Proceedings of ICMMGH 2026 Symposium: Cell and Molecular Biology: Understanding Immune Cell Functions
DOI: 10.54254/2753-8818/2026.PJ31116

The Experiences and Social Support of PLHIV: A Multi-Perspective Study

Michelle Muxiao Wang

Haidian Foreign Language Academy, Beijing, China
18518193999@163.com

Abstract. This qualitative study explores the experiences and social support needs of people living with HIV (PLHIV) through the perspectives of doctors, nurses, and community volunteers in Beijing. Drawing on six semi-structured interviews, the research identifies key emotional, social, and structural challenges faced by PLHIV and reveals the different ways in which medical and community stakeholders conceptualize support. While doctors emphasize clinical stability and biomedical management, nurses focus on emotional support and relational trust, and volunteers stress education, stigma reduction, and disclosure counseling. Thematic analysis shows convergences in understanding psychosocial burdens, but also important divergences in perceptions of stigma, role responsibilities, and care priorities. The study highlights the need for integrated, cross-sectoral support systems that bridge clinical expertise and community-based outreach to better serve PLHIV across age and social contexts.

Keywords: HIV, stigma, social support, China, thematic analysis

1. Introduction: HIV care context and stakeholder perspectives

HIV remains a critical global health challenge where stigma and fragmented support systems continue blocking comprehensive care despite medical advancements [1]. In China, this situation is complicated by an aging epidemic—44% of new infections in 2022 occurred in people over 50—yet most interventions target younger populations [2]. Healthcare providers and volunteers hold contrasting views on patient needs: doctors and nurses typically prioritize clinical outcomes like viral suppression [3], while volunteers emphasize community-level needs such as social integration and stigma reduction [4]. These differing perspectives create disconnected support systems. For instance, physicians might concentrate on medication adherence, whereas volunteers address isolation from family rejection. This gap is particularly evident in Beijing where advanced medical facilities coexist with persistent discrimination—72.1% of people living with HIV report clinical discrimination, and only 30% disclose their status to partners due to fear of rejection [5].

2. Research purpose and significance

2.1. Purpose statement and objectives

This qualitative research investigates how Beijing-based healthcare providers and volunteers perceive the daily experiences and support needs of people living with HIV [6]. The study seeks to identify where these perspectives align or diverge to develop practical strategies connecting clinical and community support systems. The primary objectives involve comparing stakeholder views on psychosocial challenges like stigma and aging-related needs, identifying unmet support requirements throughout the care journey, and proposing integrated intervention models that combine different support approaches [7].

2.2. Theoretical and practical significance

Theoretically, this work expands social support theory by examining how emotional, informational, and instrumental assistance functions within HIV care ecosystems. Previous research confirms that strong support reduces stigma's mental health impact by 40% , but how medical staff and volunteers prioritize different support dimensions remains unexplored. For example, nurses may consider "trust-building" essential for treatment adherence [8], while volunteers champion "community education" against discrimination. Practically, findings can directly improve China’s HIV response by addressing mental health service gaps [9], creating age-sensitive interventions for older patients facing compounded stigma, and developing sustainable support networks resilient to funding instability [1].

3. Literature review

3.1. Social support mechanisms and gaps

Social support functions through distinct pathways with varying effectiveness. Practical assistance like transportation subsidies directly improves medication adherence in resource-limited settings [3], though significant disparities exist—rural Chinese patients with low incomes receive 23% less support than wealthier peers, leading to delayed clinic visits [10]. Emotional support through peer counseling reduces depression rates by 40% even amidst stigma. Information sharing by volunteers, such as explaining treatment protocols, increases treatment readiness by 33% among newly diagnosed individuals. Support needs differ substantially across patient groups: older adults struggle with memory-related medication challenges [9]; long-term survivors require employment assistance to counter "survivor guilt" ; and newly diagnosed individuals often need crisis support while fewer than 30% disclose their status within the first year [5].

