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Exploring the lived experiences of patients with liver cirrhosis: A phenomenological study from Pakistan.

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ABSTRACT… Objective: To investigate the lived experiences of cirrhotic patients in Pakistan, with an emphasis on their physical, emotional, social, and spiritual struggles, while also analyzing the coping strategies they adopt to navigate and manage their condition. **Study Design:** Qualitative Phenomenological study. **Setting:** The study took place at the Liver Transplant Department of Pir Abdul Qadir Shah Institute of Medical Sciences, Gambat, Pakistan. **Period:** May and June 2024. **Methods:** Involving eight purposively selected patients diagnosed with Child-Pugh class C liver cirrhosis. Data collection occurred through in-depth, semi-structured interviews. The interviews were analyzed using Colaizzi's seven-step method, and thematic analysis was utilized to uncover key themes reflecting the patients' experiences. **Results:** Six major themes and 13 sub-themes were identified. Patients initially experienced shock and disbelief upon diagnosis. Physical challenges included fatigue, weakness, chronic pain, and cognitive decline. Emotional distress was characterized by fear, anxiety, and depression, while family support emerged as a critical coping mechanism. Social withdrawal and isolation were common, driven by stigma and physical limitations. Many patients relied on religious beliefs for strength, while some struggled with feelings of hopelessness. Healthcare experiences varied, with some reporting satisfaction and others highlighting barriers such as financial constraints and limited access to specialized care. **Conclusion:** Patients with liver cirrhosis face significant physical, emotional, and social burdens, often alleviated by familial and religious support. Healthcare professionals should integrate psychosocial interventions and family-centered education programs to enhance patient well-being. Addressing financial and accessibility barriers is also crucial in improving such patients care.

Key words: Coping Mechanisms, Liver Cirrhosis, Lived Experiences, Patient Perspective Quality of Life.

INTRODUCTION

Although modern medicine prioritizes clinical and laboratory examinations to gather crucial information on chronic illnesses, these methods alone cannot capture the full spectrum of experiences in chronically ill patients' lives. Recently, the assessment of health-related quality of life in patients with chronic diseases has become essential for understanding their emotional and mental distress, as well as the societal stigma they face.[1] A phenomenological approach enables researchers to explore individuals' daily experiences, providing a deeper understanding of their struggles, needs, and coping mechanisms while also facilitating assessing their health-related quality of life.[2]

Liver cirrhosis is an advanced chronic disease marked by scarring of the liver and eventual loss of liver function. It is a major cause of morbidity and mortality worldwide. This disease results in abdominal pain, fatigue, jaundice, and cognitive impairment.[3] Studies have shown that the health-related quality of life of patients with liver cirrhosis is significantly impacted by physical symptoms, emotional distress, societal stigma, and economic burden, affecting their overall quality of life.[4] It's crucial to assess the quality of life in patients with liver cirrhosis. This helps in estimating their adjusted life expectancy for various treatments. Studies revealed that a patient's quality of life before a liver transplant can impact their health and life span after the procedure.[5]

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Consequently, a single-point improvement in quality of life results in a 4% decrease in mortality rates following transplantation.[6]

While extensive research focuses on the clinical and quantitative management of liver cirrhosis, there is a noticeable gap in qualitative studies that capture the lived experiences of individuals affected by this disease. Current literature often neglects the subjective dimensions of patients' struggles, including emotional, social, and spiritual challenges.[7] Conducting more qualitative research to document these patients' experiences is essential, as this will allow readers to develop a more comprehensive understanding of their viewpoints.

This study aimed to bridge this gap by exploring how individuals with liver cirrhosis perceive and navigate their illness, focusing on their emotional, social, and spiritual challenges. Understanding patients' real-world experiences will enable healthcare professionals to develop comprehensive and efficient treatment plans, management approaches, and educational initiatives to enhance the life quality of individuals with cirrhosis. Furthermore, the results of this research will serve as a foundation for upcoming studies and policy development, ultimately improving the well-being of this at-risk group.

METHODS

Study Design and Settings

This qualitative phenomenological study was conducted at the Liver Transplant Department, Pir Abdul Qadir Shah Institute of Medical Sciences, Pakistan. Based on Husserlian principles, the study aimed to explore the essence of the participants' lived experiences and focused on understanding the subjective realities of individuals diagnosed with liver cirrhosis. The data was collected between May and June 2024

Study Participants

The study participants were the adult patients with liver Cirrhosis who presented to outpatient department for liver transplant evaluation at Pir Abdul Qadir Shah Institute of Medical Sciences Gambat, Pakistan. Tentatively fifteen cirrhotic patients were purposively selected to provide rich, in-depth information. However, the principle of data saturation was adhered to, and interviews were discontinued once they no longer yielded new themes or insights.

