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Mental health of women with HIV: a qualitative meta-synthesis

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Abstract

Background Women living with human immunodeficiency virus (HIV) experience significant psychological burdens due to biological and gendered factors such as pregnancy, childbirth and breastfeeding. However, a life course–based understanding of their mental health, adaptation and recovery remains limited. This study aimed to synthesise and analyse qualitative research on the mental health experiences of women living with HIV.

Methods A qualitative meta-synthesis was conducted following Sandelowski and Barroso's methodology. A comprehensive search of six electronic databases employed keywords and Medical Subject Headings. Eligibility criteria comprised women (population), mental health (concept) and HIV (context). The final studies were selected using the Critical Appraisal Skills Programme (CASP) checklist. Themes and sub-themes were generated through comparison, classification and synthesis of study findings, illustrated by participant quotations.

Results Of 2,793 studies identified, 22 met the eligibility criteria and were appraised using the CASP checklist. These studies were conducted across 15 countries, mostly in Asia, North America and Africa, providing extensive qualitative evidence. Participants included women of reproductive age and older women from diverse ethnic and social contexts. Based on qualitative findings supported by 124 quotations from the included studies, four overarching themes and nine subthemes were identified: (1) post-traumatic stress experienced after an HIV diagnosis, (2) living with HIV and womanhood: the double burden of pain, (3) struggling to endure each day with HIV and (4) yet, the ongoing lived trajectory of becoming. Women described recovery as a non-linear and unstable process marked by recurring cycles of progress and setback. These themes reflect their mental health struggles and adaptation following the existential shock, dual burden and profound suffering that accompany an HIV-positive diagnosis. Despite early emotional distress, women reported relief and empowerment through supportive relationships.

Conclusions The findings reveal how women living with HIV experience psychological distress and lifelong coping and resilience, across diverse regional, cultural, and healthcare system contexts. These insights can inform healthcare professionals, policymakers, and researchers in developing individualized, sustainable, and adaptive psychosocial care interventions globally. Future research should adopt tailored, lifespan-focused approaches and employ ethnographic methods to complement the potential limitations inherent in qualitative meta-synthesis and deepen understanding of women's lived experiences.

Keywords Qualitative research, Women, HIV, Mental health, Social stigma, Psychological distress, Resilience, psychological, Social support

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Introduction

The human immunodeficiency virus (HIV) is a major global infectious disease transmitted through bodily fluids such as blood, semen, vaginal secretions and breast milk [1, 2]. As of 2023, approximately 39.9 million people were living with HIV worldwide, with women accounting for 53%, and 79% of those women being of reproductive age [3, 4]. Over the past four decades, antiretroviral therapy (ART) has transformed HIV from a fatal illness into a manageable chronic condition. The life expectancy gap between individuals with and without HIV has narrowed significantly—from 44.3 to 7.9 years since the introduction of ART [5]. Since the mid-2010s, some countries have reached the 90–90–90 treatment targets [6], and the focus has shifted towards mental health, quality of life, stigma reduction, social integration and healthy ageing, with comorbidity management as part of the fourth target in HIV care [7–9].

Compared with the general population, people living with HIV experience significantly higher rates of depression, anxiety, emotional distress and suicidal ideation [10, 11]. Specifically, depression and anxiety affect 31% and 29% of this population, respectively, compared with 5.7% and 4.4% in the general population [12–14]. Women are particularly vulnerable due to the close link between HIV exposure and biologically and socially gendered experiences such as pregnancy, childbirth and breastfeeding. If ART is inadequate, women living with HIV may pass the virus to their infants during pregnancy, childbirth or breastfeeding, with reported transmission rates ranging from 15% to 45% [15]. These reproductive roles, combined with hormonal mechanisms and socio-cultural expectations [16, 17], increase women's risk for unique psychological burdens. Limited integration between HIV and mental health services and inadequate knowledge about HIV reinfection leads to reliance on informal support networks and difficulties in adopting appropriate coping strategies [18, 19]. Previous studies have shown that such psychological vulnerability adversely affects overall quality of life [20, 21]. While some research has reported that women living with HIV experience higher levels of post-traumatic stress symptoms than both men with and women without HIV [20, 22], findings remain inconsistent, with certain studies indicating no significant gender differences or even greater psychological distress among men in certain settings [23].

Since the late 2010s, interest in the mental health of people living with HIV has increased, leading to a rise in qualitative studies [24–26]. However, existing reviews tend to focus on a few geographic regions, such as sub-Saharan Africa, Asia and North America (particularly the United States) [22, 27, 28]. Most of the studies have reflected the particular social and cultural realities of those regions, including family-centred values and religious influences [27, 29]. Consequently, existing syntheses may offer only a partial understanding of the mental health experiences of women living with HIV across differing societies and healthcare environments. To achieve global HIV treatment targets, it is essential to identify vulnerable populations who are exposed to the disease yet face challenges in coping, while also taking into account the regional, cultural, and systemic contexts that shape their experiences.

To date, understanding a longitudinal and holistic understanding of the lived experiences, psychological adaptation and recovery of women living with HIV is insufficient. Therefore, this meta-synthesis study aimed to synthesise and interpret meaningful themes from relevant qualitative studies to provide a detailed elucidation of the mental health experiences of women living with HIV. The research question of this study is: What are the mental health experiences, and the psychological adaptation and recovery processes, of women living with HIV?

Methods

Study design

This study employed the qualitative meta-synthesis methodology proposed by Sandelowski and Barroso [30] to gain a comprehensive understanding of the mental health experiences of women living with HIV, focusing on their psychological adaptation and recovery. Although qualitative studies often provide valuable insights grounded in specific contexts, they cannot capture the full scope and continuity of lived experiences. Because primary research themes reflect researchers' interpretations, the present study focused on synthesising qualitative findings across studies, supported by participants' quotations to reconstruct thematic relationships and synthesise deeper meaning. The synthesis followed the steps outlined by Sandelowski and Barroso [30]: (1) systematic search and selection, (2) quality appraisal, (3) extraction of findings, (4) categorisation and comparison, and (5) interpretive synthesis and articulation.

Systematic search and selection

To reflect the increasing global interest in mental healthcare for people living with HIV since the late 2010s, this study systematically searched four international databases (PubMed, PsycINFO, CINAHL and Scopus) and two Korean databases (Research Information Sharing Service and Korean Studies Information Service System) for qualitative studies published between January 2019 and March 2024. The focus was on studies about women's mental health experiences that had not been covered in previous reviews. The search strategy combined free-text keywords and MeSH terms: (Female[Mesh] or Women[Mesh]) AND (Mental Health[Mesh] or Depression/psychology[Mesh] or Social stigma[Mesh]) AND

HIV Infection/psychology[Mesh]. Equivalent Korean terms were used for Korean databases.

