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Estimation of the number of people living with HIV in Arak, Iran: application of network scale-up method for hidden populations

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Abstract

Introduction: Human immunodeficiency virus (HIV) remains a significant public health challenge worldwide. In this study, we aimed to estimate the number of people living with HIV (PLHIV) in Arak, Iran, using network scale-up method (NSU).

Material and methods: This cross-sectional study was conducted among residential population in Arak located in the center of Iran. In total, 1,604 individuals participated. Sampling locations were selected by creating a list of crowded and busy centers in the city, which were considered as clusters. Two locations were then randomly selected within each cluster. The main variable was the number of PLHIV/AIDS known by each participant among their active social network in Arak during the past five years. To estimate the number of PLHIV, NSU method was used.

Results: Among the participants, 51.1% (n = 819) were females, of which 29.2% (n = 468) were identified as housewives. The mean age of participants was 39.2 years (SD: 14.1). Using the NSU method, the population size estimation of PLHIV in Arak was determined as 1,075, equivalent to a prevalence rate of 178.2 per 100,000 population (95% CI: 145.4-214.3% per 100,000 population). The size estimation of PLHIV was determined as 248 (prevalence rate: 83.1; 95% CI: 73.1-94.0% per 100,000 population) and 827 (prevalence rate: 271.5; 95% CI: 253.5-290.4% per 100,000 population) for females and males, respectively.

Conclusions: The estimated prevalence of HIV was higher than the number of detected cases in Arak. Key high-risk populations for HIV should receive more support for HIV testing and confidentiality implementation.

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Key words: network scale-up method, HIV/AIDS, Iran.

Introduction

Human immunodeficiency virus (HIV) remains a significant public health challenge worldwide [1]. According to the World Health Organization (WHO), there were approximately 39 million people living with HIV (PLHIV) at the end of 2022, with 40.4 million deaths due to HIV/acquired immunodeficiency syndrome (AIDS) globally. In 2022, 1.3 million new cases of HIV have been diagnosed, and 630,000 people have died from HIV-related causes [2]. According to the United Nations political declaration on HIV/AIDS, the aim was to reduce new HIV cases and related deaths by 95% from 2010 to 2030 worldwide. To achieve this goal, countries must accurately measure the number of new HIV cases, number

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of PLHIV, and HIV/AIDS-related deaths [3]. The proportion of PLHIV who know their status has increased from 0.31 to 0.77 between 1990 and 2017 [4]. However, the incidence of HIV is increasing in the Eastern Mediterranean Regional Office (EMRO) district where Iran is located [5]. In Iran, it was estimated that 46,000 people have been living with HIV, and 2,300 deaths have been recorded in 2022 [6]. In the covered areas of Arak University of Medical Sciences, which include a population of approximately one million people, only around 100 cases of PLHIV were reported by the Health Deputy of Arak University of Medical Sciences until 2020, which is likely an underestimation [7-9].

A study conducted in Iran revealed that people living with HIV experience high level of stigma, with a stigma score of 37 out of 48 [1]. This high stigma level leads to the concealment of morbidity among people at risk as well as lack of timely follow-up for diagnostic tests and subsequent treatment, which, despite advances in HIV treatment, do not benefit PLHIV [1]. Although there is no complete cure for HIV, the access to diagnostic and therapeutic prevention services can help managing the disease, increase survival of PLHIV, and improve their health [2]. Additionally, healthcare system should expand HIV surveillance by identifying PLHIV and reducing obstacles to referring high-risk individuals for HIV diagnostic testing and timely treatment. In this regard, having knowledge about the estimated number of PLHIV who may go beyond what is recorded and diagnosed, can be effective in identifying and implementing appropriate preventive measures.

