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Stigma and healthcare engagement among women living with HIV in high-income countries: A scoping review protocol

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ADMINISTRATIVE INFORMATION

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INTRODUCTION

Review question / Objective What is previous research evidence on 1) the types (e.g., racism, homophobia) and dimensions (i.e., enacted, anticipated, perceived, and internalized) of stigma experienced in the context of healthcare engagement* and 2) associations between stigma and healthcare engagement outcomes among women living with HIV in high-income countries from 2014 to 2025?

*For the purposes of conducting this scoping review, healthcare engagement refers to an individual's ability and desire to actively participate in their care, encompassing both intention and actual involvement in care, which is informed by patient-provider and institutional dynamics.1.

Background

Stigma is typically defined as the societal discrediting of a certain attribute.2 People living with HIV continue to experience HIV-related stigma, often alongside other overlapping forms of stigma related to social-structural marginalization.3,4 Stigma experienced by people living with HIV—including, but not limited to, stigma related to HIV, gender, and race—impedes progress towards the 95-95-95 global targets set by UNAIDS for HIV prevention and treatment.5–9 These targets include 95% of people living with HIV knowing their status, 95% of those with a diagnosis being on treatment, and 95% of those on treatment being virally suppressed.9

Research from the Global Network of People Living with HIV indicates that nearly a quarter of respondents reported some form of HIV-related stigma in a community setting within the previous year.10 Correspondingly, over half of the women living with HIV included in another Canadian study reported HIV-related stigma, while 17% and 16% also reported gender and racial discrimination, respectively. Dimensions of stigma include enacted (e.g. discrimination, denial of care), anticipated (e.g., worry or fear that one will encounter stigma), perceived (e.g., the belief that stigmatizing perspectives are held by others), and internalized (e.g., the application of stigmatizing beliefs onto oneself).

Research exploring stigma experienced specifically by women living with HIV remains particularly important given the ways gender can interplay with other forms of social-structural marginalization within healthcare contexts.8,11 For example, a US-based study examining enacted HIV-related stigma among people living with HIV suggests that women are more likely to report enacted HIV-related stigma.12 Furthermore, a systematic review and meta-analysis of international research found that women were more likely to report HIV-related stigma compared to men.3 While considerable research has focused on HIV-related stigma, some research suggests that women living with HIV experience overlapping stigmas.3 One study among healthcare providers in Canada identified associations between stigmatizing attitudes related to HIV and homophobia, racism, sexism, as well as stigma against injection drug use and sex work.4 This research demonstrates that HIV-related stigma is not always perpetrated in isolation from other types of stigmas, underscoring the importance of considering other types of stigma, rather than HIV-related stigma alone.

Research suggests that HIV-related and other types of stigma experienced by women living with HIV can contribute to less healthcare engagement, which is an essential component to achieving global targets for HIV and overall health and well-being for people living with HIV.8 For example, a systematic review and meta-analysis of research across 32 countries reported that HIV-related stigma undermined adherence to antiretroviral therapy (ART), highlighting the importance of understanding and addressing stigma experienced by people living with HIV.13 Healthcare engagement is related to, but distinct from, healthcare outcomes; rather, it is conceptualized as contributing to health outcomes.1 Conceptualizations of healthcare engagement are widely varied.14,15 A concept analysis of international healthcare engagement research identified four key components, including access (e.g., availability of resources and information), personalization (e.g., tailoring care to individual needs), commitment (e.g., internal factors that underpin motivation to engage in care), and therapeutic alliance (e.g., connection to and/or partnership with provider), overall referring to an individual's desire and ability to participate in care.1,16 Healthcare engagement includes actual participation in care, and is further informed by institutional level factors, such as confidentiality practices.1 Examples of healthcare engagement include care encounters, medication adherence, appointment attendance, and trust in healthcare providers or systems. Healthcare engagement may also be assessed via scales such as the Patient Activation measure or the Patient Health Engagement scale.17,18 Despite recognition of the importance of healthcare engagement, existing literature reviews have not consistently captured the diverse ways in which healthcare engagement is defined, operationalized, and measured among women living with HIV. In line with scoping review methodology,19 the conceptualization of healthcare engagement for the purposes of this review may be iteratively revised during the review process.

