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Understanding the Lived Experience: Case studies on HIV Diagnosis, Challenges, and Counselling Support in Bidar District, Karnataka.

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Abstract

Human Immunodeficiency Virus (HIV) continues to pose a substantial public health challenge in India, where individuals living with HIV (PLHIV) often contend with significant socio-economic, psychological, and medical barriers. Integrated Counselling and Testing Centres (ICTCs) are crucial components of India's national AIDS control program, providing essential diagnosis, counselling, and linkage to care. This qualitative case study explores the lived experiences of individuals diagnosed with HIV in Bidar district of Karnataka, focusing on the critical role of Integrated Counselling and Testing Centres (ICTCs). Through a detailed analysis of seven diverse cases including internal migrants, youth, and married individuals, the study examines the psychosocial challenges of diagnosis, the dynamics of counselling support, treatment adherence, family acceptance, and societal stigma. The findings highlight that while ICTC counsellors are indispensable in providing emotional support and linking clients to care, pervasive stigma and the fear of disclosure remain significant barriers. Family dynamics are shown to be a double-edged sword, offering both crucial support and intense conflict that can exacerbate distress and lead to non-adherence. The research also reveals that a holistic, patient-centered approach is essential to address the unique challenges faced by different populations, such as migrant workers, and to ensure long-term treatment success. Ultimately, the study underscores that effective HIV care must extend beyond clinical treatment to address the socio-cultural factors that shape a person's entire experience, emphasizing the need for continued support and community-wide education to foster a stigma-free environment.

Keywords: HIV/AIDS, Counselling, Integrated Counselling and Testing Centre (ICTC), Antiretroviral Therapy (ART), PLHIV, stigma, treatment adherence, psychosocial support, public health.

1. Introduction

Human Immunodeficiency Virus (HIV) continues to pose significant public health and psychosocial challenges globally, especially in low- and middle-income countries like India. As of 2023, India has approximately 2.4 million people living with HIV (PLHIV) [UNAIDS, 2023]. Despite advancements in

antiretroviral therapy (ART) and improved access to healthcare services, stigma, socio-cultural norms, limited awareness, and emotional distress continue to influence diagnosis, disclosure, adherence, and outcomes.

The HIV pandemic has emerged as a substantial challenge to public health and development on a global scale, disproportionately affecting women, children, and specific populations (Anderson et al., 2019). In India, the proliferation of HIV infection has been rapid since 1986, though its distribution varies across regions (Chourasiya et al., 2016). HIV counseling and testing services are crucial for preventing and treating HIV (Sam et al., 2022). Accessing accurate HIV prevention and care information, along with confidential HIV testing in a supportive environment, becomes possible through testing services (Chourasiya et al., 2016). Despite progress, challenges remain, including stigma, low awareness, and broken links between diagnosis and treatment, especially in rural areas where specialized services are limited (Ray et al., 2022) (Akullian et al., 2016). Geographical isolation, socioeconomic disparities, and limited healthcare infrastructure further exacerbate these challenges, leading to delayed diagnosis and treatment (Ezenwaji et al., 2025) (Reif et al., 2005).

HIV testing services are a critical entry point to accessing HIV-related care and treatment, and also serve as a means of accessing prevention services for those who test HIV-negative (Fajardo et al., 2023). Having good knowledge of HIV and ICTC is an important factor for clients undergoing HIV testing and counseling in health facilities (Terefe et al., 2024). Suboptimal retention in care and poor adherence to antiretroviral therapy remain significant barriers to effective viral suppression (Edwards et al., 2025). Early missed visits and attrition after initial enrollment in outpatient care can compromise the potential impact of treatment and prevention strategies (Mugavero et al., 2011).

Addressing these issues requires comprehensive strategies that improve entry to antenatal care and create supportive, stigma-free environments, including spousal support, to overcome socio-cultural obstacles (Dirisu et al., 2020). Strengthening household capacity is also vital for improving the treatment and care of people living with HIV (Mukumbang et al., 2019). Individual, household, and community-level factors are interlinked and can either mitigate or exacerbate the impact of HIV and its treatment (Masquillier et al., 2020). Addressing these barriers and improving service delivery can lead to better health outcomes and overall well-being for those affected by HIV, especially in rural areas (Terefe et al., 2024).