Four researchers (JL, YK, SL and SJ) independently conducted and cross-checked the searches. The inclusion criteria followed the PCC framework: (1) women across reproductive and older ages (population), (2) mental health experiences (concept) and (3) living with HIV (context). To reduce confounding related to sex diversity, only cisgender women were included. Studies had to present clear participant quotations; those mixing male and female quotes indistinctly were excluded, as were studies focused on biomedical HIV interventions or lacking full texts in Korean or English. Four researchers screened the titles and abstracts independently, with iterative discussions to reach unanimous decisions on inclusion. The process was documented for transparency. The flow of study selection is presented in Fig. 1 (Additional file 1).

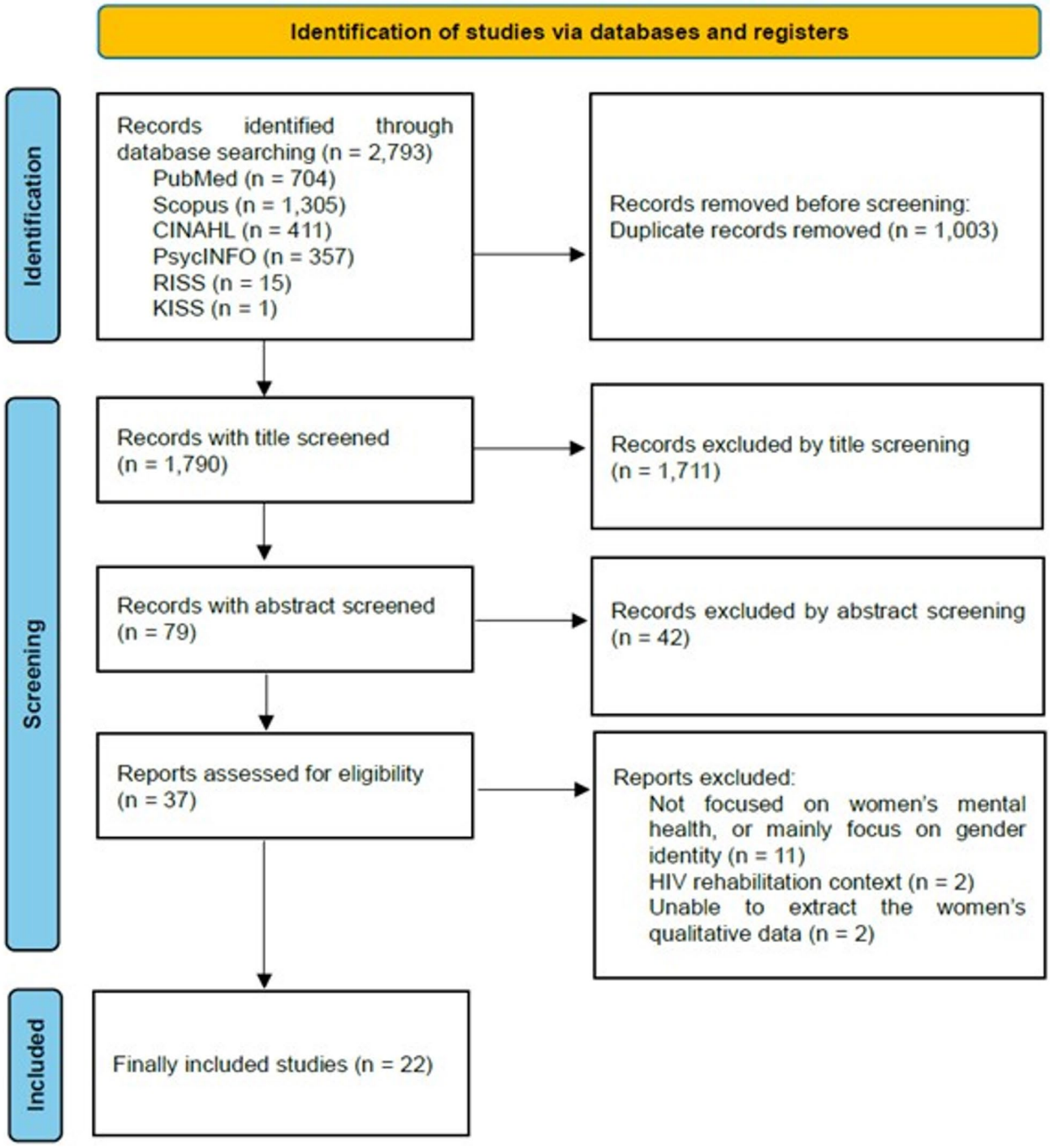

Fig. 1 PRISMA flow diagram

Quality appraisal

To ensure methodological rigour and credibility, 22 studies were appraised using the Critical Appraisal Skills Programme (CASP) qualitative checklist [31], which evaluates research design, clarity, analytic transparency and reflexivity. Rather than scoring, the focus was on conceptual and methodological coherence [30].

Two researchers independently appraised each study, with each researcher assessing 11 studies. Discrepancies were resolved through discussion and finalised by consensus to ensure consistency and transparency.

Extraction of findings

Four researchers (JL, YK, SL and SJ) independently extracted qualitative findings and participant quotations from 5 to 6 articles each using Google Sheets. To preserve authenticity, extracted data were organised into participants' verbatim expressions and authors' interpretations. To acknowledge potential interpretive biases, researcher reflexivity was recorded throughout the extraction process. The team reviewed data repeatedly, adding memos to share insights. Two researchers (JL and YK) then cross-checked all extracted findings, quotations and memos and discussed them to ensure data completeness and consensus on contextual meanings.

Categorization and comparison

Initial open coding generated codes that were categorised by conceptual similarities across studies. These categories were refined into subthemes through constant comparative analysis, which formed the basis for interpretive synthesis. Researchers documented notes for communication and identified discrepancies. For validity, all four researchers reviewed coded data and memos and resolved inconsistencies through discussion to reach consensus.

Interpretive synthesis and articulation

The research team held biweekly meetings to conduct interpretive synthesis through collaborative discussions, inductively identifying subthemes. Reflexivity was maintained by acknowledging researchers' positionalities, such as being a public health officer or a clinical nurse, whose backgrounds guided the interpretation of the social and clinical aspects of living with HIV. Subsequently, two researchers (JL and YK) refined subthemes into four overarching main themes representing women's mental health experiences, psychological adaptation and recovery patterns. The synthesis results are detailed in the findings.

Researcher Preparation and reflexivity

To enhance rigour and trustworthiness, the researchers (JL, YK, SL and SC) received formal training in qualitative methods and meta-synthesis through doctoral coursework. All had experience conducting qualitative studies and participating in related academic conferences. Three researchers had clinical nursing experience with people living with HIV, and one had expertise in the epidemiology of HIV and other infectious diseases. Throughout the synthesis, the team engaged in reflexive examination of their assumptions, held regular discussions and wrote memos to mitigate interpretive bias and promote transparency.

