qualitative study

RESEARCH

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Facilitators and Barriers to adherence to antiretroviral therapy among incarcerated

people living with HIV in Iran: insights from a

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Abstract

Background Ensuring consistent adherence to antiretroviral therapy (ART) is crucial for effective HIV treatment and achieving viral suppression. Within prisons, the prevalence of HIV is notably high, and incarcerated individuals face an increased risk of transmitting the virus both during and after incarceration. However, facilitators and barriers to ART adherence among these individuals in low- and middle-income countries remain inadequately explored. This study applied the Social Ecological Model (SEM) to investigate how various individual, interpersonal, organizational, community and policy-level factors impact ART adherence among incarcerated populations in Iran during and post-incarceration.

Methods This study employed a phenomenological qualitative approach using semi-structured interviews to gather insights. The research population consisted of people living with HIV (PLHIV) who had experienced incarceration and had been prescribed ART during their latest incarceration. Eleven PLHIV from two prisons located in Kerman and Tehran, Iran, formed the study group. Qualitative findings from the interviews were analyzed using a thematic approach. The findings were organized within the SEM framework to highlight key themes influencing ART adherence during and after incarceration.

Results Participants had an average age of 45.1 years (± 5.6). Various factors influence ART adherence during and post-incarceration. Participants highlighted the individual (e.g., HIV knowledge, previous treatment history, mental and physical health), interpersonal (e.g., family, friends, other incarcerated people, and prison health staff), organizational (e.g., ART treatment interventions, methadone maintenance therapy, and other health protocols), community (e.g., stigma, social isolation, discrimination and lack of access to community health services), and policy (e.g., financial interventions, and providing shelters) level factors influence ART adherence during and post-incarceration.

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Conclusions This study provides insights into the multi-level approach to ART adherence among PLHIV during and post-incarceration. It recommends implementing public health activities at the proposed multi-levels to maximize the synergies of intervention for the greatest impact.

Keywords HIV, AIDS, Antiretroviral therapy, Incarceration, Medication adherence, Iran

Introduction

Incarcerated people have a substantially higher risk of HIV infection than the general population [1], primarily due to their engagement in HIV-related high-risk behaviors, including unprotected sexual practices, injection drug use, and tattooing [2], as well as the overcrowded nature of incarceration settings. Incarcerated people are potentially considered bridging populations as they can transmit HIV infection to their partners [3].

The prevalence of HIV infections in prisoners has decreased in recent years. However, the prevalence of HIV infections in prisons in many countries remains disproportionately high, with one review reporting levels greater than 10% in low- and middle-income countries [4]. It is estimated that 30 million people are incarcerated annually [5], with increasing trends worldwide. HIV prevalence has been reported between 3% in prisons in Asia and 6% in prisons in Africa [6]. In Iran, a national study showed that the prevalence of HIV among incarcerated people decreased from 2.1% in 2010 to 0.8% in 2017.

While the number of people in prisons and associated HIV infection prevalence is globally increasing, HIV prevention and care in prison facilities are often substandard. According to global estimates, just 54.6% of incarcerated people reported adherence to their Antiretroviral Therapies (ART) [7]. Recent evidence from Iranian studies indicates that just 45% of incarcerated individuals diagnosed with HIV reported adhering to ART, while 44% achieved virological suppression [8]. Lack of access to community standard HIV care and ART discontinuation are particularly emerging as structural barriers to ART adherence [9]. In addition, insufficient financing, inadequate health staff, and facilities [10-12], as well as lack of integration between community and prison healthcare services [13–15], are also recognized as structural barriers to HIV care in prisons and other correctional facilities.

For people living with HIV (PLHIV) who go to prison, interruptions in care can occur when being admitted, transferred, and finally released. These interruptions consequently lead to a decreased likelihood of sustained undetectable viral load, generating drug resistance and causing a decline in quality of life and even death. They can lead to HIV transmission to others through risky behaviors, including syringe sharing among people who inject drugs and high-risk sexual behaviors. Studies have demonstrated that a range of individual and psychological factors are associated with ART adherence among incarcerated people. Lack of awareness, misperception, and negative attitudes towards HIV, ART, and ongoing drug use are considered among individual barriers to ART utilization [16, 17]. Some mental health issues, including HIV-related stigma, fear of disclosing HIV status, depression, anxiety, and despair [17–19], are also found to be associated with ART adherence among incarcerated people.

Providing HIV prevention and care in prisons and other correctional facilities varies widely across countries and settings within countries. Existing evidence reveals a landscape of barriers to ART adherence among populations in prisons across the world. However, previous studies mostly follow quantitative research designs and fail to adequately explain contextual factors. In this context, understanding the existing barriers across different individual, structural, or community levels for HIV treatment during incarceration and once released to the community could support better management of this issue.