3.2. Stigma as a structural barrier

HIV-related stigma operates through interconnected layers that systematically undermine care. Medical discrimination remains widespread, with 72.1% of Chinese patients experiencing clinic segregation or denied surgeries, exacerbating mental health burdens and reducing quality of life by 28% . Community stigma manifests as resistance to HIV education, particularly among elderly and rural residents due to cultural taboos, causing 60% of volunteer-led disclosure efforts to fail [11]. Most critically, intersectional stigma compounds these effects—68% of elderly patients endure moral judgments like "HIV is punishment" [9] , intensifying isolation through combined ageism and HIV prejudice.

3.3. Stakeholder perspectives and collaborative models

Clinicians consistently report systemic constraints, with doctors highlighting diagnostic limitations in primary care and nurses experiencing double the burnout rates due to emotional demands and infection concerns [9]. Both groups prioritize clinical metrics, sometimes overlooking psychosocial needs—a disconnect reflected when patients describe feeling "reduced to lab results" [8]. Volunteers bridge clinical-community divides but encounter unique obstacles including resistance from older communities and program instability where 70% collapse after funding ends [1].

4. Methodology

4.1. Research design and participant recruitment

This study employs a qualitative exploratory design using semi-structured interviews with six participants from a Beijing HIV support organization: two infectious disease physicians averaging eight years' experience, two specialized HIV nurses with five-plus years in follow-up care, and two community outreach volunteers with three-plus years' service.

4.2. Interview protocol and instrumentation

Conducted via Zoom (10-20 minutes each), interviews use role-specific questions derived from research objectives. Physicians discuss treatment advancements through prompts like "How have antiretroviral side effects impacted adherence compared to a decade ago?" Nurses explore psychosocial care dynamics with questions such as "What nursing approaches address patients' fear of being 'defined by HIV'?" Volunteers examine community engagement obstacles via inquiries like "Which populations resist HIV education most strongly?"

4.3. Ethical compliance documentation

Informed consent obtained through digital forms explicitly states: "Recordings will be destroyed after transcription and publications will use pseudonyms like 'Nurse A'. I may withdraw anytime without penalty"

5. Results

5.1. Doctors' perspectives

Doctors generally viewed HIV as a chronic but controllable illness, emphasizing medical advancements and improved treatment systems. They highlighted that newer single-tablet regimens have fewer side effects and better adherence compared to previous multi-pill options. In their opinion, treatment discontinuation was rarely due to external stigma, but more often resulted from patients' mental distress, internalized stigma, or financial difficulties. One physician shared a case where a patient took his own life shortly after diagnosis, stating, “He feared the disease and social rejection.” This illustrates how fear of disclosure and diagnosis-related distress can critically affect patients in the early stages.

Despite their professional knowledge, doctors acknowledged that many healthcare providers outside of HIV specialties lack sufficient understanding of HIV. They observed that some general practitioners or surgeons respond with excessive caution or discomfort. As one physician noted, “Even some liver doctors in our hospital don’t fully understand HIV and act overly cautious.” Although not necessarily intentional discrimination, these reactions reflect gaps in training. Doctors also underscored the importance of informational support from peer volunteers and counselors after diagnosis. As one said, “With the right education, patients understand this is a treatable chronic disease—not a death sentence.” While physicians operate within a clinical framework, they recognized the need for complementary psychosocial support.

5.2. Nurses’ perspectives

Nurses emphasized the importance of emotional support and building trust in patient care. Trust-building was viewed as essential to reducing fear of death and addressing family-related secrecy. They described patients’ early stages—particularly after diagnosis—as marked by anxiety and isolation. “They often think they’re dying,” one nurse remarked. Nurses responded by providing reassurance: “We explain that treatment works, and that they can live long lives.” Some nurses shared personal experiences to help patients feel understood. One mentioned telling a suicidal patient about her own upcoming surgery, which improved his outlook.

