


Please cite the Published Version

Nyashanu, Mathew, Mushonga, Florence Tafadzwa Ellah, Dada, Samuel Oluwasogo and Ekpenyong, Mandu Stephen  (2024) Examining the impact of HIV-related stigma in people living with HIV: a systematic literature review. *International Journal of Reproduction, Contraception, Obstetrics and Gynecology*, 13 (10). pp. 2875-2885. ISSN 2320-1770

DOI: <https://doi.org/10.18203/2320-1770.ijrcog20242826>

Publisher: Medip Academy

Version: Published Version

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DOI: <https://dx.doi.org/10.18203/2320-1770.ijrcog20242826>

Systematic Review

Examining the impact of HIV-related stigma in people living with HIV: a systematic literature review

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Received: 19 November 2023

Revised: 08 March 2024

Accepted: 11 March 2024

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ABSTRACT

The last 20 years have seen an improvement in access to anti-retroviral (ARVs) drugs for people living with HIV leading to improvement in health outcomes. However, despite achieving this milestone HIV stigma has continued to hamper the health outcomes of people living with HIV. This study aimed to undergo a systematic review exploring the impact of HIV stigma on people living with HIV. A systematic literature review of both quantitative and qualitative studies published between 2017 and 2021 was undertaken using the following databases: CINAHL Plus, Embase, Google Scholar, Medline, and Scopus. Reference lists from relevant studies and websites of relevant sexual health and HIV organisations were also searched. The primary search terms were “HIV and stigma” combined with “impact” or with “discrimination”, “internalised stigma” and “lack of esteem”, or “mental health” or “caused by HIV stigma” in communities, “HIV and discrimination”, “impact of HIV stigma”. Six articles were included for review and analysed using constant comparative analysis. The review identified six broad themes (lack of adherence, internalised HIV stigma, discrimination, lack of self-esteem, public stereotyping, and non-disclosure) factors having a significant influence on people living with HIV. Perceived stigma towards people living with HIV has a negative effect on health outcomes of people living with the condition. The findings of our study highlight that public stereotyping and perceived stigma in the community are the major factors impacting people living with HIV.

Keywords: HIV, Stigma, Anti-retroviral

INTRODUCTION

The introduction of Antiretroviral therapy (ART) has drastically changed the perception of acquired immunodeficiency syndrome (AIDS) and Human immunosuppressant virus (HIV) from an acute condition to a chronic condition.¹ The effectiveness of ART has allowed the management of HIV and reduction of transmission. The existence of ART has seen evidence-based prevention therapies such as pre-exposure prophylaxis (PrEP) and treatment as prevention reducing

the rate of HIV transmission.² The success of PrEP and treatment as prevention relies on individual testing, starting treatment early and adherence to ART. However, stigma acts as a barrier to testing and adherence to ART.³ In countries where ART is readily available, people are living with HIV/AIDS (PLWH) and experiencing a better quality of life and a longer life expectancy.⁴ Despite the afore mentioned, the Global HIV Prevention Coalition (GCP) 5 denoted that 1.5 million people were diagnosed with HIV in 2020. This led to the recommendation that communities should work hard to transform and end

eliminate racial and gender inequalities, discrimination, and stigma to meet the goal of ending HIV/ AIDS by 2030.⁵ According to 6 tackling stigma will lead to reduced transmission of HIV and improved quality of life experienced by (PLWH). Stigma has been identified as the major impediment in curbing the onward transmission of HIV(AIDS)as it has devastating effects on PLWH.⁷ It has a major effect on the long-term health of PLWH as it affects mental and physical health precipitating anxiety, depression, suicidal ideation and loss of self-esteem.^{8,9} Stigma is defined by Goffman as a 'discrediting mark or attribute which reduces the status of the person in the eyes of society'.¹⁰ Therefore, stigma is the portrayal of negative attitudes toward people living with PLWH. Similarly, mentions that stigma mechanisms describe the way PLWH respond to negative attitudes which exist in society and structures of power.¹¹ Stigma mechanisms encompass, enacted, experience or external stigma which is created by communities and families, this includes gossiping, prejudice, and marginalisation.¹² Enact stigma is associated with high levels of depression and anxiety, however, the level is lower in PLWH who have strong support and affection from families, partners, and communities.¹³ Symptoms of depression include low self-esteem, carelessness and forgetfulness resulting in a loss of hope in living a healthy life after HIV/AIDS diagnosis.¹⁴

