

# HIV outbreak storytelling among residents of an area in Iran: what are the overlooked implications for health policy-makers?

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## Abstract

With human immunodeficiency virus (HIV) prevalence of 0.14% in general population of Iran, a prevalence of at least 5-6% among residents of one village in Lordegan County is considered HIV outbreak. Investigating initial reactions of provincial authorities to this issue indicates a medical view overlooking social nature of HIV/acquired immunodeficiency syndrome (AIDS). Moreover, such an outbreak alarms change in epidemic patterns from localized to generalized in developing countries, such as Iran. In this perspective article, we tried to discuss such events focusing on policy. At this point, we concluded that Iran needs to represent the problem through changing policy image and policy venue in political arena. To strengthen the collaboration among all stakeholders, developing a universal pro-active strategy to facilitate resource mobilization for HIV control is necessary. Integration of social nature of HIV/AIDS, addressing and applying integrated approach to face social and economic harms as well as using a collaborative mechanism to guide various governmental, semi-governmental, and NGO sectors to control HIV/AIDS are all needed. Moreover, focusing more on adopting anti-stigma strategies and disseminating comprehensive public awareness about AIDS, can prevent Iranian society from repeating such situations, and trigger more appropriate responses if they do occur.

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**Key words:** HIV/AIDS, Lordegan, Iran, outbreak, policy analysis.

## Introduction

Human immunodeficiency virus (HIV) remain a global public health challenge. An estimated 37.9 million people worldwide live with HIV, and approximately 1.7 million new infections were reported in 2018 [1].

Despite recent advances in acquired immunodeficiency syndrome (AIDS) control worldwide, the global response to

AIDS has not yet achieved its' goals. Iran also faces many challenges in achieving national goals of AIDS control program. Some of these crucial challenges include increased cases through sexual transmission, an increasing trend in women and youth, changes in consumption patterns and types of drug abuse, low number of people identified, and low percentage of people on antiretroviral treatments [2].

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Results of a few studies addressing the field of HIV and AIDS from a policy perspective indicated fundamental weaknesses in a policy-making process and its' implementation. A study conducted in Iran showed significant challenges and gaps in AIDS policy in Iran that exists since early years of AIDS epidemic [2]. Results of another study indicated weaknesses in the implementation process, development of new policies, and stakeholders' performance in fight against AIDS [3]. One of the consequences of these deficiencies in policy-making could potentially increase the risk of outbreaks. In this perspective article, one of the most important recent outbreaks in this field was presented and discussed as well as overlooked implications of HIV/ AIDS policy-making.

### **Narrated story on social media about an HIV outbreak**

On October 2, 2019, a clip was posted and distributed online in social media that narrated a protesting community of villagers in the city of Lordegan (Chaharmahal and Bakhtiari Province) in front of governorate's office and district health network of Lordegan. The clip claimed that 200 to 300 people in Chenar Mahmoudi village were infected with HIV using a syringe contaminated with blood samples, who were waiting for the authorities to respond [4]. The Ministry of Health (MoH) immediately rejected any claim of HIV transmission by blood glucose testing with infected syringes, and rejected statistics mentioned in the clip. Furthermore, MoH claimed that the number of actual infected people was much lower, saying that investigations in that area continue for weeks. According to medical ethics rules about confidentiality principle, personal information of infected people are never disclosed [5]. Different public organizations reacted, including the Provincial Court of Justice, Provincial Security Council, Presidential Legal Affairs, the Governorate, and Islamic Parliament of Iran.

Consequently, they took steps to pursue the matter [6]. The villagers were concerned about the outbreak and their infected family members. They demanded to receive a clear response from local authorities on how the disease had been spread in their village. The MoH emphasized that the disease already existed in the village, and recent tests only identified more aspects of the issue and informed people about their disease [7].

Existing reports quoted from the Deputy of Health affiliated with MoH showed that the number of infected people was at least 70 to 90 individuals [8]. The village of Chenar Mahmoudi has a population of 1,498 residents, equal to 415 households. The citizens of this village are highly skilled in carpet weaving (known as 'kilim') and Luri custom dress-making; they often are farmers [9].

