

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

ÉTUDE DE CAS / CASE STUDY

Catherine Olivier¹

Reçu/Received: 1 Apr 2013

Publié/Published: 28 Jul 2013

Éditeurs/Editors: Ali Okhowat & Zubin Master

© 2013 C Olivier, [Creative Commons Attribution 3.0 Unported License](http://creativecommons.org/licenses/by/3.0/)

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

Affiliations des auteurs / Author Affiliations

¹ Programmes de bioéthique, Département de médecine sociale et préventive, Université de Montréal, Montreal, Canada

Correspondance / Correspondence

Catherine Olivier, catherine.olivier@umontreal.ca

Remerciements

Des remerciements particuliers vont à M. Matthew Hunt et Mme Lisa Schwartz pour m'avoir permis de travailler sur cette étude de cas pour le site web de [Humanitarian Healthcare Ethics](http://www.humanitarianhealthcareethics.org/) et pour leurs précieux commentaires. Merci au groupe d'éthique de la santé humanitaire de fournir le matériel original sur lequel la présente étude de cas est fondée. Je tiens également à remercier Ali Okhowat et Zubin Master pour les commentaires et révisions constructifs.

Conflit d'intérêts

Catherine Olivier est candidat au doctorat sous la supervision de Bryn Williams-Jones, éditeur en chef de *BioéthiqueOnline*.

Acknowledgements

Special acknowledgments go to Matthew Hunt and Lisa Schwartz for allowing me to work on this case study for the [Humanitarian Healthcare Ethics website](http://www.humanitarianhealthcareethics.org/) and for valuable comments. Thanks to the Humanitarian healthcare ethics group for providing the original material on which the present case study is based. I would also like to thank Ali Okhowat and Zubin Master for constructive comments and revisions.

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 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

1. World Health Organization. [Global Health Observatory: HIV/AIDS](#).
2. Larose, A., Moore, S., Harper, S., and Lynch, J. Global income-related inequalities in HIV testing. *J Public Health*. 2011, Volume 33, Number 3, pp 345-352
3. Basset, I.V. and Walensky, R.P. [Integrating HIV Screening into Routine Healthcare Resource-Limited Settings](#). *Clinical Infectious Disease*. 2010, Volume 50, Special issue S3, pp S77-S84

4. Obermeyer, C., Bott, S., Bayer, R., Desclaux, A., Baggaley, R., and the MATCH Study Group. [HIV testing and care in Burkina Faso, Kenya, Malawi and Uganda: ethics on the ground](#). BMC International Health and Human Rights. 2013, Volume 13, p 6
5. Gausset, Q., Mogensen, H.O., Yameogo, W.M.E., Berthé, A., and Konaté, B. The ambivalence of stigma and the double-edged sword of HIV/AIDS intervention in Burkina Faso. *Social Science & Medicine*. 2012, Volume 74, pp 1037-1044
6. Winskell, K., Hill, E., and Obyerodhyambo, O. Comparing HIV-related symbolic stigma in six African countries: social representations in young people's narratives. *Social Science & Medicine*. 2011, Volume 73, Number 8, pp 1257-1265
7. Pham H.N., Protsiv, M., Larsson, M., Ho, H.T., deVries, D.H., and Thorson, A. [Stigma, an important source of dissatisfaction of health workers in HIV response in Vietnam: a qualitative study](#). BMC Health Services Research. 2012, Volume12, p 474
8. Neema, S., Atuyambe, L.M., Otolok-Tanga, E., Twijukye, C., Kambugu, A., Thayer, L., and McAdam, K. [Using a clinic based creativity initiative to reduce HIV related stigma at the Infectious Diseases Institute, Mulago National Referral Hospital, Uganda](#). African Health Sciences. 2012, Volume 12, Number 2, pp 231-239
9. Li, L., Lin, C., Wu, Z., Lord, L., and Wu, S. To tell or not to tell: HIV disclosure to family members in China. *Developing World Bioethics*. 2008, Volume 8, Number 3, pp 235–241
10. Emllet, C.A. A Comparison of HIV Stigma and Disclosure Patterns Between Older and Younger Adults Living with HIV/AIDS. *AIDS Patient Care*. 2006, Volume 20, Number 5, pp 350-358
11. Florom-Smith, A.L., and De Santis, J.P. Exploring the Concept of HIV-Related Stigma. *Nursing Forum*. 2011, Volume 47, Number 3, pp 153-165
12. Ford, N., Zachariah, R., Mills, E. and Upshur, R. Defining the Limits of Emergency Humanitarian Action: Where, and How, to Draw the Line? *Public Health Ethics*. 2010, Volume 3, Number 1, pp 68-71
13. Mak, W.W.S., Poon, C.Y.M., Pun, L.Y.K., and Cheung, S.F. Meta-analysis of stigma and mental health. *Social Science & Medicine*. 2007, Volume 65, pp 245–261
14. Jacobi, C.A., Atanga, P.N.J.I., Bin, L.K., Mbome, V.N., Akam, W., Bogner, J.R., Kropf, S., and Malfertheiner, P. HIV/AIDS-related stigma felt by people living with HIV from Buea, Cameroon. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*. 2013, Volume 25, Number 2, pp 173-180
15. Young, S. and Zhu, Y. Behavioral Evidence of HIV Testing Stigma. *AIDS Behav*. 2012, Volume 16, Number 3, pp 736–740
16. Laurent, C. HIV testing in low- and middle-income countries: An urgent need for scaling up. *Journal of Public Health Policy*. 2013, Volume 34, pp 17–21

Suggested readings

1. Rennie, S. and Bennets, F. Desperately seeking targets: the ethics of routine HIV testing in low-income countries. *Bulletin of the World Health Organization*. 2006, Volume 84, pp 52-57
2. Angotti, N. Testing differences: the implementation of Western HIV testing norms in sub-Saharan Africa, *Culture, Health & Sexuality*. An International Journal for Research, Intervention and Care. 2012, Volume 14, Number 4, pp 365-378