The role of Integrated Counselling and Testing Centres (ICTCs) in India is pivotal in identifying HIV-positive individuals, initiating early treatment, and providing psychosocial support. Through individualized and family-based counselling, ICTCs play a central role in reducing stigma and supporting PLHIV to live healthy lives.

This study analyses seven diverse real-life case studies from ICTCs, focusing on internal migrants, youth, married individuals, and adolescents. It explores the intersecting challenges of HIV diagnosis, counselling dynamics, treatment adherence, family acceptance, and societal stigma.

Methodology

The present study uses a qualitative case study method. In this study the researcher has taken seven cases of individuals interacting with ICTC Counsellors in Bidar district of Karnataka. The seven cases illustrate and represent actual individuals, to reflect common and critical experiences frequently encountered by

PLHIV and ICTC counsellors in real-world settings. Each case study provides a concise narrative account, detailing the client's background, the specific circumstances surrounding their HIV diagnosis, the counselling interventions provided, the challenges they faced, and the observed outcomes.

The selection of these seven cases aims to capture a broad spectrum of diverse situations, ensuring representation across:

- Demographic profiles: Including variations in age, gender, marital status, educational attainment, and occupational background.
- Modes of HIV transmission: Covering both sexual and vertical (parent-to-child) routes.
- Stages of acceptance and adherence: Illustrating different levels of engagement with the diagnosis and treatment.
- Impact on family dynamics and relationships: Showcasing how HIV influences spousal, parental, and extended family interactions.
- Experiences with stigma, discrimination, and legal issues: Highlighting societal and systemic barriers.
- Role of community support and non-governmental organizations (NGOs): Demonstrating the influence of external support structures.
- Long-term outcomes: Reflecting both positive adaptations and ongoing struggles for individuals and families.

Objectives

1. To examine the psychosocial challenges faced by individuals newly diagnosed with HIV.
2. To assess the impact of stigma, family dynamics, and community perception on the well-being of PLHIV.
3. To demonstrate the role of ICTC counsellors in providing support, education, and critical linkage to care for PLHIV and their families.
4. To highlight instances of successful intervention and positive outcomes, while also acknowledging ongoing difficulties and identifying areas that require further attention and strategic development within existing HIV care and support services.

Case study 1: Story of Hope and Companionship

Mr. A is a 25-year-old unmarried male residing in an industrial area as a migrant worker. His formal education ended after completing the 10th grade, and he has been engaged in daily wage labor to support himself. He lives away from his family and works long hours in the informal sector, a common setting for many internal migrants in India. As part of a community outreach initiative, an HIV awareness and testing campaign was conducted by ICTC counsellors targeting migrant workers in the industrial belt. Mr. A, though asymptomatic and appearing physically healthy, voluntarily agreed to get tested. To his complete

surprise, the result came back HIV-positive. He was immediately referred to ICTC for confirmatory testing and psychosocial counselling. The counsellor approached the situation with empathy, providing Mr. A with emotional support and educating him on HIV/AIDS, its transmission modes, management, and prevention. Initially, Mr. A was shocked and emotionally overwhelmed by the diagnosis. However, the counsellor's patient and non-judgmental approach helped him gradually accept his status. The counsellor educated him on the importance of maintaining a healthy lifestyle, adherence to ART, safe sex practices, and regular follow-up visits. Mr. A proved to be highly cooperative and committed to his treatment. He followed the counsellor's instructions diligently, never missed a clinic visit, and began ART as prescribed. He showed excellent adherence and a positive attitude toward health maintenance. During this period, the counsellor was also supporting another client, Ms. X, a young unmarried woman who had contracted HIV through parent-to-child (vertical) transmission. Ms. X had grown up with the infection, managed her condition well, and was actively involved in regular counselling and ART adherence. Recognizing the compatibility between Mr. A and Ms. X in terms of shared background, caste, HIV status, and life goals the counsellor initiated a series of conversations with both individuals about companionship, emotional support, and the possibility of marriage. After a series of joint counselling sessions and consent from both parties, Mr. A and Ms. X decided to get married with support from the counsellor and an NGO that assisted with legal, financial, and social arrangements. Today, Mr. A and Ms. X are married and leading a healthy, stable life together. They have a child who is now 1 year and 6 months old. The child has tested HIV-negative, a result made possible through proper medical intervention, maternal ART adherence, and consistent prenatal and postnatal care. The counsellor and healthcare team closely monitored the pregnancy and delivery process to minimize the risk of vertical transmission. Both Mr. and Mrs. A are highly grateful to the counsellor, whom they refer to as their "God." They credit the counsellor with not only saving their lives but also giving them a chance to live with dignity, companionship, and family. They continue to attend every scheduled follow-up appointment and have not missed a single session since their initial diagnosis. Their treatment adherence is excellent, and their viral loads remain well managed.

