

The Social Construction and Social Representation of HIV: An Anthropological Study

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Abstract

Background: The Acquired Immune Deficiency Syndrome (AIDS) is a public health concern that affects men, women, and children. The virus does not just infect individuals; it affects all of society. By fostering a reconstruction of daily life and of social spaces, it changes the day-to-day life of those infected with the virus. In this way, the disease acquires a set of meanings that emerge from incomplete and often unconscious ideas about the virus and about how HIV develops. As a result, AIDS is often depicted as a terrible monster capable of decimating entire societies. **Research Question:** This paper presents an analysis of the life styles, experiences, and conceptions of a group of nine men living with HIV infection in Mexico using anthropological techniques. **Methods:** In order to develop a rich understanding of how the virus manages to occupy our subject's very existence we used qualitative methods which put the emphasis on the voice of the patients living with the virus. Interviews were carried out to identify how men who are seropositive go about their daily interactions, how they understand their bodies, and how much they know about HIV, AIDS, and HAART. **Results:** The diagnosis of HIV infection transforms the reality and sense of

self for each individual. A pattern emerges: first, processing the meaning of the diagnosis, then assimilating it into one's sense of self, then facing the disease, and finally combatting it. How this pattern plays out is different for each person and depends to a great extent on their level of education, their social and economic status, as well as their customs and habits. Stigma plays an important role and specific suggestions are presented for improved management of HIV at both the individual and social level.

Introduction

The Acquired Immune Deficiency Syndrome (AIDS) is a public health concern that affects men, women, and children. While poverty - in its multiple dimensions - remains a factor driving the growth of the epidemic, increases in AIDS incidence continue to occur in countries with high socio-economic indicators. The UNAIDS 2015 annual report estimates that approximately 2 million people are infected with HIV each year. On the other hand, deaths from AIDS have begun to decline and UNAIDS has proposed ending the epidemic by 2030. (UNAIDS, 2015)

While AIDS affects men, women and children, it is those groups living within the multiple dimensions of poverty who are most vulnerable to the disease and who often lack access to healthcare. It is this population which is now driving the epidemic; they represent over 90% of those affected and live primarily in developing countries. As a result, AIDS is now considered a disease of poverty. (Herrera y Campero 2002)

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HIV continues to be a stigmatized disease that is not discussed openly. They are marginalized and only the lucky ones manage to get appropriate treatment, usually too late. This makes it more difficult to develop prevention campaigns. Those with the disease prefer to hide their diagnosis for fear of being ostracized or rejected by their community. It is only when they develop opportunistic infections – an indication of advanced disease – that they seek treatment.

The virus does not just infect individuals; it affects all of society. It fosters a restructuring of daily life and of social spaces that changes the day-to-day life of those infected with the virus. This restructuring affects both their internal and external world.

The disease acquires a set of meanings that emerge from incomplete and often unconscious ideas about the virus and about how HIV develops. As a result, it is often depicted as a terrible monster capable of decimating entire societies. Words like "pandemic" and "infection" suggest that with the slightest contact one can be contaminated. It is a disease that forces its victims to isolate themselves from the rest of society.

Research Concern

Using the principles of anthropology to guide our research, this paper presents an analysis of the life styles, experiences and conceptions of a group of nine men living with HIV infection.

Subject Selection

Our inclusion criteria were that subjects came from the Mexico City metropolitan area, had engaged in high risk sexual practices prior to their diagnosis, had experienced a variety of sexual preferences and practices, had been diagnosed at different times, were taking Highly Active Anti-Retroviral Treatment (HAART), and showed good compliance with treatment for a minimum of six months.

This study used social representations as way of developing a rich understanding of how the virus managed to occupy our subject's very

existence. It was both inside their bodies and also part of the world around them.

At the moment of diagnosis, the virus begins to dominate their lives. It becomes part of their sexual practices and their relations with friends and family. While one can try to hide it at work, the virus is present at all times and in all places.

