RJNMSR
Review Journal of Neurological & Medical Sciences Review

Volume 4, Issue 6, 2026

LIVED EXPERIENCES OF PATIENTS WITH CHRONIC ILLNESSES IN A TERTIARY CARE HOSPITAL, KGN MTI BANNU KPK PAKISTAN: A QUALITATIVE EXPLORATION

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DOI: https://doi.org/10.5281/zenodo.20537854

Received	Accepted	Published
07 April 2026	19 May 2026	04 June 2026

ABSTRACT

Objective

To explore the lived experiences of patients with chronic illnesses at KGN Hospital MTI, Bannu, and to understand the challenges they face in their healthcare journey.

Methods

A qualitative phenomenological study was conducted using semi-structured in-depth interviews with purposively sampled participants. Data were analyzed using Braun and Clarke's thematic analysis framework.

Results

Four major themes emerged: (1) Physical and Emotional Burden, (2) Healthcare Access and Quality, (3) Social and Family Dynamics, and (4) Coping Strategies and Support Systems.

Conclusion

Chronic illness imposes a substantial burden on patients, both physically and emotionally. While healthcare providers offer support, gaps in access to medicines and social stigma persist. Improving healthcare services, patient education, and psychosocial support can enhance patients' quality of life.

Keywords: *Chronic illness, patient experiences, qualitative research, thematic analysis, healthcare access*

Introduction

Chronic diseases, including diabetes, hypertension, chronic kidney disease, chronic liver disease, post-tuberculosis (TB) bronchiectasis, and stroke, are among the leading causes of morbidity and mortality worldwide (1). These conditions necessitate long-term medical management and place considerable physical, psychological, and financial burdens on patients and their families. According to the World Health Organization (WHO), chronic diseases account for than 70% of global deaths, with the highest burden in low- and middle-income countries (LMICs) (1).

Pakistan faces a rising burden of chronic diseases due to a combination of factors, including lifestyle changes, increasing life expectancy, and inadequate healthcare infrastructure (2,3). Limited access to healthcare, medication shortages, and financial constraints hinder optimal disease management, often leading to poor health outcomes (4,6). Additionally, cultural beliefs and societal stigma influence health-seeking behaviors, making treatment adherence a challenge for many patients (8,11).

Understanding the lived experiences of patients with chronic diseases is important for making effective, patient-centered health-care interventions. Qualitative research provides significant insights into the personal, emotional, and social challenges these patients face, helping health-care policymakers, health-care administrator and providers address barriers to care (5,7). This study aims to to investigate the lived experiences of patients with chronic illnesses in a tertiary care hospital in Pakistan, highlighting the barriers and challenges they face and potential strategies to enhance patients outcomes.

Methodology

Study Design

This study adopts a qualitative phenomenological design to gain an in-depth understanding and investigation of the lived experiences of patients with chronic illnesses. This approach is selected because it enables exploration of personal perceptions, emotions, and daily challenges in a real-world context of chronic illness patients.

Research Team and Reflexivity

The interviews were conducted by Dr Qismat ullah , who is PGR medicine working in KGN Hospital mti bannu. Prior to study, no relationship was established with participants. Participants were informed about researcher academics background and purpose of the study but not given information about researcher personal motivation and goals.

Study Setting

This research based in depth interview of phenomenological study conducted at Khalifa Gul Nawaz (KGN)hospital MTI, bannu, kpk, Pakistan-- one of the tertiary care hospital that provides services to a mixed population from urban and rural backgrounds. This tertiary care hospital's diverse patient base offers a comprehensive setting to explore and investigate the the impact of socioeconomic and cultural factors on chronic illnesses management.

Sampling strategy and participants selection

Sampling Method:

Purposive sampling was used to recruit participants for this study capable of providing rich, detailed information

Sample Size:

Approximately 10 participants were chosen. Data saturation was achieved once new themes emerged during analysis

Inclusion Criteria

Adults (more than 18 year) who were known case of diabetes, hypertension, chronic kidney disease, chronic liver disease, post TB Bronchectisis and stroke for at least one year.

Patients receiving ongoing treatment and care at KGN hospital MTI Bannu.

**having Ability to give informed consent and articulate personal experiences

Exclusion Criteria::

Individuals with acute medical conditions and problems requiring immediate treatment and intervention

**patients with significant cognitive impairment who were not able to communicate effectively

Participants demographics

Participant Demographics

A total of 10 participants were interviewed. The demographic profile is as follows:

Table:1

CHARACTERISTRICS	DETAILS
Gender	6 Males, 4 Females
Age Range (years)	40-75 (Mean: 58 years)
Duration of Illness	8-15 Years
Education Level	2 with no formal education, 5 with primary/secondary, 3 with Higher education
Residence	4 Rural, 6 Urban

Data Collection

Data collection

Interviews:

Semi structured, in- depth interviews were conducted in Pashto and Urdu, lasting 30 to 40 minutes of each participants.

