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A qualitative assessment of barriers and facilitators to antiretroviral therapy adherence among human immunodeficiency virus patients in Jordan

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ABSTRACT

Objective: To explore barriers and facilitators to antiretroviral therapy adherence among human immunodeficiency virus patients in Jordan from their perspectives.

Methods: Qualitative one-to-one interviews with HIV patients took place in a private support center that works on the inclusion of HIV patients in the society. The inclusion criteria for the study included patients who were currently receiving treatment for HIV for more than one year, has a Jordanian citizenship or residency, were at least 18 years old, and were physically and mentally competent to conduct a reliable, spoken interview.

Results: The participants reported several barriers that negatively influenced their medication experience and adherence. These barriers included the following subthemes: *accessibility, adverse reactions, financial burden, lack of support, medication manageability, psychological factors,* and *stigma.* These facilitators included the following subthemes: *benefits and QOL*, *fear,* and *support and additional services*.

Conclusion: In summary, this is the first study in Jordan regarding HIV patients discuss the barriers and facilitator for ART adherence from their perspectives.

Keywords: antiretroviral therapy, adherence, human immunodeficiency virus, Jordan

INTRODUCTION

Human immunodeficiency virus (HIV) is the major cause of the chronic, life-threatening immunodeficiency disease, acquired immunodeficiency syndrome (AIDS) [1]. Susceptibility to have infections and cancers is higher in those patients [2]. In accordance with the Joint United Nations Programmer on HIV/AIDS (UNAIDS) data, the worldwide prevalence of HIV by the end of 2020 is 37.7 million patients, 680,000 patients died of AIDS-related illness in 2020 and 36.3 million patients have died from AIDS-related illness since the beginning of the epidemic. According to that, 67% of the cases were reported in Sub-Saharan Africa with majority of patients living with HIV disease located in low- and middle-income countries. Moreover, 230,000 patients were living in the Middle East and North Africa (MENA) [3].

With an HIV prevalence rate of 0.1%, MENA region has the fewest HIV cases per capita in the world. Specifically in Jordan, the prevalence rate of HIV is less than 0.1%. The new cases count in Jordan is considered fairly low, as Jordan reported only 21 new HIV cases between the beginning of 2020 and the beginning of 2021 [4]. By the end of 2020 there were 484 officially registered HIV cases in Jordan since the beginning of the epidemic back in 1986 [5].

Antiretroviral therapy (ART) was proven to be the most effective HIV treatment method [6], but its effectiveness depends critically on the individual medication adherence scope [7]. A 78% of the viral suppression rate is approached when the rate of adherence to ART is as high as 95%. However, the viral suppression rate is dramatically reduced to approximately 20% when the rate of adherence is decreased to 80%. To optimize the antiviral outcomes and enhance the viral suppression, the rate of adherence to ART should be maintained at 95% or more [8,9]. It was indicated that dosing time adherence, failing to maintain the blood concentration of the drug was highly associated with lower viral load and elevated CD4 cell count [10,11]. It was confirmed that poor medication adherence is an important risk factors for the emergence of drug-resistant strains of HIV, which can be transmitted to others and increases the transmission with detectable viral loads [12,13].

Different factors were found to affect patient's adherence to ART, including, hesitation, exhaustion, perceived support,

Table 1. Patients' gender and age

Patient number	Gender	Age
1	M	23
2	M	35
3	M	45
4	M	43
5	F	37
6	M	39
7	F	37
8	M	45
9	M	48
10	F	41
11	M	54
12	M	48
13	M	50
14	M	50
15	M	48
16	M	53
17	M	31
18	M	22
19	M	38
20	F	26
21	M	41
22	F	40
23	F	27
24	F	32
25	M	38
26	M	43
27	M	30
28	M	29
29	F	48
30	M	53

environmental barriers, and medication side effects [14]. In the meantime, disclosure of HIV status, social support, using reminders, life-long projects, counselling and education and improved health on ART helped medication adherence and retention in HIV patient care [15]. Pharmaceutical care, which is defined as "the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient's quality of life" is the patient-centered model of care cornerstone [16].Forming a good relationship between the patient and the provider can result in an enhanced adherence [17]. It has been proved in the literature that there is a paradigm shift from a "detached paternalistic relationship towards a more empathetic, patient-centered model of care" [18]. So, this study aim to explore barriers and facilitators to antiretroviral therapy adherence among human immunodeficiency virus patients in Jordan from their perspectives.

