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Original Research Article

Assessment of quality of life, anxiety and depression among the caregivers of chronic liver disease patients admitted to a public hospital of South Punjab Pakistan

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ABSTRACT

Background: Chronic liver disease (CLD) is a major global health concern, impacting not only patients but also their caregivers. Caregivers are essential in managing patients' physical and emotional needs, which can affect their own mental well-being and quality of life. However, limited research has explored the psychological and emotional health of caregivers of CLD patients.

Methods: This cross-sectional study evaluated the quality of life, anxiety, and depression among caregivers of CLD patients. A total of 250 caregivers were recruited from Nishtar Hospital, Multan, Pakistan. The generalized anxiety disorder-7 (GAD-7) scale was used to measure anxiety, patient health questionnaire-9 (PHQ-9) for depression, and the EuroQol-5D (EQ-5D) descriptive system for quality of life assessment.

Results: Among the caregivers, 56.8% were female, 80.4% were first-degree relatives, and 65.6% lived in rural areas. Most caregivers (43.2%) were aged 31–45 years, with 48.8% having provided care for 3–10 months. Mental health assessments revealed that many caregivers experienced mild to moderate anxiety and depression, reporting symptoms like nervousness, excessive worrying, low energy, and disturbed sleep. Quality of life assessments showed that caregivers commonly experienced slight to moderate difficulties in mobility, self-care, and performing daily activities.

Conclusions: Caregivers of CLD patients face considerable emotional and psychological challenges, including elevated levels of anxiety and depression and reduced quality of life. These findings emphasize the urgent need for healthcare systems to acknowledge the caregiver burden and offer appropriate psychological support and resources to improve caregiver well-being.

Keywords: Anxiety, Depression, Quality of life, Chronic liver disease

INTRODUCTION

Cirrhosis is a serious liver disease that can lead to illness and death.[1] Without a liver transplant, patients with severe cirrhosis often experience a poor quality of life, limited daily activities, and a lower chance of survival.[2,3] As the disease progresses, patients' quality of life declines, and they require more support to manage their condition.[4]

Caregivers play a vital role in helping patients manage their condition, but their own quality of life is often overlooked.[5] Research has shown that caregivers of patients with liver disease experience high levels of depression, uncertainty, and exhaustion due to the demands of caregiving.[6,7] In particular, caregivers of patients with a history of hepatic encephalopathy, a complication of liver disease, experience significantly higher levels of strain and burden.[8] The quality of life of both patients and caregivers is impacted by the burden of hepatic encephalopathy.[9] Effective management of end-stage liver disease is crucial not only for patients but also for their caregivers. By recognizing the impact of liver disease on caregivers, healthcare providers can provide better support and resources to improve the quality of life for both patients and caregivers.[10]

The impact of chronic liver disease (CLD) on family members is a crucial aspect that requires further research. A family's ability to cope with the challenges of CLD directly affects the patient's adherence to treatment and eligibility for a transplant. To better support caregivers, it's essential to identify the most common psychological and physical symptoms of caregiver stress. This knowledge can help develop screening tools and provide caregivers with additional resources to manage stress, ultimately leading to improved patient outcomes.

Objectives

Objectives of the study were: to assess the relationship between caregiver's age and quality of life among caregivers of patients with CLD; to determine the prevalence of anxiety and depression among caregivers of patients with chronic liver disease using generalized anxiety disorder-7 (GAD-7) and patient health questionnaire-9 (PHQ-9) scales; to examine the association between duration of caregiving and levels of anxiety and depression among caregivers of patients with CLD; to compare the quality of life, anxiety, and depression levels among rural and urban caregivers of patients with CLD; and to investigate the impact of caregiver's relationship with the patient on their quality of life, anxiety, and depression levels among caregivers of patients with CLD.

METHODS

This cross-sectional descriptive study aims to assess the quality of life, anxiety, and depression among caregivers of CLD patients admitted to Nishtar Hospital Multan, South Punjab, Pakistan. A total of 250 caregivers will be selected using a non-probability convenience sampling technique, with the sample size determined through an online Epi-info calculator at a 95% confidence interval and 5% margin of error. Data will be collected using a socio-demographic questionnaire, the GAD-7, PHQ-9, and the EQ-5D descriptive system to assess anxiety, depression, and quality of life, respectively. Data collection will take place from the start of April 2024 to the end of November 2024, with informed consent obtained before participants complete the questionnaires. The research assistant will ensure confidentiality and accuracy, and data will be analyzed using statistical package for the social sciences (SPSS) software. This approach aims to provide valuable insights into the impact of caregiving on the mental well-being and quality of life of those caring for CLD patients.

