

Boricuas ACTing UP in New York and San Juan: Diasporic AIDS Activism, Colonialism, and Anthropology

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ABSTRACT: Following from the analysis of unstructured interviews conducted with members of the first AIDS Coalition to Unleash Power's (ACT UP!) New York contingent to visit Puerto Rico with expressly activist aims, this essay traces some linkages and disconnects between HIV/AIDS activism in New York City and San Juan, Puerto Rico. Reflecting on the use of ethnographic methods in dissertation research, this essay produces one account of some of the links between different communities struggling with the appearance and entrenchment of HIV/AIDS and some of the ways in which anthropology can engage with the untold or unaccounted for histories that inform this activism and the political frame of HIV/AIDS in San Juan today. This paper analyzes and engages with the configurations of power and responsibility that brought ACT UP! New York to San Juan and explores how ethnography may bring an historical focus to the communal and individual experience of activism in order to better see its effects and different manifestations in the present.

KEYWORDS: Puerto Rico; HIV/AIDS; ACT UP

Introduction

This essay draws together observations and reflections gathered from ethnographic research carried out among social justice activists during the years 2005-2007 in San Juan, Puerto Rico. It constitutes a preliminary analysis of fieldwork carried out among social justice organizations and community initiatives in the San Juan metropolitan area. This research included my participation in organizational meetings with different groups of people affected by HIV/AIDS, and individual interviews with people living with HIV/AIDS who participated in such organizational meetings and community-based organization initiatives. These interviews aimed at drawing an oral history of such activism, and of

the experiences and political commitments that led patients and their supporters to engage in public acts of social protest, demonstration, or reclamation. Data gathered from such participation and observation indicates that politically-active individuals depend heavily on activist networks and on their affective and social ties to other activists. The organizational labour and advocacy work of such networks has led to important social and governmental responses, including the availability of drug therapies and clinical trials for people infected with HIV and living on the island, and the adoption of the HIV/AIDS patient's Bill of Rights. Not all of the activists I interviewed and worked with were members of the AIDS Coalition

to Unleash Power (ACT UP!). Some were part of the Puerto Rico chapter established in the summer of 1990. A handful participated in the planning of the delegation as members of the Hispanic Caucus of the New York chapter of ACT UP!, mostly those who remained on the island after other members of the brigade returned to New York City. This paper discusses the role of that brigade in the evolution of HIV/AIDS activism on the island. It does not, however, follow a straightforwardly historical frame for telling a story about the rise and fall of the ACT UP! Puerto Rico chapter. Instead, I reflect thematically on some of the intersections between the theoretical, methodological, and ethnographic questions that this research engaged and emphasized.¹

In a wider context, this work is concerned with the ways in which Puerto Ricans are socio-politically reproduced as colonial subjects of the United States through representational, legal, and extra-legal strategies mobilized as part of the management of such contagious and pathologized bodies. This text is a part of my doctoral dissertation, where I analyze the current structure of governance and state organization in Puerto Rico as an unincorporated territory of the United States in terms of how this political relationship has influenced the ways that HIV and AIDS have spread and become entrenched among Puerto Ricans. I also analyze some of the ways that Puerto Ricans live with and respond to HIV and AIDS, not only as epidemics or bodily circumstances, but as socio-and bio-political issues. That is, I investigate HIV/AIDS in Puerto Rico as a composite site

where the elaboration of dominating and regulatory discourses over bodies and subjects certainly takes place, but also one where everyday people forge and traffic in critical and resistant knowledge production, and modes of social empowerment.

Following from reflections on unstructured interviews with Puerto Rican AIDS activists and with members of the ACT UP! New York contingent that visited Puerto Rico in the summer of 1990, this essay traces linkages and points out cleavages between HIV/AIDS activism in New York City and San Juan, Puerto Rico. It produces one account of some of the links evidenced by this 'visit' between Puerto Ricans living in the United States and those on the island, as both communities struggled with the appearance and entrenchment of HIV/AIDS. This paper also explores some of the ways in which anthropology can engage with the untold or unaccounted-for histories that inform activism around HIV/AIDS in San Juan and the Caribbean more broadly today. This paper analyses and engages with the configurations of power that brought the ACT UP! New York contingent to San Juan, reflects on the strategies used by the group to raise awareness of the growing AIDS crisis on the island, and examines the reported experiences of Puerto Rican AIDS activists struggling against negligent state and federal agencies for access to information and treatment. My analysis relies on my informants' own analyses of the difficulties implicated by such activism, and of the political meanings of HIV/AIDS in their lives. Finally, this essay provides some exploratory questions about how ethnography may serve to bring a historical focus to the communal and individual experiences of HIV/AIDS activists in the Puerto Rican diaspora and in the diasporized island, in order to better see the effects of those negotiations and confrontations with normative and state power, as well as their social and institutional manifestations in the present.

