Antiretroviral Therapy in Egypt: Are There Any Barriers to Medication Adherence?

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Abstract

Background: Egypt provides free antiretroviral therapy (ART) to some 5000 Egyptian People Living with HIV/AIDS (PLWHA) across a number of distribution points. **Objective**: This study aimed mainly at identifying potential facilitators and barriers to ART. **Method:** Focus groups discussions (FGDs) were conducted with 33 PLWHA representing most of Egyptian geographical areas. Discussions were designed to cover socio-demographic characteristics of participants, routine investigations, monitoring & follow up measures, problems associated with drug intake, PLWHA needs, stigma, and relevant future concerns. **Results:** Participants confirmed availability of drugs without interruptions almost all months, yet, for the majority (63.7%) of participants, investigations were done during the process of tracing their clinical complaints that were behind first HIV testing, while treatment was initiated without prior relevant investigations for (36.4%) of participants. The majority (75.75%) of participants did not receive adequate counseling before starting their treatment. Almost two thirds (63.6%) of participants initiated drugs at late stage of the disease. All participants (100.0%) expressed their needs for a well-trained person at each center. The treatment had troublesome side effects in the form of drowsiness and loss of concentration among (72.72%) of participants. All (100%) of participants mentioned different stigmatizing practices against them at treatment facilities. **Conclusion:** Lack of accurate information about HIV and ART, inadequate Monitoring and follow up measures, drug side effects and stigmatizing practices against Egyptian PLWHA represent the most common barriers to ARV therapy.

Key Words: *Antiretroviral therapy, Egypt, Barriers, Medication Adherence*

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Introduction

More than 30 million people died worldwide from HIV/AIDS (PLWHA) during the last three decades.[1] The estimated total number of people living with HIV/AIDS (PLWHA) is increasing worldwide, as it was estimated that 36.7 million were living with HIV/AIDS (PLWHA) in 2010 with more than two thirds of them living in Africa.[2] This number increased to reach 33.3 million in 2015, and expected to increase on an annual basis.[3,4] One of reasons behind this

is receiving antiretroviral treatment (ART), and although almost half of patients worldwide are getting their treatment needs, yet, proper access to treatment still remains a faraway dream to accomplish.[5]

By the end of 2010, global coverage of ART reached 40%. About 10 million patients were on antiretroviral treatment (ART), but other millions lacked access to treatment [6]. In 2015, global coverage of ART reached 46%. ART not only prevents AIDS related diseases but also claimed to decrease HIV transmission and AIDS related deaths.[7]

In Middle East and North Africa (MENA) region, the estimated number of PLWHA was 230,000 by 2015 with approximately PLWHA related deaths of 38.200, with less than 12.0 % of them were receiving their ART.[3] Egypt is considered one of countries showing a considerably low prevalence for HIV epidemic at a rate of less than 0.03%.[2] First case of HIV infection in Egypt was reported in 1986. Since then, the cumulative number of reported cases with HIV/AIDS among Egyptians was 8643 by the end of 2016. Egyptian males represent more than 80.0% of infected patients. Sexual contacts represent more than two thirds infections in Egypt, and injecting drugs represents 21.2, while vertical infections from mother to her baby represent 1.8% of infections.[8]

The WHO 2013 guidelines recommends initiation of ARVs treatment to all people with a confirmed HIV infection having CD4 count 500 or less/mm^3 with special priority to those having CD4 count <350/mm^3, severe or advanced HIV disease, active tuberculosis, hepatitis B virus infection with severe liver disease, all pregnant and breastfeeding women, children younger than 5 years living with HIV, and sero-discordant couples.[3]

The specific objectives of this qualitative study among Egyptian PLWHA receiving ART was to identify facilitators and barriers to adherence to ART treatment and to highlight problems associated with drug intake.