ART adherence is a complex and multifaceted phenomenon, and ART treatments are interrupted for a wide variety of reasons and as a result of many different influences on PLHIV lives. In this context, the social-ecological model (SEM) can be considered as a theoretical framework for conceptualizing and understating barriers to ART adherence during incarceration and once released to the community. The model considers the individual and their relations to people, organizations, and the community where they reside [20]. Recently, the SEM has been used in the context of ART adherence [21], linkage, and retention to HIV care [22], and viral suppression [23].

In the present study, we have adapted the SEM to classify facilitators and barriers to ART adherence among PLHIV during and post-incarceration. This SEM framework consists of five levels including individual, interpersonal, organizational, community, and policy. The theory of this SEM implies that the individual is the target of this interrelated model, surrounded by four bands of influence representing the interpersonal, organizational, community, and policy levels. Implementing ART adherence efforts at these five levels to maximize the synergies of interventions enhances the impact of health interventions. It can lead to improved treatment and health outcomes among PLHIV during and post-incarceration. However, these factors have been studied in the general population and PLHIV and remain less understood among PLHIV during incarceration or once released to the community. Therefore, this study sought to determine facilitators and barriers to ART adherence among individuals incarcerated in Iran to inform evidence-based intervention strategies for PLHIV across incarceration settings.

Methods

Study design

This qualitative study used in-depth semi-structured interviews with 11 PLHIV to explore their perceptions and experiences of ART adherence during incarceration and once released to the community. It was conducted using the SEM, and the results were presented following the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.

Study setting

This study was conducted from May to August 2021. Using a convenience sampling, participants were recruited from HIV Voluntary Counseling and Testing (VCT) centers in Tehran (n=6) and Kerman (n=5). VCTs are the main health organizations that are responsible for providing treatment and care for PLHIV in Iran. VCTs are globally designed to equip individuals with improved skills to cope with stress. They are tested while fully informed about the disease and future risks. VCTs are also crucial for providing accessible settings, emotional and psychological support, and enhancing motivation to prevent high-risk behaviors among PLHIV. These centers comprise the largest proportion of target populations, and most PLHIV patients refer to these centers for their treatment and care.

The eligibility criteria for participation in this study were (1) individuals who experienced incarceration in Iran, (2) be aware of their HIV status and had been prescribed ART during their most recent incarceration, (3) could speak and understand the Farsi language, and (4) willingness to participate in the interview.

Data collection

An interview guide was developed by a review of relevant literature (Appendix 1). This interview guide comprised two sections: (i) general information- mainly including the participants' age, gender, marital status, education level, occupation, and history of living with HIV and (ii) the experiences and perceptions about HIV treatment and ART regimens during the incarceration and transitioning to the community post-incarceration. Two expert reviewers primarily assessed and pre-tested the interview guide with three target population members before the implementation. These early (pilot) interviews were then included in the study as they were reasonably comparable to the subsequent interviews in terms of content and the questions asked. The interviews were conducted face-toface, followed by a semi-structured approach. However, the order of the questions and answers may differ according to the participants' responses.

A VCT's staff primarily contacted the potential respondents who met the inclusion criteria to seek their interest and ability to join a private interview. During this call, the respondents were assured that refusing to engage in the interview would not affect the services provided to them. Once a respondent agreed to join the study and attend the meeting, her/his contact details were shared with the research team for setting a timetable. The respondents mostly suggested public locations, including parks and coffee shops, where interviews could be conducted. During the interview, the objectives and the activities that were involved in the study were explained to the participants. The investigator's contact details were provided, and participants' confidentiality was guaranteed. The aim of the study and inclusion criteria were explained and verbal informed consent was taken before the implementation. No names or individual identifiers were used in any reports or publications resulting from this study.

Two experienced interviewers (SM and ARR) with a background in qualitative research and who were well-skilled in interviewing PLHIV conducted the interviews in the Farsi language. Interviews were conducted independently in Tehran and Kerman. Interviews were audiorecorded and transcribed verbatim. Interviews ranged between 40 and 55 min, with the average length being 45 min. Interviews were conducted until saturation, which was reached when no new data were observed regarding the phenomenon under study.

