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# Perception of Participants towards Prevention and Control HIV/AIDS: A Qualitative Study

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#### Abstract

This qualitative study explores the perceptions and experiences of People Living with HIV/AIDS (PLHA) in Rupandehi, Nepal, focusing on awareness, stigma, and preventive strategies. Using a qualitative approach, data were collected from 40 respondents through Focus Group Discussions (FGDs) at four VCT centers. The findings reveal a significant shift in perceptions, with most participants demonstrating awareness of symptoms, transmission modes, and prevention methods, attributed to counseling and medical advancements. However, stigma and discrimination persist, especially among women, with negative attitudes from families, communities, and even healthcare providers. Socio-economic challenges, including migration, poor living conditions, and limited resources, were identified as critical factors contributing to vulnerability. Despite these challenges, respondents believed that HIV/AIDS prevention is possible through education, economic stability, healthcare access, and societal support. The study underscores the need for holistic interventions addressing structural inequalities, reducing stigma, and empowering PLHA to foster prevention and improved quality of life.

Key words: HIV/AIDS, awareness, prevention and control, stigma and discrimination.

# **Background**

Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) remain significant global public health challenges, particularly in low- and middle-income countries (Shrestha et al.,2017; Kakchhapati et al.,2018; Deuba et al., 2020; Wilson et al., 2021;NCASC,2023). Despite substantial advancements in prevention, treatment, and awareness, stigma, misconceptions, and cultural barriers continue to hinder effective control and prevention strategies (Subedi et al.,2019) HIV remains a significant global public health issue, having caused an estimated 42.3 million deaths to July 2024. Transmission continues to occur across all countries worldwide. In 2023 alone, approximately 630,000 people died from HIV-related causes, and an estimated 1.3 million individuals acquired the virus. While there is currently no

cure for HIV, access to effective prevention, diagnosis, treatment, and care, including for opportunistic infections, has transformed HIV into a manageable chronic condition. People living with HIV can now lead long and healthy lives with appropriate medical interventions and support (WHO, fact sheet, 2024).

Nepal, as a developing nation, faces unique challenges in combating HIV/AIDS (Paudel et al., 2017). According to national reports, the prevalence of HIV in Nepal is concentrated among key populations, including injecting drug users, sex workers, men who have sex with men, and migrants (NCASC, 2023). The Terai region, which includes Rupandehi District, has been identified as an area with a high vulnerability due to its proximity to border areas, significant migratory movements, and socio-economic disparities.

Public perception plays a crucial role in the success of HIV/AIDS prevention and control initiatives (Giri et al., 2014). Awareness, attitudes, and knowledge among the general population influence the adoption of preventive measures, reduction of stigma, and utilization of available healthcare services (Bhandari 2014). Understanding the perception of the people in a specific community can help tailor interventions to be more culturally and contextually appropriate.

Rupandehi District, being a socio-culturally diverse region with a mix of urban and rural settings, presents a unique case for studying community perceptions. The district's population includes individuals from various ethnicities, education levels, and socio-economic backgrounds, which can significantly impact their understanding and response to HIV/AIDS-related issues. Despite efforts by government and non-governmental organizations to disseminate information and provide services, gaps in knowledge and misconceptions persist.

This qualitative study aims to explore the perceptions of people in Rupandehi regarding HIV/AIDS prevention and control. By identifying levels of awareness, prevailing attitudes, and existing barriers, the research seeks to provide evidence-based recommendations for enhancing public health strategies in the region. Addressing these gaps is crucial for achieving the national and global targets of reducing new infections, eliminating stigma, and improving the quality of life for those living with HIV/AIDS.

## **Materials and Methods**

**Study Design**: This study employed a qualitative research design using focus group discussions (FGDs) to gather in-depth insights into the experiences, perspectives, and challenges faced by people living with HIV (PLHIV) who visit VCT4 centers. Study Setting and Population. The study was conducted at selected VCT4 centers. The target population comprised individuals living with HIV who were registered (87) as clients of these centers between 11, June to 11, August, 2024. A total of 10 respondents from each center participated, ensuring diversity in responses while maintaining manageability in the research process.

