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Scoping Review

Health-Seeking Behaviour among People Living with HIV/AIDS in India: A Scoping Review

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Abstract

Background: Acquired Immunodeficiency Syndrome (AIDS) continues to be a major global health challenge, with India having one of the highest burdens of people living with HIV (PLHIV). Despite advances in treatment, many individuals face significant barriers to timely testing, care, and treatment adherence due to poor health-seeking behavior.

Objective: This scoping review aims to synthesize existing research on the health-seeking behaviors of PLHIV in India and identify key factors influencing their decisions, to inform improved service delivery.

Methods:

We conducted a systematic search across PubMed, Scopus, and Google Scholar, following the PRISMA-ScR framework. The review included 17 peer-reviewed primary studies published in English, spanning from 2004 to May 2024. Data were synthesized using both descriptive quantitative and qualitative thematic analysis.

Results:

The review identified three primary barriers to health-seeking behavior: pervasive stigma, which delayed testing and treatment; social inequities, including gender and income disparities, that restricted access to care; and health system limitations, such as long travel distances and fragmented services, which contributed to poor retention. Conversely, the review found that peer and family support, as well as innovative digital health approaches, were key facilitators. The evidence base was concentrated in southern and western India, with critical gaps in central, eastern, and northeastern regions and among marginalized populations.

Conclusion:

Health-seeking behaviour among PLHIV in India is shaped by a complex interplay of social and systemic barriers. Based on these findings, we recommend targeted interventions to address these barriers, including stigma reduction efforts and the development of community-based, patient-centred care.Addressing evidence gaps in underrepresented populations and regions is crucial for informing scalable, equitable interventions in India.

Keywords: *Health-seeking behavior, HIV, AIDS*

Introduction

Acquired Immunodeficiency Syndrome (AIDS), caused by the Human Immunodeficiency Virus (HIV), remains a major global public health concern and a serious challenge to healthcare systems. Transmission occurs primarily through unprotected sexual intercourse, transfusion of HIV-infected blood, and the use of non-sterile, HIV-infected syringes and needles (1). Globally, HIV/AIDS has caused nearly 33 million deaths. Between 2018 and 2030, an estimated 360,000 adolescents are projected to die from HIV-related causes, equivalent to approximately 76 deaths per day (2). While advances in prevention, diagnosis, treatment, and care have significantly improved survival and quality of life for people living with HIV/AIDS, these global gains have not been equitably distributed. Many countries and populations continue to face persistent barriers to timely HIV testing, treatment initiation, and retention in care (3,4)

India continues to be among the countries with the highest burden of HIV/AIDS. An estimated 2.5 million people are living with HIV in India, with many still not accessing treatment due to barriers in health-seeking behaviour (HSB), including limited awareness, misconceptions, and challenges in navigating healthcare systems (5,6) According to India HIV Estimates 2023, 3,720 people aged 0–24 years died of HIV/AIDS-related causes, with a slight decline reported in 2024 (3,650 deaths) (7,8). Despite progress under the National AIDS Control Organization (NACO), gaps remain in ensuring early testing, linkage to care, and adherence to antiretroviral therapy (9,10)

Health-seeking behaviour is therefore critical in the Indian context. It encompasses the decisions and actions individuals take in recognising symptoms, seeking HIV testing, initiating treatment, adhering to ART, and remaining engaged in care. Identifying the barriers and facilitators to these behaviours provides insight into where interventions are most needed and how existing strategies can be strengthened.(11–13)

Evidence further shows that poor health-seeking behaviour critically undermines HIV/AIDS outcomes in both India and globally. Studies from South India have reported that delayed care-seeking, particularly among women, leads to late diagnosis and worsened disease progression, often shaped by stigma and gender inequities (14,15)

Economic constraints and limited awareness also contribute to the postponement of testing and treatment initiation, lowering the chances of timely ART uptake (16,17).Global evidence reinforces these findings, with missed clinic visits, delayed presentation, and inadequate retention in care strongly associated with higher mortality, drug resistance, and continued HIV transmission (18).Research from sub-Saharan Africa similarly demonstrates that systemic barriers such as geographic inaccessibility and fragmented health services exacerbate losses across the HIV care continuum. Together, these insights emphasise that inadequate health-seeking behaviour not only delays treatment but also worsens clinical outcomes and threatens broader public health goals.