Method

We used qualitative research design. Focus groups discussions (FGDs) were organized including key informants of PLWHA receiving ART for at least six months. The total number of participating was 33 persons in 4 FGDs; 11 females (33.3%) and 22 males (66.7%). the recruited study sample were selected form the list of clients at the national HIV/AIDS Control Program receiving ART for at least 6 months. The author intended to represent clients in the main two cities of Egypt; Cairo and Alexandria and one governorate was selected randomly to represent Upper Egypt and another one to represent Lower Egypt. The selected sample participants were 10 participants representing Capital City Cairo), 7 participants representing Alexandria, Menia City in Menia Governorate representing Upper Egypt by 10 participants and Tanta City in Gharbia Governorate representing Lower Egypt by 6 participants. Each focus group includes persons taking their ARVs from the same source. Another focus group was organized at the NAP including key persons related to ART policies and distribution. All FGDs were conducted by the same researcher who has experience in qualitative research. Discussions were conducted based on a previously prepared topic guide which included:

1. Introduction: participants were told that the facilitators wanted to have their opinions about ART policies and problems associated with ART treatment to be available with recommendations for policy

makers to improve the current situation and provide them with better quality of services. They were assured about confidentiality and asked to give their consent for participation and recording of the discussions.

2. Introduction of each person socio demographic characteristics.
3. Why and how treatment was started?
4. Measures for initiation and follow up of treatment
5. Problems associated with dispensing treatment.
6. Problems associated with treatment intake
7. Future concerns associated with ART.
8. Stigma and discrimination associated with ART.
9. Their needs.

The place for implementation of focus group discussions was the voluntary confidential counseling and testing center affiliated to fever hospitals of Ministry of Health where ART drugs are distributed. This place was chosen for being familiar to study participants and availability of secure confidential place to perform the interviews. Transcripts of the audio taped FGDs were analyzed manually using the topic guide as a reference. Categories and subcategories were identified during the analysis and quotations were used when appropriate.

Ethical considerations:

The study was implemented on approval in collaboration with Al Shehab Non – Governmental Organization according to ethical guidelines of Faulty of Medicine, Tanta University. All study participants were informed of the objectives of the study and the content of the interview and asked to give witnessed verbal consent before starting for the interviews. We did not ask for written consent to avoid disclosure of their HIV status and keep confidentiality of their state of infection.

Results:

Baseline characteristics of participants: All participants were eligible for ART therapy. 22 (66.7%) males, and 11 (33.3%) females. Most of Participants (31 (93.9%)) were 20-50years, and only two (6.1%) were older than 50 years. Secondary education was the most prevalent 13 (39.4%), while both illiterates and University graduates share six persons (18.2%). Two thirds 22(66.7%) were married, and only two (6.1%) were divorced. Most of participants were either non employed 10 (30.4%), or manual workers 15 (45.4%), while employees and professionals represented five (15.1%) and three (9.1%), respectively. The median duration of living with HIV was four years with a range between 1-13years. The median duration of ART was three years with a range between 1-9 years. Of the 33 participants, 21 (63.6%) started ART late with CD4 count lower than 350 when positive sero-status was first discovered.

According to the Egyptian National AIDS Program (NAP), total number of PLWHA currently receiving ART estimated to be 3073 representing 45.2% of all Egyptians living with HIV/AIDS at the NAP registry. No signs of inequity in offering ART which is provided for free for all eligible PLWHA across 13 distribution points covering the whole country to ensure easy accessibility to drugs. ART is distributed monthly to ensure regular supply of the drugs and to avoid shortage of treatment.

Relevant investigations: Relevant investigations for treatment initiation- as for example testing for hepatitis B and C infection- are not offered for free. For

more than one third 12 (36.4%) of participants, treatment was initiated without prior relevant investigations, while for rest 21 (63.7%) of participants, investigations were done during the process of tracing their clinical complaints that were behind first HIV testing.

"No, I didn't do any investigations prior to HIV treatment, yet, I've done renal and liver function tests after starting my therapy."

Counseling before starting treatment: The majority 25 (75.75%) of participants did not receive adequate counseling before starting their treatment. They rather sometimes received short instructions on how to take the drugs in terms of doses. There is no reference person to get back to him/her when there is need for information about the drugs. Three (9.09%) of participants were not taking drugs regularly and had long periods of abstinence because of not having clarifications of some associated problems with drug intake and ignorance of the sequalae of irregular treatment.