Case Study 2: The Challenge of Disclosure and Adherence

Mr. K, a 24-year-old married man and father of three children, had completed his education up to the 12th standard. He was employed as a daily wage laborer in the construction sector. Mr. K initially presented with persistent mouth ulcers and was referred by a private hospital to the ICTC for HIV screening. Upon testing, Mr. K was diagnosed as HIV positive. Through the counselling process, it was revealed that the mode of transmission was unprotected sexual contact with his female colleague. The counsellor requested Mr. K to bring both his wife and the colleagues with whom he had contact for further testing. However, Mr. K initially refused, citing fear of stigma and damage to his reputation at the workplace. After several counselling sessions emphasizing the importance of partner notification and testing, Mr. K agreed to bring only his wife for testing on the condition that the counsellor would not disclose the specific details of how he contracted the virus and he remained adamant about not informing his colleague. Mr. K and his wife attended a couple counselling session at the centre. During the session, the counsellor informed the wife about Mr. K's HIV status. She was visibly shocked and struggled to accept the situation. She was then tested for HIV and fortunately, her result came back negative. However, the diagnosis caused her to question her husband's morality and trustworthiness. The counsellor took the time to educate her about HIV, including its various modes of transmission, the importance of early diagnosis, and treatment options. To maintain family stability, the counsellor refrained from disclosing the actual reason for Mr. K's HIV

infection. Mr. K's parents were not informed about his diagnosis. However, his wife chose to inform her own parents, and she expressed a strong reluctance to continue living with her husband. The counsellor made significant efforts to counsel her, encouraging her to support her husband during this difficult time rather than abandon him. Mr. K was advised to initiate ART and was educated on the importance of adherence for both his own health and the prevention of transmission. Despite this, he demonstrated poor compliance with treatment. He failed to attend regular follow-up sessions at the ICTC and only came when the counsellor made repeated phone calls. In contrast, his wife regularly visited the centre for ongoing support and guidance. During these sessions, Mr. K's wife disclosed that her husband consumed alcohol daily after work and often insisted on unprotected sexual intercourse, despite her lack of interest and repeated refusals. This behaviour caused her great distress and anxiety, as she feared becoming HIV positive and worried about the long-term impact on their children's wellbeing.

Case Study 3: Battling Stigma and Legal Adversity

Mrs. P, a 19-year-old unmarried woman with an educational background up to the 7th standard, left her hometown and moved to Mumbai to work as a domestic helper in order to support her financially struggling family. During her stay in Mumbai, she entered into a romantic relationship with a man and engaged in unprotected sexual intercourse. Coming from a poor socio-economic background, she returned to her hometown after a year and married a man who suffered from epilepsy, from the same locality. At the time of marriage, Mrs. P was asymptomatic and unaware of her HIV status. A year later, when she became pregnant, she underwent routine antenatal screening at a government health facility and was diagnosed as HIV positive. Following her diagnosis, her husband was also tested for HIV and was found to be negative. The couple was referred to ICTC, where they received couple counselling. Both were counselled about the implications of the diagnosis, safe sexual practices, and treatment. Mrs. P immediately started on ART to protect both her health and of her unborn child. Her husband remained supportive during her pregnancy and stayed with her until the delivery of their child. She gave birth to a healthy baby boy who tested negative for HIV. However, four months later, her husband's parents began creating significant problems. They held strong misconceptions about HIV transmission and feared they would contract the virus by living in the same house as Mrs. P. Under pressure from societal stigma and misinformation, the husband's parents insisted that Mrs. P leave their home and return to her parental house. They forcibly took the baby from her, claiming that no one in the community would visit their house if they knew that their daughter-in-law was HIV positive. The counsellor provided multiple rounds of family counselling to the husband's parents, explaining that HIV does not spread through casual contact or cohabitation. Unfortunately, the parents refused to accept this and continued to isolate Mrs. P. Though her husband initially remained supportive, he eventually surrendered to family pressure. His parents manipulated him into considering a second marriage and distancing himself from his wife. Issues escalated further when the husband's family filed a legal case against Mrs. P and her mother, accusing them of intentionally hiding her HIV status to secure the marriage. In a desperate attempt to save her marriage and prevent divorce, Mrs. P pleaded with the counsellor to issue a false negative report. The counsellor firmly refused, citing ethical and legal obligations to maintain accurate health records. As a result of the allegations and legal complaints, the counsellor was subjected to repeated investigations and interrogations by both the police and legal authorities. This situation placed immense psychological and professional stress on the counsellor, who was only performing her duties within the ethical boundaries of her profession. Despite these challenges, Mrs. P continues to fight against the stigma and legal pressure,