Considering these systemic factors including stigma, lack of awareness, geographic barriers, and healthcare system challenges, there remains a critical need to consolidate existing evidence. Although several primary studies have explored various aspects of health-seeking among People Living with HIV (PLHIV) in India, no comprehensive synthesis of this body of work has yet been undertaken(19). This review is therefore intended to map the health-seeking behaviours of PLHIV and the factors influencing their decisions, ultimately contributing to improved service delivery and health outcomes (20,21).

Methods

This scoping review was guided by the methodological framework proposed by Arksey and O'Malley (2005) and further refined in line with the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses

extension for Scoping Reviews) checklist to ensure methodological transparency & comprehensiveness.

Eligibility Criteria

This review includes peer-reviewed primary research studies employing quantitative, qualitative, or mixed-methods designs that investigate health-seeking behaviour among individuals living with HIV/AIDS in India. Only studies published in English and available in full-text format were considered. Editorials, opinion pieces, dissertations, review articles, and conference abstracts were excluded.

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Information Sources

The search was conducted across three electronic databases: PubMed, Scopus, and Google Scholar, chosen for their broad coverage of biomedical, public health, and interdisciplinary literature. All articles published from database inception up to May 2024 were considered. To ensure completeness, the reference lists of all included studies were also screened for additional relevant publications.

Search Strategy

A comprehensive search strategy was developed using a combination of controlled vocabulary and free-text keywords. The core search string was: ("health-seeking behaviour" OR "care-seeking" OR "healthcare utilisation" OR "help seek" OR "treatment seek" OR "health information seek" OR "healthcare seek" OR "health seek") AND ("HIV Infections" [Mesh] OR HIV OR "acquired immunodeficiency syndrome" [Mesh] OR AIDS OR PLHIV), Searches were conducted across titles, abstracts, and keywords to maximise the identification of relevant literature. Filters were applied to restrict results to studies conducted in India and published in English. The search strategy was adapted appropriately for PubMed, Scopus, and Google Scholar.

The strategy was adapted for each database and filtered to include only studies conducted in India and published in English, with the full search string detailed in (Annexure-1)

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Operational Definitions Health-Seeking Behaviour: It is defined as the sequence of decisions, attitudes, and actions undertaken by PLHIV to maintain or improve their health. This includes recognizing symptoms, seeking HIV testing and counselling, initiating and adhering to antiretroviral therapy (ART), accessing follow-up and support services, and re-engaging with care after interruption. In this review, studies were included if they addressed HSB by examining any aspect of service utilisation, treatment-seeking, adherence practices, or help-seeking related to HIV prevention, care, and treatment in the Indian context. (22)

Selection of Sources of Evidence

All records identified through the database searches were screened independently by (MR). Duplicate records were removed before screening. The remaining titles and abstracts were then assessed for relevance against the predefined inclusion criteria. Full texts of potentially eligible studies were retrieved and reviewed in detail. Any discrepancies between the reviewers were resolved through discussion, and if consensus could not be reached, a third reviewer adjudicated the final decision.

Data Charting Process

A standardised data extraction form was developed and piloted by the review team to ensure consistency and clarity. Two reviewers independently extracted data from the included studies. Extracted information was compared, and discrepancies were resolved through discussion and consensus; if disagreements persisted, a third reviewer was consulted. Data were managed and organised in Microsoft Excel for charting and synthesis.

Data Items

The following information was extracted from each included study: author(s) and year of publication; study setting (geographical location and whether conducted in a rural or urban area); study design and methodology; sample size; and population characteristics such as age and gender. Information on how health-seeking behaviour was defined and measured in each study was also collected. Key findings were charted, with particular attention to barriers and facilitators of health-seeking behaviour, patterns of health service utilisation, and relevant cultural, social, or systemic influences. In addition, reported study limitations and any recommendations for practice or future research were documented.