Methods

The techniques of qualitative research were employed in this study. Qualitative methods put the emphasis on the voice of the patients who live with the virus on a day-to-day basis and have – after years of cohabitation – learned to contain and resist the virus. The necessary first step is to accept the virus as part of one's body. It is the "here" of one's body and the "now" of one's present existence. (Berger and Luckmann 1999) It is present when one is overwhelmed with pain and sadness, as well as when one has moments of pleasure and happiness. It is now part of one's body.

Research Questions

Interviews were carried out to address three key areas:

- How do men who are seropositive go about their daily interactions with social groups such as family, partners, friends, etc?
- How do they deal with their body on a daily basis in terms of nutrition, sports, use of alcohol, tobacco, and other drugs?
- How do they understand HIV and AIDS? How well are they informed about their illness and the medications they take to treat it? What is their understanding of HAART?

Results

The diagnosis of HIV infection transforms the reality and sense of self for each individual. A pattern emerges: first, processing the meaning of the diagnosis, then assimilating it into one's sense of self, then facing the disease, and finally combatting it. How this pattern plays out is different for each person and depends to a great extent on their level of education, their social and

economic status as well as their customs and habits. We found that this group of men received their diagnosis variously with surprise, indignation, acceptance, or rejection. They then went on to assimilate this new reality and recognize what it meant to be seropositive. This meant creating a new sense of self with a new understanding of what was normal. This process was influenced not only by the factors previously mentioned but also by the type of care and treatment they received in their health center.

Each subject had his own way of understanding the disease and how it expressed itself in his body; they developed their own sense of the way their body cohabited with the virus. The mere act of being a living being meant that they experienced physical sensations that they then incorporated into their understanding of what it meant to be a seropositive person. As Laín (1989) has pointed out, we live in a physical reality. Every one of us has a body with the awareness of being alive and existing. It is this conscious experience of our own bodies that allows us to “possess a world.” (Merleau Ponty 2000)

Individuals develop their own approach to assimilating the virus. By understanding how this process evolves in different settings we can describe how seropositive individuals reconstruct and modify their identity at the time of diagnosis. Sometimes the origin of the infection is obvious: the memory of when, where, and with whom emerges suddenly and refuses to go away. Others cannot remember a specific incident but are conscious of key moments and particular situations in which they may have been infected. Most had adopted some method to protect themselves from the virus.

Thus, their initial representation of the virus is related to the length of time they have been diagnosed, the information they have assimilated, and the sources of this information. For some, the doctor is the major source; for other, it is the support group.

Understanding the evolution of HIV in men who engaged in a variety of sexual practices - sometimes with men, sometimes with women -

was not a simple matter. It required us to look at differences within groups and to consider those factors - social and cultural - that made each subject an individual. We found that those who self-identified as exclusively heterosexual had far fewer partners over time than those who identified as homosexuals. Most men in both groups used no protection against STD's. When they did use protection, it was most commonly a condom.

Despite these difficulties, I decided to work with both groups. As noted by Anderson (2003) most of cases of HIV infection occur in mixed gender relationships. While the incidence of HIV infection among homosexuals has been stable, they are still the most stigmatized group and face rejection due to their sexual habits. (Orozco-Nuñez et. al. 2015)

My research also showed that the experience of living with the virus over several years allowed the subjects to accept responsibility for taking their medications. They realized that the virus was not a reason to become depressed or frustrated. They found support groups where they learned about the virus and the natural history of the disease. Participation in these groups had improved their wellbeing. They found emotional support, shared medications, and participated in workshops and lectures. I also noted that those who knew more about their disease were less likely to be co-infected. They generally kept their diagnosis a secret and felt their partners were responsible for protecting themselves (e.g. using a condom). In addition to their educational work, support groups provided a social network within their community that helped stabilize their health and wellbeing.

Only two subjects were open about their HIV diagnosis. The remaining subjects used various forms of self-isolation. Frequently, they avoided joining social networks where they might be forced to share their diagnosis.