Concerningly, global research from the People Living with HIV Stigma Index (Stigma Index) suggests that experiences of anticipated HIV-related stigma in healthcare contribute to sustained disengagement along the HIV care continuum; for example, people who have stopped taking ART cite stigma in healthcare as a deterrent to restarting ART.10 While some studies, including research based on the Stigma Index, examines HIV-related as well as other types of stigma (e.g., transphobia, homophobia) in healthcare contexts, this research focused primarily on lower- and middle-income countries (LMIC), which may not be generalizable to high-income countries (HIC).10,20–22

Synthesizing research on stigma related to healthcare engagement in HIC is essential for driving meaningful action, including policy changes and interventions that reduce stigma in HIC healthcare settings. Building on a 2020 UNAIDS report that highlights the importance of examining HIV-related stigma as it manifests in different settings (e.g., community, workplace, healthcare), this review will have a specific focus on healthcare engagement. This review will include a comprehensive evaluation of the different types of stigmas faced by women living with HIV in healthcare in the context of healthcare engagement, with important implications for improving retention in care and health outcomes, such as adherence to antiretroviral therapy (ART).23

Rationale

Few research syntheses have focused on different types of stigmas in the context of healthcare engagement among women living with HIV in HIC. Many existing research syntheses have focused on LMIC, such as Nigeria and Thailand.20–22 For example, a 2013 review from Thailand—which included people living with HIV and healthcare providers—describes ways concurrent social-structural marginalization can compound effects of HIV-related stigma—healthcare students and professionals viewed people living with HIV who use drugs or engage in sex work as less deserving of support.21 A 2023 systematic review focused on healthcare provider perspectives in Nigeria and described attitudes and beliefs around HIV-related stigma, as well as associated factors, such as gender, setting, and specialty.20 Given the ways healthcare systems and socio-political contexts across HIC differ from LMIC, it is unclear whether these findings are generalizable to HIC settings.

Furthermore, many existing reviews focus on provider perspectives,20,24,25 outlining ways that HIV-related stigma and discrimination are informed by provider positionality as well as exposure to HIV-related stigma training.20,24 For example, a systematic review of HIV-related stigma among healthcare providers in the US suggests that HIV-related stigma among providers has a negative impact of quality of care provided, is informed by intersectional stigma, and is more common among providers with limited or no HIV-related stigma training.24 Similarly focusing on the provider level, a 2019 systematic review assessed interventions to address HIV-related stigma in healthcare settings.26 While this existing research can help inform targeted training, it is naive to healthcare seekers' perspectives; therefore, it remains pertinent to better understand healthcare seekers' perspectives and experiences to ensure relevant action is appropriately responsive.

Despite evidence suggesting that women living with HIV experience overlapping stigmas,3,4,27 many existing reviews focus only on HIV-related stigma, and are therefore not responsive to the overlapping stigmas faced by women living with HIV.20,21,24–26 Furthermore, despite evidence suggesting enacted HIV-related stigma is more commonly reported among women,12 most existing syntheses examining HIV-related and other types of stigma in the context of healthcare fail to disaggregate by gender or focus on women only.28,29 For example, a systematic review and series of meta-analyses examining associations between HIV-related stigma and health outcomes did not disaggregate findings by sex or gender.29 Similarly, among 38 articles included in a systematic review of systematic reviews focusing on associations between HIV-related stigma and ART adherence, only one article focused on women living with HIV in a HIC.30 Additionally, a lack of research focusing on stigma specifically within healthcare contexts limits our understanding of how this phenomenon manifests. This is further complicated given that healthcare engagement is a multifaceted construct that is defined and measured with substantial variability.15 Therefore, mapping approaches used in research among women living with HIV will allow for a better understanding of how engagement is conceptualized and potential areas for future research. Overall, a marked lack of research focusing on HIV-related and other types of stigmas faced by women living with HIV in the context of healthcare engagement remains a critical gap in the literature. Therefore, a review dedicated to women living with HIV is needed to clarify the breadth and nature of different types of stigmas faced by this key population in the context of healthcare engagement.

From existing literature syntheses, it is clear that HIV-related and other types of stigma remain a critical barrier to optimal healthcare access and outcomes. However, there is still a need to better understand the scope of different types of stigmas experienced in the context of healthcare engagement among women living with HIV in HIC. Therefore, the proposed scoping review aims to identify primary, peer-reviewed research that focuses on stigma within the context of healthcare engagement among women living with HIV in HIC.

METHODS

Strategy of data synthesis

The proposed scoping review will follow methodology described by the Joanna Briggs Institute (JBI).19,31 A search strategy will be developed with guidance from a research librarian. The following databases will be searched in the summer of 2025: MEDLINE (Ovid), EMBASE (Ovid), and CINAHL.32.