refusing to give her husband a divorce. She expresses a strong desire to be with her child and maintain her family life, even in the face of societal rejection and legal battles.

Case Study 4: Navigating Fear and Confidentiality

Mr. R, a 21-year-old unmarried male, had studied up to the PUC and was working as a daily wage labourer in an industrial company. Mr. R had lost his father, and his mother, who worked in a clothing shop, was the sole surviving parent. He was initially found to be HIV reactive during a routine blood donation and was referred to ICTC by the blood bank for further testing and counselling. During counselling at the ICTC, it was revealed that the mode of transmission was through unprotected sexual contact when he was working in Mumbai. Mr. R was deeply distressed upon knowing his HIV-positive status. He did not inform his mother about his illness due to fear of causing her emotional pain and anxiety. He expressed to the counsellor his overwhelming fear of death and his concern about who would look after his mother if something happened to him. These worries, coupled with internalized stigma and shame, significantly affected his mental well-being. Despite his initial reluctance, Mr. R eventually opened up during the counselling sessions. The counsellor provided psychosocial support and educated him about HIV, its treatment options, and the importance of early initiation of ART and he was referred to the ART centre to begin treatment. However, due to intense feelings of stigma and fear of being recognized, Mr. R began attending the centre while wearing a face mask to conceal his identity. Over time, these feelings worsened, and he gradually stopped coming for regular follow-up sessions. He also discontinued his ART medication, which posed a serious risk to his health. Mr. R returned to Mumbai, where he restarted his HIV treatment. The ICTC counsellor maintained regular follow-up with him over phone calls to check on his well-being and to ensure that he was adhering to the prescribed medication. Although he remained distant from in-person services, the telephonic follow-ups served as a vital link to continue supporting him emotionally and medically.

Case Study 5: Vertical Transmission and Family Support

Ms. A, a young girl studying in the 9th standard, was taken to a private hospital after experiencing prolonged fever and general weakness. Concerned about her condition, her elder sister and aunt brought her to the ICTC for further evaluation and testing. The counsellor was cautious in approaching the counselling process due to the girl's young age and emotional vulnerability. However, during the session, it was revealed that the transmission of HIV in Ms. A's case was vertical – from parent to child. Ms. A's elder sister informed the counsellor that both their parents had been HIV positive and were on regular ART until their passing. It was only after Ms. A's illness that the family suspected she might also be affected and sought medical attention. The counsellor provided comprehensive counselling to Ms. A's sister and advised that she and her husband undergo HIV testing as a precautionary measure. Fortunately, both of them tested negative. The family was deeply distressed upon knowing Ms. A's HIV-positive status. They were unsure how to explain the illness to her and were concerned about how to manage her care moving forward, especially given her young age and the stigma associated with HIV. Ms. A is currently under the care of her aunt, who has taken on the primary responsibility of supporting her emotionally and medically. The family has been cooperative and regularly attend follow-up sessions at the ICTC. The aunt continues to receive counselling and guidance on how to care for Ms. A, manage her treatment, and ensure that she maintains a healthy and fulfilling life.