Another key concern was the need to treat patients equally and maintain confidentiality. Nurses emphasized that both overt discrimination and excessive attention could make patients feel singled out. One explained, “We told the staff not to whisper or act differently—just treat them like any other patient.” Confidentiality was also central; if patients preferred not to inform family members, nurses respected their wishes. “Unless it’s a critical emergency, we don’t tell their relatives,” one nurse noted. Overall, nurses served as essential intermediaries by offering both emotional support and reliable health information to encourage ongoing care engagement.

5.3. Volunteers’ perspectives

Volunteers focused on social stigma, misinformation, and disclosure-related challenges outside clinical settings. A particularly notable issue was professional resistance, where even well-educated individuals—including healthcare providers—expressed discomfort when discussing HIV. “We’ve seen doctors panic when HIV is mentioned—they don’t know how to respond,” one volunteer stated. Volunteers also addressed the issue of disclosure anxiety, particularly among older or married individuals. To assist, they helped patients assess the risks and benefits of disclosure, occasionally recommending indirect methods such as joint health check-ups with partners.

Educational outreach played a central role in their work. Volunteers frequently used interactive tools to challenge stereotypes—for example, asking participants to role-play identities such as “student,” “housewife,” or “construction worker” and discuss who is most at risk. These activities demonstrated that HIV is not confined to any single group. “It shows them that infection has no fixed identity,” one explained. Volunteers also discussed rising vulnerability among older men, particularly closeted individuals. One case involved an 84-year-old man who feared telling his daughters; with support, he successfully disclosed his status to one daughter, who responded with understanding. Their narratives revealed how volunteer-led interventions can bridge the gap between formal medical care and community realities.

6. Discussion

6.1. Shared recognition of psychosocial challenges

Doctors, nurses, and volunteers all acknowledged that HIV carries significant emotional and social burdens beyond its clinical management. Consistent with prior studies, participants identified fear of death, anxiety around disclosure, and social isolation as central concerns, particularly following diagnosis or health deterioration.Doctors noted cases where internalized stigma led to treatment refusal or suicide. Nurses emphasized the role of emotional reassurance and correcting misconceptions about prognosis. Volunteers observed these struggles in community contexts and offered practical strategies for disclosure and support. Despite differences in approach, all three groups affirmed that psychosocial support is critical for long-term care.

6.2. Diverging views on stigma

A significant difference emerged in how participants perceived stigma. Doctors, especially those in infectious disease departments, believed that discrimination was rare within hospitals and attributed stigma mainly to society or patients' internal fears. In contrast, volunteers reported frequent stigma among non-specialist medical staff, citing discomfort and misinformation. This observation supports earlier research showing that stigma persists in healthcare settings [9].

Nurses described their own process of attitudinal change—initial hesitation that gradually shifted to acceptance with clinical experience. This suggests that personal exposure to HIV care can reduce bias, though reliance on such organic change may be insufficient without institutional support and training. These differing perspectives reflect broader gaps between perceived and actual stigma in health environments.

6.3. Role-based support strategies

Participants also differed in how they understood their responsibilities. Doctors focused on providing clinical support such as diagnosis, medication, and referrals—often in response to acute needs. Nurses saw themselves as consistent caregivers, offering emotional guidance, confidentiality, and everyday reassurance. Volunteers concentrated on community education, public stigma reduction, and disclosure support, often through creative, interactive formats.

Notably, only volunteers emphasized the growing issue of older PLHIV. This suggests that certain vulnerable groups may remain under-recognized in clinical practice, reinforcing the need to better integrate medical and community-based perspectives.

6.4. Moving toward integrated HIV care

Overall, the findings suggest a need to strengthen collaboration between hospitals and community-based organizations. As UNAIDS [1] emphasizes, effective HIV responses rely on partnerships across sectors. In practical terms, this involves enhancing medical staff's training in empathy, supporting nurses in delivering sustained emotional care, and formally recognizing the role of volunteers in disclosure and outreach—especially for underserved groups like older men or hidden populations.

While prior research notes that emotional, informational, and clinical support each help reduce stigma, this study shows that such support is unevenly distributed across roles. For example, doctors may overlook emotional needs, while nurses may not have time for long-term follow-up. Cross-role collaboration and shared care protocols can help address these disparities and ensure more comprehensive support for PLHIV.

