

# Burnout and Lived Experiences among Caregivers of Chronic Liver Disease Patients

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**Abstract:** Background: Chronic liver disease occurs throughout the world irrespective of age, gender, region or race. Patients are presenting and dying from liver disease at an early age, with the average age of death from liver disease being 59 years, compared to 82-84 years for heart and lung disease. Over the 10 years there has been a fivefold increase in the development of cirrhosis among 35 to 55-year-old age group. Being a chronic disease, it also causes a burden on the care givers mental, emotional financial and physical aspects Caregiver burnout involves multidimensional factors like financial implications, disrupted family routine, interrupted role function, ineffective coping, and lack of resilience. Also exploring the experiences of caregivers of patients provides new insight into the needs and support of family members especially when they are facing loved ones with chronic diseases. It helps in reducing unmet supportive care needs and psychological distress of the caregivers. Hence the study was undertaken to assess the burnout and lived experiences among care givers of CLD patients. Methods: The research approach adopted for this study was a mixed method (Quantitative and qualitative) approach. Qualitative strand: Convergent parallel design. Quantitative strand: Descriptive Cross Sectional survey. 100 samples were selected by using purposive sampling technique. Care giver burnout index was used to assess the burnout. The statistical tests used for the analysis were mean, range, standard deviation, independent t test and ANOVA. For qualitative strand data was collected from 20 subjects using in depth interview method on a one to one basis using the interview guide and it was audio recorded. Data saturation was reached with 20 subjects. From the recorded audio verbatim and themes were extracted. Results: The results showed that overall mean score of burnout experienced by care givers of CLD patients is 50%. Among them (58%) of them were severely burnout. 34% of them were moderately burnout and 8% of them were low burnout. There is no significant association of burnout experienced by care givers of CLD patients with selected baseline variables. Exploring the experiences of caregivers of CLD patients. After data analysis, five themes 1. Feeling of entanglement of burden, 2. Financial crisis, 3. Sense of entrapment, 4. Disruption in the pace of life 5. Impact on health and ten sub themes emerged. The majority of participants reported feelings of sadness, suffering, hopelessness, and helplessness. They were psychologically distressed and their physical health was threatened. In general, the presence of a person with CLD leads to a crisis in the family and affects all aspects of their lives. It disrupts the vital balance of the family system in relationships, roles, and desires. Conclusions: The study revealed that majority of the care givers of CLD patients had severe burnout. Also exploring the experiences of caregivers of patients provides new insight into the needs and support of family members especially when they are facing loved ones with chronic diseases. It helps in reducing unmet supportive care needs and psychological distress of the caregivers.<sup>5</sup>

**Keywords:** Burnout, Chronic Liver Disease, Data saturation, Themes, Sub themes, care giver burnout index, Interview guide

## 1. Introduction

Over the last few decades, caregivers of patients with chronic diseases have received more attention, and there is a growing volume of studies demonstrating high rates of burden, stress, and mental disorders in this group of individuals.<sup>3</sup>

Cirrhosis leads to considerable morbidity and mortality, compromises the quality of life, and often necessitates assistance in activities of daily living. A caregiver bears the psychological burden of coping with the needs of the patient and the knowledge of the morbid prognosis of a loved one. This aspect is rarely recognized and almost never addressed in clinical practice.<sup>6</sup>

Caregivers often receive little attention and the main focus is on the patient. Frequent hospitalizations of the patients and factors associated with the disease can lead to the deterioration of depression and reduction of the caregiver's

quality of life. Therefore, the evaluation of caregiver's status and determination of their needs are very important.<sup>7</sup>

An estimated 15 million family caregivers in the US provide unpaid care for a loved one. Despite the fact that the physical and emotional toll on family caregivers is well-documented, little has been done to integrate caregiver support into the routine care. When asked to describe their care giving experience Caregivers often used words with negative connotations such as "frustrating," "hard," and "stressful" Comprehensive care for their family caregivers is lacking in our health system, leaving millions of individuals struggling under the weight of unmanaged symptoms, stress, and emotional burden. It is imperative for health systems and providers to identify and provide comprehensive care to the family caregivers.<sup>8</sup>

Most patients with cirrhosis are middle-aged males, often being the breadwinners of the family. In the Indian context, this is compounded by the lower mean age of cirrhosis at diagnosis, predominantly uninsured population, and limited

state-funded support. Caregiver burden is associated with depression, anxiety, and caregiver burnout and may even affect patient mortality. Yet, this is an often-ignored aspect of clinical medicine.<sup>6</sup>

Due to ongoing cost-containment efforts, there is an increased need for family-based care of chronically ill individuals. The presence of CLD at home has a significant impact on the primary caregivers and affects their overall quality of life. Care givers experienced a significantly lower mental health score with nearly one standard deviation below the reported National norm (MCS 42.4 vs. 50.0,  $P < 0.05$ ). Chronic depression and stress in the presence of inadequate resources and increasing patient dependency has been linked to decline in both physical and mental health status of patients and caregivers of other chronic disease conditions.<sup>9</sup>

