

*Original Article****A Study of Barriers to Adherence of Antiretroviral Treatment in Prisoners Living With HIV in Tehran, Iran***

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Abstract

Background and Purpose: People with chronic illnesses, such as Human Immunodeficiency Virus (HIV) infection, face many barriers in the way of adherence to the treatment. In this study, the researchers attempted to investigate the barriers and facilitators of adherence to Antiretroviral Therapy (ART) among patients with HIV.

Materials and Methods: Focus group discussion (FGD) was conducted with the primary objectives of investigating the barriers to ART adherence. Nine participants with HIV infection were recruited through a purposive sampling method at Great Tehran Prison.

Results: In terms of the influencing factors of non-adherence; the drug side effects, especially with Efavirenz, Methadone and opioids effects resolution due to interaction with antiretroviral drugs, forgetfulness, fear of hangover due to the missed or delayed Methadone use, inappropriate nutrition and lack of access to food supplements and poverty were noted by the majority of participants. In addition, there were some less, but still important factors of non-adherence among the patients, which were mentioned in the manuscript of the article.

Conclusion: The medications side effects, inappropriate methadone prescription, stigma, lack of family support, and unfavorable prison conditions were found to be the potential barriers of adherence to HIV medication, whilst a strong and realistic patient-physician relationship, psychosocial and family support, and knowledge regarding the level of CD4 were amongst the possible facilitators for adherence to HIV medication in HIV-positive prisoners.

Keywords: HIV; Prisons; Antiretroviral Therapy; Barriers

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1. Introduction

Acquired Immunodeficiency Syndrome (AIDS) was unknown until 1981, and it first became clear that the Human Immunodeficiency Virus (HIV) is the cause of the disease in 1984. Now, AIDS / HIV has become a pandemic and has been reported in nearly all countries (1). In 2016, an estimated number of 36.7 million people were living with HIV; approximately 1.8 million of new infection cases occurred and almost one million died from AIDS-related illnesses (2, 3). In Iran, the mean number of HIV infected individuals was 60761 in 2018. This included 44683 men, 15161 women, and 916 children under 15 years old. The estimates indicated an increasing trend in the number of people with HIV in general population. In 2018, the new cases of HIV in Iran among those over 14 years old were estimated to be 4267 per year (3230 males and 1037 women). These estimates suggested that at the current coverage of health services, the number of new cases of HIV in men would slightly decrease; while in women, it would slightly increase annually (Based on UNAIDS country report).

HIV and tuberculosis are the most important widespread infectious diseases and the main health problems in prisons in Iran (4). The prisoners are amongst the most restricted populations with very limited access to health services and surveys. Furthermore, the enclosed environment of prison keeps close the people from diverse backgrounds and risk factors for varying times. Thus, prisoners are among the most vulnerable people to infectious diseases, particularly HIV (5). A strict adherence to antiretroviral therapy (ART) and TB treatment, therefore, is required in order to prevent the emergence and expansion of drug-resistance strains.

There are several factors affecting the adherence to medication in HIV-infected patients, such as substance abuse, health beliefs, psychiatric status, sociodemographic factors, familial factors, and medication side effects. However, the determinants of non-adherence could vary in different contexts, particularly in a restricted environment, such as prisons. Thus, against this background, the current study aimed to explore the determinants of adherence to HIV medication in inmates with HIV infection through focus group discussions (FGDs) with the main objectives to investigate barriers and facilitators of ART adherence among HIV infected inmates in Great Tehran Prison, Tehran Province, Iran.

2. Methods

Since random sampling is not the best way for qualitative studies, we used a purposive sampling method and recruited nine participants from Great Tehran Prison. We conducted an FGD with the primary objectives of investigating the barriers to ART adherence in February 2015. Informed consent was obtained from all participants before the outset of this study.

The demographic characteristics of the participants were collected using an information sheet prior to the interview. The FDG was conducted at the prison in a room allocated for visitors with the presence of the only interviewer and inmate to protect the confidentiality and privacy of inmates' identity and information. The interviews were audiotaped and further transcribed. The researchers explored the study objectives by asking open-ended questions according to the interview guide; probe questions were then asked to investigate some statements more in detail.