The inclusion criteria included all adults (aged 18 and above) patients having either gender, labelled as Child-Pugh class C liver cirrhosis grounded on clinical, laboratory parameters, and Imaging findings for at least one year. All patients who were willing and were able to communicate freely participated in this study. Patients with other concomitant other chronic illnesses and liver cirrhosis, individuals with severe cognitive impairment or hepatic encephalopathy unable to effectively communicate and terminally or critically ill patients who were unable to complete the interview process were excluded to participate in the study.

Instruments and Data Collection Methods

Data collection involved a socio-demographic questionnaire and an interview guide. In-depth, semi-structured interviews were conducted using a guideline developed based on the literature review and the expertise of healthcare providers, incorporating open-ended questions. A pilot test with 2 participants was conducted to refine the questions for contextual appropriateness and to enhance their clarity and relevance. The dataset consists of describing cirrhotic patient's experiences, including physical, emotional, social, and spiritual aspects, as well as their interactions with healthcare professionals. The leading questions covering

I. What were your initial thoughts and feelings upon receiving the diagnosis?
II. How has liver cirrhosis impacted your ability to carry out daily activities, such as work, self-care, and household chores?
III. How did your diagnosis of liver cirrhosis affect your emotional well-being? Have you experienced any of these like feeling of fear, loss of interest in life, anger, grief?
IV. What strategies have you developed to cope with the emotional and mental challenges of living with liver cirrhosis?

V. How has liver cirrhosis impacted your social activities and social relationships with family, friends, and colleagues?
VI. What role does your family or social support network play in your care and well-being?
VII. How your religious beliefs or practices influenced your experience with liver cirrhosis?
VIII. Have you found comfort or strength in prayer, religious services, or other religious practices since your diagnosis? Can you share a specific experience?
IX. How would you describe your experiences with healthcare professionals and quality of the care and information provided to you about your illness?
X. Have you experienced any challenges in accessing healthcare services?

The interviews took place in a quiet and peaceful room within the hospital setting. Participants were encouraged to freely describe their experiences during the interview to record genuine experiences. Each interview lasted approximately 45 minutes and was recorded as audio. Audiotape recorder also was used. Additionally, non-verbal cues were documented in field notes to provide richer contextual data. Each interview was assigned a code. Afterward, the researcher listened to the recordings and made key notes. Keywords, phrases, and statements were then transcribed. Data were collected until the completing of data saturation.

Data Analysis

All interviews were audio-recorded and later transcribed. The data analysis process maintained the uniqueness of each participant's lived experience, a key aspect of phenomenological studies. The researcher transcribed the interviews verbatim in local language and verified them by repeatedly reviewing the audio recordings. The transcriptions were then translated into English, followed by the development of coding categories and the identification of major themes based on the experiences of patients with liver cirrhosis. Content analysis was employed to manually explore the primary themes and uncover the meaning structure of patients' lived experiences. The data analysis followed Colaizzi's seven-step method:

1. The researcher thoroughly read participants' descriptions to develop an empathetic understanding.
2. Key words, phrases, and sentences were identified, coded, and categorized into themes.
3. Extracted codes were assigned the formulated meanings.
4. These meanings were grouped into theme clusters, with the original descriptions reviewed for reliability.
5. The results were synthesized into a comprehensive description of the studied phenomenon.
6. A clear and definitive statement of the phenomenon was formulated where possible.
7. Finally, findings were returned to participants for validation to ensure accuracy.

To enhance validity, participants rechecked the findings to confirm interpretations. Extensive discussions were done by the authors to achieve consensus on the analysis, and an expert in phenomenological methods reviewed the process to ensure methodological rigor.

Ethical Considerations

Ethical approval was taken from the Institute Review Board (Reference no: 24/12) before initiation of the study. A verbal as well as written informed consent from all the participants was obtained. Participant confidentiality was maintained by anonymizing the data through a coding system, replacing the patients' names with numbers, and securely storing audio recordings and transcripts.

Participants were assured that their involvement was voluntary, with the right to withdraw at any time without explanation. To ensure trustworthiness, recorded documents were reviewed and shared with them. They were also informed that findings would be published in scientific journal. All collected data remained confidential and were destroyed upon the study completion.