Case Study 6: Blame, Conflict, and Separation

Mr. M, a young man with a higher primary level of education, was working as a farmer in a rural area. He was 21 years old, and his wife was 19. Their marital life took a critical turn when the wife became pregnant and underwent a routine antenatal check-up, during which she was diagnosed as HIV positive. Following the diagnosis, she was referred to the ICTC, where the counsellor provided individual counselling and educated her on the nature of HIV, its modes of transmission, and the importance of partner testing. The counsellor advised her to bring her husband for testing, and he too was found to be HIV positive. Both partners were initially given separate individual counselling sessions to address their emotions, fears, and concerns, followed by couple counselling. However, during these sessions, significant tension and conflict surfaced between the couple. Each partner began blaming the other for the infection. Mr. M, although responsible for the transmission due to his high-risk sexual behavior, refused to acknowledge his role in the situation and instead accused his wife of being the source. Complicating the issue further, Mr. M's parents also blamed the wife for transmitting HIV to their son, despite his knowledge and awareness of being the actual cause. The counsellor intervened and provided family counselling sessions to both families in an attempt to clarify misconceptions, reduce stigma, and resolve conflicts. Mrs. M was already aware of her husband's extramarital activities and suspected that he had contracted the virus from outside. Despite the couple being cooperative with the counsellor, the continuous blame and interference from their families led to severe emotional distress. As tensions escalated, the couple decided to separate. The stress of the entire situation took a toll on the pregnant wife's health, ultimately resulting in a miscarriage. The case soon became an issue of public interest and was taken up by the local village panchayat, further increasing the emotional and social pressure on the young couple. Eventually, both individuals remarried different partners, who were also living with HIV. Although they no longer attend regular in-person counselling sessions, the counsellor continues to maintain contact through phone calls to monitor their emotional well-being and ensure treatment adherence.

Case study 7: Confidentiality, Sexual Orientation, and Internalized Stigma

Mr. Z is a 23-year-old male postgraduate student currently pursuing his M. Sc degree. He resides with his family and has no prior significant medical history and appeared physically healthy and was asymptomatic. HIV awareness and testing camp was organized by an NGO at a local bus stand as part of a public health outreach program. The camp provided free and voluntary testing services to the general public. Mr. Z approached the camp for a test on a random, voluntary basis and had no apparent reason for suspicion of HIV infection. To his complete surprise, the result of the rapid HIV screening test came back reactive. Mr. Z was immediately referred to ICTC for confirmatory testing and further counselling. Upon being informed of his HIV-positive status, Mr. Z was visibly shocked and emotionally overwhelmed. He was unable to process the diagnosis and quickly went into a state of emotional withdrawal. He reported feelings of disbelief, sadness, and anxiety, and showed early signs of depression. He became silent during the counselling session and avoided making eye contact. The counsellor provided immediate emotional support and scheduled follow-up sessions to help him cope with the diagnosis. In the first few sessions, Mr. Z remained reluctant to speak openly about his possible exposure. He denied having engaged in any high-risk behaviour and repeatedly stated that he could not understand how he might have contracted the virus. However, the counsellor maintained a non-judgmental, empathetic, and supportive approach, encouraging the client to talk at his own pace. Over the course of multiple sessions, trust was gradually built, and Mr. Z began to open up. He eventually disclosed that he had been involved in sexual

relationships with male partners and admitted that some of them were unprotected. Although initially hesitant to accept this as the mode of transmission, he later acknowledged it after receiving accurate information about HIV transmission and its risk factors. Mr. Z stated that his family, including his parents, were unaware of his HIV status as well as his sexual orientation. He expressed deep fear about disclosing this information to them due to anticipated stigma, rejection, and emotional distress it might cause within the family. He mentioned that his parents are conservative and may not understand or accept his sexual identity or health condition. Mr. Z expressed a strong desire to keep his diagnosis confidential. He feared social isolation, discrimination, and negative consequences on his academic and future professional life. He also shared concerns about his mental well-being and uncertainty about living with HIV. Mr. Z currently has shown gradual improvement in terms of emotional stability and understanding of his condition. He has accepted his HIV status and is mentally preparing to begin ART. Although he remains private about his sexual identity and diagnosis, he is receptive to continued counselling support. He has begun to regain confidence and is more willing to engage in future planning regarding his health, academics, and relationships.

Findings

Based on the seven case studies from Bidar district, several key findings emerge regarding the lived experiences of individuals with HIV, the challenges they face, and the role of counselling support.

