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EXPLORING PATIENT EXPERIENCES AND PERCEIVED CHALLENGES IN MANAGING ENDOCRINE DISORDERS ACROSS DIFFERENT AGE AND SOCIOECONOMIC GROUPS

Original Article

Shabahat Arain[1]*, Maryam Saleem[2], Nasreen Alwani[3], Muhammad Owais Aijaz[4], Sohail Afsar Awan[5], Noshaba Zaheer Khan[6]
[1]PhD Scholar, Department of Zoology, University of Sindh, Jamshoro, Pakistan.
[2]Women Medical Officer, Maryam Nawaz Health Clinic, Hafizabad, Pakistan.
[3]Faculty, Aga Khan University Hospital, Karachi, Pakistan.
[4]MCPS Family Medicine, Pakistan.
[5]General Practitioner, Al Kharj Military Industries Corporation Hospital, Riyadh, Saudi Arabia.
[6]Lecturer, Government Nazareth Girls Degree College, Hyderabad, Pakistan.
Corresponding Author: Shabahat Arain, PhD Scholar, Department of Zoology, University of Sindh, Jamshoro, Pakistan, Shabahat113@gmail.com

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ABSTRACT

Background: Endocrine disorders such as diabetes, thyroid dysfunction, and adrenal conditions impose lifelong challenges that extend beyond medical management. Patients' experiences are shaped by their personal, social, and economic circumstances, influencing treatment adherence and overall well-being. Despite growing evidence on clinical aspects of endocrine care, limited research has explored patient perspectives across diverse socioeconomic and age groups, particularly in South Asian contexts.

Objective: To qualitatively explore patient perspectives on treatment experiences, lifestyle adjustments, and challenges in managing endocrine disorders among different age and socioeconomic groups in Lahore, Pakistan.

Methods: A six-month qualitative study employing a phenomenological approach was conducted in tertiary and community healthcare facilities across Lahore. Twenty-six participants diagnosed with endocrine disorders for at least one year were recruited using purposive sampling. Data were collected through semi-structured, in-depth interviews and analyzed thematically using Braun and Clarke's framework with NVivo 14 software. Ethical approval was obtained from the relevant institute.

Results: Five overarching themes with interrelated subthemes were identified: navigating treatment realities (medication adherence struggles, perceived treatment effectiveness, interaction with healthcare providers), redefining lifestyle and self-management (dietary adjustments, physical activity adaptation, self-monitoring challenges), psychosocial and emotional challenges (fear, stigma, coping mechanisms), influence of socioeconomic context (financial strain, access disparities, social support differences), and healthcare system experiences (trust in professionals, communication barriers, continuity of care). Participants described navigating illness as a complex negotiation between medical advice, economic realities, and emotional resilience.

Conclusion: The study highlights that effective endocrine disorder management requires more than medical intervention—it demands patient-centered, culturally sensitive care addressing emotional, social, and financial dimensions. Insights from this study can inform holistic and equitable endocrine care frameworks in Pakistan and similar contexts.

Keywords: Chronic Disease, Endocrine System Diseases, Health Equity, Patient Experience, Qualitative Research, Self-Management, Socioeconomic Factors.

INTRODUCTION

Endocrine disorders, encompassing a spectrum of conditions such as diabetes mellitus, thyroid dysfunctions, adrenal insufficiencies, and pituitary abnormalities, represent some of the most prevalent and chronic illnesses worldwide. These disorders often necessitate lifelong management and have far-reaching implications for physical health, psychological well-being, and overall quality of life (1). Despite advancements in medical therapies and patient education, managing endocrine disorders continues to pose significant challenges. These challenges are not confined to clinical outcomes alone but are deeply intertwined with patients' lived experiences, social contexts, and personal interpretations of illness. Understanding these experiences is pivotal in developing effective, patient-centered care models that acknowledge the complexity of managing chronic endocrine conditions (2,3). Research has shown that the experiences of individuals living with endocrine disorders vary considerably across age groups, cultural backgrounds, and socioeconomic strata. Middle-aged and older adults with type 2 diabetes, for example, often experience an evolving process of self-management characterized by the constant negotiation between bodily awareness, lifestyle demands, and emotional resilience (4,5). Patients frequently report feelings of frustration and anxiety as they adapt to the physical changes and complex treatment regimens associated with their conditions. These emotional burdens are compounded by the practical difficulties of balancing medical recommendations with social and economic responsibilities. Similarly, younger adults managing chronic conditions like diabetes often face unique psychosocial barriers as they navigate identity formation, peer relationships, and career development while adhering to demanding treatment routines (6,7)

