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LIVED EXPERIENCES OF PATIENTS WITH TYPE 2 DIABETES MELLITUS: A QUALITATIVE SYSTEMATIC REVIEW AND META-SYNTHESIS IN GLOBAL AND LMIC CONTEXTS

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Abstract

Background: *Type 2 diabetes mellitus (T2DM) is a major global and LMIC health challenge with profound psychosocial and health-system consequences. Qualitative research explains how patients interpret and live with T2DM, but findings are dispersed across settings.*

Objective: To systematically review and meta-synthesize qualitative evidence on adults lived experiences of T2DM, highlighting common themes and LMIC-specific constraints.

Methods: *We conducted a qualitative systematic review and thematic meta-synthesis. We searched PubMed/MEDLINE, CINAHL, Scopus, Web of Science and Google Scholar (January 2005–October 2025) for English-language qualitative studies involving adults with T2DM. Study quality was appraised using the CASP checklist. Findings were synthesised using inductive coding and thematic synthesis informed by Braun and Clarke.*

Results: *Twenty-five studies met inclusion criteria. Seven analytical themes were generated: (1) emotional and psychological impact; (2) cultural beliefs, knowledge and misconceptions; (3) social support, stigma and relationships; (4) physical and functional burden; (5) self-management challenges and coping strategies; (6) financial constraints; and (7) healthcare system experiences. Across contexts, fear of complications, treatment fatigue and difficulty sustaining lifestyle change were pervasive. In LMICs, these were amplified by cost, misinformation, limited access to monitoring, and system constraints such as overcrowding and stock-outs.*

Conclusion: *T2DM is lived as a long-term biopsychosocial condition. Diabetes services should incorporate psychosocial care, culturally tailored education, family-inclusive strategies, and health-system strengthening to reduce structural barriers in LMIC settings.*

INTRODUCTION

Type 2 diabetes mellitus (T2DM) is a chronic metabolic disorder characterised by hyperglycaemia due to insulin resistance and relative insulin deficiency. The global diabetes burden continues to rise, and LMICs now carry a disproportionate share of morbidity and

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mortality[1-2]. In Pakistan, national prevalence is high and the health and economic impact is substantial[3-4].

Although biomedical management emphasises glycaemic control, medication optimisation and complication screening, these indicators do not capture the day-to-day realities of living with T2DM[5-6]. Patients must negotiate lifelong dietary change, physical activity, medication routines and monitoring while managing fear of complications, stigma and the practical limits of local health systems[5-7]. Evidence increasingly highlights that diabetes-related distress and psychosocial burden significantly influence self-care behaviours, treatment adherence, and quality of life, particularly in resource-constrained settings[8,9].Qualitative studies provide essential insight into why people do or do not adhere to recommended care, how they interpret diabetes through cultural and spiritual frameworks, and what support they need[10-13]. Studies from LMIC contexts consistently show that spiritual interpretations of illness, misinformation regarding insulin, financial barriers, and inconsistent healthcare experiences can undermine engagement with evidence-based care[14],[15] and understanding these lived experiences is essential for designing patient-centred, culturally appropriate, and feasible diabetes interventions[16],[17].

This review updates an existing meta-synthesis based on the research question from the previous assignment: 'How do adults with T2DM describe their lived experiences, challenges in disease management, and coping mechanisms?' We aimed to integrate global qualitative evidence, explicitly foregrounding LMIC realities relevant to Pakistan, and to translate findings into actionable implications [18,19].

Methods

Design and reporting

We conducted a qualitative systematic review and meta-synthesis. Reporting follows PRISMA principles adapted for qualitative evidence synthesis and the ENTREQ framework.

Eligibility criteria

Included studies: (i) qualitative or mixed-method studies with clearly reported qualitative findings; (ii) adults (≥18 years) diagnosed with T2DM; (iii) exploration of lived experience, perceptions, barriers, facilitators or coping; and (iv) peer-reviewed, English-language publications (2005–2025). Excluded: type 1 or gestational diabetes-only studies, quantitative-only designs, and studies reporting only provider/caregiver perspectives.