Exploring caregivers lived experiences with CLD patients can provide individualized interventions to ease the future burden. The first occurrence of symptoms might be a shock, but daily assessments of their relatives' conditions, and they feel responsible and over time, the caregivers impressively show how they are able to incorporate their personal experiences into care giving and to accept more accountability in managing the disease.<sup>10</sup>

The suffering can be reflected in the attitude of family members when they act as caregivers of the patient. The investigator during her clinical experience found that caregivers were experiencing burnout. And there is paucity of studies in India which explore the lived experiences and burnout of care givers of chronic liver disease patients. St.Johns Medical College Hospital has a well established gastroenterology department. On an average 20-25 patients with CLD consult physician in the OPD and 4 to 5 patients get admitted in the ward every day. Hence the investigator was motivated to undertake this study.

## 2. Methodology

Formal administrative permission was obtained from the concerned authority and ethical clearance from institutional ethics committee to conduct the study.

**Qualitative strand:** The subjects were identified based on the inclusion and exclusion criteria by purposive sampling technique. The subject information sheet was given and the informed consent was obtained. Baseline data was elicited using the Proforma and modified ranking scale. Data was collected from 20 subjects using in depth interview method on a one to one basis using the interview guide and it was audio recorded. It took around 40 to 50 minutes. Data saturation was reached with 20 subjects. From the recorded audio verbatim and themes were extracted.

**Quantitative strand:** The subjects were identified based on the inclusion and exclusion criteria by purposive sampling technique. The subject information sheet was given and the informed consent was obtained. Baseline data was elicited using Proforma and modified ranking scale. Care giver burnout was assessed using care giver burnout index by

interview method. 100 subjects were recruited for this study. It took around 10 to 15 minutes for each subject.

## Statistical Analysis

For qualitative data analysis, transcribed the verbatim and extracted themes and the sub-themes

For quantitative, data analysis was done by using descriptive and inferential statistics. Descriptive analysis was calculated by mean, SD, frequency, and percentage. Association calculated by independent t-test and ANOVA

## 3. Results

The results of the study has enlightened on the different aspects of lived experiences and the extent of burnout experienced by care giver which needs to be addresses by undertaking suitable interventions.

**Table 1 (a):** Frequency and percentage distribution of baseline variables of care givers of CLD patients, n=100

S. No	Baseline Variables	Frequency	Percentage
1.	<b>Age</b>		
	18-35	40	40.0
	36-55	49	49.0
	> 56	11	11.0
2.	<b>Gender</b>		
	Male	29	29.0
	Female	71	71.0
3.	<b>Education</b>		
	Primary	5	5.0
	High School	47	47.0
	Pre University	13	13.0
	Diploma	11	11.0
	Post Graduate	14	14.0
	Illiterate	10	10.0
4.	<b>Marital Status</b>		
	Single	7	7.0
	Married	93	93.0
5.	<b>Occupation</b>		
	Employed	41	41.0
	Unemployed	5	5.0
	Housewife	49	49.0
	Retired	5	5.0
6.	<b>Income per month</b>		
	≥78,063	2	2.0
	39,033-78,062	2	2.0
	29,200-39,032	8	8.0
	19,516-29,199	19	19.0
	11,708-19,515	19	19.0
	3,908-11707	26	26.0
≤3,907	24	24.0	
7.	<b>Presence of co morbidities</b>		
	Yes	20	20.0
	No	80	80.0
8.	<b>Relationship to the patient</b>		
	Parent	19	19.0
	Children	6	6.0
	Spouse	59	59.0
	Others	13	13.0
	Siblings	3	3.0
9.	<b>Type of family</b>		
	Joint	22	22.0
	Nuclear	78	78.0
10.	<b>Family support</b>		
	Yes	48	48.0

	No	52	52.0
11.	<b>Duration of care giving</b>		
	6months to one year	25	25.0
	1-2 years	15	15.0
	>2 years	60	60.0
12.	<b>Presence of domestic help</b>		
	Yes	1	1.0
	No	99	99.0
13.	<b>Financial assistance</b>		
	Yes	8	8.0
	No	92	92.0

**Findings related to description of baseline variables of care givers:**

Table 1a shows that 49% of care givers belong to age group of 36 to 55 years, only 11% are above 56 years of age. Majority of them 71% are females and 29% are males. 47% have high school education and only 5% primary school education. 93% of them are married and only 7% are unmarried. 49% are housewives, 5% are unemployed and 5% are retired. 26% have monthly income within 10,000/, 24% have income below ≤3,907. 80% of care givers have no co-morbidities but 20% of them have co-morbidities. 59% of subjects are spouses and only 3% are siblings. 78% belong to nuclear family and 22% are from joint family. 52% have no family support and 48% have family support. 60% of them are giving care for more than 2 years, 25% less than 1 year. 99% care givers have no domestic help, 92% have no financial assistance and only 8% have financial assistance.

