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#### Dysfunctional Thoughts and Caregiver Burden in the Caregivers of Patients with Hepatitis C

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#### Abstract

The current study aimed to identify the thought patterns and caregiver burden of the caregivers of patients with hepatitis C. It was hypothesized that there is likely a relationship between dysfunctional thoughts and caregiver burden, where dysfunctional thoughts are likely to predict caregiver burden in the caregivers of hepatitis C patients. This correlational study was conducted with a sample of (N = 100) caregivers (43 men and 57 women). They were recruited from the government hospitals of Lahore by using the purposive sampling technique. The age range of caregivers was 17 to 65 years and only those who had spent more than 6 hours per day with the patient were included. Caregivers with any previously diagnosed psychological problem were excluded from the study. Their personal information and the patients' current condition were also noted. Dysfunctional Thoughts about Caregiving Questionnaire and Zarit Burden Interview was used. Dysfunctional thoughts were identified to have a significant negative association with caregiver burden and act as predictors of caregiver burden in the caregivers of patients with hepatitis C and its complications. The findings will be beneficial for reducing the caregivers burden of the patients with any infectious disease.

*Keywords:* caregivers, caregiver burden, dysfunctional thoughts, hepatitis C, transplantation

#### Introduction

One of the most common contagious diseases in the world is chronic hepatitis C (CHC) (Rosen et al., 2013). Kishta et al. (2020) explained that hepatitis C virus (HCV) is the main factor that causes/contributor to chronic liver diseases. The number of people infected with HCV has been estimated to exceed 100 million, worldwide (Isaac et al., 2021). The rate/burden of this disease in Pakistan is very high with 4.5% to 8% of the entire population suffering from this disease (Pirani et al., 2017).

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Hepatitis C has a direct impact on the liver. Hepatitis C is defined as an infection caused by a virus that directly attacks the liver and leads to its swelling (Dakic et al., 2019; Kwong et al., 2019). Most people remain unaware of their condition and do not know that they have hepatitis C infection until their liver has sustained significant damage. HCV infection is transmitted through several factors including injection drug use and contaminated blood products (Trickey et al., 2019). On the other hand, hepatitis C is not considered as a sexually transmitted contagion. The risk of transmission from mother to child during delivery and breastfeeding remains low (5% or less). Moreover, the risk of transmission of hepatitis C from the customer/patient to the healthcare worker by a needle stick injury is between 3% to 4 % if the customer/patient has hepatitis C antibodies and up to a maximum of 10% if they have hepatitis C RNA. The disease affects patients not only financially but also physically, psychologically, and in a social context for the patient and the caregiver (Moitra et al., 2020). It affects each individual differently (Rashidi et al., 2020). The most common symptoms include drowsiness, seasickness, nuisances, melancholy, upper stomach pain, intolerance to fatty foods and alcohol, and occasionally, jaundice. Chronic HCV infection is a leading cause of cirrhosis, liver failure, and hepatocellular carcinoma in the western world (Suraweera et al., 2019). The stigma linked with CHC that individual hesitated with those people who have this disease to prevent himself, leads some people with the ailment to experience disrespect for their personal well-being, humiliation, feelings of uncleanliness, lowered self-esteem, depression, social isolation, loss of income, decreased quality of life (Paul, 2019), and decline in health (Suarez, 2019). Like any serious illness, hepatitis C can badly influence a person's mental health. Hepatitis C patients experience psychological distress related to adjustment issues, depression, and anxiety. Various studies showed that chronic HCV has a deleterious impact on the quality of life (QOL) (He et al., 2022).

Dysfunctional thoughts originate from automatic thoughts and develop during early childhood due to the interplay of the environment and the individual's experiences gained in the environment. These thoughts contribute to psychological disorders, such as depression and anxiety, as well as physical diseases, such as hepatitis C (Bibi et al., <u>2020</u>). Dysfunctional thoughts, cognitive impairment, or difficulty with thinking positively, are the major issues faced by the patients with end stage liver diseases. Excessive distortion in thinking can decrease a person's

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immunity against the viruses that cause hepatitis C, while positive thinking can lead to positive outcomes (Perry et al., 2008).