Lack of validity regarding general information on the size of hidden populations, including those living with HIV, presents a significant challenge that raises doubts on the accuracy of obtained data. As such, researchers are actively seeking solutions to address this issue [10]. Routine health system data on the incidence and mortality rates are less reliable and face considerable limitations in their ability to be generalized to the population, particularly in regard to hidden populations [3]. Hidden populations pose difficulties in terms of identifying and accessing members, making them a topic of interest for sociologists, policy-makers, and health planners. Members of these groups often engage in behaviors considered socially harmful by sociologists, which can have significant financial and social consequences for society if left unrestricted. Therefore, it is crucial for researchers to understand and identify these groups to prevent potential societal complications. However, investigating these groups directly is a challenging and often impossible task [11]. Additionally, estimating the number of hidden populations through cross-sectional studies and definitive methods is less feasible in countries with low incidence rates, such as Iran, compared with countries with higher incidence rates [3, 12]. Therefore, indirect methods, such as the network scale-up method, can be useful for estimating the size of hidden populations [11, 13-15], especially where the access to these populations is limited due to stigma [16]. Accurate estimation of the size of PLHIV is critical for effective health program planning and its implementation. PLHIV place a significant burden on the budget and resources while having the potential to infect multiple individuals, further exacerbating the burden. Hence, knowing the true size of this population is essential for health policy-makers and managers to achieve their goals effectively. In this study, we aimed to estimate the population size of PLHIV in Arak in 2022, using the network scale-up method.

Material and methods

This cross-sectional study was conducted among residential population of Arak, located in the center of Iran. Arak is a metropolitan city and the capital of Markazi Province, with a population of 520,944 according to a 2016 census. A total of 1,796 individuals were invited to participate in this study, of which 1,604 individuals ultimately participated (*n* of non-participants = 192). At first, we geographically divided the city into 16 strata. Sampling locations were selected by creating a list of crowded and busy centers in each stratum, such as busy streets, shopping centers, and parks. In total, there were 55 busy streets, 42 parks, and 24 shopping centers for the whole strata, which were considered as clusters. Finally, two locations were randomly selected in each stratum. Within these locations, one passerby was selected every 15 minutes during busy hours (i.e., 9 am to 1 pm, and 3 pm to 8 pm) on all days of the week. Individuals were not approached at their workplace or home to ensure their comfort and safety while answering questions. The questionnaire was explained to participants, and data were collected through interviews conducted by two male and two female interviewers to ensure gender compatibility. Interviewers were trained prior to conducting interviews. Participants were informed about the importance and purpose of the research, and asked about the existence and number of PLHIV in their active social network after obtaining their consent. Inclusion criteria for participation were Iranian citizenship, age over 18 years, residency in Arak city, and mental ability to answer questions.

Study data

Demographic variables of the study included age, education level, reason for non-participation (only for non-participants), marital status, and occupation. Main variable was the number of PLHIV/AIDS known by each participant among their active social network in Arak during the past five years. These data were reported according to gender (male/female) and age groups (less than 18, 18-30, 31-50, and over 50 years old). "Know" in this study was defined as the number of PLHIV whom participant: 1) know by name and face, and these persons also know the participant by name and face; 2) has contacted these persons by phone or personally at least once in the last two years; and 3) can contact these individuals by phone or personally whenever necessary.

Statistical analysis

To conduct a descriptive analysis, qualitative variables were recorded using frequencies and percentages, while quantitative variables were documented with means and standard deviations. Questionnaires were analyzed after data collection, and those without answers were removed prior to analysis. Data were then coded and entered into Stata software. Prior to analysis, data were subjected to a thorough cleaning and checking process to ensure accuracy and reliability. In order to estimate the number of PLHIV, the following formula [17] was employed: m/c = e/T, where *T* is the total population size, to which the estimation is generalized, *c* is the active social network of participants, *m* is the number of PLHIV known by participants, and *e* is the number of PLHIV estimation that need to be obtained. Exact (Clopper-Pearson) method [18] was used to obtain 95% confidence intervals for all point estimation.

Results

A total of 1,796 individuals were invited to participate in the current study, of which 1,604 ultimately participated, resulting in a response rate of 89.3%. Of the non-participants, 14.6% (n = 28) did not provide data on demographic characteristics and reasons for non-participation. Demographic characteristics of the remaining participants are presented in Table 1. In summary, 43.2% of the participants (n = 83) were males, and majority (33.9%, n = 65) held a diploma, indicating completion of 12 years of formal education in Iran. Additionally, the mean age of non-participants was 41.8 years (minimum: 18 years; maximum: 76 years, SD: 13.3 years), with the most common reason for non-participation being a lack of time to complete the questionnaire, cited by 49.5% of the non-participants (n = 95). Among the participants, 51.1% (n = 819) were females, and 29.2% (n = 468) were identified as housewives. Majority of the participants (34.6%, n = 552) reported an undergraduate academic major, and 61.8% (n = 992) were married. The mean age of the participants was 39.2 years (SD: 14.1 years, range: 18-81 years). Detailed demographic characteristics of the participants are shown in Table 2, with a summary by gender.

