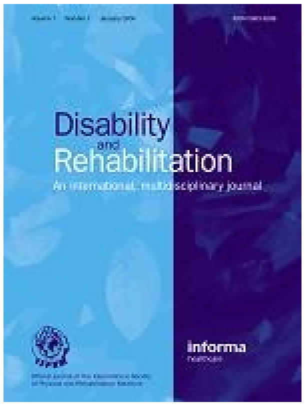

Lived experiences of persons with disabilities living with HIV in accessing HIV services in Africa: A Qualitative Systematic Review

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IMPLICATIONS FOR REHABILITATION

- Governments within Africa should commit to including PWDs living with HIV in National Strategic Plans (NSPs), which will support disability-inclusive HIV programming. The Development process of NSPs should also include PWD living with HIV.
- The inaccessibility of HIV services for PWDs living with HIV is multifaceted and intersectional. Interventions that consider the different social identities such as Gender and Socioeconomic Status of PWDs living with HIV may be more impactful.
- Understanding the specific dimensions of access impacted both the demand and supply side will facilitate efficient HIV programming for PWDs living with HIV.

Lived experiences of persons with disabilities living with HIV in accessing HIV services in Africa: A Qualitative Systematic Review

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ABSTRACT

Purpose: This qualitative review applies an intersectional lens to explore the lived experiences of PWDs living with HIV in accessing HIV services.

Methods: Using thematic analysis, the intersections relating to HIV, disability, gender, stigma and poverty were explored.

Results: Three themes were identified from the analysis (1) Intersection of Gender, HIV and Disability – *"For a man, it is easier because we women have a lot to take care of at the home and would not have enough time to go get services"* (2) Intersection of Stigma, HIV and Disability – *"…Look at that one. He's disabled, at the same time HIV-positive. He doesn't even feel sorry for himself … to die quietly at home"* (3) Intersection of poverty, HIV and Disability – *"…maybe you don't even have money to buy food and if you're on medication you need to eat frequently"*. The findings highlighted how stigma, poverty and gender collide in a hierarchy of identities to impede accessibility to HIV services.

Conclusion: Researchers and programme implementers should note the intersecting issues of marginalisation that influence inequities in access to HIV services for PWDs living with HIV. National Strategic Plans should address these specific barriers to ensure accessibility for this marginalised population.

Keywords: *HIV, Disability, Intersectionality, Access, HIV services, Persons with Disabilities living with HIV.*

Introduction

Persons with disabilities (PWDs) experience multiple forms of discrimination, marginalisation, and oppression [1-3]. These can be intensified when PWDs also live with Human Immunodeficiency Virus (HIV) as they can simultaneously experience the forms of oppression associated with having both a disability and HIV, creating barriers in accessing healthcare services [4]. These two conditions, often explained through negative sociocultural norms, can intersect with other social identities, influenced by socioeconomic status (SES), age, geographic setting, gender, education, sexuality, and religion. The intersection of different identities can create barriers to accessing resources that can impact health outcomes [5]. Social identities also exist in a social hierarchy, specific to situational and cultural contexts and stereotyping of different population groups [6] and maintained by prevailing social norms. When low-status identities, for example, being a woman, overlap with other low-status identities such as disability status, it can create further disadvantages and oppression; for example, women with disabilities living with HIV (WWD living with HIV) may experience more discrimination than their male counterparts [6,7]. While different theories (for example, double disadvantage) explain the various forms of marginalisation experienced by PWDs living with HIV [3,8-10], intersectionality provides a compelling framework for understanding the nexus of intersectional identities that exclude PWDs living with HIV from accessing HIV services [5].

Rooted in Black feminism and critical race theory, intersectionality captures the experiences of people who suffer multiple forms of oppression [11-13]. While initially focussed on gender and race [11], intersectionality has evolved to incorporate other dimensions such as culture, sexuality and dis (ability) [14]. Intersectionality highlights how social identities based on culture, sexuality, disability, gender, and race are fluid, evolving and fluctuating at different times and often overlapping, creating social inequalities [15-19]. These social identities can positively or negatively influence access to HIV services for PWD living with HIV. The ability of intersectionality to incorporate multiple social identities (dimensions) make it relevant to understanding the lived experiences of PWDs living with HIV [13].

Sociocultural constructions of persons with physical and sensory disabilities are often framed within an asexuality narrative [3], assuming a lack of sexual desire and sexual relationships [4,20]. Conversely, persons with intellectual or psychosocial disabilities are often infantilised and assumed hypersexual with limited social judgement, incapable of maintaining sexual relationships [21,22]. These sociocultural constructs of sexuality can create misconceptions about the sexual lives of PWDs and limit their access to sex education and sexual health services, potentially increasing their risk of exposure to HIV [23]. The risk of HIV infection for PWDs also relates to factors such as stigma, poverty, vulnerability to sexual violence/rape, substance abuse and lack of HIV information and services [24,25].

Other issues arising from attitudinal and structural barriers for PWDs living with HIV in accessing sexual health education and services are lack of disability-inclusive access to health facilities, for example, unavailability of sign language interpreters or information in braille or large font in health facilities and HIV outreach services and ramps [26]. Termed a “design apartheid”, lack of disability-inclusive health services design can deprive PWDs of the services they need when they need them [27]. The everyday experiences of stigma and discrimination can lead PWDs living with HIV to internalise discrimination and develop self-stigma, further discouraging them from accessing HIV services or advocating for their rights [21,28].

Globally, over 1 billion people (15% of the world population) are living with some form(s) of disability, with about 60-80 million of Africa's population living with disabilities [29], including physical, sensory, psychosocial and intellectual/developmental [30]. While the global survey on HIV and disability advocated for more epidemiological data of PWDs living with HIV [24], data around the burden of HIV among PWDs remain scarce, with few studies reporting the prevalence of HIV among PWDs [1,31]. Available studies focused on PWDs living with HIV in Africa [3,4,32-35] have been mostly quantitative or have included participants other than PWDs living with HIV. In contrast, this qualitative review focuses on the lived experiences of PWDs living with HIV and access to HIV services, drawing on intersectionality and the Levesque et al. [36] framework of healthcare access within the African context.

The Levesque et al. [36] framework presents five supply-side interreacting dimensions of accessibility: 1) Approachability; 2) Acceptability; 3) Availability and accommodation; 4) Affordability; 5) Appropriateness with complementing dimensions of the demand side: 1) Ability to perceive for one's need for healthcare; 2) Ability to seek; 3) Ability to reach; 4) Ability to pay; and 5) Ability to engage. This paper defines HIV services as all medical services available for persons living with HIV (PLHIV) in the continuum of care, transcending diagnosis, treatment, adherence, and retention in care [37]. The review is timely given the global efforts to end oppression for PWDs and end HIV as a public health threat by 2030.

