

Quality of Life and Perceived Symptom Burden Among Caregivers of Chronic Liver Disease: A Review

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ABSTRACT

Chronic liver disease is the 11th leading cause of mortality and the 15th leading cause of morbidity across the world. The World Health Organisation records deaths due to liver diseases as 3.17% in India. It is a progressive deterioration of liver functions as it is a continuous process of inflammation, destruction, and regeneration of liver parenchyma. Caregivers, who are often family members or close relatives, play a crucial role in supporting and providing care to these patients who might also be critically ill due to the diagnosis of various chronic liver diseases. They often experience exhaustion of mental, physical, and emotional arenas of health while taking care of critically ill CLD patients; this in turn affects their quality of life and also contributes towards the symptom burden experienced by the caregivers. Marital status, age, gender, social habits, employment status, economic status, etc. have been shown to significantly affect the quality of life and symptom burden experienced by the caregivers. This abstract provides a brief overview of existing research on quality of life and perceived symptom burden among caregivers of chronic liver disease. It also emphasizes the importance of addressing the mental and physical health needs of caregivers.

Design: A thorough literature search was undertaken which included major online databases (PUBMED, SPRINGER, SCIENCE DIRECT, and GOOGLE SCHOLAR).

Keywords: Quality of life, Symptom burden, Chronic liver disease

INTRODUCTION

Chronic liver disease (CLD) is a term that encompasses a spectrum of diseases characterized by decreased hepatic function as a result of chronic inflammation or insult to the liver. It is a progressive deterioration of liver function for more than 6 months, which includes synthesis of clotting factors, other proteins, detoxification of harmful products of metabolism, and excretion of bile. (Sharma A et. al). Non-alcoholic fatty liver disease was the most common cause of CLD. Globally, the burden of liver disease accounts for 2 million deaths and it is responsible for 4% of all deaths (Devarbhavi H., 2023). CLD caused 1.32 million deaths in 2017, approximately two-thirds among men and one-third among women. The prevalence of alcohol-associated cirrhosis has been estimated at 23.6 million individuals for compensated cirrhosis and 2.46 million for those with decompensated cirrhosis, worldwide. Around 10 lakh patients with liver cirrhosis are newly diagnosed every year in India (Cheemerla S et.al., 2021). The burden of liver disease in India is significant because it alone contributes to 18.3 of two million

global liver disease-related deaths in 2015(Mondal D., 2022).

The impact of cirrhosis on the health care system has been studied and it was found that the burden of cirrhosis on the family unit was associated with medical, emotional, and socio-economic perspective needs. As a result, critical patient with cirrhosis requires 9 hrs per week of informal caregiving by friends and family (Michael. L. Volk., 2020). In order to focus on the needs of the patient, unfortunately, caregivers often neglect their self-care.

Quality of life (QOL) can be physically and emotionally demanding for caregivers. The immense burden of liver disease and associated physiologic, psychological, financial, and social complexities pose threats to the quality of life (QOL) experienced by both patients and family caregivers (Woodrell, C.D., 2021). The World Health Organization Quality of Life Assessment is grouped into four larger domains such as physical, psychological, social relationships, and environment (Wong F Y., 2018). Medical outcomes study SF-36 measures 8 different domains of quality of life such as physical functioning, role limitation due to emotional health, role limitation due to physical health, bodily pain, vitality, mental health, social functioning, and general health. The study has shown that caregivers have a significantly lower mental component score (MCS) compared to the established national norms and it reported 47.9% of caregivers had depression, which is the most significant factor that affects the mental health of the caregivers. (Nguyen LD., 2015)

The burden of caregiving is particularly difficult for family members. The key contributing factors to the caregiver burden are self-perception, multifaceted strain, and over time (Liu Z., 2020). The studies showed that Zarit Burden Interview (ZBI) scale was widely used to assess the caregiver burden and a score of more than 21 indicates an increased level of burden. Factors leading to increased burden and

lower QOL of caregivers include poor mental health, the unpredictability of clinical course, lack of information and communication, and the Presence of hepatic encephalopathy (Woodrell, C.D., 2021). Women in particular experience high rates of mental and physical health problems compared to men (Michael. L. Volk., 2020). Caregivers who experienced more strain had a higher rate of mortality (63%) than the non-caregivers. (Schulz R., 1999).

However, research studies suggest that increased caregiver burden leads to lower quality of life. Understanding the caregiver burden is essential for improving the quality of care provided to patients and supporting caregivers.