Synthesis of results

The findings were synthesised using both descriptive quantitative methods and qualitative thematic analysis. The quantitative synthesis summarised the number of included studies, the study designs, the geographic distribution, and the characteristics of the populations studied. For the qualitative synthesis, the extracted findings were inductively coded by two reviewers to identify recurring concepts related to health-seeking behaviour. These codes were organised into broader categories to highlight common barriers, facilitators, and contextual factors influencing care-seeking. Themes were refined through discussion and consensus, following the principles of thematic analysis to ensure a systematic and transparent approach. Study characteristics and key findings were presented in structured tables and figures to facilitate comparison across studies. In contrast, the study selection process was documented and illustrated using a PRISMA-ScR flow diagram.

Results

A systematic search of databases, including Google Scholar, Scopus, and PubMed, initially identified 455 records. After removing 20 duplicates, 435 records remained for title and abstract screening. During this stage, 403 studies were excluded as they did not meet the predefined inclusion criteria. Subsequently, the full texts of the 32 potentially eligible studies were sought, but 4 could not be retrieved. Of the 28 full-text articles that were reviewed for eligibility, 11 were excluded for specific reasons. These exclusions included: 2 studies that did not confirm the population as people living with HIV (PLHIV), 4 that did not focus on health-seeking behavior, 3 that were unrelated to the research topic, and 2 that were found to be duplicate publications.

Ultimately, 17 studies were included in the final synthesis of the review, as detailed in the PRISMA flow diagram (Figure 1).

The characteristics of the included studies are summarized in Table 1. In terms of geographic distribution, most studies were conducted in the southern region of India (n = 6; 35.3%), with Tamil Nadu contributing the most (n = 4; 23.5%) and Karnataka contributing two (11.8%). Other states represented included Maharashtra (n = 2; 11.8%), Uttar Pradesh (n = 1; 5.9%), West Bengal (n = 1; 5.9%), Delhi (n = 1; 5.9%), and Chandigarh (n = 1; 5.9%). No studies were identified from the central, eastern, or northeastern states, such as Bihar, Odisha, Jharkhand, and Assam (Figure 2), Analysis of study design showed that nine cross-sectional studies (52.9%) were included, covering quantitative surveys, descriptive and observational designs, and behavioral and biological assessments.

Six qualitative studies (35.3%) employed methods such as focus group discussions, in-depth interviews, and phenomenological approaches.

In addition, one mixed-methods study (5.9%) combined a cross-sectional survey with qualitative interviews, and one retrospective cohort study (5.9%) used secondary data from electronic medical records (Figure 3) .

The publication years of the included studies ranged from 2004 to 2021, with notable peaks in 2009 (two studies), 2016 (three studies), and 2021 (two studies). In most other years, only one study was published, highlighting an uneven distribution of research over time. The study populations were diverse, including women living with HIV (five studies), men who have sex with men (three studies), people who inject drugs (two studies), and general PLHIV populations (seven studies). The evidence base was dominated by cross-sectional surveys, while qualitative and mixed methods design provided additional depth A key theme emerging from the findings was delayed care-seeking, which was observed in multiple studies. One study found that 97% of mothers living with HIV faced stigma, leading to a preference for anonymity and reduced access to care. Similarly, a study on married women living with HIV revealed that only 57% sought treatment due to limited knowledge and the pervasive stigma that discouraged status disclosure. This distribution of research approaches and populations studied underscores the multifaceted nature of health-seeking behavior among PLHIV in India.(Table 1).

Discussion

This scoping review synthesizes evidence on the health-seeking behavior of people living with HIV/AIDS (PLHIV) in India, highlighting stigma, social inequities, and health system limitations as central influences on care access and utilization. Barriers consistently emerged across diverse populations, including women, men who have sex with men (MSM), transgender individuals, sex workers, and children, illustrating the pervasive and multi-layered nature of the challenges in seeking HIV care. (22) Stigma, whether enacted, perceived, or internalized, was the most frequently reported barrier.

