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HIV visibility among people living with HIV in the central of Iran

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Abstract

Introduction: Human immunodeficiency virus (HIV) has had far-reaching consequences for humans as a socio-medical problem. This study aimed to estimate HIV visibility by different categories of social network and their relevant factors.

Material and methods: This cross-sectional study was conducted in Markazi Province of Iran. A total of 123 people living with HIV (PLWH) were recruited. A comprehensive list of relationships was provided, and the extent of awareness of PLWH' acquaintances about their disease was evaluated. 95% confidence interval (CI) of visibility rate was obtained using bootstrapping procedure. Potential determinants of HIV visibility were modelled with zero-inflated negative binomial regression analysis.

Results: The HIV visibility rate was estimated to be 14.8% (range, 11.3-18.3%), and HIV was more visible to one's spouse than to others (83%). The HIV visibility rate was higher in family members than non-family members, in the consanguineal family than affinal family, and in immediate family than extended family members. The duration of HIV disease, socio-economic status level, transmission route, and closeness of acquaintances were the important determinants of HIV visibility.

Conclusions: The HIV visibility rate in this study was very low. Decision of status disclosure is a potentially critical decision, resulting in positive or negative consequences. The whole society, including PLWH, can benefit from interventions helping promoting HIV disclosure. It is essential to verify the assessed parameters based on the estimated HIV visibility rates.

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Key words: visibility, HIV, Markazi, Iran.

Introduction

With 1.7 (95% CI: 1.2-2.2%) million new human immunodeficiency virus (HIV) infections around the world in 2019, HIV as a socio-medical problem has had far-reaching consequences for humans [1, 2]. According to the Ministry of Health and Medical Education's (MOHME) latest report in Iran, about 22,406 people living with HIV (PLWH) have been identified in September 2020, of which only 15,618 have received adequate care and treatment services [3].

In addition to the physical dimension, HIV/acquired immunodeficiency syndrome (AIDS) affects patients psychologically and socially in terms of prevailing beliefs in society [2]. Disclosure of HIV infection may lead to rejection, harassment, and abuse of PLWH, resulting in depression and social isolation. Furthermore, because of receiving

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emotional, financial, and social support together with job security, PLWH may be reluctant to disclose their HIV status to sexual partner, family members, co-workers, or others. Moreover, they may even refuse to disclose their disease to healthcare providers in order not to be stigmatized and discriminated, and to receive similar quality services [2]. On the other hand, the most efficient method to prevent HIV is to identify and treat PLWH, which requires HIV status disclosure by patients.

Therefore, planning for HIV prevention and control needs HIV disclosure. In other words, it requires social transparency in a community wherein people can communicate confidential and private information about themselves easily and fearlessly [4]. HIV social transparency may be affected by a variety of factors, including HIV-related stigma, culture, or religion. In Iran, due to cultural and religious conditions, there is a stigmatizing attitude towards HIV, and this can reduce the tendency of PLWH to reveal their disease [5]. A study in Tehran in 2012 showed that about 2.8% of HIV patients did not disclose their HIV status to any family member. Moreover, there is an inverse correlation between HIV disclosure and receiving social support [6]. Another study [7] in Tehran in 2014 reported that revealing the disease by pregnant PLWH has led to blame and rejection.

Social visibility or transparency and disclosure are closely related to people's social networks, meaning that people are more inclined to disclose HIV infection in their social network. A social network has been defined as a network of inter-personal communication and social interactions, and the flow of information among them [8]. The size of social network in Iranian population was estimated to be 308 people in 2013 [9], while a study in 2016 found that the social network size of PLWH was smaller than the general population [10]. Therefore, it can be interpreted that social transparency of PLWH is probably affected by their small and insufficient social network.

Social visibility of HIV and the proportion of social network members of PLWH who are aware of their illness can be estimated through quantitative and qualitative methods. To the best of our knowledge, various studies have addressed HIV disclosure among PLWH globally [6, 11-13]. However, this is the first study in the world that aimed to estimate HIV visibility using a standard quantitative method taking into account different categories of social network and their relevant factors. The visibility of HIV is an important issue in PLWH who consider and follow an effective treatment to prevent HIV transmission, seek HIV testing, and receive social support as well as reduction of HIV risk in their partners and diminishing mental impacts. Although disclosure of HIV itself is a complex procedure [14], there are some barriers affecting disclosure and HIV testing, including mistreatment by medical staff, confidentiality concerns, and HIV-related stigma, which influence inter-personal, community, and structural factors [15].

