

## People Living With HIV's Experience with Healthcare System and Their Adherence to ART

Sahar Mohamed Soliman<sup>1</sup>, Amel Ibrahim Ahmed<sup>2</sup>

<sup>1</sup> Department of Community Health Nursing, Faculty of Nursing/ Mansoura University, Egypt

<sup>2</sup> Department of Community Health Nursing, Faculty of Nursing/ Mansoura University, Egypt

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### **Abstract :**

**Background:** Seeking for health services and adherence to antiretroviral therapy are still requiring efforts to investigate the barriers that are facing People Living with HIV (PLHIV).

**Aim:** This qualitative study aimed to portray the experience PLHIV with health care system, and their adherence to ART. **Subject and Method:** A total number of 10 focus group discussions each session included six PLHIV and consumed 30-45 minutes. A purposive sample of 60 PLHIV who had experience with health care services was used. The study was carried out at a drop- in center that providing care for PLHIV that affiliated to non- governmental organization. **Results:** Three themes described PLHIV experience and satisfaction with health care system. Most of them experienced discrimination and stigmatization behaved by health care providers. Some of them were satisfied with ART services, while others did not adhere to antiretroviral therapy because of the requested personal identification card. **Conclusion:** The study concluded that the majority of PLHIV could not easily access the health care services and were unacceptable for most of them. They faced several barriers that hindering their adherence to antiretroviral therapy regimen. **Recommendations:** A decentralized and integrated health care services with engagement of PLHIV in making decision was recommended.

**Keywords:** adherence, ART, experience, health care, PLHIV

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### I. Introduction

The pandemic of Human immunodeficiency virus (HIV)/ acquired immune deficiency syndrome (AIDS) is a major public health problem. It became one of the major threats of human being all over the world. There are 36 million people living with HIV (PLHIV) globally during the year 2014. The estimated number of PLHIV was 240000 in the Middle East and North Africa Region (MENA). Although the MENA region has the lowest number of PLHIV, there is 2 million of newly HIV infection detected in 2014. This represented 26% increase in incidence rate from the year 2000 to 2014. In Egypt PLHIV represented 3% of the total PLHIV in the MENA region<sup>(1,2)</sup>.

The different health service including voluntary counseling and testing (VCT) is the starting point to life- saving for PLHIV<sup>(3)</sup>. However, the evidence indicated that delaying in persons seeking VCT is existing due to fear of stigma and discrimination<sup>(4)</sup>. On the other hand, PLHIV who requested services faced many challenges such as concentration of services in certain cities as well as the negative views of the health society toward them. They are suffering from several social and psychological problems and difficulties to access health services<sup>(4,5)</sup>. In Western Cape, South Africa, HIV-positive women are stigmatized socially and even from health providers. Accordingly, their access to services, and their engagement in social interactions were negatively affected<sup>(6)</sup>. Moreover, in a recent Egyptian study it was indicated that community members expressed their stigmatization toward PLHIV by reluctance t in seeking health services from the same of physicians and health care facilities is offering health services to PLHIV<sup>(7)</sup>.

In MENA region, ART coverage was only 18% among adults and children who needed the treatment at the end of 2012, with 20,000 people on treatment<sup>(5)</sup>. In Egypt, there is increased emphasis on treatment and services provided for PLHIV. These health services are provided through the National AIDS Program (NAP), by integration into other health services such as maternal and child health and tuberculosis health care services. Despite the executed efforts of the MENA region and Egypt specifically, there are many barriers hindering the expansion of satisfactory health care services for PLHIV<sup>(8)</sup>. An Egyptian study that was conducted in 2008, where PLHIV mentioned the NAP efforts in their support, but they were still discriminated by many of health team members<sup>(9)</sup>.

In Egypt, although there are some reported studies that describe the feature of the provided services, there is a lack of in depth exploration of the PLHIV's point of views regarding their experience with the health care system and treatment. Therefore, this study was conducted in 2015 to portray the experience of PLHIV with health care system and adherence with ART.

## **II. Aim of the Study**

The study aimed to portray the experience of people living with HIV (PLHIV) for health care and adherence to antiretroviral therapy (ART).

### **Research questions:**

1. What are the experiences of PLHIV with available health service?
2. What are the challenges PLHIV with ART facing?
3. What are the views of PLHIV regarding improving the provided health services?