7. Conclusion and recommendations

7.1. Conclusion

This study examined how different stakeholders—doctors, nurses, and volunteers—understand and support people living with HIV in Beijing. All participants recognized the emotional impact of HIV, including fear, stigma, and uncertainty. However, their roles and perspectives varied: doctors emphasized medical management, nurses highlighted relational support, and volunteers focused on education and social reintegration.The findings reveal that support systems remain uneven and sometimes disconnected. Volunteers often detect social barriers that are less visible within clinical institutions. Furthermore, groups such as older PLHIV are sometimes overlooked, pointing to the need for a more inclusive and coordinated care model.

7.2. Recommendations

To improve outcomes for PLHIV, healthcare providers and community organizations should work in close coordination. Hospitals should create structured partnerships with volunteer groups to strengthen referral systems and emotional care, particularly for socially marginalized populations. HIV knowledge should be expanded across all clinical departments, not just within infectious disease units, to reduce stigma and misinformation.Emotional support should be recognized as an integral part of care. This includes training for nurses and the incorporation of peer counselors. Community education efforts should continue to address misconceptions and promote the idea that HIV is a manageable condition. Consistent public messaging can reduce fear, support early treatment, and improve the quality of life for those living with HIV.

References

[1] UNAIDS. (2025). Community workers at the heart of a resilient HIV response in Ethiopia.https: //www.unaids.org/en/resources/presscentre/featurestories/2025/july/20250722_ethiopia
[2] Lin, L. (2025, August 3). Guangzhou medical volunteers serve homebound elders. Guangzhou Daily. https: //huacheng.gz-cmc.com/pages/2025/08/03/f2a091049b9948d6ad53ede6e7489df3.html
[3] Hoffmann, C. J., Moyo, C., & Murdoch, D. M. (2024). Structured peer-delivered ART and re-entry community strategies (SPARCS) [Clinical trial registration No. NCT06027671]. ClinicalTrials.gov. https: //clinicaltrials.gov/ct2/show/NCT06027671
[4] Shanghai Municipal Health Commission. (2025, July 15). Social forces co-participate in hospital governance. Sohu News. https: //www.sohu.com/a/859246010_120823584
[5] Long-Term Survival With HIV Study. (2007). Psychological and behavioral factors associated with the transition from adolescence to young adulthood [Clinical trial registration No. NCT00026806]. ClinicalTrials.gov. https: //clinicaltrials.gov/ct2/show/NCT00026806
[6] Wei, Y., Lin, Q., Zhao, R., & Wu, T. (2022). Factors influencing hospital volunteer motivation under multi-agent governance. Jiangsu Healthcare Administration, 33(8), 110–115.
[7] Xie, J., & Wang, H. (2022). Patient-centered clinical trials as a future mainstream model. Health News, 42(11), 34–37.
[8] iLIVE Study Group. (2025). Volunteer and healthcare professional perceptions of newly developed hospital end-of-life-care volunteer services. Palliative Medicine, 39(7), 792–802. https: //doi.org/10.1177/02692163251328197
[9] Li, X., Zhang, L., Zhou, M., & Shen, Z. (2004). Anxiety and depression of HIV-infected persons/AIDS patients and their family members. Chinese Mental Health Journal, 18(5), 329–331.

[10] Yin, Y., & Chen, H. (2019). Social support status and influencing factors among HIV/AIDS patients in Liangshan Prefecture. Chinese Journal of Disease Control & Prevention, 23(1), 110–113. https: //doi.org/10.16462/j.cnki.zhjbkz.2019.01.023

[11] McGowan, M., Bärnighausen, K., Berner-Rodoreda, A., Danhoundo, G., & Laizer, E. (2024). "The targets…are driving the agenda and that probably needs to change": Stakeholder perspectives on HIV partner notification in sub-Saharan Africa. BMC Public Health, 24(1), 123. https: //doi.org/10.1186/s12889-023-17422-9