The Role of Peer Groups in HIV Case Finding, Diagnosis, Care, and Treatment: A Qualitative Study

Narsis Ghahramani[1], Pegah Mirzapour[1], Tina Eslambeik[1], Mahdi Sheykhi[1], Sogol Alikarami[2], Abbas Boosiraz[1], Seyed Ali Dehghan Manshadi[3*], SeyedAhmad SeyedAlinaghi[1,4], Shayesteh Jahanfar[5]**

[1] *Iranian Research Center for HIV/AIDS, Iranian Institute for Reduction of High-Risk Behaviors, Tehran University of Medical Sciences, Tehran, Iran*

[2] *Pain Research Center, Neuroscience Institute, Imam Khomeini Hospital Complex, Tehran University of Medical Sciences, Tehran, Iran*

[3] *Department of Infectious Diseases and Tropical Medicine, Imam Khomeini Hospital Complex, Tehran University of Medical Sciences, Tehran, Iran*

[4] *Research Development Center, Arash Women's Hospital, Tehran University of Medical Sciences, Tehran, Iran*

[5] *Department of Public Health and Community Medicine, Tufts University School of Medicine, Boston, MA, United States*

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Abstract. People living with HIV increasingly participate as community health workers in supporting the HIV care continuum. Evidence suggests that peer interventions can reduce risky behaviors related to HIV transmission, provide relevant HIV education, and promote healthier lifestyles. In addition to HIV knowledge, peer supporters must be trained on their professional roles within clinical teams, appropriate boundaries, confidentiality practices, referral procedures, and self-care strategies in workplace settings. Conducting such studies in regions where peer interventions are underexplored can generate valuable insights and contribute to more precise reporting at both regional and international levels. A group of HIV-positive individuals, serving as peer supporters-non-clinical health advocates from within the affected community-were recruited after providing written informed consent and assurances of confidentiality. Eligibility required affirmative responses to two screening questions: "Are you willing to participate in this study?" and "Have you been serving as a peer supporter for more than six months?" A baseline survey was conducted to gather socio-demographic information (age, race/ethnicity, gender, education, prior work experience), assess HIV-related knowledge and understanding of peer roles, and document the specific activities peers perform. Additionally, data were collected on HIV self-care behaviors, including healthcare utilization, medication adherence, and risk-reduction practices. Knowledge domains included questions on viral life cycle, antiretroviral therapy and resistance, harm reduction strategies, and treatment adherence. Peer roles were assessed across various domains, including workplace expectations, boundaries, confidentiality, counselling, healthcare navigation, teamwork, communication with healthcare providers, peer readiness, and self-care. Communication skills were further evaluated based on stages of change, active listening, open-ended questioning, cultural awareness, and non-judgmental behaviors. A total of 7 participants (2 women [28.57%] and five men [71.42%]) were enrolled, with a mean age of 47.14 years. The mean duration since HIV diagnosis was approximately 12.19 years. Participants had an average peer work experience of about 9 months. All participants (100%) confirmed that peer supporters' involvement played a positive, essential role in patient diagnosis, support, and follow-up in HIV care. The findings of this study suggest that peer group involvement has a positive and significant impact on the process of HIV diagnosis, treatment, and follow-up care.

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Corresponding Author: Seyed Ali Dehghan Manshadi* and SeyedAhmad SeyedAlinaghi**
* Department of Infectious Diseases and Tropical Medicine, Imam Khomeini Hospital Complex, Tehran University of Medical Sciences, Tehran, Iran
Tel: +98 9121038450, Email: a_dehghanm@sina.tums.ac.ir
** Research Development Center, Arash Women's Hospital, Tehran University of Medical Sciences, Tehran, Iran
Tel: +98 2166947984, Email: s_a_alinaghi@yahoo.com

Introduction

Human Immunodeficiency Virus (HIV) is a lentivirus that progressively weakens the immune system and leads to Acquired Immunodeficiency Syndrome (AIDS). Over time, they lead to AIDS, a condition characterized by the progressive failure of the immune system, allowing life-threatening opportunistic infections and cancers to develop. Without treatment, the average survival time following HIV infection is estimated to be between 9 and 11 years (1).