It was found to cause delays in HIV testing and treatment initiation, discourage the disclosure of HIV status, and reduce the utilization of public healthcare services. (23) The fear of discrimination within families and communities, along with confidentiality concerns in health facilities, contributed to a cycle of care avoidance and treatment interruptions. (24,25). Importantly, stigma often intersects with gender and sexuality, disproportionately affecting women, MSM, and transgender populations.(26) This aligns with global patterns documented in Uganda and Nigeria, where HIV-related stigma is strongly associated with lower ART adherence and reluctance to access facility-based care.(27) In contrast, countries such as Thailand and Brazil have made progress by institutionalizing anti-discrimination laws, integrating HIV services into primary care, and implementing broad public education campaigns. (28,29)

Social and gendered inequities further shaped health-seeking behavior in India. Women living with HIV often had limited autonomy in health-related decisions and prioritized family needs over their own care. Rural and low-income women, in particular, faced knowledge gaps around HIV and RTI/STI services, in addition to mobility restrictions that hindered timely access (30). Transgender individuals, MSM, widows, and sex workers faced intersecting forms of exclusion, magnifying their vulnerability to delayed or disrupted care (31,32). These findings mirror experiences in South Africa and Kenya, where women and key populations encounter compounded discrimination in accessing HIV services. In contrast, countries such as Argentina and parts of Europe have advanced inclusive health models by offering gender-sensitive HIV care and legal protections for LGBTQ+ populations. (33).

Health system limitations also played a significant role. Studies reported long travel distances to ART centres, fragmented referral pathways, and inadequate counselling services as key barriers (34)

These constraints contributed to late diagnosis, interrupted treatment, and reduced retention in care, especially in rural settings. In comparison, countries such as Rwanda and Cambodia have successfully scaled decentralised ART delivery and community-based service models, resulting in improved treatment coverage and continuity(35).

Despite these challenges, some facilitators were identified. Family and peer support were shown to improve adherence and treatment continuity (36,37). Innovative approaches such as telemedicine and HIV self-testing were also recognised as acceptable and potentially scalable in the Indian context. Comparable digital health interventions have been successfully implemented in Vietnam, Peru, and South Africa, demonstrating the potential for cost-effective and stigma-sensitive HIV service delivery.

Finally, this review highlights critical evidence gaps. Most studies were concentrated in southern and western India, while central, eastern, and northeastern states were underrepresented. Populations such as adolescents, tribal communities, and rural youth remain largely absent from the research base. Moreover, the predominance of cross-sectional and qualitative designs limits causal inference and a long-term understanding of health-seeking behavior. Similar methodological gaps have been noted in countries such as Bangladesh, Ethiopia, and Pakistan. Addressing these gaps will be vital for generating more representative and actionable evidence.

From this synthesis, several key policy and program implications emerge. The geographic and financial barriers identified in the review suggest that expanding decentralized ART delivery and strengthening community-based care models are crucial. To address the social inequities discussed, it is essential to integrate gender-sensitive and stigma-reducing interventions within health services. Additionally, scaling up digital innovations such as telemedicine, when combined with robust anti-discrimination policies and public education, could significantly improve service uptake and retention in care for PLHIV in India.

These implications point towards a need for multi-level, patient-centered interventions that address not only health system limitations but also the broader social determinants of healtht

Recommendations

Improving health-seeking behaviour among people living with HIV/AIDS (PLHIV) in India requires multi-level interventions addressing stigma, social inequities, and systemic barriers. Stigma reduction should include sensitising healthcare providers, strengthening confidentiality safeguards, and community-led education to counter misconceptions and fear. Interventions must prioritise women, MSM, transgender persons, and low-income groups through peer-led outreach, counselling, and gender-sensitive support. System-level improvements such as decentralised ART delivery, mobile clinics, telemedicine, and integration of HIV services into primary healthcare can reduce geographic and psychosocial barriers. Family and peer support, including structured peer navigator models, can enhance adherence and retention in care. Finally, research should target underrepresented regions and populations and evaluate innovative approaches for scalability and effectiveness.