Historical Background

People infected with HIV living in Puerto Rico did not have access to pharmaceutical treatment or clinical protocols until the early 1990s. Many of those infected with HIV on the island during the early years of the pandemic were without recourse to

1 This paper was originally presented at the 2007 National Meeting of the Society for Applied Anthropology in Tampa, Florida as part of a double panel entitled: "Practice What You Teach: Activist Anthropology at the Sites of Cross-Talk and Cross-Fire." It is part of my doctoral dissertation under the title: Puerto Rican State Formations and HIV/AIDS. I would like to thank Drs. Anna Lorraine Anderson-Lazo and Ann Kingsolver for inviting me to participate in this panel discussion and for their help and encouragement with this essay. I have benefited from everyone who participated in the panel and the two anonymous reviewers for their comments. Thanks are also due to Drs. Edgar Rivera Colon for his incitement and to Neni Panourgia for her support. A special thanks to the activists who participated in this study.

medical treatment and suffered from extensive discrimination and stigmatization. All of the people I interviewed for this project who were in Puerto Rico during the mid to late 1980s and early 1990s reported that people infected with HIV faced profound isolation from their families and social networks, as panic over the contagion spread. Some doctors in local clinics and hospitals refused to examine or treat patients who presented with paradigmatic Auto Immune Deficiency Syndrome symptoms, such as ‘wasting’ and Kaposi’s sarcoma, and common opportunistic infections such as tuberculosis, candidiasis, and pneumocystis carinii pneumonia. The response from governmental institutions to this public health crisis was inadequate and very slow in coming. It was in no small part through the activities of ACT UP! New York’s summer 1990 Puerto Rico brigade, and especially through the subsequent consolidation of social justice organizations agitating for the rights of people living with HIV/AIDS, that the living conditions of HIV positive Puerto Ricans and those living with AIDS began to change.

This new AIDS-directed activism dovetailed with and had a profound influence over the fledgling gay and lesbian liberation movement that emerged contemporaneously with the deepening hold of the epidemic on Puerto Rican society. Although by the summer of 1990 island-based feminist and gender rights groups had already been working for years to address the crises brought about and exacerbated by the epidemic, the aggressive style of activism and public protest that ACT UP! New York’s brigade brought to Puerto Rico raised the stakes, and it provided visibility to the difficulties faced by HIV positive people. The resulting confrontations with state and institutional authorities empowered local activists (HIV negative and positive alike) and encouraged them to demand vociferously the adoption of measures for the protection of the civil and human rights of people living with HIV/AIDS, including their right to health care and access to treatment for HIV infection. These activists also stressed the general need for public programs aimed at the prevention of HIV transmission among high-risk groups. They also demanded that these prevention activities account systemically for the effects of social marginaliza-

tion and stigmatization. While this latter demand continues to this day mostly unmet, the activism of HIV positive people, along with their friends and loved ones, was crucial to the development of social service programs for people living with HIV/AIDS in Puerto Rico.

Through a cross-sectional analysis of the research conducted for this study, I have also tried to elucidate some of the different bases for activist engagements with HIV/AIDS in the Puerto Rican context. I draw from this analysis to argue that queer and feminist organizations in Puerto Rico were able to communicate to people in the US queer and Latino diasporas that the conditions of life for people with HIV on the island had become untenable, and that these trans-local communities organized on the basis of inter-sectional identities or responded to that call for assistance out of a sense of solidarity and shared struggle. These trans-local coalitions did not take place without a deep critical and collective consideration of their political and/or ideological implications. The activist strategies of ACT UP! members have had a profound impact on the strategies employed by AIDS activists. Social justice interventions such as the demand for compliance with legal safeguards that mandate patient representation within social service and state institutions, the public denunciation of corrupt government officials and of criminal administrators of state-funded social service organizations who stole millions of dollars intended for the provision of services to people with HIV/AIDS in San Juan, and the demand for access to current and new drug therapies, each engage many different bases for their particular forms of activist claims. These demands are not necessarily made on the bases of the gay liberation and empowerment framework that ACT UP! espoused, yet they demonstrate the ongoing legacy of ACT UP!’s protest ethics and aesthetics in Puerto Rico and in the Puerto Rican queer diaspora. This text also seeks to account for some of the disjunctures between these two related contexts, and the implications of such differences for inter-communal support and solidarity.