Socioeconomic disparities play a critical role in shaping how individuals experience and manage endocrine disorders. Access to healthcare resources, medication affordability, and health literacy are key determinants of self-management success. For instance, in low-income settings, patients often struggle to maintain consistent medication adherence and dietary modifications due to financial constraints or limited access to healthcare professionals (8). Cultural beliefs and community networks further influence patients' coping mechanisms, as demonstrated in studies exploring diabetes management among women in South Africa, where cultural interpretations of disease and reliance on social networks profoundly impacted health-seeking behaviors (9). The psychosocial dimension of endocrine disorders is equally critical. Many patients report feelings of isolation, stigma, or loss of identity as a result of their chronic conditions. This is particularly evident among individuals undergoing endocrine therapy for cancer, where bodily alterations and side effects significantly disrupt perceptions of self and everyday life (10). Similarly, women undergoing adjuvant endocrine therapy for breast cancer frequently describe their treatment journey as emotionally and physically taxing, often feeling inadequately supported by healthcare systems (11). Such findings underscore the need for holistic care approaches that extend beyond pharmacological management to include psychological and social support systems tailored to patients' diverse needs. Technology and healthcare accessibility further shape patient experiences. The rise of telehealth in endocrinology has introduced both opportunities and challenges for patients and providers. While teleconsultations offer convenience and improved access, especially for those in remote areas, concerns persist regarding the adequacy of virtual assessments and the quality of patient–provider rapport (12). This evolving landscape necessitates an understanding of how technological interventions intersect with patients' expectations, socioeconomic realities, and trust in healthcare systems.

Qualitative studies have consistently emphasized the importance of hearing the "patient's voice" in understanding the lived realities of endocrine disorders. By exploring how individuals perceive their illness, adhere to treatment, and navigate their emotional and social worlds, researchers can uncover the nuanced barriers and facilitators to effective disease management (13,14). Such insights are invaluable for developing interventions that are responsive to patients' needs rather than solely grounded in biomedical models of care. Moreover, understanding intergenerational and socioeconomic differences in experiences allows health practitioners to design more equitable and culturally competent care strategies. Despite a growing body of literature, there remains a significant gap in comprehensive, cross-demographic qualitative research examining how patients across diverse age groups and socioeconomic backgrounds experience and manage endocrine disorders. Existing studies tend to focus on specific populations or single disease entities, leaving broader questions about comparative experiences unanswered. This research seeks to address that gap by exploring how individuals from different life stages and social contexts perceive their journey through diagnosis, treatment, and daily management of endocrine disorders. The objective of this study is to qualitatively explore patient experiences and perceived challenges in managing endocrine disorders across various age and socioeconomic groups. It aims to uncover how factors such as age, socioeconomic status, and cultural background influence patients' treatment adherence, lifestyle adjustments, and coping mechanisms, ultimately contributing to a more patient-centered understanding of chronic endocrine care.

METHODS

This qualitative study was designed to explore the lived experiences, treatment perceptions, lifestyle adjustments, and challenges faced by patients managing endocrine disorders across different age and socioeconomic groups in the Lahore region of Pakistan. The research adopted an interpretivist paradigm, emphasizing the subjective meanings that patients attach to their illness experiences. A phenomenological approach was employed to gain deep insights into patients' perspectives, emphasizing their emotional, behavioral, and social responses to living with endocrine conditions such as diabetes mellitus, thyroid disorders, and adrenal or pituitary dysfunctions. The study was conducted over six months, from January to June 2025, in both public and private healthcare facilities within Lahore, including endocrine outpatient departments of tertiary hospitals and community health centers. These diverse settings were selected to ensure representation from varied socioeconomic backgrounds, ranging from low-income urban areas to middle- and high-income localities. The target population comprised adult patients diagnosed with an endocrine disorder for at least one year, as this duration was considered adequate for individuals to have developed self-management experiences and coping mechanisms. Participants were recruited using purposive sampling, a strategy suitable for qualitative exploration where depth of understanding takes precedence over statistical generalizability. The sample size was determined using the principle of data saturation, the point at which no new information or themes emerged from the interviews. Based on similar qualitative studies in chronic disease management and diabetes care, a sample of 24 participants was estimated to achieve thematic saturation. Ultimately, 26 participants were recruited—13 male and 13 female—ranging in age from 18 to 70 years, encompassing adolescents transitioning into adulthood, working-age adults, and older adults (15,16). Socioeconomic classification was based on self-reported income and occupation, enabling comparison across lower, middle, and upper socioeconomic groups.

