

Ethical Considerations from the Viewpoint of Headquarters Experts on HIV/AIDS Prevention and Control Strategic Program

Abstract

Background: The HIV control and prevention program is one of the Public Health programs that confronts with many ethical challenges. This study aimed to explore ethical considerations from the viewpoint of headquarters experts on HIV and AIDS prevention and control strategic plan. **Methods:** In this qualitative study with content analysis design, focus group discussion method was utilized. After purposeful introduction of the experts and previous coordination about subject and time, two discussion sessions were held with the participation of six ministry and university headquarters experts of HIV control program. After frequent reviews of the data and using deductive content analysis, main themes and subthemes were categorized. In order to transformability of the findings to similar situations, the data were checked by three external reviewers. **Results:** The participants agreed that HIV/AIDS control requires focusing on prevention, treatment, and support services, and considering the general population and all vulnerable groups. In this study, five main themes were emerged: informing and empowering to make autonomous decisions, observing confidentiality, prohibiting stigma and discrimination, and being accountable. **Conclusions:** The viewpoint of participants indicates on the more need to pay attention the mentioned ethical considerations when compiling and finalizing the program. Moreover, in addition to instructing moral norms in PH programs with a special look to HIV/AIDS and how to apply them in the formulation and implementation of program, systematic evaluation of the program by an ethical framework is recommended to ensure the achievement to the goals of program.

Keywords: AIDS, HIV, morals/ethics, qualitative research, strategic planning

Introduction

The global epidemiological situation of HIV infection is still a main concern. Although the annual number of HIV decreased from 3.4 million in 2001 to 2.1 million in 2013 and the percentage of people who live with HIV (PLHIV) since 2000 have been stabilized, the number of PLHIV increased mildly and reached 33.8 million in 2015, and epidemic remained with an unacceptable level of new infections and death due to AIDS.^[1]

Ending AIDS epidemic represents an opportunity to establish a healthier and fairer world for future generations. Universal access to prevention, treatment and care services have been proposed as “right to health.” One important strategy for controlling HIV epidemic is treatment of the patients. If PLHIV are treated under the standard antiretroviral therapy by reducing the number of

viruses in blood and body secretions, meanwhile these patients can have a healthier life because of reducing disease complications, it is also minimized the probability of transmitting disease. For this reason, now “treatment” has been known as one of the most effective methods of “prevention” of AIDS. The term “treatment as prevention” refers to reducing transmission of infection and AIDS disease. So, in the infected persons by training on preventive behaviors, in pregnant mothers by antiretroviral therapy in order to prevent infection transmission from mother to infant, and in the patients by treatment and suppression of disease, infection transmission in the community is prevented. Accordingly, three main objectives have been considered for all countries by 2020: 90% of infected individuals are identified, 90% of individuals who identified were treated with antiretroviral therapy; and in 90% of individuals under treatment, the virus is suppressed so that cannot be measured.^[2]

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Achieving these targets will lead to the end of AIDS epidemic worldwide by 2030 and will produce benefits of health and productivity. This is possible only if people through necessary training about recommendation to test be informed about their illness and tended to receive care and treatment services and have continuous access to those. In addition, the elimination of stigma and discrimination is one of the key topics for accountability and achieving the goal for reducing the transmission of disease, worldwide.^[3] Thus, the HIV/AIDS is one of the programs that encounters with many ethical challenges and achieving its goals requires ethical considerations in its formulation and implementation.

Despite applied measures for controlling the epidemic in intravenous drug users (IDUs) and reducing epidemic trend in this population group, IDU is still the most important factor in the epidemic spreads. Unsafe sexual relations are common among IDUs. Thus, controlling the epidemic requires adopting interventions that reduce high-risk sexual relationships. In recent years, evidences have been observed about increasing the number of infected women with HIV. It is estimated that the highest increase in HIV turns from IDUs to female sex workers.^[4] In absence of the effective interventions for prevention, it increases the risk of HIV transmission from mother to child.^[5]

Some PH interventions are still a threat to other moral norms such as individual autonomy, privacy, and confidentiality.^[6,7] Focus of the program on meeting the needs of people with the most risk (key populations) and respecting the rights of PLHIV requires the contemplation of the ethical considerations in designing of the strategic plan along with observation of professional ethics by health professionals. Despite controlling the HIV transmission through blood products, it is essential to control the disease based on empirical evidence and moral deliberation. This is associated with familiarity of experts involved in HIV/AIDS planning about relevant ethical considerations. Therefore, this study aimed to explore ethical considerations from the viewpoint of headquarters experts on HIV and AIDS prevention and control strategic plan.