A caregiver is defined as an unpaid kin or friend who helps to look after and assist a sick, invalid, or disabled person in their daily activities (Liu et al., 2020). The caregiving burden is defined as the adverse response towards the act of caregiving and the impact it has on the caregiver's social and occupational life, as well as their personal life (Otto et al., 2021). The caregivers of patients with chronic diseases especially face a lot of negative outcomes which include monetary, emotional, and physical issues. The caregiver burden affects negatively the people who provide the caregiving service since it causes them to experience fatigue, stress, depression, and several medical conditions including diabetes and blood pressure. They may also contract the same infection as well. As the infection gradually progresses in the patient, the caregiver becomes exhausted physically as well as emotionally (Suresh, 2023). Chien et al. (2023) stated that the caregivers who saw themselves as burdened were more likely to face a decline in their physical and mental health.

## **Clinical Significance of the Study**

In Pakistan, the prevalence of hepatitis C is the second highest in the world. It affects the patients not only physically but also exhausts them mentally, financially, and socially. The hepatitis C patient requires a caregiver to assist them even for minor daily routine activities. In Pakistan, the plight of the healthcare system is appalling and there is a severe lack of nursing homes and health insurance facilities. The deficiencies of the healthcare system transfer the responsibility of caregiving onto the family members who are already burdened with household duties. Consequently, as the disease progresses, they become physically, emotionally, psychologically, and financially hampered.

Many studies have been conducted on the prevalence, remedial medicine, and complications of hepatitis C in Pakistan. However, no research has been conducted on the wellbeing and experiences of the caregivers (Ahmad et al., 2022; Mushtaq et al., 2020). Hence, the current study aims to explore the irrational thought patterns and caregiver burden of the caregivers of hepatitis C patients. This study would also help to incentivize the authorities to provide the necessary training and facilities

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to the caregivers who work day and night for the betterment of their patients.

## Hypotheses

- There is likely to be a relationship between dysfunctional thoughts and caregiver burden in the caregivers of hepatitis C patients in Pakistan.
- Dysfunctional thoughts will likely predict caregiver burden in the caregivers of hepatitis C patients in Pakistan.

## Method

# **Research Design**

In the current study, correlational research design was used.

# Sampling Strategy

The participants were selected through the purposive sampling technique.

# Participants

A sample of 100 caregivers (47 men, 53 women) of hepatitis C patients was determined through G power was recruited from two government hospitals. Caregivers of patients with hepatitis C (liver cirrhosis, liver failure, liver cancer) of both gender within the age range 17-65 years (M = 36.17; SD = 11.49) comprised study participants. Most of the caregivers were illiterate (n = 27), followed by intermediate (n = 18) level of education. Sixty five percent were married. Around half of the caregivers lived in nuclear family system (i.e., 53%).

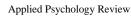
The disease related characteristics of patients showed that most of them have Hepatitis C (n = 37), followed by shrink liver (n = 24), fatty liver (n = 16), liver cirrhosis (n = 10), and liver cancer (n = 6). Among them, 91 % reported high level of worry about the illness.

# **Measuring Instruments**

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# Demographic Information Sheet

The researcher prepared a caregiver demographic questionnaire to record caregivers' and care recipients' demographic characteristics, such as caregivers' age, gender, religion, and marital status.





## The Zarit Burden Interview

The Urdu version of the Zarit Burden Interview (ZBI) (Boluarte-Carbajal et al., 2022) was used. It measures the particular burden among the caregivers of adult patients. It consists of 22 items that examine the burden related with behavioural impairments and the homecare situation. It has excellent internal consistency with Cronbach's alpha values 0.83 and 0.89. Furthermore, a test-retest reliability of 0.71 was obtained. The internal consistency of this scale in the current study was 0.91.

