Section: Community Medicine

Original Research Article

MEDICINES ARE TOO EXPENSIVE?: LIVED EXPERIENCES, COST-RELATED NONADHERENCE, AND COPING STRATEGIES AMONG ADULTS WITH DIABETES IN PUDUCHERRY—A QUALITATIVE STUDY EMBEDDED IN A MIXED-METHODS DESIGN

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ABSTRACT

Background: Diabetes care in out-of-pocket (OOP) dominant settings can create financial distress, disrupt care-seeking, and precipitate cost-related nonadherence. This mixed-methods study explored how costs shape lived experiences and coping among adults with diabetes in Puducherry.

Materials and Methods: A sequential explanatory mixed-methods design was used (Phase I: community-based cross-sectional component; Phase II: qualitative in-depth interviews). Phase II was conducted in one urban and one rural PHC field-practice area using purposive sampling. Ten adults with diabetes (5 urban/5 rural; age 38–68 years; 7 men; diabetes duration 5–20 years) participated in Tamil interviews lasting ~30–40 minutes. Interviews were audio-recorded, transcribed verbatim, back-translated, participant-validated, and analysed using manual qualitative content analysis to thematic saturation.

Results: Four themes emerged: (1) Domains of economic burden—direct costs (medicines, tests, consultations, travel) constrained continuity and reduced investigation frequency; indirect/intangible costs included productivity loss and psychosocial impacts. (2) Interplay of factors—income loss and limited insurance reinforced OOP stress; participants reported cost-related nonadherence (dose reduction/skipping). (3) Cost escalators—public-sector access barriers and complication-related referrals increased spending and opportunity costs. (4) Coping strategies—borrowing, pledging/selling assets, relying on family labour, and occasional traditional remedies/treatment modification.

Conclusion: Adults with diabetes described medicine and investigation costs as a pervasive burden that can drive nonadherence and financially damaging coping. Strengthening primary care delivery and financial risk protection may reduce avoidable hardship.

Keywords: Diabetes mellitus, Economic burden, Out-of-pocket expenditure, Cost-related nonadherence, Coping strategies.

INTRODUCTION

Diabetes mellitus is a major public health concern in both developed and developing countries. The global burden has risen sharply over recent decades, with a marked increase in the number of people living with diabetes.[1,2] In India, diabetes prevalence is substantial, with documented rural–urban differences.[3–5] Beyond morbidity, diabetes imposes a sustained economic burden because it requires lifelong care and long-term follow-up. The direct costs of medicines, consultations, laboratory investigations, and hospitalizations, together with indirect costs such as productivity loss, can strain

households and reduce economic wellbeing.[6–8] In settings where out-of-pocket payments predominate and insurance coverage is limited, diabetes-related spending may disrupt household finances and contribute to catastrophic health expenditure.[9–12] Importantly, the economic burden is not only a financial outcome but also shapes lived experience and care-seeking trajectories. The thesis review highlights that patients living with diabetes express cost-related concerns and that understanding patient perceptions and treatment experiences is essential for patient-centred care, particularly in South-East Asia where access to affordable treatments and supportive systems may be constrained.[13] Prior literature also links financial insecurity and cost-related factors to medication nonadherence and cost-reducing behaviours among adults with diabetes.[6,9]

Therefore, as part of a sequential explanatory mixed-methods inquiry conducted in Puducherry, the qualitative component was designed to explore (i) how costs affect patients and families (economic, social, emotional, and functional impacts), (ii) patient-perceived drivers of economic burden, (iii) coping strategies—including care delays or treatment modifications—and (iv) patient-informed recommendations to reduce out-of-pocket burden and prevent downstream consequences.

MATERIALS AND METHODS

Study design: This study used a sequential explanatory mixed-methods design, implemented in two phases: Phase I (quantitative, community-based cross-sectional component) followed by Phase II (qualitative component using in-depth interviews).[14,15] The qualitative findings were intended to deepen understanding of the "impact of cost" and related experiences that emerged from the broader mixed-method study framework.[14,15] This qualitative study constituted Phase II of a sequential explanatory mixed-methods design, conducted after the quantitative phase.[14,15] The qualitative component used in-depth interviews to explore lived experiences of economic burden and cost-related impacts among adults with diabetes in Puducherry.[17] Findings are reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (32-item checklist) for interviews.[16]

Study setting: The study was conducted in Puducherry district and was embedded within the broader community-based study implemented in one urban and one rural primary health centre (PHC) field practice area, where the diabetes line list had been obtained from a population-based survey (updated May 2020) at the selected PHCs. Participants for the qualitative phase were selected using purposive sampling.[17] A total of ten adults with diabetes from both urban and rural settings were interviewed.