METHODS

Setting

Qualitative one-to-one interviews with HIV patients took place in a private support center that works on the inclusion of HIV patients in the society. The center was chosen because the researchers wanted patients to be familiar with the interview place which would reflect positively on the flow of the interview. The center offers several programs to deal with treatment obstacles patients face.

Sample, Eligibility, and Recruitment

The inclusion criteria for the study included patients who were currently receiving treatment for HIV for more than one year, has a Jordanian citizenship or residency, were at least 18 years old, and were physically and mentally competent to conduct a reliable, spoken interview (**Table 1**).

After a chart review for their eligibility, a convenient sample of HIV patients were recruited by phone call or in person in the HIV center between September and November 2020. Reasons for not participating included not being interested or willing, lack of time to meet, not responding to pre-arranged phone calls, or not showing up for a pre-arranged interview appointment. Interviews were concluded after reaching apparent data saturation. Details regarding participants who were invited but did not complete the interview, as well as those that did not meet inclusion criteria were not recorded.

Procedures

The researcher approached patients in the areas determined previously. After informing each subject that participating in the study is voluntary, each participant signed a written consent form designed for the purpose of the study. Patients have been offered the choice of face-to-face interview if they are comfortable with that. Each session took between half an hours to one hour. Patient interviews were conducted in private rooms where patients felt safe and stress-free, and the interviews were conducted in the local language (Arabic). For privacy and confidentiality purposes, participants were informed that the interview was anonymized, and audio recorded. Interview sessions were conducted by using a previously set interview guide, where the focus was on topics related to facilitators and barriers to ART adherence. Within each session, the researchers took notes to capture key points. All interviews were conducted by healthcare provider who had experience in treating HIV patients.

The structured interview guide included the following: participant's history of HIV care and medication, comorbidities, experiences with current care and treatment, Facilitators and barriers to taking their medications. Interviews were audio-recorded, and each participant's statements were transcribed verbatim from the audio recordings. Demographics and information regarding patient's HIV care history were adopted from the patient's medical record. The study's protocol was approved by the institutional review board (IRB) at Jordan University of Science and Technology (REF: 20210164).

Researchers reached data saturation after 30 complete interviews. Interviews were transcribed in Arabic, and for the purpose of analysis and reporting were translated to English, then back translated to Arabic by two independent researchers. English transcripts were analyzed using a qualitative description framework. They were coded line-by-line using NVivo software package. Codes that overlapped significantly in labeled text were organized into broader themes derived from the data.

RESULTS

Overall, participants expressed clear knowledge about their ART, administration, and adverse reactions. Two overarching themes were identified describing participants adherence for ART: barriers and facilitators.

Barriers

The participants reported several barriers that negatively influenced their medication experience and adherence. These barriers included the following subthemes: *accessibility, adverse reactions, financial burden, lack of support, medication manageability, psychological factors,* and *stigma*.

Accessibility

Most participants reported that accessibility to the treatment center is one of the major barriers to adhere to ART. Some participants described their visits to the treatment center to be inconvenient because of distance *"the distance between my residence and the treatment center makes me hesitant to come in for a refill every month and this is why we are not adherent sometimes"* (P2M35). The treatment center is in the capital city of Jordan, therefore, participants residing in other provinces reported limited accessibility to their monthly refills "it is often hard for patients living in other provinces to come to this center for refills, and the medication is not available in other provinces, and this is another barrier" (P6M39). A few participants reported that opening hours for the treatment center does not fit with daily schedule and responsibilities "the main barrier is my working hours. I am sometimes late for my refills because the treatment center closes at 2 o'clock and I must be there prior to that. It is hard for me to be there before the center closes because of work schedule" (P12M48). Similarly, P22F40 reported "I am a mother and have responsibilities to my kids, I cannot go to the treatment center during their opening hours". To overcome this barrier, multiple number of participants reported that home-delivery to ART will increase their accessibility and adherence to treatment "some of us cannot make it to the treatment center, there has to be a home delivery service. I do not know how patients who live far away from the center manage to get their treatment" (P13M50).

