

## *The need for tailored ethical guidelines in HIV/AIDS care*

*Nahid Khademi<sup>1</sup>, Fariba Asghari<sup>2\*</sup>*

*1. PhD Candidate in Medical Ethics, Medical Ethics and History of Medicine Research Center, Tehran University of Medical Sciences, Tehran, Iran; CDC, Deputy of Health Affairs, Kermanshah University of Medical Sciences, Kermanshah, Iran.*

*2. Professor, Medical Ethics and History of Medicine Research Center, Tehran University of Medical Sciences, Tehran, Iran.*

### **Abstract**

In the past decades, AIDS has represented one of the most significant global health challenges to mankind. Upholding ethics and respecting patients' rights play a critical role in enhancing treatment among individuals living with HIV/AIDS. This study aimed to evaluate the adequacy of ethical considerations in the HIV/AIDS care system guidelines in Iran. For this purpose, we critically reviewed the existing policies and the Anti-Stigma and Discrimination Bylaw. We extracted articles on ethical considerations and patients' rights and classified them according to the principles of bioethics and the professional responsibilities associated with medical practice.

We found that the present guidelines address informed consent (except those related to childcare), confidentiality, and privacy. However, ethical issues such as capacity assessment, substitute decision-making, treatment refusal, and disclosure of diagnosis have been overlooked. Furthermore, a review of the Anti-Stigma and Discrimination Bylaw revealed a lack of guidance on non-discriminatory and equitable care for people of specific populations, such as drug users, female sex workers (SW), men who have sex with men (MSM), and healthcare workers exposed to HIV-positive patients.

These findings highlight gaps and deficiencies within the guidelines in addressing the rights of healthcare recipients and emphasize the need for developing dedicated ethical guidelines for the care and support of individuals living with HIV/AIDS.

**Keywords:** *Medical ethics; Ethical considerations; Care; Treatment; HIV/AIDS.*

#### **\*Corresponding Author**

**Fariba Asghari**

**Address:** Medical Ethics Research Center,  
No.23, Shanzdah Azar St., Keshavarz Blv.,  
Tehran, Iran.

**Postal Code:** 1417633114

**Tel:** (+98) 21 66 41 96 61

**Email:** [fasghari@tums.ac.ir](mailto:fasghari@tums.ac.ir)

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## ***Introduction***

HIV/AIDS is recognized as a major global health challenge, particularly in developing countries. The 2023 UNAIDS report estimates that around 39 million people globally are living with HIV, resulting in hundreds of thousands of deaths annually from related complications (1). Improving care and treatment not only enhances life expectancy for those with HIV but also reduces mother-to-child transmission, limits spread among high-risk groups, and improves the quality of life for affected individuals (2).

The World Health Organization (WHO) has introduced the 95-95-95 targets to accelerate efforts to end the AIDS epidemic (3). However, challenges persist, including treatment-related issues, inequitable access to healthcare, and late diagnosis, which significantly hinder HIV control (4). Individuals living with HIV encounter ethical barriers, socio-economic inequalities, cultural sensitivities, and community stigmatization (5).

Despite decades of global efforts, the epidemic continues to spread. The U.S. Department of Health and Human Services (HHS) has initiated efforts to end the outbreak, noting that ethical guidelines can help healthcare providers achieve

this by 2030 (6). Additionally, the latest UNAIDS/WHO guideline emphasizes the need for ethical considerations to enhance prevention efforts (7).

In fact, HIV care engages fundamental moral commitments. First, the right to life and inherent human dignity require that care systems protect the worth of every person living with HIV and enable conditions for a life of agency and flourishing (8). Second, public health goals and individual rights must be held in principled balance: prevention and partner notification aim at population benefit, yet should be pursued with respect for autonomy, privacy, and the least-restrictive means compatible with effective control (9-11). Third, justice in HIV care is both distributive (fair access to testing, treatment, and ancillary supports across regions and key populations) and procedural (transparent, non-discriminatory decision-making processes) (12).