Methods

In this qualitative study with content analysis design, focus group discussion method was utilized. The participants were introduced purposefully by the Head of HIV/AIDS Control Office of Ministry of Health and Medical Education (MOHME). After obtaining the allowance, and previous coordination for the purpose, subject, and time of meeting, two meeting sessions were held with the participation of six ministry (three staff experts of HIV/AIDS Control Office of MOHME) and university experts (three staff experts of HIV/AIDS control program of the Tehran, Shahid Beheshti, and Iran University of Medical Sciences). Each session lasted for 2 h. After ensuring the

willingness of audience to participate, the discussion was started and directed with the following key question:

What are the ethical considerations and moral norms that should be considered in the formulation and implementation of HIV/AIDS program?

The conducting and taking notes were done by the researcher and the interview was recorded simultaneously. After working on the strip, typing, and frequent review of data, the subthemes and main themes were extracted and categorized using deductive content analysis.

Trustworthiness of study

For credibility, prolonged engagement of researcher and close contact with the participants facilitated the possibility of collecting actual data and tried to select participants with a variety of education and job position, and also work experience in various settings in order to create a variety of diverse data. Thus, the findings of the study were shared with experts who were in similar situations with the participants and matching the results with their experiences was ensured (Dependability). Recording experiences of participants were done accurately and impartiality (Confirmability). In order to transform findings to similar situations, data were controlled by three experts (external check).

Results

The participants agreed that HIV/AIDS control requires focusing on prevention, treatment, care, and support, and considering the general population and all high risk and vulnerable groups including pregnant mothers and children. The five main themes were emerged in the discussion: informing and empowering to make autonomous decisions, observing confidentiality, prohibiting stigma and discrimination, and being accountable.

Informing and empowering to make autonomous decisions

Health-related autonomy

The ethical principle of respect for autonomy requires the competency and ability of individuals to decide and choose consciously and freely about his/her own life style. All participants know health-related autonomy as the key ethical consideration in the HIV/AIDS control program. They believed that “instruction is necessary to control HIV/AIDS and educations should be Client-centered”; one of them says that “The correct education and right information, and high level access to standard educational content should be given to all.”

One of the participants points out that “People will not come to test because of stigma, unless we give the accurate information to the society and develop a positive attitude.” Other participant says that “One of our duties as a physician, a health practitioner or social worker is

instructing and informing clients which in most cases are neglected.”

Other participant points out that “People should aware and familiar with their rights. One major challenge is the lack of permission to disclose the infection of the client to the patient’s spouse and/or family, while clients demand for inclusion of HIV testing in premarital tests. But firstly, unlike other diseases it has a window period and test sheet don’t have any guarantee; second, whether do not allow the person who has HIV to get married helps reducing the incidence of infection; in fact, maybe marriage and family formation prevent of transmission of HIV in the community. Therefore, spouses in pre-marriage counseling classes are informed about the possibility of HIV testing if they have had risky behaviors and that they have right to request for testing of their partners and informing about its result.”

Empowerment and support

Seeking and receiving of the care, treatment, and supportive services by PLHIV are often impaired by HIV-related stigma. Participants say that “the establishment of the positive clubs is a relevant and initiative strategy; these clubs activate in order to empowerment, avoidance of stigma and discrimination and adherence to treatment using the capacities of public and nongovernmental organizations.” One of the participants says that “these clubs supports PLHIV and their families by providing various services such as instructing and informing, empowering, health insurance covering, vocational training and employing.”

Observing confidentiality

Confidentiality is one of the important moral norms in medical ethics that fail to do it, causes loss of patient confidence and failure to adhere the treatment. This theme emerged into two following subthemes:

Patient and health care provider communication

Awareness of persons about her/his own medical condition is a right for patient and a duty for physician. Respondents referred to “the patient’s right to privacy and the right to health for the future child and the need for consultation with the patient to disclose the infection to her/his spouse”. One of them pointed out that “confidentiality causes trust and continues coming to receive services”; the other continues: “providing comprehensive services in a center without providing the necessity resources and facilities, threatens the privacy of the clients.” Another participant says that “prescription of test by all healthcare providers is another issue that threatens the confidentiality of information rather than the midwives or family health professionals.”