Research team and reflexivity (COREQ domain 1)

In-depth interviews were conducted by the principal investigator, who was trained in qualitative research methods.[16,17] The interview guide was developed from literature and refined through consultation with the guide/co-guide (trained in qualitative research) and two subject experts.[16,17]

Data collection (COREQ domain 2)

Interviews were conducted in Tamil, at a time and place convenient to participants. Each interview lasted approximately 30–40 minutes, and interviews were conducted in a setting conducive for participants to speak freely.[16,17] An interview guide was used to explore domains relevant to the study objectives, including participants' illness journey, health-seeking behaviour, life changes after diagnosis, perceived economic burden, and emotional/psychological impacts.[17] Interviews were audio recorded with consent, transcribed verbatim in Tamil, and back-translated into English by the principal investigator for analysis.[16,17] Participant validation was undertaken at the end of each interview by summarizing key points and allowing participants to modify or clarify responses.[16,17] Interviews continued until data saturation was achieved.[18]

Data analysis (COREQ domain 3)

Data were analysed using manual qualitative content analysis.[19] Codes and categories were developed from transcript data, and themes were generated describing domains of economic burden and coping strategies used by participants to manage diabetes-related financial stress.[19]

Ethical considerations: Ethical approval was obtained from the Institutional Ethical Review Committee, Indira Gandhi Medical College and Research Institute, Puducherry (No. 276/IEC-30/IGMC&RI/PP/2020). Written informed consent was obtained before interviews. Participant information sheets described study purpose, confidentiality, risks/benefits, voluntariness, and investigator contact details.

RESULTS

Participants: Ten adults with diabetes participated in in-depth interviews (5 urban; 5 rural). Ages ranged from 38 to 68 years; 7 were men and 3 were women. Duration since diabetes diagnosis ranged from 5 to 20 years across participants.

Overview of themes

Manual content analysis generated four themes: (1) Domains of economic burden (direct, indirect, and intangible costs), (2) Interplay of factors leading to economic burden, (3) Factors likely to escalate the "cost of care", and (4) Coping strategies to meet financial burden/catastrophic expenses.

Theme 1. Domains of economic burden (direct, indirect, intangible)

Direct cost burden (medicines, tests, consultations, travel) and its consequences

Participants described how high out-of-pocket spending constrained access to care and continuity of treatment, especially when medicines were purchased privately; some reported shifting from private to government facilities due to cost.

They also reported reducing the frequency of laboratory investigations because tests were expensive, and some rural participants highlighted difficulty paying for long-distance travel to access "reputed" providers.

Illustrative quotations included: "Medicines are too expensive" (Participant 1) and "forced to start treatment at the Govt care facility" (Participant 7).

Indirect and intangible costs (productivity loss, caregiver burden, social/psychological impacts)

Participants described functional limitations and dependence on family members, job loss/forgone income (including after severe complications such as foot problems), and experiences suggestive of caregiver burden and social isolation.

Theme 2. Interplay of factors leading to economic burden

Participants described a reinforcing cycle in which illness-related disability and impaired productivity contributed to loss of wages/income, increasing reliance on out-of-pocket spending "beyond capacity to pay," while lack of insurance aggravated financial stress. Within this context, self-care was sometimes deprioritized against competing household needs, and cost-related nonadherence emerged—participants described reducing dosage or skipping medicines to make supplies last longer.

One participant summarized conditional purchasing of medicines based on available money: "I would get medicine only if I have money." (Participant 1).

Theme 3. Factors likely to escalate the "cost of care"

Health-system barriers contributing to higher costs and preference shifts

Participants reported barriers at public facilities—overcrowding, long waiting queues, fragmented services requiring multiple visits/locations, unclear follow-up timing for investigations, and perceived inadequate communication—leading some to seek care in private facilities and incur higher out-of-pocket costs.

Higher costs associated with complications and tertiary-level care pathways

Some participants described increased spending when referred for complications and care at large hospitals, citing repeated visits, rotating doctors, and high opportunity costs due to travel time and lost wages.

A participant described the burden of repeated visits and changing doctors: "running around for eight days… [then] some other doctor." (Participant 7).