In Iran, the National Center for Communicable Disease Control has developed six guidelines focused on the prevention, control, and care of HIV/AIDS, addressing timely diagnosis, treatment adherence, patient counseling, monitoring treatment outcomes, and healthcare

provider evaluations to ensure active engagement in care and treatment. Although a national Specialized Guide on Research Ethics related to HIV/AIDS exists for studies in this field (13), there is no integrated, ethics-grounded clinical guideline for the treatment and care of people living with HIV/AIDS. The guidelines mentioned above are as follows:

- 1- Guideline for the Management of Care and Treatment of Adolescents and Adults with HIV/AIDS: This guideline covers care and treatment for adolescents and adults, emphasizing timely treatment, therapy adherence, and psychological support (14).
- 2- Guideline for the Management of Care and Treatment of Children with HIV/AIDS: The text covers the treatment of HIV in infants and children, focusing on identifying infection status, starting ART, and monitoring throughout the treatment process (15).
- 3- Guideline for the Prevention of Mother-to-Child Transmission (PMTCT) of HIV: This document outlines strategies to prevent HIV transmission from mothers to newborns, ensuring that infants born to mothers with HIV remain uninfected (16).

- 4- Guideline for the Management of Occupational Exposure to HIV: This guideline helps healthcare professionals and workers implement protective measures when working with individuals living with HIV/AIDS (17).

- 5- Guideline for the Management of Non-Occupational Exposure to HIV: This document offers healthcare professionals protocols for treating individuals potentially exposed to HIV through shared injection equipment or unprotected sex with HIV-positive individuals (18).

- 6- Guideline for the Care and Treatment of Sexually Transmitted Infections (STIs): This guideline concerns healthcare professionals in behavioral counseling centers for the timely identification and treatment of individuals showing STI symptoms (19).

The above-mentioned guidelines for healthcare providers, alongside the Anti-Stigma and Discrimination Bylaw, are aimed at improving the human rights status of individuals living with HIV/AIDS. Issued by the Ministry of Health, this bylaw outlines the responsibilities of various health sectors in four sections and 22 articles (20).

A critical question arises regarding whether these guidelines adequately incorporate standard ethical principles. Is there a need for specialized ethical guidelines to better support healthcare professionals in upholding the rights of individuals living with HIV/AIDS? To align with the World Health Organization's emphasis on ethical considerations in healthcare delivery for this population, the authors assessed the existing care guidelines for their effectiveness in addressing ethical concerns. This analysis seeks to determine if current guidelines meet ethical standards or if dedicated guidelines are required to provide better care and support for people living with HIV/AIDS.

## ***Methods***

This study examines the inclusion of ethical considerations in the six care guidelines for patients living with HIV/AIDS, utilized by healthcare professionals in behavioral counseling centers and other healthcare facilities in Iran. Additionally, the study reviews the Anti-Stigma and Discrimination Bylaw in this context.

The analysis involved a thorough review of all sections of each guideline conducted by one of the authors (N.K.), who has experience in behavioral diseases and expertise in ethical

issues. In this process, articles that explicitly or implicitly addressed ethical considerations and patients' rights were identified and extracted.

Each article identified in the guidelines was categorized according to bioethical principles—respect for autonomy, beneficence, non-maleficence, and justice—and professional responsibilities based on medical professionalism. The categorized articles were presented in a series of tables. To ensure the reliability of the categorization, the second author (F.A.) reviewed the results. Any disagreements were discussed, and a consensus was reached through deliberation. Finally, in a normative analysis step, two ethicist authors appraised each provision and gap against a bioethics frame based on human rights—dignity, Patients' Rights Charter, justice, and least-restrictive balancing of individual rights with public-health goals—treating each identified 'omission' as an ethical under-specification requiring a reasoned justification and practical safeguard.

