

# A QUALITATIVE ASSESSMENT OF HIV PATIENTS' ADHERENCE TO TREATMENT AND THEIR NEED FOR PHARMACEUTICAL CARE SERVICES IN JORDAN

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## Abstract

**Objectives:** The objectives of this study were to assess the barriers to treatment adherence and need for pharmaceutical care services among HIV patients in Jordan.

**Method:** This is a qualitative in-depth interview study. Participants were recruited with the assistance of a Non-governmental organization specialized in HIV patients. Fifteen patients were interviewed using a pre-designed interview guide. Recorded interviews were transcribed verbatim, and de-identified prior to analysis. Results were then imported into QSR International's NVivo 11 Software.

**Results:** Three main themes emerged from the interviews. Those included patient-related factors, medication-related factors and Healthcare professional related factors. This study found that a number of barriers that decreased adherence in HIV patients included stigmatization, fear from disclosure, dosage form of the drug, adverse events, and poor cooperation from healthcare professionals. On the other hand, supporting factors included family and friends support, electronic mobile reminders, feeling responsible to raising children, religious beliefs, and feeling improvement while using therapy. Furthermore, the study illustrated that HIV patients need to have a specialist pharmacist in their healthcare team who delivers specialized pharmaceutical care services which may increase patients' adherence.

**Conclusion:** Adherence to HIV treatment is subjective and related to various barriers and supporting factors. Participants reported a strong need for pharmaceutical care services, HIV specialized pharmacists, and a pharmacist that treats them with empathy and understand what they are going through. There is still a need to develop educational programs and implement proper counseling in order to improve Jordanian pharmacist awareness about HIV disease and treatment options.

## Introduction

HIV is the major cause of AIDS which is a chronic, potentially life-threatening immunodeficiency disease 1. Thus, making those patients more susceptible to have opportunistic infections and cancers 2.

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) data, the prevalence of HIV in the global world was estimated 36.9 million people, 940,000 patients of them died of AIDS-related illness in 2017. Adding to that, 66% of the cases were reported in Sub-Saharan Africa and the vast majority of the people living with HIV disease were located in low- and middle-income countries 3. Furthermore, 18,000 patients were living in the Middle East and North Africa 3. Apart from the international statistics, the total number of HIV/AIDS cases were registered in Jordan were 1,080 patients since 1986, as reported by a health ministry official in 2014. Over the last 28 years, 65.29% of patients had the disease via sexual intercourse, 22.68% through blood transfusion and 2.41% by drug injection. However, a rising in new incident cases is

noticed; 54 new cases were reported in 2014 4, 92 new cases were reported in 2015 5, and 103 new cases were reported in 2016 6.

Treatment failure is common among HIV patients 7,8. Poor adherence was strongly associated with virological failure among patients on ART 9,10. HIV/AIDS patients should have an adherence level of at least 95% as a requirement for optimizing ART and maximizing virological suppression 11.

Several factors were found to affect adherence to ART, including psychological reactions such as depression, disappointment, hesitation, forgetfulness, and exhaustion, perceived support, contradictory beliefs, and environmental barriers. Moreover, medications' side effects were found to affect HIV patients' adherence 12. Meanwhile, disclosure of HIV status, social support, use of reminders, life-long projects, counseling and education, and improved health on ART facilitated medication adherence and retention in HIV care 13.

Forming a good patient-provider relationship can enhance adherence 14. 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' 15. The patient-centered model of care is the cornerstone of pharmaceutical care 16. Pharmaceutical care is defined as "the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient's quality of life" 16.

A new pharmaceutical care model, known as Ability-Motivation-Opportunity (AMO) has been developed 17. In this model, healthcare providers should have the ability to provide individualized pharmaceutical care to each patient, as well as they should be able to motivate the patients to reach goals with drug therapy. Finally, they should have the proper opportunity to provide pharmaceutical care with personal consultations, through information, communication, and learning technologies. With this approach the results were satisfying and assisted patients to take better care of themselves, following their treatment, determining goals to control their disease 17. Based on the above evidence, this research aimed to find the barriers and facilitators of adherence to ART among HIV positive patients in Jordan and to assess their need to pharmaceutical care services.

## Methods

### Study Design and Setting

This study is an exploratory qualitative study that aimed to describe pharmaceutical care needs for HIV patients in Jordan using in-depth interviews. The study was conducted at Forearms of Change Center over 8 months period starting from March 2019 to September 2019. The Forearms of Change Center encourage HIV/AIDS patients in Jordan to cohabit with their disease and give them positive support and help. The study's protocol was approved by the Institutional Review Board (IRB) at Jordan University of Science and Technology (reference number: 7/124/2019).