Medical professionals play an important role in these processes. First off, they are the ones who make the diagnosis, a critical moment in education about the disease. We concur with Herrera *et. al.* (2008) that: "medical services vary greatly in quality. In places where the medical staff changes

frequently, services are usually of lesser quality. Medical personnel vary in their knowledge of the disease and their approach to treatment. Patient characteristics also play a role: how long the patient has been with the clinic, whether the patient is demanding or submissive, their ethnicity, social class, gender and sexual orientation." As noted by Kleinman and Benson (2004): "the sick patient must be realistic. but the doctor should feel a sense of personal engagement to his patients. Patients and doctors should unite to face the moral problems posed by illness and define their common approach." (Kleinman and Benson 2004:25)

All of these many factors influence how patients are accepted, cared for, treated, and followed when they are HIV infected. Some will take the diagnosis poorly; they become agitated, fearful and anxious. Such feelings cause some to avoid the physician. Others look upon physicians as the perpetrators of HIV stigma and rejection. Kang et. al. (2005) shows how these ideas can threaten the treatment protocols of medical professionals.

Any study of HIV must necessarily address the physical body. It is not simply the passive recipient of attributes and categorization. It is also an object whose value changes as its meaning evolves. It is the outward manifestation of our various "selves."

The diagnosis of seropositivity has ambiguous meanings for the body. An "unhealthy" body demands attention and care. It is also the place where sensations, behaviors and feelings are suppressed because of stigma. Finally, the body also evokes a need to be healthy and remain healthy. The body absorbs the virus into its very self. These contradictory impulses require the body to reinterpret itself as it experiences sickness. This new conception of the body is subject to the fact that we live in a *here* and a *now*. The body is a single entity whose properties can be negative, positive, or neutral. Both moral and aesthetic criteria govern how we structure our self.

An anthropological approach to HIV requires us to examine seropositive patients in their diversity, while taking into account the interaction

between the physical, the biological and the cultural in daily life. We must explore the belief systems of patients to understand the concerns, prejudices and fears that lead us to modify our perception of the body.

Our interviews uncovered that it was common for subjects to keep their diagnosis secret because of fears over stigma and rejection. People still consider HIV as a dangerous disease which is highly contagious. Even saying the name out loud can put someone at risk. This remains true despite the fact that the ways of contracting HIV are well known. Yet most people continue to label, reject, and marginalize all people with HIV infection.

Pharmaceutical advances have done much to reduce deaths due to opportunistic infections, but much work remains to be done. While HIV can be suppressed now with medications, the recent interest in bareback sex (sexual activity, usually penetrative, without condoms) reminds us of the need to develop new preventive strategies to block new infections and co-infections amongst populations engaging in high risk practices.

Each of our nine subjects approached their diagnosis of HIV seropositivity in a personal and individual manner. Their daily experiences lead to a new set of representations and actions. Their body became the receptacle of new understandings, experiences, habits and values.

Based on this research, the following recommendations can be made:

- The consistent use of condoms during all sexual activities must be promoted more vigorously. There is a huge gap between what our subjects knew about the correct use of condoms and what they actually did during sex.
- We need more workshops and courses that recognize and accept different sexual preferences without prejudice.
- We need more workshops, courses and talks on HIV in order to demystify its threat, and reduce the stigma, fear, and rejection that have developed because of wide-spread ignorance about the disease. These activities should be holistic (including information about diet and exercise) and should be addressed initially at the families of

those who are seropositive. These activities should also be integrated into official institutions to allow their greater diffusion in general society.

- We should encourage the creation of more support groups. Our subjects found that support groups offered spaces for discussion of issues that went beyond simply being seropositive. They became places where medications were bought, shared, or exchanged. More institutions of this nature should be created and supported with a focus on the seropositive and those with whom they share their diagnosis.

- Our subjects often referred to the advice given by medical specialists concerning diet and its importance. But few of them followed the advice they were given. It would be important to develop educational materials - flyers, posters, trifold - with detailed information on diet.

- Workshops and discussion groups should be held in local churches and with religious groups for the family members of those who are seropositive. These religious settings offer an important place for psychologists to participate.

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