Moreover, participants who frequently travel or had to reside outside Jordan on a short time reported challenges to get their ART "the medication is not available in one of the countries that I frequently travel" (P25M38). Three participants reported that did not have access to their medication while they were in prison "honestly, I went to prison multiple times, and I had to stop taking my medication there. I did not have access to my medication there and I was isolated. To be frank, I stopped taking my medication for six months" (P8M45).

Adverse reactions

Most participants reported that their current ART is well tolerated in comparison to the previous one. However, a few participants reported that they are uncomfortable with adverse reactions of the current ART "the new medication increased my weight and caused swelling of some glands around my neck" (P22F40). Couple of participants reported that their ART made them neurotic and experience disproportional anger "the most annoying thing about my medication is that it makes me neurotic and quickly loss control of my temper. This did not stop; I still experience such side effects" (P9M48). The adverse reactions of ART were reported as a barrier for adherence by few participants "the medication is extremely annoying; it causes stomach problems and makes me tiered. I vomit 15 minutes after taking my pill and go to bed right away because of the fatigue. This makes me feel depressed. I also missed my period since I started taking my medication. I cannot adhere to my medication because of these side effects" (P24F32). One participant suggested that some patients would seek complementary medicine to avoid the side effect of ART "the side effects that patients experience at the beginning of therapy make them stop taking it and rely on complementary medicine and herbs" (P14M50).

Financial burden

Despite the availability of ART in the treatment center for free for Jordanians, participants reported that indirect cost to care (i.e., transportation) is one of the main barriers for adherence "I do not have enough money to go the center every month for a refill" (P21M41). The cost of transportation was frequently described as a barrier for participants "I could not always adhere to therapy……when I was living in Aqaba, I could not afford the transportation expenses to Amman. I did not have money" (P15M48). One participant reported that he could not adhere to his ART because he did not have enough money to afford a daily meal "I need support for transportation expenses and my daily meals, so I take my medication after lunch meal. There were days when I could not afford to eat anything, and I cannot just take my medication on an empty stomach" (P26M43). As for non-Jordanian participants, non-profit organizations (NGOs) cover the expenses of HIV medications especially for refugees. However, some participants reported that they had to stop taking their treatment when the NGO stopped the fund "the organization the covers my treatment expenses stopped the fund for a month. I am a refugee, and I could not afford the medication from my own pocket. Forearms of Change center partially covered the expenses, until another organization covered my treatment expenses again" (P10F41). Moreover, some participants who had to travel to other countries reported that they stopped taking their medication as they could not afford it "I had to stop taking my medication for seven months. I was in Turkey then and the medication was expensive, and I could not afford it" (P9M48).

Medication manageability

A few participants reported challenges in taking their ART. Some participants complained about the frequency of doses and reported it as a barrier for adherence "taking multiple doses per day is a lot, this is a reason for noncompliance. Also taking a pill before and after meals is another reason for noncompliance" (P15M48). Some participants could not commit to taking the pill as the same time every day because they cannot have their meals at the same time every day or oversleeping "I try to take my pill every morning at breakfast or as soon as I wake up, I take a small snack and take my pill afterwards. However, I am not committed to this plan as I oversleep sometimes. Honestly I cannot to taking my pill as scheduled (the participant reported a pill for anxiety that makes him oversleep in the morning)" (P1M23). One participant (P25M38) had trouble swallowing the tablet and suggested that she would have better compliance if the medication was in a liquid dosage form. Moreover, most participants suggested that they would have better adherence if the treatment center increased the number of pills dispensed on each visit "I hope they (treatment center) would increase the number of pills dispensed so we do not run out of pills" (P8M45).

Psychological factors

A few participants reported that psychological factors such as stress and anxiety made them stop or consider stopping taking their medications “I constantly have stress and anxiety that often make me consider stopping my medication…… my psychological condition make me hate myself and lose the will to get the treatment” (P3M45). One participant (P8M45) reported that he had emotional problems that made him consider suicide and neglect his medication. Some participants reported that medication itself might be responsible for their anxiety and stress “taking the medication makes me uncomfortable, stressed, and anxious. I am not sure if the medication is the reason behind it or if it is something else” (P8M45). Few participants neglected their follow up appointments and refills because visiting the treatment center reminds them of their illness “I stopped going to the center a few times, sometimes for months or a whole year. Refilling my medication constantly remind me of my illness and how I was fired from my job because of it” (P15M48). Similarly, two participants reported that taking their medications every day is the reason for their stress and depression as it is a constant reminder of their illness “the medication affects my psychological well-being. Every time I take my medication, I remember how I got the infection and my suffering with the person who gave it to me. This makes depressed constantly” (P22F27).