Instruction of the healthcare practitioners in order to change their attitudes has been considered as one of the most important objectives of the HIV/AIDS strategic plan. One

of the participants says that “Some physicians, dentists and gynecologists reject clients quickly after being informed of HIV, while this attitude must be corrected that one-third of the cases has been identified and two-third of cases has not been identified and thus, they should always be ready because of possibility of hepatitis and other communicable diseases and their transmission which indicates on a need for improving their attitude.”

Data gathering actions

Data collection and surveillance are the health measures which are conducted to control disease and to provide the health of populations. One of the participants says “Requesting the national identification code at the time of providing information by the clients for registration in the database system due to confidentiality threat can affect the accuracy of information”. Another participant points out: “In the epidemiological surveillance and data management system, information confidentiality has been considered, although access to these data need to be addressed more.”

Prohibiting stigma and discrimination

In continuation, two themes of stigma and discrimination were expressed as twins by participants; they point out that “the two terms of stigma and discrimination are brought together” and believed in prohibition of stigma. They believed that “although categorizing population to at risk and risky groups are inevitable for targeting and serving care, this categorization should not cause stigma and discrimination.” One of them says: “The root of stigma is in the false belief due to difference in the way of infection transmission, discrimination is imposed in two ways, internal: By patients and external by service providers while the manner of infection shouldn’t have impact on access and treatment.”

One of the participants meanwhile referring to the need to reform of the law and its implementation says that “on the one hand, HIV screening is mandatory in maintenance and rehabilitation centers for addicts. On the other hand, if HIV is detected, PLHIV are discriminated and expelled on the pretext of possibility of transmission of HIV to others and their rights are not respected.” Another participant says: “Even HIV screening is a hidden condition for employment somewhere, and if the HIV is detected, that person is not employed.”

Being accountable

When the target indicators of the program are determined based on its benefits, the manner of monitoring and evaluation of those should be determined in order to announce the results to people and especially affected groups for accountability, and trust building to receive community support for future programs.

From the participants’ point of view “collaborative planning has been considered by organizations involved

and beneficiary groups as strength. Also, in the first year of implementation, providing the necessary infrastructures, monitoring and evaluation and the revision of the program to ensure that its implementation have been considered by different organizations involved.” One of the participants says “There should be some comprehensive services, people should feel the sense of commitment and addressing of their needs, service interruptions effect on the adherence to treatment and cause drug resistance.” Another participant says that “these services should be comprehensive and holistic and look at the patient as a human being.”

In connection with the commitment of policy makers, participants believed that “changing the president or the Minister of Health can affect implementation of the program and achievement of the goals; despite the approval of the program and its budget, and endorsing and announcing it by the Supreme Council of Health and Food Security to all organizations, usually at the implementation phase, the budget problem is expressed by some of the organizations involved. Therefore, the implementation should be ensured by all organizations.”

Discussion

In investigation of the viewpoint of headquarters experts on ethical considerations of the HIV/AIDS strategic plan, moral norms were emerged in five main themes. The first theme emerged was the reinforcement of autonomy. According to the recent theories of justice, autonomy is one of the six essential dimensions of human well-being that means to achieve it and should be provided.^[8] Promotion of autonomy is a central value in a fair society; a society in which growing conditions was provided for the ability to reason and make decision.^[9] PH is a moral action and public education is a key component of health services. Health education is a necessary component of PH campaigns to achieve the ultimate goal of reducing morbidity and mortality. Since education for informing and empowering people to decide autonomously and choosing healthy behaviors looks as an important step to achieve health outcomes and success of PH program.^[10]

One of the most important measures to control and reduce the incidence of HIV/AIDS is the implementation of continuous education for all healthcare staff to raise awareness about HIV and universal precautionary actions, stigma, and discrimination, and address the misconceptions and underlying fear among them about HIV transmission. Therefore, East Mediterranean Regional Office (EMRO) has published a package of modules training for healthcare workers until each country in the region with its implementation creates the human capacity to cope with HIV.^[11]

Another important issue that participants emphasized was empowerment and support of PLHIV. The international human rights system has recognized the status of HIV as

a field of discrimination needs support. At the same time, HIV causes inequalities to increase the rate of infection among women, children, marginalized groups, and poor people resulted in refocus on the economic, social, and cultural rights. In this regard, the content of the right to health has been defined increasingly as access to prevention, treatment, care, and supporting services for children and adults.^[12] Establishment of positive clubs is also one of the major actions to empower and support of PLHIV and their families.^[13] However, it seems that community health and well-being require to fostering autonomous individuals with a preventive approach.