### Study Participants

HIV patients attending the Forearms of Change Center were invited to participate in this study. One researcher identified potential participants that met the inclusion/exclusion criteria and explained the study objectives and procedure. The inclusion criteria were: patient's [?]18 years old, HIV positive and receiving ART. Patients who were on ART for less than six months and non-Jordanian residents/citizens were excluded from the study. Written informed consent was obtained from all participants and they were informed that their participation is voluntary, and they can withdraw at any time. Participants were given alphanumeric code to refer to interviewees' identification and ensure anonymity in the study. For example, the alphanumeric code P1F35 indicates that the participant number 1 is a 35 years old female.

### In-depth interviews

Participants were offered to conduct the interview over the phone or face to face. Each session took between half an hour to one hour, utilizing a semi-structured questionnaire, so open and semi-structured questions were used in the interviews. Face to face interviews were conducted in private rooms to avoid any interruptions or distractions and to make participants comfortable. All interviews were conducted in Arabic to

ensure participants' understanding of interview questions and expressing themselves in their native language. All interviews were audio-recorded and later transcribed.

The interview questions were developed after reviewing previous literature 12,13,18,19, followed by rounds of reviews and discussions by all authors. The interviews started with questions to elicit socio-demographic information and history of illness followed to a set of questions that explored: 1) HIV patients' compliance to medication therapy, 2) HIV patients' perception and needs of patient care provided to them.

### Analysis

Recorded interviews were transcribed verbatim. Transcripts were reviewed to explore: HIV patients' facilitators and barriers to ART compliance and HIV patients' perception and needs of patient care provided to them. Thematic analysis was performed on the transcripts by two authors. Discrepancies were resolved by consensus. Transcripts were stored and organized using QSR International's NVivo 11 Software. Descriptive statistics were used to analyze quantitative data, and the results are presented as percentages and frequencies using the Statistical Package for Social Sciences (SPSS) version 25.

## Results

A total of 18 HIV patients participated in this study. However, three participants withdrew from the study. The mean age of the remaining 15 participants was  $37.53 \pm 7.67$  years and 60.0% (n=9) were males (Table 1). Participants had a mean duration of cohabitation of 10.2 years and have on medication therapy for 8.7 years. Nearly all participants were taking Stribild? (elvitegravir, cobicistat, emtricitabine and tenofovir) with a mean of  $806.4 \pm 313.2$  CD4 cell count (Table 1).

### Thematic Analysis

#### Compliance to ART

Two overarching themes described factors related to participants' compliance to ART: patient-related, and medication-related (Table 2). These factors were not always a motivator or a facilitator for a better compliance, some of these factors were reported as a barrier as well.

##### Patient-related factors

In this overarching theme, participants reported factors related to their own self-motivation and self-efficacy that ultimately describe their compliance to ART. These factors included the following three sub-themes: *psychological reactions, family and friends, and routines & reminders*.

*Psychological reactions* : Participants reported a wide range of emotions that positively or negatively affected their compliance to ART. Stigmatization was frequently mentioned by participants as a factor that negatively affected their compliance as they avoid taking their medications in front of others. The fear of being judged by others led some participants to hide their medications and only take their medication when they were alone.

In one extreme case, participant reported that HIV patients can fear for their own lives if they were ever caught taking ART. However, fear was not always an emotion that negatively influences compliance. Some participants reported that their fear of transmitting the disease to others was a motivator for a better compliance.

Participants also reported positive emotions that contributed to their ART compliance. Self-confidence was among these emotions. Some participants reported that their self-confidence positively influenced their coexistence with HIV infection, and the willingness to be strong which ultimately increased their adherence to ART. Participants' self-consciousness of their well-being also motivated them to regularly take their medications. One participant expressed his happiness for being HIV positive because he became more interested in taking care of himself and his own health.

*Family and friends:* Getting support from family or friends motivated participants to regularly take their medications. Families' support was not limited to reminding participant to take their medications, it also influenced participants' compliance to follow up visits to their physicians and lab tests. Children were another source of motivation for participants who have children. Participants with children reported they are always thinking about their children and their constantly remind themselves that they have to live longer to be there for their children. Two participants were concerned about transmitting the infection to their children if they did not adhere to therapy.

Despite that some participants did not inform their families about their infection, some chose to share it with their friends. Friends support appeared to influence participants' attitudes toward their infection and ultimately their compliance to therapy.

*Routines & reminders :* A few participants reported that they rely on a daily routine to remind themselves to take their medications. Another participant reported. Other participants chose to put their medication in a place where it is always checked or use a phone alarm.