Therefore, the results of this study could be the beginning of a plan aiming to reduce barriers and increase HIV disclosure rate as a vital component in proper planning to provide appropriate medical and social services to PLHIV, and prevent the spread of the disease in communities.

Material and methods

Study setting and population

This cross-sectional study aimed to estimate HIV visibility rate among Iranian population. Markazi Province, where the study was conducted, is located in the center of the country, with a population of 1,444,000 people [16]. HIV-positive individuals were recruited from two major PLWH care centers administered by the Arak University of Medical Sciences (AUMS) and the Saveh University of Medical Sciences (SUMS). Since these two care centers provide care services for PLWH in the whole Markazi Province, the study sample can be representative of all PLWH in this province.

Eligible participants were 18 years of age and older, and were residents of the city over the past five years whose HIV status was confirmed by laboratory tests. PLWH were invited to participate in the study using convenience sampling method.

Gaining the trust of participants was a critical factor of this study; therefore, three of the experts who worked in care centers and were in close contact with participants were trained and interviewed participants face-to-face or over the phone. Data collection was permitted after explaining the purpose of the study to participants, obtaining verbal informed consent, and assuring anonymity and confidentiality of information. Moreover, a private room was designated to conduct interviews in the same center.

Data collection

The interview checklist contained four sections. Study objectives and explanation about the study details were provided in the first section. In the second section, the extent to which participants' active social network members were aware of their disease was inquired. The active social network was defined as "people whom you know and who know you by name, with whom you can interact, if needed, and with whom you have contacted over the last two years personally, over the phone, or by e-mail". Additionally, standard methods were introduced for estimating the size of such a network [17, 18]. In order to address all participants' active social network relationships and increase their recollection, a comprehensive list of relationships was provided in the rows of one table, including two primary categories, i.e., family and non-family.

The family category itself included two sections, such as consanguineal (blood-related family) and affinal (marriage-related family, also called in-laws, i.e., husband's relatives) family, each consisting of two sub-categories of immediate and extended family. The immediate family, also known as first-degree relatives, included mother, father, brother, sister, son, and daughter. The extended family, also known as second- or third-degree relatives, comprised aunts, uncles,

and cousins. The non-family category included friends, neighbors, or work acquaintances. The relationship table also had three columns containing total number of each relationship, number of adults in a previous column, and number of adults aware of HIV. The awareness of under-18 social network members was not addressed, because their lack of awareness could not attribute to HIV visibility but their age. Furthermore, participants' age was over 18 years, because the estimation of PLWH in the society is usually for those aged over 18 years. Therefore, in order to adjust crude estimations, the visibility rate among PLWH was established among those aged 18 years or more, since the prevalence of AIDS among those under 18-year-old is very low.

The examples of questionnaire items were as follows: "How many aunts do you have?", "How many of your aunts are over 18 years old?", "How many of them (over 18 years old aunts) are aware of your HIV-positive status?".

The third section included a 12-item questionnaire evaluating stigma among PLWH according to Reinius *et al.* [19]. This questionnaire was standardized and validated among Iranian PLWH by the authors of this study. The questionnaire had four sub-scales, including negative self-image (NSI), personalized stigma (PS), concerns about public attitudes (CP), and disclosure concerns (DC). Each sub-scale had three items, with each item scored from 1 to 4.

The last section included information about their disease, including duration of disease, method of transmission, and demographic variables, such as age, gender, level of education, marital status, and socio-economic status (SES). In order to assess the socio-economic status, asset index (living standards measure of household [20, 21]) and principal component analysis were employed. Finally, the SES obtained through principal component analysis was categorized as the poorest, poor, intermediate, rich, and the richest.