**Table 1 (b):** Frequency and percentage distribution of baseline variables of CLD patients, n=100

S.N	Baseline variables	Frequency	Percentage
1.	<b>Age</b>		
	18-35	16	16.0
	36-55	56	56.0
	>56	28	28.0
2.	<b>Gender</b>		
	Male	77	77.0
	Female	23	23.0
3.	<b>Education</b>		
	Primary	11	11.0
	High school	40	40.0
	Pre university	8	8.0
	Diploma/	14	14.0
	Post graduate	8	8.0
	Illiterate	19	19.0
4.	<b>Occupation</b>		
	Employed	41	41.0
	Unemployed	34	34.0
	Housewife	18	18.0
	Retired	7	7.0
5.	<b>Marital status</b>		
	Single	8	8.0
	Married	90	90.0
	Widowed/Divorced	2	2.0
6.	<b>Bread winner of the family</b>		
	Yes	51	51.0
	No	49	49.0
7.	<b>Co morbidities</b>		
	Yes	48	48.0
	No	52	52.0
8.	<b>History of alcoholism</b>		
	Yes	53	53.0
	No	47	47.0
9.	<b>Extent of dependability/</b>		

10.	<b>disability</b>		
	Slight	97	97.0
	Moderate	2	2.0
	Severe	1	1.0
11.	<b>Stage of CLD</b>		
	Stage I	2	2.0
	Stage II	31	31.0
	Stage III	59	59.0
	Stage IV	8	8.0
11	<b>Frequency of hospital visit per year</b>		
	1-10 times	66	66.0
	11-20 times	29	29.0
	21- 30 times	5	5.0

**Findings related to description of baseline variables of CLD patients:**

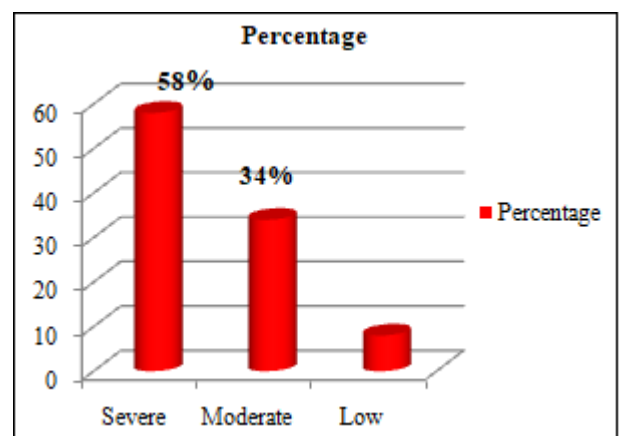
56% of patients belong to the age group of 36- 55, 28% are above 56 years and 16% belong to 18-35 years. 77% of patients are men, 23% of patients are females. 40% have completed their high school education and 19% are illiterates. 41% of patients are employed, 7% are retired, and 34% are unemployed. 90% are married, only 10% are unmarried. 51% are bread winner of the family and 49% are not bread winner of the family. 52% patients have no co-morbidities, but 49% have co-morbidities. 53% have history of alcoholism and 47% are non alcoholics. 97% have slight dependability and only 1% has severe dependability. 59% have stage III CLD and only 8% has stage IV CLD. 66% visits hospital 10 times per year, only 5% visits more than 21 times per year.

**Table 2 (a):** Range, Mean, SD, Mean %, of burnout of care givers n=100

Variable	Max score	Range	Mean	SD	Mean %
Burnout	60	15 - 58	30.03	9.87	50.00%

**Findings related to burnout experienced by the care givers of CLD patients:**

Care giver burnout index was used to assess the burnout of care givers. The overall mean score of burnout is 30.03 ±9.87. Among them (58%) of them were severely burnout. 34% of them were moderately burnout and 8% of them were low burnout.



**Figure 1:** Bar diagram depicting the level of burnout among care givers

**Findings related to association of burnout with selected baseline variables:**

Statistical Significance was observed in burnout score of care givers with family support 52 % (27.08) and without 48 % (33.23). The burnout scores of the caregivers female 71 % (28.66) and male 29 % (33.38) did differ significantly (p=0.29) in our study. Statistical significance was seen in those care givers with co morbidities 20 % (34.25). Statistical significance was observed in the burnout scores of frequency of hospital visit per year 1-10 times 66 % (32.27). burnout scores were high in nonalcoholic liver disease patients 47 % (32.83) than the alcoholic liver disease 53 % (27.55) which is found to be statistically significant p=.007.