HIV is transmitted between individuals via blood transfusion, tissue/organ transplantation, breastfeeding, and sexual intercourse. Within the host, these viruses can spread via either cell-free or cell-to-cell transmission (2).

With over 33 million deaths and more than 38 million people living with HIV by the end of 2019, HIV/AIDS continues to represent a significant global public health concern. Although global efforts have generally reduced the incidence of HIV, its prevalence is increasing in certain countries and regions, particularly among key populations (3).

In most geographic areas, key populations — which account for more than 95% of new HIV infections — include men who have sex with men (MSM), people who inject drugs (IDU), prisoners, sex workers and their clients, and transgender individuals. However, in the WHO African Region, where more than two-thirds of people living with HIV reside, the infection remains widespread in the general population (3).

Although global incidence has declined, recent reports show a rise in HIV cases in the Eastern Mediterranean Region, including Iran.(4). In 2019, it was estimated that 59,000 (95%CI 33,000 to 130,000) people were living in Iran with HIV, and each year, about 4,100 (95%CI 1,200 to 12,000) new infections and 2,500 (95%CI 1,200 to 5,600) AIDS-related deaths occur in the country (5).

According to the report from the Iranian national HIV registry system, 38,966 people were diagnosed with HIV infection by the end of 2018. The majority were male (83%), and they were aged 16-40 years (67.6%). The number of HIV-infected people who died due to any cause was 15,845 by the end of 2018 (5).

Key populations often have reduced willingness and limited access to conventional healthcare services at all levels, resulting in lower uptake of antiretroviral therapy (ART) (6). This highlights the need for alternative, community-based approaches, such as peer support interventions, to reach these populations more effectively.

In Iranian society, HIV remains a highly stigmatized and taboo subject, which contributes to barriers to care-seeking behavior. In a cross-sectional study conducted among 123 people living with HIV (PLWH) in 2019, the total mean stigma score was 37.03, indicating a high level of stigma. The most critical factors determining HIV-related stigma were socioeconomic status, transmission method, duration of disease, and education level. This study suggests the need for more effective interventions to reduce HIV-related stigma among Iranian PLWH (7).

Two domains of stigma (discrimination and fear) were significantly associated with a low mean score in the physical domain of quality of life (QOL) (8).

Patients in Iran commonly report problems such as ostracism, depression, anxiety, a tendency to get revenge a lack of fear of infecting others, frustration, social isolation, relationship problems, and fear due to the social stigma. Their psychological problems included Marriage problems, family conflict, lack of family support, economic hardships inhibiting marriage, and social rejection of patients' families (9).

Forgetfulness was a major factor in ART non-adherence. Moreover, a high number of ART, lack of knowledge about the medication's worth, and transportation problems (each with 13.3%) were the main reasons for ART non-adherence (10).

Treatment of people with a substance use disorder living with HIV/AIDS requires physical, psychological, and social attention along with drug treatments (11). It is estimated that about half of people living with HIV meet the criteria for one or more mental health disorders (12).

Peer supporters—individuals who share similar characteristics or have had similar lived experiences—can build trust and communicate more effectively with patients compared to traditional healthcare providers (13).

A systematic review in 2015 examined the impact of support groups for people living with HIV on clinical outcomes. 90% of the articles reported positive results regarding the impact of support group interventions on key outcomes. Support groups were associated with reduced mortality and morbidity, increased retention in care, and improved quality of life (14).

A systematic review of nine studies was conducted in 016. Peer-based interventions primarily focused on improving adherence to antiretroviral therapy (ART) or evaluating retention and adherence through viral suppression. Five (56 %) were conducted in sub-Saharan Africa. Overall findings were mixed on the impact of peers on ART adherence, viral suppression, and mortality. While positive effects of peer interventions on linkage and retention were found, few studies assessed these outcomes (15).