Another participant noted constraints in accessing "free" medicines due to clinic timings and daily-wage work: "medicines were given for free… [but] difficult to collect… as I am a daily labourer." (Participant 3).

Theme 4. Coping strategies to meet financial burden/catastrophic expenses

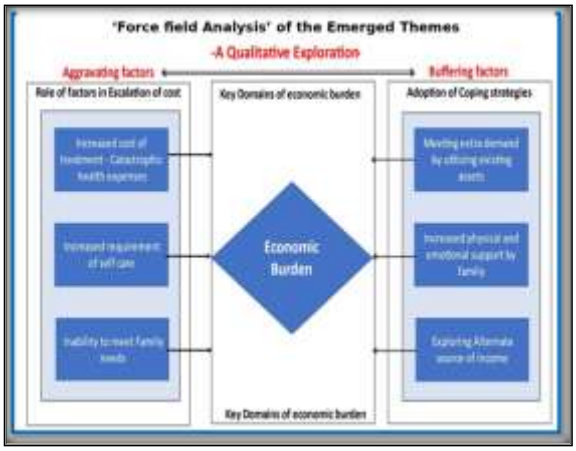

Figure 1: Force Field Analysis of the emerged themes: The central diamond shows the core outcome (Economic Burden). The left panel lists aggravating factors that increase the burden, while the right panel shows buffering (coping) factors that reduce it. Arrows indicate the direction of influence toward the economic burden.

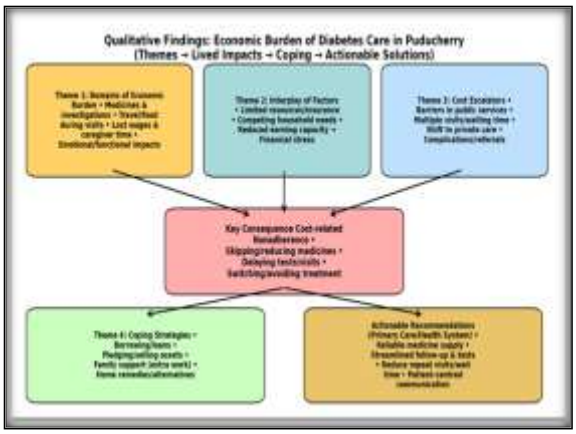

Figure 2: Infographic summarising qualitative themes on the economic burden of diabetes care in Puducherry. The infographic presents the four major themes identified through in-depth interviews: (Theme 1) domains of economic burden (direct medical costs such as medicines/investigations, non-medical costs, indirect costs and psychosocial/functional impacts), (Theme 2) interplay of factors contributing to financial stress (limited resources/insurance, competing needs, reduced earning capacity), (Theme 3) cost escalators (public-sector access barriers, repeated visits/waiting time, shift to private care, complications/referrals), leading to the key consequence—cost-related nonadherence (skipping/reducing medicines and delaying care). (Theme 4) coping strategies (borrowing, pledging/selling assets, family support, alternative practices) and participant-informed actionable recommendations for primary care/health system strengthening (reliable medicine supply, streamlined follow-up/testing, reduced repeat visits, improved patient-centred communication) are also depicted.

Participants described multiple strategies to manage financial stress, including seeking additional livelihood sources, pledging gold/jewels, borrowing from relatives/friends, and using limited assets.

Quotations illustrated indebtedness and distress ("fed up repaying interest on the loan"—Participant 5),

asset liquidation ("sold them to compensate my medical needs"—Participant 1), and sequential coping ("pledged jewels… [then] asked loan"—Participant 7).

Some participants also described reliance on family labor to cope financially (e.g., spouse working due to reduced ability to work).

Cost-related treatment modification and alternative practices

In addition to skipping/reducing medicines (Theme 2), some participants described shifting to traditional/home remedies or avoiding allopathic medicines due to concerns about side effects and external messaging, sometimes followed by complications.

An illustrative quote was: "I tried… Vendayam… only to avoid medicine." (Participant 8).

Participant-informed implications and recommendations captured in the thesis

The thesis summarizes determinants linked to out-of-pocket payments (e.g., inadequate insurance, perceived stress, limited family support; poor access/waiting time and medicine supply issues in public facilities leading to private preference) and collates suggested recommendations for addressing these.