#### Medication-related factors

This overarching theme included three sub-themes: *adverse events, medication benefits, and inconvenience .*

*Adverse events:* Nearly half of the participants were complaining about the side effects of the drugs (e.g., vomiting, diarrhea, and vertigo). Some patients suffered from hallucinations and insomnia forced them to stop their medication. One participant reported that he suffered from drowsiness and after taking his medication falls asleep. Other patients refused to take their medications because of fat deposition in the abdomen area and the extremities become lean, this leads bodybuilding patients to keep away from taking drugs and the price was their life.

*Medication benefits .* Living a long healthy life with no fear of suffering from the complications of HIV infection was a one factor that encouraged participants to be compliant with ART therapy. Participants reported that their CD4 cell count and viral load improved after taking their therapy and their body weight becoming better. All of these benefits motivated participants to adhere to their therapy.

*Inconvenience .* The majority of participants reported the inconvenience of taking pills every day. Some patients had to take numerous pills every day which influenced their attitudes toward adherence. Similarly, participants who were taking one tablet daily reported inconvenience.

#### **HIV patients' perception and needs of patient care**

The second part of the interview resulted in three main themes that describe participants' perceptions of the level of patient care provided to them and their needs for a higher level of patient care. These themes are: *Inappropriate care, the need for pharmaceutical care and specialist HIV pharmacist* (Table 3)

##### Inappropriate care

Participants reported that their HIV health care team are not cooperative and sometimes they often feel neglected. Some participants believe that their healthcare professionals do not have sufficient knowledge to manage and follow up with HIV patients

Participants also reported that they often stigmatized by health care professionals. It is difficult for patients' to accept their illness and adhere to therapy if they do not get proper care from their healthcare professionals. Some participants reported that some healthcare providers fear treating them. This rejection by healthcare professionals pushed some participants not to inform healthcare professionals about their infection

##### The need for pharmaceutical care

Almost none of the participants were familiar with pharmaceutical care prior to the interview. The majority of participants reported that they did not have a pharmacist in their healthcare team.

The majority of the participants had poor knowledge about pharmacists' role in the health care team. Most of the participants believed that pharmacists' role is limited to dispensing medications. One participant seemed to have adequate knowledge of pharmacists' role. All participants agreed that do not receive adequate patient care and empathy from their pharmacists. Moreover, participants reported that pharmacists hardly go over directions on how to take medications and do not discuss any follow-up plans with them.

#### Specialist HIV pharmacist

Participants had positive attitudes and agreed to have a specialist HIV pharmacist part of their healthcare team. Participants highlighted the importance of having a pharmacist with knowledge and expertise in HIV therapy to ensure safe and effective therapies

A few participants reported that they are not receiving adequate pharmaceutical care from their pharmacists which negatively influenced their views on pharmacists' role in patient care

According to the participants, the presence of a specialist HIV pharmacist in their health care team and implementation of PhC may positively influence the adherence of the patients to their treatment.

### Discussion

This study explored HIV patients' facilitators and barriers to ART compliance in addition to their views, perceptions and needs of patient care provided to them. The thematic analysis results identified key barriers for HIV patients' compliance and suggest inappropriate patient-care and discrimination against HIV patients in Jordan.

Two major themes related to patients' compliance to ART have emerged from the obtained data: patient-related, and medication-related. Each theme branches to sub-themes, either facilitate or obstruct the medication adherence. Patient-related factor that contains sub-themes such as psychological reactions, family and friends support, and reminders. In which, stigmatization, fear, happiness, strong beliefs and self-confidence are the main factor identified among psychological reactions sub-theme. 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<sup>20,21</sup>. 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<sup>22</sup>. Whilst stigmatization was frequently mentioned as a complex phenomenon to decrease medication adherence, happiness, strong beliefs and self-confidence were reported as facilitators for adherence. Surprisingly happiness, which was mentioned by a few participants is that the infection making them more caring for their health status. Moreover, being one of the infected persons gives him/ her the chance to help other HIV persons.

As been observed from this study having family and friend support adds on to patient satisfaction and can invoke participant adherence. The participants highlight the importance of the friend's support since its difficult most of the time to tell the family about their infection. Having support from their friends helped them to rise again and being stronger; which is illustrated in other literature<sup>23,24</sup>.

Apart from family and friend support, reminders are identified as an important facilitator for adherence. Having the advantage from associating ART therapy with a repeated habit such as lunch or putting the drugs on a place where is always checked for assuring the drug had been taken enhance their adherence; which in fact generally consistent with the findings of Bezabhe *et al.* a qualitative study conducted in Ethiopia on twenty-four patients, where the use of electronic devices such as mobile phone and alarms, helped AIDS patients to take their drugs without the need of others reminding<sup>13</sup>.

