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Multi-Level Barriers and Facilitators to Breast Cancer Adherence in India: CFIR- ERIC Insights from a Tertiary Centre

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Abstract

Background

Breast cancer remains a leading cause of mortality in India and other low- and middle-income countries (LMICs), threatening the United Nations Sustainable Development Goal (SDG) 3.4 target for non-communicable diseases. While clinical advancements exist, treatment adherence remains a critical challenge. This study explores the multi-level systemic and psychosocial determinants of breast cancer treatment adherence by uniquely integrating implementation science with applied medical humanities.

Methods

Conforming to COREQ-32 guidelines, a formative qualitative study was conducted at a tertiary public hospital (National Cancer Institute, NCI-AIIMS Jhajjar, India). Data from 25 In-Depth Interviews (IDIs) and 3 Focus Group Discussions (FGDs) with patients, caregivers, and healthcare professionals were analysed using NVivo. Findings were deductively mapped to the Consolidated Framework for Implementation Research (CFIR) and matched with Expert Recommendations for Implementing Change (ERIC) strategies.

Results

Institutional data indicated an overall treatment adherence rate of 71.6% (33 out of 116 patients defaulted). Key qualitative barriers driving this non-compliance included severe financial exhaustion and travel logistics (Outer Setting), infrastructural deficits causing mean hospital wait times ranging from 3 weeks for a biopsy to 8 weeks for surgery (Inner Setting), and profound caregiver strain (Characteristics of Individuals). Facilitators included familial solidarity and empathetic staff behaviour. Crucially, systemic delays and financial toxicity inflicted a collective moral injury and biographical disruption on the family unit, underscoring the deeply relational autonomy of Indian patients.

Conclusion

Securing breast cancer adherence in LMICs requires moving beyond the provision of subsidized therapeutics. Tertiary centres must deploy scalable ERIC strategies—specifically dedicated financial navigators and outpatient workflow optimizations—integrated alongside culturally adapted Narrative Medicine. Simultaneously addressing these logistical bottlenecks and humanistic disruptions is essential to mitigate familial burden, foster health equity, and advance global mortality reduction targets.

1. Introduction

The escalating burden of breast cancer in India mirrors a broader crisis across low- and middle-income countries (LMICs), threatening the achievement of the UN Sustainable Development Goal (SDG) 3.4, which targets a one-third reduction in premature mortality from non-communicable diseases (NCDs) by 2030 [1, 2]. Despite the availability of subsidized treatment modalities at tertiary centres, patient adherence is frequently derailed by systemic bottlenecks and catastrophic out-of-pocket (OOP) expenditures that drive families into severe economic hardship[3, 4].

While global clinical guidelines for breast cancer management exist, relying solely on Western-derived knowledge is insufficient for LMIC contexts. As Bhoo-Pathy et al.[5] argue, healthcare systems in Asia cannot simply "adopt" Western oncology frameworks; they must "adapt" them to account for distinct socio-economic profiles, systemic resource constraints, and profound cultural health beliefs. Therefore, understanding the root causes of treatment disruptions through a localized lens is critical for improving patient outcomes and treatment adherence in India.

This study utilizes the Consolidated Framework for Implementation Research (CFIR) to systematically diagnose the multi-level determinants of care[6, 7]. Uniquely, this research integrates the CFIR structural diagnosis with the principles of Applied Medical Humanities—specifically Narrative Medicine[8]. While implementation frameworks define *where* systems fail, medical humanities articulate *how* these failures disrupt human dignity and relational autonomy, a dual-lens integration that remains exceptionally rare in LMIC oncology literature. By establishing an evidence-based, culturally contextualized blueprint for a North Indian tertiary centre, this research aims to propose highly scalable interventions applicable to similar resource-constrained environments globally.

2. Methods

2.1 Study Design & Setting

Conforming to the Consolidated Criteria for Reporting Qualitative Research (COREQ-32) guidelines, a formative qualitative study was conducted at the National Cancer Institute (NCI-AIIMS Jhajjar, Badsa). This research was part of the overarching project *"Designing and Implementation of a Healthcare Model in Breast Cancer Patients with Stage II."* These interviews were a part of a multicentre ICMR funded project, the protocol of which has been previously published[9]. Ethical approval was obtained from IEC-AIIMS vide Ref no AIIMSA00059/03.11.2023, RP-33/2023. All participants were enrolled after due written and verbal consent process. The research was done in accordance with the Declaration of Helsinki.