Ethical considerations

The current study was conducted with the supervision and approval of the Ethics Committee of Arak University of Medical Sciences (ethic code: IR.ARAKMU.REC.1398.250). Informed consent was obtained from all participants before the onset of the study. The questionnaires were provided to the authors after they were completed by the staff of high-risk behaviors center, without revealing identities and recognizable personal details of the participants.

Statistical analysis

HIV visibility was estimated using formula 1, as follows:

$$\text{HIV visibility} = \frac{\text{The total number of adults who were aware of HIV}}{\text{The total number of adults in respondent's social network}}$$

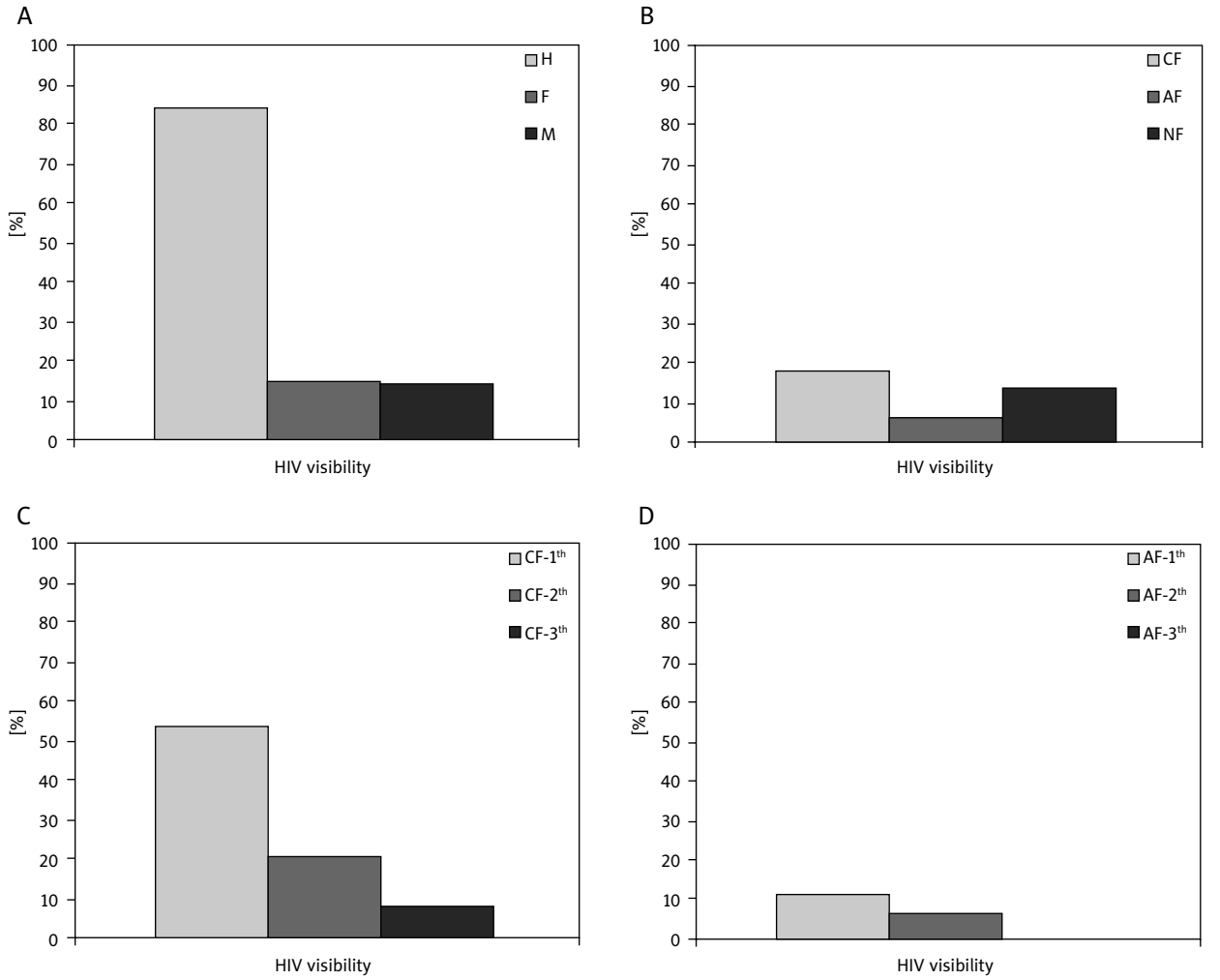
95% confidence interval (CI) was calculated using bootstrapping procedure and drawing 1,000 repeated independent samples (with replacement). HIV visibility of 95% CI was also estimated based on social network members (Figure 1).