Methodology

The research question "What are the lived experiences of PWDs living with HIV in accessing HIV services in Africa?" was guided by the PICo mnemonic of the Joanna Briggs Institute (JBI) approach to qualitative systematic review:

Population: Persons with disabilities living with HIV greater than or equal to 15 years of age. Although the age of menarche among boys and girls has declined, our choice of 15 years corresponds with international policy and research in sexual and reproductive health, capturing 15 years and above as the starting age for sexual activity and reproduction [38].

Phenomena of Interest: Lived experiences of PWDs living with HIV in accessing HIV services.

The inclusion criteria and exclusion criteria adopted the JBI approach to a qualitative systematic review (meta-aggregation) [39]. The approach is underpinned by Husserlian Phenomenology, which focuses on people's experiences and aligns with the focus and research question for this review. This reinforced the significance of a qualitative systematic review guided by the JBI approach to answering the research question. Additionally, it was used for its strength of exploring barriers or facilitators in accessing services and informing healthcare delivery [39].

Types of studies: This review included qualitative research. Quantitative and mixed-method studies were excluded. Empirical research was included, while editorials, commentaries, expert opinions, book reviews, policy documents or literature/systematic reviews were excluded.

Types of participants: Studies reporting experiences of PWDs living with HIV were included. The focus of disability was physical, sensory, psychosocial, and intellectual disabilities. Studies that involved PWDs who are not HIV positive were excluded. The focus was on men and women with permanent disabilities living with HIV. Studies focussing solely on other populations such as family members, community development workers, healthcare providers and social workers were excluded. Studies that included PWDs living with HIV and other types of participants were included.

Context of studies: Studies included were those conducted in Africa between 2004 and 2021. The year 2004 was selected because it was the landmark year when the global HIV/AIDS and disability survey was published [24]. Africa was chosen because of the diversity of sociocultural beliefs that exacerbates the prevalence of HIV and disability. Studies conducted in non-African countries were not included. Studies published in other languages were excluded. While HIV is sometimes considered as episodic disability [40], this review recognises HIV as a condition, so articles that refer to HIV as episodic disability were excluded.

Search Strategy (Appendix 1)

A systematic peer-reviewed literature search was conducted between 20th August and 27th September 2020. An updated search was also conducted between 16th November and 16th December 2021. The search was conducted in six databases: PubMed, SCOPUS, Web of Science, CINAHL, Medline, Embase.

The literature search included only peer-reviewed articles published in English. Including only peer-review articles was done to increase the trustworthiness of the findings. Keywords were developed from the review topic. The keywords inclusive of the Boolean, truncation and limiters were combined on all six databases: A search syntax from the CINAHL database is provided in Appendix 1. The search syntax was developed in consultation with the School of Public Health and Social Work librarian.

Study Selection

The systematic literature search resulted in 5,838 studies which were exported to Endnote for data management. The following results were identified from the databases: Medline (1139), CINAHL (403), Embase (1891), PubMed (1488), Web of Science (914), Scopus (3). Endnote identified 2,642 duplicates. An updated search was conducted between 16th November and 16th December 2021 with the following results: Medline (1241), CINAHL (436), Embase (304), PubMed (1595), Web of Science (156), Scopus (756). The abstract and title screening resulted in the selection of 49 papers for full-text reading. At the end of this process, eight studies were finally selected and 41 excluded because:

- They were literature or systematic reviews.
- Included PLHIV who did not have a disability or whose disability was not explicitly stated.
- Papers that captured HIV as an episodic disability.
- Included PWDs who were not HIV positive.

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) template flow diagram presents the study selection process (figure 1).

Data Extraction and Synthesis

All critical data from the included studies were extracted using an evidence table (table 3). Although this review followed the steps outlined in the JBI approach, synthesis was done through thematic analysis with some leanings towards thematic synthesis because of its flexibility with theoretical frameworks such as intersectionality [41,42]. The six phases of Reflexive Thematic Analysis (RTA) were employed for analysis [43]. The analysis included:

(1) Familiarisation: This process occurred by reading and re-reading all included articles by AAP, JK and JD. This process was to understand the findings and major arguments in the papers while also being conscious of the overall purpose of this review. The authors also met to discuss their thoughts about the articles. Insights at this stage facilitated coding.

(2) Generating Codes: Coding was initially done inductively, relying on the patterns identified from the papers. Examples of codes here were “staying at home”, “dying at home”. Deductive coding followed, underpinned by intersectionality as the theoretical framework. AAP and JK used an intersectional lens to code while JD coded, noting the dimensions of access to healthcare [36]. AAP, JK and JD held meetings to discuss the codes in relation to the frameworks used (Intersectionality and Levesque access to healthcare framework).

(3) Constructing themes: The construction of themes was done by AAP, JK and JD, focusing on the purpose of the paper and the frameworks employed. Themes were constructed by linking similar codes together. The dimensions of access related to the themes were also linked to the themes at this stage.

(4 & 5) Revising and defining themes: The themes were revised and defined intersectionally by ensuring that all arguments under each aligned with the paper's purpose. The authors developed figure 2 for a clearer picture of the findings at this stage.

(6) Producing the report: This involved writing up the findings following steps 1-5. AAP was responsible for this while JK and JD reviewed the report and provided feedback in ordering the themes to ensure a coherent story was reported.

Quality Appraisal

The included studies' quality appraisal followed Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI). In their comparison of three quality appraisal instruments, Hannes et al. [44] found the JBI-QARI the most coherent compared to the Evaluation Tool for Qualitative Studies (ETQS) and Critical Appraisal Skills Program (CASP) Checklist. A quality appraisal was conducted because of its value to the trustworthiness of the results and recommendations [45].

The JBI-QARI checklist facilitates quality appraisal by allowing the researcher to check the congruity of the philosophical objective, research methodology, research aims, research methods, data analysis, interpretation of results, researcher’s positioning and influence, representation of participants voice and ethical consideration. Two reviewers identified and discussed the questions arising from the checklist (table 1).

[Insert table 1 here]

Results

The eight included studies were published between 2013 and 2020. The countries in the review are Ghana, Zambia, Uganda, and South Africa. Out of the eight studies, five were from Zambia [5,23,46-48]. Two were conducted in three countries of Ghana, Uganda, and Zambia [49,50], with one study conducted in South Africa [51]. Six of the studies employed interviews as data collection methods [5,23,46-48,51], while two studies used Focus Group Discussions (FGDs) [49,50]. The total number of study participants was 509, with seven studies including men and women [5,23,47-51]. One study included only women [46]. Despite these disparities, the quality of all studies was assessed to be high, with none being below 70% (table 1). The summation of the themes is presented in table 2.