Limitations of the Review

The review's limitations include a potential for language bias due to the exclusion of non-English and grey literature, challenges with reproducibility from relying on Google Scholar, and its descriptive nature, which means it doesn't assess the quality or effectiveness of interventions.

Conclusion

This scoping review provides a concise synthesis of the evidence on health-seeking behavior (HSB) among people living with HIV/AIDS (PLHIV) in India. Our study identified three primary barriers: pervasive stigma, which delayed testing and treatment; social inequities, including gender and income disparities, that restricted access to care; and health system limitations, such as long travel distances and fragmented services, which contributed to poor retention. Conversely, the review found that peer and family support and innovative digital health approaches were key facilitators.

Based on these findings, we recommend two key actions: first, interventions should target underrepresented regions and populations, as our review found a significant lack of research in central, eastern, and northeastern Indian states, as well as among adolescents and tribal groups. Second, a focus on stigma reduction and the development of community-based, patient-centered care is critical to improving service uptake and retention in India.

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Figure 1: PRISMA Flow Diagram of Study Section

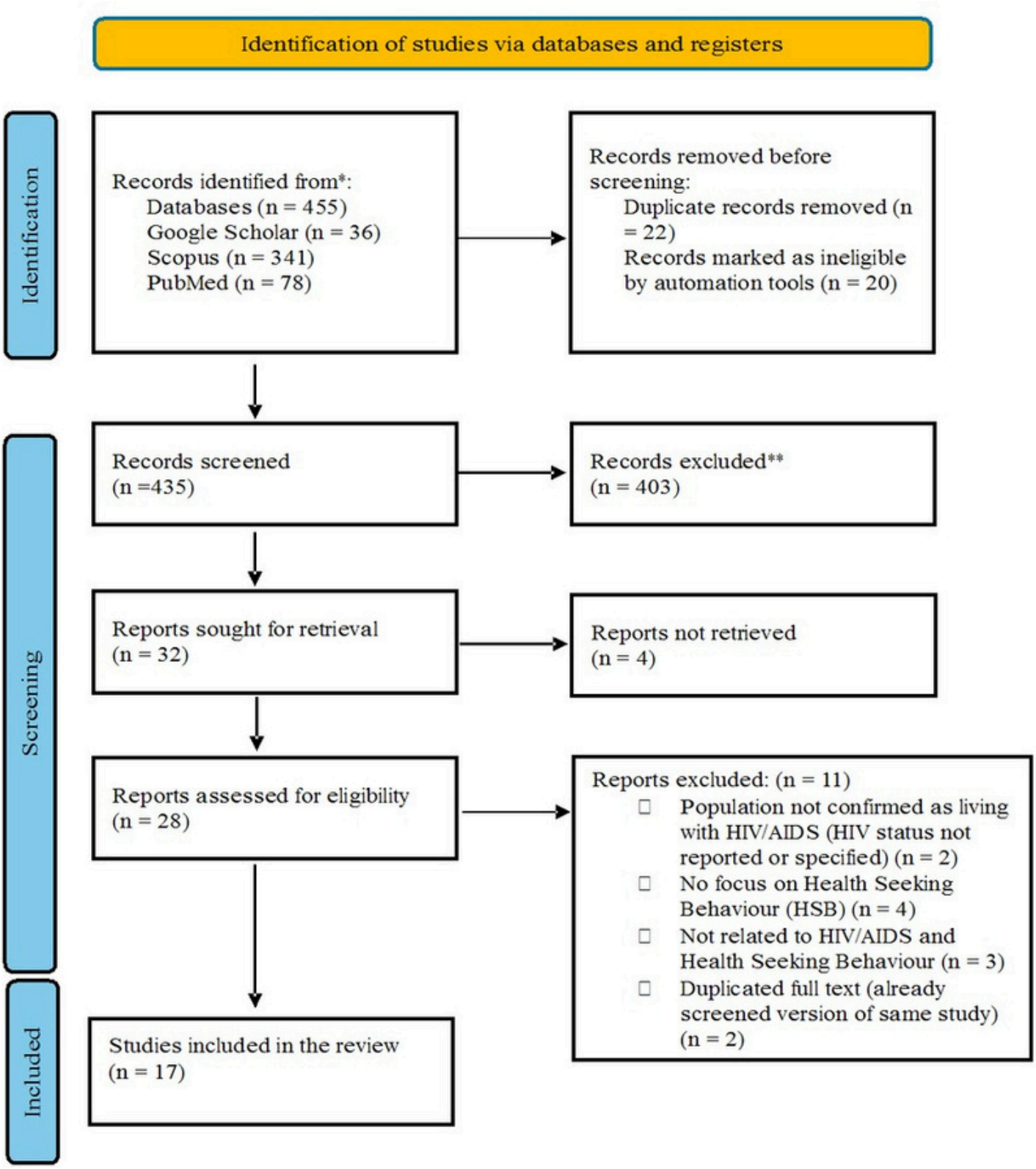

Figure 2: Geographic Distribution of Studies on HIV-Related Stigma in India

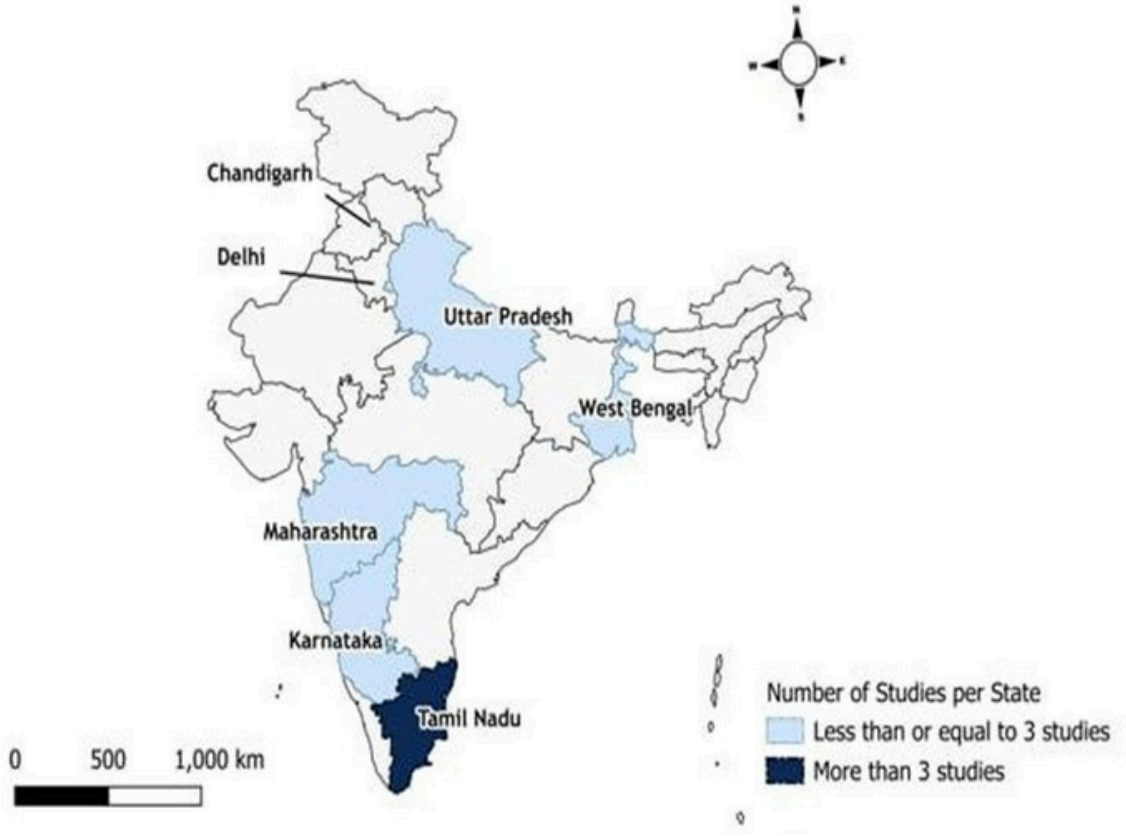

Figure 3: Study Design Distribution Among Included Studies

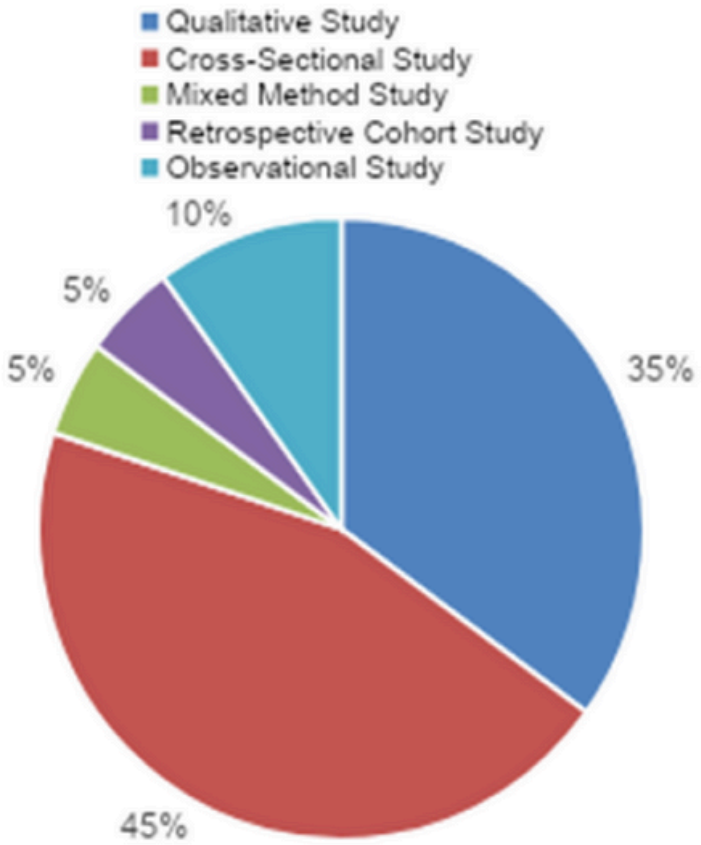

Table-1 Barriers to Health-Seeking Behavior Among People Living with HIV/AIDS in India: A Summary of Studies.