2.2 Participant Selection & Reflexivity

Purposive sampling ensured diversity in age, socio-economic status, and treatment stage. The cohort comprised 25 IDIs (8 patients, 8 caregivers, 9 healthcare professionals [HCPs]) and 3 FGDs. Interviews were conducted by trained qualitative researchers. To mitigate inherent researcher bias, reflexive journaling was maintained throughout the data collection and analysis phases, acknowledging how the

researchers' clinical and academic backgrounds might influence the interpretation of patient narratives of suffering and systemic critique.

2.3 Data Collection & Analysis

Semi-structured interviews were audio-recorded, transcribed verbatim, and translated. Thematic analysis was managed using NVivo software. Following Braun and Clarke's[10] six-step framework, independent coding was performed by two researchers. Interrater reliability was established with a Cohen's Kappa coefficient of 0.80, indicating strong agreement. Themes were subsequently mapped deductively onto the updated CFIR domains.

3. Results

Institutional clinical tracking during the study period revealed an overall treatment adherence rate of 71.6% (33 out of 116 patients defaulted). The qualitative data contextualizes the systemic and psychosocial drivers behind these dropout rates[Figure 1].

3.1. Intervention Characteristics & Outer Setting

The treatment modality itself was perceived positively when available, but access was heavily constrained by the Outer Setting. Financial exhaustion emerged as the primary barrier, driving catastrophic OOP costs [Table 1].

"We had to borrow money just to travel here. The treatment is supposed to be affordable, but the travel and living costs leave us with nothing." — (Caregiver, Male, 45)

3.2. Inner Setting (Healthcare Environment)

Systemic hospital factors heavily influenced engagement. Quantitative institutional data revealed severe infrastructural deficits causing mean hospital wait times ranging from 3 weeks for a biopsy to 8 weeks for surgery, breeding profound distress and clinical deterioration[Table 1].

"You wait all day just to be told the machine is down or the doctor is in emergency. It breaks your spirit more than the disease." — (Patient, Female, 39)

3.3. Characteristics of Individuals (Patient & Caregiver Factors)

Emotional distress and disease ignorance were highly prevalent, occasionally leading to a reliance on alternative Ayurvedic medicine and delayed presentation. Caregivers faced intense physical and financial strain. Facilitators included profound familial solidarity and spiritual coping[Table 1].

"When I heard the word cancer, I felt everything was over, but my family gave me the strength to fight." — (Patient, Female, 33)

Table 1
CFIR Domains mapped to Barriers, Facilitators, and proposed ERIC Strategies

CFIR Domain	Key Identified Barriers	Key Identified Facilitators	Mapped ERIC Implementation Strategy
Outer Setting	Financial exhaustion; high travel/OOP costs; lack of state funding awareness.	N/A	**Access New Funding**: Integrate state aid into onboarding. **Build a Coalition**: NGO partnerships for housing.
Inner Setting	Mean wait times of 3 weeks (biopsy) to 8 weeks (surgery); lack of beds; online booking errors.	Empathetic staff behavior; centralized treatment.	**Change Physical Structure**: Consolidate diagnostics. **Conduct Cyclical Small Tests of Change**: Optimize OPD queues.
Characteristics of Individuals	Caregiver physical/financial strain; disease ignorance; alternative medicine reliance.	Familial emotional support; spiritual resilience.	**Distribute Educational Materials**: Culturally tailored literacy. **Involve Family Members**: Integrated psychological support.
Process	Communication gaps; misinformed treatment decisions; delayed adherence.	Effective counselling when time permits.	**Tailor Strategies**: Deploy dedicated Patient Navigation Helplines to manage coordination.

4. Discussion

The findings of this study underscore that effective breast cancer management extends far beyond clinical intervention. Financial toxicity, logistical hurdles, and infrastructural deficits interact to create substantial bottlenecks [Table 1]. To translate these findings into actionable improvements, we utilized the CFIR-ERIC matching approach to propose targeted strategies designed to mitigate the specific barriers identified in this research[11] .