Using the NSU method, the population size estimation of PLHIV in Arak was determined as 1,075, equivalent to a prevalence rate of 178.2 per 100,000 population (95% CI: 145.4-214.3% per 100,000 population). The size estimation of PLHIV was determined as 248 (prevalence rate: 83.1; 95% CI: 73.1-94.0% per 100,000 population) and 827 (prevalence rate: 271.5; 95% CI: 253.5-290.4% per 100,000 population) for females and males, respectively, after adjusting for the visibility rate of HIV/AIDS in the province. The visibility rate indicated the extent to which individuals within an active social network are aware of the concealed behavior in question. This value should be multiplied by the inverse of visibility fraction to accurately determine the prevalence of desired behavior within the society. Distribution of the estimated PLHIV by age group was as follows: among those under 18 years, 18-30 years, 31-50 years, and over 50 years, it was estimated to be 0, 58, 165, and 25 for females, and 25, 322, 422, and 58 for males, respectively.

Discussion

The present study revealed a high estimated prevalence of HIV among the residents of Arak, a metropolitan city

Table 1. Demographic characteristics of non-participants

Variable	Total, *N* (%)	Male, *n* (%)	Female, *n* (%)
Education level			
Illiterate	19 (9.9)	12 (14.5)	6 (7.4)
Elementary	24 (12.5)	7 (8.4)	13 (16.0)
Middle school	14 (7.3)	6 (7.2)	8 (9.9)
High school	65 (33.9)	29 (34.9)	31 (38.3)
Undergraduate academic	49 (25.5)	28 (33.7)	19 (23.5)
Post-graduate academic	4 (2.1)	0 (0.0)	4 (4.9)
Doctorate	1 (0.5)	1 (1.2)	0 (0.0)
Reason for non-participation			
Lack of time to complete the questionnaire	95 (49.5)	46 (56.1)	32 (40.0)
No interest	77 (40.1)	26 (31.7)	43 (53.8)
No knowledge	16 (8.3)	9 (11.0)	4 (5.0)
Illiterate	1 (0.5)	1 (1.2)	0 (0.0)
No recall	1 (0.5)	0 (0.0)	1 (1.3)
Age (years)			
Mean, SD	41.8 (13.3)	39.6 (13.1)	44.2 (13.1)

Differences between totals and others were due to data missing.

Table 2. Demographic characteristics of participants

Variable	Total, *N* (%)	Female, *n* (%)	Male, *n* (%)
Education level			
Illiterate	65 (4.1)	41 (5.0)	24 (3.1)
Elementary	155 (9.7)	88 (10.8)	65 (8.5)
Middle school	183 (11.4)	90 (11.0)	92 (12.1)
High school	534 (33.3)	271 (33.2)	255 (33.5)
Undergraduate academic	552 (34.4)	274 (33.5)	273 (35.8)
Post-graduate academic	101 (6.3)	50 (6.1)	50 (6.6)
Doctorate	7 (0.4)	3 (0.4)	3 (0.4)
Age (years)			
Mean, SD	39.2 (14.1)	38.7 (13.7)	39.8 (14.7)
Employment			
Housewife	468 (29.2)	466 (57.1)	0 (0.0)
Employee	259 (16.1)	111 (13.6)	145 (19.1)
Student	179 (11.2)	110 (13.5)	68 (8.9)
Worker	88 (5.5)	3 (0.4)	85 (11.2)
Self-employment	340 (21.2)	64 (7.8)	270 (35.5)
Unemployed	83 (5.2)	28 (3.4)	54 (7.1)
Retired	177 (11.0)	34 (4.2)	139 (18.3)
Marital status			
Single	489 (30.5)	223 (27.7)	257 (34.7)
Engaged	10 (0.6)	9 (1.1)	1 (0.1)
Married	992 (61.8)	531 (66.0)	453 (61.1)
Divorced	14 (0.9)	10 (1.1)	4 (0.5)
Widow(er)	58 (3.7)	32 (4.0)	25 (3.3)