[Insert table 2 here]

1st theme: Intersection of Gender, HIV and Disability – *"For a man it is easier because we women have a lot to take care of at the home and would not have enough time to go get services".*

The review showed men and women living with a disability and HIV experienced processes of marginalisation and access barriers to HIV services. The research also indicated that women are likely to experience more access barriers, such as family responsibilities than men due to sociocultural norms.

This additional disadvantage is related to the sociocultural construction of gender in Africa and patriarchal norms characterised by social stratification based on sex, with men having more power than women [52]. These gendered sociocultural norms limited women's capacity to make health-related decisions and access care. As a result, their "ability to seek" HIV services was negatively impacted [36]. Conversely, men experienced fewer barriers in seeking care.

The Female Burden

Women with disabilities living with HIV experienced oppression in their homes and relationships because of their identities as women and living with both a disability and HIV. These identities converged to create multiple disadvantages, including abandonment by partners and sole parenting [5]. Importantly, the gender identity of women overshadowed the disability identity and HIV positive status identity due to powerful cultural beliefs surrounding gender in Africa [5]. For example, A 25-year-old woman in Zambia spoke about how difficult it was for women to access HIV services because of their gender roles:

> For a man it is easier because we women have a lot to take care of at the home and would not have enough time to go get services [50].

This quote indicates how her culturally defined gender role collided with HIV to prevent access to care. Based on this quote, gender roles that portray women as carers of the home [53] took a central role in limiting women's ability to seek HIV services [36].

An implication of gender identity for women was the priority given to men during hospital visits. A 54-year-old woman with a hearing impairment in Zambia explained the disparity in wait times between men and women.

> Men are treated first. Women wait in a queue until they are done with them [men], then they start calling names of women [50].

Sociocultural norms related to gender resurfaced at the intersection of disability and HIV and negatively influenced women's access to HIV services. The already busy lives of women may limit the ability of women to seek HIV services, leaving them more disadvantaged than men and consequently leading to more negative health outcomes [36]. While the woman was not explicitly clear on whether the men she spoke of had HIV and disability, the scenario still communicated the disadvantage women experienced. Men seemed to be prioritised over women, highlighting a gender hierarchy [6].

Women with disabilities living with HIV within some African settings often suffer abandonment by their husbands due to their HIV status or disability identity, leaving them with additional family responsibilities, including being a sole parent [5,46,49-51]. Since marriages in some African settings are largely informal [54], it may be difficult for abandoned mothers to claim damages and receive benefits from the man, a practice which is applicable in some African countries [55]. This issue leaves the children and mothers at a significant disadvantage [56].

The evidence suggested that some women lived with a disability before marriage, with HIV diagnosed later. In explaining her ordeal of abandonment, a 36-year-old Zambian woman with visual impairment noted:

> In terms of the family, I had a husband. So my husband, he saw that I was sickly, so he left me and went to his parents… He said, 'I can't manage to live with a wife who is sickly. So it's better I go and look for others who are not sickly… [5]

This quote illustrated abandonment due to her HIV diagnosis and not her visual impairment, suggesting a hierarchy of identities where an HIV positive status identity overshadowed disability identity. Analysis of this scenario indicated that the husband left not because of the inability of the woman to undertake a female role but because of her HIV diagnosis. Regarding access, Levesque et al. [36] describe "ability to seek" as the dimension where minority groups are discouraged from seeking care due to abuse or neglect. In this example, a WWD living with HIV abandoned by her husband now has little or no treatment support. This may lead to low self-esteem and confidence and a lack of access to HIV services.

A woman from Zambia interviewed in the Wickenden et al. [46] study presented a different narrative. While still married, she had little to no, support from her husband. She reported that his support diminished once she was diagnosed with HIV. In her case, the husband abandoned his responsibility of looking after the family.

> …meanwhile, you've got somebody you are calling a husband in the house, and him, he has refused. How can you feel even if it were you, how can you feel? [46].

The quote highlighted how living with HIV can negatively affect some women with disabilities' relationships with their husbands. It demonstrated how a diagnosis of HIV can contribute to further disadvantage and have more negative impact than disability. The WWD living with HIV was forced to assume the role of the family provider and take care of her health and well-being. In the two scenarios above, HIV dominated the women's social identities. While both lived with disabilities, the stigma around HIV positive status exacerbated their disadvantage [5,46], supporting the argument that women may experience more HIV related stigma than men in some African settings, at least partly likely to be because women who are HIV positive are often assumed to be promiscuous [57]. The dimension of access implicated in the instances above may also relate to the "ability to seek" care [36] due to her changing role as the family provider. In this new role, HIV positive status identity intersects with gender, culture and disability and may accord the woman little time to access HIV services. A collision that reveals the various identities at play.

The Male Advantage

Contrary to women's negative experiences, men with disabilities living with HIV (MWD living with HIV) had different experiences in relation to accessing HIV services. Despite living with disability and HIV, men were not abandoned by their spouses but instead supported by their partners to access Antiretroviral Therapy (ART). This could suggest that women conformed to the sociocultural norms that assigned them as carers of their husbands and home [53].

Yoshida et al. [5] reported in their intersectional case study of John, whose wife supported him in attending hospital appointments and fetching his medications because of his visual impairment. While John's loss of his ability to work affected his pride as an African man, the support of his wife was still available to him [5]. Although John's HIV diagnosis was before his loss of sight, his "Ability to seek" HIV services [36] was not limited due to the support he enjoyed. While his wife's disability or HIV status was not stated, remaining with the husband may be because of the gender roles within some African settings where women are expected to care for their home and families [53]. Additionally, remaining with their partners may be a way to evade the "sociocultural penalties of divorce" [58], such as the stigma and humiliation often directed at divorced women in some African settings [59].

Within many African patriarchal systems, men are regarded as breadwinners and heads of the house responsible for the provision, creating higher respect for men than women [60]. This patriarchal system may also explain why MWD living with HIV still enjoyed the support of their families. While John suffered stigma from some family members due to his inability to provide for the family, his wife, who became the breadwinner, remained and supported him. This suggested that men may still benefit from patriarchal privileges even when they are not breadwinners.

While the intersection of disability, HIV, and gender presented disadvantages for women, men enjoyed some level of support and privilege than women, giving them more access to HIV services and may result in better health outcomes for the men.

Although disability, HIV, and their negative impact may affect all genders [61], the patriarchal African setting and prescribed gender roles may compound women's oppression. These patriarchal disadvantages limited the ability of women to seek care and HIV services, an essential dimension in the framework of access to healthcare [36]. The collision of three social identities of HIV positive status, disability and gender of women collided to limit their access to HIV services.