An interview guide was developed to investigate and explore multiple domains: physical symptoms, financial burdens and stress, emotional distress, social dynamics and coping mechanisms and strategy

Recording and transcription

*All interviews were Audio recorded with consent from participants, transcribed verbatim, and lastly translated into English.

Data application:

Transcripts systematic coding done manually

A detailed code-book was made collaboratively to ensure that both inductive (emergent) and deductive (theory based) codes were captured

Table:2 Thematic categories identified in the data

THEME	DESCRIPTION/DEFINITION
1. Functional and Physical limitations	Participants report with persistent pain difficulty in performing routine task and muscle weakness
	Mostly Patient experience difficulty in walking or engaging in physical activities due to chronic illness
2. Psychological and Emotional burden	Worsening health condition , uncertainty about the future and prognosis causes significant Psychological distress
	Some patients show feelings of isolation and despair, affecting their quality of life
3. Financial constraints	High expenses for medication diagnostic test and hospital visits create financial strain.
	Many patients are unable to do job due to their illness leading to loss of income
4. Health-care access, barriers and challenges	Patients are unable to get timely consultation with relevant medical experts
	Long travel distances to other city hospital make regular followup difficult especially for rural patients
5. Quality of health-care services	Patients receive little guidance on disease management, medication adherence and lifestyle modifications
	Emotional and mental health are often neglected in routine health care interaction
6. Social and Family support	Some patients depends heavily on family members for routine activities in emotional values
	Some of them feel guilty for depending family member, leading to emotional distress

7. Social isolation and stigma	Some patients encounter discrimination due to myths and misconception of people about chronic illness
	Fear of stigma and spread of diseases results in patients avoiding social gatherings and community involvement
8. Coping mechanism and adaptation	Patients make significant modification in diet physical activity and sleep pattern to mange symptoms
	Many find relief in Faith prayer and spiritual practices as a part of their coping mechanism
9. Alternative health-care seeking behaviour	Some patients are in search of complementary treatment along side modern medicine due to cultural belief
	Some patient prefer traditional healers over hospital based treatment
10. Health-care improvement recommendation	Patients suggest that health-care provider should offer more information and counseling on chronic disease on self management
	Many patient want to receive improve d access to medication and specialist and lower health-care cost

Data Analysis

The collected data were analyzed using Braun and Clarke's six steps thematic analysis framework

1. Familiarization:

Researchers read the transcripts several times to immerse themselves in the collected data

2. Generating initial codes:

Meaningful and important segments of text were highlighted and assigned preliminary codes

3. Theme identification:

Codes were grouped into potential and important themes reflecting common patterns

4. Reviewing themes:

Themes were checked and examined for internal coherence and external differentiation

5. Defining themes:

Clear definitions and names were given to each theme.

6. producing the Report:

Themes were organized and grouped into a narrative supported by illustrative quotes.

To ensure clarity of analysis a table (table 3) was constructed to map themes and sub themes along with representative data extracts

Ethical Considerations

Ethical approval was received from the institutional review board of Khalifa Gul Nawaz (KGN) Hospital MTI. Informed consent was obtained from all candidates to make sure confidentiality.

Results

A total of 10 participants were interviewed , consisting of 6 males and 4 females with various chronic illnesses, including diabetes, hypertension, chronic kidney disease, post TB bronchiectasis, chronic liver disease and stroke. Their ages ranges from 45 to 76 years with average duration of illnesses of 10—14 years . Data analysis showed four key themes that encapsulates their experience.

Each themes explanation is given as under.

1. Physical and Emotional Burden

Participants presented with persistent fatigue, chronic pain, breathlessness, and psychological distress, including depression and anxiety.Many described their routine activities as exhausting needed frequent periods of rest and help from family members.

> "I feel exhausted on and off. Even small tasks are difficult now."

"I wake up feeling tired and even a short journey make me breathless""

"I am always in-fear about complications. What if my situation gets worse?"

""The pain never completely comes into end even with medicines""

Psychological distress was common , with many participants expressing their feelings of depression, anxiety, and fear of disease progression. Their uncertain situations and financial stress associated with medical expenses Worsened their mental health.

"" I'm in fear and uncertain what will happen to me in the next few coming years.

"" My every visit to hospital or doctor , I fear of bad news ""

2. Health-care Access and Quality

Most of the participants struggled with access to health care , telling about financial constraints ,limited availability of medicines and lack of specialist care. Many had to travel large distance to other cities for specialist consultation which was physically exhausting and financially draining.