Inclusion criteria

Caregivers aged 18 or older, providing care to CLD patients, willing to participate and able to provide informed consent, and caregivers involved in caregiving for at least one month were included.

Exclusion criteria

Caregivers under 18 years, those not directly involved in caregiving, caregivers unable to complete the questionnaires due to language or cognitive limitations, individuals with pre-existing mental health conditions unrelated to caregiving, and non-consenting individuals or those who withdraw after consent were excluded.

The study adhered to ethical principles for medical research. The following ethical protocols were observed.

Voluntary participation

Participation in the study was voluntary, and participants had the right to withdraw at any point without any consequence.

Confidentiality

All data were anonymized, and participant identities were kept confidential. Data was stored securely and only accessible to the research team.

Informed consent

Participants were provided with clear information regarding the study's objectives and procedures before they provided their consent.

RESULTS

The study examined various demographic characteristics of caregivers. The study included 250 caregivers, with 56.8% female (142/250) and 43.2% male (108/250). Most caregivers (80.4%) were first-degree relatives of the patient, while 19.6% were second-degree relatives. A majority (65.6%) lived in rural areas, and 34.4% lived in urban areas. The duration of caregiving varied, with 48.8% providing care for 3-10 years, 33.6% for 11-20 years, 12% for 21-40 years, and 5.6% for 41-60 years. In terms of income, 44.4% earned between 13,000-30,000 PKR, 39.2% earned 31,000-50,000 PKR, 10.8% earned 51,000-70,000 PKR, and 5.6% earned between 71,000-80,000 PKR. The caregivers' ages ranged from 16 to 80 years, with the largest group (43.2%) aged 31-45 years, followed by 31.2% aged 16-30 years, 22.4% aged 45-60 years, and 3.2% aged 61-80 years given in Table 1.

Primary health questionnaire for depression

The data indicates that many caregivers experienced mild to moderate mental health symptoms over varying durations. A significant proportion reported feeling little interest or pleasure in doing things, with 69.6% experiencing this symptom for several days. Similarly, 71.6% reported feeling down, depressed, or hopeless for several days, and 63.6% had trouble sleeping during the same period. Feeling tired or having low energy was also a common symptom, affecting 56.8% of caregivers. Issues with appetite, such as overeating or poor appetite, were reported by 56.4% of caregivers, and 45.6% expressed feelings of worthlessness. Furthermore, 47.2% had difficulty concentrating on tasks like reading or watching television, and 63.6% noticed slower movement or speech for several days given in Table 2.

Table 1: Demographic details.

Variables	Frequency	Percentage
Gender of caregivers		
Female	142/250	56.8
Male	108/250	43.2
Relationship of caregivers with patient*		
First relation	201/250	80.4
2nd relation	49/250	19.6
Residential area of caregivers		
Rural	164/250	65.6
Urban	86/250	34.4
Duration of caregiving		
3-10	122/250	48.8
11-20	84/250	33.6
21-40	30/250	12.0
41-60	14/250	5.6
Socioeconomic status (monthly income of caregivers)		
13000-30000	111/250	44.4
31000-50000	98/250	39.2
51000-70000	27/250	10.8
71000-800000	14/250	5.6
Age of caregivers		
16-30	78/250	31.2
31-45	108/250	43.2
45-60	56/250	22.4
61-80	8/250	3.2

*First relation include mother, brother, sister, husband, wife, son, and father; second relation include cousins, friends, grandmother, grandfather, mother in law, brother in law, and sister in law

It is important to note that the majority of caregivers (76.8%) did not have thoughts of being better off dead or self-harm, though 17.6% did experience such thoughts for several days. Overall, while most caregivers reported mild to moderate mental health symptoms, a smaller percentage faced more persistent or severe challenges.

Generalized anxiety disorder-7

The data indicates that many caregivers experienced varying levels of anxiety-related symptoms. A majority, 62.0%, reported feeling nervous, anxious, or on edge for several days.

Table 2: PHQ-9 scale variables with frequency and percentage.

