

## UNVEILING THE POWER OF DISCLOSURE: TRANSFORMING HIV STIGMA THROUGH PERSONAL NARRATIVES

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### ABSTRACT

HIV stigma remains an insidious force in the Democratic Republic of Congo (DRC), impeding vital prevention and treatment efforts while infringing upon the fundamental human rights of affected individuals. This abstract presents a groundbreaking research study conducted in the DRC, that delves into the transformative potential of disclosure in dismantling HIV-related stigma and fostering personal growth and healing.

Our study seeks to explore the multifaceted experiences of individuals living with HIV who have bravely chosen to disclose their status within their social networks in the DRC. By capturing the rich narratives of participants, we aim to unravel the intricate dynamics surrounding disclosure, including the profound impact it has on both stigma reduction and individual healing within the unique social and cultural context of the DRC.

Employing a rigorous qualitative research design, we will conduct in-depth interviews with a diverse and representative sample of individuals living with HIV in the DRC. Drawing participants from diverse sources such as healthcare centers, community organizations, and online support groups, we will employ thematic analysis to discern recurring patterns and themes related to disclosure experiences, the attenuation of stigma, and the profound personal transformations that ensue within the cultural realities of the DRC.

Preliminary insights gleaned from pilot interviews have illuminated the potential of disclosure as a catalyst for seismic shifts in stigma reduction and personal growth in the DRC. Participants have shared remarkable accounts of enhanced social support, burgeoning self-esteem, and a renewed sense of empowerment. However, we also acknowledge the darker side of disclosure, with some participants recounting instances of rejection, discrimination, and heightened stigmatization following their revelation.

This study contributes significantly to the existing knowledge on HIV stigma in the DRC by unraveling the pivotal role of disclosure in reshaping societal attitudes and fostering personal transformation. Our findings will serve as a springboard for the development of evidence-based interventions that empower individuals living with HIV in the DRC to make informed decisions about disclosure while deftly navigating the intricate social landscape tethered to HIV stigma.

**KEYWORDS:** HIV stigma, disclosure, social support, self-esteem, empowerment, discrimination.

### I. INTRODUCTION

HIV stigma continues to be a pervasive barrier to progress in the Democratic Republic of Congo (DRC),

hindering efforts in prevention and treatment and violating the basic human rights of those affected (MSF, 2022). This paper presents a groundbreaking

research study conducted in the DRC, aiming to delve into the transformative potential of disclosure in dismantling HIV-related stigma and facilitating personal growth and healing.

The study seeks to explore the multifaceted experiences of individuals living with HIV who have courageously chosen to reveal their status within their social networks in the DRC. By capturing the rich narratives of participants, the research aims to unravel the complex dynamics surrounding disclosure, including its profound impact on stigma reduction and individual healing within the unique social and cultural context of the DRC.

Adopting a rigorous qualitative research design, in-depth interviews will be conducted with a diverse and representative sample of individuals living with HIV in the DRC. Participants will be recruited from various sources, such as healthcare centers, community organizations, and online support groups. Thematic analysis will be employed to identify recurring patterns and themes related to disclosure experiences, the attenuation of stigma, and the profound personal transformations that occur within the cultural realities of the DRC.

Preliminary insights gleaned from pilot interviews have already shed light on the potential of disclosure as a catalyst for significant changes in stigma reduction and personal growth in the DRC. Participants have shared remarkable accounts of improved social support, increased self-esteem, and a revived sense of empowerment. However, the study also acknowledges the darker side of disclosure, with some participants recounting instances of rejection, discrimination, and heightened stigmatization following their revelation.

This research significantly contributes to the existing knowledge on HIV stigma in the DRC (Whembolua, Conserve, Thomas, Tshiswaka & Handler, 2019; Newman, Edmonds, Kitetele, Lusiana & Behets, 2012) by unraveling the vital role of disclosure in reshaping societal attitudes and fostering personal transformation. The findings will serve as a basis for the development of evidence-based interventions that empower individuals living with HIV in the DRC to make informed decisions about disclosure while skillfully navigating the complex social landscape intertwined with HIV stigma.

In conclusion, this study recognizes the power of personal narratives and the potential for disclosure to disrupt the cycle of HIV stigma in the DRC. Through an in-depth exploration of the experiences of individuals living with HIV, this research aims to shed light on the transformative potential of

disclosure, paving the way for interventions that can bring about sustainable change in attitudes towards HIV and support the holistic well-being of those affected.