## ***Results***

### ***Management of Care and Treatment of Adolescents and Adults with HIV/AIDS***

This guideline briefly addresses some ethical considerations, including informed consent. According to this document, healthcare providers are required to provide essential information at the beginning of treatment:

*"... Healthcare providers should supply patients with the necessary information about the benefits and advantages of treatment..."*

The guideline also emphasizes the patient's right to make free and informed decisions regarding treatment:

*"... The ultimate choice to accept or refuse antiretroviral therapy rests with the patient..."*

The guideline fails to address the assessment of a patient's decision-making capacity. It lacks guidance on communicating an HIV-positive diagnosis in such a manner as to minimize harm and encourage treatment engagement. It also does not explicitly mention maintaining confidentiality or clarify when healthcare providers may be allowed to breach it (Table 1).

#### *Management of Care and Treatment of Children with HIV/AIDS*

This guideline addresses minimal ethical considerations; for example, it does not include provisions on obtaining **children's assent**.

Moreover, it overlooks important ethical issues related to how healthcare providers should communicate the HIV diagnosis to young children or disclose the child's HIV status to parents or guardians, as well as the need to maintain the child's privacy and confidentiality of medical information. The document also lacks guidance for healthcare providers on how to handle situations in which parents or guardians refuse treatment for the child. Additionally, it does not provide recommendations for resolving conflicts between autonomy and beneficence—such as cases in which treatment is in the child's best interest. Still, it is refused by the parent or guardian (Table 1).

#### *Management of the Prevention of Mother-to-Child Transmission (PMTCT) of HIV*

This guideline offers minimal attention to ethical considerations. Regarding **informed consent**, it emphasizes the pregnant woman's right to autonomy and choice in undergoing HIV testing: *"HIV testing for pregnant women should be conducted with counseling and with the woman's informed consent."*

The guideline fails to address the crucial issue of communicating HIV diagnoses to pregnant women, particularly those who test positive during labor. It also lacks guidance on balancing

the mother's confidentiality with disclosing the infant's HIV status to the father. Additionally, there are no recommendations on obtaining consent to prophylactic care for infants born to HIV-positive mothers. Other ethical concerns, such as maternal refusal of cesarean delivery, formula feeding choices, and prophylaxis administration to prevent HIV transmission, are also not covered (Table 1).

#### *Management of Occupational Exposure to HIV for Healthcare Workers*

This guideline mandates recording the exposed individual's information in their medical file, with attention to confidentiality:

*"During the request for testing, confidentiality of the test results must be maintained."*

The document also emphasizes the need to assess the HIV status of the source of exposure, if known, and requires that this testing be conducted with the individual's informed consent:

*"If the source of exposure is identified, the individual's HIV status should be assessed following informed consent."*

This guideline lacks clarity on ethical considerations for healthcare providers when a

source individual refuses testing. There is no direction on how to ethically persuade someone to consent or on the steps to take if consent cannot be obtained. Key unanswered questions include: Can mandatory testing occur without consent? What ethical obligations do healthcare workers have if a surrogate decision-maker opposes HIV testing? How should providers ethically disclose a positive HIV diagnosis to the source individual or their surrogate? These gaps underscore the need for more explicit ethical guidance that supports healthcare workers while respecting individuals' rights (Table 1).

#### *Management of Non-Occupational Exposure to HIV*

While this guide touches on some ethical considerations, several key issues remain insufficiently addressed. Regarding informed consent, the guideline emphasizes the importance of providing information to exposed individuals:

*"Healthcare providers should strive to provide the necessary information to encourage exposed individuals to engage in safer behaviors."*

The guideline also highlights the right of individuals to make free and informed decisions:

*"During the initial evaluation of the exposed individual, HIV testing should be conducted*

*following national guidelines and with the individual's consent."*

However, the guideline does not address capacity assessment to determine whether the individual is competent to make informed decisions about testing and treatment.