## **III. Subject and Method**

### **3.1. Study design:**

Qualitative phenomenology study design was used to achieve the aim of this work by using focus group discussion (FGD) <sup>(10)</sup>.

### **3.2. Study Setting:**

The study was carried out at the drop- in center for PLHIV that affiliated to the "Support for Development Foundation", Alexandria Governorate, Egypt, during the year 2015.

### **3.3. Subjects:**

A purposive sample of PLHIV (n= 60), who were invited to participate in FGD and agreed to participate in the study. The inclusion criteria of participants were PLHIV aged more than 18 years and on ART for more than one year. Recruiting of PLHIV continued until now new data being obtained by new participants.

### **3.4. Data collection:**

FGD consisted of ten sessions conducted with PLHIV. Each session included six PLHIV, and consumed 30-45 minutes. The total consuming time was 5 - 7.5 hours. Sessions were conducted in comfortable environment for PLHIV. Each FGD was steered by two researchers. One of them managed the FGD starting by presenting the aim and the proceeded with following questions and the other recorded their response. PLHIV refused audio recording because they found it to affect the anonymous criteria of the study.

The Focus group questions were stated as follows:

- Q1. Describe your experience with health care system related to PLHIV?
- Q2. How did you feel about the provided health services?
- Q3. Describe your feeling toward the provided health services?
- Q4. How did you find the health care providers?
- Q5. What are the challenges that you find in obtaining the required health care services?
- Q6. Describe your compliance to the ART?
- Q7. Describe the obstacles that hinder your compliance to the ART?
- Q8. What do you suggest to improve the provided health care services for PLHIV?

These questions of the FGD were translated from Arabic into English and vice versa to ensure the meaning consistency. The Arabic version of these questions were pilot tested for clarity on six PLHIV before conducting the study. Questions were modified according to the findings of pilot test.

### **3.5. Data analysis:**

Simple frequency table was used to present the demographic data of participated PLHIV. Data was collected in Arabic and subsequently translated into English. Thematic analysis was used to analyze PLHIV's descriptions of their experiences with health care services and adherence to ART. Pre- identified themes were used in thematic analysis. The interview transcriptions were analyzed to search for common themes and similarities, and variations among patients' views. Data was coded and similar codes were identified and grouped together under categories and subcategories. Similar categories were organized together under common themes. To check the validity of the findings, the two researchers reviewed the raw data and clarity of analysis in relation to the emerging categories and agreed themes. Feedback of participants on the final findings' themes was obtained from PLHIV who agreed themes.

### **3.6. Ethical consideration:**

All participants from PLHIV were informed about the study aim, and oral consents were obtained. They were informed that there is no any obligation to participate in the study and they have the right to refuse participation or to quit of focus group session (FGS) at any time. They were also assured that quitting of the

study would not affect services provided to them by the foundation. Participants were also assured that their data would be used only for research purpose in a confidential way.

#### IV. Results

Table 1 described socio-demographic features of the 60 people living with HIV (PLHIV). Age of studied group was more than 30 years in half of them, (53.3%). About two thirds were women (66.6%), 70 % were married and 75 % were non-educated.

**Table 1: Socio- demographic Characteristics of Participated PLHIV**

Items	N= 60	%
<b>Age</b>		
≤30 years	25	41.6
> 30 years	35	53.3
<b>Gender</b>		
Male	20	33.3
Female	40	66.6
<b>Marital status</b>		
Married	42	70
Single	18	30
<b>Level of education</b>		
Educated	15	25
Non-educated	45	75

The present results included three main themes about health care service and ART adherence and their suggestions for improving adherence:

#### 4.1. Accessibility and acceptability of Health care services:

The experience of PLHIV with the provided health care services was illustrated in four sub categories as following:

##### 4.1.1. The coverage of health care services

About one quarter of them were satisfied with the provided care in fever hospital in terms of location, and staff caring in humanistic manner. PLHIV expressed their satisfaction by declaring:

"The fever hospital is good place for providing care" (FGS= Focus group session number, PC= Participant code) (FGS 1: PC: A, B, E, FGS 3: PC: B, D, FGS 6: PC: A, F).