The levels of anxiety are high on receiving a positive HIV diagnosis, resulting in shock, feelings of anger, self-blame, numbness, denial, and sadness.¹³ In 2011, highlighted that although emphasis is put on confirmatory HIV tests and follow-up reviews, it is paramount to refer a newly diagnosed individual to community workgroups.¹⁵ The role of community work groups is to help PLWH cope with a diagnosis of HIV, this will help reduce anxiety and depression.¹⁶ Depression and anxiety can lead to risky behaviour resulting in transmission of HIV and reduced adherence to ART.¹⁷ Establishing support networks for newly diagnosed PLWH is paramount as it will help them to understand the available services at their disposal and the diagnosis.

Internalised stigma (perceived or felt stigma, is described as real or anticipated fear of community attitudes and discrimination arising from an adverse attribute such as HIV.¹² Negative societal traits resulted in self-blame for acquiring HIV, rejection, discrimination and stereotyping 18. Internalised stigma is the acceptance of the negative community and societal negative traits by PLWH. Internalised stigma affects PLWH mentally and physically, resulting in poor ARV adherence and acts as a barrier to HIV disclosure.⁴ Disclosure allows the use of protection during sex to protect sexual partners and adherence to ARV thereby reducing HIV transmission.¹⁸ PLWH who experience better social support are more likely to disclose their status to family or partners.¹⁹ It is important to eradicate HIV stigma because disclosure of HIV status is influenced by perceived stigma from family and society.²⁰ Describes anticipated stigma as the awareness and expectation that PLWH will experience

negative attitudes from communities, families, friends, and healthcare workers. The expectations of the impact of an HIV-positive result are usually drawn from hearing and witnessing of unpleasant experiences by PLWH from families, society, and health workers.²¹ The negativity encompasses discrimination, rejection, isolation, shame, and fear of life after an HIV-positive result.²² Anticipation of the foregoing act as a barrier to regular HIV testing and convincing those at risk of HIV not to test due to fear of experiencing stigma.²⁰ Anticipated stigma also affects and delays testing among marginalised groups such as men who have sex with me (MSM) Transgenders and sex workers.

They fear social and health workers anticipated stigma such as racism, heterosexism, and transphobia.²³ Anticipated stigma from health care develops dissatisfaction in PLWH as they will withhold information about challenges in dealing with their diagnosis and taking ART, resulting in poor health outcomes. Health care-related stigma may be driven by a lack of knowledge with regards to HIV transmission and management of PLWH resulting in excessive use of precautions or nursing patients in isolation.²⁴ The main drives of stigma within health care services include institutional or organizational procedures, personal disapproval of certain behaviours or stigmatising of certain groups of patients.²¹ However, healthcare workers might not be aware of stigma and how it affects the patients.²⁵ The reduction of stigma in health care settings improves the relations between PLWH resulting in improving the quality of care delivered and the creation of a supportive environment.

Eradicating stigma and discrimination is paramount to the success of ART initiatives to reduce the transmission of HIV. PLWH have low ART adherence as they fear that family or friends see them taking medication, raising suspicion and resulting in inadvertent disclosure of their HIV status.⁸ Conversely, found that family support was essential in maintaining adherence as it gives PLWH a need to protect and reduce HIV transmission to partners.²⁰ Considering the above assertions this research study was set to explore the impact of HIV stigma on people living with HIV.

METHODS

A systematic literature review was undertaken using guidelines for identification of both qualitative and quantitative articles for utilisation in the study. Clear guidelines were set, objectives, were formulated selection criteria and defined a search strategy for identifying papers were produced. The selected articles were analysed and synthesised the results using published guides for assessing qualitative and quantitative studies.^{27,28}

Search methods

A systematic search was undertaken for qualitative and quantitative studies on the impact of HIV stigma on people

living with HIV. The following databases were utilised to search for the relevant articles CINAHL Plus, Embase, Google Scholar, Medline, and Scopus.