Results

All 22 studies met at least 7 of the 10 CASP criteria, indicating satisfactory methodological quality (Additional file 2). Researchers reviewed each study multiple times and systematically summarised key information—such as research aims, methodology, participant characteristics, data collection and findings (Table 1). This rigorous approach allowed for the assessment of both checklist compliance and methodological congruence, demonstrating how study designs aligned with their aims.

An in-depth meta-synthesis of qualitative findings on the mental health experiences of women living with HIV uncovered four themes and nine subthemes, supported by 124 participant quotations across the included studies. These overarching themes, reflecting mental health experiences, psychological adaptation and recovery, included the following: (1) post-traumatic stress experienced after an HIV diagnosis, (2) living with HIV and womanhood: the double burden of pain, (3) struggling to endure each day with HIV and (4) yet, the ongoing lived trajectory of becoming (Fig. 2). These themes are illustrated by quotations summarised in Table 2.

Post-traumatic stress experienced after an HIV diagnosis

Following an HIV diagnosis, women often reported experiencing emotional shock and intense psychological distress. Responses included helplessness, fear, depression, sadness and isolation. Internalised stigma often made it difficult for women to disclose their status, reinforcing secrecy and deepening feelings of guilt.

Emotional shock and confusion after an HIV-positive diagnosis

Women living with HIV often experience profound emotional shock and psychological distress upon diagnosis (A2, A4, A6, A10, A11, A13, A14, A15, A19, A20, A21 and A22). Common reactions include fear, helplessness, denial, grief and social withdrawal. In some cases, the emotional burden led to disorientation or fainting, escalating into mental health crises that required professional care (A11, A13, A20 and A21). Anticipated negative societal reactions—such as judgement or rejection—were

Table 1 Summary of the included studies ($n = 22$)

No.	Author (year), country, setting	Aim	Participants (number, demographic characteristics)	Methods & Analysis	Findings (main theme)
A1	Nkulu-Kalengayi et al. (2023), Sweden, single-centre (1 community organisation)	To explore perceptions, experiences of sexual and reproductive health and rights of WLHIV	Swedish & African migrants ($n = 12$); aged 25–61 years; 6 single, 6 partnered	IDI; thematic analysis	1. Reconsidering sexual and reproductive life with HIV: reorientation after diagnosis 2. (Mis)perceptions of HIV affecting sexual and reproductive life – abusive treatment and internalisation 3. A paradoxical shift of responsibilities
A2	Payán et al. (2019), Dominican Republic, multi-centre (3 clinics)	To explore the various ways in which an HIV-positive diagnosis impacts the identity and behaviour of urban dwellers in low-resource communities	Latin American ($n = 30$); aged 20–56 (mean 38) years; not reported	Semi-structured, IDI; content analysis	1. Impacts of an HIV diagnosis: perceived psychological and emotional impacts of a diagnosis; diagnosis during pregnancy and postpartum; feelings of depression and reduced self-worth; denial and fear; perceived psychosocial impacts of a diagnosis – fear of disclosure and perceived stigma 2. Post-diagnosis turning points: survival identity, motherhood identity 3. Integration: mobilising support and resources through social networks; positive impact of connecting with networks of PLHIV
A3	Omotoso (2021), Nigeria, single-centre (1 clinic in rural setting)	To understand barriers to HIV status disclosure	Nigerian ($n = 17$); aged 28–48 years; 6 single/divorced/separated, 11 married	IDI; thematic analysis	1. The fear of social stigmatisation 2. Poor support from HIV-care providers 3. Socioeconomic dynamics
A4	Sadati et al. (2019), Iran, single-centre (1 HIV centre in urban setting)	To explore psychosocial experiences of WLHIV infected by their husbands	Iranian ($n = 10$); aged 28–50 (mean 34.8) years; 5 widowed, 3 remarried, 2 married;	FGI; content analysis	1. Onomatophobia 2. Social stigma 3. Discrimination 4. Self-stigma
A5	Phakisi et al. (2019), South Africa, single-centre (1 community health centre in urban setting)	To explore breastfeeding experiences of WLHIV	Black South African ($n = 15$); aged 20–40 years; 9 single, 6 married	Unstructured, IDI; thematic analysis	1. Positive experiences – well informed, satisfaction and motivation 2. Negative experiences – anxiety, guilt, feeding incongruence, family pressure and conflict 3. Challenges encountered – mixed feeding, misinformation, resuming work
A6	Mukerji et al. (2023), India, multi-centre (≥ 2 clinics and communities)	To explore mental health of Indian WLHIV experiencing intersectional stigma	Indian ($n = 31$); median 35 years; not reported	Semi-structured, IDI; interpretive phenomenology, thematic network analysis	1. Intersectional stigma results in poor mental health – 'I am just not able to take this', 'I feel very, very sad', 'If only God took me away right now', 'The fear stays with me' 2. Stress of intersectional stigma leads to poor physical health – 'I won't take my medicines anymore', 'From worrying the CD4 falls', 'If I worry my body feels very weak'
A7	Nguyen et al. (2024), Vietnam, single-centre (1 clinic)	To explore reproductive and maternal health challenges of WLHIV	Vietnamese ($n = 30$); aged 36–45 years; 4 single 13, married/cohabiting, 8 widowed, 5 divorced/separated	Semi-structured, IDI; thematic analysis	1. Family planning 2. Pregnancy and perinatal care 3. Postpartum care and support 4. Child caring and parenting

Table 1 (continued)

