

Disclosure of HIV Positive Status: A Challenge Facing HIV Control, Alexandria, Egypt

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Abstract

Background: Egypt is reported to have a growing HIV epidemic especially among injecting drug users and men who have sex with men. There is no published research studying disclosure among those living with HIV in Egypt. The study aimed to estimate disclosure rate, motives, barriers, consequences, and association with sexual behavior. **Methods:** Eighty (80) people living with HIV -16 years old and above- were selected using a systematic random technique from those regularly attending Alexandria National AIDS program center for treatment supply. A designed semi-structured interview questionnaire was used to collect data. **Results:** Self disclosure rate was 78.8%. Socially unaccepted behaviors associated with HIV transmission are significantly associated with non disclosure. Seeking support was the main motive. Sister and mother were first to disclose to (79.3%). Anger and rejection was significantly associated with disclosure of HIV transmission through socially unaccepted behaviors. Denial of disease was the parents' reaction in 4.8%. Female sex workers and men having sex with men were regretting disclosure to their sexual partners in most occasions and usually have unprotected sex. **Conclusion:** Culture, traditions, and religious beliefs play an important role in disclosure motives and consequences in Egypt. Public awareness regarding disease nature and high risk behaviors, and encouraging screening among high risk behavior groups should be integrated in the control program. Disclosure of HIV status and having protected sex should be discussed with all HIV diagnosed cases irrespective of their marital status.

Key words: HIV; AIDS; Disclosure; Unprotected sex; Egypt

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Introduction

As the whole world is facing a Human Immunodeficiency Virus (HIV) pandemic, The Eastern Mediterranean Region (EMR) is ranked the first World Health Organization (WHO) region with an expanding epidemic. There is growing number of cases diagnosed with HIV all over the region.¹ Egypt is reported to have

a growing epidemic especially among injecting drug users and men who have sex with men in spite of the Egyptian National AIDS program efforts.^{2,3}

Disclosure of HIV sero-positive status is a difficult and stressful matter. The association of HIV infection with drug use and sexual behavior often makes HIV +ve

persons not accepted in the society.^{4,5} Egypt is an Arabic and Islamic country where drug use, extramarital sexual relations and homosexuality are criminalized. Those involved in these acts are usually rejected by the society and accused of guilt and shame.^{3,6} Interruption of social relationships with family and friends, stigma, discrimination, and violence are common risks associated with disclosure of one's HIV positive status.^{4,5,7} On the other hand, disclosure of HIV +ve status was proved to have a good impact on individual's health. It prevents social isolation, improves self esteem with subsequent compliance with treatment and improvement of physical health. It also has a marked impact on preventing transmission of infection by decreasing probabilities of unprotected sex as well as other risky behaviors.^{8,9}

The Egyptian National AIDS program is focusing mainly on providing HIV testing, counseling, and Antiretroviral therapy. The last published report from the program stated that several studies were conducted to estimate population and gender affected, and to assess preventive measures, cost benefit analysis of prevention, stigma, and test-treat-retain care cascade. On the other hand, there is no published research studying disclosure of HIV status among those living with HIV in Egypt.^{3,10,11,12}

The present study aimed to estimate self disclosure rate among those living with HIV in Alexandria, Egypt; and to identify disclosure motives, barriers, consequences, and association with sexual behavior.

Methods

A cross sectional survey was conducted among people living with HIV in Alexandria, Egypt. The study was carried out in Alexandria Hepatology; Gastroenterology; and Infectious diseases hospital (formerly Alexandria Fever

Hospital). It is a specialized governmental hospital providing health services to HIV/AIDS patients as one of the national AIDS program centers. It serves four Egyptian governorates.

Target population and sampling: There were 813 HIV positive registered cases in the study center during the year 2016. Only 450 cases were regularly attending the center for their monthly supply of antiretroviral treatment. The target population included all HIV positive cases who are regularly attending the center. Those below 16 years of age were excluded as they don't have ID card to receive the treatment supply by themselves.