Information sources and search strategy

We searched PubMed/MEDLINE, CINAHL, Scopus, Web of Science and Google Scholar. Search strings combined terms for T2DM with 'qualitative', 'lived experience', 'perceptions', 'barriers', 'self-management' and synonyms. Reference lists were hand-searched.

Selection process

Two reviewers screened titles/abstracts, assessed full texts, and resolved disagreements by discussion. The PRISMA flow diagram summarises identification, screening and inclusion (Figure 1).

Quality appraisal

Methodological quality was appraised using the CASP qualitative checklist. Quality was not used to exclude studies; it informed confidence in individual findings.

Data extraction

We extracted country/setting, sample characteristics, methods, analytic approach, and author-reported themes and supporting quotations.

Synthesis approach

We used inductive coding to develop descriptive themes and then higher-order analytical themes. We compared findings across settings to identify convergence and LMIC-specific variations. A thematic map of the analytical framework is presented (Figure 2).

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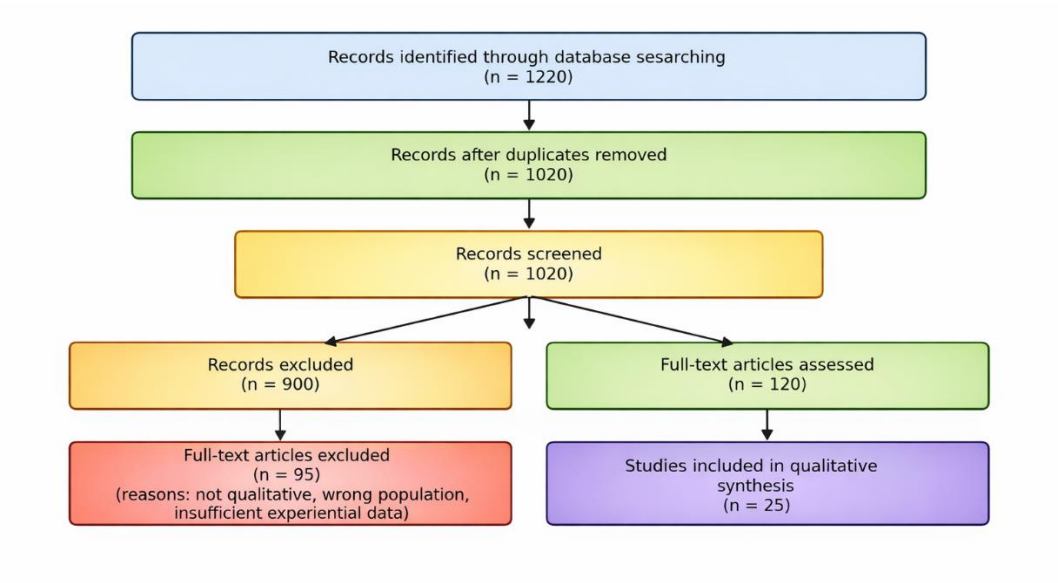


Figure 1 (PRISMA flow diagram): visual summary of study identification, screening, eligibility and inclusion