The impetus for this paper comes from a desire to situate the actions of ACT UP! New York’s Puerto Rico delegation and of the subsequent island chapter

within a set of political questions that were incumbent upon these activists to consider and negotiate. The significance of the different social contexts surrounding the New York and Puerto Rico epidemics was not lost on these ACT UP members, nor on those with whom they collaborated on the island before, during, and after the summer of 1990. In fact, all interviewees reported that the group questioned and debated extensively the appropriateness of the ACT UP! NY model for Puerto Rico, with the concern that social realities and conditions were so different that they would necessarily imply difficulties for the successful transferral of activist strategies espoused by the organization.

While these interventions and demonstrations had been largely successful in the United States as a way of making the epidemic visible and in terms of generating community empowerment, some ACT UP! New York members worried that their protest strategies would not translate effectively or usefully to activist groups on the island, because they relied on a radical performance of homosexuality and bodily entitlement. An awareness of the critical urgency of the situation for people living with HIV/AIDS on the island led these New York-based activists, many of whom had been born or raised on the island, or had lived there for part of their lives and were familiar with the political climate of political organizing there, to risk being perceived as culturally insensitive. They travelled to Puerto Rico knowing that they faced the possibility of community antagonism to their presence and their methods, and they did indeed encounter some local hostility, expressed mostly through the accusation that the group's activities were too extreme, or too loud, or too uncouth as to be socially respected or effective. Nevertheless, the brigade had a lasting effect not only on the AIDS policies adopted by the Puerto Rican government, but also on the social arena. A number of the activists who were part of that brigade relocated to Puerto Rico and decided to remain on the island and continue to be active as community representatives. Beyond these material effects, the development of such trans-local activist networks had a profound effect on the terms of public discourse about HIV/AIDS, and on other social activist networks, especially in terms of

the modes of expression and performative protest that the group engaged.

Methods

Five people directly involved in the creation of the ACT UP! Puerto Rico organization were interviewed for this essay, four men and one woman. All interviews were conducted in San Juan, Puerto Rico and were carried out in Spanish and some English. Through an initial interview with an HIV positive gay man, I connected with the four other interviewees, some of whom were people that I already knew through my personal and social networks. Each of these people who participated in ACT UP! protest and community organization activities provided a unique perspective on the events of 1990 and the ACT UP! NY brigade, and on the debates that it instantiated and re-capitulated. I conducted unstructured interviews with these activists, allowing our conversations about the history of the ACT UP! NY Puerto Rico delegation to travel the distance between their recollection of particular events, discussions, and persons, and their analyses of the group's composition, context, coordination, and strategies. These interviews illuminated the political concerns that pervaded activist strategies and networks across diasporic contexts. Those interviewed provided their views and opinions on the effectiveness of different activist strategies developed and adopted by various activist groupings, and shared their sense of what was accomplished, the limitations faced, and the ongoing effects of these groups and initiatives. Their analyses provide an anchor for thinking about the bio-political effects of U.S. political dominance in Puerto Rico and about HIV/AIDS as an epidemic whose social dimensions bring embodied subjections into sharp relief.

The events I refer to in this text are matters of public record, substantiated in newspapers of record and other media, where the names of activists are clearly stated and in many cases their photographs printed alongside. All five of the interviewees have been public figures, open about their HIV status or about their participation in AIDS activism, appearing often (to varying degrees) in the media as spokespeople for advocacy groups, health care initiatives, and social change organizations.

I have also drawn from and made use of the archives of the ACT UP! Oral History Project, an initiative of the New York Public Library System that collects video and audio recordings of statements given by people who were involved in the organization, transcribing and archiving them for public use. One of the informants I interviewed in Puerto Rico for this paper was interviewed for the ACT UP! Oral History Project, wherein he described his participation in ACT UP!, including his participation in the New York Latino Caucus and the Puerto Rico delegation.

The Latino Caucus and the Puerto Rico Delegation

Three of the five people interviewed for this study were living in New York City in 1990, where they participated in meetings of the ACT UP! New York chapter and were central to the creation of a Latino Caucus within the larger organism. These three are all Puerto Rican gay men who maintained strong social links to Puerto Rico despite having migrated to New York. In the case of at least one of these men, their residence in New York was the direct result of an HIV diagnosis, in the context of the dearth of case management, clinical treatment, or even appropriate symptom management for AIDS patients in Puerto Rico. All three were fundamental to ACT UP! New York's resolution to send a delegation of activists to San Juan, Puerto Rico during the summer of 1990, after working hard to convince the group's membership at large of the urgency of such an endeavour.