2nd theme: Intersection of Stigma, HIV and Disability – *"…Look at that one. He's disabled, at the same time HIV-positive. He doesn't even feel sorry for himself … to die quietly at home".*

Stigma within PWDs living with HIV themselves, communities, households, and health facilities was an important factor in PWDs living with HIV accessing HIV services. All eight studies in this review reported that stigma and discrimination were experienced by PWDs living with HIV [5,23,46-51]. The dimensions of access implicated are from the supply (appropriateness) and demand (ability to reach) sides [36].

Stigma within Communities

The multi-site study conducted in Ghana, Uganda and Zambia reported the difficulty for PWDs living with HIV (men and women) to access public transport and the stigma experienced by other transport users and drivers [50]. Across all three sites, double payment was requested from PWDs living with HIV because of their crutch or wheelchair or refusal to transport them to the hospital. In other cases, it was a struggle to find someone to escort them to the hospital in addition to the extra transport cost they had to bear. A 58-year-old visually impaired man in Zambia noted:

> We, the blind, we have challenge – most of our guides do not want to guide us to the areas where the services are offered simply because they fear the community associating them with the HIV/AIDS [50].

This quote suggests that the stigma associated with the HIV positive status identity had a more significant impact than disability. Stigma in this example may limit the "ability to reach" dimension of access relating to mobility and availability of transport for PWDs living with HIV to reach HIV services physically [36].

Considering PWDs living with HIV required assistance to reach health facilities, they risked a breach of their HIV seropositive status confidentiality. Confidentiality has been breached at different service points in health care facilities in African settings [62]. This was the concern of a 40-year-old physically impaired man in Zambia.

> Sometimes we get to be escorted by family members or friends due to the fact that we can't manage moving alone. So you'll find that the one who escorted you gets to know all your HIV status details and yet information is supposed to be confidential [50].

While HIV status disclosure is voluntary for PLHIV, PWDs living with HIV may not seem to enjoy this privilege because of the impact on the "ability to reach" dimension of healthcare that compelled them to have their HIV status involuntarily disclosed to people who support them to hospitals. HIV services are usually offered confidentially to avoid the accompanying stigma [63]. While HIV status disclosure is encouraged because it promotes HIV treatment [64], PLHIV still reserve the decision to disclose to other people or not. This raises concerns for PWD living with HIV, who may opt for non-disclosure of their HIV status but still need support attending the hospital. They face the contention of unwillingly disclosing their HIV status or not accessing HIV services. The dimension of access implicated here is the factors of “availability and accommodation” [36], which relate to how services are organised and the extent to which they meet the needs of the PWD living with HIV, whose confidentiality may be breached if they require a support person to accompany them to medical consults.

Stigma from PLHIV and health practitioners

Attitudinal stigma was also reported among PLHIV and health practitioners. A PWDs living with HIV recounted their experience of stigma from other PLHIV.

> when one goes at the health center to collect those medicines, the people there. . .the so- called able-bodied, they pass comments, Look at that one. He’s disabled, at the same time HIV-positive. He doesn’t even feel sorry for himself. If it was me. . .I wish maybe I die [47].

This quote highlighted how PLHIV assumed a less disadvantaged position than PWD living with HIV. It communicated the realities of discrimination faced by PWDs living with HIV among people with whom they share an identity of being HIV positive. This othering by PLHIV may be premised on their need to gain power, making them feel more valued and empowered than PWDs living with HIV [65]. In the hierarchy of identities, PLHIV not experiencing disability assumed a more privileged role than PWDs living with HIV. This highlights how disability negatively overshadows the HIV positive status identity within the healthcare system. Within this context, PLHIV assumed more power than PWDs living with HIV [13]. The Parsons et al. [47] study does not describe the disability types of its participants, thereby preventing a critical analysis of the diversity in experiences among the participants.

The reports of stigmatising attitudes among health practitioners also discouraged PWDs living with HIV from accessing HIV services. A Zambian participant recounted:

> ...the doctor was surprised at me. He had laughed at me saying, “Can you also have HIV?” I then answered him that, “Doctor, I’m human. I also have the same feelings that you have. It’s only that the legs are the ones that differentiate us. . .But I had told them that. . .a lot of disabled people come to the hospitals. You dis- courage us. . .that’s not how it’s supposed to be. A disease that an able-bodied person can have, even me I can have it [47].

This participant highlighted the pervasive negative stereotype and assumptions of asexuality demonstrated by doctors, which may discourage PWDs living with HIV from presenting at health facilities for ART. This relates to the “availability and accommodation” dimension of access based on health practitioners' stigmatising attitudes and beliefs [36] and may indicate a gap in their professional capacity to provide responsive and respectful care to PWDs living with HIV. One consequence of this attitudinal stigma is health staff prioritised persons without disabilities leading to long wait times in hospitals for PWDs living with HIV. A WWD living with HIV noted:

> ... I’d take maybe five hours just standing in the queue. They can’t even get a chair ... when our able-bodied friends reach there, they’re quickly given the file and sometimes even a place to sit [23].

Stigma from within (Self-stigma)

Another form of stigma reported in two studies was self-stigma, where a stigmatised group become aware of and believe the negative stereotype towards them [47,49]. The stigma experienced by PWDs living with HIV affected their self-esteem, causing withdrawal from treatment services. As a result, some preferred “to die quietly at home” [47].

A Zambian participant explained:

> ...If someone laughs at me, it didn't feel as if I was a person. I even came to the extent sometime to. . .feel that I should just get out of this world and maybe be a dead person, so that they don't intimidate me in this way [47].

The negative stereotypes associated with HIV positive status identity and disability identity can become internalised, causing a devalued feeling which may mitigate access to HIV services by affecting the "ability to seek" HIV services dimension of healthcare [36]. The disempowering impact of self-stigma can reduce PWDs living with HIV agency in making decisions that impact their health [66].

3rd theme: Intersection of poverty, HIV and Disability – *"…maybe you don't even have money to buy food . . . and if you're on medication you need to eat frequently."*

This review revealed participants' concerns about income insecurity, livelihood, and the negative impact on their HIV treatment [5,23,48,50]. The findings show the linkage between lack of jobs and the ability to afford food, a requirement for HIV services such as ART [67]. Drawing from the Levesque et al. [36] framework, affordability, the direct or indirect cost of a patient's healthcare, is applicable here.

In narrating her ordeal about lack of jobs, A 38-year-old Zambian woman with physical impairment narrated:

> We really suffer more because we are disabled. There are no jobs found. There are no business prospects and financial hardships [48].

In this quote, the lack of jobs suggests PWDs living with HIV are excluded from the labour market. In this example, the participant believed it was her disability rather than her HIV positive status that limited employment opportunities. However, in other instances, the most significant impact on income security was the HIV positive status identity. Some participants, for example, blamed their job loss on their HIV status, as recounted by a 52-year-old man with visual impairment.