For calculation of minimum sample size required, Epi InfoTM 7 software (CDC, Atlanta) was used. Based on 450 cases as target population, 90% reported disclosure rate⁴ and 95% confidence level; the minimum sample size required is 80 cases. Eighty HIV +ve cases aged 16 years and above were selected using a systematic random sampling technique.

Data collection: Data was collected using a designed semi-structured interview questionnaire format. The questionnaire was designed to collect data regarding cases' socio-demographic characteristics, high risk behavior associated with catching infection, duration since diagnosis, HIV serostatus of husband/wife, self-disclosure, disclosure motives and barriers, relation to persons who disclosed to, immediate and late consequences of disclosure, and cases disclosure behavior with their sexual partners.

Ethical considerations

An ethical approval from Alexandria Faculty of Medicine Ethics Committee and Egyptian Ministry of Health were obtained. The aim of the study was clarified to each participant before enrolment. Privacy and confidentiality

were ensured all through the research work conduction.

Data analysis: Data were analyzed using The Statistical Package for Social Sciences SPSS, version 18 (SPSS Inc, Chicago). Participants' responses in the semi-structured interview questionnaire were organized and coded before data entry. Quantitative variables were presented as range, mean and standard deviation. For qualitative variables, frequency and percentage from total were used. Chi-Square test of significance was used to assess the association between disclosure behavior and the risk behavior associated with catching the infection. 5% level of significance was used to interpret the result.

Results

The age of the studied cases ranged from 19 to 65 years with a mean age of 36.13±12.3 years. Males constituted 51.3% (n=41) of the total sample. As regard their marital status, slightly more than one third (36.3%, n=29) were single. Married, widow and divorced represented (27.5%, 19%, and 10%) respectively. Table one shows the educational and occupational status of studied cases.

As regard the high risk behavior associated with HIV transmission, half of the studied cases (50%, n=40) had either drug addict HIV +ve husband (n=37) or HIV +ve wife (n=3). The remaining cases were either men who have sex with men (40%, n=32), injecting drug addicts (7.5%, n=6), or female sex workers (2.5%, n=2). The duration since diagnosis with HIV infection ranged from 1 to 22 years (3.98±4.1 years). The majority of studied cases (78.8%, n=63) disclosed their HIV +ve status to others. The high risk behavior associated with HIV transmission is significantly associated with disclosure of HIV +ve status (X²=6.05, P=0.014). The

majority (90%, n=36) of those who caught the infection through sexual relations with **Table (1) Distribution of studied people living with HIV according to their education and occupation**

Social characteristics	Frequency (n=80)	%
Education		
• Illiterate	22	27.5
• Read & write / Basic education	17	21.2
• Secondary	23	28.8
• University & higher	18	22.5
Working status		
No	44	55
Yes	36	45
• Professional / semiprofessional	14	38.9
• Skilled / semiskilled	19	52.8
• manual	3	8.3

their husband/wife disclosed their sero-status compared to (67.5%, n=27) of those who caught the infection through socially unaccepted risky behaviors (Table 2).

Table (2) Distribution of studied people living with HIV according to the risk factor associated with infection and self Disclosure of their sero-status

Risk factor associated with HIV infection	Self Disclosure (n=80)		X ² test
	Yes	No	
Transmission from infected husband/wife	36 (90%)	4 (10%)	X ² =6.05 P=0.014*
Risky behavior	27(67.5%)	13 (32.5%)	
• Men have sex with men	32 (40%)		
• Injecting drug addicts	6(7.5%)		
• Female sex workers	2(2.5%)		
Total	63 (78.8%)	17 (21.2%)	

Barriers to disclosure as stated by those who kept their HIV status secret (n=17, 21.2%) are revealed in table (3).