Data analysis

The SEM was applied as the theoretical framework for qualitative data analysis. Considering this framework, the qualitative analysis included both deductive and inductive thematic explorations in which codes and themes were derived inductively from the interview transcripts and notes. The codes were categorized into sub-themes and mapped in the domains of the SEM. They were subsequently added to the codebook as they emerged during analysis. Qualitative data coding was performed in MAX-QDA 12 (VERBI GmbH, USA) by a trained research team member (AB). To improve the reliability and validity of findings, the initial set of open codes, themes, and subthemes was discussed by available participants and subsequently reviewed by the entire research team to improve the credibility and trustworthiness of the qualitative study. Codebook revisions and coding questions were resolved with the research team based on ongoing discussion and revisions. In case of discrepancies among the research team, an individual expert was invited to revise the codebook and themes. Finally, all themes are

Table 1 Demographic characteristics of participants to evaluate the experience and perceptions of people living with HIV with the experience of incarceration about antiretroviral therapy

Gender	Age	marital status	Diag- nosis period (years)	ART adher- ence status	Living status	Literacy level	HIV infection de- tection location	Frequency of Impris- onment (Numbers)	Employment status
Man	50	Divorced	15	Optimal [*]	With Parents	Secondary school	Before prison	Many times,	Shopkeeper
Woman	45	Single	5	Quit	Homeless	High school diploma	Prison	Many times,	On disability
Woman	44	Deceased spouse	10	sub-optimal	With child	Primary school	After incarceration	4	On disability
Man	44	Married	16	Optimal	Private house	Unfinished High school diploma	Prison	Many times,	Repairman
Man	47	Married	17	Optimal	Private house	Secondary school	Between prisons	6	Self-employed
Woman	41	Deceased spouse	14	sub-optimal	Private house	Primary school	Fourth time in prison	8	Unknown
Woman	41	Married	10	sub-optimal	Private house	Primary school	Before prison	1	Housewife
Man	45	Married	15	Optimal	Private house	High school diploma	Before prison	3	On disability
Man	55	Single	11	sub-optimal	Homeless	Illiterate	Between prisons	Many times,	Scavenger
Man	34	Single	8	Quit	Living with Parents	Primary school	Prison	4	Worker
Man	51	Separated	12	sub-optimal	Homeless	High school diploma	Before prison	Many times,	Unknown

*Optimal(good) adherence means taking all ARTs in a correctly prescribed dose one week before the study

**Many times denotes the frequency of imprisonment over 10 times

Table 2 Barriers to ART adherence among people living with HIV in Iran during incarceration

Theme	Sub-theme
Individual	Poor HIV knowledge
	Poor HIV perception
	Substance use disorder, and forced withdrawal
	Previous ART treatment side effects and
	outcomes
	Poor mental health
	Poor physical health
Inter-personal	-
Organizational	Poor health literacy
	lack of clearly defined and consistent health protocols
	Transferring individuals among prisons
	Inconsistency in healthcare protocols and behaviors of the prison staff
	lack of personal control, and management of conditions
	Unsustainable HIV assessment, treatment, and follow-up programs
	Existing inequalities among prisons in differ- ent geographies
Community	Misinformation
	Discrimination
	Stigma and negative attitudes
	Fear of disclosing HIV status by receiving ART
	drugs
	Social isolation
Policy	-

narratively summarized under their respective socioecological headings and further represented by selected participant quotes.

Results

A total of 11 individuals (7 males and 4 females) participated in the study. On average, participants were 45.1 (\pm 5.6) years old, were in prison for 10.4 (\pm 8.1) years, and were diagnosed with HIV for 12 (\pm 3.7) years. Most of the participants were under diploma (n=8; 72.7%). All participants started ART after their HIV diagnosis, and nine (81.8%) were on ART at the time of the study. Five participants (45.4%) reported complete ART adherence, four participants (36.3%) reported occasional interruptions and irregular use of ART medication, and two participants (18.1%) quit ART medication by their own decision. See Table 1.

Qualitative results

Many of the major themes that arose from qualitative interviews were related to and contingent on broader socio-ecological aspects of optimal ART adherence during incarceration and once released to the community. As such, we have placed each theme into a modified and respective socio-ecological heading and have provided descriptions and participant quotes to outline each of these factors in detail below. The major overarching socio-ecological headings include Individual, Organizational, Interpersonal, Community, and Policy. See Table 2.

Barriers to ART adherence during incarceration Individual factors

The major individual-level factors that PLHIV described as influential to their optimal ART adherence during and post-incarceration included HIV perception and knowledge, previous ART treatment outcomes, and mental and physical health. Poor perception of HIV was reported as a barrier to patient engagement and medication adherence among PLHIV during incarceration. Most respondents perceived HIV diagnosis as a death sentence. Seven respondents referred to medical consequences (e.g., death and disability) and social consequences (e.g., family life, social relationships) of the disease while evaluating the outcome and effectiveness of medical treatments. Some respondents stated that when they were diagnosed with HIV in prison, they anticipated a premature and painful death, which also had a major impact on their mental status and caused severe depression and frustration.