Reference lists from relevant studies and websites of relevant sexual health and HIV organisations were also searched. Subject limiters were then applied to remove any papers that were not directly relevant to the topic, and abstracts of these articles were then read and those not meeting the study inclusion criteria were eliminated from the review figure 1 shows the selection and elimination process of the articles. The primary search terms were “HIV and stigma” combined with “impact” or with “discrimination”, “internalised stigma” and “lack of esteem”, or “mental health” or “caused by HIV stigma” in communities, “HIV and discrimination”, “impact of HIV

stigma*”, using the Boolean search operators to define the relationship between the keywords.

Inclusion criteria and studies selection

Only studies which were peer-reviewed, written in the English language, and published between 2017 and 2021 that examined the impact of HIV stigma in America, Australia, Europe and in the UK were included in this review. All studies included were primary as they could offer insight into the phenomena under study. The included studies were selected based on the relevance of their titles, contents of the articles and abstracts as summarised in the flow diagram in Figure 1.

Table 1: Evaluating reviewed articles.

Authors	Findings	Strength	Weakness	Gap
Mo et al ³⁰	Interpersonal level feel responsible for the infection by expressing feelings of shame and guilt as they attribute it to their sexuality and sexual activities. Physical: side-effects of medication and severe symptoms, which became apparent to others, leave them feeling negative about themselves and isolated from others, as they feel frustrated and distressed. TV advert describing a fatal pyramid of AIDS. The major message was that HIV was equivalent to death. Portraying that drug users, gay men and promiscuity lead to HIV acquisition people in Hong Kong have poor knowledge about HIV. ² Social rejection by family and society and discrimination in health care settings.	This is the first study to explore the experiences and factors causing self-stigmatization of PLHIV in Hong Kong. The present study suggests that providing PLHIV knowledge of the disease is still the key and first step in stigma reduction.	Convenience sampling result cannot generalize PLHIV in Hong Kong PLHIV are protected therefore participants were for NGOs. They presented a diverse background. Participants self-select, they might have had positive attitudes to Living with HIV. Participants shared their experiences and gave of stigma examples. However, there was no comparison from their prior experiences to what they shared in the study to show the progression in coping with stigma.	The participants shared their experiences as PLWHIV; however, the study was not ongoing. Therefore, there was no way of assessing if they have improved coping and how they cope with stigma.
Hargreaves et al ³¹	Stigma affects ART adherence if mental health is affected. Viral suppression was low in people who did not disclose their diagnosis to the researcher and those who reported internalised stigma. also reported less adherence to ART and hiding them. Experienced and perceived stigma was not associated with Poor viral suppression.	The random sampling of 21 communities was representative of the population. The findings that internalized stigma can cause lower viral load suppression are consistent with our research studies.	The data of those who did not self-report their HIV status was missing in this study. Research and measurement of stigma are complex and subject to bias and is not possible to capture all aspects of Stigma.	Therefore, the items we included to assess stigma may not have captured all the subtle experiences of stigma of PLHIV in our study setting.

Continued.

Authors	Findings	Strength	Weakness	Gap
Kimera et al³²	<p>Youth felt devalued, isolated, fear, injustice and lack of prospects leading to internalized and anticipated stigma.</p> <p>Enact stigma was experienced in schools, homes and communities through discrimination verbal abuse, gossip and bullying.</p> <p>They also isolated themselves and they were unique in terms of daily medicating, illness, and weight loss.</p> <p>The vulnerability was felt by parents of those in positions of trust in orphanages as they lost the sense of trust and belonging.</p> <p>Due to power disparities, the youth lack the mental capacity to challenge their families or carers which adds to internal stigma.</p> <p>Live in constant fear of death from HIV.</p> <p>Non-disclosure and non-adherence to medication resulted from stigma.</p>	<p>The participants knew each other, interacted freely and supported each other.</p>	<p>The participants were in urban areas therefore their views might differ from those in rural areas.</p> <p>This was not a representation of other YLWHA who did not belong to the participants' group.</p>	<p>Need for further studies.</p> <p>To explore how to address stigma from PLHIV and those portraying the stigma's perspective.</p>
Turan et al³³	<p>Perceived community stigma was associated with mental, emotional, and cognitive these were caused by internalised stigma (reduced self-esteem depression, isolation, self-blaming).</p> <p>Perceived community stigma also led to poor medication adherence.</p> <p>Identifying the source of anticipated stigma is important to tackle stigma.</p>	<p>Exploring how specific stigma mechanisms affect other stigma mechanisms is a new approach to HIV research</p>	<p>The utilisation of self-reporting measuring analysis might have been biased.</p> <p>The study was a cross-section and longitudinal study could give a comparison of stigma over a period to assess changes.</p> <p>The study sample cannot be generalized as participants were recruited from a university that offered social and health care, Finally, in this exploratory study we tested multiple mediational models with a moderate sample size.</p>	<p>The need for studies with larger samples to explore the effects of perceived community stigma on PLWHIV health outcomes.</p> <p>There may be individual differences that moderate the association between perceived community stigma and internalized stigma and future research can also examine these individual differences.</p>
Adam et al³⁵	<p>HIV status disclosure was by direct communication to spouses, sexual partners, and children. This was influenced</p>	<p>Ethnicity and religious affiliations were some of the factors</p>	<p>Participants feared disclosure of their health status to the public.</p> <p>At times the interviews have to</p>	<p>The effect of region and ethnicity on HIV disclosure needs to be explored.</p> <p>The finding in this study is that</p>