**Participants Selection Method:** A purposive sampling technique was used to select participants. Being a registered client of the VCT4 center, willingness and ability to participate in the study and provision of informed consent were the criteria of inclusion.

Information Collection Technique: Focus Group Discussions (FGDs) were the primary information collection method. Each FGD included 10 participants from each VCT4 center to facilitate meaningful interactions and discussions. The discussions were guided by a semi-structured discussion guide designed to explore the key insides of the study. Each FGD session lasted approximately 80–90 minutes.

To ensure confidentiality, participants were assigned codes that were used by the note-taker to identify individual voices during transcription and referencing of quotations. Each focus group was assigned a unique identification number, which was recorded on the discussion forms, notes, audio files, and transcript documents. Audio recordings were transcribed into Word documents and securely stored on a password-protected laptop. The transcriptions were thoroughly proofread against the audio files by both the transcriber and a supervising researcher to ensure accuracy, address any missed or misheard words, and clarify unclear terminology. Notes were translated into English from the local languages where necessary.

# **Data Analysis and truth worthiness**

The data were analyzed using conventional content analysis, employing the constant comparison method. This approach is particularly suitable when there is limited existing theory or research on the phenomenon being studied (Hsieh, & Shannon, 2005). To ensure the reliability and validity of the analyzed data, four key criteria—credibility, dependability, conformability, and transferability—were applied as outlined by (Guba & Lincoln, 1994, Fatemeh et. all, 2017).

## **Ethical Considerations**

Each participant was provided with detailed information about the study, including its purpose, procedures, potential risks, and benefits. Consent forms were signed before participation. All collected data was anonymized to protect the identities of participants. Any identifiable information was securely stored and accessible only to authorized personnel. Participation in the study was entirely voluntary, and participants were free to withdraw at any point without any consequences.

#### Limitations

The study relied on self-reported data, which may be subject to recall bias or social desirability bias. Findings may not be generalizable beyond the specific VCT4 centers included in the study.

Result Demographic Characteristics of the Participants

Age of the participants	Frequency	Percent
26 Years	3	7.5
28 Years	5	12.5
32 Years	15	37.5
35 Years	5	12.5
42 Years	12	30.0
Total	40	100
Gender of the participants		
Male	26	65
Female	14	35
Total	40	100

The data provides a demographic overview of the participants study about people's perceptions of the prevention and control of HIV/AIDS. The most represented age group is 32 years old, comprising 37.5% of the total participants (15 out of 40). This suggests that middle-aged individuals may have been more engaged or accessible for the study. Participants aged 42 years represent the second-largest group, making up 30% (12 out of 40). This highlights a significant representation of older adults in the study. Individuals aged 28 and 35 years each account for 12.5% (5 out of 40). These groups are moderately represented, showing some variation in the age range of respondents. The smallest groups are 26 years old participants, constituting only 7.5% (3 out of 40. Male participants make up the majority, constituting 65% (26 out of 40). Female participants account for 35% (14 out of 40). The study has a diverse age representation, with a higher concentration of middle-aged and older adults, and Younger participants are underrepresented and men were more involved or more accessible for this study.

# Status of Awareness about Symptoms

Assessing awareness of HIV/AIDS symptoms is vital to understanding the knowledge levels among respondents. Thus the question related to Symptoms of HIV/AIDS were asked to the respondents .The study found that individuals who had been on ART for five years or more were more open to discussing HIV/AIDS-related topics. Most participants were able to identify the symptoms of HIV/AIDS, a recognition they attributed to awareness campaigns led by local NGOs.

For example, a 42-year-old woman (FGD 3) from a socio-economically disadvantaged group, whose husband had passed away from HIV-related complications five years earlier, openly shared her understanding of the disease. She identified persistent fever, prolonged diarrhea, significant weight loss, and general weakness as symptoms she had experienced, leading her to suspect an HIV infection.

Participants rated the severity of self-reported symptoms based on whether they required immediate medical attention (serious) or were manageable without urgent care (mild). Serious symptoms included persistent fever with headache and body ache, diarrhea lasting more than two weeks with dehydration, marked weight loss, severe itching, high-grade prolonged fever, facial discoloration, anemia, jaundice, stress-related unconsciousness, and gland enlargement (glandular tuberculosis). Conversely, mild symptoms encompassed mild fever, short-term diarrhea, fatigue, headache, lymph node enlargement, and mild anemia.