"I was counting down the days to my death. Because it has been said that whoever gets AIDS dies very quickly, with a lost face and disgrace. I mourned for this and cried in a corner" (Participant 10).

PLHIV frequently suffered from mental health problems during incarceration. The problem of poor mental health among incarcerated people was considerably perceived as higher than the general population. Almost all respondents reported HIV-related self-stigma during incarceration. In line with this concept, some respondents demonstrated some forms of self-loathing as they did not feel good about themselves and experienced feelings of shame, disappointment, or embarrassment about having HIV, blaming themselves and deserving of punishment for the disease.

"I am a frustrated person who thinks that everything is over for him because when everyone looks at you as if you are scum or a dangerous parasite, why should you live? I don't like myself, let alone others" (Participant 3).

Our findings indicated that incarcerated persons with mental health problems had several other vulnerabilities such as substance use disorders, and isolation from their social networks. Substance use among the respondents was associated with immorality behaviors that prevented healthy behaviors, such as optimal treatment compliance and ART adherence among the respondents.

"Many [incarcerated PLHIV] do not take medicine at all. Most are also drug users and don't seek treatment at all [24]. Due to drug use disorder issues including drug expenses, and getting drugs; nothing will be left to adhere to treatment" (Participant 3).

Although harm reduction interventions are implemented in most incarcerated settings, all respondents had a history of drug use in prison. As drugs were not routinely accessible during the incarceration, most participants experienced forced withdrawal and its physical consequences (e.g., stomach ache, foot pain, long-term headaches, etc.) that have discouraged them from monitoring their HIV status or maintaining their compliance with medical treatments. Experiences of severe side effects due to ART regimens were also reported as a barrier to adherence to ART medications.

"When you take medicine [ART regimen], during the first days you feel excessive sleepiness, or you don't like to eat some special foods, or you want to eat something else, but you have to sleep and wake up and eat as they [the prison's officers] order ... This makes it difficult for us" (Participant 11).

Organizational factors

Some respondents believed that a range of prison context factors contributed to poor ART adherence. These factors included a lack of clearly defined and consistent health protocols, an atmosphere of misinformation and false awareness, negative attitudes towards HIV, explicit reception of drugs in prison, and lack of personal control, and management of conditions (sleep and nutrition).

According to participants who have experienced transferring between prisons or detention centers, the rules and procedures vary among prisons, administrators, periods, and jurisdictions. This leads to inconsistent behaviors, ranging from empathetic and protective actions to fragile behaviors and intolerance toward patients. Inconsistency in healthcare protocols and prison staff behaviors caused major difficulties for most patients, including interruptions of treatments and poor ART adherence.

"We do not have anything called a routine checkup in these prisons. Rarely does anything happen? The way I found out is that you only get tested for HIV just when a prison inspector wants to come and visit the prison... sometimes, they do not accommodate you to test for HIV even if you voluntarily request it yourself. Some prisons are unaware of these things" (Participant 3).

In addition, HIV assessment, treatment, and follow-up programs are not sustainable, and in some cases, a kind of show-off is in place. Some respondents also highlighted significant geographical inequalities between large prisons, generally located in Tehran and Alborz provinces, and prisons in other cities, in terms of HIV screening, diagnosis, and treatment programs.

"My last prison was in [anonymized] 6 months ago, and one year ago in [anonymized] I was in a state of temporary detention. They have nothing to do with HIV tests and medicine [ART regimen]. The same is true for other small prisons. Then I came to the capital city of the province. They used to test everyone for HIV." (Participant 1).

Poor health literacy, false awareness, and the spread of misinformation among incarcerated people lead to significant misconceptions and negative attitudes toward HIV. These factors intensified HIV stigma and consequently impacted HIV treatment among PLHIV.

"They [incarcerated people] acted very unknowingly. Some are thieves; some are swindlers, well, they are very illiterate. Even they did not know how they got infected ... they assumed it was transmitted through a shared glass, through conversation and other similar things" (Participant 7).

"To many, we looked like a monster, or maybe the devil ourselves. That's why my friend didn't say anything [about his HIV status]; he didn't take any medicine. His symptoms recurred, ultimately leading to his death" (Participant 6).

Issues related to receiving ART in prisons were frequently reported to negatively impact optimal ART adherence among incarcerated people living with HIV. On the one hand, patients feared that in taking their ART medications, their roommates might discover their HIV serostatus and reject them (social stigma). On the other hand, HIV infection and its pharmacological consequences have several impacts on their sleep and appetite, which are restricted or suppressed because of the prison's rules and regulations. Therefore, lack of proper disease management and optimal medication adherence were frequently reported by PLHIV as the most critical barriers to ART adherence during incarceration.