**Organization and presentation of qualitative data**

**Table 3a:** Frequency and percentage distribution of baseline variables of care givers n=20

S.N	Baseline Variables	Frequency	Percentage
1.	<b>Age</b>		
	18-35	5	25.0
	36-55	13	65.0
	> 56	2	10.0
2.	<b>Gender</b>		
	Male	4	20.0
	Female	16	80.0
3.	<b>Education</b>		
	Primary	1	5.0
	High School	9	45.0
	Pre University	2	10.0
	Diploma	4	20.0
	Post Graduate	2	10.0
	Illiterate	2	10.0
4.	<b>Marital Status</b>		
	Single	1	5.0
	Married	19	95.0
5.	<b>Occupation</b>		
	Employed	9	45.0
	Unemployed	2	10.0
	Housewife	9	45.0
6.	<b>Income per month</b>		
	19,516-29,199	4	20.0
	11,708-19,515	6	30.0
	3,908-11707	3	15.0
	≤3,907	7	35.0
7.	<b>Presence of co morbidities</b>		
	Yes	4	20.0
	No	16	80.0
8.	<b>Relationship to the patient</b>		
	Parent	2	10.0
	Children	2	10.0
	Spouse	16	80.0
9.	<b>Type of family</b>		
	Joint	3	15.0
	Nuclear	17	85.0
10.	<b>Family support</b>		
	Yes	4	20.0
	No	16	80.0
11.	<b>Duration of care giving</b>		
	6months to one year	6	30.0
	1-2 years	2	10.0
	>2 years	12	60.0
12.	<b>Presence of domestic help</b>		
	No	20	100.0
13.	<b>Financial assistance</b>		

Yes	3	15.0
No	17	85.0

The data in table 3a shows that 65% care givers belong to the age group of 36-55; only 10% are above the 56 years. 80% of care givers are females and only 20% are men. 45% have completed high school education and 10% are illiterate. 95% are married, only 5% are single. 45% are employed and 45% are housewives and only 10% are unemployed. 35% have monthly income below Rs.3907/ and only 15% have monthly income around Rs.10000/. 80% have co-morbidities and 20% has no co-morbidities. 80% of subjects are spouses, 10% are parents, and 10% are children. 85% belong to nuclear family, 15% are from joint family. 80% have family support, 20% have no family support. 60% of them are giving care for more than 2 years, 30% are less than one year. None of care givers have domestic help. 85% did not have any financial assistance and 15% have financial assistance.

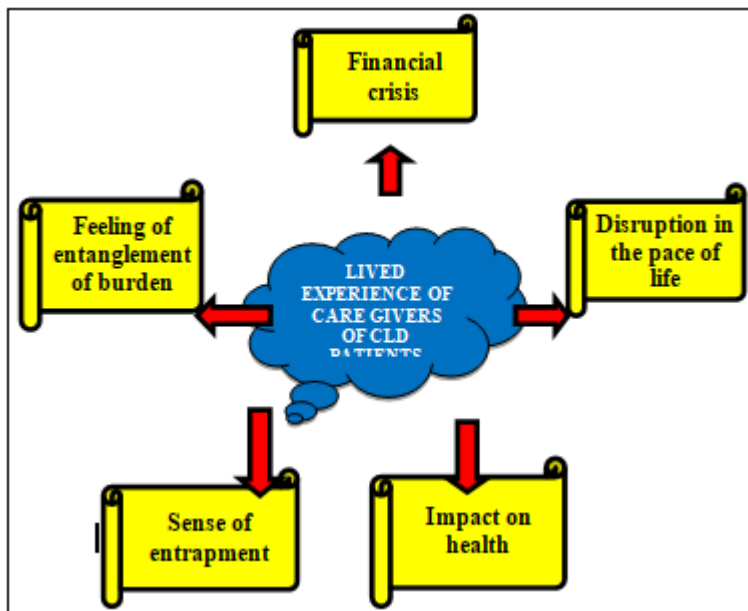
**Table 3 (b):** Frequency and percentage distribution of baseline variables of CLD patients n=20

S.N	Baseline variables	Frequency	Percentage
1.	<b>Age</b>		
	18-35	3	15.0
	36-55	13	65.0
	>56	4	20.0
2.	<b>Gender</b>		
	Male	19	95.0
	Female	1	5.0
3.	<b>Education</b>		
	Primary	2	10.0
	High school	8	40.0
	Pre university	2	10.0
	Diploma/	2	10.0
	Post graduate	2	10.0
	Illiterate	4	20.0
4.	<b>Occupation</b>		
	Employed	7	35.0
	Unemployed	11	55.0
	Housewife	1	5.0
	Retired	1	5.0
5.	<b>Marital status</b>		
	Single	2	10.0
	Married	18	90.0
	Widowed/Divorced		
6.	<b>Bread winner of the family</b>		
	Yes	14	70.0
	No	6	30.0
7.	<b>Co morbidities</b>		
	Yes	11	55.0
	No	9	45.0
8.	<b>History of alcoholism</b>		
	Yes	13	65.0
	No	7	35.0
9.	<b>Extent of dependability/disability</b>		
	Slight	20	100.0
10.	<b>Stage of CLD</b>		
	Stage I	1	5.0
	Stage II	5	25.0
	Stage III	8	40.0
	Stage IV	6	30.0
11.	<b>Frequency of hospital visit per year</b>		
	1-10 times	14	70.0
	11-20 times	4	20.0
	21- 30 times	2	10.0

The data in 3b shows that 65% of patients are between the age group of 36-55 and 20% of them are above 56 years. Most (95%) of patients are men and only 5% are women. 40% have completed their high school education, and 20% are illiterates. 55% of patients are unemployed, 35% are employed, 5% are retired and 5% are housewife. 90% are married and only 10% are unmarried. 70% of patients are the bread winner of the family, 30% are not the bread winner of the family. 55% have

co-morbidities and 45% have no co-morbidities. 65% are alcoholics and 35% are non alcoholics. All (20%) of them have slight dependability. 40% of them have stage III CLD, 30% have stage IV CLD, 25% have stage II CLD, and only 5% have stage I CLD. 70% have to visit hospital for 10 times a year, 10% of them are more than 20 times per year.