Patients reported severe financial exhaustion and high OOP expenses, aligning with previous literature highlighting financial toxicity as a primary driver of treatment abandonment in India[3]. These travel-related adherence barriers directly mirror findings from neighbouring regions, such as Pakistan and Bangladesh, where transport logistics and hidden OOP costs are primary drivers of chemotherapy non-compliance and treatment abandonment[12–14]. This demonstrates that the barriers identified are not isolated institutional failures but systemic LMIC challenges. Addressing these specific barriers—through ERIC strategies like integrating state funding directly into patient onboarding—is a direct prerequisite for advancing SDG 3 (Good Health and Well-being) and SDG 10 (Reduced Inequalities)[1], ensuring that life-saving cancer care is not exclusively accessible to urban, affluent populations.

The inner setting was characterized by a lack of resources, causing delayed surgeries (up to 8 weeks) and diagnostic delays[Table 1]. Institutions must implement ERIC strategies to *Change Physical Structure*

and Equipment by reorganizing outpatient departments and consolidating investigations. Furthermore, *Conducting Cyclical Small Tests of Change* can iteratively improve workflow and decrease waiting periods for appointments.

Patients and families exhibited ignorance related to the disease, occasionally leading to a reliance on alternative medication. This aligns with foundational literature indicating that unique Asian health beliefs heavily influence treatment acceptance, necessitating localized psychosocial interventions [5]. Caregivers also faced immense physical and emotional strain. Healthcare systems must *Distribute Educational Materials* through culturally tailored campaigns and integrate routine psychological counselling.

Viewed through the culturally situated lens of applied medical humanities, the systemic barriers identified via the CFIR framework are not merely logistical hurdles; they are profound disruptions to the collective familial fabric. In the Indian context, where autonomy is deeply relational and kinship-bound[15], gruelling hospital wait times and financial toxicity do more than strip individual agency—they inflict a collective moral injury. They often force households into agonizing ethical dilemmas, weighing a mother's life against the long-term economic survival of the family[4] .

A breast cancer diagnosis here rarely represents a purely individual 'biographical disruption'[16]. Instead, it is a structural disruption of the woman's entrenched roles in caregiving. Because socio-cultural frameworks in Asia differ fundamentally from the West, the facilitators identified—such as robust familial solidarity—highlight the critical need for culturally adapted Narrative Medicine. Pioneered by Rita Charon[8, 17], this practice emphasizes the clinical capacity to recognize, absorb, and interpret the stories of illness. By training overburdened oncologists to recognize cancer not merely as a biological pathology, but as an 'illness experience' intimately intertwined with kinship obligations [18], LMIC healthcare systems can shift from simply processing high patient volumes to genuinely healing families.

5. Limitations

While this study utilizes a robust theoretical framework with high interrater reliability (Kappa = 0.8), it is limited by its cross-sectional design and single-centre setting at a well-resourced tertiary public hospital (NCI-AIIMS Jhajjar), which may restrict generalizability to rural, decentralized, or private healthcare sectors. Furthermore, the reliance on self-reported qualitative narratives inherently introduces potential recall and social desirability biases. Future research should therefore employ longitudinal, mixed-methods designs across diverse LMIC settings to triangulate these qualitative CFIR-based insights with quantitative clinical adherence and survival outcomes.

6. Conclusion

Securing breast cancer treatment adherence in India requires moving beyond subsidized therapeutics to address the severe systemic bottlenecks and catastrophic financial exhaustion that inflict profound moral injury and biographical disruption on patients and their families. To bridge the gap between clinical

efficacy and real-world adherence, LMIC healthcare systems must deploy targeted ERIC implementation strategies—such as dedicated financial navigators and structural outpatient queue optimizations—alongside the empathetic, relational ethos of culturally adapted Narrative Medicine. By simultaneously addressing both the logistical and humanistic dimensions of care, tertiary centres can mitigate familial disruption, foster health equity, and meaningfully advance global non-communicable disease (NCD) mortality reduction targets.

Declarations

Disclosures:

• The authors have nothing to disclose.

Conflict

• -of-interest statement: The authors have no conflict of interest

Funding statement:

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• A data sharing statement: Data will be shared by the corresponding author on request

• We confirm that written and verbal consent was received from all participant before interviews.

• Clinical trial number: not applicable.