Inclusion criteria comprised individuals aged 18 years or older, clinically diagnosed with an endocrine disorder for at least 12 months, currently receiving treatment, and able to communicate fluently in Urdu or English. Exclusion criteria included individuals with cognitive impairment, severe psychiatric illness, or concurrent terminal disease that could impede participation or bias perceptions. Recruitment was facilitated through endocrinologists and diabetes educators who identified eligible patients during routine consultations. Those expressing interest were approached by the research team and provided with detailed information regarding the study's purpose and procedures. Data were collected through semi-structured, in-depth interviews conducted face-to-face in a private and comfortable setting within the respective hospitals or clinics. Each interview lasted between 45 and 70 minutes and was guided by an interview schedule developed specifically for this study. The guide included open-ended questions focusing on four core domains: (1) patients' understanding and interpretation of their condition, (2) experiences with treatment and healthcare providers, (3) lifestyle modifications and coping mechanisms, and (4) perceived challenges and social support systems. Probes were used to encourage participants to elaborate on their thoughts, ensuring depth and richness of data. The interview guide was pilot-tested on three participants to assess clarity and cultural appropriateness, following which minor linguistic adjustments were made. All interviews were audio-recorded with participants' permission and supplemented by field notes documenting non-verbal cues and contextual observations. For participants uncomfortable with recording, detailed written notes were maintained. Interviews were conducted in Urdu to facilitate expression in participants' native language and later translated into English for analysis. To ensure translation accuracy, back-translation was performed by a bilingual expert, and any discrepancies were resolved through consensus among the research team.

Data analysis followed Braun and Clarke's six-phase thematic analysis approach, which involved familiarization with data, generation of initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final report. Each transcript was read multiple times to ensure immersion in the data, after which meaningful text segments were coded manually. Codes were then collated into potential themes representing shared patterns across participants' narratives. NVivo software (version 14) was used to organize and manage data efficiently, allowing cross-comparison of themes across different demographic and socioeconomic groups. Reflexivity was maintained throughout the analysis process to minimize researcher bias, with reflective memos documenting the researcher's evolving interpretations and assumptions. To ensure trustworthiness, the study adhered to established qualitative rigor criteria: credibility, transferability, dependability, and confirmability. Credibility was achieved through prolonged engagement with participants and triangulation of data sources. Member checking was conducted by summarizing key interpretations to participants for validation. Transferability was enhanced by providing detailed contextual descriptions, allowing readers to assess applicability to other settings. Dependability was maintained through an audit trail of methodological decisions, while confirmability was achieved through independent peer debriefing within the research team. Ethical approval for the study was obtained from the Institutional Review Board of the relevant institute. All participants provided written informed consent after receiving a full explanation of the study's objectives, procedures, potential risks, and confidentiality assurances. Participation was voluntary, and individuals retained the right to withdraw at any stage without any repercussions on their medical care. Data were anonymized using unique identification codes, and all digital files were stored on password-protected computers accessible only to the research team. The primary outcome measures were thematic insights capturing the subjective experiences of patients regarding treatment adherence, lifestyle modification, psychosocial challenges, and the role of socioeconomic and cultural factors in disease management. The study aimed to illuminate the multifaceted realities of living with endocrine disorders, contributing to the development of patient-centered, culturally sensitive healthcare strategies tailored to the Pakistani context.