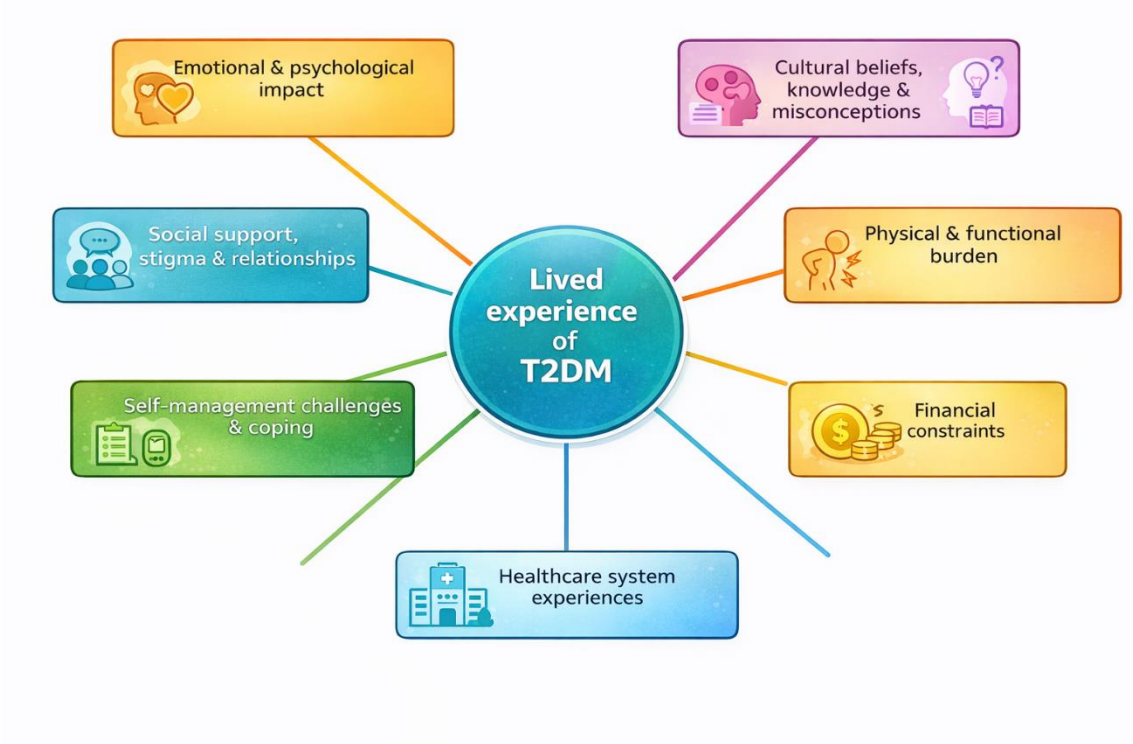


Figure 2 (Thematic map): analytical framework showing the seven themes clustering around the lived experience of T2DM

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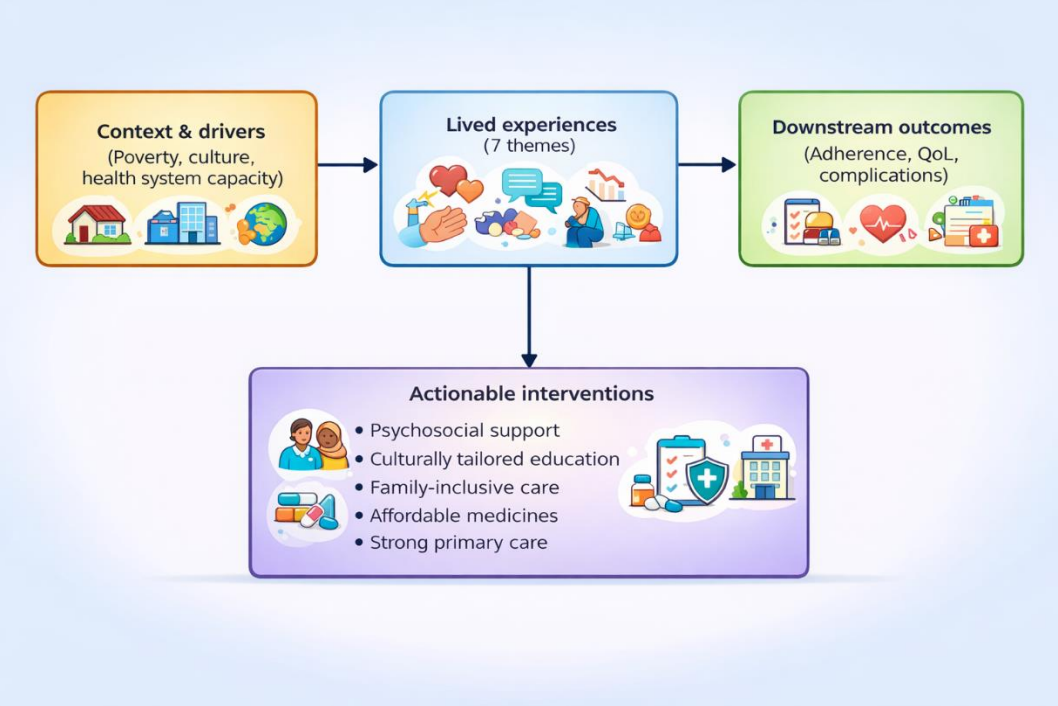


Figure 3. Conceptual model linking context to lived experience, outcomes and intervention entry points

Results

Included studies

Twenty-five studies were included, spanning South Asia, the Middle East, sub-Saharan Africa and high-income settings. Most used semi-structured interviews and thematic or phenomenological analysis. LMIC studies commonly recruited participants from public hospitals or clinics and highlighted constraints in affordability and access.