> ... upon realising that we're positive, we were told 'We cannot employ you' [48].

These quotes presented how disability and HIV positive status were ranked differently in the hierarchy of identities [6] and used as oppressive tools to deprive PWDs living with HIV of jobs. Also highlighted is the fluidity of identities where PWD living with HIV, who had jobs, lost them due to their HIV positive status identity. An indication that social identities are subject to change [18]. The deprivation of these jobs may limit the "ability to pay" dimension for PWDs living with HIV, who desire to purchase food to facilitate their ART intake [36]. In patriarchal systems like Africa, men's masculinity and dominance over women is also linked to their earning rights and ability to provide for the family [60]. Therefore, the loss of jobs for an African man may affect his ability to pay for food for himself and transcends to his family.

Yoshida et al. [5] discussing Thandi, a woman with a physical disability living with HIV who had experienced difficulty securing a job and could not maintain a diet with the sufficient nutritional requirements of ART. As a result, she resorted to transactional sex and begging to afford food for herself and her children. Her failure to get enough food for her ART to increase its efficacy negatively impacted her health, with her being "weak and sleepy". Thandi was reported to slide into a "vicious cycle of poverty and disability" fuelled by the intersection of her disability, HIV positive status, gender and poverty [5].

Ultimately, income, food insecurity, disability, and HIV intersected in contributing to health inequities among participants. A woman with physical impairment living with HIV recounted:

> You came having eaten only in the morning. The whole day you are just there [in line], maybe you don't even have money to buy food . . . and if you're on medication you need to eat frequently [23].

A 38-year-old physically disabled man in Uganda reflected on his experience of being poor and not buying food, which negatively affected his regular ART intake.

> We have only one challenge of being poor. . . . the medicine requires us to eat something, so you see that many will become reluctant and not take the medicine simply because they do not have the money to buy the food to accompany the medicine…[50].

In these quotes, a demand-side dimension of access, the ability to pay, was strongly articulated. Recognising that a nutritious diet improves ART adherence and its efficacy [67], it may be difficult for PWDs living with HIV to adhere to HIV treatment in the absence of food that appears to be more prioritised.

This review reported that the government's top-down approach towards PWDs living with HIV impacted their health outcomes [68]. While begging was found to be a common coping strategy, it was legislated against making begging unlawful. However, while making begging a crime, no additional social support for PWDs living with HIV was provided to bridge the food security gap previously filled through begging. A 38-years-old woman with a physical disability explained her frustration:

> ... they've put in place the law that that is strong: "You must stop begging". Now you have children, what are they going to eat? They don't consider that we eat? We are also humans like them. "You must stop begging". Sometimes people in the roads, we just

> beg because of poverty and the mercy of God. Maybe he can just say that, "The government forbade [48].

Access to HIV services such as ART may become less prioritised in the hierarchy of needs for a person who is food insecure and unemployed [69].

Community-Based Organisations (CBOs) were noted to support PWDs living with HIV. Participants in Uganda spoke of the support from CBOs to improve their livelihoods and prevent them from begging. A 58-year-old man with a physical disability echoed this strongly:

> We as HIV positive and physically disabled people often get groups through which we can access services such as counselling, medicines, and knowledge. For example, here in Jinja, we have [CBO]; . . . we may engage in poultry farming starting from 2 chickens to find means of how to help ourselves. That is why we are thankful to [CBO], and other NGOs which have given us pigs, seedlings for agricultural farming which we rear and gain money and also get food for our personal nutrition in the long run… [50].

The support of CBOs, which provided access to income-generating activities, had a ripple effect of providing access to money and food. The likelihood of PWDs living with HIV who have jobs and food to prioritise HIV services such as ART may become high in the hierarchy of needs [69]. Additionally, it boosts their "ability to pay" for direct and indirect costs related to their treatment [36].

While PWDs living with HIV may have wanted to access ART, the lack of food fuelled by lack of jobs and government support exacerbated the inequities they experienced. The lack of uptake of ART by PWDs living with HIV is not their inability to take the medication but unemployment and food insecurity which limited their uptake of ART. This highlighted the significance of employment and food as determinants of health [69], without which the uptake of ART was hardly considered. Affordability and the ability to pay dimensions of access strengthened the findings from this theme.

[Insert figure 2 here]

[Insert figure 3 here]

[Insert table 3 here]

Discussion

This review adds to the body of knowledge about the ongoing debate regarding the discrimination experienced by PWDs living with HIV when attempting to access HIV services. We adopted an intersectional lens in communicating the negative experiences for PWDs living with HIV regarding HIV services. This review clearly showed that the inaccessibility of HIV services for PWDs living with HIV is negatively influenced by the interactions with other identities such as gender, poverty, stigma, and sociocultural beliefs.

This review highlighted that WWD living with HIV experienced more disadvantages in their relationships than their male counterparts, creating inequities in accessing HIV services [5,46,51]. These disadvantages included abandonment, neglect of caring and family responsibilities by husbands. Women with disabilities living with HIV were expected to take on extra responsibilities of looking after themselves and their children. In contrast, MWD living with HIV continued to reap the benefits of remaining married and being supported to access HIV services. This form of inequity for WWD living with HIV and privilege for MWD living with HIV echoes the patriarchal African setting, which subjugates women and privileges men [70]. The man is seen as the head of the family, while the woman is expected to care for and nurture the home [71]. Two studies, the Wickenden et al. [46] and Yoshida et al. [5], reported that HIV was contracted by WWD living with HIV post-marriage, which triggered their husbands to abandon them. However, the inclusion of only women in the Wickenden et al. [46] study may have introduced bias where men's voices were silent but nevertheless provided valuable insights into the sociocultural norms related to masculinity in African settings where men assumed a more powerful role than women [52].

Although some men from this review reported low self-esteem because of not meeting their masculine roles of providing for the family [5], they were still cared for by their families. The experiences of MWD living with HIV regarding their masculinity and how it impacts their access to HIV services may benefit from further exploration. Another scenario was the priority given to MWD living with HIV during hospital visits and ART uptake [50]. This suggests that patriarchy plays a role in causing disparity between MWD living with HIV and WWD living with HIV. There is consonance with a previous study that noted the disadvantages experienced by WWD in relationships [72].

Economic barriers and poverty were highlighted as factors that caused inequities in health and limited access to HIV services for PWDs living with HIV [5,23,48,50]. The unavailability of jobs and government support was a catalyst for the financial hardship experienced by PWDs living with HIV. This elicited a disadvantage for PWDs living with HIV regarding accessing HIV services because they lacked the money to purchase food which was a health requirement for their medication. Given that jobs and food are social determinants of health [69], accessing ART services becomes a less priority for PWDs living with HIV when these determinants are not satisfied. The review shows that both men and women had issues related to poverty, but it will be essential to further explore the different experiences among men and women. This finding is consistent with Rohleder et al. [35] who highlighted the negative impact of poverty in accessing HIV services among PWDs. This review found CBOs supported PWDs living with HIV to access HIV services [50] by using a bottom-up approach which potentially empowered PWDs living with HIV with skills to provide for themselves, thereby encouraging more ART uptake and access to HIV services for PWDs living with HIV. This is in contrast to the government's top-down approach, which only prevented PWDs living with HIV from begging on the street and could be disempowering.

