

INTRODUCTION

The Eye of Fátima

“My husband was a big drunk. We point to him as an example of how *not* to behave,” Fátima replied to my question concerning people in her support group who stop taking their HIV medications. Fátima was HIV positive and the president of her group, *Ajuda à Próxima* (Help Your Neighbor), the second “AIDS association” established in Cabo Delgado Province in 2006. The group was a recipient of project donations from the government in the form of farming implements, seeds for planting, a plot of land, several goats, and a chicken coop. Fátima’s husband, also HIV infected, had recently died. “He was on a drinking binge,” she told me. “[He would] leave home early, and come home late. He stopped [treatment] for twenty-seven days before he finally died last January. He had the human right to *not* take his pills, you know.” I frequently heard seemingly out-of-place “human rights” statements like this in Pemba. One person told me he had the human right for the government to buy him a house and give him a monthly stipend for being HIV positive. Another said he had the human right to divorce his wives, which he had done on seven separate occasions, each time marrying a younger woman and paying the appropriate bride price. This reflected a common belief that sex with a virgin could cure someone of HIV infection—and a unique view on the purpose of “rights talk.”

Fátima continued, “Now that he’s gone, I’m doing my own experiment.” I leaned forward a little. “My health is improving and my CD4 is normal,” she said, “and I don’t miss a single pill. Sex with my husband was reinfecting me! It made my viral load increase, and I felt sicker. Without our sex together, I’ve had no reinfection and am starting to feel better.” It took me a moment to realize that the experiment she referred to concerned chastity, and I didn’t challenge her conclusions. “But there are always problems, you know. The problem now is that these pills make me forget things all of the time.” She glanced down at her cell phone and keys resting on the glass table between us as if she was worried about them and then looked back up at me.

Patients often complained about medication side effects. Forgetfulness isn’t all that common but is probably preferable to other common problems, such as persistent fatigue or nausea. Seated with Fátima in the lobby of Hotel Cabo Delgado on comfortable chairs, it seemed we were far from her village, about twenty kilometers away. My interviews with others in her support group occurred on

wooden stools in their abandoned chicken coop, which was isolated enough to be a safe place to answer questions about HIV from an inquisitive white foreigner. The now-empty chicken coop, the missing goats, and the overgrown plot of land that produced no food were all evidence of failed support group projects, hardly morale boosters for patients who had hoped, as the promise went, to “generate” their own income.

I had heard a lot about Fátima. She was locally considered a great leader. Several members of her AIDS association told me she had saved their lives, taught them how important it was to take the pills, and encouraged them to have patience with their families and others in the community who “talked bad” about HIV and the people who had it. Fátima was in Pemba City (Cabo Delgado’s provincial capital) for a government-hosted training to educate support group leaders on the new “Law 12/2009,” which was related to the rights and responsibilities of people living with HIV and AIDS in Mozambique (República de Moçambique 2009). There had been many training courses for AIDS associations at that time in an effort to manage the burgeoning number of such groups in the country. When I first came to Pemba in 2007, there was one AIDS association in the province. Two years later, there were twelve officially registered with the government; several others were attempting to become registered.

From one perspective, the new law seemed well timed, coming along with government efforts to distribute treatment in more clinic facilities and locations than ever before. From another perspective, the law was just barely catching up. Article 4 of Law 12/2009 guaranteed the right to free treatment in the country, but antiretroviral medication (ARVs) had already become much more accessible over the past five or six years in places far from the capital city of Maputo—places like Pemba in the provinces. This was sped along through the “day hospitals” or HIV/AIDS-specific treatment facilities with their own pharmacies, health care staff, and waiting areas. Another component of Law 12/2009 required patients to comply with their treatment regimens. That stipulation may sound reasonable, but it was hardly enforceable given the complex factors associated with adherence to medication.