The non-verbal communications were also recorded by a note-taker and accounted for in data analysis. The transcripts were reviewed and participants approved the validity of the statements. We performed the content analysis. Furthermore, the reliability and validity of data analysis were assessed and modified taking into account other researchers' and experts' opinions and comments.

Ethical consideration: An institutional review board of Tehran University of Medical Sciences, Iran reviewed and approved the study protocol. Moreover, all the prisoners gave informed consent. Approval No. 9021598014.

3. Results

Table 1 describes the main results in brief.

Table 1. Barriers to adherence of antiretroviral treatment in prisoners living with HIV in Great Tehran Prison based on FGD results

Factors	
The effect of antiretroviral drugs	- Drug adverse effects
	- Drug interactions
The role of addiction and methadone maintenance treatment	- Drug use and its effect
	- The role of methadone maintenance treatment
The impact of social conditions	-The HIV stigma
	- Unfavorable prison conditions
	- Poverty
	- Lack of family support
Others	- Communication with physician
	- Access to anti-retroviral drugs
	- CD4 counts
	- Psychosocial support
	- Inappropriate nutrition
	- Lack of attention to other illnesses

1.3. The effect of antiretroviral drugs

- Drug adverse effects

The majority of participants complained about several side effects of Efavirenz at the ART initiation (the first two to three months), such as nightmares, hallucinations, and hangover states. In addition, they believed that inappropriate

methadone administration led to exacerbation of these complications. There were also other adverse effects, such as dizziness, weakness and lethargy, insomnia and anorexia with other antiretroviral drugs.

"Anti-HIV drugs, at the beginning, lead to insomnia, nausea, hallucinations and

nightmares bothering us. Clonazepam is effective for insomnia and helps us have a comfortable sleep; however, they cut it off after coming into the jail...Medications make me faint and dizzy and it leads into dizziness."

"We often use drugs, because using HIV drugs make our body weak, and our need to methadone and multivitamins increases, as well, along with ART."

- Drug interactions

Two participants who had hepatitis C believed that hepatitis is not a barrier to the use of antiretroviral drugs. Three people who were on anti-tuberculosis prophylaxis regimen said that they should take many pills; however, this has little effect on reducing adherence to treatment. Some patients believed that antiretroviral drugs interfered with morphine, and after taking these drugs, they would require more morphine.

"Medications make our body morphine free; I use drugs and I have to inject more morphine when I take medications. We have no problem with the number of pills, if it is set up with our sleep!"

"I will eat five in the morning and three in the evening, and because of my health, we have to eat many pills and it is hard for us. I think that HIV drugs are effective on hepatitis, as well, so I'm willingly taking them ... I have hepatitis C and I think I'm taking HIV drugs better because I have hepatitis C..."

2. 3. The role of addiction and methadone maintenance treatment

- Drug use and its effect

All the participants had a history of addiction; five of them were even infected with HIV through injection. It seems that addiction (especially heroin) had negative effects on drug adherence; as some

participants noted, it could lead to forgetfulness or inconsiderate and irregular use of HIV medications.

"Addiction and drug use have a negative effect on the consumption of medications, make you reluctant ... "

"Addiction makes you forget about taking medication ..."

"When I was addicted, I used my tablets regularly, but the CD4 did not change and did not go up, as if it [morphine] would eliminate the effect of the drug..."

"If they give us 2-3 cigarettes a day, they have a positive impact on our drug intake! We see those who smoke and feel the smell of it, and we get worse and we feel craving for smoking... "

- Methadone maintenance treatment

It appeared that the lack of a suitable treatment program for those taking methadone in prison and occasionally delay or missing methadone prescription, could lead to inmates refraining from taking HIV medications. This was attributed to the exacerbation of hangover feeling following antiretroviral drugs intake, particularly Efavirenz; as the most participants believed that a regular and timely methadone prescription has positive effects on adherence to HIV treatment.

"I've had methadone experience of one year and helped get my HIV drug better. When we came to this prison, methadone was discontinued, thus, my weight dropped."

"They used to give us methadone in the previous penitentiary along the HIV pills, but they do not give it here and have banned it. Methadone did not have any interference with these drugs."

"If we get pills at the right time and take methadone pills in the morning on time, we would have no problem and we would not

have hangover. Otherwise, we have to avoid taking the yellow pill at night..."