## Dysfunctional Thoughts about Caregiving Questionnaire

The Dysfunctional Thoughts about Caregiving Questionnaire (DTCQ) Montorio et al. (2009) was used to identify specific beliefs in the caregivers of dependent elderly people. This questionnaire was translated into Urdu to make it more understandable. DTCQ consists of 16 items rated on a 5-point Likert scale, ranging from 0 = totally disagree to 4 = totally agree (range: 0 to 64, higher scores indicate more barriers or obstacles). It has good psychometric properties including Cronbach's alpha value of .89, test-retest reliability of .60, and a correlation of .58 with the Dysfunctional Attitudes Scale. The internal consistency of this scale in the current study was 0.81.

## Procedure

After the approval of the synopsis by the research committee of the university, data was collected for the pilot study from 5 caregivers. Amendments were made on the basis of the results of the pilot study and then the main study was conducted, for instance, item wording was changed to make it easier. Written consent was taken from the participants and they were ensured of the confidentiality of their responses. Afterwards, Caregiver Demographic Questionnaire, Dysfunctional Thoughts/Dysfunctional Attitudes Scale, and Zarit Burden Interview (ZBI) were verbally administered in a sequence. The data was collected from 100 participants and analyzed to find out the results. All ethical considerations were followed during this study.

## Results

Table 1 indicates a significant positive relationship between disease and dysfunctional thoughts but an inverse relationship between disease and caregiver burden. Likewise, it describes a significant inverse relationship

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between dysfunctional thoughts and caregiver burden in the caregivers of patients with hepatitis C and its complications. This reflects that although disease disturbed the thoughts of caregivers but dysfunctional thoughts did not interfere in the care of patients.

## Table 1

Descriptive Statistics and Intercorrelation for Disease Conditions, Dysfunctional Thoughts, and Caregiver Burden in Caregivers of Patients with Hepatitis C and its Complications

	1	2	3	М	SD
1. Disease	-	.25*	26**	3.19	1.49
2. Dysfunctional Thoughts		-	47**	44.30	9.80
3. Caregiver Burden	-		-	32.32	17.24

*Note*. *N*=100

## Table 2

Descriptive Statistics and Intercorrelation for Dysfunctional Thoughts and Caregiver Burden in Caregivers of Patients with Hepatitis C in its Initial Condition

	1	2	М	SD
1. Dysfunctional Thoughts	-	49**	42.15	9.42
2. Caregiver Burden	-	-	35.25	19.07

#### *Note. N*= 60

The results mentioned in Table 2 show a highly significant inverse relationship between dysfunctional thoughts and caregiver burden in the caregivers of patients with hepatitis C in its initial condition. It depicts that the caregivers of such patients experience dysfunctional thoughts but bear less burden in the care of their patients.

## Table 3

Descriptive Statistics and Intercorrelation of Hepatitis C and its Complications with Dysfunctional Thoughts and Caregiver Burden in Caregivers of Patients with Hepatitis C and its Complications(N=100)

Ν	r	Μ	SD
17	57*	39.05 38.41	11.92 25.10
	N 17	<u>N</u> r 1757*	



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Conditions	N	r	М	SD
Hepatitis C				
ZTCQ	27	24	43.85	8.09
ZBQ			32.00	15.44
Fatty Liver				
ZTCQ	16	63**	42.56	8.24
ZBQ			37.37	17.62
Shrink Liver				
ZTCQ	24	38	46.91	10.89
ZBQ			30.95	15.30
Liver Cancer				
ZTCQ	6	33	47.66	9.99
ZBQ			22.00	9.73
Liver Cirrhosis				
ZTCQ	10	36	48.90	6.08
ZBQ			24.20	5.07
<b>N</b> . <b>N</b> 100 det	0.1 110			1 7 1

*Note.* N=100, \*\*p<.01. HC= Hepatitis C, ZBI = Zarit Burden Interview, DTCQ = Dysfunctional Thoughts about Caregiving Questionnaire.