RESULTS

Analysis of interview data revealed five overarching themes and several interrelated subthemes that captured the nuanced experiences of patients managing endocrine disorders in the Lahore region. Each theme reflected the complexity of living with a chronic condition and the influence of individual, social, and systemic factors on self-management and well-being. The first major theme, **Navigating Treatment Realities**, encompassed the daily negotiation patients experienced while adhering to prescribed regimens. Many participants described their struggle with balancing multiple medications and coping with fluctuating symptoms. The subthemes included *medication adherence struggles*, *perceived effectiveness of treatment*, and *interaction with healthcare providers*. Patients often expressed ambivalence toward long-term medication use, as one middle-aged participant shared, “Sometimes I feel these medicines control my body, not me. Missing a dose feels like losing control.” Another remarked, “Doctors change my medicine often, and I never know which one will really work.” These narratives reflected uncertainty and a lack of confidence in consistent therapeutic outcomes. The second theme, **Redefining Lifestyle and Self-Management**, captured how participants adapted their daily routines and restructured their lifestyles. The subthemes included *dietary adjustments*, *physical activity adaptation*, and *self-monitoring challenges*. Dietary restrictions were particularly burdensome for those from low-income households who lacked access to recommended foods. A participant commented, “The doctor says avoid fried food, but that’s what we can afford most days.” Others struggled with regular exercise due to fatigue or limited safe spaces, revealing the intersection of medical advice and practical constraints. Despite these barriers, several participants described developing personalized routines to maintain equilibrium between treatment adherence and daily life responsibilities.

The third theme, **Psychosocial and Emotional Challenges**, illuminated the emotional toll of living with a chronic endocrine disorder. Subthemes identified were *fear of disease progression*, *stigma and social isolation*, and *coping mechanisms*. Participants frequently voiced anxiety regarding long-term complications and dependency on others. One young woman with thyroid disease stated, “I feel people look at me differently since I gained weight. It’s like they think I’m careless.” Emotional exhaustion and self-blame were recurring sentiments, yet many demonstrated resilience by engaging in faith-based or community support mechanisms to maintain psychological stability. The fourth theme, **Influence of Socioeconomic Context**, emphasized how economic and social standing shaped disease management experiences. Subthemes included *financial strain*, *access disparities*, and *social support differences*. Patients from lower socioeconomic strata reported inconsistent follow-up visits due to cost barriers. “Sometimes I skip my tests because they are too expensive. I just pray my sugar levels are fine,” shared a participant from a low-income neighborhood. Conversely, patients with stable financial resources were able to sustain treatment adherence and reported better psychological well-being, underscoring structural inequalities in healthcare access. The final theme, **Healthcare System Experiences**, highlighted the pivotal role of healthcare infrastructure and professional interactions in shaping patient satisfaction and trust. The subthemes identified were *trust in healthcare professionals*, *communication barriers*, and *continuity of care*. Participants valued empathetic doctors who listened to their concerns, but many described rushed consultations and fragmented care pathways. A retired patient expressed, “Every visit feels like starting over; they never remember my history.” Such experiences reflected systemic inefficiencies and underscored the need for integrated, patient-centered continuity of care. Overall, the thematic analysis demonstrated that managing endocrine disorders extended far beyond clinical treatment; it was a dynamic process shaped by personal resilience, social context, and healthcare accessibility. Patients constantly negotiated between medical advice and lived realities, constructing individualized coping strategies amid systemic challenges. The interconnected nature of these themes illustrated the multifactorial dimensions of chronic disease management and the urgent need for holistic healthcare models that consider emotional, economic, and cultural determinants of health.