"While we were few in numbers, we requested those sisters [female prison officers] do not call us for receiving [ART] medicine so that no one would discover our disease status. But these attempts failed and my roommates ultimately discovered my disease and made me attempt suicide" (Participant 7). "When they [prison officers] wanted to give us [ART] medicine, they usually shouted "Come and take your medication". Well, other incarcerated people would wonder what kind of medicine they were taking; they would even make guesses about what our disease might be." (Participant 8).

Community factors

Social stigma and discrimination were frequently experienced and reported as the most contributing barriers to optimal ART adherence among incarcerated people living with HIV. Social stigma is commonly associated with negative judgment, rejection, and humiliation by other incarcerated people. During incarceration, experiencing high levels of social stigma poses major mental consequences and threats to treatment outcomes, as mentioned by several respondents. Most respondents also revealed major discrimination from other incarcerated people and prison officers.

"There are a lot of negative attitudes. Outside the prison, you can change your house or make yourself invisible, but in prison, not at all. It's tough when they [other incarcerated people] discover you're living with AIDS. That's why I was so annoyed and once attempted suicide" (Participant 9).

"My roommate was used to consuming the same substance as I did, and his health condition was very bad. Once he found out that I was HIV-positive, he said, "Why does an HIV-positive want to survive?" If he does not die today, he will probably die tomorrow" (Participant 5).

"Earlier, I wondered why HIV-positive individuals do not disclose their HIV status and why they don't announce it. They replied Why should we disclose as if others know our disease status, we will be very likely annoyed, and they would tease us" (Participant 8).

Facilitators of ART adherence during incarceration *Individual factors*

Although the main focus of responses was on barriers to ART adherence during incarceration and once released to the community, some respondents provided positive narratives about facilitators of ART adherence. Qualitative results indicated that knowledge and experience about the disease had helped overcome misconceptions and negative emotions among the incarcerated PLHIV and encouraged them to maintain medical treatments. In addition, numerous participants stated that HIV knowledge, awareness, and prior experience of successful adherence to ART medications before the incarceration positively influenced and fueled ART adherence among the Iranian PLHIV during the incarceration. **Table 3** Barriers to ART adherence among people living with HIV in Iran once released to the community

Theme	Sub-theme		
Individual	Negative emotions		
	Poor mental health		
	ART treatment side effects and outcomes		
	Drug use		
Inter-personal	-		
Organizational	-		
Community	Stigma		
	Social isolation, abandonment, and rejec-		
	tion due to incarceration		
	Fear of disclosing the HIV status		
Policy	Unemployment		
	Poverty		
	Homelessness		
	Lack of free transportation		

"Call it HIV, but it is not a serious disease. It is less dangerous than many diseases. Thank God we do not have cancer. This disease is easier than many diseases if you get along with it" (Participant 2). "Outside the prison, medicine was good for me. If I didn't take it, I would feel bad. I was used to drugs, and there [in prison] was a doctor. I went there and said I had HIV. He just initiated my treatment program and gave me pills regularly" (Participant 8).

Interpersonal factors

Some respondents believed that receiving social support from the medical staff and their peer incarcerated individuals during the incarceration encouraged them to maintain compliance with their treatment and continue their ART treatments. According to these respondents, medical staff's positive and empathic behaviors, particularly prison physicians, have positively motivated them to adhere to ART medications.

"The doctors outside the prison may have mistreated us, but the prison's doctors treated us very well, knowing what the disease was, and consequently encouraged us" (Participant 7).

In addition, receiving instrumental support from the peer incarcerated individuals and the prison staff facilitated accessing and taking ART medications during incarceration.

"In prison, we also had a pill dad, a man who brought us pills. He was such a coon, and friendly that all incarcerated people loved him. He was coming to make us all happy... He was used to bring our medicine on time" (Participant 4).

Barriers to ART adherence once released to the community

Barriers to ART adherence among PLHIV once released to the community are summarized in Table 3.

Individual factors

PLHIV frequently suffered from mental health problems once released to the community. Confusion, forgetfulness, self-stigma, and disappointment were common mental issues among most respondents. Negative feelings such as fear of disease disclosure, ignorance, hopelessness, and depression were also commonly reported by respondents.

"An HIV-positive person who has just been released from prison is in turmoil. Most HIV-positive incarcerated people also use drugs. Drug use makes us depressed. Imagine you have HIV, you have gone to prison, probably no one is waiting for you outside, many people will not want to see you, and nothing will be left of you." (Participant 3).

