

# Disclosure of HIV status and stigma in rural communities in Brazil: A conundrum for researchers

## ÉTUDE DE CAS / CASE STUDY

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### Résumé

La stigmatisation et la discrimination sont des conséquences fréquentes après la divulgation de statuts séropositifs; ces facteurs sont particulièrement problématiques dans les communautés rurales où « tout le monde connaît tout le monde ». Dans cette étude de cas, les chercheurs, qui mènent des études ethnographiques sur le terrain dans les zones reculées du Brésil, ont décidé de se faire passer pour des amis ou des parents des sujets de recherche vivant avec le VIH afin de protéger les sujets de la divulgation accidentelle de leur statut sérologique aux membres de leur communauté. Ces actes de « tromperie délibérée » soulèvent des questions sur l'honnêteté et l'intégrité dans la recherche et la façon d'équilibrer les enjeux de confidentialité dans la communication des résultats de recherche aux communautés et au grand public.

### Mots clés

VIH / SIDA, la stigmatisation, la communauté rurale, l'éthique, l'usurpation d'identité, la confidentialité, l'anonymat des sujets de recherche, la tromperie

### Summary

Stigmatization and discrimination are common consequences following disclosure of HIV serostatus; such factors are especially problematic in rural communities where “everyone knows everyone”. In this case study, researchers conducting ethnographic field studies in remote areas of Brazil decided to impersonate friends or relatives of research participants living with HIV as a means to protect participants from inadvertent disclosure of their serostatus to fellow community members. These acts of “wilful deception” raise issues about honesty and integrity in research, and how to balance issues of confidentiality with communicating research findings to communities and the broader public.

### Keywords

HIV/AIDS, stigma, rural community, ethics, impersonation, confidentiality, anonymity of research participants, deception

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Aucun déclaré

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### Conflicts of Interest

None to declare

## Introduction

### **Ethical issues concerning stigma and the disclosure of one's HIV status**

The ability to disclose one's HIV serostatus has important public health implications with regards to reducing HIV transmission and in intervention planning by local health authorities and policy-makers. For example, the necessity to conceal one's status due to fears of stigma may motivate people living with HIV/AIDS to avoid seeking health services or compromise their adherence to pharmacological treatments. The decision to disclose one's HIV/AIDS status is difficult and involves a complicated decision-making process where an individual must weigh many benefits<sup>1</sup> and risks of divulging their serostatus to others. Disclosing one's serostatus can make people vulnerable to financial hardship (e.g., denial of employment opportunities), scapegoating, threats to personal well-being, social exclusion, abuse and disruption in interpersonal and intimate relationships [1-4]. These stigma-related factors have an overarching negative impact on one's perception of "self" and feelings of self-worth [5]. While likely to raise challenges in most social contexts, disclosure of an individual's HIV status is especially difficult in small rural villages where there is little privacy and the risks of experiencing discrimination by fellow community members are significant.

Investigations focusing on populations with HIV thus need to be sensitive to the personal values and social contexts of people living with HIV/AIDS; one crucial value is that of upholding confidentiality. In addition to being essential for building trust between HIV-positive research participants and researchers, confidentiality is also indispensable for protecting study participants from the significant risks of harm noted above.

### **Presentation of the case**

This case study describes one phase of an HIV/AIDS research project conducted in rural areas of Brazil. The aim of this investigation was to understand the life experiences, beliefs and behaviours of people living with HIV/AIDS in poor rural areas of the Northern area of Minas Gerais State. Ethics approval for the research was obtained from the Research Ethics Board of the Federal University of São Paulo, located in a large urban centre of the country. In order to better understand the home and community environments, and the life experiences of people living with HIV/AIDS, ethnographic observations were conducted in fourteen rural communities (semi-structured in-depth interviews conducted in research participants' homes). At the time of the study, no published research was yet available concerning HIV in rural areas of Brazil.

### **Recruiting participants and obtaining informed consent**

In the initial phase of the study, potential research participants were approached at an HIV outpatient clinic during their medical consultations. Several participants were interviewed on more than one occasion in order to help establish trust with the researcher. Establishing trust was essential since these interviews centred on sensitive and deeply personal topics ranging from representations of HIV/AIDS illness, HIV/AIDS transmission, experiences of living with HIV/AIDS in a rural context, sexual practices, sexual orientation, and relationships within families and communities.