The nexus between HIV, disability, poverty, and gender caused more disadvantages for some WWD living with HIV, who could not secure jobs to feed themselves and their children. Their inability to secure employment resulted in them engaging in transactional sex, a risk to themselves and others. A South African intersectional study corroborates our findings by communicating the disadvantages WWD experience regarding securing employment which leaves them economically disadvantaged than MWD [72]. Poverty presented the challenge for WWD living with HIV to access HIV services despite their caring responsibilities. A study in Kenya reported a similar outcome about WWD living in poverty who did not prioritise medical services due to their caring responsibilities [73].

Within this review, attitudinal and self-stigma prevented PWDs living with HIV from accessing HIV services. Attitudinal stigma from PLHIV, health practitioners and communities impeded PWDs living with HIV from accessing treatment [47,50]. Although PWDs living with HIV shared the identity of HIV seropositivity with PLHIV, they experienced attitudinal stigma from PLHIV, who assumed a more privileged role because they did not have a disability. This stigma discouraged PWDs living with HIV from accessing HIV services. While PWDs living with HIV desired HIV services, stigma was an impediment. Cultural beliefs were reported as underlying factors exacerbating the stigma experienced by PWD living with HIV. While some authors agree that cultural beliefs fuel stigma and discrimination in HIV and disability fields [74,75], other contrasting arguments support culture as a positive force in Africa [76]. The intersection of culture, HIV and disability and the effect on HIV services for PWDs living with HIV is highlighted.

Incorporating the Levesque et al. [36] access to healthcare framework in this review has allowed for an objective assessment of the access issues PWDs living with HIV face. As noted by Cu et al. [77], some challenges were experienced in delineating some dimensions of access.

We recognise that adopting an intersectional lens may have contributed to this difficulty where access was explored from different points. However, this also reveals the framework's flexibility in working with other frameworks like intersectionality.

The discrimination of PWDs living with HIV in HIV programming is reported in the Ward et al. [78] study. The study highlighted the exclusion of PWDs in National Strategic Plans (NSPs) of countries in Eastern and Southern Africa – NSPs provide direction in a country's response to the HIV epidemic, especially in deploying resources and funds. The exclusion of PWDS in NSPs communicates a deprioritisation in the HIV response. This exclusion is a factor that slows the Joint United Nations Programme on HIV/AIDS (UNAIDS) [79] 95-95-95 global goal of ending HIV as a public health threat by 2030 [80]. The UNAIDS 95-95-95 strategy aims that 95% of people living with HIV are diagnosed by 2030, 95% of diagnosed people enrol for antiretroviral treatment by 2030, 95% of people in treatment achieve an entirely suppressed viral load by 2030 [79]. Therefore, African states must commit to including PWDs living with HIV in NSPs.

Limitations and Implications for research

This review excluded editorials, commentaries, expert opinions, book reviews, policy documents or literature/systematic reviews. Although this exclusion could omit some other realities, including only peer-reviewed studies was to ensure the trustworthiness of the findings. Only eight studies met the inclusion criteria for this review. These may represent very few studies in a review within Africa. However, the eight studies explored the experiences and emic perspectives of PWDs living with HIV who suffer marginalisation in accessing HIV services. This review does not attempt to present Africa as homogenous and recognises that different settings will have different situations. The conceptualisation of access is complex, and the use of the Levesque et al. [36] access framework presents only one aspect of that narrative that negates power relations analysis. The use of other access frameworks might offer other interesting insights on this subject. However, adopting the Levesque et al. [36] framework provides an objective understanding of access from the supply and demand side. This review revealed the disadvantages experienced by WWD living with HIV, further research focusing on the experiences of MWD living with HIV will contribute to this discourse. While this paper recognised HIV as a condition, there is a growing body of evidence that reports on HIV as an episodic disability and its role in preventing access to HIV services. This may be a consideration for other reviews in this field.

Conclusion

This review has highlighted that PWDs living with HIV experience disadvantages that make accessing HIV services difficult. The disadvantages are further exacerbated by intersectional identities such as poverty, ethnicity, and gender. The patriarchal system in African settings suggests women experience more disadvantages than men in terms of HIV services. Attention in research and interventions should focus on the intersecting issues of marginalisation that influence their inequities in health. The peculiarities of MWD living with HIV will also benefit from more research.

The analysis of access in this paper may offer guidance on targeting interventions on both the demand and supply sides to facilitate access to HIV services for PWDs living with HIV (figure 2).

A call is made to governments within Africa to commit to including workable plans to address the needs of PWDs living with HIV in NSPs. The NSPs should guide how HIV services must be offered to PWDs living with HIV, considering the diversity of disability types. A one-size-fits-all is not sustainable concerning PWDs living with HIV. It will also be important to include PWDs during the development of NSPs. African states must be deliberate about ensuring disability-inclusive programming while also fast-tracking the achievement of the 95-95-95 UNAIDS goal of ending HIV as a global health threat by 2030.

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Declaration of Interest

The authors declare no conflict of interest.

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Table 1: Critical Appraisal of Included Studies

References	JBI Critical Appraisal Questions									% of criteria achieved
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	
[46]	Y	Y	Y	Y	Y	N	N	Y	Y	Y	80%
[43]	N	Y	Y	Y	Y	N	Y	Y	Y	Y	80%
[44]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
[45]	Y	Y	Y	Y	Y	N	N	Y	Y	Y	80%
[47]	N	Y	Y	Y	Y	N	N	Y	Y	Y	70%
[23]	Y	Y	Y	Y	Y	N	N	Y	Y	Y	80%
[5]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
[48]	Y	Y	Y	Y	Y	N	N	Y	Y	Y	80%

Table 2: Summarisation of Themes

S/No	Theme	Subthemes
1.	Intersection of Gender, HIV and Disability –*"For a man, it is easier because we women have a lot to take care of at the home and would not have enough time to go get services"*	A. The Female Burden B. The Male Advantage
2.	Intersection of Stigma, HIV and Disability – *"…Look at that one. He's disabled, at the same time HIV-positive. He doesn't even feel sorry for himself … to die quietly at home"*	A. Stigma within communities B. Stigma from PLHIV and health practitioners C. Stigma from within (Self Stigma)
3.	Intersection of poverty, HIV and Disability – *"…maybe you don't even have money to buy food . . . and if you're on medication you need to eat frequently."*	