**Thematic representation of lived experiences of care givers of CLD patients**



**Figure 2:** Schematic representation of themes

**Table 4 (a):** Themes with its subthemes

Common Meanings	Sub Themes	Themes	
Feeling of being tied down	Emotional exhaustion	Feeling of entanglement of burden	
Unpleasant effects of care giving			
Over burdened			
Feeling of powerlessness			
Hopelessness			
Time consuming			
Lack of concentration			Mental exhaustion
Loss of interest in routines			
Feeling of tiredness			
Additional tasks	Physical exhaustion		
Threat to self care			
Lack of insurance /credit support			
Loss of employment due to illness	Financial crisis	Financial crisis	
Being in debt/ loan			
Expensive treatment			
Adamant	Demanding	Sense of entrapment	
Expectations			
Lacking means to retreat	Being tied down		
Restrictions on daily life			
Feeling of less independent	Lack of freedom		
Inner turmoil			
Threat to family life			
Threat to social life	Added responsibility	Disruption in the pace of life	
Lack of time			
Hindrance to usual routine			
Negative views of the society	Role change		
Weakening of family status among relatives and acquaintances			
Lack of time	Lack of dignified life		
Poor recognition of care giver needs			
Pre existing ailments of the care giver			
Negative vibes from the family, neighbours	Neglect of health	Impact on health	
	Lack of support		

**Feeling of entanglement of burden**

The caregivers expressed feelings of helplessness, hopelessness, and powerlessness. Feeling of being tied down with the care giving role. They were over burdened with work, stress and tension. They expressed unpleasant effects of care giving like the patients were not satisfied, grumbling and demanding,

*Participant 1: Enough this life I don't want to live anymore. Many times thought of committing suicide. My son got promise from me. So I am living.*

*Participant 12: I hate life. I was pampered petted so much and never knew pain but now it is my routine life*

*Participant 3: Too much anger, irritation, tension, and stress but I control. No girl should go through my pain and mental agony. I pray that nobody should get drunkard husband.*

*Participant 5: My life goes everyday with tears. I am not able to proceed. Fed up of crying.*

*Participant 6: I could not digest my husband struggling; often his stomach becomes big, not able to eat, breathlessness, seeing all this I become very dull and hopeless.*

*Participant 8: My sons marriage is fixed, jewels all taken suddenly came to know that he is sick (blood vomiting) and we never knew that he was drinking. And now doctor told if he is alright also he may live for 2 or 3 months because his liver is fully damaged. I am in utter hopelessness.*

Care givers expressed loss of interest in routines unable to concentrate on other works, also care giving is time consuming. Feeling of tiredness, threat to self care and become exhausted physically and mentally.

*Participant 1: My father-in-law is physically handicapped, giving bath, food and changing diaper added to that my husband also sick. I don't get sleep. I don't feel like eating I am feeling tired so much.*

*Participant 13: I have to do A-Z work. No help. Nobody even to bring water and give me. I am already old.*

*Participant 2: My son is mentally challenged. I have to do everything for him (ADL). After doing everything I have to go for work. So much I become tired not able to continue my life.*

*Participant 4: I don't eat sleep not able to concentrate on anything I am fully upset and depressed because he is our everything. He is our world. He is righteous man so god is testing him.*

**Financial Crisis**

Loss of employment due to sickness, being in debt, and loan, no insurance and support from family members and friends, treatment is also expensive.

*Participant7: He sold all the land. He wants to drink, eat, does not need a family. I can't keep money anywhere at*

*home. So much taking treatment also waste. I don't know how I will manage the money lenders and bank people. So much debt.*

*Participant 15: very much struggling to manage the family financially. Because he is not going for work due to his illness. With my salary I have to meet hospital expenses, both the kids are studying in matriculation school. Very difficult yet managing*

*Participant 16: My father was earning one and a half lakhs per month. But now not going for job. Due to pandemic my sister also lost job. Myself and my younger brother are studying in st.josephs college. Financially we are so much down.*

**Sense of entrapment**

Care givers expressed that their loved ones are too demanding, adamant and expecting so much from them. They lack means to retreat, feeling of less independent and restrictions on daily life.

*Participant 13: I can't go anywhere or talk to someone I am always occupied because my husband and son both are sick. And sometimes they fight among themselves. Even I thought to run away but how can I do that?*

*Participant14: I don't have freedom. I need freedom. I want to eat what I like and go where I like (eating paani poori, going somewhere out, being with my parents etc) but nothing happens.*

*Participant 13: I can't go anywhere or talk to someone I am always occupied because my husband and son both are sick. And sometimes they fight among themselves. Even I thought to run away but how can I do that?*

**Disruption in the pace of life**

Care givers expressed threat to family life, threat to social life, weakening of family status among relatives and acquaintances, Hindrance to usual routine.