Just then, Fátima said something else unexpected: “You know, [HIV] patients go and fuck whoever. The association has a big problem with this—policing sex. You just can’t monitor these things; it’s too difficult.” On the table between us, her cell phone buzzed and she excused herself to take the call. After a quick discussion, she put it down again and said, “This man who keeps calling . . . he wanted to ‘cleansé’ me after they buried my husband. I was freed from this tradition because of my HIV status. Everybody knows about this, but this man, he still wants to try anyway.” Widow cleansing is practiced in parts of Africa (Kotanyi and Krings-Ney 2009). It involves sexual activity between one or more relatives of the dead man and the surviving wife in an effort to stake a claim and break

the spiritual bond or any remaining supernatural attachment between the dead man and his wife. “Normally, anyone who wanted to pay could have done this. There were many of them. I took some men to the hospital and did a [HIV] test for them so they would stop asking, but this one [on the phone], he won’t stop.” I asked no further questions about this. No other interview participants had mentioned widow cleansing, but then again, Fátima was not a typical interview participant. Completely comfortable and unreserved, she was also the largest Mozambican woman I had ever met, easily weighing more than 230 pounds—a desirable feature for many men. A decade ago HIV was known as “the thinning disease” in southern Africa. Treatment has certainly changed that classification. Not only do people generally retain their weight, but they often gain some (another side effect of the pills).

Her cell phone buzzed again, and she picked it up to type a message. “Now most people use condoms to do the cleansing or just let the sperm fall outside of the female,” she stated rather lackadaisically, distracted and staring at the phone screen. She locked eyes with me again. “Women are weaker than men, you know? Biologically, our CD4 is very undeveloped . . . We all suffer a lot. My husband’s CD4 was always lower than mine, but I had more symptoms. I never understood this.” The interview was almost over. “You should keep going with your reports. Tell them there in your country that we want a vaccine. The government has to find a cure so that our children don’t grow up with this virus.”

I thanked her and began to pack up my things when Fátima cast her gaze on a man who had just come up the stairs and was looking around the lobby. She said good-bye to me, got up, and went to greet him. This was the man who had been calling and texting her, the one who had wanted to “cleanse” her back in February. They started together down the stairs to leave the hotel, and I couldn’t help wondering if this was some sort of date. I noticed then she had left her keys and phone on the table. Her side effects must have kicked in again. I picked up the items, shouted her name, and ran down the stairs after her. As I handed them over, she smiled at me one last time before they went out onto the street.

Fátima’s husband, Marcos, had been a cofounder of Ajuda à Próxima the year prior, in 2008. They had started the support group together, facilitated meetings, and recruited new members. Trained in how to conduct home-based care for other people with HIV and a regular attendee at the day hospital, he was aware of what would happen to him when he ceased to take his pills. He and Fátima had come to the revelation about their condition together and saw rapid improvement in their health as they began their pharmaceutical treatment. Not even Fátima could explain why Marcos did what he did. It wasn’t for lack of food, the most common complaint patients have—Mieze is a farming village. It wasn’t poor clinic access—health care staff, aware of what he was doing, had even brought pills to his front door.

Marcos's decision didn't appear rational, but it was very intentional. He had *let* the virus kill him. Everyone, including Fátima, watched it happen, but they couldn't change his mind. With all the support available to him—the clinic, the group, and his own activist wife—what else could possibly have been done to save this man's life? Perhaps the prime suspect in his death was the *nipa* he drank constantly as his health slipped away—the clear, corn-based moonshine that is a cheap and available option in towns and villages all over Mozambique. In Caridade, the AIDS association with which I worked most closely, in Pemba City, I saw the same process unfold with numerous group leaders and members.

The *nipa*, however, points to a broader set of problems and social determinants of health that medicine can't adequately address—loss of hope, feelings of inadequacy, and internalized stigma and stress. The patient reflects these and embodies them, serving as a living representation, an example of society's challenges to care for itself. They are the “suffering body of the city” (Marcis and Inngs 2004: 453). It has become obvious that HIV treatment access—the main demand in the AIDS world of activism—is not sufficient for a total restoration of health for some patients. Biomedicine has its limits, and the dissemination of *some* kinds of moral messages needs to accompany it in order to move beyond them.

Morality and behavior are sensitive topics for anthropologists, who look upon the deployment of certain terms, images, and concepts with immense skepticism—particularly if they result in the molding of populations into efficient and adaptable subjects. We had to be careful about this, especially at first in the AIDS era. The imposition of risk categories—homosexual, Haitian, poor, African—threatened to displace needed attention to structural violence (Farmer 2006). There was a strong sense that people were getting blamed for being victims in the early days of the pandemic (Sabatier and Renee 1987). Anything less than treatment access—getting drugs into bodies—was viewed as woefully inadequate. Just prevention, just education, or just trainings were considered mere distractions.

