Telling the truth about HIV? Testing and disclosure in a culture of stigma

ÉTUDE DE CAS / CASE STUDY
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Résumé
La stigmatisation du VIH est l'un des obstacles les plus notables à l'accès à des tests individuels, ce qui altère sérieusement les efforts mondiaux dans la lutte contre le VIH / SIDA. Puisque la stigmatisation est fortement ancrée dans les habitudes culturelles et sociales locales, les travailleurs de la santé, qui offrent des programmes humanitaires de dépistage, de conseil et de prévention du VIH dans les pays à faible et moyen revenu (PFR-PRI), sont devenus une alternative sérieuse aux fournisseurs de soins de santé locaux. Cette étude de cas porte sur certains des dilemmes éthiques auxquels les travailleurs de la santé humanitaires doivent faire face lorsqu'ils sont confrontés à la stigmatisation associée au VIH.

Mots clés
VIH / SIDA, la stigmatisation, humanitaire, des travailleurs de la santé, les pays à faibles et moyens revenus

Summary
HIV stigmatization is one of the most notable barriers to individual testing, seriously impairing global efforts in the fight against HIV/AIDS. Because stigmatization is strongly embedded in local cultural and social habits, humanitarian healthcare workers providing HIV testing, counselling and prevention programs in low and middle income countries (LMICs) have become a serious alternative to local healthcare providers. This case study addresses some of the ethical dilemmas that humanitarian healthcare workers face when confronted with HIV-associated stigma.

Keywords
HIV/AIDS, stigmatization, humanitarian, healthcare workers, low and middle income countries

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Conflicts of Interest
Catherine Olivier is a PhD candidate under the supervision of Bryn Williams-Jones, Editor-in-chief of BioéthiqueOnline.

Background
As part of global efforts in the fight against HIV/AIDS, nongovernmental organizations (NGOs) and governments worldwide have elaborated a number of testing, counselling and treatment policies and programs. According to the World Health Organization (WHO), these programs now cover 119 countries and enabled 95 million individuals to be tested for HIV in 2010 [1]. Nonetheless, levels of
voluntary counselling and testing (VCT) remain low in many low and middle income countries (LMICs), especially within lower socioeconomic groups [2]. Routine testing for HIV in regular clinical encounters in epidemic countries, pre-natal routine testing and opting-out testing have thus been suggested by the WHO and adopted in a number of countries [3]. However, doctors and healthcare staff are not always well equipped to provide the recommended strategy to HIV testing, which entails informed consent, counselling and confidentiality (i.e., the 3C’s strategy). Routine testing policies hence raise a significant number of ethical issues for both caregivers and patients.

Concerns pertaining to patient autonomy, confidentiality, access to treatment and human rights to healthcare are among the most notable ethical issues raised in this context [4]. These ethical issues are further exacerbated by the stigma that is associated with HIV/AIDS in many LMICs. Stigmatization of HIV infected individuals is often physical as people are afraid to touch or share common living spaces with infected individuals [5]. In many settings, the stigmatization can be ethical in nature as being infected with HIV remains associated with immoral behaviour and unavoidable death [6,7], including social with social exclusion, discrimination and psychological impacts counting among the most important barriers to HIV testing [6,8]. Not surprisingly, voluntary disclosure of HIV status to partners or family members is often very difficult to achieve [4,9].

Physicians often themselves fear being infected when treating HIV infected individuals [10,11], and may refrain from telling patients their HIV status. NGOs that provide testing and treatment services through outpost clinics can become an alternative for these doctors, often placing the burden of disclosing HIV patient status on humanitarian healthcare workers. Because of resource constraints and social context, not everyone who tests positive for HIV has access to treatment [12]. Humanitarian workers often face difficult choices of whom to include in the AIDS treatment programs, how to respect individual choices concerning HIV treatment, and how to deal with the risks of stigmatization for HIV infected individuals.

**Case Description**

As part of my medical training, I had been working in an outpost clinic on the outskirts of Kinshasa, the largest city of the Democratic Republic of Congo. One morning, I came upon a frail man sitting on the floor by the door. He had been waiting for us since sunrise with a folded piece of paper in his hand. As I approached him, he handed me the stapled paper and told the local nurse working with me that he had been ill for a while and went to the district hospital to seek help. He saw a doctor who performed a series of tests and who then gave him the paper and told him to come here. The man could not read and did not know the contents of the paper. I unfolded the paper and saw that it contained the results of an HIV test. The man had tested positive.

The local nurse standing beside us looked at me and explained that I could not tell the man that he had HIV. She told me that the stigma associated with HIV/AIDS is so strong in the region that disclosure of his HIV status would be more harmful to him than the help we could provide. Increased violence in the country was menacing our clinic. Our organization had thus announced temporary guidelines that restricted the inclusion of new patients in our HIV/AIDS program, making him ineligible to start treatment with us.

As I stepped away from the nurse and the patient, I found myself in a state of turmoil and discomfort. I did not understand why the nurse would not tell the man his HIV status. For me, it was essential that he know his status in order to protect others in the community from infection and limit the spread of the virus. I was also angered by the guidelines announced by my organization that forced us to exclude him from care. Finally taking a moment to reflect on the situation, I realized I was facing an important ethical dilemma.
Discussion

The risk of stigmatization the patient faces can be a critical element for his wellbeing. Stigmatization can be extremely harmful for individuals leading to negative self-perception, voluntary exclusion and even suicide \[13,14\]. The stigma associated with HIV testing can result in concealment and lead individuals to wait too long before getting tested \[15\]. In fact, the proportion of individuals who are tested in an appropriate timeframe to receive efficient treatment in many LMICs is low; only 20% of adults and 28% of children are tested, leaving most unaware of their HIV status \[16\]. HIV infected individuals can fall victim to verbal and physical harassment, psychological pressure, and discrimination by their social environment \[14\]. Furthermore, caregivers find they are also stigmatized in society when treating HIV infected patients, which can lead them to limit their involvement in HIV treatment as seen in the present case \[8,11\]. Stigmatization can seriously limit the benefits of HIV testing and treatment, and is thus a serious problem that requires careful consideration when offering HIV testing, counselling and treatment.

Healthcare providers have an obligation to consider concerns of HIV stigmatization when providing care to patients. They also have a responsibility to provide the best care possible, which may include informing patients of their HIV status. Knowledge of HIV status can increase the chances that individuals will seek, adhere and comply with antiretroviral treatment that can help them regain a normal life. It may also lead individuals to adopt preventive measures, such as having fewer sexual partners and increasing their use of condoms. As such, informing a patient of their HIV status is an ethical obligation. Since healthcare providers also have a moral duty to protect the community, prevention of HIV infection by testing and counselling strategies is part of the promise they hold towards the population. Responsibilities towards patient and population health thus contribute to making patient HIV status disclosure an ethical duty in the present case.

As a healthcare provider, I found myself in a difficult situation where my moral duty to tell the truth placed the patient at risk of serious stigmatization. As I returned to the local nurse working with me, convinced of my duty to tell this man of his HIV status, the patient had left without knowing he had HIV. To this day, I struggle with these thoughts and a number of questions come to mind:

1. What was my responsibility towards the patient with regards to the risk of stigmatization he is exposed to in his community?
2. How does this risk balance with the public health risk of letting a person that has HIV go around without knowing his HIV status?
3. Is it acceptable to infringe the patient’s right to be protected from stigmatization for the good of public health?

However, these questions fall short of an answer every time. I guess they remain part of the greatest ethical dilemma I faced and, in the end, did not know how to resolve.

References


**Suggested readings**