RESULTS

Data collection continued until data saturation, reaching a number of 08 participants. The dataset consists of describing cirrhotic patient's experiences, including physical, emotional, social, and spiritual aspects, as well as their interactions with healthcare professionals. Following themes were identified after the data was transcribed and thematic analysis was done. The study included eight participants with cirrhosis (four men and four women), aged 45 to 63 years. The duration of illness varied: one participant had been diagnosed for one year, four for two years, two for three years, and one for four years. Data analysis identified six main themes and 13 sub-themes, detailed below.

A. Initial Reactions

Shock and Disbelief:

Patients initially expressed denial and surprise upon diagnosis (e.g., "I couldn't believe this was happening to me." Reported by Patient 07).

B. Physical Challenges

I. Fatigue and Weakness:

A prevalent issue among all patients, significantly impacting daily activities (e.g., "I struggle for simple tasks." Reported by Patient 01).

II. Discomfort:

Discomfort due to chronic abdominal pain, was a noteworthy challenge (e.g., "The right hypochondrial pain is constant." Reported by Patient 04).

III. Cognitive Decline:

Forgetfulness and confusion were also reported by some of the patients (e.g., "I forget frequently what I do." Reported by Patient 05).

C. Emotional Responses

I. Fear and Anxiety:

A common reaction, with concerns about disease progression and future consequences (e.g., "I felt like my life was over." Reported by Patient 01).

II. Sadness and Depression:

Many patients reported depressive symptoms and emotional distress (e.g., "I feel like a shadow of myself." Reported by Patient 01).

III. Family Support as a Coping Mechanism:

Most participants relied on their families for emotional and physical support (e.g., "My family takes care of me." Reported by Patient 5).

D. Social Impact

Isolation and Withdrawal:

Majority of the patients reported reduced social engagement due to physical limitations or embarrassment (e.g., "I feel like a burden." Reported by Patient 2).

E. Religious and Spiritual Practices

I. Believe in Faith:

Majority of the patients found relief in faith and prayer (e.g., "My faith gives me strength." Reported by Patient 01).

II. Hopelessness:

Some patients struggled with their faith and questioned their fate (e.g., "Is this a punishment from God for me?" Reported by Patient 4).

F. Healthcare Experiences

I. Positive Experiences:

Some patients were satisfied with their care (e.g., "I feel like I am in good hands." Reported by Patient 03).

II. Negative Experiences:

Others felt neglected by healthcare providers (e.g., "I feel like they don't really care and listen to me." Reported by Patient 02).

III. Barriers to health care Access:

Limited availability of specialized care and financial constraints were common issues among majorities (e.g., "It's frustrating to cover long distances for checkups." Reported by Patient 8).

DISCUSSION

This study explored the experiences of individuals living with liver cirrhosis, focusing on various aspects of the disease, including physical, emotional, social, and religious challenges. Participants faced additional difficulties such as financial burdens and a lack of disease awareness. The physical toll of the illness, its potential future complications, life-threatening nature, and social struggles were identified as key contributors to mental health issues. Furthermore, stressors such as fatigue, anxiety, and financial constraints significantly impacted their mental well-being and social functioning.

Patient	Age	Gender	Occupation	Initial Reaction	Physical Challenges	Emotional & Social Impact	Coping Mechanisms	Healthcare Experience	Future Outlook
1	52	M	Construction Worker (Stopped working)	Shock & Fear	Weakness, struggles with simple tasks	Anxiety, feels like a burden, withdrawn socially	Family support, faith	Positive experience	Concerned about disease progression
2	60	F	Housewife	Sadness & Confusion	Body aches, difficulty moving	Feels isolated, lost interest in life	Prayers, Quran recitation	Negative, feels dismissed by doctors	Hopes for improved health
3	48	M	Teacher	Denial	Fatigue, weakness, difficulty dressing	Nervousness, copes through walks	Walking, religious connection	Satisfied, trusts his doctor	Hopeful, seeks information actively
4	55	F	Lady Health Worker	Fear	Fatigue, chronic pain, unable to work	Depression, hopelessness, isolation	None	Struggles with transplant access, no donor available	Fearful of decline, frustrated with treatment limitations
5	62	M	Farmer	Confusion	Memory issues, forgetfulness, cognitive decline	Anxiety, relies on family for support	Strong faith in God	Good relationship with doctors but lacks medication access	Accepts condition, grateful for family support
6	57	F	Retired Policewoman	Anger & Devastation	Fatigue, insomnia, muscle cramps	Isolation, grief, feels like a burden	struggles with faith	some doctors are empathetic others dismissive	Fear of losing life, actively searches for treatment online
7	63	M	Retired Businessman	Shock & Disbelief	Ascites, malaise, difficulty managing daily tasks	Anger, stress, strong family support	Faith, time with grandchildren	Satisfied, caring doctor	Hopeful, made lifestyle changes (diet, exercise)
8	45	F	Housewife	Scared	Fatigue, low energy	Worrisome, strong family support	Faith, time with children	Struggles with accessing specialist care	Worried about illness impact on family