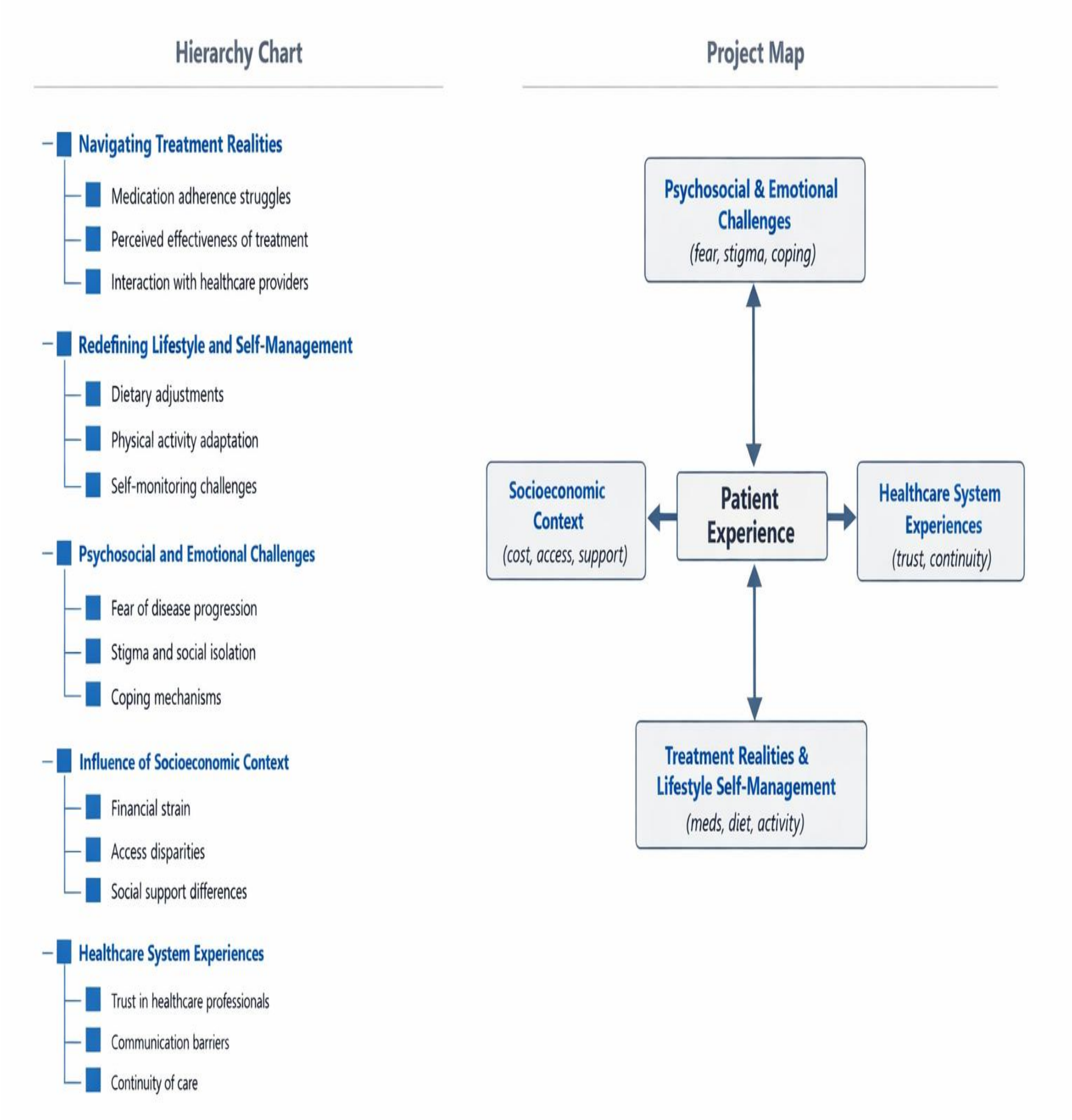

Figure 1 Determinants of Patient Experience

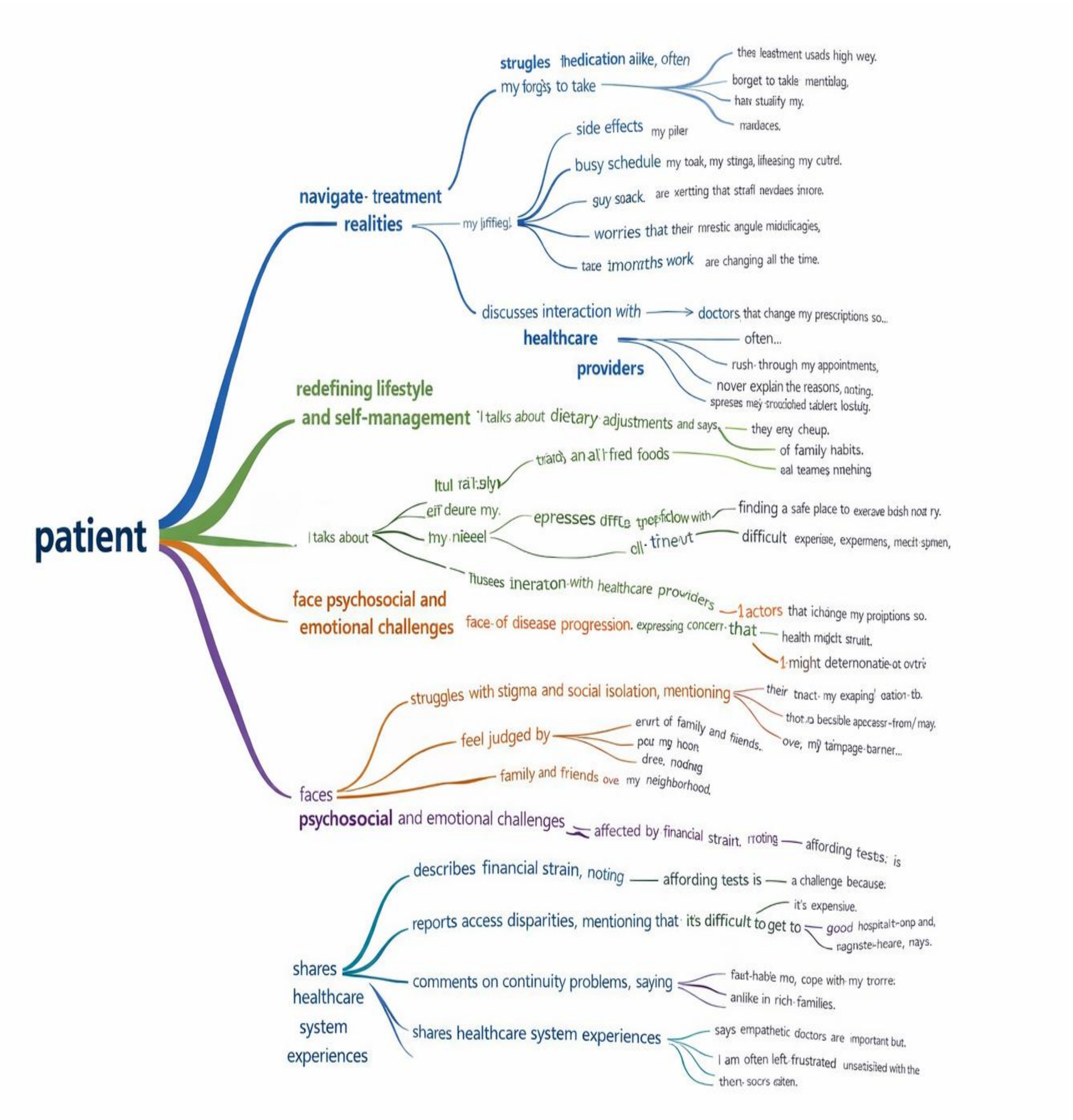

Figure 2 Patient Experience and Care Challenges

DISCUSSION

In interpreting the findings of this qualitative study, the central themes that emerged offered a multifaceted view of how individuals with endocrine disorders in the Lahore region navigated treatment, lifestyle adaptation, psychosocial stressors, socioeconomic constraints, and interactions with the healthcare system. These lived experiences resonate with and extend insights from recent qualitative research on chronic disease management, particularly in endocrine-related contexts. The theme of **Navigating Treatment Realities** highlighted patients' ongoing struggle with medication adherence and variable confidence in treatment effectiveness. This aligns with findings from recent studies on endocrine therapy, where adherence challenges are a dominant aspect of patient experience and are closely tied to perceived side effects and limited support structures. Research on breast cancer patients undergoing long-term endocrine therapy identified similar barriers to adherence and emphasized the importance of tailored information and management strategies to support patients in maintaining treatment regimens over time. In that work, multidimensional symptom burden and psychological distress were linked to difficulties in adherence and coping, underscoring gaps in supportive care that extend beyond prescription practices (16,17). The second theme, **Redefining Lifestyle and Self-Management**, revealed how patients enacted dietary changes, established exercise routines, and struggled with self-monitoring within the constraints of their socioeconomic and environmental conditions. These findings mirror broader literature on diabetes self-management in resource-limited settings, where patients frequently cited gaps in knowledge, structural barriers, and personal motivations as key influences on effective self-care. Although much of the earlier diabetes literature focused on barriers to self-management behaviors, the Lahore data further emphasized how cultural and economic contexts shape the translation of clinical advice into sustained daily practices (15,18).