Available drugs: Participants confirmed availability of drugs without interruptions almost all months. Only one occasion of drug shortage were mentioned during the early period of political instability in 2011. The stocks of drug were delayed at the airport which lead to temporary shortage of drugs. Some of those who needed drugs during that period were supplied by doses to cover the shortage by some peers.

Initiation of treatment: It was noticed that the majority of participants in this study initiated drugs at late stage of HIV infection (63.6%). Those with late initiation were usually first discovered to have HIV infection due to severe manifestations which were mainly diarrhea, fever, Herpes zoster, loss of weight and multiple abscesses.

"I was complaining of diarrhea, high fever, and multiple abscesses for more than three months. I have discovered that I got the disease when I was hospitalized and tested."

"I had renal problems, diarrhea, and weight loss. I was tested for HIV, the results showed low CD4 then started medications."

"Soon after my husband died, I had complaints of fever, weight loss, and abscesses. I started treatment after being tested positive**."**

Distribution of ARVs: Drugs were distributed at centers located mainly at Fever Hospitals. Each month the client should sign a drug request form the authorized person in the distribution center and then dispense the drugs from the hospital pharmacy. The pharmacy at each center identifies specific days for drug dispensing. Problems arise when the monthly drugs stock finishes at a day other than the specified ones for treatment distribution. All participants mentioned that the administrative process to get the drugs is simple and easy.

Drug monitoring and follow up

a- ***Monitoring by CD4:*** The main method of monitoring treatment is by CD4 count. The test is available for free by the Ministry of Health labs at Cairo (for residents of Greater Cairo and Upper Egypt), Alexandria (for residents of Alexandria and Lower Egypt) and at Tanta (for residents of Delta governorates). The majority 24 (72.72%) of participants were performing tests regularly as recommended every 3-6 months. Participants from outside Cairo and Alexandria reported difficulty in compliance with CD4 testing because of travel difficulties.

"Many patients from Upper Egypt have financial and health problems that prevent them to come to Cairo for **CD4** testing."

Monitoring by viral load

Only 6 (18.18%) participants had viral loads in the Central Lab. All of them (100.0%) were residents of Cairo. However, they did not understand its meaning. Again they did not find the chance to ask a reference person about it.

"They told me my virus load is less than 50.I didn't get what they mean."

Monitoring of clinical manifestations and side effects

All participants expressed needs for a trained person at each center. Four (10.12%) of them were suffering from distressing side effects for several weeks and did not know how to deal with. They found no one to give them medical advices. Two of them (50%) reported abstinence of ARVs intake and adoption of traditional medicines.

"I can't sleep because of itching, medication I'm taking at night makes me as if I'm drug-addict."

"I'm not taking my medicine for 3 month now. I'm taking, instead, Herbal remedies."

"We need someone who cares, someone who conducts thorough medical examination. We just come here only to get our medications**."**

Problems associated with drug intake: More than two thirds 24 (72.72%) of participants mentioned that the evening drug leads to drowsiness. For those working by night, this side effect is troublesome. Two (6.06%) participants were drivers who need to work by night. To overcome this symptom, one of them reported taking half tablet of Tramadol to keep awake and the other one postpone or neglect the evening tablet to drive safely.

“I’m a car driver, I have to take Tramadol to oppose the drowsy effect of night-tablet."

3.9-HIV stigma: All participants were keen not to let others know about their taking of ARVs. They want to keep their HIV sero-status confidential. They keep drugs outside the carton boxes. Whenever by chance they were noticed by somebody to take drugs, they were asked why. This is usually embracing to them. Some of them claim taking drugs for some disease other than HIV and succeeded to convince their relatives and friends by their claims.

"I told my relatives I have got cancer to get their sympathy. They help me a lot with my treatment."

"If someone asked me about it, I would tell them it's just some antibiotics and vitamins. On some occasions, I had to take my medications inside the toilet."

"It happened once that my friend noticed me taking my pill. He asked me about that drug, and I told him it is just an analgesic. He asked for a pill to relieve his headache."

Some participants keep the drugs in their pockets or cars. These persons were sometimes exposed to legal problems. In occasions they were stopped at police checkpoints, presence of these drugs arise suspicions that drugs are narcotics. This situation was reported by three participants two of them were working as drivers.