"When we take methadone, our day goes well, we take the pills well, and our nutrition gets better."

3.3. The impact of social conditions

- The HIV stigma

According to most of the participants, they were being treated contemptuously and disrespectfully by families, friends, prison staff and authorities, and even inmates, which played an important role in reducing adherence to the treatment.

"Because of the stigma and the bad attitude of people around us, I decided not to take my pills, but I was persuaded to endure these conditions. We are separated from the rest and others distract us. And the staff's misconduct affects the consumption of drugs."

"The elders {in prison} bludgeon the HIV positive newcomers, and they do not give us any space. The disease causes others stigmatize us and do not let us in among themselves."

"The cynical look of prison personnel, for example, they shout: AIDS and TBs come for pills...When the family finds out they would reject us and they would not support us."

"Instead of us fearing the ordinary people, because of our weak immune system and the chance of getting infected from them, they're afraid of us and stigmatize us."

"The concerns, for example, about the family, which do not let me home and giving food from behind the door caused me injure myself. Even though the doctor told them the ways virus could be transmitted, they continued to stigmatize me."

- Unfavorable prison conditions

In most participants' opinions, forced open-air refreshments in cold weather is inconvenient and even cause them respiratory infection; however, prison authorities have not yet attended this issue. In addition, inappropriate diet in prison causes malnutrition, further weakness, and consequently, poor adherence to treatment.

"It is called social help (work), which exists only outside not in here."

"The authorities do not care about us; at least, they can differentiate between us and healthy people; for example, we cannot stand for three hours in a queue of social worker under the sunshine just to ask a question! After that, we do not desire to take our pills, because we are tired and want to rest and sleep the rest of the day, and then we would rather not eat the drug that day."

"I had a letter from the doctor that I should not go out for refreshment; they told me to tear and throw it away, and they do not care about letters; three hours in the morning and three hours in the afternoon force us to go out for refreshment, we are not like healthy people and we easily get sick."

"The foods here are not good at all, since all include starch and soy, ... no meat and no vitamins."

"Medication itself is itching, and soy causes more itching and it gets worse."

"lunch and dinner Lentils and rice and soy; we do not see the color of the red meat."

4.3. Communication with physician

It appeared that an intimate and friendly relationship between doctor and inmate and receiving appropriate consultation about the disease and related drugs from physician, could lead to a morale reinforcement and trust toward continuation of treatment. On the contrary,

the staff's ignorance of prisoners' health had a negative effect on adherence to the treatment.

"Doctor; He is an angel and listens carefully to us and gives us hope. He does not wear masks in front of us. He spends time with us and makes us happy."

"About the profit (of adherence), the doctor said it increases the length of our lives."

"Another doctor told us the importance of regular drug intake and that if we miss the time of one of them, our CD4 will be disarranged."

"We were supported mostly by doctors until now. Confraternities do not support us at all. Charity institutions do not exist."

"They do not care about our sanitation and healthcare situation, especially when we become sick. They do not care if we have another disease, because they know we have AIDS."

5. 3. Access to anti-retroviral drugs

Some of the participants stated that anti-retroviral drugs were not given to the patients at the designated times of the day. In addition, sometimes, few drugs were not available or even a different drug may be provided instead of the right one as a naïve person may handed them out. These problems could have decrease the adherence to ART.

"I have been in this prison for 2 months, and I have not taken the drugs properly for a month because the staff did not do their jobs and did not supply our tabs; for example, we only got the yellow tabs for 10 days."

"They do not have an exact time for the drugs, one night at 8, the other at 10."

"The main problem is irregularity in preparation of the drugs; there's nobody in charge of this, and the prisoners order these drugs."

"They do not give them on time; for example, one time they give tabs twice a day; another day they give us none."

6.3. CD4 counts

It appeared that the descending trend in CD4 count and the fear of disease deterioration with non-adherence motivate that inmates to take their medication properly.

"My CD4 before coming to the prison was 450; now it reached 120; if we realize that our CD4 could reach to a higher number by medication, we will continue the therapy, because our spirit would become better!"

"My CD4 was 270, and due to not taking the drugs, it further decreased to 94; however, after taking the medications, now, it's 117."

"When I got my drugs regularly with methadone, I had CD4 of 250, but when I did not use my drugs properly and cut off my methadone, my CD4 decreased too much..."