Stigma

Participants reported that negative attitudes, and judgments towards people living with HIV (i.e., stigma) is one of the main barriers to adhere to ART “social stigma forces us not to adhere to therapy and follow ups” (P11M54). Some participants were concerned that their families or friends will find out about their illness, therefore, they avoid taking their medication in front of them “sometimes I forget to take my medication, it is hard to take it when I go out with people. I am afraid that they will know about my disease” (P5F37). Some participants reported that they constantly hide their medications or put them in different bottles to avoid stigma “my husband and I have HIV and our families do not know. We put our pills in a vitamin bottle to hide it from our families” (P20F26). Some participants reported that stigma prohibits them sometimes from visiting the treatment center for refills “my social life is terrible, and I do not care about my wellbeing. I cannot go to the center every month because my family is watching me all the time and I cannot go anywhere specially during this COVID-19 pandemic” (P24F32). One participant (P11M54) suggested stigma would make HIV patients question the efficacy of their therapy “people are influenced by some media that scared them from socializing with HIV patients or even shake hand with them. This fear makes us question if the medication is really effective.”

Facilitators

The participants reported several factors that would positively influence their medication experience and adherence. These facilitators included the following subthemes: *benefits and QOL*, *fear,* and *support and additional services*.

Benefits and QOL

Nearly all participants perceived the benefits and quality of life improvement from ART. Therefore, they are constantly motivated to take their medication “without this medication, my life would be over. It’s the only way to save my life, keep my body healthy, and go one with my daily activities” (P26M43). Some participants reported that medication made them feel that they longer remember have a disease and they are living a normal life “my life is better now. The medication makes me live a normal life and I am physically and psychologically healthy. I cannot imagine my life without it because I am finally living a normal life” (P5F37). Other participants reported that they are grateful for the medication as they had uninfected kids and their families are healthy because of it “the medication make me feel healthy. I started a new career, I got married and had three kids and we are expecting and none of them is infected. I consider myself a disease-free person” (P6M39). Moreover, some participants reported that their motivation to take the medication is influenced by their side-effects free experience “I never had any side effects with it, on the contrary I feel relieved when I take my medication” (P2M35).

Fear

Most participants reported that fear of getting sick was their number one motivator to commit to ART “I did not try to stop my medication because I fear the dangerous consequences. If I stop, I will be admitted to the hospital and the thought of it terrifying. My parents will know about my illness, and I will be a social outcast” (P27M30). Some participants had experienced a deterioration in their condition because they stopped taking their medication. This experience made them more aware of the consequences “I am committed to taking my medication as there was an incidence where I stopped taking it and I got sick. It was a very annoying experience. When I started taking my medication, I felt better” (P21M41). One participant (P23F27) reported if anything happens to her, her daughter will be alone in this world. Her fear of getting sick or dying is her primary motivator for compliance.

Support and additional services

Most participants reported that support from healthcare providers, family, and friends is an important motivator from them to commit to their ART. Participants described support from the treatment center and healthcare providers in different ways. For some participants, respectful and proper treatment had an important role in their commitment to ART. “I stopped taking my medication for one year because I was offended by one of the doctors at the center… I started taking my medication again because I was encouraged by another doctor and a nurse who were nice to me” (P2M35). While other participants reported that their adherence will improve if the treatment center provide additional services such: patient education and reminders for refill “my adherence will improve if there are follow ups from the treatment center and phone call reminders for my refills” (P4M45). One participant (P17M31) that the healthcare providers should give more attention to the psychological wellbeing of newly diagnosed patients prior to initiating the ART. Moreover, home delivery of refills was frequently reported as a motivator for compliance “during COVID-19 lockdown, the treatment center crew delivered a two-month refill to my house, this definitely increased my adherence” (P11M54).