Among those who disclosed their HIV +ve status (n=63), (71.4%, n=45) disclosed their sero-status immediately after diagnosis. Sister and mother were the first choice for disclosure (79.3%). With time

pass after diagnosis, all of them (n=63) disclosed to one or more of their first

Table (3) Distribution of disclosure barriers among studied people living with HIV who didn't disclose their sero-status

Disclosure barriers*	Frequency	%
Fear of rejection by family and friends	14	43.8
Fear of Stigma	13	40.6
Fear of secondary disclosure to others	3	9.3
Fear of family stigmatization by others	2	6.3
Total responses	32	100

*cases were allowed to select more than one answer

Table (4) Distribution of studied people living with HIV who disclosed their sero-status according to time of disclosure and persons who disclosed to

Disclosure time & persons	Frequency n=63	%
Time of first disclosure		
Immediately after diagnosis	45	71.4
Less than one year after diagnosis	9	14.3
More than one year after diagnosis	9	14.3
First one to disclose to		
Sister	30	47.6
Mother	20	31.7
Father	7	11.1
Daughter /son	3	4.8
Friends	3	4.8
Persons who disclosed to other than the sexual partner*		
First degree family members	63	100
Close friends	13	20.6
Work owners	1	1.6

*cases were asked to report all who disclosed to i.e. categories are not mutually exclusive

degree family members (i.e mother, father, sister, brother, old children). (Table 4)

The main motive for disclosure was the need for psychological, social, and financial support (77.8%, n=49). Among ten cases (15.9%), HIV status was accidentally disclosed at the time of first hospitalization or on receiving laboratory investigation results. Two widow female cases (3.2%) from rural areas had to disclose to their old children to get an excuse for travelling to Alexandria city

monthly for receiving her antiretroviral treatment supply. Only one female case (1.6%) disclosed to her work owner to set an excuse for absenteeism in case of illness and for going to receive her monthly antiretroviral treatment supply.

Immediate reaction for disclosure varied from sympathy (75.1%, n=36) to anger and rejection (38.1%, n=24). Three cases (4.8%) stated that their parents completely deny their illness when they disclosed to them. Those cases explained their parents' reaction by those illiterate parents didn't know the nature of that disease and the cases are totally asymptomatic. There is a significant association between the immediate reaction and the high risk behavior associated with HIV transmission. Sympathy was felt by all disclosed cases who caught the infection through sexual relations with their spouses (n=36). On the other hand, after exclusion of the three cases that parents deny their illness, all disclosed cases that caught the infection through other routes (n=24) were faced by immediate anger and rejection (Table 5). The late reactions following disclosure are shown in table (6). Those cases who received the needed psychological support and social support following disclosure stated that this lead to improvement in their physical and mental health and compliance with treatment.

As regard the disclosure behavior of studied cases with their sexual partners, all studied females (n=37) and males (n=3) that caught the infection through sexual relations with their husband/wife were diagnosed at the same time with their spouses. Three studied drug addicts (50%) were married and their wives were diagnosed at the same time while the other three drug addicts (50%) were divorced long time before diagnosis. On the other hand, the studied female sex workers and

men who have sex with men stated that they were regretting disclosure of their

Table (5) Distribution of studied people living with HIV who disclosed their sero-status according to the risk factors associated with infection and immediate reactions following disclosure

Risk factors associated with HIV infection	Immediate reaction following Disclosure (n=63)			Monte Carlo test
	Sympathy	Anger/ rejection	Denial	
Infected husband/wife	36 (100%)	0	0	P<0.001*
Risky behavior	0	24 (88.9%)	3 (11.1%)	
Total	36 (57.1%)	24 (38.1%)	3 (4.8%)	

HIV serostatus to their sexual partners in most occasions and they usually have unprotected sex.