No.	Author (year), country, setting	Aim	Participants (number, demographic characteristics)	Methods & Analysis	Findings (main theme)
A8	Ayuttacorn et al. (2019), Thailand, multi-centre (≥ 2 clinics)	To explore disclosure of HIV status among Shan female migrant workers in Chiang Mai	Shan (Myanmar migrants, *n* = 18) & healthcare providers (*n* = 29); aged 23–54 (mean 38.6) years; 13 married/cohabiting, 5 separated/divorced/widowed	Semi-structured, IDI; content analysis	1. Public health policy and HIV-positive status disclosure 2. Difficulty telling a new husband/regular partner their HIV-positive status 3. The need for financial and relational security 4. Non-disclosure, a barrier to condom use 5. Unsafe sex despite disclosure of positive HIV status 6. HIV stigma among family members and the community 7. ART adherence 8. Perceived risk of HIV transmission and risky sexual behaviour
A9	Bakare et al. (2020), Namibia, multi-centre (≥ 2 communities)	To explore psychological, socio-cultural effects of forced and coerced sterilisation	Namibian (*n* = 7); aged 38–44 years; 2 married, 2 in a relationship, others single/separated/divorced	Semi-structured, IDI; content analysis	1. Psychological symptoms 2. Physical effects or negative health effects 3. Sterilisation and culture 4. Negative social effects 5. Support and coping
A10	Bhadra et al. (2020), Vietnam, multi-centre (≥ 2 clinics)	To explore depression and coping strategies among WLHIV	Vietnamese (*n* = 20); aged 28–49 (mean 37) years; 8 married, 7 widowed, 5 divorced/separated	IDI; thematic analysis	1. Depression, HIV, and disruption of gender roles 2. Acute depression after diagnosis – initial reaction of diagnosis, sudden loss of social support 3. Chronic depression due to HIV/AIDS – internalised stigma, perceived stigma, experienced stigma 4. Preventing and coping with depression – preventive measures against depression, overcoming acute and chronic depression, overcoming suicidal ideation
A11	Cianelli et al. (2022), USA, single-centre (1 HIV clinic)	To explore psychosocial impact of living with older WLHIV	African American/Hispanic (*n* = 28); aged 50–77 (mean 57.4) years; 20 single/in relationship, 17 living alone	Semi-structured, IDI; content analysis	1. Social impact of HIV: isolation and non-disclosure 2. Threats to health and well-being: physical, psychological, and economic challenges living with HIV 3. HIV as a death sentence: sense of impending doom 4. Spirituality: belief in God 5. HIV treatment adherence: using antiretroviral treatment
A12	Etowa et al. (2021), Canada, Nigeria and USA, multi-centre (≥ 2 communities)	To understand experiences of WLHIV during their child's infancy	African/Caribbean/Black (*n* = 61: Canada 11, USA 20, Nigeria 30); all mothers, mixed marital status	Semi-structured, IDI; thematic analysis	1. Breastfeeding and bonding with baby 2. Fears for baby and fears of HIV disclosure 3. Maintaining physical and mental health and wellness 4. Sources of support

Table 1 (continued)

No.	Author (year), country, setting	Aim	Participants (number, demographic characteristics)	Methods & Analysis	Findings (main theme)
A13	Fauk et al. (2023), Indonesia, multi-centre (2 HIV clinics)	To explore suicidal ideation and attempts among WLHIV	Indonesian (Yogyakarta 26, Belu 26, *n* = 52); aged 18–60 (majority 20–39) years; 8 single, 23 married/remarried, 15 widowed, 6 divorced	Structured, IDI; Ritchie and Spencer's framework analysis	1. Psychological challenges and suicidal ideation and attempts among WLHIV 2. Lack of awareness of HIV management strategies and anticipated and experienced stigma 3. Lack of support during the early stages of HIV diagnosis and an overloaded burden 4. Broken families and relationships and suicidal ideation and attempts
A14	Fauk et al. (2022a), Indonesia, single-centre (1 HIV clinic)	To explore self-response to psychological challenges and HIV stigma	Indonesian (*n* = 26); aged 20–49 years; 5 single, 13 remarried, 8 divorced/widowed	Structured, IDI; Ritchie and Spencer's framework analysis	1. HIV-related challenges WLHIV faced following their HIV diagnosis 2. Women's self-response to HIV-related challenges facing them
A15	Fauk et al. (2022b), Indonesia, multi-centre (≥ 2 HIV clinics)	To explore mental health challenges and the associated factors among WLHIV who are mothers of CLHIV	Indonesian (*n* = 23); aged 24–43 years; 3 single, 15 married, 5 widowed	Structured, IDI; Ritchie and Spencer's framework analysis	1. The experience of mental health challenges 2. Daily life challenges associated with their children's condition of living with HIV 3. Social factors: unsympathetic expressions and comments from others 4. Religious advice from family members
A16	Hampton et al. (2020), USA, single-centre (1 HIV treatment centre)	To explore the ways in which HIV-related stigma impacts intrapersonal experiences	African American (*n* = 16); aged 28–63 years; 7 single, 4 married, 3 divorced, 1 separated, 1 widowed	Semi-structured, IDI; interpretive phenomenological analysis	1. Increased vulnerability 2. Processing the diagnosis of HIV/AIDS 3. Surviving HIV/AIDS 4. Quality of life
A17	Herron et al. (2022), Australia, single-centre (1 community organisation)	To explore the experiences of long-term and ageing with HIV	Australian-born and migrant (*n* = 11); aged 35–64 years; 7 single, 4 partnered (7 mothers)	Semi-structured, IDI; grounded theory	Women negotiated gendered roles and identities as they grappled with ongoing and intertwined health and psychosocial challenges over their life course. Development of co-morbidities, experiences of stigma, gendered social roles, financial precarity and limited social support amplified the challenges of living with HIV and cumulatively impacted women's health and well-being as they aged with HIV.
A18	Mackworth-Young et al. (2020), Zambia, single-centre (1 community)	To explore strategies to avoid unintentional disclosure of HIV status	Zambian (*n* = 7); aged 17–19 years; none currently married (some in relationships); all perinatally infected	Observation during 1-year; ethnography	1. Maintaining silence – 'I won't tell them about my status' 2. Secrecy around ART 3. Veiled language 4. Secrecy through stories – 'I tell lies every single day' 5. Fear and anxiety around secrecy 6. Secrecy and silence beyond HIV

Table 1 (continued)

No.	Author (year), country, setting	Aim	Participants (number, demographic characteristics)	Methods & Analysis	Findings (main theme)
A19	Marg et al. (2020), USA, single-centre (1 community)	To understand health issues, strengths and ageing related priorities of older WLHIV	American (Black, non-Hispanic White, Hispanic White, Asian, multiracial, *n* = 9); aged 50–68 (mean 57) years; none currently married (single, widowed, or divorced)	Semi-structured, FGI; the Rigorous and Accelerated Data Reduction technique	1. Mental health 2. HIV co-morbidities 3. Resiliencies 4. Social determinants of health
A20	Marks et al. (2023), USA, single-centre (1 community organisation in urban setting)	To explore WLHIV experience stigma and discrimination	American (Black, White, multiracial, *n* = 14); aged 27–65 (mean 47.9) years; 6 single, 4 in relationship, 2 married, 1 separated, 1 widowed (all mothers)	Semi-structured, FGI; consensual data analysis	1. Stigma and discrimination 2. Source of stigma and discrimination 3. Response to stigma and discrimination 4. Coping with stigma and discrimination 5. Support
A21	McMillian-Bohler et al. (2023), USA, multi-centre (≥ two clinics)	To explore stigma and disclosure among WLHIV	American (mostly African American/Black, *n* = 22); aged 38–62 (mean 52.2) years; none currently married (single/divorced/widowed)	IDI; adaptive leadership framework for Chronic Illness	1. Technical challenges: (a) identifying misconceptions about HIV, (b) recognising the need for support 2. Technical works: (a) providing encouragement and affirmation, (b) making referrals for support, (c) assisting with plans for disclosure 3. Adaptive challenges: (a) fear of rejection related to disclosure, (b) lack of trust 4. Adaptive work: establishing a trusted network to open up 5. Achievement of adaptive leadership: integrating HIV into one's life
A22	Yang et al. (2021), Botswana, multi-centre (≥ two clinics and communities)	To explore stigma, structural vulnerability and 'what matters most' among WLHIV	Batswana (*n* = 84, IDI 46/FGI 38); mean 41.9 years; mostly married/partnered (majority mothers)	Semi-structured, IDI and FGI; deductive, content analysis	1. Cultural capabilities that 'matter most' to womanhood 2. How 'what matters most' shapes HIV stigma 3. How achieving 'what matters most' protects against HIV stigma 4. Structural vulnerability – healthcare policies reinforcing vulnerabilities

A = Study number listed in Additional file 1, *ART* Antiretroviral Therapy, *CLHIV* Children Living with HIV, *FGI* Focus Group Interview, *IDI* In-depth Interview, *PLHIV* People Living with HIV, *WLHIV* Women Living with HIV

deeply internalised even before disclosure, reinforcing stigma and guilt (A2, A4, A13, A14, A15, A19 and A21).