Differences between totals and others were due to data missing.

located in the center of Iran. The estimated number of PLHIV in this study was 1,075, which is approximately 11 times higher than the number of identified cases registered by the health system. The estimated numbers of HIV cases were 248 and 827 for females and males, respectively, with majority of them being 31-50 years old in both genders. This finding is different from reports of consulting centers, prisons, and hospitals in Iran, where the observed HIV male cases were reported ten times more than females, and majority of them being within 25-35 years old. Therefore, interventional policies should focus on females and people aged 35-50 years. This matter is of great importance, and requires increased attention and focus on interventional policies, particularly among females and individuals aged 35-50 years. The estimated prevalence of PLHIV in this study was lower than in some other countries. For instance, a study in Spain [19] estimated the number of PLHIV as 141,000, equivalent to a prevalence rate of 0.36%. In India [20], the estimated HIV prevalence among adults was 0.31%. Additionally, in Fars Province [21] located in south of Iran, the estimated number of PLHIV was 14,925, while only 5,112 cases were identified, showing an underestimation of almost three times. However, while the number of HIV cases in Iran is underestimated, it is more accurate than in some countries in the Middle East [22]. For instance, according to the WHO, Iraq reported about 220 new diagnosed HIV cases, Saudi Arabia 1,400, and Iran reported 10,700 new HIV cases during 2015-2020 [23].

There are several reasons accounting for the underestimation of PLHIV in this study. These include high HIV-related stigma among PLHIV, general population, and health staff [1] as well as underestimation in HIV key populations, such as male and female sex workers and intravenous drug users [24]. A study in Singapore [25] estimated the population size of male clients of female sex workers as 72,000, female sex workers as 4,200, men who have sex with men as 210,000, and intravenous drug users as 11,000 cases, which were higher than the diagnosed cases. Similarly, another study in Iran [26] showed that the prevalence in drug users was higher than in the reported averages. Furthermore, a significant difference was observed between the estimated cases of high-risk HIV groups and identified cases in Kerman. This discrepancy may contribute to the underestimation in identifying PLHIV [11]. In contrast to the pattern of underestimation of key populations in countries such as

Iran, in developed countries including Germany, almost all opioid-addicted individuals were in contact with a health system, which is important for controlling the HIV/AIDS epidemic [27]. To reduce the gap between identified and estimated cases, several implementations may be helpful. These include normalizing HIV testing, reducing HIV-related stigma among the general population and health providers, introducing more key-population-friendly HIV testing strategies, such as community-based testing, establishing network-based HIV testing, and improving HIV testing to find undiagnosed people, as these strategies have shown to have a higher yield [1, 5]. Additionally, increasing knowledge about HIV is considered to increase willingness for testing among people in the community. Educational status, wealth status, and media exposure are important variables for intervention measures to reduce inequality in HIV-related knowledge [28]. Moreover, key HIV populations should receive more support in terms of HIV testing and confidentiality implementation.

The current study have some limitations. Due to the sensitive nature of the questions, the collected data are likely to be affected by non-response and social desirability biases, reducing their validity. Additionally, it was not possible to select participants using random sampling methods; therefore, an accessible sampling method was employed, but the sample was selected from all the crowded and busy centers in the city, on all days of the week, and by selecting one passerby every 15 minutes, in order to decrease selection bias. Furthermore, some participants may have refused to provide true responses to the questions, making the findings susceptible to information bias [29].

It is recommended to conduct future studies with larger sample size, and compare the results of NSU method with other methods for estimating the size of hidden population.

Conclusions

In the study, it was found that the estimated prevalence of HIV was higher than the detected cases in Arak. Key high-risk HIV populations should receive more support for HIV testing and confidentiality implementation. Stigma associated with HIV/AIDS is considered one of the factors that may prevent individuals from seeking HIV diagnosis. Having knowledge about the actual number of PLHIV who may go beyond what is recorded and diagnosed, can be effective in identifying and implementing appropriate preventive measures against the spread of HIV, evaluating the success of intervention programs in the past, and assessing future healthcare needs.

Disclosures

1. Institutional review board statement: The study was approved by the Ethics Committee of Arak University of Medical Sciences, with approval number: IR.ARAKMU.REC.1398.031.
2. Assistance with the article: None.
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4. Conflict of interests: None.

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