had severe depression. A study done in Greece evaluated the relationship between anxiety and depression in MHD patients and their caretakers, and they found that caretakers had significant anxiety when their patients had anxiety as well (42.3%), and caretakers had significant depression when their patients had depression as well (17.6%).[7] Another study done in Iran showed that caretakers had a moderate to severe care burden and had a poor standard of health.[15]

Caretakers experience colossal responsibility in taking care of their patients, which affects their mental and physical health and creates a burden on them. In our study, HTN was the most common comorbid condition among the caretakers, followed by DM. We found that most diabetic participants had moderate depression, whereas minimal depression was found in nondiabetic participants. With an increasing number of ESRD patients and dependence on renal replacement therapy (RRT), the burden on caretakers is increasing. In developing countries, formal paid caretakers are challenging to arrange due to cost; hence, most caretakers are family members. A meta-analysis of 61 studies that included 5,367 caregivers from 21 countries showed that the quality of life of caretakers was below the general population and that most of the caretakers were the patient's spouse.[3]

Table 1: Baseline parameters of study participants (n=185)

Variable	No.	%
Age	44.8±12.4	
Years on Hemodialysis	3.8±2.8	
BDI-II scores	10.5±7.4	
Gender		
Male	123	66.5
Female	62	33.5
Marital status		
Unmarried	38	20.5
Married	142	76.8
Widow	1	0.5
Divorced/Separated	4	2.2
Education		
Uneducated	24	13
Primary	14	7.6
Secondary	21	11.4
Intermediate	45	24.3
Graduate	69	37.3
Above graduation	12	6.5
Work status		
Jobless	22	11.9
Housewife	37	20
Indoor(office) work	79	42.7
Outdoor (Field) work	43	23.2
Student	4	2.2
Monthly household income		
< 50,000 PKR	84	45.4
50,000-100,000 PKR	48	25.9
> 100,000 PKR	53	28.6
Earning persons in household		
One	99	53.5
Two	62	33.5
Three	18	9.7
Four	4	2.2
Five	2	1.1
Diabetes mellitus	32	17.3
Hypertension	56	30.3
Ischemic heart disease	5	2.7
Smoker	21	11.4
Betel nut addiction	23	12.4

This study showed that most caretakers were children of patients followed by spouse. As a developing country, in Pakistan, immediate family members, especially children, are usually the caretakers of their parents, especially if they have a chronic

disease like chronic kidney disease (CKD). This could be the reason for minimal depression among children as caretakers in our study. In another study done in Pakistan, the majority of caretakers were spouses followed by children of MHD patients. They had mild to moderate burden of care to their patients, and depression in caretakers was associated with the number of years their patient was on MHD.[16] A similar result was found in our study as most moderately depressed participants were taking care of their patients for more than five years.

Table 2: Association of study variables with intensity of depression in care takers of MHD patients

Parameter	Score of Depression						P value
	Minimal		Minor		Moderate		
	No.	%	No.	%	No.	%	
Gender							
Male	66	66.7	35	66	22	66.7	0.997
Female	33	33.3	18	34	11	33.3	
Age (years)							
≤ 35	30	30.3	15	28.3	6	18.2	0.073
35-50	41	41.4	23	43.4	9	27.3	
> 50	28	28.3	15	28.3	18	54.5	
Education							
≤ Primary	7	7.1	17	32.1	14	42.4	<0.001
Secondary-High school	19	19.2	31	58.5	16	48.5	
Graduate and above	73	73.7	5	9.4	3	9.1	
Marital status							
Single	28	28.3	11	20.8	4	12.1	0.144
Married	71	71.7	42	79.2	29	87.9	
Work status							
Jobless	8	8.1	8	15.1	10	30.3	<0.001
Housewife	18	18.2	11	20.8	8	21.2	
Outdoor (field) work	7	7.1	23	43.4	13	39.4	
Indoor (office) work	66	66.7	11	20.8	2	6.1	
Monthly household income							
< 50,000 PKR	6	6.1	46	86.8	32	97	<0.001
50,000-100,000 PKR	41	41.4	6	11.3	1	3	
> 100,000 PKR	52	52.5	1	1.9	0	0	
Earning persons in house							
One	36	36.4	34	64.2	29	87.9	<0.001
Two	40	40.4	18	34	4	12	
Three and above	23	23.2	1	1.9	0	0	
Years on Hemodialysis							
≤ 1 year	31	31.3	9	17	2	6.1	<0.001
1-3 years	39	39.4	14	26.4	3	9.1	
3.1-5 years	23	23.2	15	28.3	6	18.2	
Diabetes Mellitus							
No	86	86.9	46	86.8	21	63.6	0.006
Yes	13	13.1	7	13.2	12	36.4	
Hypertension							
No	74	74.7	38	71.7	17	51.5	0.036
Yes	25	25.3	15	28.3	16	45.5	
Ischemic Heart Disease							
No	98	99	53	100	29	87.9	0.001
Yes	1	1	0	0	4	12.1	
Relationship with patient							
Parent	13	13.1	5	14.7	16	48.5	<0.001
Sibling	22	22.2	9	17	7	21.2	
Spouse	25	25.3	22	41.5	7	21.2	
Children	39	39.4	17	32.1	3	9.1	