Discussion

Disclosure of HIV positive status is inversely related to the degree of stigma posed by the society. Stigma associated with high risk behaviors attributed to HIV transmission usually acts as a barrier against disclosure.^{13,14} This can explain the significant association found between socially unaccepted risky behaviors and non disclosure in the studied sample. It also explains the disclosure barriers stated by those who didn't disclose their HIV status. However, only 1.6% of those who actually disclosed their positive HIV status felt stigma following disclosure and this may be attributed to selective disclosure strategy adopted by them as most of them disclose to their mother and sister. Although the National AIDS program efforts succeeded in lowering stigma in health care settings affiliated to the program³ but at the community level, negative attitudes and stigma is almost universally associated with HIV/AIDS.⁶ The need for psychological and social support was the main motive behind disclosure of HIV status. This is similar to what was reported by several studies conducted in different countries with different cultures and reflecting the life long, stigmatizing, infectious nature of that disease.^{7-9,13,14} Two of the studied widowed females had to disclose their HIV status to

their old children to take an excuse for travel to Alexandria city for receiving the monthly treatment supply. This raised a new motive for disclosure not previously reported in reviewed literature and attributed to the Egyptian traditions especially in rural areas which give men the right to control over women's movement.

As a reflection to the revealed main motive behind disclosure, sister and mother were the first one to disclose to by the majority of cases. They represent the trusted family members who usually expected to give the needed support.^{15,16}

Studied cases that caught the infection through sexual relations with their spouses were considered victims by their family members as revealed by the immediate reaction followed disclosure. On the other hand, those who caught the infection by socially unaccepted risky behaviors were faced by negative reactions. So; stigma, discrimination, and rejection associated with HIV are not a matter of disease infectivity but it is a matter of association with unaccepted risky behavior by the Egyptian community. The complete denial of the possibility of having HIV as a response to disclosure that reported by three cases may be attributed to the low level of HIV/AIDS knowledge reported in Egypt health issues survey where only 70.5% of studied men and women have heard about HIV/AIDS.⁶

Disclosure of HIV positive status to sexual partners is considered a corner stone in

disease control. With the increasing numbers of newly diagnosed HIV cases, **Table (6) Distribution of studied people living with HIV who disclosed their sero-status according to late reactions following disclosure**

Late reactions following disclosure*	Frequency n=63	%
Receiving support from some family members & friends	44	69.8
Avoidance by some family members	23	36.5
Avoidance by friends	8	12.7
Feel of stigma by family and friends	5	7.9
Complete denial of disease	3	4.7
Family harming and stigmatization by others	1	1.6
Divorce	7	14.6 [#]

*Categories are not mutually exclusive, #Percentage from cases who were married at diagnosis (n= 48)

Centers for Disease Control and prevention (CDC) expanded the preventive measures to include encouragement of HIV positive cases to disclose their status to their sexual partners. Disclosure may encourage partners to have protected sex and give the HIV negative partner the chance to seek medical care for pre and post exposure prophylaxis.¹⁷In Egypt, encouraging married HIV positive cases to disclose to their spouses and discussing the importance of having protected sex is an accepted issue. But regarding singles including men who have sex with men and sex workers, this is not any easy matter as extramarital sexual relations and homosexuality are criminalized and socially unaccepted because of traditions and religious beliefs.¹⁸ So, the reported non disclosure of HIV status to sexual partners and having unprotected sex by studied homosexual men and female sex workers can be considered as a major challenge facing HIV/AIDS control measures in Egypt.

Moreover, what was revealed regarding diagnosis of HIV infection among both

husband and wife at the same time may be attributed to lack of knowledge among those who have high risk behaviors about HIV risk and modes of transmission.

The main limitation of this study is that included people living with HIV were those who regularly attended the HIV treatment center for receiving antiretroviral therapy. So, the obtained results cannot be generalized on those who are living with HIV in Egypt.

Conclusions

Disclosure of HIV status is a long life process. It is an instrument used by those who are living with HIV to gain needed social and psychological support. Trust on one's response is the main requirement for disclosure. Public health awareness regarding the HIV epidemic, disease nature, modes of transmission and risky behaviors should be integrated in the Egyptian National AIDS program services as well as encouraging HIV screening among those who have high risk behaviors for early detection of cases and application of preventive measures before transmission to their sexual partners.

During counseling, disclosure of HIV status and having protected sex should be discussed with all HIV diagnosed cases irrespective of their marital status.

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