Table-I. Represent summarized data in tabular form

Similarly, Lim and colleagues reported that patients with cirrhosis frequently experience anxiety, social withdrawal, regret, diminished sexual relationships, and financial difficulties.[8]

Chronic diseases reduce quality of life and limit patients' social activities, further impacting their physical and emotional well-being.[9] Similarly, our findings indicate that most participants experienced a diminished quality of life secondary to various challenges. Younossi and colleagues evaluated the quality of life in 120 patients with chronic liver disease, finding that 51% had cirrhosis. Among these, those with Child-Pugh B and C cirrhosis had the lowest quality of life scores.[10] Bryce and colleagues reported that patients with cirrhosis awaiting transplantation experienced a significant decline in health-related quality of life.[11] Adibi et al.[4] also noted that patients with cirrhosis had lower utility, indicating a diminished quality of life.

Among the important subthemes we noted among the cirrhosis individuals' experiences was the social support provided by the family members and colleagues. Our study also highlighted the essential role of family support. A strong patient-caregiver relationship plays a crucial role in mental support and adherence to treatment. Similarly, the patient satisfaction with their medical team significantly enhances commitment to care. Additionally, patient-centered care fosters greater engagement in treatment. This has been reported by other study as well.[12]

From a physician's perspective, the initial stress experienced by patients at the time of diagnosis presents an opportunity to motivate behavioral change. Brown et al.[13] suggested that patients experiencing heightened anxiety about their condition were more receptive to lifestyle modifications, making early educational interventions particularly effective. To better support cirrhotic patients, clinicians should strive to understand their experiences, as this can help identify individual priorities and improve patient-centered care.[14] Recognizing patients' fears and anxieties and addressing their emotional distress are fundamental responsibilities of caregivers. The highest quality of care is achieved when patients feel a sense of overall well-being, which encompasses psychological, social, cultural and economic factors.[15]

Our findings indicate that the majority of patients found comfort and strength through their religious beliefs, which helped them confront their illness and navigate various challenges. Engaging in prayers, worship, and visiting holy places fostered courage and hope and enabled patients to better cope with their condition. Several studies have similarly identified religion as a significant supportive measure and resilience for individuals facing chronic illness.[16]

We experienced that fatigue and generalized aches were the commonest symptoms among our cohort which limited the patient physical activities of the patients while performing daily life activities. Similarly, a previous study conducted in South Korea also found that fatigue scored the highest among all reported symptoms among the cirrhotic patients.[17] Furthermore, some of our patients faced limited availability of specialized care and financial constraints, and complained neglected by healthcare providers'. Cirrhosis of the liver had got a significant negative impact on patients' finances and employment, affecting their daily lives. Due to the severity of their symptoms, they were unable to work, leading to increased dependency on their families—a finding consistent with previous studies.[18,19]

The majority of our patients relied on family and social support, which were key factors in helping them cope with their psychological and mental challenges. This was also reported by others too.[20]

This study has several limitations, including a small sample size from a single health center, variations in individual experiences, and differences in participants' physical and emotional states at the time of the interview. Additionally, the nature of qualitative research limits the generalizability of findings. To enhance the applicability of these results, future studies should incorporate quantitative approaches with a multicenter design and a larger patient population.

CONCLUSION

This study revealed that patients with liver cirrhosis experienced significant social, physical, psychological, and financial challenges. Despite these hardships, patients employed various coping strategies, including religious attachment and seeking social support, to manage their struggles. In light of these findings it is suggested to implement customized emotional and social support strategies, including family-centered educational initiatives and improved mental health interventions, to help patients effectively manage the challenges associated with cirrhosis.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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3	**Nosheen Zafar:** Methodology.
4	**Sarah Arif:** Data analysis.
5	**Sadaf Rasheed:** Formatting.
6	**Junaid Sarfraz Khan:** Conceptualization, supervision.