*Participant 9: My role as a breadwinner of the family is changed. Now my work is to cook at home drastic change I am nowhere connected to the kitchen but now I do*

*Participant 16: I have sacrificed literally every penny of my recreational activities (movies, biking) roam around everywhere with my fathers money. But now everything changed. My student life is gone. I am the elder one at home. I have to be strong and support the family.*

**Impact on health**

Poor recognition of care giver needs, Pre-existing ailments of the care giver, Negative vibes from the family, neighbors

*Participant 7: I don't have anybody to look after or care for me never bothered whether I ate slept nothing. Not able to eat nobody is bothered also. I feel very sick and tired. I have diabetes also.*

*Participant2: I don't have anyone to whom I can share my feelings. I am left alone. I don't get any family support.*

#### 4. Discussion

The findings of the study is discussed and organized under the following headings:

- Discussion related to baseline variables
- Discussion related to burnout experienced by caregivers of CLD patients
- Discussion related to association of burnout with selected baseline variable
- Discussion related to lived experiences of care givers of CLD patients

##### Discussion related to the description of baseline variables of care givers

A total of 100 patients and their caregivers were included in the study. Among them 49% of the care givers belonged to the age group between 36-55 years, and 71% of the care givers in this study were females. Most of the care givers (47%) had completed high schooling. Almost 93% of the care givers were married and most of them were (59%) spouses.

The findings of the Study is supported by the study conducted in

Brazil in which majority caregivers were females (66%). The mean age of the primary caregivers was 46.8 years. Most of the caregivers (81%) were spouses. Mean years of education was 10.3 years with 36% being educated beyond high school. Another Study conducted in Chandigarh showed that majority of the caregivers were women (82%), and most were spouses (64%). The mean age of the caregivers was 47.6 years, and some had completed secondary schooling (37.7%).

80% of the care givers reported having no co-morbidities. Nearly 49% of the care givers were housewives, which demanded continuous availability of care giving role. 26% of the care givers belonged to the lower or middle class family. The monthly income was between (3908-19,515). Most of the caregivers (60%) were taking Care of their patients for more than 2 years.

The findings of the Study is supported by the study done in Virginia in which majority of caregivers were not on any medications but 17% were on anti-depressants, 12% on non steroidal anti-inflammatory drugs, and 1% on narcotics. The findings of the Study are supported by the study done in Chandigarh India almost all (97%) of our patients and care givers belonged to the lower or middle socioeconomic class. Another similar study is done in California showed that the median length serving as the patient's primary caregiver was 6 years. The reported median length of time spent care giving per week was 40 hours.

92% of them did not have any financial assistance (Insurance). 52% of the care givers did not receive any support from the family. 78% of them were living in the nuclear family. 99% of care givers did not have any domestic help. The findings of the Study is supported by the study done in Turkey Most caregivers received low level of support from other available family members or other institutions (Insurance).

##### Discussion related to the description of baseline variables of CLD patients

In this present study (77%) of the patients were men and (56%) belonged to the age group of 36- 55. Almost 40% patients had done their high schooling. 90% of CLD patients were married and majority (51%) of them were the bread winner of the family. Only 41% of CLD patients were employed at the time of the study and reported having to stop working because of sickness. 53% of them alcoholics.

The findings of the study are similar to the study done in Brazil where the patients were predominantly men (70.5%) and had a mean age of 50. This may be because alcoholism is found to be more in men compared to women. Another study done in USA in showed that significantly lower education level found in our study emphasizes that cirrhotic may have poor knowledge and coping strategies for managing their chronic disease, further contributing to functional disability. Similar studies done in Chandigarh India Only 44% of the patients were working at the time of the study. The finding of the study is similar to the study done in Brazil showed that the most common etiology of liver disease were alcohol (34%) and hepatitis C (19.7%). Another study done in Chandigarh India found that majority (44%) had alcohol as the underlying etiology.

52% of patients did not have any co morbidities and 48 % of them were living with co morbidities. 66% of them had to visit the hospital every month. 59% of them were in 3<sup>rd</sup> stage of CLD. 97 % of the CLD patients experienced slight disability and were dependent on the care givers for their needs.

The findings of the study is similar to the study done in USA in which showed that with advancing age, individuals had several co morbidities (e.g. arthritis 62%, cardiac disease 31%, diabetes 18%, cancer 16 %); Annually, cirrhosis results in 50,000 hospitalizations (22); approximately 20% are readmitted within 30 days (23). 43% had compensated and 57% had decompensated cirrhosis at the time of coding. Individuals with cirrhosis had greater impairment of ADLs compared to the comparison group ( $p < 0.001$ ), with 38% indicating at least one impaired ADL.