Considering HIV prevalence of 0.14% in the general population of Iran [10], the prevalence of at least 5-6% among residents of this village (up to 50 times higher than the general population) indicates an outbreak of HIV. The residents of this village said that they had been infected with HIV because of a blood glucose testing program admi-

nistered by a health house of the village for all the residents, and all participants of the program were infected with HIV through infected injection syringes. In contrast, health authorities denied such a possibility, attributing the cause of known factors, including using shared syringes by drug users and unsafe sexual intercourses. Furthermore, they added that a community-based test was conducted following the detection of a high-risk place of the infection, and some positive cases were detected [4, 5].

## **Material and methods**

### **Policy implications on the HIV outbreak**

Medicalization perspective to HIV/AIDS would lead to depoliticizing it. Extending this single-dimensional approach may limit solutions to quick-fix medical explanations of complex problems. Moreover, it may undermine the legitimacy of human rights [11], and lead to unsustainable, transient, superficial, and pain-killing interventions. However, it should be noted that this approach cannot be applied to all people, and may also have some significant disadvantages. First, this approach cannot be a pro-active strategy for a complex problem (a great problem). Furthermore, it can inhibit collaborative networks, including policy, advocacy, meeting human rights, and avoiding social exclusion of individuals living with HIV/AIDS. This issue needs solutions that require structural, political, social as well as legal, environmental, and organizational approaches, such as decriminalization and harm reduction. It should promote socio-economic status and control of the increasing of informal settlements, and marginalized urban slum population that calls for health promotion activities. Additionally, this medical perspective cannot facilitate resource mobilization for this problem. It remains a reductionist approach to the problem, and other institutions and organizations remain passive to exposure to HIV/AIDS. Overall, investigating the initial reactions of health authorities to the issue implies a single-dimensional medical view of the issue and non-significance of social nature of HIV/AIDS by overlooking the role of other structures, institutions, and organizations outside health sector. Therefore, one of the most important aspects of influencing the policy-making process and adopting appropriate approaches to respond to community issues, is the nature of the problem [12-14]. Wicked problems, due to multifaceted nature, complexity of their solutions, and high sensitivity of the subject, require a formulation based on holistic and systematic approach [15]. The HIV epidemic is one of the most pressing issues globally, with inter-connected relations between issues at different economic, political, social, and cultural levels [16]. HIV in a society is directly related to a variety of stigmatized behaviors, such as drug use and sexual behaviors. Therefore, inadequate formulation and reductionist approach of medical view cannot produce positive changes to control this emerging disease. Evidence suggests that interactive and socially pro-active measures

between internal and external stakeholders of health system are inadequate, and reductionist medical perspective on this phenomenon is a social problem as one of the long-standing policy problems in Iran. Thus, changing stakeholders' approach to the infection from biomedical to social is the most important thing that the Iranian community need to control the epidemic and reduce its' consequences, including stigma and discrimination [12, 17].

Effective measures, such as adoption of important rules and regulations for AIDS control, establishment, development, active involvement of non-governmental organizations, positive clubs to support those infected as well as remarkable activities of drop-in centers and behavioral counseling to destigmatize AIDS in Iran, have all been conducted. However, there are still some taboo topics about HIV, sex, drug abuse, injection, stigma, and discrimination in Iranian society, which provide obstacles in formulating relevant but inadequately enforcing or suspending policies, suppressing the illness. This has led health centers to reduce service coverage, increase numbers of hidden infections, and further spread of the disease into the community, challenging the achievement of 90-90-90 vision by 2020 and 95-95-95 vision by 2030 [17, 18].

Detecting new cases at a level of 30% in 2014 was the main gap in the cascade continuum in Iran. One of the main reasons for this gap could be the stigma surrounding the infection, and testing and detecting infected people. Moreover, HIV-associated knowledge is not sufficient among the general population, especially within the youth generation, in which high-risk behaviors are more prevalent [19, 20]. These obstacles also led the system to late detection of outbreaks, such as in Lordegan.

### Similar experiences in the world

Unexpected rise in the prevalence of HIV/AIDS in a region such as the Lordegan County, is not exclusive to Iran, and there have been numerous experiences from different countries over the past two decades. Events that have taken place in Cambodia, China, and Pakistan were affected by many reasons inside and outside health system, and were primarily dependent on a unique role of social outlook and public participation [21-25]. Table 1 summarizes coordinates of these events and social aspects of the problem. The general public's low awareness of the disease and its stigma were common for all events.