The potential determinants of HIV visibility were modelled with zero-inflated negative binomial regression analysis (Table 2). Negative binomial regression analysis was used because the variance exceeded the mean, and zero-inflated was applied because many acquaintances were not aware of HIV disease of participants; as a result, an excess zero responses were generated. In the statistic model, each person was considered as a cluster layer, and therefore, cluster robust standard error was employed for adjusting the correlation existing between the responses of participants regarding their network members. At first, univariate analyses were performed and then, variables with p-values of less than 0.2 were modelled with a multi-factorial model. All analyses were done using Microsoft Excel (2019) and Stata software (version 12).

Results

In this study, 123 PLWH (> 18-year-old) were recruited from HIV care centers administered by AUMS and SUMS in Markazi Province. The majority of PLWH were men (66%), 50.4% were married, and a significant part was illiterate or had primary education (44.7%). The mean (standard deviation) age of the participants was 41.1 ± 8.9 years (range, 20-60 years). Most participants were infected through intravenous drugs' injections (51.2%). The average time from the diagnosis to the interview (standard deviation) was 79.9 ± 56.2 months (range, 1-221 months). At the time of the study interview, 63.9% of the participants were asymptomatic. The total mean stigma score from stigma questionnaire was 37.03 (± SD: 4.89) out of 48, which was associated with highly perceived stigma by PLWH. Among the sub-scales, CP (10.07 ± 1.38) and NSI (7.39 ± 2.13) showed the highest and lowest mean scores, respectively (Table 1). The total number of adult family members in the participants' social networks was 6,242, with immediate family members and extended family members comprising 20% and 80%, respectively. The total number of non-family adults was 3,140. Another classification of the participants' active social network included husband (nearly 1%), affinal family (13%), consanguineal family (53%), and non-family members (33%). The participants' active social networks included the sex ratio of 48% for females and 52% for males.

The visibility rate (95% CI) of HIV was estimated to be 14.8% (range, 11.3-18.3%). A total of 17 (13.8%) participants had not spoken about their disease to anyone. HIV was much more visible to one's spouse than to other persons (83%); however, the spouse was not fully informed (Figure 1A). Non-family members were less informed about HIV status than family members; the visibility of HIV was higher for the consanguineal family than for affinal family (Figure 1B), and HIV was considerably more visible for immediate family than for extended family members (Figure 1C). HIV visibility was almost equally visible for females and males in the participants' networks. However, as for the immediate consanguineal family members, females were a little more informed about HIV compared with males (55% visibility



PLWH – people living with HIV, H – husband, F – females, M – males, CF – consanguineal family, AF – affinal family, NF – non-family

Figure 1. Human immunodeficiency virus (HIV) visibility among active social network of people living with HIV in Arak, Iran, 2020. **A**) Comparison of HIV visibility among PLWH's spouses, and female and male members of their social network. **B**) Comparison of HIV visibility among PLWH's consanguineal family, affinal family, and non-family. **C**) Comparison of HIV visibility among PLWH's immediate and extended consanguineal family members. **D**) Comparison of HIV visibility among PLWH's immediate and extended affinal family members. The y axis shows HIV visibility as a percentage, which is calculated by dividing the number of adults aware of HIV status by the total number of adults listed in any given category

rate for females, and 49% for males). Consequently, PLWH's mothers and sisters were more likely to inform others about their HIV disease than fathers and brothers.

To conduct analytical analyses, univariate analysis was first performed. It was found that, at 0.2 significance level, the visibility of HIV was not associated with the participants' age, gender, education, occupation, or marital status. Therefore, they were not included in the next step (multi-factorial analysis). In the multi-factorial analysis, every variable with a higher *p*-value was deleted by backward elimination approach until all remaining *p*-values were less than 0.05.