##### Discussion related to burnout experienced by caregivers of CLD patients:

Care giver burnout index was used to assess the burnout of care givers. Over all mean score of care giver burnout is  $30.3 \pm 9.87$ . Among them (58%) of them were severely burnout. 34% of them were moderately burnout and 8% of them were low burnout.

Similar study done in Nepal showed that the assessment of burden among the caregivers found the mean burden score to be  $46.99 \pm 4.6$ . The categorization of burden revealed 4% with little or no burden, 30% with mild to moderate burden, and 49% with moderate to severe burden and 17% with severe burden. Moderate to severe burden was also reported by another study done in Saudi Arabia.

An exploratory study done in Canada on End-stage cirrhosis: exploring the perspectives of patients and their caregivers. The study revealed that patients with

decompensated cirrhosis experience low health-related quality of life. Another study done in Italy on Factors Associated With Poor Health-Related Quality of Life of Patients with Cirrhosis showed all domains of health-related quality of life, were altered in cirrhosis (by 9% to 42%), mainly in younger patients<sup>14</sup>.

Another study done in Europe on Health related quality of life in people with advanced chronic liver disease. Results showed that Health Related Quality Of Life is more significantly impaired in patients with cirrhosis than in both healthy controls and in patients with non-cirrhotic chronic liver disease. Impairment increases with increasing severity of cirrhosis (MELD score or Child-Pugh score).<sup>15</sup>

Similar study was conducted to investigate burnout and related factors in caregivers of outpatients with schizophrenia. Results showed that Emotional Exhaustion and Personal Accomplishment subscale scores of the caregivers were significantly different in terms of patients' adaptation to treatment (respectively;  $p=0.010$ ,  $p=0.030$ ).

Another study done in Korea on Structural Relationship of Burnout and Related Variables among Family Caregivers of Cancer Patients. Results showed that Perceived health status, perceived stress, and hope showed statistically significant direct effects on burnout of family caregivers. Social support affected burnout of family caregivers indirectly. These variables explained 68.5% of total variance in burnout.<sup>23</sup> A Cross sectional, descriptive study design was done in Nepal on Burden and Depression among Caregivers of Hemodialysis Patients. Almost half of the caregivers had moderate to severe burden with around 17% having severe burden. Also, 35% of the caregivers had moderate to severe depression.

Another study done in Brazil on Patients on the Waiting List for Liver Transplantation: Caregiver Burden and Stress. Caregivers of patients with alcoholic liver disease showed higher depression and overall burden scores than caregivers of patients with liver disease due to other etiologies. Caregivers showed significantly high levels of burden, stress, and depression<sup>4</sup>.

A contradicting result was found by Roux et al, which showed low burden perceived by the caregivers. This may be because they have adapted to the situation.

#### **Discussion related to the association of burnout with selected baseline variables of care givers**

With regard to age though there was no statistical significance found, the mean percentage of burnout was higher in elderly 11% (33.27) than middle aged people 49% (29.35). This may be because the elderly may have their own health issues and co morbidities and the energy in them will be less compared to the younger age group.

The caregivers who were married 93% (29.57) had lower burnout scores than other (single 7% (36.17)). This may be the result of being adjusted with demands and challenges of married life. Care givers burnout were higher in those with less education than those with higher education. (Primary education 5% (36.60).

With regard to relationship the highest mean score 13 % (32.0) of burnout was among others (daughter in law, son in law). This may be due to their relationship by law, which may affect their intimacy. Statistical Significance was observed in burnout score of care givers with family support 52 % (27.08) and without 48 % (33.23). This explains that the family support is very important in times of crisis. The burnout scores of the caregivers female 71% (28.66) and male 29 % (33.38) did differ significantly ( $p=0.29$ ) in our study. Statistical significance was seen in those care givers with co morbidities 20 % (34.25). This may be due to the fact that co-morbidities will add up to the burden already faced due to CLD.

Similar findings were found in a study done in Nepal in which the caregivers above the age of 40 had higher burden, also showed that burden is high in caregivers having less than 10 years of formal education and in those who perceive lack of social support. Caregiver burden was also significantly associated with marital status, socioeconomic status and relationship to the patient, and co morbidities, also showed that spouse were found to have lower mean value of caregiver burden as compared to other relations.

Though most of the care givers were housewives 49% (29.37), their burnout was comparatively less than those who were unemployed 3 % (31.33) and retired 5% (34.60). The care givers who lived in a joined family 22 % (29.41) had less burnout than in nuclear family 78 % (30.21). Duration of care giving influenced their burnout levels. The care givers who were taking care of their loved ones more than 2 years 60% (30.15) had less burnout scores than minimum years 15% (32.67) of care giving. This shows the way people adapt to situations when they are exposed to it for long time.

#### **Discussion related to the association of burnout with selected baseline variables of CLD patients**

Present study reveals that the mean age of patients who were above 56 had higher burnout scores. Burnout was high among the patients who were married 90 % (30.36). Burnout scores was high in females patients 23 % (33.04) than male 77 % (29.13), With regard to education of patients burnout scores were high among the educated pre university 8 % (36.75) post graduate 8 % (31.75) patients who had co morbidities 48 % (29.50) had less burnout than 52 % (30.52) than the others. 93% of patients had slight dependability and the burnout scores were high in patients with Stage II CLD 31 % (33.68). This may be because of their dependability on care givers.