Variables	Frequency	Percentage
Little interest or pleasure in doing things		
Not at all	39	15.6
Several days	174	69.6
More than half the day	37	14.8
Feeling down, depressed, or hopeless		
Not at all	49	19.6
Several days	179	71.6
More than half the day	22	8.8
Trouble falling or staying asleep or sleeping too much		
Not at all	54	21.6
Several days	159	63.6
More than half the day	37	14.8
Feeling tired or having little energy		
Not at all	50	20.0
Several days	142	56.8
More than half the day	58	23.2
Overeating or appetite poor		
Not at all	71	28.4
Several days	141	56.4
More than half the day	38	15.2
Feeling bad about yourself		
Not at all	114	45.6
Several days	105	42.0
More than half the day	31	12.4
Trouble concentrating on things, such as reading the newspaper or watching television		
Not at all	72	28.8
Several days	118	47.2
More than half the day	60	24.0
Moving or speaking so slowly that other people could have noticed		
Not at all	54	21.6
Several days	159	63.6
More than half the day	37	14.8
Thoughts that you would be better off dead, or of hurting yourself		
Not at all	192	76.8
Several days	44	17.6
More than half the day	14	5.6

Regarding the inability to stop or control worrying, 52.0% of caregivers experienced this symptom for several days. A similar pattern emerged with excessive worrying about different things, where 47.2% of caregivers experienced it for several days, and 24.0% felt it for more than half the day. When it came to trouble relaxing, 53.2% reported this for several days. Restlessness, making it hard to sit still, was reported by 55.2% for several days, while 34.4% reported no issues. Becoming easily annoyed or irritable was less common, with half of caregivers (50.0%) reporting no such feelings, but 34.0% experienced this symptom for several days given in Table 3. Finally, 55.6% of caregivers felt afraid that something awful might happen, though 34.0% did not experience this feeling at all. Overall, while most caregivers experienced anxiety-related symptoms for several days, a significant portion reported minimal or no issues.

Table 3: GAD-7 scale variables with their frequency and percentage.

Variables	Frequency	Percentage
Feeling nervous, anxious or on edge		
Not at all	55	22.0
Several days	155	62.0
More than half the day	40	16.0
Not being able to stop or control worrying		
Not at all	92	36.8
Several days	130	52.0
More than half the day	28	11.2
Worrying too much about different things		
Not at all	72	28.8
Several days	118	47.2
More than half the day	60	24.0
Trouble relaxing		
Not at all	79	31.6
Several days	133	53.2
More than half the day	38	15.2
Being so restless that it is hard to sit still		
Not at all	86	34.4
Several days	138	55.2
More than half the day	26	10.4
Becoming easily annoyed or irritable		
Not at all	125	50.0
Several days	85	34.0
More than half the day	40	16.0
Feeling afraid as if something awful might happen		
Not at all	85	34.0
Several days	139	55.6
More than half the day	26	10.4

EQ-5D descriptive system scale for quality of life

The data reveals the caregivers' experiences with various aspects of health and well-being. Regarding mobility, most caregivers (57.6%) reported slight problems. In terms of self-care, a significant number (36.8%) experienced moderate problems and 39.6% had slight problems. When it came to usual activities like work, study, and housework, 42.0% of caregivers reported slight problems and 31.2% experienced moderate problems. For pain or discomfort, 42.0% reported slight pain. Lastly, regarding anxiety or depression, half of the caregivers (50.4%) reported slight levels of anxiety or depression, and 34.0% experienced moderate levels given in Table 4. Overall, the data suggests that while many caregivers experience slight to moderate challenges across various areas, some also report significant difficulties, particularly with self-care, usual activities, and emotional well-being.

Table 4: EQ-5D descriptive system scale variables with their frequency and percentage.