Now that there is widespread consensus on the feasibility of scaling up treatment and providing universal coverage, it is clear that the support group, as its own intervention, has been left behind. Billions of dollars have been garnered for global health—almost U.S.\$230 billion since the year 2000 (IHME 2015)—much of it to help save lives from HIV. Compared with the rise of multinational institutions such as UNAIDS and initiatives such as the President's Emergency Plan for AIDS Relief (PEPFAR), entailing massive flows of personnel and technical assistance, it is troubling that a basic model for an effective HIV support group remains elusive.

The Mozambican AIDS associations are an interesting case study because they could have been more effective—state and donor involvement, and even

some AIDS activists, made them much less so. By the time AIDS associations were well established, in 2006 and 2007, antiretroviral therapy (ART) was increasingly available in Mozambican clinics. Patients did not join AIDS associations because it was a requirement or even because they feared death. Patients joined AIDS associations because they wanted, or had been promised, not just treatment but something *extra*—involvement in a project, a handout or payout, a job or a salary.

These associations were wondrously ambiguous. They were supposed to act a little like NGOs but also as spaces for emotional support and advice. They were supposed to apply for project funding but also be self-sustaining and collect membership dues and fees. They were supposed to create their own action plans, set goals, and adhere to fiscal budgets. Yet they also had to deliver on the demands of their partners, provide cheap labor, and answer to the needs of international NGOs or state programs, which in some cases relied upon them for data collection and service delivery. They were supposed to be open to anybody for membership but remain patient-centered and choose leaders to make decisions for them in a presumed atmosphere of egalitarianism.

The bureaucracy involved in running and participating in an AIDS association was reasonable for a secondary-school-educated Mozambican but just complicated enough to preclude subsistence farmers or those living in isolated, rural areas from getting involved and seeing any tangible results. Some members got paid; others did not. The interactions that occurred at the group level generated solidarity, along with greed and jealousy. Mozambican AIDS associations were not shining examples of either civil society or a therapeutic community, yet they contained the seeds of both. They were uniquely Mozambican, pieced together from components of a socialist past and nominally “of the people,” yet they also hearkened to the global community of HIV-positive patients that social scientists praised as naturally occurring, ubiquitous, and unstoppable.

Anthropologists studying HIV have begun to note the trouble with portraying civil society as utopian (Bähre 2007; Marsland 2012; Marcis 2012). Initial enthusiasm about patients coming together in protest against poor drug availability and perceived unfair government policies sparked a high level of interest in the concept of social solidarity. Famous examples of this emerged in the headlines and drew worldwide attention—the AIDS Coalition to Unleash Power (ACT UP) in the United States and the Treatment Action Campaign (TAC) in South Africa—that portrayed people with HIV as a united front, politically combative ideologues formed and shaped by overly bureaucratic institutions whose inaction was letting people die unnecessarily.

To describe the phenomenon, theorists latched onto the idea of *biosociality*, a concept that emphasizes patient mobilization and highlights the formation and activity of groups of people who identify with one another based on a common

genetic or biomedical illness. Patients latched onto the idea of human rights, positioning treatment as foundational to the physical and mental well-being of high numbers of people and thus covered under international treaties and agreements, of which most African nations are signatories. The struggle for HIV treatment, in this light, was a political one, a function of overcoming stigma and seeking inclusivity in health care and government programs.

The HIV support group was supposed to be a breeding ground for this approach. It was intended as a site for the stimulation of demand for care and the realization of benefits owed to affected persons on the part of states and institutions responsible for their protection and welfare. From this perspective, it is social recognition, from the state or similar authority, which mitigates powerlessness. It is social recognition that legitimates the person and his or her group, drawing attention to the issue and inviting concern, assistance, and intervention. Social science has labeled this *biological citizenship* (Rose and Novas 2005; Petryna 2013), the claiming of resources as recompense for a chronic illness through appealing to objective or expert evaluation in order to save lives or meet basic needs.

The results of this can manifest in a number of different ways. In a perfect world, it would level the playing field, allowing those most severely impacted to live as healthily as possible. It would point to the fruits of patient advocacy, overturning misconceptions and dispelling ignorance. It would also legitimate efforts at empowerment and facilitate fellowship among those affected. HIV-positive support groups were supposed to be the site for the practical application of activism, holding government accountable, taking charge of their lives, managing the impressions that others have about them, and offsetting stigma. In the popular imagination, these groups came to be recognized as something both old and new, civil society but with humanitarian features, a privileged kind of social movement, deserving of encouragement and even financial support—if they fulfilled the roles set out for them.