This document emphasizes confidentiality and privacy, requiring that personal information be recorded securely:

*"The personal information of the exposed individual should be documented in their medical file, and confidentiality must be upheld to the highest standard."*

It is also specified that HIV test results should be handled confidentially: *"During the testing process, confidentiality must be maintained, and individuals exposed through sexual contact should be reassured that all actions will respect their privacy."*

The guideline lacks clarity on key ethical challenges, for instance, what steps healthcare providers should take when individuals refuse care, or how to balance encouraging compliance with respecting autonomy. It also does not specify how to ethically communicate a positive HIV diagnosis to the individual or their surrogate decision-maker (Table 1).

### *Management of Care and Treatment of Sexually Transmitted Infections (STIs)*

This guideline outlines the principles of care and treatment for individuals with high-risk sexual behaviors and addresses some ethical considerations, though only to a limited extent.

Regarding informed consent, healthcare providers are instructed to provide the necessary information to patients at the start of treatment:

*"Patients must receive information from healthcare providers about the personal benefits of treatment and the importance of treating sexual partners to break the chain of transmission."*

The guideline also emphasizes patient autonomy, stating:

*"Patient consent is essential for receiving diagnostic and therapeutic services."*

Additionally, it addresses confidentiality and privacy:

*"Confidentiality must be ensured for both the patient and their sexual partner during care approaches."*

The importance of maintaining privacy during contact tracing is also highlighted:

*"The preferred method for notifying sexual partners is through healthcare workers while maintaining confidentiality."*



However, several critical ethical considerations are not addressed in the guideline. There is no mention of evaluating the patient's decision-making capacity or designating a surrogate decision-maker when the patient lacks capacity. Moreover, there are no instructions on how healthcare providers should respond if a patient refuses treatment or how to encourage compliance while respecting patient autonomy (Table 1).

*Anti-Stigma and Discrimination Bylaw for Individuals Living with HIV/AIDS*

This bylaw refers to measures aimed at reducing stigma and discrimination and improving access to healthcare services for individuals living with HIV in general and ambiguous terms. For example, regarding the responsibilities of the health sector, it states:

*"Confidentiality protocols regarding the data and reports of individuals living with HIV must be developed and communicated to healthcare service providers."*

It also states: *"Necessary arrangements and facilities for access to post-exposure prevention services must be provided."*

However, this bylaw does not specify what **ethical considerations** should guide the development of these protocols.

It emphasizes confidentiality and privacy, stating: *"...HIV test results are confidential, and disclosing an individual's test results to others without their consent is prohibited..."*

Article 9 of the bylaw addresses patient consent, capacity, and substitute decision-making for receiving services:

*"Any form of coercion to undergo testing, diagnostic procedures, or HIV-related treatment is prohibited. For individuals lacking legal capacity, HIV testing may be conducted with the consent of their legal representative."*

*The document further states that the above rule does not apply when an individual's life is at risk, or in emergency situations where obtaining informed consent from the patient or their substitute decision-maker is not possible.*

The question here is: If a conflict arises between the substitute decision-maker and healthcare providers regarding HIV testing, what ethical considerations should healthcare providers follow? Additionally, what measures should healthcare providers adopt to reduce stigma and discrimination, especially for individuals engaging in high-risk behaviors? Moreover, the guideline does not specify the ethical considerations that healthcare providers should



take into account if they are infected with HIV through occupational exposure (Table 1).