METHODS

To gather information related to the quality of life and experienced symptom burden among caregivers of chronic liver disease, a literature review using a search of electronic databases was conducted. The footnote chasing was also done and related studies were included in the analysis. To search the articles in PUBMED, an advanced methodological search strategy was used: Quality of life, AND symptom burden, AND caregivers of chronic liver disease. Many studies were found and were chosen based on specific criteria like research-based studies, studies written in the English Language, and free full text.

METHODOLOGICAL CHARACTERISTICS:

The reviewed studies were both quantitative and qualitative studies. Most of the studies were cross-sectional, Prospective, retrospective Cohorts, and while others were descriptive. Quality of life was assessed by using a Short Form (SF-36) health survey questionnaire consisting of 36 items measuring eight domains and a Zarit burden Interview (ZBI) consisting of 22 items rated on a 5-point Likert scale that ranges from 0 (never) to 4 (nearly) scores ranging between 0–88, was used to assess the caregiver burden. This review article also

encompasses multicentric study references. In those studies, the method of data collection used was majorly interviews and self-reported questionnaires. The range of sample size for the seven studies ranged from 25– 2528 caregivers of chronic liver disease which included different age groups across the world.

DISCUSSIONS

Though extensive research has been done among the caregivers of chronic liver disease, the evidence related to the quality of life and caregiver's burden is still lacking. There is a need to explore how caregiver burden affects the quality of life while taking care of the patients with chronic liver disease. Understanding the contributing factors for symptom burden will help the caregivers to reduce the burnout and improve their quality of life. There is a wide variety of ease interventions can carry out to support the caregivers.

A study done by (Shrestha D., et al) reported that the important predicting factors contributed to the higher caregiver burden were repeated hospital admissions, alcoholism, and lower socio-economic status. Majority of the caregivers experienced mild to moderate burden (43%) and 25% had mild depression. A Chinese study done by Wei., et al revealed that presence of comorbidities and lower economic contributed to higher caregiver's psychological burden. Several studies showed that history of hepatoencephalopathy has an impact on the caregiver burden. Patients with history of hepatoencephalopathy present with significant cognitive impairment associated with difficulty in employment and driving, it causes extra burden to the caregivers.

In a study done by Bajaj et al, the caregiver burden was significantly higher among patients with history of hepatoencephalopathy, Zarit burden Score was 16 and Total Perceived Caregiver Burden was 75.4. The burden that caregiver experienced was profound in "impact on personal health" in both Patients with HE

(17.8%) and without HE (15.6%). This study also identified that the caregivers experience mild (18%), moderate (5%) and severe depression (5%) and burden is influenced by depression. Previous HE also negatively affected the employment capability and financial status of patients and caregivers.

One of the most prevalent complaints among the caregivers of chronic liver disease patients were chronic depression, stress, and anxiety. It occurs due to the presence of inadequate resources and increasing patient dependency has been linked to decline in both physical and mental health status of patients and also the caregivers. The impact on mental health among caregivers is seen in patients undergoing liver transplant. (Domínguez-Cabello E., et al) identified that they experience anxiety rather than depression. The mean score of anxiety of relatives was 10.80 ± 5.07 compared to which mean score of depression 6.65 ± 4.07 ($p=0.820$). This finding is consistent with several studies (Bolden L., et al, and therefore, caregivers require adequate counselling and psychological support.

It is evident that the caregivers of CLD experience anxiety and depression in their daily lives which can also affect their quality of life. Lower on quality-of-life domains of limitation in role functioning due to emotional health, vitality, mental health, and social functioning. (Nguyen, L D et al.,)

Family caregiver physical QOL has been shown to be negatively impacted by caring for older patients and the presence of refractory ascites, and feelings of uncertainty. (Hansen L., et al). A similar findings was found in a study done by (Woodrell C D., et al) among patient with end stage liver disease and their caregivers showed that refractory ascites and history of hepatoencephalopathy had worse physical and mental quality of life of patients and their caregivers.

CONCLUSION

The review identifies that quality of life and experienced symptom burden among caregivers of chronic liver disease; particularly women are mostly taken care of patients. This poses significant caregivers' burden and frailty which leads to poor quality of life. The simplest intervention is to provide health education and communication to the caregivers while they are taking care of their loved one. To minimize the caregiver burden, health care policies can provide training to the caregivers and financial support. Addressing for psychological wellbeing and coping strategies help the caregivers to improve the quality of their life.

Declaration by Authors

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