This book is primarily about the dysfunction of AIDS associations, the utility of rights-based demands, and calls for social transformation. Expectations about political AIDS activism first made patienthood cogent and then led to yet another example of “dysappearing bodies” (Imrie 2005: 98)—patients appear to disappear into the framework of national health systems, becoming voiceless. Once taken for granted and now highly visible everywhere, AIDS activists have now demanded themselves out of existence, barely able to claim special privileges anymore. AIDS activism, its short-term goals and its consumability and expendable nature, manifested itself in Mozambique as just another kind of “governmentality” (Lemke 2001; Ingram 2010; Foucault 2010), allowing for the imposition of certain morals, attitudes, and modes of living onto entire groups of people without their obvious and active consent. Gone, consequently, are the

grassroots “movements.” Still remaining are the multinational institutions and bureaucracies that rose up around them.

Now part of an antiquated system, the Mozambican AIDS associations never really achieved what they wanted, which was to participate in the HIV/AIDS “industry” and to be fully vested in the programs taking place around, for, and with them. They were provided a model with which to do this, and it did not suffice. The reasons are informed by the contours of history and the parameters of a global health industry that leaves no corner of the world untouched. During my time with Caridade¹—the group that took me in, allowing me to live and work with them as if I were a member myself—AIDS activism in Mozambique rose and fell, decidedly, in relation to the demands of the state. This challenges the idea that involvement in activism is liberating or counterhegemonic. While these beliefs are deep-seated and rooted in history, by better understanding Caridade and groups like it, a broader understanding of what activism “does” for people is possible, even in a low-income (or “less-developed”) state like Mozambique.

A DEVELOPING NATION?

Mozambique ranks 181 out of 187 on the United Nations Human Development Index (UNDP 2016), a low position shared with South Sudan. A country of twenty-eight million people, life expectancy is about fifty-five years. Little more than half of Mozambicans (59 percent) are literate, and there is a 69 percent primary-school dropout rate.² The population in multidimensional poverty³ is 70 percent and 90 percent of working Mozambicans make less than \$3.10 per day. According to the IMF (2014), agriculture provides a living for almost 80 percent of Mozambicans; efforts to reduce poverty were strong in the immediate postwar period (after 1992) but have since tapered off. Mozambique faces serious challenges regarding gender equality. Though parliament is composed of 40 percent women, maternal mortality is high and so is teenage pregnancy, ranking Mozambique 139 out of 159 countries on the Gender Inequality Index. Mozambique also has one of the worst global shortages of human resources for health, with only three doctors and twenty-one nurses per one hundred thousand inhabitants.

During the 1990s, after the end of protracted colonial and civil wars, Mozambique became a darling of the international development (and business) communities. An influx of NGOs, loans from the World Bank and IMF, and private sector investment saw the economy rise on average of 4.73 percent per capita per year. Recently, this has waned. The country is now facing the possibility of a debilitating debt crisis related to secretive bank loans the government took out amounting to more than one billion dollars (Quinn 2016). Once hailed as

a shining example of “Africa rising,” a counternarrative of development failure in Mozambique is quickly becoming well established (Brooks 2017).

A lack of optimism around HIV/AIDS may similarly be unfolding. Mozambique has the fifth largest HIV epidemic in sub-Saharan Africa, and prevalence recently rose from 11.5 percent in 2009 to 13.2 percent in 2015 (INS 2015). The difference is more pronounced in select provinces, including Cabo Delgado, where most of the research for this book occurred. From 2009 to 2015, prevalence in Cabo Delgado increased from 9.5 percent (one of the lowest in the country) to 13.8 percent (hovering around the national average). An estimated 1.5 million people in Mozambique are living with HIV, and modeled data suggests that 223 new infections and 108 deaths occur per day (UNAIDS 2016b). There is some good news—the number of HIV-positive persons on antiretroviral therapy (ART) has increased over the years. Almost a million adults (990,000) were estimated to be enrolled in treatment programs in the country in 2016, or roughly 65 percent, versus just 13 percent in 2009 (MISAU 2017a).