"You forget your name or house address, let alone adhering to treatment. However, in prison, despite all its evils, it is most likely to receive your pills on time" (Participant 6).

Fatigue and lethargy, ART side effects, and resistance were also reported as physiological barriers to optimal ART adherence among the respondents. These physiological consequences of ART drugs negatively influenced the motivations and healthy behaviors of the respondents while living in the community.

"HIV weakens the body. No matter what kind of diet you have, your face shows it if you do not take medicine. That eats you from inside. Once you take its medications, you are completely lethargic" (Participant 6).

Community factors

Social isolation, abandonment, and rejection were referred to as common social consequences of imprisonment and intensified mental health problems while returning to the community. Social isolation and rejection prevented access to health services in the community.

"Drug users are extremely emotional and look at everything very carefully. You can't play a role as they find the truth and understand your intention very well" (Participant 1). Fear of disclosing the HIV status was also reported as a barrier to visiting community health centers and consequent ART adherence by respondents.

"One of the problems that incarcerated people do not take medicine is that they make it obvious. It bothers us that they give medicine too often. Everybody sees it. One part of the hospital is the behavioral diseases ward. A lot of people have a negative look at it. Many people are afraid to go there. Maybe something happens, and they will take us all to some islands one day. This is how most people believe. They say maybe some friends or family members see us. They don't go to that ward. I wish taking this medicine would be somewhat secret, and no one could see us" (Participant 4).

Policy factors

As most respondents had no occupation or income while returning to the community, affording the essential life expenses and needs was difficult, preventing them from engaging in healthy behaviors such as optimal ART adherence. Participants frequently reported homelessness and poverty as factors that negatively influenced their treatment outcomes. This highlights the role of financial and social protection interventions to address inequalities and societal vulnerabilities at the policy level.

"When you do not have a house to sleep, rest, or at least to keep your medicine, what treatment will you adhere to? Because it is difficult to move and store medicines" (Participant 7).

"Those who visit [confidential] Hospital and get their medicines rarely have financial support and fail to afford their life needs. Those who are from marginal areas do not even have the money for their transportation. For example, a woman who visited and received her son's medications insisted on receiving a three or four-month regimen instead of a two-week regimen because of not having enough money for transportation. She believed that the transportation costs several times their life costs and she couldn't afford it" (Participant 10).

Facilitators to ART adherence, once released to the community

Community factors

Once released to the community, the respondents received social support from family members, particularly from their spouses and close friends, which motivated them to follow health protocols and adhere to ART. Page 8 of 12

"I swear that my wife is an angel. In my house, she supports me in every way; she does not let me be worried about anything. She helps me in any way. At the due time, she forcibly pours it into my throat and gives me my medicine" (Participant 5).

Discussion

This study aimed to investigate barriers to ART perceptions and experiences among PLHIV recently released from incarceration settings in Iran. The results highlighted the complex intersection of various socio-ecological factors embedded in several levels (including at the individual, interpersonal, community, and organizational/policy levels) that worked alone and in conjunction to impact PLHIV's ART adherence during incarceration and once released to the community.

At the individual level, incarcerated PLHIV experienced and perceived major barriers to receiving treatment and maintaining optimal adherence during and post-incarceration. Poor HIV knowledge, misconceptions, and erroneous attitudes are frequently reported among incarcerated individuals around the world [25]. Although there is no apparent association between HIV awareness and the risk of contracting HIV infection among Iranian incarcerated individuals, existing research demonstrates that less educated incarcerated individuals have a higher risk of engaging in risky behaviors such as having unprotected sex compared with their more educated peers [26, 27]. Also, it has been found that incarcerated individuals have lower rates of HIV awareness than the general population [28]. Lower levels of education and poor HIV knowledge were previously reported as barriers to optimal ART adherence [29, 30].

Our findings suggest that prior successful experience of ART adherence or HIV treatment has facilitated optimal ART adherence and treatment compliance during incarceration. Previous research has found that individuals with previous HIV treatment experience fewer challenges in adhering to HIV treatment and consequently accept the HIV treatment easily [31]. Prior successful experience along with rising HIV awareness might lead to a positive perception of the benefits of treatment and increase medication adherence among PLHIV [32]. Beyond HIV knowledge and experience of ART treatment, other physical and mental health issues such as drug use side effects, and depression are significantly contributed to the optimal treatment outcomes [30]. Existing evidence suggests that untreated mental illness, especially depression and social isolation, predicts lower ART adherence among PLHIV [33, 34]. Therefore, implementing behavioral and biomedical interventions to address individual dynamics of optimal ART adherence and assessing the effectiveness of these interventions is considered the primary step [35].