"The officer asked me about my drugs, and I didn't know what to say."

3.10 Associated stigma and discrimination: All participants mentioned stigmatizing practices against them at treatment facilities.

"Once I was asking a nurse about a physician, she replied: are you asking for the physician treating AIDS people?

"My stepmom didn't know my situation. She came to visit me at hospital. When she asked about ward 19 and been told that it's for AIDS patients, she stepped back. Since then, I've been separated from my wife."

Discussion

This study identified several barriers to ART use among Egyptian PLWHA. Lack of accurate information about HIV and ART was frequently mentioned by most of participants. They stated that counseling about the effects of the treatment was inadequate. There is likely a number of reasons stand behind this: excessive burden on healthcare workers, counseling is usually directed to medical rather than social issues, and finally, hierarchical issues that make it difficult for patients to ask healthcare workers freely personal questions. These findings are consistent with findings of a Zambian study.[9] However, these results put for consideration a need for review and assessment of relevant information provided to PLWHA.

Clinical assessment and laboratory tests play a key role in assessing individuals before ART is initiated and then monitoring their treatment response and possible toxicity of ARV drugs.[2] Discussions with participants showed that such investigations were not routinely performed. Needed investigations during drug intake which may be necessary to ensure early detection of any side effects or complications on vital organs were not routinely done as mentioned by all participants. Only those interested and have information about possible side effects were keen to perform investigation which are made on their expense. Treatment policies of NAP did not mandate follow up investigations. Patients receiving ARVs when asking for such investigations at the hospital from where they take the treatment were faced with refusal as such investigations are not for free and only made for free for inpatients only. Financial constraints and lack of information about importance of follow up investigations are usually the main reasons for not being done by PLWHA receiving ARVs.[10, 11]

Another major theme to emerge from this study is relevant to side effects associated with the drug. Our results concur with cited information that refers to long term ART use can be burdensome to many PLWHA.[10-13] Participants were concerned about experiencing certain side effects: drowsy feeling for drivers, and allergic manifestations, to name a few. These side effects – related issues could be dealt with at three levels:[13]

-First, thorough clinical examination and laboratory investigations conducted prior to prescribing the drug.

-Second, close monitoring for patients administered the drug with short-interval periodic medical examination.

-Third, PLWHA should be informed about potential side effects of the drug through a comprehensive health education program tailored according to their needs.

The most salient finding of our study is that stigma is still one of the main problems facing PLWHA in Egypt. Participants mentioned different stigmatizing practices against them while taking the treatment. It seems that self-stigma is another problem. Participants showed high sensitivity to some behaviors by health care workers which may be part of the current practices in health care facilities in Egypt. One aspect of stigma is specifying certain places only for dispensing ARVs. Such places are now well known by health care workers, hospital patients and their visitors as the place for drugs for HIV/AIDS patients. The inpatient ward specified for isolation of patients with AIDS associated diseases is known to all as the ward for AIDS patients. At points where ARVs are distributed at the hospital pharmacy, pharmacy workers used to speak loudly

about drugs being for HIV treatment which may disclose the positivity of HIV client in front of others. Generally speaking, participants complained of improper treatment by some health care workers at facilities dispensing drugs. They mentioned that there should be continuous efforts to reduce stigma among health care workers against them. Identifying PLWHA stigma as a significant barrier to ART therapy was cited at many research studies.[14-16] While the global community has made great decisive steps in the direction of reducing PLWHA-related stigma and discrimination, our study is a solemn reminder that greater efforts need to be taken for further reduction.

Ultimately what our findings, in concomitant with other findings[15-16] reveal is that logistic issues such as PLWHA need to travel to a quite few number of facilities in Egypt to conduct relevant investigations, and to obtain refills constituted a barrier to ART therapy. One potential solution, is to increase number of facilities that provides relevant investigations, and also increasing number of drug refill points, and finally put geographical distribution of Egypt into consideration.