This initial emotional shock did not subside quickly but often marked the beginning of a prolonged period of psychological turmoil. The diagnosis elicited a sustained loss of self-worth and emotional paralysis, perceived as insurmountable. These feelings persisted over time, accompanied by chronic stress, grief and social isolation (A2, A4, A6, A11, A13, A14, A15, A19, A20 and A21). In some studies (A2, A4 and A11), the psychological burden also manifested in physical symptoms, such as reduced motivation, social withdrawal, appetite loss and weight decline. Denial often delayed or disrupted treatment engagement (A2, A4, A10, A11, A13, A19 and A21), and in severe cases, distress progressed to suicidal ideation or behaviour (A4, A10, A11, A13 and A21).

Internalised stigma rooted in fear and loneliness

Fear and emotional distress following an HIV diagnosis were not always the result of direct experiences of stigma or discrimination. Several studies have indicated that such responses are often influenced by internalised social attitudes, including pre-existing stereotypes, moral judgements and misconceptions about HIV, even before any interpersonal interaction (A1, A2, A6, A9, A10, A11, A12, A13, A18, A20 and A21). Anticipated social rejection and fear of moral condemnation contributed to increased anxiety and self-stigmatisation. Limited knowledge about HIV transmission further intensified this internalised fear, leading patients to become overly cautious and exhibit avoidant behaviours in social contexts (A14 and A16). In particular, internalised stigma considerably disrupted social connectedness. Social withdrawal,

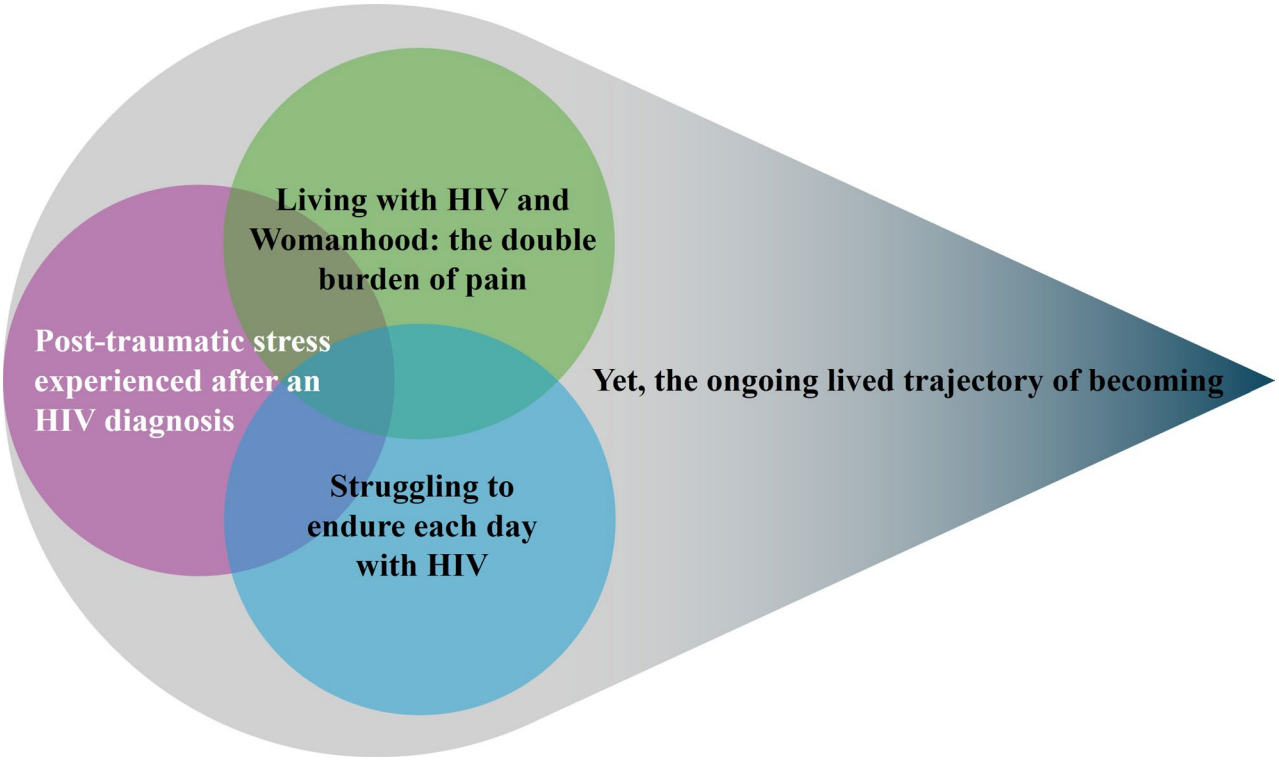

Fig. 2 Mental health experience of women with HIV

relational severance and a profound sense of isolation were frequently reported across studies (A1, A2, A6, A9, A10, A11, A12, A13, A14, A16, A17, A18, A20 and A21). Women who experienced continuous social disconnectedness perceived themselves as entirely alone and unworthy of love or support (A6, A9, A10, A11, A12, A13, A16, A18, A20 and A21). Their emotional challenges included deep sadness, hopelessness and a sense of moral culpability or perceived sinfulness (A1, A6, A10, A11 and A13). These internal struggles were often accompanied by self-imposed restrictions on daily life, including the avoidance of social interaction and external engagement (A2, A6, A9, A10, A11, A12, A13 and A21).

Burden of keeping HIV status secret

Across studies, disclosure of HIV status emerged as a persistent psychological and emotional burden. Participants described disclosure as an intensely distressing and shame-laden act, often associated with fear, sadness and emotional breakdown (A8, A11, A15, A17, A18 and A21). Non-disclosure continued for extended periods after diagnosis, indicating the enduring nature of disclosure-related anxieties (A2, A4, A6, A8, A11, A18 and A21). Furthermore, secrecy carried substantial emotional and relational costs. Recurrent themes included anxiety surrounding potential unintentional transmission, worries about bringing shame to loved ones and fear regarding long-term familial implications (A2, A4, A6, A8, A17 and A18). Participants commonly reported feelings of guilt and moral discomfort, particularly related to concealing the truth or managing daily interactions through omission or deception.