The respondents consistently noted fever and body ache as the earliest signs of HIV/AIDS. Early recognition of these symptoms is critical for timely diagnosis and treatment, which can prevent severe complications and reduce the likelihood of virus transmission to others. Raising awareness about these early signs is essential to improving public health outcomes and fostering proactive healthcare-seeking behavior.

## Status of Awareness about Modes of Transmission

During FGD session the participants were asked about the mode of transmission of HIV. All respondents demonstrated an understanding of how HIV/AIDS is transmitted. They identified unsafe sexual contact with an infected person, exposure to infected blood, sharing needles and syringes, using contaminated blades, organ transplantation, and mother-to-child transmission as the primary modes of transmission. Their knowledge reflected alignment with scientific medical understanding, particularly regarding the role of unsafe sexual practices as a significant factor in the spread of HIV/AIDS.

Participants highlighted (N-5) that the spread of HIV/AIDS is influenced by multiple factors, including migration patterns, socio-economic conditions, living and working environments, and the availability of health services. This underscores the interconnectedness of awareness, prevention, and broader socio-economic contexts.

In earlier periods of HIV/AIDS prevalence within the community, there were misconceptions about casual transmission, such as through shared clothing, utensils, or food. However, this misunderstanding has substantially decreased due to awareness programs, medication accessibility, and training sessions organized by local NGOs with

the support of international agencies. These efforts included engaging family members and community leaders to dispel myths and reduce stigma.

The information provided by PLWHA about the modes of transmission underscores the importance of awareness as a cornerstone for prevention. It highlights how enhanced understanding of transmission routes directly supports the adoption of preventive measures and reduces misconceptions, thereby contributing to better management and control of the disease.

# **Experience about infection of HIV**

During the Focus Group Discussion (FGD) sessions the respondents were request to share their experience about infection of HIV/AIDS; many respondents were hesitant to discuss their experiences related to HIV infection. This reluctance stemmed from concerns about self-dignity and the belief that such personal matters did not require justification or exposure. This highlights the stigma and shame often associated with HIV, which can discourage open discussions about the circumstances of infection. Despite the initial unwillingness, some participants eventually shared their stories after prolonged efforts to build trust and familiarity. Their narratives provide valuable insights into the socio-economic, emotional, and psychological factors contributing to their HIV infections.

A 35-year-old woman described her painful journey, which began with marital discord and economic hardship. Following her husband's infidelity, she relocated to Butwal, where she initially supported herself by selling vegetables. Through a chance encounter, she was introduced to commercial sex work, initially facilitated by a colleague. Over time, she independently built her clientele. After several years in the trade, she experienced symptoms such as persistent diarrhea and weight loss, leading her to seek medical help at a Voluntary Counseling and Testing (VCT) clinic. Her subsequent diagnosis of HIV initiated her journey into antiretroviral therapy (ART) and marked a turning point in her life.

This case underscores the interplay between economic vulnerability, lack of social support, and exposure to high-risk behaviors as key factors contributing to HIV infection.

Similarly, a 32-year-old man shared his life story, which was shaped by early family disruptions and economic struggles. After losing his mother, he took on family responsibilities but faced additional challenges when his father remarried. Dropping out of school, he migrated to India for work, where he engaged in high-risk behaviors such as visiting commercial sex workers under the influence of alcohol.

He discovered his HIV-positive status during a medical checkup required for overseas employment. The diagnosis had a profound emotional impact, including feelings of despair and suicidal ideation. Despite these challenges, he rebuilt his life by joining a community-based organization (NAMUNA) as a CHBC (Community Home-Based Care) worker, providing support to other People Living with HIV/AIDS (PLHIV). Over time, he reconciled with his estranged wife and daughter, demonstrating resilience and the possibility of rebuilding relationships of post-diagnosis.

This narrative highlights the role of migration, peer influence, and lack of awareness as contributors to HIV infection, while also emphasizing the potential for recovery and reintegration through support systems and employment in community health services.