"All Health care providers in the fever hospital are kind with me" (FGS 2: PC: C, D, E, FGS 9: PC: A, D).

On the other hand, about one third of participants mentioned that they are suffering from long distance between their residence and fever hospital (where they receive health care services). They said:

"Long distance between our residence and fever hospital to receive health care services" (FGS 5: PC: C, FGS 7: PC: F, FGS 8: PC: C, F).

"I live too far from the hospital and I use more than one bus to reach it" (FGS 1: PC: C, FGS 9: PC: B, E).

Other issues were raised in relation to receiving health services from private health care sector and health insurance. Nearly half of participants reported that private health care sector refuse providing care for PLHIV. In addition, they wished health insurance organization to provide health services for them.

"The private clinics and hospitals did not provide health care services for HIV patients" (FGS 1: PC: A, C, E, FGS 4: PC: A, D, F, FGS 5: PC: B, C, D, FGS 10: PC: A, B, F).

"Health insurance hospital did not provide health care services for HIV patients" (FGS 1: PC: B, C, E, F, FGS 3: PC: C, F, FGS 5: PC: A, B, C, D, FGS 10: PC: A, C, E).

##### 4.1.2. Antiretroviral therapy (ART) services

Less than half of PLHIV were satisfied with the ART service and the presence of a pharmacy at fever hospital that facilitates obtaining their medication:

"The treatment services is more than excellent" (FGS 1: PC: A, B, E, FGS 3: PC: B, D, FGS 6: PC: F).

"There is a clinic and pharmacy in the fever hospital,...and the medication services are more than excellent". (FGS 2: PC: B, E, FGS 3: PC: B, FGS 6: PC: A, F).

Some participants mentioned that they receive medication in confidential circumstances, and the way of providing ART is acceptable.

"There is a great confidentiality in medication delivery, which encourages me to get the treatment". (FGS 1: PC: E, FGS 3: PC: B, FGS 6: PC: F)

On the other hand, more than one third of PLHIV did not seek ART because of using of patients' full name, which leads to unacceptable confidentiality level.

"I do not use treatment because of requesting my full name". (FGS 5: PC: F, FGS 8: PC: A, B, C FGS 9: PC: D, FGS 10: D, E)

Among factors that lead to unsatisfactory of ART service, are the centralization of receiving treatment at one hospital, narrow timing for medication delivery, and the irregular availability of ART. These were mentioned by two thirds of PLHIV who said:

"Long distant to receive discourage me to go for receiving treatment" (FGS 1: PC: C, FGS 5: PC: C, FGS 7: PC: F, FGS 9: PC: E).

"There is only one hospital that provide treatment" (FGS 3: PC: A, C, FGS 6: PC: C, D).

"The drug sometimes is not present" (FGS 3: PC: A, C, FGS 6: PC: C, D).

#### **4.1.3. Health education**

There is no consensus among PLHIV regarding health education despite the existence of session weather of health education or support group. Nearly half of participants showed satisfaction of these sessions, and most of them were satisfied with the availability of printed materials

"There are health education and support group session" (FGS 1: PC: F, FGS 5: PC: C, F).

"There are some printed materials and booklets" (FGS 6: PC: A, FGS 7: PC: B, FGS 10: PC: E).

Most of PLHIV found these health education sessions useful, and nearly two thirds of participants preferred individual health education rather than group health education

"There is a good individual health education sessions"(FGS 1: PC: F, FGS 6: PC: D)

"I prefer individual health education"(FGS 2: PC: A, FGS 7: PC: A, E)

Twenty-three PLHIV found that, health education sessions being limited to medication instructions. They were interested in receiving information related to dietary regimen.

"I knew only instructions about taking medication 2 hours after meals time" (FGS 3: PC: E F, FGS 8: PC: C, F, FGS 9: PC: A, FGS 10: PC: C, E)

"I need health education about dietary regimen" (FGS 1: PC: E, FGS:8 PC: D )

#### **4.1.4. Discrimination and stigmatization**

The majority of participants mentioned that they are discriminated and stigmatized by health care providers. They reported that discrimination and stigmatization behaved when health care providers refused to treat PLHIV. Stigmatization was felt especially in private clinics, labor rooms and dental clinics. Moreover, about half of participants mentioned that sanitary workers at health care setting were dealing with them in unacceptable manner:

"There is a great stigma from health care providers...many of them refused to care for me when they knew that I am HIV patient"(FGS 1: PC: A, FGS 4: PC: F, FGS 6: PC: B, D, FGS 10: PC: F ).