Living with HIV and womanhood: the double burden of pain

For women living with HIV, stigma and discrimination are often intensified by gendered social norms and their status as a marginalised group. Beyond the general stigma associated with HIV, women are judged and excluded because of prevailing assumptions about female sexuality, reproductive roles and caregiving responsibilities. These intersecting forms of stigma imposed a compounded burden unique to women, shaping their experiences across social and institutional contexts.

Social stigma and discrimination against women living with HIV

Stigma against women living with HIV was not limited to the infection itself but was amplified by gendered cultural assumptions. Women stated that they were often perceived as sexually immoral or labelled as sex workers solely based on their HIV status, regardless of the actual mode of transmission (A3, A4, A14, A15, A17, A20, A21 and A22). In some cases, women felt that they were unfairly blamed for infecting others, which reinforced the association of HIV with female sexual deviance and

Table 2 Themes emerged from qualitative meta-synthesis

Themes	Sub-themes	Illustrative Quotes	Studies
Post-traumatic stress experienced after an HIV diagnosis	Emotional shock and confusion after an HIV-positive diagnosis	*"I die of fear when I hear the name of the disease." (A4)* *"We don't want to face it. That's a big barrier. Denial." (A19)*	A2, A4, A6, A10, A11, A13, A14, A15 A19, A20, A21, A22
	Internalised stigma rooted in fear and loneliness	*"I was afraid of people's eyes… people would know that I was infected." (A9)* *"I was so scared that I would die soon… they could get the virus from me. I felt pressured." (A14)*	A1, A2, A6, A9, A10, A11, A12, A13, A14, A16, A17, A18, A20, A21
	Burden of keeping HIV status secret	*"I was very careful not to let others know because I did not want to be rejected." (A2)* *"If the others knew about this, they would look down on me and be disgusted with me… I'm afraid to be treated like this." (A8)*	A2, A4, A6, A8, A11, A15, A17, A18, A21
Living with HIV and womanhood: the double burden of pain	Social stigma and discrimination against women living with HIV	*"In their (healthcare professionals) mind, people who contracted HIV must be 'naughty' (a female sex worker)." (A14)* *"Even if I stay at home and he is around with many women, his family will say that I'm the one who gave him HIV." (A22)*	A1, A3, A4, A7, A8, A9, A13, A14, A15, A17, A18, A19, A20, A21, A22
	Concerns about motherhood and caregiving responsibilities	*"I feel so limited… if I get pregnant, then the baby will come out positive." (A1)* *"As Africans, e-v-e-r-y-o-n-e expects me to breastfeed… It gives a lot of stress. You are always scared to bottle feed the baby when there are people. You want to hide, you want to be in isolation." (A12)*	A1, A5, A7, A8, A12, A13
Struggling to endure each day with HIV	Intensified crisis from despair and disrupted family relationships	*"My husband went to Bali, slept with prostitutes, and contracted HIV. He passed it on to me. I am furious… I prepared poison at night to put in his drink and mine in the morning so that we would die." (A13)* *"She (her mother) took out all my clothes. I was asked to use my own plate and glass… I was put in a separate room. My food was given to me through the bottom of the door, just like you would do for a dog." (A14)*	A2, A4, A7, A13, A14, A15, A20, A21
	Social isolation due to misconceptions and prejudice	*"Neighbors told people not to play with my children because their mother is HIV positive… I was very angry. I felt very sad… I brought a paper with negative test results, but the teacher wouldn't listen." (A7)* *"If I have touched any foods, then people would not eat those foods… Some avoided me, did not even want to shake hands with me." (A14)* *"A lot of employment places if you document it, you don't get hired." (A20)*	A1, A2, A4, A7, A9, A13, A14, A16, A17, A18, A19, A20, A21
Yet, the ongoing lived trajectory of becoming	Support and peace from significant others	*"The support groups have helped me so much… I began to see how many people had HIV." (A2)* *"The counsellor gave me lots of advice, and the main points were that I have to accept myself and my condition, think positively, not get stressed, start the treatment… my husband supported and helped me." (A14)*	A1, A2, A7, A9, A10, A13, A14, A18, A20, A21
	A sense of resilience and willingness to overcome HIV	*"It is just a part of me… you have to internally be ok with it living with HIV with not being ashamed and just let everybody know I am still me." (A21)* *"If the children weren't here making me get out of bed and get up and make them breakfast, if I didn't have that motivation then I probably wouldn't." (A17)*	A1, A2, A8, A11, A12, A14, A17, A18, A19, A20, A21, A22

A = Study number listed in Additional file 1

moral failure. This discrimination extended into healthcare institutions, where some women were coerced into sterilisation, denied appropriate care or treated dismissively by healthcare providers (A1, A4, A9, A15, A17, A21 and A22). This institutional mistreatment revealed structural inequalities at the intersection of gender and HIV status. Negative responses were also commonly encountered in familial, community and social spaces, where women experienced judgement, exclusion and verbal abuse (A1, A3, A4, A7, A9, A14, A15, A17, A19, A20, A21 and A22). Repeated exposure to such environments often re-activated emotional trauma, mirroring the psychological distress experienced upon diagnosis. Many women described a recurrent pattern, with external stigma triggering renewed internalised stigma, prompting social withdrawal and isolation (A3, A7, A8, A9, A15, A17, A21 and A22).

Concerns about motherhood and caregiving responsibilities

Women of reproductive age expressed profound fear and guilt related to pregnancy, childbirth and breastfeeding—experiences that are culturally and biologically associated with womanhood (A1, A5, A7, A12 and A13). Many feared transmitting the virus to their children, which often led to hesitation or avoidance in future pregnancy planning (A1, A12 and A13). These anxieties were amplified by stigmatising cultural narratives that question the legitimacy or morality of mothers with HIV. The conflict between reproductive desires and perceived social disapproval contributed to psychological distress, including

heightened anxiety, insomnia and feelings of inadequacy as a mother (A5, A12). In some cases, the emotional burden mirrored the trauma experienced upon diagnosis (A5, A12 and A13).

Struggling to endure each day with HIV

Women living with HIV described the post-diagnosis period as marked by deep emotional and relational struggles. They not only faced exclusion or mistreatment from family members, but their families also grappled with social stigma and discrimination. These combined pressures led to family relationship crises, further isolating the women and intensifying distress within the household.