Analytical themes

Seven themes were synthesised. While themes were broadly consistent across geographies, LMIC studies gave greater emphasis to affordability, misinformation and health-system limitations.

Theme 1: Emotional and psychological impact

Diagnosis and ongoing management were associated with shock, fear, anger and sadness. Many participants reported anxiety about future dependency and fear of complications (blindness, amputation, dialysis). 'Diabetes distress'—treatment fatigue, frustration and worry—was repeatedly described. In LMIC settings, emotional burden was intensified by financial stress and uncertainty about obtaining medicines and tests. Over time, some patients moved toward acceptance, particularly when supported by respectful clinicians, family encouragement and clear education. However, acceptance often co-existed with persistent fear during symptom flares or after witnessing severe complications in peers.

Practice implication: routine psychosocial screening and brief counselling should be embedded within diabetes clinics; clinicians should normalise distress and link risk reduction to achievable steps rather than fear-based messaging.

Theme 2: Cultural beliefs, knowledge and misconceptions

Patients framed diabetes using cultural and spiritual explanations. Several LMIC studies described misconceptions about causes and cure (e.g., fate, spiritual causes, or curability via herbs). Misinformation also surrounded insulin, contributing to delayed initiation or missed doses. Conflicting dietary advice from different

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health workers created confusion and reduced trust. Where structured education existed, patients showed better understanding and greater confidence. Community narratives (e.g., 'insulin causes harm') were powerful and could override clinical advice.

Practice implication: education should be culturally tailored, repeated over time and delivered in plain language; common myths should be addressed directly, and community influencers can be engaged to improve acceptance of evidence-based care.

Theme 3: Social support, stigma and relationships

Social context shaped day-to-day management. Family support often enabled adherence through help with food choices, transport, medicines and encouragement. Yet communal eating and family routines could hinder dietary change, and patients described pressure to eat traditional foods during gatherings. Stigma was reported in multiple contexts; some concealed their diagnosis to avoid blame or pity, leading to reduced social participation. Role changes were significant: reduced capacity to work or fulfil household responsibilities created feelings of dependency and burden. Some studies noted impacts on intimate relationships due to fatigue, body image concerns or sexual dysfunction.

Practice implication: family-inclusive counselling and community messaging can reduce stigma and align household practices with diabetes-friendly routines.

Theme 4: Physical and functional burden

Participants described fatigue, neuropathic pain, visual problems and reduced mobility as persistent burdens. Fear of worsening complications was common, and functional impairment often threatened income, especially in LMIC settings where livelihoods depend on physical work. Some described cyclical patterns where symptoms worsened when medicines were unaffordable or unavailable. Physical losses triggered grief and contributed to low mood, while successful symptom control improved confidence and perceived quality of life.

Practice implication: proactive complication screening, pain management, foot-care pathways and functional support can reduce disability and improve lived experience.

Theme 5: Self-management challenges and coping strategies

Dietary change was frequently described as the hardest task. Patients struggled to reduce staple carbohydrates and sugary foods, particularly when these are central to cultural identity and social life. Healthy foods were perceived as expensive, making 'ideal diets' unrealistic for poorer households. Medication adherence was challenged by forgetfulness, side effects, complex regimens, needle fear and practical barriers to insulin storage. Self-monitoring was limited in many LMIC settings due to cost of glucometers/strips; patients often relied on symptoms rather than readings. Despite these barriers, patients developed coping strategies: portion control, recipe modification, reminders, walking in groups, peer advice and faith-based resilience.