Table 3: Empirical studies included in the review

No	Reference	Country	Study aim	Study design/Theoretical framework	Participants, sample size, Disability types.	Data collection strategies/ Sampling strategies	Key finding
1.	[49]	Ghana, Uganda, Zambia	“explores access to and use of HIV information and services among persons with disabilities.”	Qualitative Grounded theory approach/none	70 persons with a sensory or physical disability living with HIV 21 Government officials and Service providers/program managers of HIV services 56 Caregivers of people with intellectual disabilities 66 persons with hearing impairment 71 Persons with visual and	16 groups of Focus Group Discussions (FGDs) Key informant interviews 7 groups of FGDs 10 groups of FGDs 11 groups of FGDs	“The multiple overlapping vulnerabilities of disability and HIV are not coincidental. Some of the greatest obstacles faced by persons with disabilities include social inequalities, poverty, lack of access to education and health services, and human rights violation.”

					physical disabilities		
2.	[46]	Zambia	"To explore how HIV, disability and gender shape the perspectives of HIV-positive women with disabilities regarding intimacy and gender roles."	Qualitative/none	12 women with hearing, mobility, visual and intellectual impairment living with HIV	Semi-structured in-depth interviews. Snowballing	The double burden (HIV and Disability) impact on women demonstrates a loss of intimacy and changes in their gender roles.
3.	[47]	Zambia	To explore the stigmatising experiences towards PWDs living with HIV on the intersection of HIV and disability	Qualitative/Interpretive Framework and Narrative theory	21 PWD living with (Visual, mobility, hearing and intellectual impairment)	Interviews Purposive and snowballing sampling	Stigma impacts the willingness of PWDs living with HIV to continue HIV treatment (Antiretroviral Therapy), disclose their HIV seropositive status, and their social relations.
					11 Key informants (HIV community-based organisation , Disabled people's organisation, Health services, a Government department)	Interviews	

4.	[48]	Zambia	To explore the experiences of work among PWD living with HIV.	Qualitative	21 (12 women, 9 men) PWDs living with HIV (physical, hearing, visual and intellectual impairments)	Semi-structured in-depth interviews Maximum variation sampling strategy Snowballing	There are limited work options and opportunities for PWD living with HIV. The existing social stigma exacerbates this.
5.	[50]	Ghana, Uganda, Zambia	To explore the experiences in accessing HIV services among persons with disabilities who are living with HIV.	Qualitative	76 PWDs living with HIV (41 females; 35 males) (physical, visual and/or hearing impairments)	FGDs Convenience sampling	While some favourable disability tailored services to facilitate access in Uganda, there were similar challenges in accessing health services in all three research sites. Challenges reported were relating to HIV testing and counselling, stigmatising attitudes by health practitioners and other patients, inaccessible physical structures, lack of disability-inclusive educational services, lack of disability-inclusive skills for health providers, lack of interpreters. The

							study reported that women experienced more issues of access to health services because of gender-related roles.
6.	[23]	Zambia	To explore perceptions and experiences of HIV-related health services for PWDs who are also living with HIV.	Qualitative Interpretive study	21 PWDs living with HIV (physical, hearing, visual and/or intellectual impairments) 11 Key informant interviews (people working in the field of HIV and/or disability – HIV community organisation, Disabled people's organisation, Health service, a Government department)	Semi-structured in-depth interviews Semi-structured in-depth interviews	The findings of this study reported disability-related discrimination when accessing HIV services, communication challenges, especially regarding confidentiality and mobility challenges impacting antiretroviral therapy.
7.	[5]	Zambia	To explore experiences of	Qualitative/Intersectionality	21 PWDs living with HIV (9 men,	Semi-structured in-depth interviews	PWDs living with HIV experience

			disability and HIV among women and men in Zambia		12 women) (hearing, visual, mobility and intellectual impairment)	Purposive sampling Snowballing sampling	oppression about accessing health services. Living with HIV and disability had negative implications for their social roles and relationships.
8.	[51]	South Africa	To understand experiences of disability in patients living with HIV in South Africa.	Qualitative	19 PWDs living with HIV (Visual, mobility, cognitive impairment) 12 PWDS with other health conditions	In-depth interviews Purposive sampling Maximum variation sampling	The activity levels relating to mobility, domestic life, self-care, work, and livelihood was affected due to the impairments of PWD living with HIV.