Continued.

Authors	Findings	Strength	Weakness	Gap
	<p>by the intimacy, commitments and aspirations shared. However, health professionals disclosed some patients' HIV, and some disclosed it to several people. Non-disclosure was influenced by internalised stigma such as self-blame and shame. Community stigma (verbal and physical abuse) and family-related stigma (refusal to sleep or eat together) were experienced. Hospital and healthcare professionals' stigma against PLWH is minimal.</p>	<p>influencing disclosure. Although these findings seem inconsistent in the literature suggest that this is an area that warrants further research. They also recommend studies on the ethics of health professionals in disclosing patients' HIV status.</p>	<p>stop, and the questions evoke sad emotions.</p>	<p>healthcare professionals disclosed. the involvement of healthcare professionals in HIV status disclosure</p>
Moussa et al³⁴	<p>Internal stigma led to low self-esteem, suicidal tendencies isolation and missing hospital appointments. Those discriminated against by health institutes, by being declined treatment had high levels of internal stigma. Women reported more elements of internal stigma It also affected them socially and financially as some decided not to get married or have children. Others did not apply for jobs or go for promotions. Sociodemographic-people lower levels of education presented higher levels of internal stigma and those who worked full time experienced high internal stigma Family support was important as those who felt family members judged them upon disclosure experienced high levels of internal stigma.</p>	<p>The sample was considered a representative of PLHIV in the MENA region their valuable information on internal stigma was collected. The use of the Stigma Index to measure internal stigma is also a strength of this study as it is a validated instrument that has been used internationally. Interviewers were PLHIV allowing them to be an active part of the study and putting participants at ease during the completion of the questionnaire</p>	<p>The stigma Index tool was not specifically formulated for people in Mena therefore lacks relevant aspects specific to this region/study. It was not possible to evaluate stigma and discrimination over a period as this study was a cross-sectional study.</p>	<p>The study is not analysing the effect of internal stigma on trans-, and those discriminated due to gender identity and sexual orientation.</p>

Source (Nyashanu, Mushonga and Epenyong 2024)

Table 2: Themes addressed by each article.

Ref	Lack of adherence	Internalised HIV stigma	discrimination	Lack of self-esteem	Public-stereotyping	Non-disclosure
Ziersch et al¹²	X		X		X	X
Mo et al³⁰	X				X	X
Hargreaves et al³¹	X		X			X
Kimera et al³²	X	X			X	
Turan et al³³	X	X		X		
Adam et al³⁵		X		X		

Continued.

Ref	Lack of adherence	Internalised HIV stigma	discrimination	Lack of self-esteem	Public-stereotyping	Non-disclosure
Moussa et al ³⁴		X		X		

Source (Nyashanu, Mushonga and Epenyong 2024)

Quality assessment

The literature obtained was appraised using critical appraisal tools. The quality of the research/evidence was evaluated using a quality appraisal tool. The tool used for the qualitative studies was the critical appraisal skills programme 27 checklist (Table 1). The Critical Appraisal Skills Programme checklist was used to reveal the validity by removing bias and evaluating the quality of the studies to ensure reliability.