Sno	Author(s)	Year	Country	Study Population	Setting	Sample Size	Study Design	Aim	Stigma Type	Key Findings (Health-Seeking Behaviour + Impact of Stigma)
1	Beena Thomas et al.	2008	India	Mothers living with HIV	Urban (Chennai)	60	Qualitative (FGDs) Study	To explore perceptions and needs of mothers with HIV	Enacted, Perceived	Delayed care-seeking; 97% faced stigma; preferred anonymity; reduced access
2	Shiva S. Halli et al.	2020	India	Married WLHA (15–29 yrs)	Urban & Rural (Karnataka)	633	Cross-sectional Study	To assess sexual health and RTI/STI care	Perceived, Social/Cultural	Only 57% sought treatment; limited knowledge; stigma reduced disclosure
3	Amrita Gupta et al.	2016	India	Transgender individuals (Hijra)	Urban slum (Mumbai)	110 + 5 IDIs	Mixed-method Study	General health, treatment-seeking & expenses	Intersectional, Structural	Low public facility use (16%); high costs; 84% unaware of insurance
4	Mandeep Kaur et al.	2024	India	Adults on ART (≥18 yrs)	Tertiary care hospital (Chandigarh)	75	Cross-sectional Study	To assess perceived health, QoL & care-seeking	Perceived	84% preferred same ART center; social QoL most affected
5	Anne Marie Chomat et al.	2009	India	PLHIV, families, ISM providers	Rural & Semi-urban (Vellore)	77 interviews	Qualitative (FGDs)	HIV health beliefs, ART delay & ISM use	Perceived, Social/Cultural	ART delayed due to ISM reliance; gender gaps in knowledge/access
6	S. Rajasekaran et al.	2009	India	HIV-positive children	Urban (Tambaram, Chennai)	1,768	Retrospective cohort	To assess pediatric care patterns & barriers	Enacted, Structural	Long travel; high follow-up dropout; TB co-infection ignored early
7	Yanni M. Cheng et al.	2019	India	FSWs & peer educators	Urban (Pune)	22	Qualitative (FGDs)	Perceptions of HIVST	Enacted, Structural	Preferred community centers; avoided brothel testing; privacy
8	Saikat Datta et al.	2016	India	PLHIV	Rural (Darjeeling, West Bengal)	454 participants	Observational cross-sectional study	Factors influencing stigma & openness	Perceived, Social/Cultur al, Internalized	Higher stigma in men; reduced provider openness
9	Abyramy Balasundaram et al.	2014	India	Adults on ART	Urban (Puducherry)	130	Cross-sectional	Family support & treatment behavior	Enacted	20% delayed ART; family support improved adherence
10	Matthew Mimiaga et al.	2015	India	MSM (Kothi, Panthi)	Urban (Chennai)	55 (46 FGDs + 9 IDIs)	Qualitative Descriptive Study	To assess healthcare avoidance and stigma in MSM	Enacted, Social/Cultur al, Internalized	Avoided healthcare; secrecy increased risky behavior
11	Khan Iqbal Aqeel et al.	2021	India	MSM (18+ yrs)	Urban (Agra)	52	Cross-sectional Study	Sexual health & care-seeking among	Enacted, Perceived	79% hid identity; preferred private care; 70% sought help

12	Piyush Kumar Gupta et al.	2017	India	HIV+ children	Urban (Delhi)	216	Cross-sectional Study	Sociodemogr aphic profile & pre-treatment behavior	Structural	Delayed diagnosis; multiple contacts before ART registration
13	Nalini Tarakeshwar et al.	2007	India	Adults on ART	Mixed (urban NGO, rural origin)	50	Mixed (Qualitative & Cross-sectional) Study	Social Cognitive approach to HIV care	Intersectional, Social/Cultur al, Internalized	Women faced isolation; stigma reduced adherence
14	Mamta Manglani et al.	2021	India	HIV+ children	Urban & Semi-urban (Maharashtra)	583	Comparative cross-sectional Study	Effectiveness of telemedicine	Structural	Telemedicine improved TB screening & care quality
15	Sonali Sarkar et al.	2018	India	Mothers of HIV+ children	Urban (Puducherry)	11	Qualitative Study	Caregiver perspective on stigma & disclosure	Perceived, Social/Cultur al	Used euphemisms like “vitamins”; avoided telling child; preferred distant centers
16	Reshmi Mukerji et al.	2025	India	WLHA (widows, sex workers etc.)	Urban & Semi-urban (Kolkata)	31 women living with HIV and 16 key	Qualitative Study	Violence, help-seeking & stigma	Intersectional, Social/Cultur al, Internalized	Violence, eviction, shame reduced care-seeking
17	Mishra et al.	2009	India	Female sex workers	Urban (5 Karnataka districts)	2,312	Cross-sectional Study	Syphilis prevalence & access	Enacted, Intersectional, Structural	21.2% avoided care; preferred anonymous/private clinics

Annexure -1

Search strategy

S.no	Strategy	Result
1	("health-seeking behavior" OR "care-seeking" OR "healthcare utilization" OR "help seek*" OR "treatment seek*" OR "health information seek*" OR "healthcare seek*" OR "care seek*" OR "health seek*")	37,179
2	("HIV Infections"[Mesh] OR HIV OR "Acquired Immunodeficiency Syndrome"[Mesh] OR AIDS OR (PLHIV) OR People Living with HIV	572,307
3	India [Title/Abstract]	154,476
4	1 AND 2 AND 3	78

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• Conflict of Interest Statement

The authors declared "No Conflict of Interest" with this publication.

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