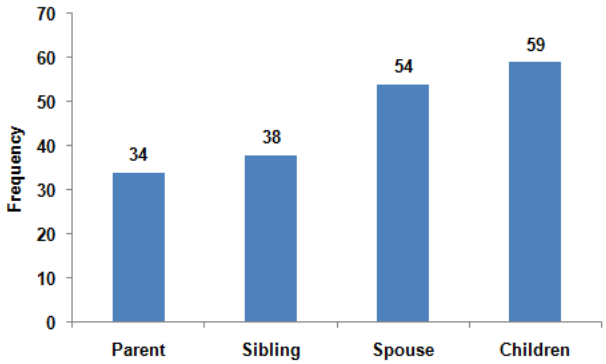

Fig. 1: Relationship with patients

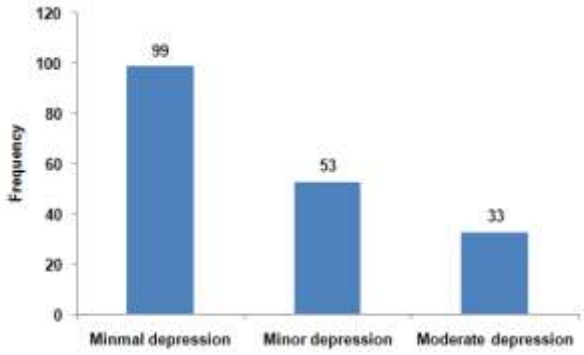

Fig. 2: Categories of BDI score

In a study done in Nigeria, caretakers had 31.6% of anxiety as compared to the control group 5.3%, caretakers had 31.6% of depression as compared to the control 3.5%, 49.1% of caretakers had mild to moderate caretaking burden whereas 33.3% had a high score, females had elevated depression score.[17] In another study, 40% of females were primary caretakers of MHD patients, and out of them, 75% were spouses, 40.74% of patients, and 43.82% of caretakers had depression.[18] In a study done in Iran, caretakers had a moderate to severe care burden in 72.5% of the caretakers associated with low financial status.[12] In our study, the majority had minor depression in low-income group, whereas minimal depression was found in the high-income group. Out of these participants, those with only one earning family member were moderately depressed. We found an association of the level of education and nature of the job with the level of depression which we did not find in other studies.

With emerging treatment modalities of depression, e.g. school-based programs for children, interventions for behavioral aspects, exercise plans, behavioral and intellectual programs, social psychotherapy and anti-depressants, people with depression can be better managed. More than 75% of patients suffering from depression in many developing countries are not treated because they remain undiagnosed. This is likely due to lack of resources, absence of trained staff, and social pressure. In contrast, people who do not suffer depressive symptoms are usually misdiagnosed with depression and given antidepressants in many developed countries.[19] Timely referral to a psychologist/psychiatrist can help cure depression.

Our study was done in a single specialist renal center. Though we cater rural population too, being part of a modern city, we are not a true representative of rural life. This is the limitation of our study. Yet our study highlighted some significant associations with depression in caretakers of MHD. More studies are needed in this context.

CONCLUSION

Depression and mental health disorders are the most neglected problem in our population. Responsibility of caretaking is huge, and the caretaker has to deal with the patient's mental and physical well-being, while taking care of their own self. This increases the burden on caretakers, and they ultimately suffer sadness and develop depression. Depression in extreme form can leads to self-harm and suicidal ideation, which can ultimately lead to suicide. Mental health in care takers is a neglected domain which needs to be addressed properly. This study will help treating physicians of MHD patients to have a formal conversation with caretakers, to counsel them, and to refer them to a psychologist/psychiatrist, if needed, for early diagnosis and treatment of mental health issues and depression.

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