At the organizational level, lack of consistent HIV prevention and treatment procedures was frequently reported as a common barrier to optimal ART adherence during incarceration. Since the early years of the 2000s, harm reduction programs, including methadone maintenance treatment (MMT), have been widely established across incarceration settings in Iran. MMT has been found as one of the most important measures of harm reduction programs and has recently led to the effective reduction of drug injection and shared practices [12-14] and high-risk sexual behaviors [12, 15-19]. MMT improves the mental and physical conditions of PLHIV and reduces the risk of diseases such as HIV/AIDS and hepatitis [20, 21]. However, our findings suggest that MMT procedures are less likely to operate consistently. According to PLHIV, who experienced different incarceration settings, inequalities and geographical disparities are likely associated with poor utilization of health protocols in these settings. Recent evidence revealed that lack of adequate skilled health personnel, and inaccurate implementation consistently influenced the quality of harm reduction strategies, and HIV care service delivery and finally caused ART adherence interruptions [36–40]. In response to this challenge, exact implementation plans and period evaluations are required to ensure high quality and consistency of health protocols across settings and geographical regions.

At the community level, the overall atmosphere of the incarceration settings about HIV influences HIV testing and treatment adherence among incarcerated PLHIV. Incarcerated PLHIV may fear that, by expressing an open interest in learning about transmission modes of HIV and HIV treatment protocols or requesting a clinical visit, they are openly admitting to engaging in sexual activities or using drugs, which may cause others to view them in a negative light [26]. In response to this challenge, a well-established body of existing literature insists on the urgent need for HIV/AIDS prevention efforts, including health education programs across incarceration settings, to increase the incarcerated individuals' knowledge of HIV/AIDS, and to improve their attitudes and practices concerning this disease [26, 41].

During incarceration, a lack of social support from patients, family, friends, and other incarcerated people leads to a decrease in ART adherence [42]. Therefore, emotional and social support due to good relationships between patients and other incarcerated people can be considered an effective strategy to improve ART adherence during incarceration. It was previously confirmed in different studies [24, 43]. Improving patient-physician relationships is reported as a facilitator of ART adherence during imprisonment. Improving patient-physician communication through education helps improve the optimal adherence to HIV treatment remarkably [44]. The participants believed stigma was a major barrier to ART adherence during incarceration. These results were confirmed in other studies [45, 46]. Therefore, employing trained staff and oriented healthcare workers for counseling and training incarcerated people can be considered an interventional strategy to improve ART adherence at the interpersonal level.

Interviews indicated that PLHIV who experienced incarceration were at higher risk of sub-optima ART adherence once released to the community. The results highlighted the complex intersection of socio-ecological factors embedded in several levels (individual, interpersonal, community, and organizational/policy levels) associated with sub-optimal ART adherence among PLHIV once released to the community. At the individual level, drug use, ART side effects, and negative emotions were reported as major barriers to ART adherence once released to the community. In addition, a range of community-related factors, including stigma, social isolation, and abundance, were reported as contributing factors to sub-optimal ART adherence. At the policy level, poverty and homelessness were reported as major barriers to optimal ART adherence post-incarceration. Evidence suggests that economic factors also influence ART adherence, and people with poor economic levels reported lower ART adherence [47, 48]. Therefore, providing incarcerated PLHIV with job opportunities and financial or social protection aids may help them improve their economic level when transitioning to the community and consequently improve the treatment outcomes and optimal ART adherence.

The study's findings are supported by a great body of literature describing the care gap where PLHIV who were incarcerated are at risk of losing access to ART treatments upon release to the community [49-54]. Recent findings from Iran have identified a significant shortcoming of current MMT programs, highlighting prisoner release as one of the key challenges of these initiatives [36]. Recent evidence identified barriers to HIV care utilization encountered by incarcerated PLHIV in order to inform future intervention strategies. Their findings highlighted the importance of social determinants of health, citing barriers to care such as lack of social support, stigma, discrimination, substance use, as well as lack of knowledge about ART [9]. Another study highlighted the role of gender inequalities in ART adherence to PLHIV once released to the community, pointing to the potential added gendered impacts of incarceration and unique challenges faced by women living with HIV in the postrelease period [55]. According to existing literature, social determinants of health are strongly associated with ART adherence among PLHIV post-incarceration worldwide. In this context, recent evidence has introduced potential interventions to address the care gap PLHIV encounter

once released to the community, including intensive case management, cell phone provision [54], incentivizing undetectable viral loads as well as engaging peers to work with participants as navigators along criminal justice system trajectories [56]. Facilitating support for addictions and addressing other social and structural barriers to achieving optimal health is also recommended to bridge the care gap [54].