The experiences shared by these respondents illustrate the multifaceted nature of HIV infection, which often stems from a combination of socio-economic vulnerability, personal circumstances, and lack of awareness about preventive measures. Both cases highlight critical issues such as stigma, the emotional toll of diagnosis, and the importance of support networks in fostering resilience and recovery.

These stories also underline the importance of community-based interventions, education, and economic empowerment in reducing HIV transmission. Addressing the underlying factors—such as poverty, migration, and lack of awareness—can significantly contribute to the prevention and management of HIV. Moreover, integrating PLHIV into healthcare roles, as seen in the second case, can promote empathy-driven care and serve as a powerful example of how individuals can rebuild their lives while contributing to the broader fight against HIV/AIDS.

# Experience and perception about Social stigma, discrimination

Social stigma and discrimination remain significant challenges for People Living with HIV/AIDS (PLHA). During FGDs, the participants were asked to share their experience and perception about social stigma and discrimination, maximum participants shared their experiences of being negatively perceived and treated by their families, friends, neighbors, and even healthcare professionals due to their HIV status. The accounts revealed that stigma and discrimination are deeply rooted in societal norms, misconceptions about HIV transmission, and gender inequalities, further exacerbating the challenges faced by PLHA.

#### **Experiences of Male PLHA**

Male participants reported mixed experiences regarding support from their partners and families. Some faced rejection and abandonment, as in the case of a 32-year-old migrant worker whose wife left him after disclosing his HIV status. She accused him of immorality and publicized his condition without his consent, leaving him socially isolated.

Conversely, there were examples of resilience and support, such as a 41-year-old laborer whose wife and son provided unwavering care. This support significantly contributed to his emotional and physical well-being, showcasing the importance of close family bonds in mitigating the impact of HIV-related stigma.

# **Experiences of Female PLHA**

Female participants were more vulnerable to stigma and discrimination, reflecting societal and cultural norms that perpetuate gender inequality. Many women reported being ostracized by neighbors and relatives, treated as outcasts even within their own families. A 42-year-old housewife shared how her in-laws separated her and her husband from the family and prohibited them from using shared facilities like bathrooms due to unfounded fears of casual transmission.

This compounded discrimination was also observed when women sought emotional support. Instead of empathy, they faced further stigmatization, illustrating how deeply entrenched misconceptions about HIV/AIDS exacerbate their social isolation.

# **Discrimination in Healthcare Settings**

Participants expressed disappointment at the discriminatory behavior of healthcare workers, particularly nurses and laboratory technicians. While some doctors displayed professionalism and compassion, other healthcare staff lacked sensitivity and perpetuated stigma. For instance, a 35-year-old woman recounted being referred to as a "different type of case" in her native language, which she found deeply offensive and discriminatory. Such behavior highlights gaps in training and awareness among healthcare professionals, which undermine the trust and confidence of PLHA in the medical system.

The experiences shared by PLHA during the FGDs emphasize the pervasive stigma and discrimination that persist in various aspects of their lives. Male and female PLHA face different challenges, with women disproportionately bearing the brunt of societal and familial rejection due to entrenched gender biases.

Supportive relationships, particularly from immediate family members, emerged as a critical factor in helping PLHA cope with the emotional and social challenges of living with HIV. Conversely, the absence of support and the presence of stigma can lead to isolation, emotional distress, and reduced quality of life.

Discrimination within healthcare settings further compounds the challenges faced by PLHA, underscoring the need for targeted training and sensitization programs for healthcare workers. These programs should focus on eliminating bias and promoting compassionate care. By addressing these issues holistically, we can foster a more inclusive and supportive environment for PLHA, enabling them to lead healthier and more dignified lives.

# Perception and experience toward the prevention and control of HIV/AIDS

Awareness of prevention and control methods for HIV/AIDS is essential to combat the spread of the virus, reduce stigma, and empower individuals to protect themselves and their communities. During focus group discussion session questions were asked to the participant about prevention and control measures of HIV/AIDS. The key perception and experience shared by the respondents is given in the following sub-headings.