1. Diverse pathways to diagnosis: The case studies highlight that HIV diagnosis occurs through various channels, not just through symptomatic presentation. While some individuals like Mr. K and Ms. A sought testing due to physical symptoms, others, such as Mr. A and Mr. Z, were diagnosed through voluntary and routine screenings at outreach camps or blood donation drives. This underscores the critical importance of widespread community-based testing initiatives in identifying asymptomatic individuals and facilitating early intervention.

2. Central role of ICTC Counsellors: ICTC counsellors were instrumental in every case, acting as a crucial link between diagnosis and treatment. They provided more than just medical information; they offered psychosocial support, crisis management, and emotional guidance. In Case Study 1, a counsellor's empathetic approach led to Mr. A's acceptance of his diagnosis and eventual marriage. In Case Study 3, the counsellor stood firm on ethical principles despite legal pressure, demonstrating the professional and moral fortitude required in these roles. The consistent follow-up, whether in person or via phone, as seen with Mr. R and Mr. M, was vital for maintaining treatment adherence and emotional support.

3. Pervasive stigma and fear of disclosure: Stigma remains a significant barrier to both disclosure and treatment adherence. Mr. K refused to inform his colleague and was reluctant to bring his wife for testing due to fear of social repercussions. Mrs. P's in-laws, driven by misconceptions, forced her out of her home and took her child. Mr. R's fear of his mother's emotional pain and societal judgment led him to conceal his identity with a mask and eventually discontinue treatment. Mr. Z's case further illustrates the compounded stigma of living with HIV alongside his sexual orientation, leading to immense fear of rejection from his family and community.

4. Family dynamics as a double-edged sword: Family plays a complex role in the lives of PLHIV. It can be a source of immense support, as seen in Case Study 5 where Ms. A's aunt took on the responsibility of her care. However, family can also be a source of significant conflict and distress. Mrs. P's husband,

initially supportive, surrendered to his family pressure, leading to separation and legal battles. Mr. M's parent's conflict by blaming his wife, ultimately contributing to the couple's separation and Mrs. M's miscarriage. This highlights the need for family-centric counselling to address misinformation and mediate conflicts.

5. Challenges with treatment adherence and long-term care: While some individuals, like Mr. A and Ms. A, show excellent adherence, others struggle. Mr. K's poor compliance and Mr. R's discontinuation of ART demonstrate that diagnosis and initial counselling do not guarantee sustained engagement with care. Factors such as alcohol use, fear of public exposure, and emotional distress contribute to non-adherence. The counsellor's persistent follow-up via phone was a key strategy in mitigating these challenges, particularly for clients who are geographically distant or resistant to in-person visits.

6. Intersection of socioeconomic status and HIV: The case studies involve individuals from diverse backgrounds, including migrant workers (Mr. A) and daily wage laborers (Mr. K, Mr. R). Their mobility and living situations create unique challenges, such as accessing continuous care when moving for work. The case of Mrs. P also shows how poverty can compound vulnerability, as her family's financial struggles indirectly led to her moving to Mumbai and entering into a high-risk relationship.

Conclusion

The case studies from Bidar district offer a profound look into the multi-faceted challenges and coping mechanisms of individuals living with HIV. They underscore that the experience of an HIV diagnosis is not solely a medical event, but a complex interplay of personal, social, and cultural factors.

First, the findings demonstrate the critical and indispensable role of ICTC counsellors. These professionals are more than just information providers; they are lifelines who offer consistent emotional support, ethical guidance, and practical assistance. Their ability to build trust and maintain follow-up, even in the face of client resistance or legal adversity, is central to the success of HIV care.

Second, the pervasive socio-cultural stigma surrounding HIV remains the most significant barrier to acceptance, disclosure, and sustained care. The fear of being rejected by family, or discriminated against in the community often leads to secrecy, psychological distress, and poor treatment adherence. This not only requires individual counselling but also broader community education and awareness programs.

Finally, the findings highlight the need for a holistic, patient-centered approach that extends beyond the clinic. This approach must address the diverse needs of different populations, including internal migrants, young people, and individuals with complex family dynamics. It must also recognize that successful outcomes, such as the hope and companionship found by Mr. and Mrs. A, are often the result of comprehensive support that addresses not just the viral load, but the person's entire lived experience. Continued support and strategic development of HIV care services are essential to ensure that every individual living with HIV can lead a life of health, dignity, and acceptance.

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