The next moral norm emerged was observing confidentiality. WHO has recommended five ethical considerations of confidentiality, informed counseling and consent, correct test results, and connect to prevention care and treatment services as “5Cs” for continuity of care in HIV control program. Participants notified observing confidentiality from the perspective of both clinical ethics and PH ethics. They highlighted well the importance of the confidentiality of information and the need for “limitation of access to information” in reporting the names of PLHIV and tracking infected cases and remarked considering them in the implementation of program. The data collection is a PH measure that is associated with the added risk of information disclosure and violation of confidentiality.^[14] Another problem is disapproving PLHIV by physicians that is contrary to professional ethics, which implies the need for a specific guide of professional ethics for HIV and its link with the patients’ rights so that resulted in revisions of relevant regulations. Legal reform should be based on the systematic legal review, which assesses the rules against international guidelines on HIV/AIDS and human rights. Governments should ensure that legislation protects the rights of education, equality in privacy and confidentiality, and consent voluntarily and consciously to HIV testing and treatment.^[15]

Stigma and discrimination were two major moral norms that respondents emphasized for measuring the quality of services. HIV-related stigma is defined as a PLHIV devaluation process. Stigma leads to discrimination which resulting in an unfair treatment of a person based on real or perceived condition of her/his HIV status. Stigma and discrimination have been recognized as the major barriers to provide quality services by health care providers.^[16] Equality and nondiscrimination and irretrievable in international human rights agreement are pillars that rely on other human rights.^[17] The Paris declaration states that to achieve the objectives 90-90-90 by 2020 discrimination should be reduced to zero and the number of cases of severe adult infections be reduced to 500,000.^[16] The purpose of EMRO from the production of training modules package for healthcare staffs are to create the necessary human capacity and reduce stigma and discrimination against HIV infection.^[11]

Accountability was the last ethical consideration of the program that was emphasized by the participants. According to the “5Cs,” program sustainability and adherence to treatment to prevent new cases of HIV and preventing death require the commitment and accountability of PH officials. Implementing the “health in all policies” approach enables the government to act seamlessly in responding to health need.^[18] This approach considers the effects of other policies and laws on health through social determinants of health and realizes when the health-related policies and laws are planned and implemented in all sectors.^[19] So that its endpoint be the elimination of health inequality gaps. Studies have also recommended the effective use of individual and community resources, especially spiritually and social capital, and integrating spiritual care into mental health services of PLHIV.^[20,21] Positive clubs provide psychosocial support for PLHIV and their families and their contribution to preventing epidemic spread.^[22]

It seems that some moral norms were neglected from the perspective of participants. They include the balance of benefits and burdens of the program for increasing effectiveness of the program, and distributive justice.^[23] The principle of justice as a central principle in PH ethics emerged implicitly only for access to services and educating to prevent stigma against discrimination. Although participants stated targeting all groups and supporting PLHIV as strengths of the program, but they did not mention the equitable distribution of interests and opportunities. Lifestyle resulted from interplaying individual agency and social determinants of health include structural factors and living conditions. Therefore, controlling the prevalence of HIV in addition to educating and empowering people and respect for autonomy requires distributing benefits and opportunities based on the need and addressing the structural factors.^[24]

Conclusions

The participants proposed some of the major moral norms in planning HIV/AIDS control strategic program. Their viewpoints indicate the more need to pay attention on the mentioned ethical considerations when compiling and finalizing the program and then ethical evaluation of the program. Considering the importance of HIV/AIDS control strategic plan in addition to instructing moral norms in PH programs with a special look to HIV/AIDS and how to apply them in the formulation and implementation of program, systematic evaluation of the program using an ethical framework is recommended to ensure the achievement of the goals of program.

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Conflicts of interest

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