The final multivariate model showed that increasing the duration of HIV disease significantly decreased its visibility. With each level of increasing the disease duration, HIV visibility decreased by 26%. Increasing the SES level of PLWH was significantly associated with decreasing the visibility of HIV. With each level increasing SES from the poorest to the richest, HIV visibility decreased by 13%.

In terms of transmission route, the results revealed that intravenous drug use and unknown routes were the highest and lowest visibility rates, respectively. Marital sex, extramarital sex, and unknown route were almost 20%, 50%, and 40% less visible than intravenous drug use, respectively, of which the last one was statistically significant. Regarding the closeness of acquaintances, first-degree family members and third-degree family members were related to the high-

est and lowest visibility rates, respectively. Second-degree family, non-family, and third-degree family members were almost 35%, 40%, and 65% less informed about HIV, respectively.

Discussion

Based on the results of the study, the visibility of HIV was very low among the Iranian population. HIV was much more visible to one's spouse than for others; however, the spouse was not fully informed. Moreover, non-family members were less informed about HIV than family members, HIV visibility was higher for consanguineal family than affinal family, and HIV was considerably more visible for immediate family than to extended family members. Other factors affecting HIV visibility were the duration of HIV disease, SES, and transmission route.

To the best of our knowledge, this is the first study in the world estimating HIV visibility using a standard quantitative method based on different categories of social networks and relevant associated factors. In the present study, HIV visibility measured in the Iranian general population was found to be very low.

HIV disease is stigmatized due to its association with norm-violating behaviors, such as having multiple sex partners, commercial sex work, sex between men, and intravenous drug use. In other words, PLWH are considered responsible for their HIV disease personally [22]. In Islamic countries, such as Iran, HIV-related stigma can be even much worse due to restrictive laws about sexual relationships. Many studies have stated that the disclosure of HIV status could lead to stigma, causing permanent social, psychological, and physical well-being consequences [22, 23].

Furthermore, stigma can be higher in people who are not referred to receiving HIV care. This matter may be created by a belief in misconception that PLWH are infected because of immoral extramarital sexual life, which is common thinking in Iranian population. This issue can mostly be affected by their families and healthcare providers, and may result in high level of stigma among PLWH and delaying of treatments [24].

Table 1. Descriptive characteristics of people living with HIV members

Variables	*n* (%)
Gender	
Female	42 (34.0)
Male	81 (66.0)
Age	
Mean (SD)	41.1 (8.9)
Time since HIV diagnosis (months)	
Mean (SD)	79.95 (56.2)
Stigma	
Mean (SD)	37.03 (4.89)
SES	
Poorest	26 (21.14)
Poor	24 (19.51)
Intermediate	24 (19.51)
Rich	25 (20.33)
Richest	24 (19.51)
Route of transmission	
Extramarital sex	18 (14.6)
Marital sex	32 (26.0)
Intravenous drug use	63 (51.2)
Education level	
Illiterate/elementary	55 (44.7)
Guidance school	46 (37.4)
Diploma	13 (10.6)
Academic	9 (7.3)

Table 2. Determinants of HIV visibility

Determinants	Crude		Adjusted after backward elimination		
	RR	95% CI	RR	95% CI	*p*-value
Time since diagnosis	1.22	1.06-1.40%	1.26	1.09-1.47%	0.002
SES	0.93	0.84-1.02%	0.87	0.79-0.96%	0.004
Transmission route (ref., intravenous drug use)					
Marital sex	0.41	0.17-0.99%	0.48	0.21-1.11%	0.080
Extramarital sex	0.96	0.76-1.20%	0.82	0.56-1.2%	0.083
Unknown	0.28	0.07-1.05%	0.38	0.14-0.98%	0.045
Closeness of relationship (ref., first degree)					
Second degree	0.80	0.71-0.90%	0.64	0.53-0.77%	< 0.0001
Third degree	0.51	0.30-0.88%	0.36	0.21-0.63%	< 0.0001
Non-family	0.78	0.67-0.91%	0.62	0.49-0.77%	< 0.0001

RR – rate ratio, CI – zero-inflated negative binomial confidence interval

Therefore, many PLWH prefer not to disclose their HIV status, depriving themselves from benefits of acquiring prevention, care services, and social support [22, 25]. In other words, PLWH often prefer to decline their medications in order to keep their social capital.