A critical appraisal skill program provides a background within which to consider issues in a clear way.²⁹ For the

quantitative literature, a critical tool developed by 28 was used (Table 2 for The Coughlan, Cronin and Ryan appraisal tool). The tool is specific to quantitative research and divides the critique into two sections for clarity.²⁸

In the first section of the appraisal, it incorporates elements prompting the credibility of the research concentrating on the information of the authors and the purpose of the study. While the second section mixes the elements prompting the robustness of the research, this tool was chosen for the clear, thorough, and comprehensive steps presented by.²⁸

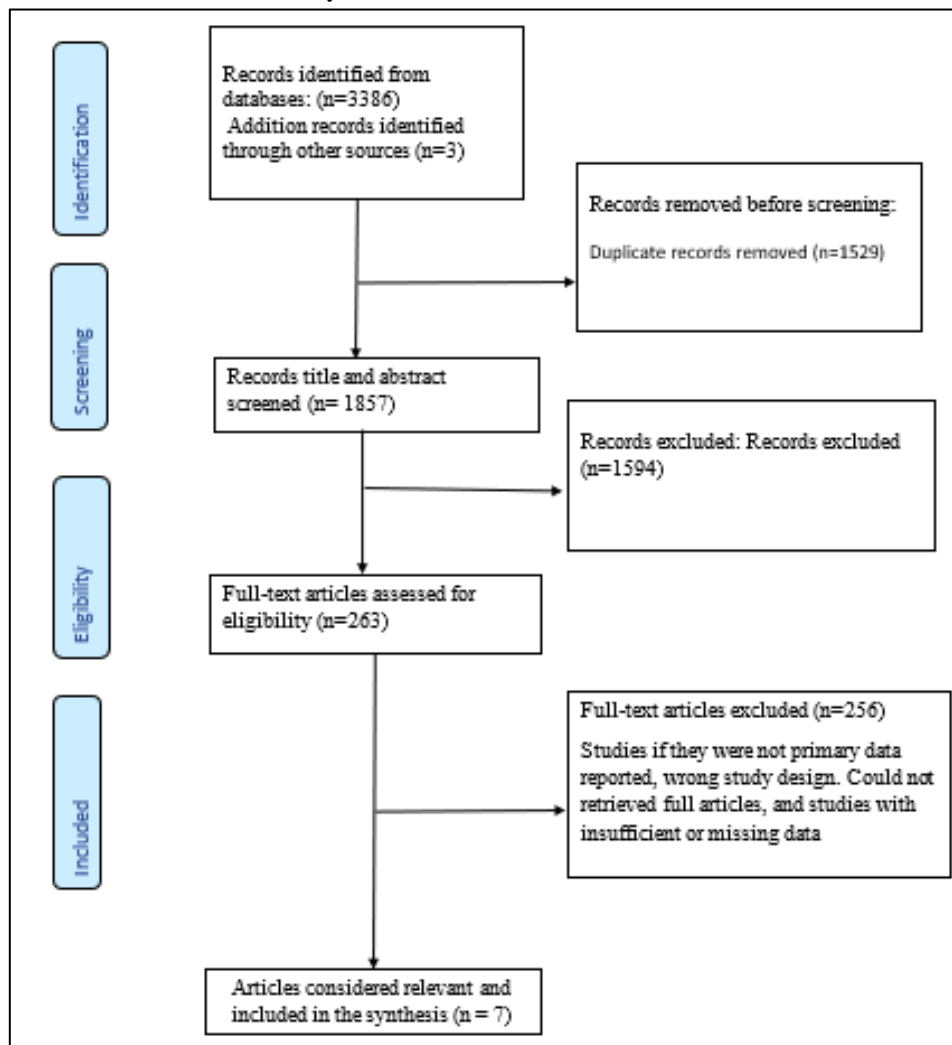


Figure 1: PRISMA flowchart of study selection process.

Data extraction

Two of the reviewers (1 and 3) performed the data extraction for this study. Information was extracted from

eligible articles based on predefined criteria. Information such as the author’s name, year of publication, research aim, the study design, sample size, data analysis methods and their key findings. Extracted data from the included articles are summarised in PICO (Table 1).

Synthesis

In the included studies themes in the qualitative and quantitative data were incorporated in the text, and differing methods were used. The findings are therefore summarised in a narrative manner rather than using direct comparison.