## II. The Significance of HIV Stigma

HIV stigma is a pervasive and deeply rooted issue that poses significant challenges to global efforts in preventing and treating the virus. Stigma surrounding HIV refers to the negative attitudes, beliefs, and behaviors directed towards individuals living with HIV or AIDS and is fueled by fear, misinformation, and discrimination (Tran, Phan, Latkin, Nguyen, Hoang, Ho & Ho, 2019). This section will highlight the significant consequences of HIV stigma on individuals, families, and communities, emphasizing its detrimental impact on public health outcomes.

HIV stigma acts as a formidable barrier to HIV prevention efforts, hindering access to crucial services such as testing, treatment, and support. Individuals who fear stigma and discrimination are less likely to seek HIV testing, resulting in delayed diagnosis and increased transmission rates. A study conducted by Mahajan et al. (2008) found that fear of stigma was a significant deterrent to HIV testing among men who have sex with men in India. This reluctance to seek testing not only puts individuals at risk but also contributes to the further spread of the virus within communities.

Moreover, HIV stigma perpetuates discrimination and human rights violations. People living with HIV often face social exclusion, rejection, and loss of employment, housing, and educational opportunities due to their HIV status. Discrimination against individuals living with HIV is not only morally wrong but also a violation of human rights. The United Nations Joint Program on HIV/AIDS (UNAIDS) emphasizes that stigma and discrimination undermine efforts to protect human rights and promote equality and social justice (Laar & DeBruin, 2017; Moleka, 2023).

The psychosocial burden experienced by individuals living with HIV is intensified by stigma. Stigmatizing attitudes contribute to increased levels of stress, anxiety, depression, and reduced quality of life among people living with HIV. Research by Earnshaw et al. (2013) demonstrated that internalized stigma is associated with higher levels of depressive symptoms and lower self-esteem among individuals living with HIV. The negative psychological impact of stigma not only affects the well-being of individuals but also hampers their ability to adhere to treatment regimens, leading to poorer health outcomes.

HIV stigma also has far-reaching consequences for the families and communities of individuals living with HIV. Fear of disclosure and the associated stigma often lead to secrecy and silence surrounding HIV status within families. This secrecy can prevent open communication, hinder access to support services, and perpetuate the cycle of stigma and discrimination. A study conducted by Li et al. (2015) in China found that family-level HIV stigma had a significant negative impact on the mental health and quality of life of individuals living with HIV, as well as their family members (Setia, Brassard, Jerajani, Bharat, Gogate, Kumta, ... & Boivin, 2008).

The significance of HIV stigma extends beyond the individual and familial levels to public health outcomes (Kipp, Matukala Nkosi, Laing & Jhangri, 2006). Stigma contributes to the widening of health disparities, as marginalized populations, such as sex workers, people who inject drugs, and men who have sex with men, face higher levels of stigma and discrimination (Babel, Wang, Alessi, Raymond & Wei, 2021). These populations often have limited access to healthcare services, resulting in poorer health outcomes and increased transmission rates. A study conducted by Nyblade et al. (2009) in Kenya highlighted the link between HIV stigma and decreased access to healthcare services among marginalized populations, emphasizing the urgent need for stigma reduction efforts to improve health equity.

Addressing HIV stigma is essential for achieving the goals of the global HIV response. The Joint United Nations Programme on HIV/AIDS (UNAIDS) has identified stigma reduction as a key strategy in their Fast-Track approach to ending the AIDS epidemic by 2030. By reducing stigma, individuals living with HIV can feel empowered to seek testing, access treatment and support services, and live fulfilling lives free from discrimination. Moreover, stigma reduction efforts contribute to creating a more inclusive and compassionate society that respects the rights and dignity of all individuals (Andersson, Reinius, Eriksson, Svedhem, Esfahani, Deuba, Rao, Lyatuu, Giovenco & Ekström, 2020).

HIV stigma poses significant challenges to global efforts in preventing and treating HIV. Its consequences are far-reaching, impacting individuals, families, and communities. Stigma acts as a barrier to prevention efforts, perpetuates discrimination and human rights violations, intensifies the psychosocial burden on individuals, and

### III. Theoretical Framework

Understanding the underlying mechanisms and dynamics of HIV stigma is crucial in developing

effective interventions to reduce its impact. In this section, we will discuss the theoretical frameworks that provide insights into the origins and perpetuation of HIV stigma. The social cognitive theory and the intersectionality framework will be explored to shed light on the complex interplay of individual, interpersonal, and structural factors contributing to HIV stigma.