"" The nearest hospital doesn't have my required medicines , so I have to go to another city and hospital to get them""""

"" I need dialysis but I have to wait for weeks and months because their are not enough machines """"

Many participants showed expression of frustration over the lack of counseling and patients education in hospitals.

They reported that mostly doctors concentrate on prescribing medications but didn't counsel and discuss long term disease management or emotional well being.

"" Doctors don't not have enough time to explain my disease condition to me""

"" I don't know what dietary changes or what foods i should avoid ""

Limited financial resources, medication shortages, limited finances resource, an absence of rehabilitation services and dialysis were major barriers/challenges to care (6,9).

> "Sometimes I can't find the required medicine. Other times, I can't afford it ."

"The doctors approach are good, but there's no proper counseling or rehabilitation services for people like us."

3. Social and Family Dynamics

Family members support varied among participants. While some patients described their family support strong , others felt like a burden on their loved ones.

"" My family members do each and everything for me , but I feel guilty that they have to do so much for me ""

" My family pays for my medicines, but I know it is not easy """

Social stigma and fear to spread the disease was particularly evident among patients with chronic liver disease and post TB bronchiectasis, as they were mostly avoided by others due to misconceptions about disease transmission and spread.

"" People behave and show me attitude as i have something contagious ""

"" Even my close family members and relatives hesitate to share food with me"

While some patients have strong family support, others experienced social stigma and isolation (8).

> "My family cares a lot of me, but I feel I am burden to them."

"Most people avoid me because they think my illness is contagious."

4. Coping Strategies and Support Systems

Despite these barriers and challenges, patients used various coping mechanisms including social support,faith and lifestyle adjustments. Many participants found themselves comfort in religious practices saying that prayers helped them to cope with uncertainty and fear.

""I have left my situations/ conditions everything in God's hands""

""Reciting the Quran and prayers gives me peace of mind and heart""

Several participants have adopted routine exercise, daily dietary modifications, and compliance to medications to manage their condition. However, lack of health education and counselling made it difficult for some patients to understand the importance of lifestyle changes.

""I always try to eat less sugar and take less tea but I don't know what else to do""

Patients used medication compliance, religious practices to cope and daily dietary modifications (10,11).

> "I always try to eat healthy diets and take my routine medication on time."

"Prayers help me stay positive."

Table:3 The table below summarizes the key themes, subthemes and participants original wording

THEMATIC CATEGORY	SUBTHEME	KEY FINDINGS	PARTICIPENT ORIGINAL WORDINGS
11. Functional and Physical limitations/Burden	Chronic fatigue and pain	Participants report with persistent pain difficulty in performing routine task and muscle weakness	I feel exhausted on and off. Even small tasks are difficult now
	Mobility Issues	Mostly Patient experience difficulty in walking or engaging in physical activities due to chronic illness	I wake up feeling tired and a short journey make me breathless
12. Psychological and Emotional burden	Fear of disease progression and anxiety depression	Worsening health condition , uncertainty about the future and prognosis causes significant Psychological distress	My every visit to hospital or doctors I fear of bad news and my disease worsening. I always in fear about complication, what if my situation get worse.
	Hopelessness and depression	Some patients show feelings of isolation and despair, affecting their quality of life	I am in fear and uncertain what will happen to me in next few coming years
13. Financial constraints	High cost of treatment and medication	High expenses for medication diagnostic test and hospital visits create financial strain.	Some time I can not find the required medicine, other time I can not afford it.
	Unemployment	Many patients are unable to do job due to their illness leading to loss of income	I don not even apply for job due to fear of my disease
14. Health-care access, barriers and challenges	Limited availability of specialists	Patients are unable to get timely consultation with relevant medical experts	I need dialysis but I have to wait for weeks and months because there are not enough machine
	Distance challenges	Long travel distances	The nearest hospital

	and Transportation	to other city hospital make regular followup difficult especially for rural patients	does not have my required medication so I have to go another city and hospital to get that.
15. Quality of health-care services	Lack of patient education	Patients receive little guidance on disease management, medication adherence and lifestyle modifications	Many patient showed expression of frustration over the lack of counseling and patient education in hospital
	Limited psychological support and counselling	Emotional and mental health are often neglected in routine health care interaction	Doctor do not have enough time to explain my disease condition to me and care of me
16. Social and Family support	Emotional and practical support from family	Some patients depends heavily on family members for routine activities in emotional values	My family pays for my medicine but I know it is not easy
	Feeling like a burden	Some of them feel guilty for depending family member, leading to emotional distress	My family member do each and every ting for me, but I feel guilty that have to do so much for me.
17. Social isolation and stigma	Community misconception and myths about chronic illness	Some patients encounter discrimination due to myths and misconception of people about chronic illness	People behave and show me attitude as I have something contiguous
	Reduce Social interaction	Fear of stigma and spread of diseases results in patients avoiding social gatherings and community involvement	Even my close family member and relative hesitate to share food with me. Most people avoid me because they think my illness is contagious
18. Coping mechanism and adaptation	Dietary and lifestyle modification	Patients make significant modification in diet physical activity and sleep pattern to mange symptoms	I always try to eat less sugar and take less tea but I do not know what else to do. I always try to eat health diet and to take my routine medication.