RESULTS

Themes

The impact of HIV stigma on people living with HIV included the following lack of adherence to treatment protocols, Internalised HIV stigma, Discrimination, Lack of self-esteem, public stereotyping and non-disclosure. Table 2 shows the themes and the various articles that have addressed the theme.

Lack of adherence

One of the common impacts of HIV stigma was the lack of adherence to treatment protocols by People living with HIV (PLWH). Due to fear of being stigmatised or noticed by members of the public.¹² Noted that HIV stigma caused isolation leading to delayed testing and diagnosis including limits to accessing health services for treatment or counselling. Furthermore, the authors reported a lack of adherence to treatment protocols and feelings of shame and self-blame.³⁰

Assert that mass media blame PLWH leading of fear of taking medication or adhering to treatment protocols.³¹ noted that stigma among PLWH led to hiding of medication and skip of treatment protocols. Similarly, reported that PLWH felt devalued thereby impacting on their uptake of medication.^{32,33} Espoused HIV stigma has a negative impact on medication adherence leading to poor adaptation to medical protocols.

Internalised HIV stigma

Some authors reported internalised stigma impacting PLWH leading to negative life experiences.³⁴ noted the negative feeling or beliefs of internal stigma was rife among PLWH leading to suicidal feelings.³³ Asserts that PLWH tend to blame themselves with what is sometimes known as perceived stigma leading to a negative self-image.³² Reported that PLWH were strongly affected by their personal; status leading to self-stigmatisation.³⁵ asserts that internalised stigma led to the loss of confidence among PLWH.

Discrimination

The authors felt that discrimination was one of the problems that affected PLWHIV leading to discrimination in different spheres of life.³¹ reported that PLWH felt discriminated against because of their condition.³⁰ Assert that PLWH were prone to discrimination due to HIV

infection noted that PLWH were being discriminated in many spheres of their life due to their HIV status.¹²

Lack of self-esteem

The authors reported that people living with HIV felt a loss of self-esteem due to suspicions and blame from communities asserts that PLWH showed a lack of self-esteem and confidence due to rejection by friends and family. In the same vein, noted that PLWH felt depressed and lacked self-esteem due to different societal criticisms.³³⁻³⁵ Espoused that the impact of stigma leads to self-esteem and confidence resulting in withdrawal.

Public-stereotyping

The authors in the included articles reported public stereotyping of people living with HIV leading to negative life experiences.³² Believed that negative feelings from members of the public or communities can lead to stereotyping of PLWH.¹² asserts that there was a biased feeling towards PLWH that they were responsible for their present status.³⁰ concluded that PLWH were treated as suspects in communities leading to stereotyping of their behaviour.

Non-disclosure

Some authors reported that most of the PLWHIV felt that they did not need to disclose their HIV status due to the reaction from members of the public.³¹ believed that disclosure caused PLWH to feel depressed thereby withdrawing from community support contacts and treatment services.³²

Noted that PLWH felt that they were being stigmatised leading to non-disclosure of their status.¹² asserts that HIV stigma impacted upon PLWH resulting in unwillingness to disclose their status.

DISCUSSION

Lack of adherence to treatment for people living with HIV can lead to negative health outcomes.³⁶ More importantly, it can result in relapsing and subsequent development of the condition into full-blown AIDS.³⁷ In this study, stigma was identified as one of the prime causes of lack of adherence to treatment protocols among people living with HIV. The lack of adherence emanated from fear of being noticed by others when taking medication. Considering this assertion, communities must be educated about the importance of taking medication when diagnosed with HIV. Furthermore, there is a need to normalise taking HIV medication through raising awareness in communities as a strategy to increase medication adherence among people living with HIV.

Internalised stigma has far-reaching consequences on the health and well-being of people living with HIV.³⁸ Through internalised stigma, many people living with HIV

have felt a sense of rejection because of their belief that the community does not approve of their status.³⁹ The study identified internalised stigma as causing negative life experiences among people living with HIV. Such negative experiences included feeling suicidal and blaming themselves for contracting HIV.^{32,33} In light of the aforementioned impact, there is a need to foster resilience through training people living with HIV to accept their condition and stop internalising bad feelings about themselves. Furthermore, there is a need to raise awareness in communities on the general impact of HIV on people living with the condition.