The highest HIV visibility was observed in PLWH's spouses, but they were not fully informed. A total of 17% of the participants who had a steady partner/ spouse had not informed them about their HIV status, which in case of HIV disease is a matter of concern. There is an important moral responsibility of HIV-positive individuals for their sexual partners/ spouses, and HIV disclosure is essential to stop the spread of HIV. In line with the current findings, a study conducted in France reported almost 85% of HIV visibility in steady partners/ spouses [26]. In two other studies carried out among African women, it was found that only 65% and 37% of them disclosed their HIV status to their partners [27, 28]. This was due to the fear of rejection, as some studies have reported an unfavorable reaction of partners or even abandoning PLHIV upon hearing their HIV-positive status [13].

In total, non-family members were less informed about HIV than family members, but the rate of disclosure was higher in non-family than third-degree family members. The visibility of HIV was higher for consanguineal family members than it was for affinal family members, and HIV was considerably more visible for immediate family than for the extended family members. Also, in similar studies, HIV visibility rate in immediate family members and even among friends was much higher than in extended family members, which is in line with the findings of this study [26]. The higher rate of disclosure among consanguineal family members could be due to the possibility of further blame from affinal families than consanguineal families [29].

It was also found that the visibility of HIV significantly increased with the time of diagnosis, which agrees with similar studies [22]. This could be due to the adjustment of disease status with passing time, and possible result of learning coping strategies [30]. Moreover, it may be also due to the fear of isolation and loss of social network members in caring and supporting of people living with HIV in advanced stages, as the time of diagnosis increases [6].

Regarding the route of transmission, intravenous drug use, marital sex, extramarital sex, and unknown route were the highest to lowest rates of disclosure, respectively. The unknown route is most likely to be extramarital sex, but due to the related stigma and reluctance of the participants to disclose it, the real route was not disclosed. In general, as expected, extramarital sex (unknown route was considered extramarital sex) was related to the lowest visibility, which was due to the large stigma surrounding the norm-violating sex behaviors, especially in Islamic countries. This finding is also corroborated by other reports [22]. According to the religious and cultural structures of Iranian population, extramarital sex is considered a sin [31], and can justify the results obtained from this study.

Finally, it was observed that the increase in the SES level of PLWH from the poorest to the richest was significantly associated with the decrease in the visibility of HIV. Similarly, other studies have reported that a lower level of SES is associated with a higher rate of disclosure [32, 33]. This could be due to the higher level of social position and occupation of prosperous patients as well as the fear of ending a relationship by disclosing HIV status.

Strengths and limitations

This is the first study in the world to estimate HIV visibility using a standard quantitative method, based on different categories of social networks and their associated factors. The most important challenge was to gain the trust of PLWH to participate in the study. To overcome this issue, the experienced interviewers who worked in care centers and were in close contact with the participants were well-trained, and became responsible for collecting data; hence, gaining the trust of the participants. This study covered around 87% of all PLWH identified in the area, which was another strength of the study, increasing the generalizability of the results.

For further research, it is recommended to design NSU studies and adjust their crude estimations considering the results of this study.

Conclusions

The HIV visibility rate in this study was very low. HIV was much more visible to a spouse than to others. Non-family members were less informed about HIV than the family members, the visibility of HIV was higher in consanguineal family and immediate family members. HIV visibility was also associated with increasing the duration of HIV disease and lower level of SES. Moreover, intravenous drug use, marital sex, extramarital sex, and unknown route were related to the highest and lowest rates of disclosure, respectively. A disclosure decision is a potentially critical decision, with positive and negative consequences. The whole society, including PLWH and their social network members, can benefit from interventions helping promoting HIV disclosure while decreasing the related stigma. Moreover, in order to administer HIV prevention programs appropriately, there is need to adjust the assessed parameters based on the estimated HIV visibility rate of this study.

Disclosures

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4. Conflict of interests: None.

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