Although some systematic reviews have explored model-based educational interventions for HIV prevention in specific subgroups, such as adolescents in Iran (16), there is an apparent lack of studies examining the role of peer support in the broader HIV care continuum. Existing evidence remains limited in scope and does not sufficiently address the lived experiences and contributions of peer supporters in the diagnosis, treatment, and care of individuals.

This study aims to explore the role of peer groups in HIV screening, diagnosis, care, and treatment. It seeks to identify the strengths and challenges of peer-based support and assess its impact on patient outcomes.

Materials and Methods

Study design and setting

This study employed a qualitative design, using Focus Group Discussions (FGDs), to explore the role of peer groups in HIV detection, care, and treatment. The research was conducted under the supervision of Tehran University of Medical Sciences, with ethical approval from the university's Biomedical Research Ethics Committee under the ethical code number IR.TUMS.IKHC.REC.1402.513.

Participants and recruitment

Seven individuals living with HIV, actively engaged as peer supporters at a Positive Club, were purposively recruited. Eligibility criteria included being HIV-positive, having at least six months of peer work experience, and providing written informed consent. Participants were briefed on confidentiality and voluntarily agreed to participate in the study after answering two screening questions about their willingness and experience in peer roles.

Data collection

FGDs were conducted in a private room at Imam Khomeini Hospital, Tehran. Each session was audio-recorded with the participant's permission. The discussions were facilitated by the principal investigator, with a co-facilitator for note-taking and validation. A semi-structured interview guide was used, covering four domains: (1) socio-demographic information (age, gender, education, work background), (2) knowledge about HIV and peer roles, (3) descriptions of peer activities (13 predefined activities), and (4) self-care behaviors related to HIV (healthcare usage, medication adherence, risk reduction practices).

Survey instrument

The knowledge domain assessed topics such as viral life cycle, drug resistance, harm reduction, and adherence to therapy. Peer role activities were evaluated based on workplace expectations, confidentiality, boundary management, counselling, navigating the healthcare system, teamwork, communication skills, and self-care. Communication skills were specifically examined through stages of change, active listening, open-ended questioning, cultural sensitivity, and non-judgmental behavior.

Categorization criteria

Peer activities were classified into five main domains: (1) early detection, (2) emotional support, (3) care and treatment support, (4) harm reduction and behavior change, and (5) care referral facilitation.

Data analysis

Descriptive statistics were used to summarize participant characteristics and individual survey responses. Content analysis was applied to analyze FGD transcripts, focusing on extracting themes related to the roles and perceived impact of peer supporters across the HIV care continuum.

Results

A total of 7 individuals participated in the study, including 5 men (71.4%) and 2 women (28.6%). The participants' ages ranged from 38 to 53 years, with a mean age of 47.14±9.93 years. On average, they had been living with HIV for approximately 12.19 years. All participants had been actively engaged in peer support work for at least 6 months, with an average duration of peer involvement of about 9 months at the time of data collection (Table 1).

Most of them were members of Positive Clubs and had prior experience providing support to other people living with HIV in clinical or community settings.

Table 1. Demographic data of participants

Number	Age	Gender	Marital status	Education	Duration of HIV (months)	Duration of Employment as a peer (years)
1	46	male	Married	Bachelor's Degree	180	13
2	51	male	Married	Diploma	240	18
3	50	male	Single	Diploma	80	5
4	52	male	single	Sub-Diploma	180	8
5	40	female	single	Diploma	92	6
6	53	female	Married	Diploma	132	8
7	38	male	single	Diploma	120	5

Thematic analysis

The interview texts were carefully reviewed to find common ideas. Similar thoughts and shared experiences were grouped into two main and each theme had some subthemes (Table 2).