Participants who informed their family and friends about their illness received support and help to remember taking their medication on time “when I was in Poland, my friends knew about my disease. They used to remind to take my medication, and this made me committed to taking my medication just before I go to bed or as soon as I wake up" (P1M23). Another participant (P10F41) reported that her husband gets the refill for her every month and that is the reason behind their commitment to treatment. On the other hand, some participants reported that they feel alone in their illness experience as they cannot tell their friends and family about their illness "I am alone in this, I do not have anyone to care for me or remind me to take my medication or even encourage me" (P8M45).

Participants also suggested that support groups and meetings with other HIV patients who have been on ART to share their experiences will be beneficial "there should be support groups where former patients meet the newly diagnosed ones to share their experiences and encourage the newly diagnosed to adhere to therapy" (P11M54).

DISCUSSION

This study explored the barriers and facilitators toward patient self-reported adherence to ART. The thematic analysis results identified key barriers for HIV patients' self-reported adherence in Jordan and their needs to overcome them. Two overarching themes related to patient self-reported adherence have emerged from the collected data: barriers and facilitators. Each theme branches to secondary themes, either assist or obstruct the medication adherence. The accessibility to the medication was one of the major barriers related to ART adherence. As most of the patients reported that the accessibility to the treatment center is difficult from their place of living which made the trip inconvenient due to the distance. Other main sub-themes of the barriers include stigma, lack of support, psychological, and financial burden. The minority reported barriers for the RT adherence were adverse reactions of the medication and medication manageability. Stigmatization creates a great challenge for HIV patient, arise from the perception that HIV persons are scared to be asked about ART medications or they fear if someone has knowledge about these therapies. This was agreed by many different studies, where patients fear to take the bill in front of other people such as their work colleague to avoid being expelled from their job [19, 20]. People living with a high level of stigma are 3.3 times more likely to be non-adherent to ART therapy than from people with a low level of stigma [21]. Although the treatment is free for Jordanians, but participants reported that the indirect costs like transportation was too much when they couldn't afford food. For non-Jordanian HIV patients, the funding organizations used to temporarily stop their funding, which in turn leads to non-adherence. Psychological factors like stress and anxiety are very important when it comes to HIV patients, as it affects their adherence as well as the outcomes of the treatment. Limited non-adherence cases were due to adverse effects of the medication like weight gain, swollen neck, and uncontrolled temper. Few participants reported that their non-adherence is due to the inability to manage the dose frequency, timing, and dosage form.

The other emerging theme is the facilitators which also merges into sub-themes. Support and additional services were the major facilitator in ART adherence as some participants reported that support from the surrounding motivates them to adhere to their medication. So, when their healthcare providers, family and friends are involved in motivating them, this leads to improved ART adherence. Benefits of the ART and QOL improvement are reported by almost all participants. This is due to the therapeutic effects of the ART that makes the patient feel better and improves their symptoms. Fear of getting sick when skipping the ART was reported by most of the participants. This theme was enhancing their adherence to their medication as they know that getting sick will not be better than any of the barriers. According to previous literature, individual, personal and social, institutional, and policy measures all played a role in motivating participants to join and stay in the program [22-26]. Good quality post-test HIV counseling, belief in the effectiveness of ARVs to prevent the spread and promote health, privacy of HIV status [27-30], lack of social stigma at healthcare facilities, positive women-health giving employees, and free HIV services were all attributed to greater uptake and adherence [22-26].

Implication of the Study

The findings of this study reflect the importance of availability of approaches to recognize and counsel HIV patients who have doubts about ARV efficacy early inside the program, the establishment of supporting HIV patients in need, an ongoing campaign to reduce stigmatization at the local level, the availability of sufficient human resources, the decrease of long waits, and enhanced privacy during repeat visits.

CONCLUSION

In summary, this is the first study in Jordan regarding HIV patients discuss the barriers and facilitator for ART adherence from their perspectives. These barriers included the following subthemes: *accessibility, adverse reactions, financial burden, lack of support, medication manageability, psychological factors,* and *stigma.* These facilitators included the following subthemes: *benefits and QOL*, *fear,* and *support and additional services*. The findings of this study were discussed the important of the availability of approaches to recognize and counsel women who have doubts about ARV efficacy early inside the program, the establishment of supporting women in need, an ongoing campaign to reduce stigmatization at the local level, the availability of sufficient human resources, the decrease of long waits, and enhanced privacy during repeat visits.

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