"All labor hospitals refused me and I delivered at the fever hospital and I delivered at the fever hospital" (FGS 4: PC: D)

"I found problems in dental treatment and installing a contraceptive lop". (FGS 10: PC: A).

"The workers at the clinics deal badly with me" (FGS: 6: PC: A, B, FGS: 7: PC: E)

#### **4.2. Factors affecting ART adherence:**

PLHIV reported some factors that negatively affecting their adherence to ART. Some of these factors were related to the system of administering ART where other factors were related to the medication itself. Among the system of administering ART linked factors was the unsatisfactory confidentiality in dispensing ART. This was viewed by some of PLHIV who did not receive ART regularly because of personal identification card request.

"I do not like receive ART because they use a card with name". (FGS 5: PC: F, FGS 8: PC: A, B, C FGS 9: PC: D, FGS 10: D, E)

Other negative issue that induced less ART adherence was unavailability of the treatment most of the time. This was revealed by some participants, who also shared the doses with their children.

"The absence of the treatment for the evening dose" (FGS 3: PC: B, FGS 5: PC: E)

"Not all of the time I comply with doses, because the treatment for children is not always available so I give my children from my doses" (FGS 3: PC: A, FGS 6: PC: C, FGS 7: PC: F).

"We are not complying because we share the ART doses" (FGS 4: PC: B, FGS 7: PC: D).

Furthermore, an ART side effect was among factors that lead to interruption of treatment regimen. This factor was a crucial cause of non-adherence among PLHIV. Most of them mentioned that they interrupt treatment because of its side effect that affected their lifestyle. They reported that side effect of ART lead to loss of appetite, while other PLHIV stopped ART because they could not be able to carry out their daily activities such as driving due to drowsiness effect.

"I am not complaining to taking treatment because of medication side effects" (FGS 1: PC: F, FGS 5: PC: B, D, FGS 8: D, F, FGS: 9: PC: A, FGS 10: PC: B).

"I stopped the ART because I have lost the appetite, however I am still taking the night doses" (FGS 1: PC: E, FGS: 8 PC: D, F ).

"I feel drowsy and unbalanced,.....so I interrupted the medication" (FGS 1: PC: E, F, FGS 5: PC: B, D, FGS 8: D, F, FGS: 9: PC: A, FGS 10: PC: B).

"I could not able to receive treatment night doses .....Night dose could make me drowsy while driving" (FGS 7: B, FGS 10: PC: F)

"I do not adhere to ART because I feel dizzy... as I had a car accident before" (FGS 10: PC: F).

Other PLHIV interrupted medication because they thought that they were pregnant and they afraid from its effect on their fetus. One woman said:

"I have stopped ART for a week because I thought that I was pregnant" (FGS 10: PC: A ).

#### **4.3. PLHIV suggestions to overcome challenges of provided health services**

##### **4.3.1. Suggestions related to health care system**

Participants pointed out several suggestions for improving the provided health care services for PLHIV. The majority of PLHIV emphasized on providing health education and raising awareness sessions to health care providers and the community as a whole to eliminate stigmatization and discrimination.

"Providing raising awareness sessions about HIV among the community members"

"Training and awareness for the health care providers about decreasing stigmatization regarding HIV patients" (FGS 1: PC: A, FGS 4: PC: B, F, FGS 6: PC: B, D, FGS 10: PC: D, F).

Other PLHIV mentioned that confrontation of the community is a way to overcome the stigma and discrimination. They showed their interest in providing raising awareness sessions for health care providers by themselves as trail for removing the barriers and stigma,

"I want to provide raising awareness sessions by myself to reduce stigma" (FGS 3: PC: A, FGS 4: PC: B, FGS 5: PC: C).

"When the patients talk about themselves, barriers with the people could be removed" (FGS 3: PC: C, FGS 4: PC: B, D, FGS 5: PC: C, F).

As regarding to other health care services, some women suggested establishing a labor department at the Fever hospital, "To develop a delivery room at the Fever hospital" ((FGS 4: PC: D, FGS 10: PC: A).