# Awareness of Prevention Methods

The study reveals that the majority of PLHA believe HIV/AIDS is preventable, and this understanding is influenced by their awareness of various socio-economic and behavioral factors. The participants identified multiple dimensions—such as migration, employment opportunities, socio-economic conditions, healthcare access, and education—as key elements in the prevention and control of HIV/AIDS.

In the past, HIV/AIDS was perceived as a fatal and morally stigmatized disease, especially in rural areas. This perception has shifted over time, largely due to the

introduction of medical treatment, counseling programs, and social support systems. The evolving narrative among PLHA reflects a growing recognition of how education, awareness, and support can play a critical role in combating the disease.

# **Community-Level Challenges**

Participants highlighted that many in their communities are engaged in agriculture, daily wage labor, or seasonal migration, but they lack access to adequate food, animal products, and other resources necessary for maintaining good health. These economic vulnerabilities make individuals more susceptible to diseases, including HIV/AIDS, emphasizing the importance of addressing structural factors such as food security, better working conditions, and access to healthcare.

# **Changing Perceptions and Stigma Reduction**

Respondents emphasized the need to educate the broader community about the realities of HIV/AIDS transmission and to work towards reducing social stigma and discrimination. Many stated that earlier misconceptions about the disease being unpreventable or linked to "bad habits" have shifted, paving the way for a more informed and supportive approach to prevention and control.

# **Findings**

Most respondents identified key symptoms such as persistent fever, prolonged diarrhea, significant weight loss, and general weakness, largely due to NGO-led awareness campaigns. Fever and body ache were commonly noted as early signs. Participants distinguished between serious symptoms requiring immediate medical attention (e.g., severe diarrhea, gland enlargement) and mild symptoms (e.g., short-term diarrhea, mild anemia). Respondents identified unsafe sexual contact, exposure to infected blood, needle sharing, and mother-to-child transmission as key routes, reflecting alignment with scientific knowledge. Misunderstandings about casual transmission have significantly declined due to targeted awareness campaigns and community engagement. Economic hardship, migration, and lack of social support often led to high-risk behaviors, increasing infection risks. Support systems, ART access, and community-based programs enabled resilience, reintegration, and personal transformation for PLHIV. PLHIV faced stigma from family, neighbors, and healthcare providers, often rooted in misconceptions about transmission and societal norms. Women experienced compounded discrimination due to gender inequality, while men reported mixed support from families. Instances of bias and insensitivity among healthcare workers undermined trust in medical systems. Participants recognized prevention methods and the importance of addressing socio-economic and behavioral factors to reduce transmission. Economic vulnerabilities such as food insecurity and poor access to healthcare were identified as barriers to effective prevention. Growing awareness and education programs have shifted community attitudes, reducing stigma and promoting informed prevention measures.

#### Discussion

This study was conducted in the Rupandehi district of Lumbini Province, Nepal, with a sample of 40 People Living with HIV/AIDS (PLHIV) at four Voluntary Counseling and Testing (VCT) centers. The findings highlight the complex nature of HIV/AIDS awareness, experiences, and the challenges faced by PLHIV.

# **Awareness of Symptoms**

The study reveals that most respondents could identify early symptoms of HIV/AIDS, such as fever, weight loss, and diarrhea. This early recognition is critical for timely diagnosis and treatment. Similar findings were reported by Imran et al. (2014) in their study on HIV/AIDS awareness. The distinction made by participants between mild and serious symptoms underscores the need for educating communities about symptoms requiring immediate medical intervention. Promoting early recognition and encouraging proactive healthcare-seeking behaviors are essential for reducing complications and preventing the spread of the virus.

## **Awareness of Modes of Transmission**

Respondents demonstrated a solid understanding of HIV transmission, accurately identifying routes such as unsafe sexual contact, exposure to infected blood, and mother-to-child transmission. This reflects the success of targeted educational initiatives. Fadi et al. (2022) reported similar findings in Saudi Arabia, where a high percentage of respondents displayed good knowledge of HIV/AIDS. However, the earlier prevalence of misconceptions—such as beliefs in casual transmission through shared utensils or clothing—indicates the ongoing challenge of dispelling myths in rural or less-informed communities. The observed reduction in such misconceptions highlights the pivotal role of community-level interventions and training sessions in enhancing public health literacy.