	Emotional and Religious coping strategies and mechanism	Many find relief in Faith prayer and spiritual practices as a part of their coping mechanism	I have left my situation/condition every thing In God hand. Reciting the Quran and prayer give me peace of mind and heart.
19. Alternative health-care seeking behaviour	Use of a herbal and traditional medicine	Some patients are in search of complementary treatment along side modern medicine due to cultural belief	Prayers help me stay positive. I used herbal medication and traditional techniques which make me quit relaxed from year.
	Trust in non-medical healers	Some patient prefer traditional healers over hospital based treatment	Traditional treatment are easy and inexpensive and within reach of us.
20. Health-care improvement recommendation	Better patient education	Patients suggest that health-care provider should offer more information and counseling on chronic disease on self management	I do not know what dietary changes or what food should i avoid. The doctor approach are good but there is no proper counseling and rehabilitation services for people like us.
	Accessible and affordable treatment	Many patient want to receive improved access to medication and specialist and lower health-care cost	We can not found specialist care and improved medication within our financial resources.

Discussion

Our findings match with previous studies of lived experience of chronic illness patients in low and middle income countries (LMICs,)which show health-care access limitation financial burdens and lack of patient education as major challenges (6,7,9). Studies from South Asia show social stigma's impact on psychological distress among chronic patients (8).

Health-care access remains a important challenge/barrier, with limited availability of medication and rehabilitation services in Pakistan (9). Additionally, mental health issues, such as anxiety and depression, are often neglected in chronic disease management programs (10).

Many patients continue to search alternate treatments or rely on traditional healers, reflecting a lack of trust in modern medicine (11). Community-based health education and counseling is crucial to addressing these cultural beliefs and improving treatment compliance.

Physical and emotional burden

Consistent with prior studies, chronic illness patients in this study also showed physical discomfort, constant fatigue and psychological distress. Uncertainty about disease prognosis and chronic pain led to significant depression and anxiety. These findings emphasis the urgent need for integrated mental health support in chronic illness management programs.

Health-care access and Quality

The limited availability of specific modern medicines , advanced diagnostic facilities and specialist care was a major challenge for participants, similar to Findings in previous studies. Financial burden and constraints further worsened these issues, as patients had to choose between meeting household expenses and buying medicines. Health insurance coverage is limited or yet to be started sehat card insurance in some area's but limited to few specific conditions of admitted ward patients, leaving most patients to pay out of pocket for chronic disease management.

Social and family dynamics

While some patients experienced strong family support others received social stigma and isolation particularly those with chronic liver disease or post TB conditions.

Social misconception and lack of education about chronic illnesses can lead to further stress, isolation and reluctance to seek health care. This highlights the need for public health awareness campaigns to reduce the stigma and promote inclusive community support.

Coping mechanisms and support systems

Among participants a key coping mechanism was religious faith , consistent with studies showing that spirituality helps patients to manage chronic illnesses. However, the lack of structured patient education and counselling program limits patient's ability to make informed lifestyle changes. Self management programs and community based health education and intervention can empower patients to take an active role in their disease management.

Recommendations for health care policy and implications for practice

1) Expand excess to medications and specialist care

Government and NGOS interventions are needed to advance and improve drug availability and specialist services in rural , undeserved and periphery areas.

2) integrate mental health support in chronic illnesses management

Proper counselling, chronic illnesses prognosis education and psychological support should be part of routine chronic disease care

3) Enhance patient education and health literacy

Hospitals based both government and NGOs sponsored programs should be implemented to educate patients regarding exercises, nutrition and medications adherence.

4) social stigma addressing through public awareness campaigns

Educational efforts and counselling should reduce misconceptions and myths about chronic illnesses.

5) **Improving Health-care Access** – Expanding rehabilitation services , dialysis and medication availability.

6) **Integrating Psycho-social Support** – Incorporating mental health services by family physician and specialist into chronic illness management both at primary and tertiary care level

Conclusion

Chronic illnesses enforce emotional, physical, social and financial burdens on patients. While some receive family support, others face social stigma and health-care access barriers and challenges. A multidisciplinary approach involving patient education, counseling, health-care improvement and psycho-social support programs is essential for better patient outcomes and results.

To address these challenges a holistic approach needed, incorporating mental health support, patient education, improved health-care services system and stigma reduction programs

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