##### **4.3.2. Suggestions related to ART**

Regarding PLHIV's suggestions to improve the accessibility to ART, they suggest allocation of evening time to receive their treatment, while others suggest that weekly treatment dispense would be better.

"I prefer that the medication to be dispensed also at evening plus the morning time" (FGS 2: PC A, C, FGS 5: PC: C, FGS 6: PC: D)

"Dispensing doses of medication should be weekly" (FGS 5: PC: C, FGS 6: PC: D) .

However, few participants expressed their views to overcome the negative effect of ART on their lifestyle by selecting dose time that does not interfere with their daily life activities such as mealtime and working time.

"If the medication dose could be at night only, it will not be contradicted to meal time (FGS 1: PC: E, FGS: 8 PC: D).

Other Participant found that providing incentives that cover transportation expenses would motivate people to adhere with treatment.

"Providing incentives and social support will help in treatment adherence"(FGS 1: PC: C, B FGS: 7 PC: F, FGS 9: E).

## **V. Discussion**

The study reflected the experience of people living with HIV (PLHIV) with health care system and their adherence to ART through illustration of three main themes: (a) accessibility and acceptability of health care services, (b) adherence to ART, (c) suggestions to overcome challenges of the provided health care services. This study was conducted in Egypt with PLHV who spent at least one year on ART. Findings of this study might be different from a previous Egyptian study that was conducted during 2008, and concluded that about three-quarters of the PLHIV found the accessibility to needed health care services and ART was easy. However, their findings in interviewing PLHIV were similar to the present study in reporting satisfaction with the support provided by National AIDS Program's staff. That study also reported a similar results of PLHIV who suffered from the negative attitude of the health care providers<sup>(9)</sup>. Moreover, recent studies reported that PLHIV still have poor access to health care services<sup>(11, 12)</sup>.

Among the factors that lead to poor accessibility to both health care services and ART are the feeling of stigmatization and discrimination, unacceptable level of confidentiality, centralization of health services and their own poor economic level. Factors reported by PLHIV of the present study are in the same line with other studies that concluded that fear of poor information confidentiality, stigma, and lack of financial resources were among barriers of accessing and/ or seeking health care services and ART<sup>(12, 13)</sup>.

Discrimination and stigmatization that expressed by health care providers are major barriers for PLHIV in receiving the needed health services. The participants of this study as well as PLHIV of other studies suffered from unsatisfactory reactions of health care providers when latter refuse to treat them. For instance, labour hospitals and private clinics refused to deliver women with HIV as reported in this study. The same situation was reported by Abdeldaim 2015, who found that women with HIV in Egyptian society being discriminated by some health care providers. Some physicians refused to examine them. Some doctors and nurses pointed out that HIV came to those who had multiple sexual relations<sup>(14)</sup>. Furthermore, discrimination against PLHIV by health care providers was reported in Ethiopia and Europe<sup>(15, 16)</sup>.

Negative behavior of health care providers and reluctance of physician and nurses in providing services to PLHIV were pointed out in recent Egyptian study. These included inadequate knowledge about HIV and its preventive measures and cultural concepts that stigmatize PLHIV as being of bad moral<sup>(17)</sup>. Similar findings were reported in rural KwaZulu-Natal in South Africa. More than half of their PLHIV mentioned that some health care providers did not treat them with a respectful manner<sup>(18)</sup>. In addition, a systematic review revealed that over half of PLHIV experienced stigma<sup>(19)</sup>.

Moreover, other authors mentioned that practicing discrimination by health care providers toward PLHIV was due to their fear from infection, disbelieving in effectiveness of infection control measures<sup>(15, 20)</sup>. The majority of PLHIV participated in the present study showed their acceptance of the presence of health education sessions, counseling, and support group. However, they found that health education sessions were insufficient and limited to medication instruction only, which did not fulfill their educational needs. This was also in same line with other studies that revealed dissatisfaction of PLHIV with the provided health education and counseling<sup>(5, 21)</sup>. Hffeejee 2010 and Setayesh 2014 reported that insufficient counseling and health education issues could be contributed to the reason of employing them as primarily educational intervention rather than adopting as therapeutic modality<sup>(5, 22)</sup>.