# Socio-Economic and Psychological Factors

The socio-economic and psychological factors associated with HIV infection were evident in the narratives of PLHIV. Economic vulnerability, lack of social support, and migration often drove individuals toward high-risk behaviors, contributing to the spread of HIV. Extensive evidence, such as the studies by Levi et al. (2018) and Rajaraman et al. (2006), supports the link between poverty and higher HIV prevalence. Lower the gross national income (GNI) and per capita income correlates with reduced antiretroviral treatment coverage, further exacerbating HIV prevalence. Despite these challenges, stories of resilience and recovery—including reintegration into families and communities—illustrate the transformative impact of antiretroviral therapy (ART), community support, and employment in health-related roles. These findings underscore the need for holistic strategies that address socio-economic vulnerabilities while providing robust healthcare support.

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# Stigma and Discrimination

Persistent stigma remains a significant societal barrier to effective HIV/AIDS management. Women disproportionately bear the brunt of stigma due to entrenched gender inequalities, facing rejection and isolation even within their families. Discrimination in healthcare settings further exacerbates these challenges, exposing gaps in sensitivity training for healthcare workers. Similar findings were reported by Subedi et al. (2018) in Pokhara, Nepal, where high levels of felt stigma led to nondisclosure of seropositive status. Fatemeh et al. (2017) and Farhad et al. (2019) also noted that fear of stigmatization in women persists, even after starting treatment. Addressing stigma requires a multifaceted approach that includes education, community engagement, and structural reforms to ensure empathy-driven care and social acceptance.

# **Evolving Perceptions and Structural Interventions**

The shifting perception of HIV as a preventable and manageable condition reflects significant progress in awareness efforts. However, socio-economic conditions, migration, and limited access to resources remain significant barriers to prevention and control. Participants emphasized the need for comprehensive community education to combat lingering stigma and misconceptions. Structural interventions—such as improving healthcare access, ensuring food security, and providing economic opportunities for PLHIV—are essential for sustainable prevention and management of HIV/AIDS.

## Conclusion

The study highlights the complex interplay of social, economic, cultural, and health-related factors influencing the lives of People Living with HIV/AIDS (PLHA) in Rupandehi, Nepal. The key findings reveal a gradual but significant shift in perceptions and experiences regarding HIV/AIDS, driven by awareness programs, medical advancements, and social support systems.

While significant progress have been made in improving awareness and access to treatment. Addressing the socio-economic and cultural factors surrounding HIV/AIDS remains critical. By fostering a supportive environment through education, healthcare, and socio-economic interventions, it is possible to further reduce the impact of stigma and discrimination and empower PLHA to lead healthier and more fulfilling lives..

## **Implication of the study**

This study has several critical implications for public health policy, healthcare delivery, community engagement, and socio-economic interventions aimed at managing and preventing HIV/AIDS.

• The findings highlight the need for sustained educational programs to improve awareness of HIV/AIDS symptoms and modes of transmission, especially in rural and socio-economically disadvantaged areas. Campaigns should address early symptom recognition and emphasize the importance of timely diagnosis.

- Efforts to reduce misconceptions about casual transmission must continue, with culturally sensitive strategies that engage local leaders and community groups to combat stigma.
- The discriminatory attitudes reported in healthcare settings point to an urgent need for sensitization programs. Healthcare workers must be trained to provide stigma-free, empathetic care to People Living with HIV/AIDS (PLHIV).
- The pervasive stigma, especially against women, requires focused interventions to address gender inequalities and societal biases. Communitywide efforts, including educational programs and advocacy campaigns, can help foster acceptance and reduce discrimination.
- Continuous monitoring of awareness levels and healthcare access can help identify gaps and measure the effectiveness of interventions..
- Comprehensive sex education programs that address HIV/AIDS should be integrated into school curriculums, targeting youth to reduce future infection rates.
- Providing vocational training and employment opportunities for PLHIV can reduce economic vulnerabilities, promote reintegration, and enhance their quality of life.
- Further research is needed to explore the intersection of socio-economic factors, gender dynamics, and HIV vulnerability. This can inform tailored strategies for prevention and management.

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