Variables	Frequency	Percentage
I would like to ask you about mobility. Would you say that		
No problem	45	18.0
Slight problem	144	57.6
Moderate problem	42	16.8
Severe problem	19	7.6
I would like to ask you about self-care. Would you say that		
No problem	28	11.2
Slight problem	99	39.6
Moderate problem	92	36.8
Severe problem	31	12.4
I would like to ask you about usual activities, such as work, study, housework, family		
No problem	23	9.2
Slight problem	105	42.0
Moderate problem	78	31.2
Severe problem	44	17.6
I would like to ask you about pain or discomfort. Would you say that		
No pain	24	9.6
Slight pain	105	42.0
Moderate pain	92	36.8
Severe pain	29	11.6
I would like to ask you about anxiety or depression. Would you say that		
Not	5	2.0
Slight	126	50.4
Moderate	85	34.0
Severe	34	13.6

Caregivers' self-reported health status, as measured on the EQ-5D VAS, ranged from a minimum of 10 to a maximum of 95, with an average score of 50.05. The relatively large standard deviation of 15.840 suggests there is a considerable variation in the health status perceptions among the caregivers.

On applying Chi square test, it has been shown that there is no relation between gender and depression or anxiety ($p>0.05$) but residential area has significant relation with depression with more residents of urban areas suffering from depression

A one-way analysis of variance (ANOVA) was performed to compare the effect of depression on quality of life.

A one-way ANOVA revealed that there was a statistically significant difference in quality of life between at least two groups (F between groups df=3, within groups df=238) ($F=49.205$, $p<0.001$).

Tukey’s HSD test for multiple comparisons found that the mean value of quality of life was significantly different between severe depression and mild, moderate or moderately severe depression (p≤0.05).

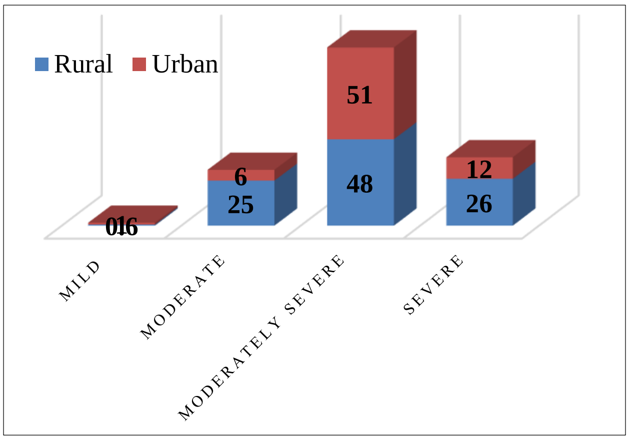

Figure 1: Depression relation with residential status.

Welch and Brown Forsythe tests were also significant (p<0.001).

Similarly, a one-way ANOVA was performed to compare the effect of anxiety on quality of life.

A one-way ANOVA revealed that there was a statistically significant difference in quality of life between at least two groups (F between groups df=2, within groups df=238) = (F=33.527, p<0.001).

Tukey’s HSD test for multiple comparisons found that the mean value of quality of life was significantly different between severe depression and mild or moderately anxiety (p≤0.001).

Welch and Brown Forsythe tests were also significant (p<0.001).

DISCUSSION

This study aimed to assess the demographic characteristics and mental health status of caregivers, particularly focusing on depression, anxiety, and quality of life. The findings highlight significant mental health challenges among caregivers, with notable differences based on gender, residential area, and caregiving duration.

Our study observed that the majority of caregivers were female (56.8%) and lived in rural areas (65.6%), consistent with other studies that show a higher proportion of female caregivers and rural caregivers facing mental health difficulties, likely due to fewer support resources in rural settings. Research by Pinquart and Sörensen similarly found higher stress among female caregivers due to caregiving demands, with rural caregivers facing more isolation and fewer social support systems, which could explain their higher incidence of depression.[11]

Regarding the mental health of caregivers, a significant proportion reported experiencing symptoms of depression, such as feeling down or hopeless (71.6%), trouble sleeping (63.6%), and low energy (56.8%). This is in line with other studies, such as that by Vitaliano et al, which also found that caregivers experience higher rates of depression compared to the general population.[12] Furthermore, 45.6% of caregivers in our study reported feelings of worthlessness, and 47.2% had trouble concentrating, which aligns with findings from researchers like Luthar and Cichetti, who noted that caregiving is associated with cognitive difficulties and emotional strain, especially when care demands are chronic and intense.[13]

In terms of anxiety, 62% of caregivers in our study reported feeling nervous or anxious for several days, and 52% experienced difficulty controlling their worrying. These findings are comparable to studies by Schulz and Sherwood, who highlighted that caregivers face heightened anxiety levels due to constant worry about the patient’s health and their own well-being.[14] Anxiety levels can exacerbate caregiver burden and reduce the quality of life, as demonstrated in our study, where anxiety and depression were significantly linked to lower quality of life scores (F-33.527, p<0.001).[15]