In ACT UP! New York meetings, especially within the Latino Caucus, activists discussed what they knew and what they had heard about the health situation of HIV positive people and people living with AIDS in Puerto Rico and demanded that the organization as a whole take decisive action. In the words of one Latino Caucus member, Moisés Agosto:

We started planning around those events that were going to happen during that whole summer. One of them was the secretary [of health Sullivan] going. The other was the National Commission hearings in Puerto Rico. The other was this gay pride time,

even though there was not a parade at that point. And there were other activities I can't remember. So we went. We organized ourselves, and we had to go there and organize people, because we could not fly all of ACT UP! to Puerto Rico. So what we decided was that the committee was going to go—some of us—and we were going to work to mobilize people. There were a lot of touchy issues related to me coming from there, knowing that having the Americans, or what is perceived as coming from the Americans, coming with some sort of political movement—even though it was related to health, it was political. To impose a point of view to those that were already doing some grassroots work—we had to be careful with that. I always think that is very important that, no matter how liberal you are, you cannot lose sight of that. And also, come on, growing up in a colony where you hate all these things that you have been imposed to have. So we went to Puerto Rico. It was quite a trip. [ACT UP! Oral History Project, New York Public Library System, NY]

Agosto's recollection of the debates around the appropriateness of the Puerto Rico delegation as a project that the ACT UP! members should sponsor and support, clearly demonstrates an anxiety about the colonial relationship between the US and Puerto Rico, and a desire to carry out careful activism that really took into serious consideration the politics of activism and the appropriateness of activist models to particular situations.

The Latino Caucus presented a proposal to the Organizing Committee for a delegation of about 40 people who would carry out a variety of prevention and education activities once in PR, including needle exchange, community meetings, protests, and demonstrations. After heated debates about whether this proposed activity was appropriate to the goals of ACT UP! NY and to the needs and desires of Puerto Rican community activists, the proposal was approved and plans set in motion for the trip. The delegation to Puerto Rico was funded solely by ACT UP! NY with private monies donated by wealthy members of the organization, as was the case with most ACT UP! initiatives. Joey Pons, who was one of the Latino Caucus members that travelled to the island remained in Puerto Rico after the other mem-

bers of the ACT UP! NY delegation had returned to NYC because he thought it irresponsible to open up the field of civil disobedience and aggressive AIDS activism in Puerto Rico without providing sustained support to the community members and activists who would then have to confront and contend with the effects of the demonstrations. The other two informants interviewed for this study, Fernando Sosa and Mayra Santos Febres, were living in San Juan, Puerto Rico at the time of the delegation's arrival there in July of 1990. They participated in the events that took place while the NY delegation was in town and they continued to work with the organization once ACT UP! Puerto Rico was established. Fernando Sosa, especially, was highly involved in the organization subsequently, organizing and participating in ACT UP! Puerto Rico events until the organization's dissolution in the mid to late 1990's.

Blood of What Nation?

ACT UP! employed innovative and often risky protest strategies, such as engaging in direct action and civil disobedience to interrupt the business-as-usual *laissez faire* attitude held towards sick and dying people infected with HIV, the carrying out of sex positive sex education among both out and closeted gay men, exchanging used hypodermic needles for new ones, in-your-face activism (such as the use of stage blood, die-ins, kiss-ins, and stage makeup worn on faces to make them look like skulls), and especially exploiting public fears through the rendering of the dangerous, contagious, and terrifying body of the infected (or presumed to be infected) person as a performative protest object. As David Gere (2004) has argued,

the generally accepted notion was that if high-risk blood were to pass through a break in your skin, it would kill you, slowly. The genius of this particular ACT UP! action, then, [the use of stage blood] was in transforming the prevalent signification of AIDS. By smearing this supposedly tainted blood all over themselves, the protesters were able to transmute it into a sign not of gay contagion but of government guilt. [65]

In every case where ACT UP! used stage blood, the effect was to confound and frighten the police operatives present at their demonstrations. While in

the US this actually resulted in massive arrests during predominantly peaceful protests (such as the one that took place in front of the FDA offices in Rockville, Maryland in 1988) because it was perceived that the activists were endangering public welfare, in Puerto Rico these strategies had the opposite effect. Police operatives present at the demonstrations were reportedly afraid to touch the stage-blood-smearing protesters and in large part for this reason did not arrest them, even when they interrupted mass at the upscale San Juan Cathedral, nor when they lay their bodies down as a group in front of the Governor's Mansion in Old San Juan.