**Table 1.** Stated and suggested ethical considerations in national guidelines for HIV prevention and control

Guideline Title	Target Group	Ethical Stated in the National Guideline	Considerations	Suggested Ethical Considerations
1 Management of Care and Treatment of Adolescents and Adults with HIV/AIDS	Adolescents and adults	Informed -Providing necessary information to the patient - Free decision-making	Consent: necessary	Informed -Assessing the patient's decision-making capacity -How to communicate the diagnosis - Confidentiality and privacy
2 Management of Care and Treatment of Children with HIV/AIDS	Children	-	-	Informed -Providing the necessary information to the child -Assessing the patient's decision-making capacity -Children's right to choose and agree to receive services -How to communicate the diagnosis to the child -Disclosing the child's diagnosis to parents or guardians -Confidentiality and privacy -Parental refusal of treatment - Conflict between informed consent and beneficence
3 Prevention of Mother-to-Child Transmission of HIV	Pregnant women and newborns	Informed -Providing necessary information to the pregnant mother - Mother's right to choose and make free decisions	Consent: necessary	Informed -Assessing the patient's capacity -How to communicate the diagnosis - Ethical dilemmas such as conflict between the mother's right to confidentiality and disclosure of the baby's status to the father -Obtaining informed consent for prophylactic care -Refusal of care (e.g., cesarean delivery, formula feeding) - Refusal of prophylactic treatment for the mother and newborn
4 Management of Occupational Exposure to HIV/AIDS	Healthcare workers (HCWs)	Informed -Providing necessary information to the exposed HCW -Right to choose care - Confidentiality and privacy	Consent: necessary	Informed -Refusal of HIV testing by the source of exposure -How to communicate the diagnosis to the source or their substitute - Refusal of care by the source of exposure
5 Management of Non-Occupational Exposure to HIV	General public	Informed -Providing necessary information to individuals - Right to choose care - Confidentiality and privacy	Consent: necessary	Informed -Assessing the patient's capacity - How to communicate the diagnosis to the exposed individuals -Refusal of testing by the exposed individuals - Refusal of care by the exposed individuals
6 Care and Treatment of Sexually Transmitted Infections (STIs)	Patients with STIs	Informed -Providing necessary information to individuals -Right to choose care and treatment - Confidentiality and privacy	Consent: necessary	Informed -Assessing the patient's capacity -How to communicate the HIV diagnosis - Refusal of care and treatment services
7 Anti-Stigma and Discrimination Bylaw	People who live with HIV/AIDS	Informed -Providing necessary information to individuals - Right to choose treatment -Assessing capacity - Confidentiality and privacy	Consent: necessary	Non-discriminatory and fair treatment of patients Non-discriminatory and fair treatment of key populations Non-discriminatory treatment of workers exposed to HIV

## ***Discussion***

While the goal of the national HIV prevention and control program is to develop a comprehensive framework for managing the disease nationwide, a review of the guidelines from an ethical principles and professional responsibilities perspective reveals several ethical challenges. These challenges can impact the effectiveness of HIV care and lead to adverse outcomes in the treatment of individuals living with HIV. Some of these challenges are discussed below:

### ***Decision-Making Capacity***

Respect for patient autonomy and informed consent are fundamental ethical principles requiring healthcare providers to support individuals living with HIV who have decision-making capacity. This involvement enhances diagnosis and treatment adherence (21, 22). Factors influencing informed consent processes for HIV-positive patients highlight the importance of assessing their decision-making capacity. If patients lack this capacity, substitute decision-makers should be consulted (23). Conflicts between substitute decision-makers and healthcare providers can create ethical

challenges, but prioritizing the patient's best interests is essential (24).

### ***Refusal of Treatment***

One ethical challenge noted in the guidelines is the lack of direction on managing treatment refusal in individuals living with HIV, which can lead to infection transmission. Treatment refusal can take various forms, and understanding these distinctions is crucial. It can pose risks to third parties, such as the mother-to-child transmission of the virus, or parental refusal affecting children's health. Healthcare providers must prioritize the child's well-being while respecting parental autonomy, underscoring the need for a practical guide for physicians (25). For many patients, fear of social repercussions from disclosing their HIV status contributes to treatment refusal. In children and adolescents, the primary factor is often their limited decision-making capacity. Therefore, it is essential to evaluate and address each patient's reasons for refusal (26).

### ***Considerations for Promoting Public Health***

Confidentiality and privacy are essential for fostering trust between patients and healthcare

providers (27). However, reporting specific diseases may sometimes be necessary to protect public health. Healthcare providers must act in the patient's best interest while adhering to legal requirements and public health obligations (28). For example, when a patient is identified as HIV-positive, it is essential to maintain confidentiality and, at the same time, implement preventive measures to reduce the risk of transmitting the virus to their sexual partner and, in the case of pregnancy, to the fetus. Furthermore, contact tracing of the patient's previous sexual partners is necessary to protect the public. Still, it should be done while respecting the privacy of infected individuals and the principles of confidentiality.