Practice implication: co-designed self-management plans using locally available foods, simplified regimens and affordable monitoring strategies improve feasibility and adherence.

Theme 6: Financial constraints

Economic hardship shaped almost every aspect of diabetes experience. Patients described difficulty affording medicines, laboratory tests, transport and recommended diets. Rationing medicines and delaying visits were common. Complications and hospitalisation created catastrophic costs, reinforcing a vicious cycle of illness and poverty. The inability to afford recommended care generated helplessness and moral distress.

Theme 7: Healthcare system experiences

Patients valued respectful communication and clear education from clinicians. Negative experiences included long waiting times, short consultations, poor continuity, stock-outs and limited access to educators. In hospital settings, participants often praised clinical expertise but criticised non-clinical issues (cleanliness,

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administrative delays). Poor experiences reduced trust and discouraged follow-up.

Discussion

This qualitative systematic review and meta-synthesis brought together evidence from 25 qualitative studies to develop a comprehensive understanding of how patients live with type 2 diabetes mellitus (T2DM) across both global and low- and middle-income country (LMIC) settings. Although many experiences were common across regions, patients from LMICs consistently reported more intense emotional distress, greater financial strain, and more pronounced health-system challenges, all of which substantially influenced their ability to manage the condition. Collectively, the seven analytical themes demonstrate that diabetes is not experienced solely as a medical diagnosis, but rather as a long-term condition that affects emotional well-being, social roles, and economic stability.

Emotional distress was a prominent feature throughout the diabetes journey, beginning at diagnosis and continuing during long-term management. Participants frequently described fear of complications, uncertainty about disease progression, and exhaustion related to ongoing treatment demands, reflecting the concept of "diabetes distress," which is increasingly recognised as a factor adversely affecting glycaemic control and quality of life[20-21]. Evidence suggests that this distress is more pronounced in resource-constrained settings, where worries about medication affordability and access to care further intensify psychological burden[8-9]. Some participants described a gradual movement toward acceptance, particularly when supported by empathetic healthcare providers and clear, structured education, consistent with prior research demonstrating the importance of clinician–patient relationships in psychological adjustment[23]. Nevertheless, fear often resurfaced during symptom worsening or when complications were observed in others, indicating that acceptance is fluid and fragile rather than a fixed outcome. These findings support international guidance recommending routine psychosocial assessment and integration of mental health support into routine diabetes care[24].

Cultural beliefs and misconceptions strongly shaped patients' understanding of diabetes, particularly in LMIC contexts. Misinterpretations regarding disease causation, curability, and insulin use were widespread and frequently influenced treatment decisions. Similar patterns have been documented in qualitative syntheses from South Asia and sub-Saharan Africa[10-11], where spiritual explanations and reliance on traditional remedies commonly delay initiation of evidence-based treatment. Fear and misinformation surrounding insulin therapy have also been identified as key contributors to suboptimal glycaemic control and delayed treatment intensification[25]. Inconsistent or conflicting dietary advice from healthcare providers further eroded trust in the health system. However, evidence indicates that culturally tailored education programmes, delivered repeatedly and in accessible language, can improve understanding, confidence, and adherence to treatment[14-15]. Involving community leaders and peer educators may be particularly effective in addressing entrenched misconceptions and improving acceptance of biomedical care.

Social relationships were found to have both supportive and restrictive influences on diabetes self-management. Family support often facilitated adherence by assisting with medication use, diet, and clinic attendance, yet communal eating practices and social expectations frequently made dietary modification difficult[12-13]. These findings align with qualitative evidence showing that diabetes management is deeply interwoven with family routines and cultural food practices. Stigma related to diabetes was reported across multiple settings and led some individuals to conceal their diagnosis, resulting in social withdrawal and reduced help-seeking. This mirrors existing literature linking diabetes-related stigma to poorer self-care behaviours and psychological outcomes[26]. Additionally, disruptions to social and occupational roles—particularly reduced work capacity or income—contributed to feelings of dependency and

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burden, especially among economically vulnerable individuals. Family-centred counselling approaches and community-based anti-stigma interventions have demonstrated potential in mitigating these social challenges[16].