These direct action strategies had not been seen in Puerto Rico before AIDS activists engaged them, with the exception of civil disobedience carried out in Vieques against the US Navy. They therefore had a large impact on social movements and social justice activists who observed the response of the media, the police, and the state to the group's demands. I argue here that ACT UP! NY/PR's legacy in Puerto Rico is vibrant and alive in the present, not only in the current activism of AIDS patients and advocates, but also evidenced in the performativity of protest bodies in other political arenas. No other group, however, has quite the same capacity as those living with HIV/AIDS to enact their bodies as sites of social terror, where the fear and ignorance of policy makers and people in powerful positions is made manifest *in situ*. The effect of this power is to demonstrate the link between fear and ignorance about HIV/AIDS and governmental inaction, neglect, and inadequate response to the epidemic. It is in this sense that ACT UP! depended on the performance of contagious embodiment to achieve social justice aims.

Successful as this strategy was in placing living bodies right at the site of prejudice and fear in order to both humanize and exploit them for political gain, it was not without consequences for those who engaged in it. Activist burn-out, discrimination due to public identification as an HIV positive person (even when this was not actually the case), and the social ostracizing of activists who had been publicly identified in this way were common. Interviewees also reported that many Puerto Ricans were uncomfortable with the strategies employed by ACT UP!

members and responded with a sense of embarrassment or regulatory anxiety about the public exposure that this protest movement represented.

Nevertheless, the gains achieved by AIDS activism in Puerto Rico are invaluable. Clinical trials, access to pharmaceutical therapy, complementary health services, case management, housing provisions, patient representation on policy boards and institutions, public education campaigns, and hospital and other social services for HIV/AIDS patients in Puerto Rico are all the direct result of AIDS activism. The social and political context in which these gains in visibility, access, and representation must be enacted and mobilized, however, has always and continuously undermined their effectiveness. And this is because it is a colonial context in which economic and social resources are severely limited by the unequal application of the US constitution to this island territory where governmental corruption abounds, and where the criminal negligence of patients and the mis-use of HIV/AIDS resources continue to be a serious impediment to the successful management of HIV/AIDS as a social problem.

By Way of Conclusion

In an extended interview with an activist with more than twenty years of protest and advocacy experience whom I will here call Manuel, he noted that an increase in recognition and awards for HIV activists often seems to coincide with their approaching death, and thus, he confided, he often becomes preoccupied with his own mortality when he receives awards, recognitions, honours, or requests for interviews, such as the one I conducted with him. Nevertheless, I conclude that employing ethnographic interviews with noted activists, whose lauded literary, activist, or social products now circulate transnationally, opens up yet another layer of historical inquiry regarding the structures of power that the Puerto Rican ACT UP! organization sought to transfigure. What these 'war' stories convey, when they are told again in conversations among activists committed to an ongoing process of reflection and change, is that such embodied and critical moments as the ACT UP! New York's needle exchange committee's field trip to the barrio known as La Perla, where they carried out the first

needle exchange to take place on the island, permanently transformed ways of knowing and acting on behalf of social justice aims for people living with HIV/AIDS, as well as ways of inhabiting diasporic activist terrains.

Recent activism in Puerto Rico continues to draw on the strategies of ACT UP! As mentioned by one activist during an interview, organizers knew that the importation of a US activist model to Puerto Rico wouldn't last, but also that the point was to spark local activism through the delegation's ground-setting work, and a community activism infrastructure, which put HIV/AIDS in the public eye and a face to the AIDS epidemic in Puerto Rico. The performance, as well as ongoing performativity, of these events, protests, and demonstrations pervades other areas of life. These new strategies of embodied deviance included recruitment in bars using pick-up techniques, as well as the events, protests, and demonstrations carried out by the delegation. The effects of these strategies run deep: the body of panic, its performativity of contagion; the visibility of the terrifying fluid. Hence, this essay is only the beginning of a reflection on how the retelling of the stories that explain the contexts in which these strategies emerged, raises for consideration various and multi-directional effects of the relationship between the ACT UP! organization of New York and that of Puerto Rico, including the production of new forms of protest and diasporic activism as such.

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