Medication-related factors were found to have a contrasting effect on adherence. Regarding the side effects; suffering from a number of side effects such as vomiting, diarrhea, vertigo, fat deposition, hallucinations, insomnia, and drowsiness negatively affects patients' medication adherence. This was in line with a previous study where 27% of AIDS patients afraid from the side effects of the drugs<sup>25</sup>. Also, another study recruited

3414 antiretroviral-naive HAART patients revealed that 628 patients (18.4%) have discontinued their regimen because of drug toxicity<sup>26</sup>.

Living a long healthy life, away from relapses of the health status or suffering from other diseases that may occur because deterioration in the immunity, was a critical factor that encourages the patient to keep on with ART therapy. The patients noticed that their CD4 cell count and viral load improved after taking their therapy and most of the patient body weight relatively increased. All these improvements motivate the patients to continue their therapy. This was also found in previous studies<sup>27,28</sup>.

Finally, participants complained about the number of bills that were taken, the continuity on therapy for long life and taking the drug daily, the pharmaceutical form of the drug and the need for special storage conditions for certain forms such as the jell. All of which make the patients feel disturbed. In fact unfortunately not mentioned or highlighted in the literature previously.

Notably, no study was conducted to assess awareness and knowledge regarding pharmaceutical care among such population in Jordan. Consequently, this study was implemented to better understand the type of pharmaceutical services HIV patients received. Sadly, the vast majority of the participants said that they didn't have a pharmacist in their healthcare team, while in fact there is a pharmacist in their healthcare teams. Unfortunately, according to the participants the only services the pharmacist provides are just dispensing medication and the vast majority didn't know what the pharmacist roles are. All of the participants agreed that there are insufficient pharmaceutical services provided, with little or even sometimes no respect for those patients, which is actually contrasts the ultimate goal of the application of pharmaceutical care <sup>29</sup>.

The present study illustrated that when the participants were asked "Do you need an experienced pharmacist and expert medication to follow your treatment, medications, and doses?" the participants demonstrated a positive attitude and overall agreement which was observed when they were provided a suggestion about the presence of the specialist pharmacist in HIV. According to the participants, the presence of a specialist pharmacist in their health care team and the implementation of pharmaceutical care may positively influence the adherence of the patients to their treatment. This was consistent with other studies which concluded that applying pharmaceutical care services shown positive outcomes with improving medication use, adherence, and surrogate outcome<sup>30-32</sup>. Pharmaceutical care services were found to give the pharmacists the opportunity to improve HIV patients adherence rate and to enhance treatment response with higher CD4 percentage <sup>32</sup>.

Among the strengths of this study, is that it was the first study comprehensively examine the effect of several factors that affect ART therapy adherence among HIV Jordanian patients. However, there are some methodological limitations. One of the limitations of this study was the fact that most of the HIV/AIDS patients were unwilling to take part in the interviews due to fear of their disease being revealed and its consequences like stigma and being boycotted due to the country's cultural attitudes, whilst when the participants were assured that their data would be kept confidential in all stages of this research and that they were free to withdraw from the interviews whenever they decided not to continue, this limitation was resolved to some extent. Moreover, we were challenged with a small sample size, firstly this is a qualitative study and it is known that usually, a small sample is recruited, secondly, our tradition and fear from disclosure decrease the participant's motivation to be one of the volunteers.

## Conclusions

In conclusion, the results of this study provide preliminary data about the factors affecting medication adherence among HIV Jordanian patients and their level of awareness and perception toward pharmaceutical care. From the collected results we noticed that adherence to the treatment of HIV is not constant and mono-dimensional but is a function of different factors. Hence, the infected individual may show feeble adherence in a specific time and under specific circumstances having desirable adherence under a different circumstance. Thus, the treatment of people living with HIV needs psychological supports in addition to ART therapy. Nevertheless, there is still a need to develop educational programs and implement proper counseling in order to improve Jordanian pharmacist awareness about HIV disease and treatment options.

## Conflict of interest

None of the authors have any conflict of interest.

## Funding

None

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Table 1. Socio-demographic characteristic of the participants.docx available at <https://authorea.com/users/287165/articles/411790-a-qualitative-assessment-of-hiv-patients-adherence-to-treatment-and-their-need-for-pharmaceutical-care-services-in-jordan>

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Table 2. List of themes and sub-themes in relation to compliance to ART.docx available at <https://authorea.com/users/287165/articles/411790-a-qualitative-assessment-of-hiv-patients-adherence-to-treatment-and-their-need-for-pharmaceutical-care-services-in-jordan>

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Table 3. List of themes and sub-themes in relation to HIV patients\selectlanguage{english}' perception available at <https://authorea.com/users/287165/articles/411790-a-qualitative-assessment-of-hiv-patients-adherence-to-treatment-and-their-need-for-pharmaceutical-care-services-in-jordan>