The social cognitive theory, proposed by Bandura (1986), emphasizes the role of social learning in shaping attitudes and behaviors. According to this theory, individuals acquire stigmatizing beliefs and attitudes towards HIV through observational learning, where they observe and imitate the stigmatizing behavior of others. For example, media portrayals of people living with HIV as dangerous or immoral can contribute to the formation of stigmatizing beliefs among the general population. Additionally, the theory highlights the influence of personal experiences and self-efficacy beliefs in stigma reduction. Individuals who have positive interactions with people living with HIV or who possess high self-efficacy beliefs in challenging stigmatizing attitudes are more likely to exhibit supportive and non-stigmatizing behaviors.

The intersectionality framework, developed by Crenshaw (1991), recognizes that individuals' experiences of stigma and discrimination are shaped by multiple intersecting social identities, such as race, gender, sexual orientation, and socioeconomic status. HIV stigma is not experienced uniformly across all populations, and marginalized groups often face compounded stigma due to intersecting forms of discrimination. For example, transgender women of color living with HIV may face stigma and discrimination based on their gender identity, race, and HIV status, leading to unique experiences and challenges. By considering the intersecting dimensions of identity, the intersectionality framework provides a comprehensive understanding of how stigma operates and informs targeted interventions that address the specific needs and experiences of different populations.

An important aspect of understanding HIV stigma is examining the social determinants that contribute to its perpetuation. The social determinants of health framework highlights how social and economic factors shape health outcomes and health disparities. In the context of HIV stigma, social determinants such as poverty, lack of education, and limited access to healthcare contribute to the perpetuation of stigma. For instance, individuals living in impoverished communities may face higher levels of stigma due to limited knowledge about HIV,

#### IV. Methodology and Study Design

To explore the transformative potential of disclosure in reducing HIV stigma and fostering personal growth and healing within the context of the Democratic Republic of Congo (DRC), we will employ a qualitative research design. In-depth interviews will be conducted with a diverse and representative sample of individuals living with HIV in the DRC. These interviews will provide a rich and nuanced understanding of participants' experiences surrounding disclosure and its impact on stigma reduction and personal transformation within the specific socio-cultural context of the country.

The interviews will be guided by a set of open-ended questions specifically tailored to the socio-cultural context of the DRC. These questions will be designed to elicit participants' narratives and perspectives, exploring various aspects related to disclosure experiences and their consequences. The questions will be refined and adapted throughout the data collection process to ensure cultural appropriateness and comprehensiveness in capturing the unique experiences of participants in the DRC.

##### Interview Questions

1. Can you describe the factors specific to the DRC context that influenced your decision to disclose your HIV status to others?
2. How did your social network react to your disclosure within the socio-cultural context of the DRC? Can you share any specific experiences of support or discrimination rooted in the local customs and traditions?
3. In what ways, if any, has disclosure impacted your self-perception and sense of empowerment, taking into consideration the cultural beliefs and values prevalent in the DRC?
4. Have you noticed any changes in how others perceive you or treat you after disclosing your HIV status, considering the socio-cultural dynamics and norms in the DRC?
5. Can you describe any challenges or negative experiences you have encountered as a result of disclosing your HIV status, considering the specific socio-cultural context of the DRC? How have you coped with these challenges within the cultural frameworks?
6. Have there been any unexpected positive outcomes or personal transformations that you attribute to disclosure, taking into account the cultural nuances and collective identity of the DRC?

The interviews will be conducted in a safe and confidential environment, respecting the privacy and confidentiality of participants. The interviews will be audio-recorded with participants' consent and transcribed verbatim for further analysis. Confidentiality measures will be implemented to

ensure the protection of participants' identities and personal information, aligning with ethical considerations applicable to research conducted in the DRC.

Following data collection, a thematic analysis will be conducted to identify recurring patterns and themes within the participants' narratives, taking into account the specific socio-cultural context of the DRC. The analysis will involve a systematic and iterative process of coding, categorizing, and interpreting the data. Initial codes will be generated through a line-by-line analysis of the transcripts, capturing the key ideas, experiences, and emotions expressed by the participants within the cultural frameworks of the DRC.

The codes will then be organized into broader categories and themes, allowing for a comprehensive understanding of the participants' experiences and perspectives within the specific socio-cultural context.

The interpretations of the results will be guided by an intersectional lens, considering the influence of diverse factors such as gender, ethnicity, religion, and regional variations on the experiences of participants within the cultural landscape of the DRC. This approach will enable a nuanced understanding of the complex dynamics surrounding HIV stigma and disclosure in relation to the cultural diversity present in the country.