Table 3 indicates a highly significant inverse relationship of dysfunctional thoughts with caregiver burden for the caregivers of patients with hepatitis C in its initial phase. It also shows a significant inverse correlation for the caregivers of patients with hepatitis C and its complications. It indicates that the caregivers of patients with complicated conditions of hepatitis C experience dysfunctional thoughts but not or less burden in the care of their patients.

## Table 4

Regression for Dysfunctional Thoughts as Predictors of Caregiver Burden in Caregivers of Patients with Hepatitis C and its complications (N=100)

Voriable	Caregiver Burden			
Variable	В	SE B	β	
Constant	52.17	9.93		
Dysfunctional Thoughts $R^2$	-0.51*	0.20	37	
$R^2$	0.14			
F	6.19			

*Note. N*=40 \*\**p* < .01.

Table 4 shows that dysfunctional thoughts significantly but negatively predict caregiver burden.

#### Table 5

Regression for Dysfunctional Thoughts as Predictors of Caregiver Burden in Caregivers of Patients with Hepatitis C in its Initial Phase (N=100)

Variable		Caregiver Burden	
Variable	В	SE B	β
Constant	77.15	9.99	
Dysfunctional Thoughts $R^2$	-0.99**	0.23	49
$R^2$	0.22		
F	18.46		

*Note. N*=60 \*\**p* < .01.

The Table 5 shows that dysfunctional thoughts significantly but negatively predict caregiver burden of the caregivers of hepatitis C patients and its complications.

#### Discussion

In the current study, the mean age of the participants was 36 years. The majority of the participants were married. Most of them were literate and had education above matriculation. They also showed a very high level of worry about their respective patient's illness. The findings of the current study are consistent with Ufere et al. (2022). The study reported the mean age of caregivers as 48 years. Whereas, the mean years of education of caregivers was  $12.4 \pm 2.6$  years. Another study by Stroffolini et al. (2019) reported that HCV infection accounts for economic as well as health burden in caregivers.

Kobayashi et al. (2021) reported that the majority of the participants (51%) showed symptoms of stress. The results of the current study fully supported the hypothesis. The results showed that caregiver burden is significantly but negatively associated and predicted by dysfunctional thoughts in caregivers of both low and severe category of hepatitis C. The results also reported a negative correlation in caregiver burden and dysfunctional thoughts. A study conducted by Shrestha et al. (2020) found that the caregivers of severe liver diseases are more likely to experience caregiver burden and associated psychological illnesses, such as depression and anxiety.

The current study presents results inconsistent with previous researches in this regard. This might be due to cultural variation as Pakistani society has a collectivistic culture where families share all types of burden, such as emotional, social, and financial burden. However, when disease enters in its complicated phase, it requires frequent medical checkups and visits to the hospitals. In this case, caregivers have to spare their time and energy which might be difficult when they have to take academic or official leaves. However, their family support and sharing of burden by other family members might be the cause of low caregiver burden.

#### Conclusion

The current study revealed that dysfunctional thoughts are negatively associated with caregiver burden. The caregivers did not experience any burden due to their dysfunctional thoughts. There can also be other stressors such as financial burden and social burden.

## **Limitations and Suggestions**

The data was collected only from two hospitals; therefore, the results cannot be generalized. The sample size was not equal in terms of gender; therefore, no depiction about the burden by the specific gender could be done.

## **Future Implications**

The current research would be beneficial for mental health professionals to devise strategies for caregivers so they may better deal with upcoming stressors with reference to hepatitis C. Family counseling can be provided to improve the treatment process.

## **Conflict of Interest**

The authors of the manuscript have no financial or non-financial conflict of interest in the subject matter or materials discussed in this manuscript.

## Data Availability Statement

The corresponding author will provide the data associated with this study upon request.



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