The findings of the study was supported by the similar study done in Chandigarh India showed that the median age of the patients was 50 years and most were males, the disease affected the primary earning members of the family. Patient factors such as severity of liver disease, alcohol as etiology, previous decompensations in the form of HE or Ascites, and prior hospital admissions were associated with higher perceived burden. Patients from lower socioeconomic class and poor educational status of both patients and caregivers also led to higher burden.



Statistical significance was observed in the burnout scores of frequency of hospital visit per year 1-10 times 66 % (32.27). Burnout scores were high in nonalcoholic liver disease patients 47 % (32.83) than the alcoholic liver disease 53 % (27.55) which is found to be statistically significant  $p=.007$ . The findings of the study was similar to the study done in California which showed that frequent hospitalizations for any cause were the strongest predictor of caregiver burden, and active alcohol use in the patient was not a significant predictor.

### Discussion related to lived experiences of care givers of CLD patients

The purpose of this study was to explore the experiences of caregivers of CLD patients. After data analysis, five themes were emerged from the study. That are 1. Feeling of entanglement of burden, 2. Financial crisis, 3. Sense of entrapment, 4. Disruption in the pace of life, 5. Impact on health and ten sub themes emerged.

The first theme was feeling of entanglement of pain. The care givers expressed emotional physical and mental exhaustion Feeling of being tied down and over burdened. Unpleasant effects of care giving like Feeling of powerlessness, Hopelessness, Feeling of tiredness, Additional tasks, Threat to self care. Time consuming, Lack of concentration, Loss of interest in routines etc.

The second theme was financial crisis which most of the care givers expressed like lack of insurance and credit support, expensive treatment, being in debt and loan, loss of employment due to illness also due to pandemic.

The third theme was sense of entrapment. Care givers experienced lack of freedom they felt less independent and went through lot of inner turmoil. Feeling of being tied down; Lacking means to retreat, Restrictions on daily life. Moreover care givers felt that their patients are more demanding Adamant, and high Expectations, all these added their burnout levels and affected their quality of life.

The fourth theme was disruptions in the pace life. Care giving was an added responsibility and there was threat to family life, threat to social life, and Lack of time for self and family. Most of the care givers had complete role changing, like it was a hindrance to usual routine. Some of the care givers had to go through less dignified life and humiliations because of history of alcoholism of their patients. Negative views of the society, weakening of family status among relatives and acquaintances disrupted their pace of life.

The fifth theme was impact on health. Care givers impressively expressed that they had no time for themselves which made them to neglect their own health. Pre existing ailments of the care givers and poor recognition of their needs by the family, and negative vibes from the family and neighbors added their burnout levels.

Thus, majority of participants experienced feelings of sadness, suffering, hopelessness, and helplessness. They were psychologically distressed and their physical health was threatened. In general, the presence of a person with CLD leads to a crisis in the family and affects all aspects of

their lives. It disrupts the vital balance of the family system in relationships, roles, and desires.

These finding of the study was found to be similar with the study done in Switzerland from which emerged five themes 1. Feeling overwhelmed by their loved one having unexplainable symptoms and behaviors; 2. Learning that this and previous experiences were complications of liver disease; 3. Becoming aware of the symptoms of hepatic encephalopathy; 4. Having feelings of being tied down and 5. Experiencing and overcoming obstacles in working with healthcare professionals. This study provides insight into caregivers' experiences and the consequences for their lives. The first occurrence of symptoms was a shock, but receiving the diagnosis was seen as an important step in understanding and learning. Caregivers provide daily assessments of their relatives' conditions, and they feel responsible for medication management. Over time, the caregivers impressively showed how they were able to incorporate their personal experiences into care giving and to accept more accountability in managing the disease.

Another similar study done in Bahrain from which emerged three themes (1) the burden of care, (2) comforts, and (3) coping. The findings showed that the lived experience of home care giving includes physical, emotional and financial burdens, combined with a lack of professional support. The collective experience was infused with intense emotions because of a lack of structured support, resulting in negative emotions that frequently affected the caregivers' well-being and their ability to care for the ill person. Nevertheless, caregivers tried to maintain care and comforts for their terminally ill relative in the home. Caregivers utilized three coping mechanisms, faith, personal strategies and distribution of the care responsibilities among family members.

## 5. Summary

The study revealed that majority of the care givers of CLD patients had severe burnout. Also exploring the experiences of caregivers of patients provides new insight into the needs and support of family members especially when they are facing loved ones with chronic diseases. It helps in reducing unmet supportive care needs and psychological distress of the caregivers.

This study was a benefitting study for the investigator. This helped the investigator to understand the burnout experienced by the care givers of CLD patients. The constant support and direction from the guide and co-guide, co-operation from the management and the participants were of immense help for the completion of this study.

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