In order to conduct further ethnographic observations within small rural communities, several ethical issues needed to be carefully addressed before starting the fieldwork. During this first stage of the study, the researcher and participants discussed issues pertaining to non-disclosure of a participant's HIV status within their home communities. The interviewees agreed to participate in the ethnographic fieldwork under the condition that the researcher would not reveal their HIV status to other members

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<sup>1</sup> Benefits include, for example, avoiding the significant stress from concealing one's serostatus and treatment for HIV. Specific to rural areas of Brazil, upon disclosure of one's HIV status, financial support is available from health municipalities to receive treatment. As HIV treatment is only offered in readily accessible urban areas, health municipalities help cover expenses associated with obtaining treatment outside of rural communities (e.g., travel, shelter and food expenses).

of the community, and under the further condition that the researcher not mention anything that might connect the participants to HIV treatments at outpatient clinics. It became evident that procedures regarding how to protect the participants' confidentiality had to be developed. The resulting decision of the researcher was to use deceit in the form of impersonating friends or distant relatives of research participants in order to conceal a participant's serostatus.

### **Observations from the field**

Being small communities – some with fewer than 2000 residents – the arrival of a 'foreigner' did not go unnoticed. Residents would often approach the researcher to introduce themselves and ask what the researcher was doing in these isolated areas. In accordance with the agreement made during the process of obtaining consent, the researcher presented herself as a distant relative or friend visiting a fellow member of their community.

While many communities were unaware of the HIV status of research participants, in some cases the serostatus of participants was known before the debut of the field study. Several participants shared experiences of stigmatization within their communities following disclosure of their health condition. Indeed, under such circumstances it was common for the researcher to witness stigmatizing behaviour by others. One of the narratives described by a 29-year-old woman revealed how following her use of a public phone, people would immediately clean the phone with alcohol. In several other cases, HIV-positive members of the community were relegated to live in isolated areas outside the family home, often in derelict and substandard buildings with few amenities. One example was that of a female participant exiled to living in a small cabana away from her family; following the disclosure of her HIV status, a living space was built especially for her out of trees and a plastic roof covering. These examples illustrate common discriminatory practices and social rejection experienced by people living with HIV/AIDS. This unfortunate reality also demonstrates why it is critical to develop strategies to carefully – and discreetly – manage issues related to HIV/AIDS stigma when conducting research in the field, especially when investigations are conducted in rural communities.

### **Questions to consider**

1. Other than employing deceptive tactics, how can the wish of HIV-positive people for non-disclosure of their serostatus be protected during research in rural communities where discriminatory practices toward people living with HIV are known to occur?
2. Is it ethical to employ cover stories and impersonations within these communities as a strategy to protect research participants with stigmatizing health conditions? What challenges does this situation raise in terms of the ethical imperative to uphold transparency, integrity and truthfulness when conducting research?
3. Should the cover story procedure (or any other forms of deception used when conducting research) be described in the methodology section of research publications (e.g., explained as a mechanism used when conducting ethnographic observations within rural communities)?
4. How can the results and information obtained by the researcher be used to benefit the communities where the research was conducted? Describe more and less ethical means to present research findings to these communities in terms of the non-disclosure wishes of people living with HIV.
5. Is it sufficient to obtain research ethics approval from a research ethics board located in a major urban area (e.g., São Paulo) where they might not be able to fully assess the local cultural aspects of isolated rural communities, or should ethics approval be sought from a research ethics board in the region where the research will be conducted?
6. Is it ever justified for a community to know someone's HIV/AIDS status regardless of the individual's desire to keep their health condition confidential? Whose needs are more important to protect from a public health perspective: people living with HIV/AIDS, or the community at large?

7. A primary focus of this case study centres on issues of obtaining consent from individual research participants. A growing body of scholarship in public health ethics (see: [6]) questions whether *individual* consent is sufficient in certain contexts, namely in situations where a research project implicates vulnerable population groups, such as poor, isolated rural communities in the developing world. In such circumstances, some argue [6] that it is necessary to obtain *community* consent, for example from community leaders, to conduct research implicating such populations. How might the need for community consent compromise the research activities described herein and what would be an ideal strategy to obtain this consent?

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## Further Readings

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