PLHIV in the present study may not completely adhere to ART because of the mentioned inaccessible and unacceptable system of delivering medication, low confidentiality, and irregular availability of ART. This situation in Egypt is similar to all MENA countries that provide ART free, while services are often centralized in certain sites that are not easily accessible to all PLHIV<sup>(5)</sup>. Moreover, the results of Busisiwe et al. (2008)<sup>(13)</sup> revealed that PLHIV identified barriers to ART adherence to be fear of stigma and the desire of not disclose their HIV status. Also in Addis Ababa it was reported that stigma, and discrimination were negatively affecting patients' ART adherence levels<sup>(23)</sup>.

Side effect of ART was also mentioned by PLHIV of the present study to be another factor that lead to interruption of treatment. They reported that side effects of ART negatively affect their lifestyle pattern. This is by interrupting their daily activities due to feeling of dizziness or affection of their appetite as well as misconception that ART should not be taken during pregnancy. Several studies revealed that adherence to ART was undermined by the side-effects of antiretroviral drugs and insufficient counseling in MENA region<sup>(5)</sup>. Another study reported that the main barrier to ART adherence was the fear of side effects such as dizziness and headaches among nearly two thirds of the non-adherent population in Nepal<sup>(24)</sup>. In studies that were conducted in Texas city and San Francisco Bay Area, the side effects and dosage schedule that interfere with the daily activities were among the most common reasons of non-adherence to ART among women with HIV<sup>(25, 26)</sup>.

According to the WHO "Consolidated guideline on HIV prevention, diagnosis, treatment and care for key population, 2014", it was insisted during the present study insisted to involve PLHIV in deciding the pathway of improving the provided health services, by expressing their suggestions for improvement<sup>(27)</sup>. They suggested that health care services that provided to PLHIV would be improved by building the skills of health care providers through raising awareness and knowledge about HIV in purpose of avoiding discrimination and stigmatization against PLHIV. On national and international levels, it is highly recommended to execute efforts in developing knowledge and skills of health care providers including communication skills as well as working on attitude change toward PLHIV<sup>(16, 20, and 28)</sup>.

Patients always prefer the treatment regimen that does not interfere with their lifestyle and daily activities. Other study indicated that PLHIV favored to visit health care facility more few times and achieve the purpose of visit in less time<sup>(29)</sup>. Furthermore, PLHIV preferred customizing the ART regimen according to their lifestyle with intensive guidance on medication precautions, side effects, and self-management skills including dietary requirement and activities<sup>(30)</sup>.

Suggestions of PLHIV who participated in the present study were going on line of the mentioned previous researchers. They suggested ART delivering system and dose timing to be modified for not being interfered with their daily activities and overcoming the bothering side effect of treatment. They also suggested comprehensive health education sessions that include instructions about dietary regimen.

## **VI. Conclusion And Recommendations**

Based on the views of the studied group it might be concluded that one quadrant of PLHIV were satisfied with the provided service in the fever hospital and NAP staff. The majority of PLHIV were satisfied

with individual health education than group education and some of them asked for dietary education. On the other hand, health care services described by PLHIV to be inaccessible mainly for specialized health care and health insurance services as well as centralization of ART dispensing and its irregular availability. PLHIV expressed their dissatisfaction with behaving manner of health care providers, as they showed discrimination and stigmatization against PLHIV. In addition, they did not accept to disclose their identity to utilize health care services including receiving ART. All of these features plus the side effects of ART were considered downgrading factors in their adherence to ART and/ or utilization of health care services. PLHIV suggested that health care system should require some improvement in terms of providing specialized health services, strengthen knowledge and skills of health care providers in relation to HIV, as well as reforming the health system to fulfill the needs of PLHIV. Accordingly, this study is recommending the following:

- Establishing a framework for providing integrated health care services to include decentralized and flexible health services.
- Adoption of health education as therapeutic modality for raising awareness of PLHIV will induce better self-management and ART adherence.
- Engagement of PLHIV in decision making for the provided health services as well as activating their roles in stigma reduction strategies, this could be considered corner stone in improving care for PLHIV.
- Stigma reduction strategy should be established and emphasized in large scale that involves both governmental and private health care sectors.
- The anonymous health care services including ART delivery should be modified and viewed as essential theme for increasing the utilization of health services by PLHIV.

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