Conclusion

Among PLWHA in Egypt, we found that lack of accurate information about HIV and ART, inadequate periodic medical examinations & laboratory investigations, potential side effects associated with the drug, stigmatizing practices against them, and logistic issues related to drug refill, healthcare workers and providing facilities constitute the most common barriers to ARV therapy. Subsequently, thorough clinical examination & laboratory investigations prior to prescribing the drug, close monitoring for patients administered the drug with short-interval periodic medical examination, tailored comprehensive health education program, and increasing number of relevant facilities & refill points could be corner-stone of increasing Egyptian PLWHA adherence to ART therapy.

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References:

1. Guthrie BL, Choi RY, Liu AY, Mackelprang RD, Rositch AF, Bosire R, et al. Barriers to antiretroviral initiation in HIV-1-discordant couples. J Acquir Immune Defic Syndr. 2011; 58(3):e87–93.

2. UN Joint Programme on HIV/AIDS (UNAIDS), Global AIDS Update - 2016, June 2016, available at: http://www.refworld.org/docid/574e8d394.html [accessed 29 May 2017]

3. World Health Organizations: HIV and adolescents: Guidance for HIV testing and counselling and care for adolescents living with HIV Guidance document. November 2013. Available at www.who.int. Accessed on May 29th 2017.

4. Danzig S, et al. Poor immunological recovery among severely immunosuppressed antiretroviral therapy-naïve Ugandans. HIV/AIDS – Research and Palliative Care, 2013; 5:309-319.

5. Palella FJ Jr., Delaney KM, Moorman AC, Loveless MO, Fuhrer J, Satten GA. Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators. N Engl J Med. 1998; 338(13):853–60.

6. Cambiano V, Rodger AJ, Phillips AN. 'Test-and-treat': the end of the HIV epidemic? Curr Opin Infect Dis. 2011; 24(1):19–26.

7. Muessig KE, Smith MK, Powers KA, et al. Does ART prevent HIV transmission among

MSM? AIDS (London, England). 2012; 26(18):2267-2273.
8. UNAIDS Regional Support Team for the Middle East & North Africa: 2013 Regional Report for the Middle East and North Africa.
9. Murray LK, Semrau K, McCurley E, et al. Barriers to acceptance and adherence of antiretroviral therapy in urban Zambian women: a qualitative study. AIDS care. 2009; 21(1):78.
10.Curran K, Ngure K, Shell-Duncan B, Vusha S, Mugo NR, Heffron R, et al. 'If I am given antiretrovirals I will think I am nearing the grave': Kenyan HIV serodiscordant couples' attitudes regarding early initiation of antiretroviral therapy. AIDS. 2014; 28(2):227–33.
11.Hodgson I, Plummer ML, Konopka SN, Colvin CJ, Jonas E, Albertini J, et al. A systematic review of individual and contextual factors affecting ART initiation, adherence, and retention for HIV-infected pregnant and postpartum women. PLoS One. 2014;9(11):e111421
12.Kahn TR, Desmond M, Rao D, Marx GE, Guthrie BL, Bosire R, et al. Delayed initiation of antiretroviral therapy among HIV-discordant couples in Kenya. AIDS Care. 2013; 25(3):265–72.
13.Tabatabai J, Namakhoma I, Tweya H, Phiri S, Schnitzler P, Neuhann F. Understanding reasons for treatment interruption amongst patients on antiretroviral therapy—a qualitative study at the Lighthouse Clinic, Lilongwe, Malawi. Glob Health Action. 2014; 7:24795.
14.Posse M, Meheus F, van Asten H, van der Ven A, Baltussen R. Barriers to access to antiretroviral treatment in developing countries: a review. Trop Med Int Health. 2008; 13(7):904–13.
15.Da Silva M, Blevins M, Wester CW, Manjolo J, Jose E, Gonzalez LC, et al. Patient loss to follow-up before antiretroviral therapy initiation in rural Mozambique. AIDS Behav. 2015; 19(4):666–78.
16.Sutcliffe CG, van Dijk JH, Muleka M, Munsanje J, Thuma PE, Moss WJ. Delays in Initiation of Antiretroviral Therapy Among HIV-infected Children in Rural Zambia. Pediatr Infect Dis J. 2016; 35(4):e107–12.