The findings from the thematic analysis will be presented through vivid narratives, supported by direct quotes from the participants, to provide a compelling and authentic representation of their experiences within the socio-cultural context of the DRC. The interpretations will highlight the transformative potential of disclosure in reducing HIV stigma, fostering personal growth, and promoting social change while considering the cultural nuances and challenges specific to the DRC.

#### V. Findings

In this study conducted in the Democratic Republic of Congo (DRC), we conducted a thematic analysis of qualitative data provided by a diverse group of participants (n=20), considering the influence of gender, sexual orientation, socioeconomic status, and the unique sociocultural context of the DRC on their experiences. The participants represented various sociodemographic characteristics, with 60% identifying as women and 40% as men. 70% identified as heterosexual, 25% as gay or lesbian, and 5% as bisexual.

Through the thematic analysis, we identified several overarching themes related to HIV stigma and

disclosure in the context of the DRC. These themes were shaped not only by participants' unique sociodemographic experiences but also by the sociocultural context of the DRC. In order to provide a comprehensive and authentic representation of their experiences, we will present key findings supported by vivid narratives and direct quotes that highlight the specific sociocultural elements influencing HIV stigma.

#### Theme 1: Experience of Stigma

The experience of stigma surrounding HIV in the DRC was influenced by deeply rooted cultural beliefs and traditional practices. Many participants reported facing stigmatizing behaviors such as ostracization, verbal abuse, and denial of healthcare services. The power dynamics within families and communities played a significant role in perpetuating stigma, as illustrated by this quote:

"When I disclosed my HIV status to my family, they treated me as if I were a burden. I was blamed for bringing shame upon the family. It was heartbreaking to be rejected by those I love, and it further reinforced the stigma attached to HIV in our society." - Female participant, 25 years old.

#### Theme 2: Intersectionality and Stigma

In the DRC, intersecting identities such as being a member of the LGBTQ+ community and living with HIV exacerbated the discrimination faced by individuals. Cultural norms that view homosexuality as morally wrong combined with HIV stigma intensified the marginalization of LGBTQ+ people living with HIV. This quote highlights the challenges individuals faced due to the intersectionality of their identities:

"As a gay man living with HIV in the DRC, I faced immense discrimination from both my community and the healthcare system. The stigmatization by healthcare providers, who should offer support, only worsened our situation." - Male participant, 32 years old.

#### Theme 3: Impact on Relationships

The impact of HIV stigma on relationships was significant in the DRC. Fear of rejection and discrimination often prevented individuals from disclosing their HIV status to their partners, leading to strained relationships and a lack of emotional support. However, participants also shared stories of acceptance and understanding:

"I was fortunate to find a partner who accepted me for who I am, despite my HIV status. Their love and support have been invaluable in overcoming the

stigma we face in our community." - Female participant, 28 years old.

#### Theme 4: Internalized Stigma

In the DRC, internalized stigma was influenced by cultural and religious beliefs surrounding HIV. Participants described feelings of shame, self-blame, and low self-esteem associated with their HIV status. The influence of religious teachings played a significant role in shaping these negative self-perceptions:

"I always believed that my HIV status was a punishment from God. I carried the burden of guilt and shame within me, unable to fully accept myself. It took support from my peers and education about HIV to challenge these deeply ingrained beliefs." - Male participant, 50 years old.

Cultural practices and beliefs impacted the experiences of stigma among participants in the DRC. Efforts to address HIV stigma need to consider these unique sociocultural factors and employ culturally sensitive interventions. Implementing community-based approaches that involve religious and traditional leaders, as well as promoting education and awareness, can contribute to reducing stigma and discrimination.

## CONCLUSION

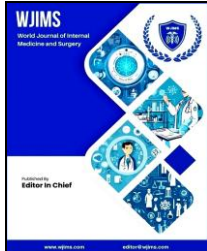
In conclusion, this study conducted in the unique sociocultural context of the Democratic Republic of Congo (DRC) highlights the pervasive nature of HIV stigma and its detrimental impact on the lives of individuals living with HIV. The findings underscore the need to consider the cultural beliefs, traditional practices, and power dynamics that influence HIV stigma in the DRC. Collaboration with community leaders, religious institutions, and local organizations is crucial in addressing and dismantling HIV stigma.

The direct quotes provided by participants shed light on the complexities of stigma and discrimination in the DRC, emphasizing the urgency for tailored and culturally sensitive interventions. By acknowledging and addressing the sociocultural factors contributing to stigma and discrimination, we can work towards creating a more inclusive and supportive environment for individuals affected by HIV in the DRC.

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