The theme of **Psychosocial and Emotional Challenges** offered important insight into the emotional burden and stigma experienced by patients, particularly those whose visible symptoms influenced social interactions. Research in endocrine conditions has shown that psychosocial issues, including distress and anxiety, frequently co-occur with physical symptoms and can significantly affect quality of life and self-management capabilities. For example, studies exploring psychosocial dimensions in endocrine disorders such as diabetes and obesity have documented how affective disorders and social perceptions influence treatment engagement and overall well-being (19). The fourth theme, **Influence of Socioeconomic Context**, exposed how limited financial resources and uneven access to care shaped patients' interactions with healthcare and continuity of treatment. This observation is consistent with qualitative studies from other low- and middle-income settings that highlight structural inequities as major determinants of chronic disease outcomes. For instance, research on diabetes care in rural South Asia demonstrated that economic strain and health system barriers directly impeded patients' ability to access medications, adhere to follow-up schedules, and engage with preventive care. Although these studies focused more narrowly on specific geographic or disease contexts, their findings underscore systemic challenges that intersect with personal management strategies (20,21). The final theme, **Healthcare System Experiences**, reflected the importance of communication and continuity in shaping patients' satisfaction and trust. Patients valued empathetic, collaborative interactions, and expressed frustration with rushed consultations and fragmented care. This perspective echoes findings from experience mapping in diabetes care, where patients consistently reported unmet needs for personalized, patient-centered care and clearer communication across care transitions (22).

Taken together, these findings underscore critical implications for clinical practice and health policy. The prominence of medication adherence struggles and lifestyle adaptation barriers highlights the need for structured education programs tailored to cultural and socioeconomic contexts. Psychosocial support mechanisms should be integrated into routine care, not only to mitigate distress but also to strengthen patients' capacity for self-management. Moreover, health systems must prioritize continuity of care and communication training to foster trust and engagement, particularly in chronic disease settings where long-term relationships between patients and providers are essential. Strengths of the study included its in-depth phenomenological approach, purposive sampling across age and socioeconomic strata, and systematic thematic analysis. The use of participants' own narratives enriched the data with contextual nuance that would be obscured in purely quantitative work. However, limitations should be acknowledged. The qualitative design inherently limits broad generalizability, and the sample was drawn exclusively from healthcare settings in Lahore, potentially excluding voices of individuals with limited access to formal care. Future research could expand to rural settings and incorporate mixed-methods designs to corroborate qualitative themes with quantitative measures of adherence and health outcomes (23). In conclusion, the study's findings contribute to a nuanced understanding of how patients living with endocrine disorders experience and navigate the complexities of chronic disease management. They reinforce the need for holistic, patient-centered care models that integrate psychosocial support, culturally adapted education, and structural interventions to address socioeconomic barriers. Continued research that bridges patient experiences with health system interventions will be essential in improving outcomes for individuals with endocrine disorders in Pakistan and comparable contexts.

CONCLUSION

This study concluded that managing endocrine disorders in the Lahore region is a deeply personal yet socially influenced journey shaped by five interlinked themes: **navigating treatment realities** (medication adherence struggles, perceived treatment effectiveness, interaction with healthcare providers), **redefining lifestyle and self-management** (dietary adjustments, physical activity adaptation, self-monitoring challenges), **psychosocial and emotional challenges** (fear, stigma, coping mechanisms), **influence of socioeconomic context** (financial strain, access disparities, social support differences), and **healthcare system experiences** (trust, communication barriers, continuity of care). Collectively, these insights emphasize the need for holistic, equitable, and empathetic endocrine care models.

AUTHOR CONTRIBUTIONS

Author	Contribution
Shabahat Arain*	Substantial Contribution to study design, analysis, acquisition of Data Manuscript Writing Has given Final Approval of the version to be published
Maryam Saleem	Substantial Contribution to study design, acquisition and interpretation of Data Critical Review and Manuscript Writing Has given Final Approval of the version to be published
Nasreen Alwani	Substantial Contribution to acquisition and interpretation of Data Has given Final Approval of the version to be published
Muhammad Owais Aijaz	Contributed to Data Collection and Analysis Has given Final Approval of the version to be published
Sohail Afsar Awan	Contributed to Data Collection and Analysis Has given Final Approval of the version to be published
Noshaba Zaheer Khan	Substantial Contribution to study design and Data Analysis Has given Final Approval of the version to be published

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