Intensified crisis from despair and disrupted family relationships

The subtheme involved a crisis arising from deteriorated family relationships. Efforts to return to life before diagnosis proved unfeasible and often heightened emotional strain at home (A2, A4, A7, A13, A14, A15, A20 and A21). Family members, also influenced by HIV-related misinformation, responded with fear, denial or confusion—contributing to conflict and disrupting care efforts (A2, A4, A13, A14, A20 and A21). Some women learned of their diagnosis after being infected by a partner, leading to feelings of betrayal and loss of trust. Others who had transmitted HIV to family members expressed profound guilt and faced blame from those around them. This often escalated family tensions and, in some cases, led to emotional distancing. Moreover, it resulted in physical separation or loss of contact with family members (A13 and A15). Women living with HIV were deprived of basic needs, such as food, clothing and safe shelter, as well as their dignity, which intensified feelings of shame and worthlessness (A4, A13, A14, A20 and A21). Even close relationships became strained or severed, leaving women without support (A2, A4, A13, A14, A20 and A21). At the peak of relational crisis, some participants reported having suicidal thoughts, such as considering ending their lives along with those they held responsible. A few had partially acted on these thoughts (A13 and A14).

Social isolation due to misconceptions and prejudice

Beyond the family, women faced exclusion and prejudice in daily life. Participants described avoidance, verbal discrimination and social rejection from the general public regardless of the transmission risk (A4, A7, A9, A13, A14, A16, A17, A19, A20 and A21). Even brief contact, such as handshakes, led to rejection, underscoring persistent public fear and misinformation (A4, A7, A9, A14, A16, A17, A20 and A21). Stigma also extended to uninfected family members, particularly children, who were excluded from schools or community life (A7 and A14). These ripple effects fractured broader social networks, increasing household-level isolation. Despite recovery efforts, many had difficulty facing stigma alone (A7, A14, A17, A18, A19, A20 and A21). The effect of stigma and prejudice extended beyond emotional well-being to disrupt functional recovery (A7, A14, A17, A18, A19, A20 and A21), notably through employment discrimination that led to economic insecurity and heightened fears about ageing without support (A17, A19 and A20). Some participants faced extreme poverty, even nearing homelessness (A19). Their distressing experiences highlight how misinformation and systemic stigma act as chronic stressors, underscoring the need for sustained social and structural support across family, community and institutional levels (A1, A2, A18, A19 and A20).

Yet, the ongoing lived trajectory of becoming

Women living with HIV experience profound psychosocial transformation as they regain psychological stability and start to envision new life trajectories, supported by significant others. Through resilience and a newfound willingness to engage with life, they begin to overcome internalised stigma, share their HIV status and reclaim social roles—gradually learning how to live meaningfully with HIV.

Support and peace from significant others

Despite early emotional distress, many women experienced relief and empowerment through relationships with supportive individuals (A1, A2, A7, A9, A10, A13, A14, A18, A20 and A21). Disclosure experiences varied—some initiated it themselves, whereas others were encouraged by trusted people; however, in both cases, affirming responses helped foster emotional adjustment and adaptive coping (A1, A2, A14, A18 and A21). Support from healthcare providers, counsellors, family, friends, peer groups and religious communities highlights the importance of multilevel support. Realising that they were not alone, some women reaffirmed their agency and strengthened their resilience.

In particular, peer interactions were crucial in helping women reimagine their future, pursue new goals and rediscover meaning and joy (A1, A14, A18, A20 and A21). This change was accompanied by a strengthened commitment to actively engage in life and confront social stigma. It also fostered re-engagement with care, improved medication adherence and a more proactive approach to self-care (A1, A2, A9, A13, A14 and A21).

A sense of resilience and willingness to overcome HIV

Drawing on their growing inner strength and a renewed willingness to live with HIV, many women gradually developed a sense of resilience and a strengthened desire to reclaim their lives (A2, A8, A11, A12, A14, A17, A20,

A21 and A22). This transformation did not happen overnight but developed through emotional processing, reflection and sustained support. Resilience was fostered through religious faith, strong family and peer relationships and a sense of responsibility for their children. These supports laid the groundwork for emotional adaptation and facilitated the journey of living with HIV. Participants described a gradual process of confronting shame and internalised stigma, supported by reflection and encouragement from others. Through this progression, many women cultivated a greater sense of self-acceptance over time. With increased access to reliable HIV-related information and ongoing emotional support, they began to develop a deeper understanding of their condition and increased confidence in their ability to manage it—eventually gaining the courage to disclose their HIV status. This transformative leap enabled them to re-engage in previously avoided conversations and take on meaningful social roles, reflecting a growing sense of agency and a stronger stance against social stigma (A1, A2, A8, A11, A12, A14, A17, A18, A19, A20, A21 and A22).

Discussion

The World Health Organization (WHO) recommended immediate treatment regardless of laboratory indices and promoted preventive strategies, such as daily oral pre-exposure prophylaxis for at-risk populations [32]. The importance of mental health management has expanded the global HIV response beyond clinical indicators to encompass lived experiences. This meta-synthesis analysed qualitative studies published from 2019 to 2024 and revealed that, despite advancements, women living with HIV continue to face a dual burden shaped by gendered norms, stigma and social disconnection. Nevertheless, their resilience—often grounded in support from significant others and personal resolve—was consistently observed.

This meta-synthesis included studies conducted across diverse regions, including Asia, Africa, North America, Latin America, Europe and Oceania. Across these contexts, the mental health experiences of women living with HIV were consistently associated with fear of disclosure, experiences of stigma and identity disruption. However, the specific manifestations of these experiences varied according to regional and national contexts, health systems, gender norms, cultural values and socioeconomic conditions. For instance, in many Asian and African countries, structural stigma and family-centred cultural norms often intensified internalised stigma and suicidal ideation, and were reflected in tangible challenges such as forced sterilisation and conflicts surrounding breastfeeding. In contrast, studies from North America and Europe more frequently emphasised life-course approaches to coping, including the development of disclosure strategies, identity reconstruction and the use of resilience resources alongside healthcare access. These findings suggest that the mental health of WLHIV is not merely an individual psychological response but a socially and culturally constructed experience. While the findings of this meta-synthesis may not be statistically generalisable to all WLHIV globally, they offer contextually rich and transferable insights that support analytical generalisation. This underscores the need for tailored intervention strategies that are sensitive to regional, socio-cultural and systemic contexts rather than relying on one-size-fits-all approaches.