Quotes from participants are included to present their actual words and clarify the findings.

Table 2. Thematic structure of patient interviews on HIV care and peer support

Theme	Subtheme
1. Knowledge of HIV and Its Challenges	1.1 Diagnosis and Start of Treatment 1.2 Medication Benefits and Drug Resistance
2. The Role of Peer Support	2.1 Helping with Early HIV Testing 2.2 Support during Diagnosis 2.3 Encouraging Treatment Adherence 2.4 Group Support in Positive Clubs 2.5 Peer Help after Treatment

Theme 1: Knowledge of HIV and its challenges

Subtheme 1.1: Diagnosis and start of treatment

Most participants (71.4%) stated that HIV treatment began soon after their diagnosis. They mentioned that lab tests and clinical evaluations helped doctors choose the right medication.

"My treatment started shortly after I was diagnosed. I had a few tests first, and then they gave me the medicine" (Participant 3). "CD4 count and other tests helped decide what treatment I needed" (Participant 1).

Subtheme 1.2: Medication benefits and drug resistance

Three participants (42.85%) believed that HIV medication helps stop the disease from getting worse and lowers the chance of transmission. All participants agreed that medication reduces the risk of transmitting the virus to others.

"The medicine helps stop it from reaching the AIDS stage or causing other problems like TB" (Participant 1).

Four participants (57.14%) were aware of drug resistance and said it can happen when medications are not taken regularly or correctly.

"I stopped taking my medications for two months. When I started again, they didn't work" (Participant 1). "I gave up taking them for six or seven months. My health got worse, and after that, the medications didn't help anymore" (Participant 7).

Theme 2: The role of peer support

Subtheme 2.1: Helping with early HIV testing

Five participants (71.4%) stated that peer supporters can help individuals at risk get tested earlier. They used shared experiences and trust to encourage testing in communities like people who use drugs or members of the LGBTQ+ community.

"Because I've had the same struggles when I talk to others like me, they listen better" (Participant 4). "I can go and talk to kids working on the street or in parks. I know many of them could have HIV" (Participant 6).

Subtheme 2.2: Support during diagnosis

Participants reported that having a peer with them at the time of diagnosis provided emotional support, increased their knowledge, and helped them feel less isolated.

"When I heard the diagnosis, I was in shock. Having someone next to me who had gone through the same thing made a big difference" (Participant 7). "She treated me kindly when I got the news. That helped a lot" (Participant

4).

Subtheme 2.3: Encouraging treatment adherence

Six participants (85.7%) shared that peer supporters helped them stick to their medication schedule by explaining the benefits and motivating them.

"I told her to keep taking her meds. I had been through the same thing, and now I feel better" (Participant 6).

"Peers help you avoid mistakes because they've already been through the process" (Participant 1).

Subtheme 2.4: Group support in positive clubs

Four participants (57.14%) said being part of a group like a Positive Club gave them more motivation. They can feel a sense of community and be understood.

"When I come here, I feel better. No one judges me" (Participant 5). "We talk, share experiences, and support each other. It's very helpful" (Participant 3).

Subtheme 2.5: Peer help after treatment

Six participants (85.7%) reported that peer support remained helpful even after they started treatment. They learned how to take their medication properly and deal with their daily challenges.

"I've worked with many people in the community. I can help them not be afraid of treatment and show them how to manage it" (Participant 4). "Doctors prescribe the meds, but peers help us understand how to use them in real life" (Participant 6).

Participants consistently described the positive impact of peer support in all areas of HIV care, including testing, diagnosis, treatment, group interaction, and post-treatment care. Peer supporters helped build trust, provided encouragement, and offered practical advice based on shared experience (Table 3).