### Discussion on policy implications

Few studies in Iran on the relationship between HIV and social issues have shown that potential social factors influence HIV policies in Iranian society. For example, HIV taboos in some organizations were among the most critical factors in a group of officials' opposing views on sex transition, lack of information on high-risk sexual behaviors, and resistance to authorities providing sex education [19, 26-28].

Alonzo and Reynolds (1995) stated that HIV is a medical-health phenomenon, with broad social, cultural, and economic dimensions. It has become a social construction and, more specifically, a social stigma [29]. Numerous studies in Iran have identified stigma and discrimination as one of persistent challenges of HIV. One of the main plans of the United Nations is zero stigmas and discrimination against patients by 2030 [17, 26, 30].

However, one of the effects of taboo and HIV impacts country's education and information system. This widespread influence has blended with a traditional situation and functions, becoming a barrier to providing useful and adequate information and education to community [17]. It also causes the community to not respond appropriately to something like the recent outbreak in Lordegan. Most recent studies on awareness of young age groups and women, as the two groups are most vulnerable to HIV transmission, showed low awareness of this disease, with 19.1% in women and 37.3% in youth [19, 31].

Another essential factor influencing HIV policy in Iran is social and economic harm, such as addiction, poverty, prostitution, high-risk sexual behaviors, and marginalization. In reviewing HIV-related literature, a wide range of factors, including medical, social, economic, behavioral, and cultural have been identified as accelerating the spread of HIV.

Meanwhile, poverty, gender, culture, and stigma have been cited as structural drivers for the spread of HIV [32-34]. Also, the centralized political and policy-making system with a top-down approach, limits the adequate involvement of non-governmental organizations (NGOs) in solving the problem, which is the most critical and influential issue in HIV political context in Iran and similar countries [17, 35].

The political structure of Iran is inflexible, with strict exposure to issues, such as prostitution, homosexuality, high-risk sexual intercourse, criminal view on drug use and addiction, and consequently, HIV and HIV-related issues [36]. This approach leads to ignoring various dilemmas, disguise or omission of essential statistics or reports, complicity, and limitation in conducting accurate, neglected, or obscure problems [37].

The latter case clearly showed a lack of precise statistics on the number of patients and dimensions of the issue to the Iranian society. One of the reasons for health policy failure is the involvement of other organizations and institutions in the policy-making process. Sometimes, their participation in an issue is damaged by lack of awareness and disregarding the social nature of HIV/AIDS as well as more security-conscious view on the subject. In the current situation, a comprehensive mechanism to guide activities of various governmental, semi-governmental, and NGOs to control HIV and pursue the goal of zero new cases, many stakeholders are mainly island-based, not integrated, temporary, sometimes non-continuous, and more scientific/technical, and less political/strategic corporations [3, 17].

The outbreak of HIV among people in a rural area in Iran and other similar epidemics in countries like Iran, with localized or concentrated epidemics, was alarming for policy-

**Table 1.** Characteristics and features of various examples of HIV outbreaks in Africa and Southern and Southeast Asia regions

Country, location/year	Features area	Transmission way and morbidities	Estimation of morbidity	Practical actions taken by government	Reasons of HIV outbreak
China, Henan province/Early 1995	One of the worst areas in terms of people with a positive test for HIV	Blood collection and plasma samples through blood donors	After screening conducted in 2004, tens of thousands of infected FPDs were identified	Introduction and enforcement of laws banning commercial collection of blood and blood products in 1995 Strengthening the management of blood supplies Establishing two national sentinel surveillance sites in Henan in 1995 Expanding coverage of 46 sentinel surveillance sites in 2006	Frequency of plasma donation in combination with the following conditions: • re-use of tubing • mixing of plasma from multiple donors during blood collection • subsequent re-infusion of mixed red blood cells
Pakistan, Ratodero Taluka in Larkana district/Southern Sindh province/Early 2019	About 200,000 inhabitants, some of whom were among the poorest in Pakistan, with high illiteracy rates	Re-use of contaminated syringes	Of the 3,012 people who got an HIV test, 876 were HIV-positive, and 82% were children under the age of 15	Cancellation of medical license of accused physician at the beginning of the event Renewal of physician licensure by government and employment the physician in a public hospital To establish a new HIV/AIDS ART Treatment Center for children at Shaikh Zaid Children Hospital	Poor governance and corruption of the local government Addition of control of unregulated clinics Repackage of used syringes to sell as new ones To treat most people by quack doctors in rural areas Poor knowledge of the general population about the HIV/AIDS
Cambodia, Rhoka village/Western Battambang province/2014-2015	Poor and war-torn	Contaminated medical equipment Re-use of disposable syringes by unauthorized physician	Of the 1,407 people who tested HIV, 212 or 249 had a positive HIV test, 20 times the national average	Injection safety intervention was designed, focusing on healthcare worker training in safe injection practices, along with a community-focused awareness campaign to reduce demand for unnecessary injections	High community demand for medical injections Limited access to safety-engineered devices Lack of training and knowledge regarding appropriate indications for injections among healthcare workers Possibility of economic pressure or reasons for medical providers to improve profit margins