Discrimination is a major deterrent to accessing HIV testing, disclosure, treatment, and community support services.⁴⁰ PLWH experiences discrimination from those they expect to support them in coping with their diagnosis.⁴¹ They experience discrimination by health workers, in cases where they are denied treatment or confidentiality, and privacy is breached.⁴² The study acknowledged that discrimination experienced by PLWH is from many spheres of their lives.

Discrimination can also present in the form of inadequate care or information given to PLWH as providers might omit discussions regarding safe sex or contraception.⁴³ It is essential to spend time exploring the understanding and fears of those receiving HIV diagnosis and to inform them about the available support systems. Educating the health workers and communities about the HIV mode of transmission, the effectiveness of ARVs to normalize HIV is essential to eradicate discrimination.

Lack of self-esteem may be a result of feelings of shame, guilt, anger, Self-blame, lack of self-worth and support from partners and families affected by HIV.⁴⁴ Furthermore, daily activities such as remembering to take ARVs, safe sex and good health might be neglected resulting in deteriorating health and transmission of infection.⁴⁵ Lack of self-esteem is also associated with signs and symptoms of depression and non-conformity to education by health worker.⁴⁶

The findings of this study acknowledged that lack of self-esteem negatively affects the physical and mental well-being of PLWHIV. It also raised the need for support from partners as this may encourage feelings of self-worth and compliance with ARVs and health-related information. Community stakeholders need to support groups that discuss and share information about coping with a positive HIV diagnosis and maintaining good health. Furthermore, there is a need for community support groups living with HIV to build self-esteem through the support of people living with HIV.

Public stereotyping of HIV is blamed on the mass media's early depiction of HIV as a deadly disease.⁴⁷ Despite the progression in the management of the disease, fear and negative attitudes have remained regarding HIV diagnosis. Public stereotyping of people with HIV includes them

being labelled as promiscuous, drug users, homosexuals, and sex workers.⁴⁸ This leads PLWHIV to feel internalized stigma as they experience feelings of inferiority and self-blame.⁴⁹

Conversely, those who endorse the stereotyping usually perceive themselves as not associated with the label therefore at lower risk of acquiring HIV.³⁰ This results in dire consequences of behaving in risky behaviour, such as having unprotected sex and not attending regular HIV screening.⁵⁰ The study reported public stereotyping of people living with HIV leading to negative life experiences. Mass media should disseminate information focusing on the positive role of ARVs, family, community, and health support to the well-being of PLWHIV. Community stakeholders should engage PLWHIV to work with other community workers to educate and support PLWHIV in coping with public stereotyping.

Non-disclosure of one's HIV status is due to fear of rejection, stigma and discrimination from partners, families, communities, and health carers.⁵¹ This study highlighted that non-disclosure is influenced by the anticipated reaction and response of family or friends to disclosure of HIV-positive status. Non-disclosure is considered beneficial to protect relationships, by avoiding rejection and as safeguarding from abuse by partners.⁵² However, non-disclosure can lead to psychological effects, such as anxiety, depression and self-blame resulting in poor quality health.⁵³

Non-disclosure increases the risk of HIV transmission and increases the chances of acquiring secondary infections as condom negotiation and ARV adherence is challenged without support from partners or families.⁵³ PLWHIV should be given information on the long-term effects of non-disclosure and allowed to express their fears, tackle self-esteem and reduce stigma. It is important to tackle the component that causes non-disclosure in communities. HIV counselling services should educate communities about the important role of HIV disclosure in the health and well-being of PLWHIV, partners and the community.

Strengths and limitations

The main strength of this scoping review is that it examines HIV-related stigma in people living with HIV. A comprehensive search was conducted to retrieve the most up-to-date and relevant articles for this review. Again, the researchers of this study also conducted a detailed quality appraisal of the reviewed articles.

CONCLUSION

This scoping review supports the idea that perceived stigma towards people living with HIV has a negative effect on the health outcomes of people living with the disease. The findings of our study highlight that public stereotyping and perceived stigma in the community are the major factors impacting people living with HIV.

Funding: No funding sources

Conflict of interest: None declared

Ethical approval: Not Required

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Cite this article as: Nyashanu M, Mushonga FTE, Dada SO, Ekpenyong MS. Examining the impact of HIV-related stigma in people living with HIV: a systematic literature review. *Int J Reprod Contracept Obstet Gynecol* 2024;13:2875-85.