Eligibility criteria

Inclusion criteria: 1) focus on women living with HIV (i.e., the target population must be women, including cis, trans, and non-binary gender identities); 2) study is set in a HIC defined by the Organization for Economic Cooperation and Development (OECD)22; 3) include an assessment of stigma (i.e., homophobia, transphobia, xenophobia, sexism, racism, classism, anti-sex work stigma, anti-drug use stigma, stigma related to sexual activity) in any form (i.e., enacted, perceived, anticipated, internalized or related analogues) in the context of, or in association with, healthcare engagement (i.e., occurring within a healthcare setting or with a healthcare provider, or associated with a healthcare engagement outcome, see Table 1 for additional examples); 4) published in English due to language capacities of reviewers; 5) published in or after 2014; 6) one of the following primary research study designs: cohort study, cross-sectional, case-control, and mixed-methods (inclusive of quantitative findings only).

Exclusion criteria: 1) non-peer reviewed articles (e.g., conference proceedings, commentaries, editorials, abstracts); 2) non-human study; 3) other study design (e.g., experimental or quasi-experimental, qualitative, and literature syntheses, including systematic, scoping, rapid, or narrative reviews); 4) study population is not contemporary (i.e., before 2014); 5) conducted outside of HIC.

Source of evidence screening and selection

Title/abstract and full-text screening will be completed by two students (MSO, BL) using the predefined eligibility criteria. Each article will be screened by both reviewers at both the title/abstract and full text stages. Any conflicts will be resolved with between the two reviewers. If consensus cannot be reached, the lead investigator (KD) will be consulted.

Data management

References will be managed using Covidence during the screening process.32 All data, including extractions, will be stored on a password protected platform. Data extraction will include information on study characteristics (i.e., study setting, sample selection criteria), types and dimensions of stigma examined, stigma measurement tools and method, healthcare engagement concepts, associations between stigma and healthcare engagement where reported, and overall findings. The extraction table will be updated iteratively in conjunction with the data extraction process to ensure it captures necessary information from included articles. A PRISMA flow diagram will be used to show results at each stage of the review process.

Reporting results / Analysis of the evidence

Analyses of studies included in the review will be descriptive in nature.31 After extracting data from each included study, findings will be summarized, including describing how frequently different types/dimensions of stigma were examined, common measurement tools, and which settings are most represented in the literature. For articles that report on associations between stigma and healthcare engagement, a summary of findings and directionality will be included. Additionally, healthcare engagement concepts will be summarized. The review will also highlight key areas and gaps for future research that examines stigma related to healthcare engagement among women living with HIV. 7

Language restriction

Included articles will be restricted to those published in English due to the language capacities of the reviewers.

Country(ies) involved Canada

Keywords Stigma, HIV, Women living with HIV, Healthcare, High-Income Countries

Dissemination plans Stigma remains a primary barrier to optimal healthcare outcomes, impeding progress towards international goals for HIV treatment and prevention. Better understanding stigma in the context of healthcare engagement among women living with HIV in HIC will support interventions and policy changes that can address these issues. The proposed scoping review will address this need by providing a synthesis of quantitative literature that examines different types of stigmas within the context of healthcare engagement among women living with HIV in HIC.

Findings from the proposed scoping review will be shared through traditional academic channels, including conferences and manuscript publication. Additionally, findings will be synthesized for sharing among participants and staff of the SHAWNA (Sexual Health and HIV/AIDS: Longitudinal Women's Needs Assessment) project as an in-person presentation and one-page reference document.

Contributions of each author (Describe each author's contribution after their names).

Mika S. Ohtsuka – MS Ohtsuka conceptualized this review and wrote the first draft of this protocol, as well as the final draft incorporating coauthor input. They will lead the search and screening process, as well as extraction, synthesis, and writing the first draft of the review manuscript.
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Gina Ogilvie – Dr. Ogilvie provided feedback on the scoping review protocol and will provide feedback on the review process and manuscript.
Anne Gadermann – Dr. Gadermann provided feedback on the scoping review protocol and will provide feedback on the review process and manuscript.
Kathleen Deering – Dr. Deering supervises MS Ohtsuka's doctoral thesis. She supported the conceptualization of this review and provided feedback on the scoping review protocol. She will supervise the review process, including data extraction/synthesis, and drafting of the review manuscript.

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