Table 3. Evaluating the role of the peer from the perspective of the people present in the study, based on the questions considered

Question	Effective factors from the perspective of the peer group
The role of the peer group in HIV diagnosis	Creating the possibility of counseling in peer groups Creating the possibility of counseling in general communities, encouraging laboratory and rapid diagnostic tests Creating awareness about HIV
The role of the peer group at the time of HIV diagnosis	Softening the type of approach Providing accurate and credible information to the patient Increasing life expectancy Managing the condition Increasing the sense of belonging
The role of the peer group in adherence to treatment	Strengthening the understanding of the treatment method Reducing the trial-and-error path Making the treatment credible
The role of the peer group in the positive club	Reducing the cost of treatment Increasing information about the disease Increasing morale Increasing participation in treatment Increasing self-confidence in expressing problems Increasing motivation for treatment
The role of the peer group in post-treatment care	Exchange of experiences Clarifying thoughts about other problems of patients Clarifying drug interactions Introducing the correct use of drugs

Discussion

Based on our study, most participants (74.99%) considered the presence of a peer group appropriate and effective for diagnosis, initial support, adherence to treatment, participation in peer groups, and post-treatment care. This rate of willingness to attend a peer group was based on the personal experiences of people of diverse ages, genders, job statuses, and educational backgrounds. Previous studies have investigated the impact of peer groups on patients' treatment outcomes.

Several international studies have reached similar findings to our study, demonstrating the positive effect of peer support interventions in improving outcomes for people living with HIV (PLWH). For instance, a study from Australia reported that peer support was invaluable for recently diagnosed individuals in aspects of emotional, social, and psychological challenges of an HIV-positive diagnosis. Connection with other people living with HIV (PLWH) was a key benefit of peer involvement for the participants (17).

In line with our findings on improving treatment adherence, a study from Vietnam showed that severely immunosuppressed patients (clinical stages 3 or 4) receiving antiretroviral therapy experienced a significant improvement in quality of life after 12 months when supported by trained peers, compared to those receiving standard care (18).

Similarly, a study conducted in France in 2005 aimed to evaluate the peer support intervention for adolescents living with HIV. The results showed that the peer support group had a beneficial effect on adolescents' acceptance and understanding of their HIV infection and improvement in psychological well-being, potentially even influencing biological outcomes (19).

The role of peer support in improving ART adherence was also confirmed by a 2018 study from Nigeria, which found higher adherence rates among participants supported by peer groups than in a control group (20).

Furthermore, a review of 20 studies from low- and middle-income countries, primarily in sub-Saharan Africa, concluded that peer support groups have a positive influence on treatment adherence, retention in care, emotional well-being, and coping skills (14).

A more recent systematic review and meta-analysis of 20 randomized controlled trials (2001-2020) found moderate to high certainty that face-to-face peer support improves ART adherence, retention in care, viral suppression, and virologic failure. However, this review also noted that most studies were conducted in the USA, with limited representation from Asia and Africa, suggesting a gap in evidence from settings like Iran (21).

In the context of Iran, HIV-related stigma is pronounced. A multicenter study conducted in six cities reported significantly high levels of internal (99%) and external (62%) stigma among PLWH, which reflect the pervasive nature of social discrimination in the country (22). Both internal and external stigma are independently associated with lower quality of life (QoL) scores (mean=52.5), and a strong relationship between stigma and quality of life has been concluded; thus, reducing HIV-related stigma—both in society and within healthcare environments—could play an important role in improving QoL among PLWH in Iran (23).

Additionally, psychological and social burdens are widely reported, including family rejection, depression, anxiety, social isolation, and, in some cases, feelings of revenge or disregard for transmission risk. Social challenges such as unemployment, homelessness, lack of stable housing, and the absence of supportive community structures are commonly reported (9).

In an Iranian qualitative study, most PLWHs identified family and social rejection as their most serious psychological burden, leading to depression, anxiety, and, in some cases, feelings of revenge and disregard for transmission risk. While PLWH emphasized stigma and discrimination as their most pressing social issues, healthcare managers cited social rejection as the primary concern, suggesting a gap between patient and institutional perspectives. Participants

Patients are motivated to seek services due to fear of disease progression, hope for the future, and staying healthy, but some still face barriers such as financial hardship, fragmented services, transportation difficulties, lack of trust in the healthcare system, and fear of medication side effects, which can make problems (24).