Author Contribution

A.A., S.M., B.B., R.S., S.D. wrote the main manuscript. A.A., B.B., and R.S. prepared the figures and tables and did the analysis. B.B. , M.C., and R.S conducted interviews and transcribed it. S.M., R.T., A.K., J.S., A.S., J.M., and N.K.J. were responsible for Concept Design. All authors were responsible for Manuscript Review and Approval.

Data Availability

ALL DATA GENERATED(INTERVIEW TRANSCIRIPTS) WILL BE SHARED BY CORRESPONDING AUTHOUR UPTO A PERIOD OF 5 YEARS FROM DATE OF PUBLICATION

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Figures

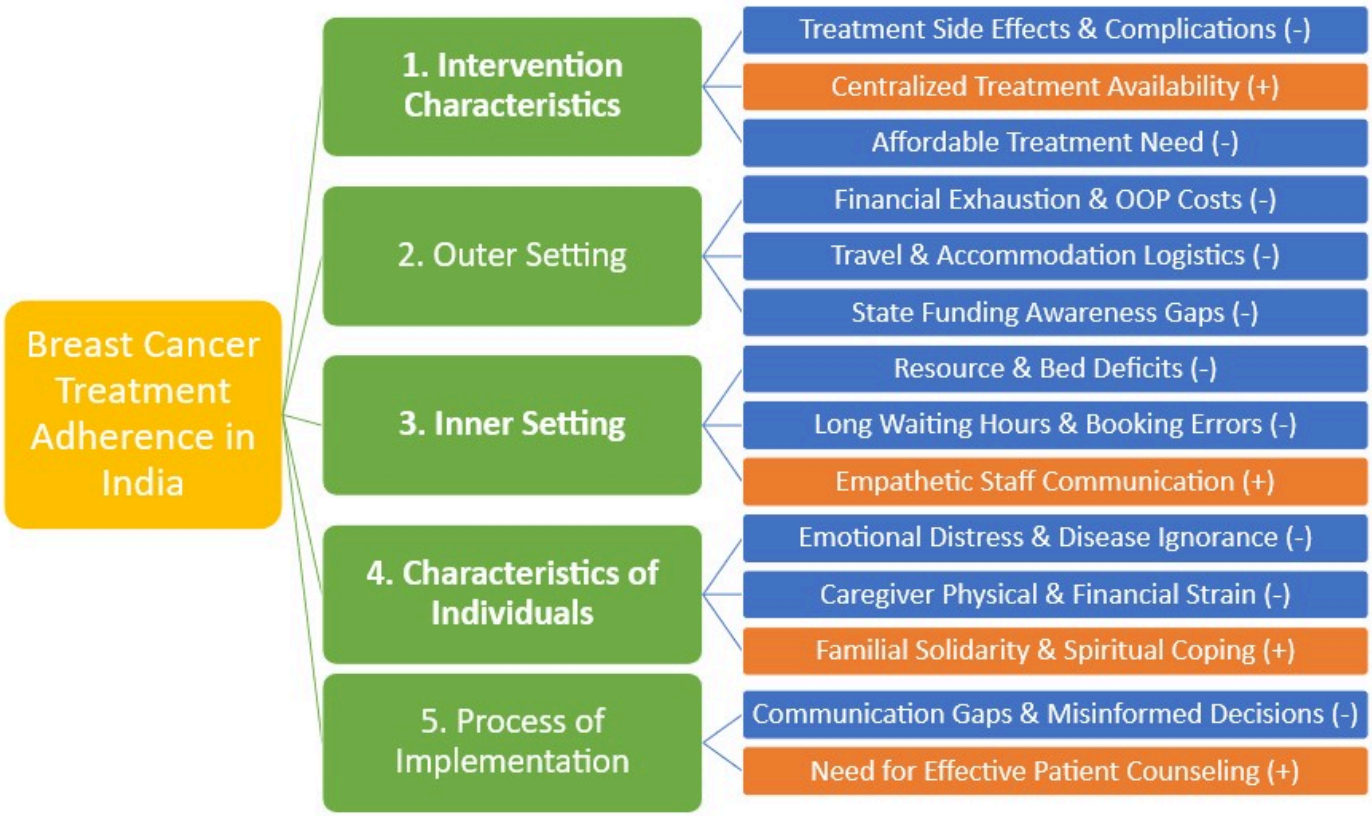


Figure 1

Thematic Tree Diagram showcasing the 5 CFIR domains branching into identified sub-themes