The quality of life among caregivers was found to be moderate, with 42% reporting slight pain and 50.4% indicating slight anxiety or depression. These findings corroborate with studies by Haley et al, which suggested that caregiver burden negatively affects physical and emotional well-being.[16] The EQ-5D VAS score (mean=50.05) in our study is consistent with the results from a study by Pereira et al, where caregivers reported lower health status scores compared to non-caregivers.[17]

Additionally, our study found significant differences in quality of life based on depression and anxiety levels, supported by ANOVA results (F-49.205 for depression and F-33.527 for anxiety), suggesting that mental health significantly impacts caregivers' perceived quality of life. These findings echo previous studies, including one by Gallagher-Thompson et al, which indicated that higher levels of depression and anxiety correlate with lower quality of life in caregivers.[18]

The relationship between the residential area and depression is particularly noteworthy. Our study revealed that urban caregivers were more likely to experience depression, which may be due to the heightened pressures and isolation experienced despite living in urban settings, possibly linked to work-related stress and fewer community-based support networks.[19] This contrasts with rural caregivers, who may have different social dynamics, but often face other barriers such as limited access to healthcare and fewer social services.

The findings from our study are consistent with existing literature, which suggests that the caregiving role, particularly in the context of chronic illness, leads to significant psychological distress. The mental health challenges of caregivers often go unaddressed, despite their importance in the well-being of both the caregiver and the patient.[20]

Our study differs from others in several key aspects, particularly in terms of the comprehensive assessment of both demographic factors and mental health outcomes, specifically depression and anxiety, among caregivers. First, while many studies focus primarily on depression or anxiety alone, your research provides a more holistic view by examining a wide range of mental health symptoms using both the PHQ-9 and GAD-7 scales. This dual focus on depression and anxiety, along with the inclusion of quality of life measures (EQ-5D), offers a more complete picture of caregiver well-being compared to studies like those of Vitaliano et al, which mainly focused on the depressive symptoms and physical health burden of caregivers.[12] This approach helps in understanding the complex interplay between emotional distress and physical health outcomes in caregivers. Second, your study examines the impact of residential area on caregivers' mental health, finding that urban caregivers experience more depression than their rural counterparts. This contrasts with other studies, such as that by Schulz and Sherwood, which generally focus on caregiving stress without delving into the specific differences between urban and rural caregivers.[14] This distinction is particularly important, as it highlights the need for tailored interventions that account for the different challenges faced by caregivers in different living environments.

Limitations

This study has several limitations. The small sample size and convenience sampling limit the generalizability of findings. Its cross-sectional design prevents assessment of causality or changes over time. The use of self-reported tools (GAD-7, PHQ-9) may introduce response bias, and the lack of objective clinical assessments is a drawback. Important confounding factors such as caregiver burden, social support, coping strategies, and patient characteristics (e.g., disease severity, comorbidities) were not considered. Additionally, the absence of a non-caregiver comparison group restricts broader context, and the study's specific cultural and socioeconomic setting further limits generalizability. Selection bias may also have influenced the results.

CONCLUSION

In conclusion, the mental health and quality of life of caregivers are significantly affected by depression and anxiety, and these impacts vary based on factors such as caregiving duration, gender, and residential area. Our findings highlight the need for targeted interventions to address caregiver mental health, particularly in rural and urban areas, where different support mechanisms may be required. Future research should explore the effectiveness of specific interventions for improving caregiver well-being and the potential role of community support services.

Recommendations

The implications of this study are significant, highlighting the need for healthcare providers to prioritize the assessment and management of caregiver burden, anxiety, and depression. The findings suggest that caregivers of patients with chronic liver disease require targeted interventions to alleviate their burden and promote their well-being. Healthcare providers should consider incorporating caregiver support services into the management plan for patients with chronic liver disease. This may include counseling, support groups, and respite care. Additionally, healthcare providers should educate caregivers about the importance of self-care and provide them with resources to manage their physical and emotional health. Policymakers should also consider the development of programs and services to support caregivers, including financial assistance, respite care, and mental health services. By addressing the needs of caregivers, we can improve the quality of care for patients with chronic liver disease and promote better health outcomes for both caregivers and patients.

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