These problems mainly affect vulnerable groups such as women and people with advanced stages of HIV. A cross-sectional study in Iran showed that being female or having progressed to AIDS was linked to worse mental health, while strong social support helped improve psychological outcomes (25).

Since many people living with HIV in Iran belong to disadvantaged groups—like people who inject drugs or those with lower education—peer supporters who share similar life experiences may be more effective in helping them access care.

Research from other countries also supports the use of peer-based programs in settings where cultural sensitivity matters. For example, a review of peer-led HIV services for immigrant communities found that peers helped increase HIV testing by raising awareness, reducing stigma, and building trust through familiar language and informal conversations (26). These same strategies could be very useful in Iran, where stigma, misinformation, and limited access to personalized services remain major barriers to care.

The place of living is significantly correlated with external stigma, patients' level of awareness regarding policies, rights, and laws, being under stress to reveal HIV status, and having access to ART (22). With the development of community-based care models in some settings, support groups could offer PLHIV an opportunity to share experiences and become more engaged in their care (14).

Despite the positive aspects of providing and receiving support, HIV-positive peers report that they also encounter resistance and other challenges during their involvement. This has been reported in research examining burnout among peers (27,28).

Limitations

This study has several limitations. First, a small sample of our study that was drawn from a single urban clinic in Tehran may limit the generalizability of the findings and is not representative of HIV-positive populations in Iran. Second, as a qualitative study relies on self-reported data, peer responses may have been influenced by social desirability bias. Although focus group discussions often encourage open dialogue, they may also lead participants to conform to dominant opinions, especially on sensitive topics like HIV. Peer group discussions often prompt participants to discuss topics they may hesitate to raise in individual conversations, especially when the interviewer is from a different class or racial/ethnic group. On the other hand, participants may change their views if they feel pressured to conform to the attitudes expressed by other group members. Additionally, this study did not include perspectives from healthcare providers or family members, which could provide a more comprehensive understanding of peer involvement.

Implications and Future Directions

Despite these limitations, the study illustrates the importance of peer supporters for improving HIV diagnosis, treatment adherence, and psychosocial support. Given the widespread stigma, fragmented services, and emotional burden faced by PLWH in Iran, peer-led programs could be an effective and culturally appropriate intervention. Future research should explore the long-term outcomes of peer support using larger, more diverse samples and quantitative designs. Moreover, attention must be paid to the well-being of the peer supporters themselves, as previous research has reported risks of emotional burnout and stress. Establishing formal training, supervision, and mental health support for peer workers should be considered as part of any peer-based HIV intervention.

Practical Recommendations and Suggestions

The integration of trained peer supporters into HIV counseling and treatment services is recommended, especially in post-diagnosis care. Structured peer-led counselling sessions may enhance treatment adherence, reduce stigma, and foster a more patient-centred approach to care. Additionally, peer involvement should be supported by formal training, supervision, and access to mental health resources to prevent burnout. The presence of a peer in counselling centers is necessary for post-diagnosis counselling and improved care and treatment. Peer group counselling can also be highly beneficial in promoting adherence to treatment.

This qualitative study explored the perceived role of peer groups in the diagnosis, treatment, and follow-up of people living with HIV in Iran. The findings revealed that peer supporters play a valuable role in encouraging early diagnosis, supporting emotional adjustment during diagnosis, improving treatment adherence, and facilitating post-treatment care. Participants consistently emphasized the effectiveness of peer involvement in improving both clinical outcomes and psychological well-being. These results highlight the potential of peer-based interventions to complement existing healthcare systems and address the unique cultural and social challenges faced by people living with HIV (PLWH) in Iran.

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