7.3. Psychosocial support

According to all participants, one of the reasons for not taking medications was the disappointment in medication effectiveness, and consequent depression. Factors such as family and social support, hobbies such as music, certainty in medication effectiveness, and CD4 count increase following medication appeared to have a positive effect on spirit, and increased the life expectancy of prisoners.

"There is a major disappointment; I think, no matter I take these drugs or not; we are going to die after 2 years... these thoughts about the shortness of life can result in not taking the drugs."

"I have a daughter and all I hope is to be able to see her; I do not want to die here! And that's why I take my drugs."

“We take our drugs for the sake of the family’s love and whoever sympathetic to us.”

“I have no visitors, because I myself do not want, but hope is the most effective factor, and it is related to the person; we have to be motivated... it’s only God who decides on how long a man lives...”

“The music calms us down; amusement affects the consumption of our drugs.”

4. Discussion

In this study, we investigated the barriers and facilitators of adherence to HIV medication among the prisoners living with HIV. It appeared that the medication complications, such as hallucinations, feeling of hangover and weakness (especially with Efavirenz); and addiction (especially Heroin) played important roles in non-adherence to HIV medication. Hence, appropriate side effect management, counselling and encouraging the inmates to be adherent to the therapy was found to be critical. Consistent with the earlier studies (6, 7), as the methadone consumption could affect the severity of side effects, delayed or inappropriate dose of methadone could reduce the adherence of the patients to antiretroviral medications, while appropriate methadone coverage could be a facilitator for ART adherence.

Unfortunately, people living with HIV are extremely stigmatized in Iran; therefore, they are reluctant to disclose their HIV status worrying about being avoided, rejected or discriminated by others(8). In addition, similar to the findings of previous studies (9), the HIV stigma, unfavorable prison environment, and disgraceful behavior of staff and other inmates were among the most important environmental factors that can act as barriers to adherence among prisoners living with HIV. On the

other hand, the intimate and friendly patient-physician relationship and the psychosocial support could be very helpful in reinforcing the morale and getting them to trust the treatment. Furthermore, appropriate training should be made available at the community and prisons, as the above-mentioned social factors are all connected with erroneous attitudes and inadequate knowledge of society regarding the HIV (10-12).

Evidence showed that the patients’ awareness of CD4 level could influence the medication adherence (13). Similarly, in our study, it seemed that the low CD4 level and fear of disease deterioration motivated the patients to be more concerned about medication adherence. In addition, as the adherence to the treatment could increase, the CD4 level started to rise, and consequently enhanced the patients’ morale to adhere to the medication.

In one similar research, held in a clinic of a large hospital located in a peri-urban area in South Africa, participants reported some problems different from those of our participants (14). For example, economic issues were one of the factors that was reported to affect the adherence to the treatment. Probably, the reason that these factors remained unreported in our study was the different context of our study, as well as the differences in economic situations of two countries.

Mobile-based functionality, such as text messaging or online chatting, was found to enhance adherence to medication (15). In addition, sociocultural factors could have different impacts on medication adherence in different countries. For instance, evidence from African countries indicated that spiritual healings and prayers could negatively affect the adherence to the therapy (14-16).

Even though the strict roles of prison and small number of HIV infected inmates, just allowed us to conduct one focused group discussion, we could manage to exploit a rich information regarding the barriers and facilitators of adherence to HIV medication among prisoners living with HIV. The qualitative approach allowed us to identify several aspects of a HIV infected inmate's life, which could hardly be obtained through a quantitative approach. Despite these strengths, there were some drawbacks, as well. Since the adherence is not a static process, the interviews limited our knowledge to the current situation and medication adherence of inmates, and not the changes and determinant over the time. In addition, in this study, females were not included, while the determinants and outcomes could be different between opposite sexes at the correctional facilities. In conclusion, the medications' side effects, inappropriate methadone prescription, stigma, lack of family support, and unfavorable prison conditions were potential barriers of adherence to HIV medication, whilst a strong and realistic patient-physician relationship, psychosocial and family support, and knowledge regarding the level of CD4 were amongst the possible facilitators for adherence to HIV medication in HIV-positive prisoners.

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Conflicts of Interest

The authors have no conflict of interest.

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