An HIV diagnosis often precipitated an existential shock, threatening identity and disrupting meaning beyond the biomedical frame. The early post-diagnosis period was shaped by a complex interplay of emotional trauma and socio-cultural expectations. For women, this was deeply entangled with caregiving roles, family breakdown and isolation—issues that could not be addressed by medical intervention alone. Societal expectations surrounding motherhood and caregiving responsibilities further compounded this burden, intertwining with HIV-related stigma to impose a uniquely gendered emotional toll. Internalised stigma and social discrimination remain pervasive [20, 28], with some women reporting that even their children faced blame or mistreatment [33]. Such experiences not only limit access to support systems [34] but also erode women's self-worth and damage essential social relationships. As social ties weakened, emotional burdens intensified, with loneliness, anxiety, depression, guilt and lethargy emerging as persistent barriers to recovery. Compared with men, women expressed heightened fears of relational loss, concealed their status [35] and reacted with distress even at the mention of the word 'AIDS', underscoring the depth of internalised fear. Navigating secrecy and disclosure across personal, familial and socio-cultural domains imposed an additional psychological burden—complex, enduring and difficult to resolve. Moreover, a lack of HIV-related knowledge—particularly regarding transmission and prognosis—combined with internalised stigma, often prevented women from seeking support. This compounded sense of isolation hindered both access to care and autonomy in motherhood-related decision-making [36]. Persistent stigma in the workplace and community further affected not only individual well-being but also family functioning [21]. Importantly, gendered and structural stigma did not occur as a singular event but as a cumulative, recurring force that disrupted the trajectory of emotional recovery and reinforced women's marginalisation over time. These overlapping challenges—stemming from both HIV-related stigma and gendered expectations—generated a dual burden that left many women feeling trapped. This

finding highlights the need for mental health support to rebuild social connection and self-identity.

These complex and overlapping challenges highlight the need for recovery that extends beyond symptom relief to encompass psychological and social dimensions, such as rebuilding relationships and restoring self-identity. This perspective aligns with the integrated recovery-oriented model [37], which views recovery as a multidimensional and individualised process. The existential shock, dual burden and intensely distressing period following an HIV-positive diagnosis were not experienced as a linear or uniform process. Rather, women described a non-linear, unstable recovery process, marked by recurrent progress and setbacks. In this context, recovery was understood not only as the alleviation of symptoms such as anxiety and depression but also as a deeper, ongoing process. This process involved restoring life's meaning, rebuilding relationships and reclaiming self-determination. Recovery was supported by access to accurate information, reduction of stigma and active participation in social life, including informed decisions related to motherhood. Ultimately, recovery also meant breaking out of isolation and regaining a sense of belonging within society.

When significant others—such as healthcare providers, family, peers and community organisations—offered early emotional reassurance and fostered trust, they provided a stable emotional foundation for care engagement, improving the effectiveness of medical and social interventions, reducing psychological distress and supporting recovery. Recovery also encompassed practical aspects, such as resuming caregiving roles and regaining routine control. Moreover, non-judgemental structural support from community organisations was essential for sustainable recovery. These findings emphasise that relational support networks are key motivators for women's healthcare engagement and treatment adherence [38, 39] by helping rebuild social connections and identity and enhancing emotional resilience and self-esteem.

National systems also contribute structurally. The Centers for Disease Control and Prevention (CDC) in the United States offers guidance on HIV testing, prevention and treatment while coordinating HIV cluster detection and response to optimise care delivery [40]. Similarly, the Korea Disease Control and Prevention Agency (KDCA) employs an integrated national HIV management system that facilitates personalised tracking and recommends timely screening—typically within four weeks post-exposure—to help prevent further transmission [41].

Globally, the Global Partnership for Action to Eliminate HIV-Related Stigma and Discrimination spearheads initiatives in research, legal reform, education and fair media representation [42]. Since the Coronavirus Disease 2019 (COVID-19) pandemic, the demand for remote, customisable digital interventions has increased—such as private counselling, online support groups and smartphone-accessible services [43]. Among these, HIV-focused chatbots that provide information and emotional support have demonstrated promising outcomes [44].

Taken together, counselling, treatment, education and supportive systems are crucial immediately after an HIV diagnosis, ensuring comprehensive management of both mental and physical health during the early stages. Counselling should be personalised, reflecting each patient's context, and ideally involve family or other significant individuals. Social isolation, workplace discrimination and community exclusion must be prevented. Rather than relying on one-time interventions, sustained, long-term support systems are needed, tailored to the social and healthcare context of each country. Among these, digital strategies are increasingly relevant. For example, chatbots offer anonymity, non-judgemental interaction and 24/7 accessibility [44]. Their adaptability to the emotional states of the users—and customisation of gender or age characteristics—can ease face-to-face communication pressures and improve user satisfaction. Such digital tools may serve as effective alternatives to traditional, relationship-based support for women experiencing stigma and isolation.

This study has limitations. Social disconnectedness was exacerbated by the COVID-19 pandemic [45]; however, this meta-synthesis did not include pandemic-related experiences of women living with HIV due to the absence of eligible qualitative studies. Moreover, only English-language qualitative studies were considered, which may introduce selection bias, and efforts to include unpublished data were limited. Nonetheless, the review included research from varied cultural and socioeconomic contexts. Thus, future studies should adopt ethnographic approaches to gain a better understanding of mental health issues influenced by social, cultural and religious factors, including those arising during pandemic periods. Additionally, life-course perspectives are essential to explore sustained mental health support strategies.

Conclusions

By integrating findings from existing qualitative studies, this qualitative meta-synthesis comprehensively examined the evolving mental health experiences and resilience of women living with HIV, spanning from the point of diagnosis throughout the course of a chronic illness. Despite significant advances in ART, women living with HIV continue to endure persistent psychological distress from the moment of diagnosis onwards. Despite these challenges, many demonstrated a strong determination to reclaim their sense of agency and dignity. Given the pivotal role of relational connections in recovery, interventions that support the reconstruction of social

relationships and self-identity are essential. Utilising community resources alongside the development of digital support systems—such as online counselling and peer support platforms—can provide effective avenues for such support. Given that pregnancy, childbirth and parenting are major developmental milestones for women living with HIV, healthcare providers should act as companions who help break down stigma and promote a positive self-identity, thereby facilitating the restoration of social connectedness.

Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
CASP	Critical Appraisal Skills Programme
CDC	Centers for Disease Control and Prevention
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CLHIV	Children Living with Human Immunodeficiency Virus
COVID-19	Coronavirus Disease 2019
FGI	Focus Group Interview
GBD	Global Burden of Disease
HIV	Human Immunodeficiency Virus
IDI	In-depth Interview
KDCA	Korea Disease Control and Prevention Agency
PCC	Population, Concept, Context
PLHIV	People Living with Human Immunodeficiency Virus
PsycINFO	Psychological Information Database
WHO	World Health Organization
WLHIV	Women Living with Human Immunodeficiency Virus

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

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Authors' contributions
Conception and design of the work (JL, SL, SC, SK, YK); acquisition of data (JL, SL, SC, YK); analysis (JL, SL, SC, YK); interpretation of data (JL, SL, SC, YK); drafting of the paper work and subsequent revisions (JL, SK, YK); All authors read and approved the final manuscript version.

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Data availability
The datasets analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
This study used only previously published literature, did not involve any personal or human-derived data, and was therefore exempt from the Ethics Committee of the Institutional Review Board of Yonsei University Health System. No new participants were recruited, and informed consent and consent to publish were not applicable.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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