But these numbers eclipse some important undercurrents, including tension between humanitarian NGOs and better-financed global initiatives like PEP-FAR. In chapter 5, I will problematize these apparent treatment gains in several ways. Significant declines around HIV knowledge and awareness indicate the disease’s momentum is not decelerating. Continuing foreign aid and “intervention” is still needed, raising questions about national sovereignty and lingering dependence.

Undoubtedly, one of Mozambique’s most serious problems is how members of the ruling party benefit disproportionately from development aid when compared to the general population (Cunguara and Hanlon 2012). Though Mozambique is nominally democratic and held up as an international success story, big projects backed by foreign investors play questionable key roles in relationships and national improvement schemes. The openness to global capitalism that the country displays is anchored in industry (Gisselquist, Pérez Niño, and Le Billion 2014) and partnership with China (Alden and Chichava 2014) in ways that are environmentally harmful and do not lift the masses out of poverty. Power is concentrated in the hands of an elite few, allowing Mozambique to create hundreds of millionaires at a rate that rivals that of any other African country. All this has occurred despite the nation’s failure to meet any of the Millennium Development Goals (Brooks 2017). In chapter 2, I will discuss in depth Mozambique’s history—the wars and now privatization—and how this dovetails with the potential of a free and fair civil society in the form of the AIDS associations and the HIV-positive persons who formerly comprised them.



FIGURE I.1. Map of Mozambique (Pemba shown)

CHAPTER OUTLINE

In chapter 1, “Studying HIV and HIV-Positive People,” I provide an overview of HIV/AIDS from an anthropological perspective and discuss the methods used to collect my data and write this ethnography. Despite humanity’s best efforts, the virus remains a sustained pandemic and a threat that transcends conventional biomedical thought, imposing itself on our social worlds and marking the recent era of globalization. Since its “discovery” in the 1980s, HIV has taken many lives as well as the time and resources of researchers and charities attempting to prevent and treat it. An important aspect of the global response to HIV involved civil society reactions. People with AIDS (PWAs), as a social category, emerged from identity politics, with the earliest examples of activism entrenched in gay rights and demands for medical equality and quicker progress.

By the time AIDS activism exploded in southern Africa, coalescing famously in the Treatment Action Campaign (TAC), social scientists had already helped implode misleading risk categories—like homosexual or Haitian—and HIV was widely recognized as a social justice issue. The figure of the AIDS activist was powerful and inspiring, paving the way for greater treatment access, especially on the African continent. Though AIDS activism is now in decline—an effect of its perceived strength and momentum—the need for resilient support groups remains, especially in places like Mozambique.

Chapter 2, “‘Movements’ of the Past: Mozambique, Caridade, and Treatment in Africa,” discusses how HIV came to be an important concern to the Mozambican government and how AIDS associations became part of the response. Not long ago, international health experts urged caution in administering HIV treatment on the continent. Treatment in the public sector was withheld from patients in this part of the world, out of fear that locals would be unable to comply with complex pharmaceutical regimens. As AIDS activists carried out protests and NGOs implemented pilot projects, hesitation to treat Africans was waylaid.

Eventually, HIV treatment access was placed squarely on the agendas of global health initiatives and NGOs alike. Interest grew for supporting and even creating such groups to serve as the community face of HIV and encourage others to begin treatment. In chapter 2, I introduce Caridade, a support group for HIV patients that, when we first met, was just starting out in Pemba City. Medical NGOs and the government were keen to partner with Caridade, providing funding, office space, and other resources. Ideally, Caridade would flourish like other AIDS activist groups before it. But in Mozambique, relations between the state and civil society are fraught with tension. A history of centralized power in this postcommunist country makes voluntary associations between and among citizens difficult to take hold and evolve.

Chapter 3, “AIDS Associations in Cabo Delgado Province,” highlights the institutional and organizational features of Mozambican AIDS activism. Pemba City’s first HIV/AIDS support group, Caridade, is located in the heart of its busiest neighborhood. The office functions as a kind of drop-in center for people seeking help with an HIV diagnosis, and the group grew quickly in influence and reputation. Initially funded by a single NGO, other partners began to take notice and employ Caridade leaders and members in their community health projects. There was some pressure on the group to conform to outside expectations in terms of collecting and reporting data, adhering to financial policies and requirements, and adapting or modifying the group’s goals and objectives.