makers. It showed that countries should be more cautious about changing pattern of the outbreak in their countries, presuming social issues related to HIV and other high-risk behaviors. In that case, vulnerability of the general population due to HIV and other similar infections, including hepatitis and other sexually transmitted infections, could change over time. In summary, the problem has many social aspects, which anchor all people's individual and social behaviors, and require collective actions across different sectors. Thus, decision-makers should know the specific population, including marginalized and high-risk residents, and be aware of what could drive an epidemic in the following years.

The HIV epidemic is a great problem that requires avoiding reductionist perspective and instead of focusing on holistic, context-based solutions at economic, social, political, cultural, and community levels. Achieving the goal of ending HIV epidemic by 2030 in Iran and in similar counties require supporting policies with participatory and sustained popular approaches as well as sustainable policy-making with active and consistent presence of a wide range of stakeholders within and outside health system. The multidisciplinary nature of HIV infection and its' close association with addiction, sexual behaviors, and social harms, such as increasing informal settlements, urban slum population, aggravated employment, and socio-economic status, requires extensive inter-sectoral coordination. It should be noted that active role of the key actors, effectiveness of their activities, and lack of coordination and interaction among them, are the main issues, which have always been and have not changed over the years. At this point, Iran needs to represent the problem and change image of the policy in political arena. Therefore, the government should recognize social harms in health as a community-based approach, and incorporate into the policy process socially responsible groups, employing NGOs and civil society organizations to develop and implement policies and move towards community-based policies. Focusing on adopting anti-stigma strategies and disseminating comprehensive knowledge about AIDS can prevent Iranian society from repeating such situations, and trigger more appropriate responses if they do occur. Table 2 summarizes the most important overlooked implications of HIV policy in Iran.

## Conclusions

The HIV epidemic is a wicked problem that requires avoiding reductionist perspective as an alternative focusing on holistic, context-based solutions at economic, social, political, cultural, and community levels. Achieving the end of the HIV epidemic by 2030 in Iran and similar counties require aligning policies toward participatory and sustained popular approaches as well as sustainable policy-making, with an active and consistent presence of a wide range of stakeholders within and outside the health system. It should be noted that the multidisciplinary nature of HIV infection and its' close relevance to addiction and sexual be-

**Table 2.** Main overlooked implications for policymakers

Strengthen the collaboration among all stakeholders within and outside health sector
Development of a universal pro-active strategy for complex (wicked) problems to cover all diverse factors contributing to HIV/AIDS control
Facilitate the resource mobilization for HIV/AIDS control program
Incorporation and integration of social nature of HIV/AIDS considerations in all interventions and measures applied
Addressing and applying an integrated approach to face social and economic harms, including addiction, poverty, prostitution, and high-risk sexual behaviors, and marginalization apart from HIV/AIDS
Apply a collaborative mechanism to guide various governmental, semi-governmental, and NGO sectors to control HIV/AIDS

haviors needs extensive inter-sectoral collaboration among a wide range of stakeholders inside and outside the health sector. The issue of stakeholders' participation in the policy-making process in Iran remains a major problem. Coordination between them and effectiveness of their actions are also in doubt. At this point, Iran needs a new image and re-structure venues of the policy. Therefore, community-based approaches to AIDS problem are predominantly required. A comprehensive approach to health-related social harms, adopting anti-stigma strategies, and disseminating comprehensive knowledge about HIV/AIDS can prevent Iranian society from repeating of such situations.

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## Conflict of interest

The authors declare no conflict of interest.

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