Physical symptoms such as fatigue, neuropathic pain, visual impairment, and reduced mobility had a marked impact on daily functioning and overall quality of life. Recent longitudinal research supports these findings, showing that symptom burden is often a stronger determinant of perceived health status than glycaemic indicators alone[27,28]. In LMIC settings, where physical labour is a primary source of income for many households, functional decline directly threatened financial security, reinforcing the cycle between illness and poverty[29]. Participants' descriptions of symptom deterioration during periods of medication unaffordability underscore the clinical consequences of inconsistent treatment access. Evidence supports proactive screening for complications, integrated pain management, and accessible foot-care services as effective measures to reduce disability and improve patient-reported outcomes[19].

Across settings, dietary modification was consistently described as the most challenging component of self-management, particularly when recommended diets conflicted with cultural practices or exceeded financial means. This is consistent with recent qualitative and mixed-methods research indicating that idealised dietary advice is often perceived as unrealistic or unattainable in LMIC contexts. Medication adherence was further complicated by factors such as complex regimens, fear of insulin, side effects, and limited access to self-monitoring tools. Despite these constraints, many patients demonstrated resilience by adopting practical coping strategies, including portion control, peer support, walking groups, reminder systems, and faith-based coping. Evidence suggests that self-management interventions co-designed with patients and adapted to local realities—prioritising feasibility rather than perfection—are more likely to result in sustained adherence.

Financial hardship emerged as a central and pervasive theme influencing nearly all aspects of the diabetes experience, including emotional well-being, treatment adherence, and healthcare utilisation. Patients frequently reported rationing medications, postponing clinic visits, and avoiding recommended investigations due to cost. Recent global analyses confirm that out-of-pocket spending on diabetes care remains catastrophic for many households in LMICs, even in settings with public healthcare services. The moral distress experienced by patients unable to afford recommended care highlights diabetes as a condition shaped by broader structural and socioeconomic inequities rather than individual choices alone. Health systems research strongly supports policy measures such as subsidising essential medicines, expanding insurance coverage for chronic care, and strengthening public-sector supply chains to reduce financial barriers[26].

Experiences within healthcare systems played a critical role in shaping patients' engagement with care. Respectful communication, continuity of care, and clear explanations promoted trust and adherence, whereas long waiting times, brief consultations, medication stock-outs, and poor continuity discouraged follow-up. These observations are consistent with recent patient-experience research emphasising the importance of person-centred communication and relational continuity in achieving positive diabetes outcomes[27],[28]. In LMIC hospital settings, participants often expressed confidence in clinicians' technical expertise while simultaneously reporting dissatisfaction with non-clinical aspects of care, reflecting broader system capacity limitations. Strengthening primary care–based chronic disease models, expanding the role of diabetes educators, and improving service organisation may enhance continuity, trust, and overall patient experience[29]

Implications for practice

1) Integrate routine psychosocial screening and brief counselling within diabetes clinics.
2) Provide culturally tailored education that directly addresses common myths and insulin misconceptions.
3) Use family-inclusive counselling to align

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household routines with diabetes-friendly diets and medication support.
4) Develop locally feasible self-management plans, including affordable monitoring pathways.
Implications for policy Policies should prioritise affordable access to essential medicines, lab testing and monitoring supplies; strengthen primary care; and invest in diabetes education workforces. Improving service reliability (stock-outs, waiting time) is likely to improve both lived experience and clinical outcomes.

Strengths and limitations

Strengths include the systematic approach, synthesis across diverse settings, and explicit attention to LMIC constraints relevant to Pakistan. Limitations include English-language restriction, variability in study reporting depth, and the challenge of transferring findings across different health systems. This is a qualitative synthesis and does not estimate pooled frequencies; the graphical figures are interpretive summaries.

Conclusion

Adults living with T2DM experience intertwined emotional, cultural, social, physical, economic and health-system challenges. Patient-centred care should integrate psychosocial support, culturally responsive education, family engagement, and health-system strengthening. In LMICs, reducing out-of-pocket costs and improving service reliability are central levers to improve lived experience and outcomes.

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