Although this study provides critical insights into barriers to ART adherence across incarceration and community settings in Iran, there are some notable limitations. First, as qualitative research is open-ended, respondents have more control over the content of the data collected, and the investigator fails to verify the results objectively. Second, investigating causality and replicating the study is problematic in qualitative studies. Nevertheless, this study is one of the recent attempts to address critical issues of ART adherence in the context of a middle-income country. It provides new evidence about the facilitators and barriers to optimal ART adherence among the Iranian ex-incarcerated PLHIV to improve HIV treatment and control programs.

Conclusion

This study emphasizes the intricate challenges of achieving optimal ART adherence among incarcerated individuals in Iran, both during imprisonment and after release, while addressing a variety of interconnected factors impacting PLHIV undergoing ART treatment. Utilizing the SEM framework, the study illustrates the influence of factors at the individual, interpersonal, organizational, community, and policy levels. Within this framework, enhancing ART adherence among incarcerated PLHIV necessitates a coordinated, multi-sectoral strategy that accounts for the social and structural determinants highlighted in this research. Furthermore, strategies aimed at linking incarcerated PLHIV to HIV care services, along with providing shelters and protective initiatives to reduce their vulnerabilities, are essential for bridging healthcare gaps and improving their well-being.

Appendix 1- interview guide

Dear Madam/Sir,

The main purpose of the questions is to identify barriers to medication adherence in people living with HIV during incarceration and once released to the community. If you have a history of incarceration in the past five years and have been prescribed ART during the incarceration, please answer the following questions based on your experiences or field observations.

The demographic of the respondents (filled by the interviewer):

Age:....

Gender: Female 🗌 Male 🗌 Other 🗌 Marital status: Single 🗌 married 🗋 divorced 🗌 Other:....

Location of detecting HIV infection:...... History of incarceration:.....

History of receiing ART during incarceration:...... Adherence to ART: Optimal sub-optimal Quitted. Qualitative questions:

- 1 Please tell me a little about yourself, how old are you? How many literacy classes do you have? where do you live? (Other necessary background questions are asked during this question (marriage status, job, children, etc. are asked).
- 2 Which prison were you in, and how long were you there?
- 3 When did your test become positive for HIV? Before prison or in prison?
- 4 If you have been in prison before, how was your treatment before you entered prison? Did you have any particular problem?
- 5 If you have been in prison before, how did you follow up the treatment when you went to prison?
- 6 If it is specified inside the prison, how did you get tested in the prison?
- 7 Please tell me about how you were treated in prison. What problems were there to get the drugs?
- 8 Were there things to seriously pursue your treatment in prison or not?
- 9 How was your drug use in prison?
- 10 Did you know people in prison who have your problem but do not take medicine? What makes these people not take medicine?
- 11 When you came on leave or after your release, how did you follow up the treatment?
- 12 What support and help do you think can help people who need treatment?
- 13 Our goal in this interview was to know what problems HIV-positive people face in prison and after prison, which cause them not to pursue treatment seriously and regularly. Now, in addition to what you said, if you have anything else to say in this regard, please tell me.

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Author contributions

AB contributed to the project concept and manuscript design, qualitative data interpretation, critical review of the manuscript writing, and discussion of the manuscript. ARD contributed to gualitative data collection, and analysis, data interpretation, and writing of the manuscript. MSB worked on data analysis, data interpretation, and writing of the manuscript. NG worked on literature search, data interpretation, and writing of the manuscript. SM contributed to qualitative data collection and analysis, data interpretation, and writing of the manuscript. SASA worked on data analysis, data interpretation, and writing of the manuscript. FM contributed to manuscript design, qualitative data interpretation, critical review of the manuscript writing, and discussion of the manuscript. MK contributed to manuscript design, qualitative data interpretation, critical review of the manuscript writing, and discussion of the manuscript. GM contributed to manuscript design, gualitative data interpretation, critical review of the manuscript writing, and discussion of the manuscript. MK contributed to manuscript design, gualitative data interpretation, critical review of the manuscript writing, and discussion of the manuscript. HS worked on the project concept and manuscript design, supervising, critically reviewing the manuscript writing and discussion of the manuscript. All authors read and approved the final manuscript.

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Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

Participation in this study was entirely voluntary and oral consent was acquired at the beginning of qualitative interviews. The Research Ethics Committee of Kerman University of Medical Sciences has approved the project following the tenets of the Helsinki Declaration and the national ethical guideline for medical research (IR.KMU.REC.1400.674).

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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