DISCUSSION

Principal findings (linking findings to participants and themes)

In this COREQ-reported qualitative phase, participants described cost of diabetes care as a pervasive lived experience, not merely a financial metric. Accounts consistently emphasized recurrent spending on medicines and investigations as the dominant source of distress, with additional burden from travel/time costs and productivity loss, shaping day-to-day functioning and family life. These experiences mapped onto the study themes of domains of economic burden, interplay of factors leading to burden, escalation of cost, and coping strategies. The interviews also highlighted cost-related nonadherence (reducing/interrupting medicines or delaying care when money was unavailable) and the resort to financially damaging coping mechanisms such as borrowing and pledging/selling assets, indicating vulnerability to longer-term impoverishment.[6–12]

Comparison with literature (situating findings; avoiding over-claiming)

The findings obtained from this research align with evidence that diabetes requires long-term, recurrent expenditure and that household costs extend beyond direct medical payments to include indirect and non-medical expenses.[6–8] Participants' narratives of financial strain and care compromise are consistent with broader work showing that high out-of-pocket (OOP) spending can impoverish households and deepen inequities in access to care.[9,10] The described pathways toward catastrophic spending resonate with studies on catastrophic health expenditure (CHE) and its determinants, including limited risk pooling and financial vulnerability.[11,12] Given the increasing burden of diabetes globally and in India, these lived experiences represent an important patient-centred complement to epidemiologic estimates.[1–5]

Strengths and limitations (credibility, reflexivity, transferability)

The strength of this research is its conduct within a sequential explanatory mixed-methods design, enabling qualitative exploration of cost impacts that complement quantitative estimates.[14,15] Data collection used in-depth interviews and purposive sampling, with interviews conducted until saturation, supporting adequacy of thematic coverage.[17,18] Reporting follows COREQ, enhancing transparency about interview-based methodology and interpretation.[16] Analysis using qualitative content analysis supports systematic theme development.[19] Limitations include the small sample size intrinsic to qualitative research and potential recall or social desirability bias, particularly regarding adherence behaviour and coping strategies. Transferability may be greatest to settings with similar healthcare access patterns and OOP-dominant financing. Inference should therefore focus on conceptual insights (mechanisms and experiences) rather than prevalence estimation.

Implications (actionable recommendations grounded in participants' accounts)

Participants' accounts suggest that reducing diabetes-related financial strain requires both financial protection and service delivery improvements that make low-cost care practically accessible.[10–12] The narratives indicate that barriers in public-sector care (e.g., multiple visits, waiting time, and difficulties collecting medicines for daily-wage workers) may contribute to preference shifts toward private care and higher OOP spending. Health-system responses that strengthen continuous medicine availability, streamline follow-up and investigations, reduce repeat visits, and improve patient–provider communication may reduce cost-related nonadherence and help prevent downstream complications. These actions are consistent with the broader public health priority of strengthening chronic disease care in the context of rising diabetes burden.[1,2,13]

Trustworthiness/Rigour

Credibility of this research was supported through audio-recorded in-depth interviews, verbatim transcription, and participant validation at the end of each interview by summarizing key points and allowing clarification/modification, with interviews continued until data saturation was achieved. Dependability was strengthened by the use of a predefined interview guide (developed from literature and refined with supervisory/expert input) and a systematic manual content analysis approach for coding and theme development. Confirmability was enhanced by basing codes and themes on the transcript data and maintaining analytic decisions

within the content analysis process. Transferability is supported by describing the study setting (urban and rural Puducherry) and participant context, allowing readers to judge applicability to similar settings.

CONCLUSION

Adults with diabetes in Puducherry described the cost of care—especially expensive medicines and investigations—as a persistent burden influencing daily life, care-seeking, and adherence. In response, participants reported cost-related nonadherence and reliance on coping strategies such as borrowing and pledging/selling assets, reflecting risk of longer-term financial harm. These qualitative findings support patient-centred system strengthening and financial risk protection to reduce avoidable out-of-pocket burden and mitigate downstream complications associated with interrupted care.[6–12]

RECOMMENDATIONS

This study provides actionable insight into how diabetes costs drive distress, nonadherence, and harmful coping (borrowing/asset sales) in Puducherry. Through this research it is recommended translating these themes into a patient-centred PHC package: ensure uninterrupted medicine availability, bundle labs and follow-up on the same day, reduce repeat visits/queues, and strengthen counselling on adherence and evidence-based self-care. Pair service fixes with financial protection (insurance enrolment support, transport vouchers for rural patients, and referral navigation). For research scale-up, include caregivers and frontline staff, expand interviews across socioeconomic strata, and test whether the package reduces cost-related nonadherence and complications using pragmatic mixed-methods evaluation and patient cost measures.

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