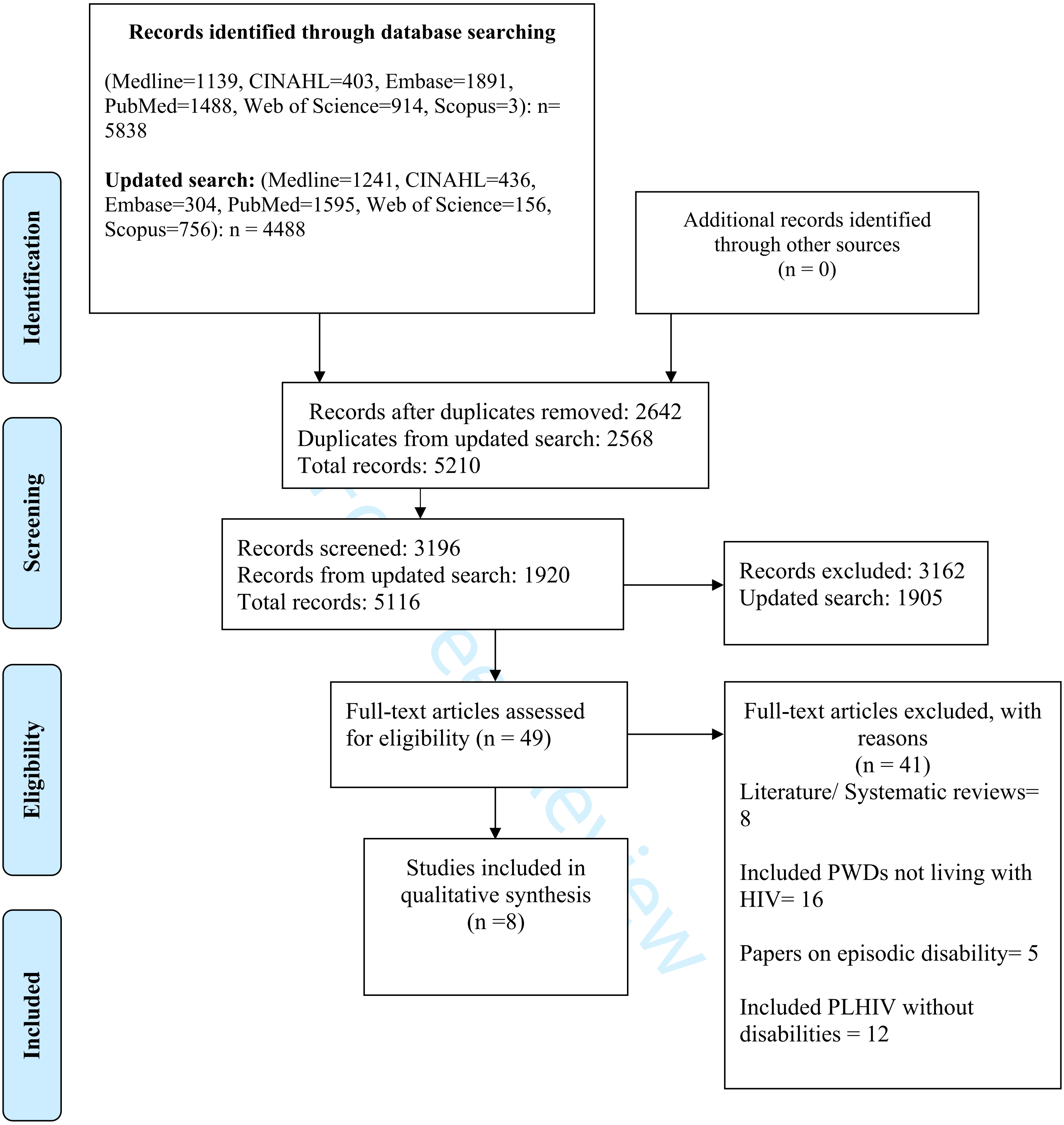

Fig 1: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) template

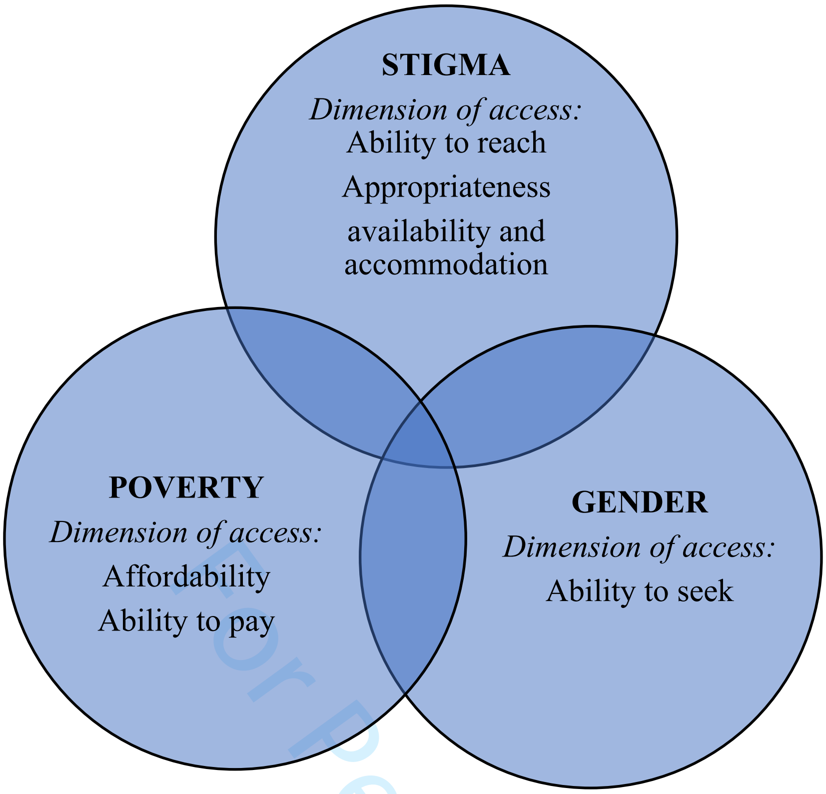

Fig 2: The intersection of gender, poverty, stigma and the dimensions of access impacted for PWDs living with HIV

Alt text for illustration [26 words]
A 3 circle Venn diagram with each of the circles having three major words of stigma, gender and poverty illustrating that they are all linked together.

Long description for illustration [81]
A 3 circle Venn diagram with each of the circles having three major words of stigma, gender and poverty illustrating that they are all linked together. Within each circle contains the dimensions of healthcare access that relate to each circle. Within the circle of stigma, the dimensions are Ability to reach, Appropriateness, Availability, and accommodation. Within the circle of gender, the dimension of access is Ability to seek. Within the circle containing poverty, the dimensions are Affordability and Ability to pay.

Appendix 1: A search strategy from the CINAHL database.

Syntax	Limiters/Truncation/Boolean	Results
S1 **“Lived Experience*”** OR Experience* OR stor* OR perception* OR Challenge* OR Issue* OR problem* OR attitude* OR access* OR barrier* OR facilitators OR enablers OR accessibility OR stigma	OR “” *	1,641,034
S2 HIV OR HIV/AIDS OR "HIV and AIDS" OR “Human Immunodeficiency Virus” OR AIDS OR “HIV treatment” OR PLHIV OR “Antiretroviral Therapy” OR ART OR “ART drug*” OR “HIV positive”	OR “” *	194,755
S3 "Health Service*" OR "Healthcare" OR Health OR hospital OR “health facilit*” OR clinic OR “HIV service*”	OR “” *	2,222,503

S4 "Persons with Disabilities" OR "Persons with Disabilit*" OR “people with Disabilit*” OR “Disabled persons” OR “Disabled people” OR Disabled OR disabilit* OR impaired OR impairment OR immobility OR handicap* OR wheelchair OR paralysed OR “physical disabilit*” OR “intellectual disabilit*" OR "learning disabilit*" OR "sensory disabilit*" OR cognitive OR "developmental disabilit*" OR Deaf OR Blind OR Immobilit* OR Immobile	OR “” *	504,647
S5 Africa OR Africa* OR Algeria OR Angola OR Benin OR Botswana OR “Burkina Faso” OR Burundi OR Cameroon OR “Cape Verde” OR “Central African Republic” OR Chad OR Comoros OR “Congo-Brazzaville” OR “Congo-Kinshasa” OR “Cote d'Ivoire” OR Djibouti OR Egypt	OR “” *	141,786

OR “Equatorial Guinea” OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR “Guinea Bissau” OR Kenya OR Lesotho OR Liberia OR Libya OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Morocco OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Senegal OR Seychelles OR “Sierra Leone” OR Somalia OR “South Africa” OR “South Sudan” OR Sudan OR Swaziland OR “São Tomé and Príncipe” OR Tanzania OR Togo OR Tunisia OR Uganda OR “Western Sahara” OR Zambia OR Zimbabwe		
S1 AND S2 AND S3 AND S4 AND S5	Date of publication: 2004-2020 OR “” *	403