Delving into everyday life with the group revealed new partnerships and funding to be a grand source of division and conflict. Meetings could be difficult, especially when the group no longer seemed to provide support to one another

or those who rely on it for help. Amid nostalgic talk of Caridade's glory days, new HIV support groups began to form and splinter off, especially to take advantage of new donor money available for AIDS civil society. The state response to this growing civil society amounted to an attempt at control and standardization. Policies and procedures were instituted for such groups to register for formal status. In the swirl of trainings and workshops designed to capacitate civil society, the activities of groups were diverted and redirected. Paradoxically, this unfortunate outcome served as justification for greater state and NGO involvement, as civil society appeared to need help because it functioned less well than expected.

Chapter 4, "Challenges to HIV/AIDS Activism in the 'Subuniverse' of Cabo Delgado," highlights the community-oriented features of AIDS activism. Most publicity on and about AIDS activists is generated from urban or cosmopolitan settings. But in northern Mozambique, the most common type of activist was not particularly well educated or politically oriented. Patient-activists in isolated areas seek different kinds of resources and benefits; their aesthetic tastes and practical needs are not the same as those in larger towns and cities. Patient-activists described here occupied a unique existence, a "subuniverse" of the activist dimension. They related to one another and to those around them in ways that did not contribute to the preferred narrative embraced and espoused by mainstream, urban, globally aware AIDS activists.

As a result, the challenges faced here went undisclosed and were poorly acknowledged. HIV patients continued to face problems that in other settings may have been dealt with more comprehensively. Due to stigma, some were afraid to live openly and did not discuss the virus with others. Due to poor education, myths and opinions about HIV and its transmission circulated unimpeded and remained poorly addressed. Programs staffed and run by people with HIV did not function independently and relied heavily on state and NGO technical assistance. Alcoholism was rampant yet not discussed, and many patients dropped out or could not comply with treatment programs. Despite lengthy and sustained attention to the medical needs of HIV patient and activists, a sound model for addressing basic emotional and psychological concerns remained elusive.

Chapter 5, "the (Dis)integration of the Day Hospitals," highlights the political dimensions of HIV activism in Mozambique. The nationwide closure of "day hospitals," or AIDS clinics, resulted in downgraded services, drug stockouts, and diminished treatment access. Activists responded with organized street protests and by picketing government offices. Their anger was directed toward the country's minister of health, who claimed the facilities were wasteful, unnecessary, and unsustainable. While the protests pitted patients against their own government, the day hospital closures did not happen in a vacuum. Similar changes were occurring in other developing countries geared toward integrating disease-specific services into national health systems. Evaluated against this backdrop,

the traditional tactic of AIDS activists—to enact localized protests—had no effect. Their primary demands, to provide treatment for all, were already adopted by the wider international community, undermining the activist cause and dispersing the power and clarity of the patient voice.

The AIDS activists' mistake was focusing too heavily on medicine and pills as opposed to tightly knit communities and associations. Chapter 5 exposes the tension and debate around "health systems strengthening," identifying as the winners not civil society but political and governmental elites. Close examination of the AIDS activist community in Mozambique, after health systems strengthening, reveals a loss of momentum, intense competition and careerism, and an accompanying deflation of purpose and vision. Having already degenerated to the level of "slacktivism" through half-hearted advocacy and minimal support for ordinary HIV patients, the efficacy and authenticity of AIDS activism in Mozambique appears to have come to an end.

The final chapter, "Biosocial Governmentality," points out that activism's effects on ordinary support groups were much less empowering than imagined. The theoretical concept of biosociality—a shared social consciousness based on a disease diagnosis—has brought attention to patient groups, but political involvement made them a target for the market and paved the way for dissolution. I discuss how Caridade fizzled out and unraveled, becoming a source of prestige and income for just a few of its more prominent members. HIV patient groups in Africa qualified as a site for experimentation in the world of global health. What should have been a thriving point of contact bridging the lay-expert divide instead became a source of cheap NGO labor and the logical place for gauging potential receptivity to expand pharmaceutical markets in developing nations.

Activism, by trafficking in the same language and currency as the institutions it claims to challenge—demands, recognition, and power—is just as capable of shaping mood and desire as any other art of governance, stripping patient groups of their diversity and compromising alternative models. Considering a greater variety of sources as examples of biosociality, researchers can help fix this problem. High-level donors and funders still call for greater patient involvement. There is still a need for patient groups to improve adherence and inspire hope for people at risk of being lost to the system. AIDS activism, perhaps in a different, more practical and accessible form, may have an additional role to play in the future.