



The Invisible Citizens' Revolution

HIV/AIDS and Citizenship in the LGBTI Community of Quito, Ecuador

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the invisible citizens' revolution

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Introduction

hiv/aids in the lgbti community in ecuador

- ❖ LGBTI population vulnerable to HIV/AIDS. High HIV prevalence within the LGBTI community in comparison to the general population, while only a small percentage of this group has access to HIV prevention, care, treatment and support services
- ❖ Not much data available on the experiences of PLWHA in the LGBTI community, especially not in English
- ❖ How do these populations experience and challenge the way they are treated and perceived by health care professionals, politicians, and larger society?

my research questions and objectives

- ❖ Expand insights regarding sociopolitical and medical experiences of LGBTI, to contribute to minimizing their vulnerability to discrimination, exclusion and HIV infection
- ❖ Deepen our understanding of the functions of citizenship and how its empowering abilities and its limitations directly impact the lives of LGBTI people living with HIV/AIDS in Quito

bridging the gaps objectives

- ❖ Improve quality of & access to HIV prevention, treatment, care and services
- ❖ Improve human rights of key populations
- ❖ Integrate specific services for key populations within general health system
- ❖ Strengthen capacity of civil society organizations that work with HIV and key populations
- ❖ Develop & strengthen a comprehensive approach on HIV & key populations by alliance partners



hiv/aids and Citizenship

- ❖ As vulnerable populations, PLWHA within the LGBTI community share a marginal position and stigmatizing experience because of their sexual orientation/gender identity and their HIV-status
- ❖ Biological citizenship: individuals come together on the basis of shared biological circumstances and use the clout of the group to demand, for example, that their rights are respected or their access to care or treatment is improved:
 - “The damaged biology of a population has become the grounds for membership and the basis for staking citizenship” (Petryna 2002: 5)
- ❖ In Ecuador, PLWHA’s claims relate to shared goals such as rupturing taboos and discriminatory values, extinguishing exclusion, and to have their rights to health care, work, education and a life free of discrimination guaranteed

the citizens' revolution

- ❖ Under president Correa, more democratic practices and transparency created new political openings and opportunities for a more powerful civil society
- ❖ Correa's Citizens' Revolution is a political, economic and social project in which democratic citizenship and citizen participation take up central roles
- ❖ Citizenship goes beyond the duty of the state to guarantee rights to all its constituents on a universal basis. Much importance is ascribed to the sociocultural aspect of being a full-fledged citizen, with all the recognition, inclusion and participation opportunities implied with it
- ❖ Potential for PLWHA, particularly those within the LGBTI community, to influence their own social and political position; they may be more vulnerable, they are also in a unique position to challenge current figurations of citizenship

Research questions

- ❖ How do people living with HIV/AIDS in the LGBTI community employ their biosocial circumstances to put forward resistant forms of citizenship and subsequently challenge barriers to treatment?
 - ❖ What are the Ecuadorian LGBTI community's experiences with stigma and exclusion, and do these affect their access to health and function as barriers to treatment?
 - ❖ Do LGBTI living with HIV/AIDS organize themselves to put up resistance and claim better lives?

Methods

10 weeks of fieldwork in Quito

- ❖ Individual experiences and the organizational work to cope with HIV/AIDS were studied
- ❖ Participant observation
 - ❖ Office of local Bridging the Gaps partner *Equidad*. Daily office dynamics, internal and external meetings, lobby activities, conferences and cultural events
 - ❖ Workshops with LGBTI and parents, PLWHA
 - ❖ Prevention and sexual education activities in venues frequented by LGBTI
 - ❖ Medical visits in public and private hospitals
- ❖ In-depth interviews
 - ❖ PLWHA in Quito's LGBTI community
 - ❖ Equidad Staff
 - ❖ Staff of other stakeholders, such as partner NGOs *Kimirina* and *La Coalición*

findings

- ❖ Stigma, discrimination and exclusion continue to impede HIV responses. Self-stigmatization another hindering factor
- ❖ The promise of full, inclusive citizenship for all of Ecuador's citizens regardless of sexual orientation, gender identity, or HIV status has not been fulfilled yet
- ❖ The Citizens' Revolution has not been a straightforward success in terms of more chances to influence policy making and bring about a true social transformation, but has given more opportunities to engage in a struggle over respectful and equal treatment and to fight stigma
- ❖ The silence and marginalization PLWHA endure make it difficult to enjoy a sense of community and to spread the prevention message, claim broader citizenship, and fight against discrimination
- ❖ Without going public PLWHA can only put up resistance in the doctor's office, this makes their efforts against discrimination fragmented

recommendations

Stigma & discrimination primary issues to target

- ❖ Advances towards fuller and more inclusive citizenship should be built upon by boosting state-civil society collaboration on adequately ensuring human rights. More intensive collaboration with Ombudsman and Ministry of Justice
- ❖ Sensitization training of health care professionals, policy makers, and educators
- ❖ HIV awareness and sexual education campaigns amongst risk and general populations. Dislodge HIV from promiscuity discourse, fight harmful conservative ideologies by stimulating dialogue in small settings
- ❖ Revamp prevention campaigns amongst risk populations
- ❖ More collaboration between organizations for PLWHA and LGBTI to prevent fragmentation
- ❖ Continue to emphasize agency of local NGOs, instead of implementing interventions from the top. This is a positive aspect of Bridging the Gaps, but there is room for improvement; assist local partners with monitoring and evaluation tools and, as always, more funding

questions & discussion