#### *Communicating a Positive Test Result*

Healthcare providers face significant challenges when delivering a positive HIV test result. Inaccurate or insensitive communication can lead to severe consequences like suicide, divorce, and mental health issues. Therefore, providers must consider social, cultural, gender-related, and personal factors, stigma, discrimination, societal laws, and job loss risks when communicating an HIV diagnosis (29).

Informing children about their HIV status is particularly complex and requires input from parents and providers, considering the child's

knowledge, developmental stage, and cultural environment. Standardized guidelines are therefore needed to help determine when and how to disclose this information to children.

Opinions vary on how much information parents or caregivers should share. Some advocate for limited information, while others argue for age-appropriate details to help children understand their condition (30). Research indicates that school-aged children typically grasp an HIV diagnosis, whereas younger children should receive information gradually as their cognitive and emotional abilities develop (31). Furthermore, there are ethical questions about who should communicate the diagnosis and what support the child needs afterward. Our findings indicate that current guidelines insufficiently address these issues in communicating HIV diagnoses to children of varying ages.

#### *Justice in Access to Healthcare Services*

Equitable access for people living with HIV/AIDS is a moral obligation grounded in the right to health, non-discrimination, and justice, and failure to ensure access predictably worsens population health. Although the Ministry of Health has issued the anti-stigma bylaw, it has not been satisfactorily integrated into the care and treatment guidelines. For example, there is

no specific guide for healthcare providers on non-discriminatory and fair treatment when providing services to babies born to mothers living with HIV or children whose parents engage in high-risk behaviors, such as injection drug use or unsafe sexual practices.

Similarly, the bylaw lacks instructions on non-discriminatory practices for healthcare providers when delivering services to individuals from key populations, such as prisoners, injection drug users, sex workers (SW), men who have sex with men (MSM), or individuals engaging in other high-risk sexual behaviors. Additionally, the guidelines do not address how to provide equitable care to patients co-infected with other infectious diseases, such as hepatitis B and C or tuberculosis (TB), alongside HIV. Moreover, ethical considerations have not been outlined for non-discriminatory and fair treatment of healthcare workers who have become infected with HIV through occupational exposure. To address these gaps and ensure fairness and equality in care and treatment, practical guidelines must be developed.

#### *Expansion of Technology in Healthcare Services*

Another critical issue to consider in HIV care guidelines is the rapid advancement of science. Modern technologies, such as digital tools for

patient data recording, remote care, telemedicine for treatment, and assisted reproductive technologies for infertile couples, offer opportunities for faster service delivery but also introduce ethical challenges that need to be addressed in the revision of HIV care and treatment guidelines.

The rise of e-health interventions demands new ethical considerations regarding privacy and data security for participants, emphasizing the need for updated guidelines and training for healthcare providers (32). Studies suggest that ethical considerations must be adapted and updated in line with the needs emerging from new technologies and artificial intelligence (33-34). The nature of AI systems can potentially weaken doctor-patient relationships in HIV care, making it essential to design appropriate ethical guidelines in this regard (35).

### ***Conclusion***

Our evaluation of the guidelines shows that while they outline strategic actions for preventing and controlling HIV, they inadequately address ethical considerations. Key challenges include decision-making capacity, substitute decision-making, managing treatment refusal, delivering positive diagnoses, and ensuring equitable access

to services. This study highlights the gaps in protecting service recipients' rights and emphasizes the need for dedicated ethical guidelines for individuals living with HIV.

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### ***Conflict of Interests***

Authors declare having no conflict of interest.

### ***Ethics Considerations***

This study complies with the Helsinki Declaration. Since this review article involves no human participants or specimens, there are no ethical issues. The dissertation protocol was approved by TUMS research ethics committee (Ethics approval code: IR.TUMS.MEDICINE.REC.1403.128).

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