**Aids, Activism and Altruism[[1]](#footnote-1)**

* Silke Roth, *University of Southampton*

Review essay, accepted for publication in *Sociology*, 23 January 2018

Benita Roth

**The Life and Death of ACT UP/LA: Anti-AIDS Activism in Los Angeles from the 1980s to the 2000s**

Cambridge: Cambridge University Press, 2017, £ 49.99 Hardback, £ 21.99 Paperback, (ISBN: 9781107106314), 206 pages.

Ann Swidler and Susan Cotts Watkins

**A Fraught Embrace: The Romance and Reality of AIDS Altruism in Africa**

Princeton and Oxford: Princeton University Press, 2017, £27.95, (ISBN: 97806911391173924), 304 pages.

Sara de Jong

**Complicit Sisters: Gender and Women’s Issues across North-South Divides**

New York: Oxford University Press, 2017, £ 56, (ISBN: 9780190626563), 240 pages.

*2999 words*

*A global problem*

The 21st International AIDS conference in Durban, South Africa in 2016 is the most complex meeting I have ever attended. The world’s largest conference on any global health issue brought together a wide range of actors and constituencies including academics, activists, governmental, non- and inter-governmental organizations, community organisations and faith groups, the pharma industry and celebrities. During the plenaries, where the latest scientific findings, governments’ promises and celebrities’ uplifting or critical messages were shared, a group of sex workers counted the minutes during which sex work was not mentioned. Whereas the highest proportion of participants came – unsurprisingly – from the Global North (in particular the US and the UK), sub-Saharan countries (in particular South Africa and Kenya) were strongly represented. Even though much scientific progress has been made in the past thirty years, questions about meaningful interventions and the resources needed for making necessary and affordable treatment available remain. Three recent books take up the complex issues that are presented by the AIDS epidemic, the AIDs (and aid) industry and activism in insightful ways. Moreover, these studies are of great interest for everyone concerned with activism, altruism, intersectionality and North-South encounters.

*AIDS Activism in the 1980s and 1990s*

The emerging AIDS crisis of the 1980s might have shaped sexual relations just as significantly as the sexual revolution of the sixties and seventies. Only a few decades after the de-criminalisation of homosexuality in many Western countries, the emerging AIDS crisis in its early stages was most visible among Western gay communities. However, as became clear quite quickly the virus affected gay and straight men and women from different class backgrounds and racial-ethnic groups in the Global North and the Global South. The decriminalization of homosexuality and the availability of the contraceptives, in particular the pill, liberalized sexual relations for gay, straight and bi-sexual women and men. The AIDS crisis led to new forms of discrimination and to education advocating behavioural change to prevent the sexual transmission of the virus.

The AIDS crisis also sparked committed, creative, and complex forms of activism bringing together constituencies from different backgrounds. The forms of activism include service provision, advocacy and direct action seeking media attention and putting pressure on local, national and international governments to devote more resources for the prevention and treatment of HIV and AIDS. Scholars of social movements know that complex issues require compromises that can lead to conflicts within activist communities. The complex history and structure of ACT UP/LA, which reflects compromises and conflicts, is analysed with great clarity in *The Life and Death of ACT UP/LA: Anti-AIDS Activism in Los Angeles from the 1980s to the 2000s* by Benita Roth.

The AIDS Coalition to Unleash Power/New York (ACT UP/NY) started in May 1987 as a direct action protest group. It sparked the formation of over hundred ACT UP groups around the world. In December 1987, ACT UP/Los Angeles (LA) formed in West Hollywood, a diverse but segregated metro-scape characterized by prior LGBT activism. Located between Hollywood studios and affluent Beverly Hills the mostly white neighbourhood was home to a mix of Jewish refugees from Europe, Russians, Ukrainians, hippies and hipsters. Unlike New York and San Francisco, in the more spread-out neighbourhoods of LA, the gay and lesbian community was less visible and their experience thus more alike to the rest of the US. Benita Roth’s study of ACT UP/LA thus supplements the existing studies of ACT UP which tended to focus on ACT UP/NY.

ACT UP/LA always went beyond representing only the needs and interests of white gays and lesbians. Roth describes the multiple projects at local and national levels and discusses what she calls the intersectional crises of the coalition. ACT UP/LA brought together a diverse group of people ranging from activists from the Lavender Left, a gay and lesbian socialist group and AIDS service workers involved in the AIDS Hospice Foundation (AHF). Within the group, there were tensions between those who more narrowly wanted to fight for making antiretroviral drugs available to those who urgently needed them and a broader demand for adequate healthcare paying attention to the most vulnerable groups including drug users, prisoners, prostitutes, poor and people of colour. Benita Roth’s account of the Life and Death of ACT UP/LA makes fascinating reading for everyone who is interested in the challenges of organizing heterogeneous constituencies.

Roth describes ACT UP/LA as a feminist-friendly organization, but notes that women tended to be marginalised and therefore early on formed a Women’s Caucus. This development inadvertently led to a compartmentalization – making women responsible for women’s issues rather than mainstreaming gender, i.e. highlighting that research on the treatment and prevention of AIDS needs to take gender differences into account rather than focusing research on men’s health only or focusing on women only as mothers or men’s sexual partners passing on the virus.

ACT UP/LA staged a number of successful protests and engaged in a variety of actions serving different groups affected by AIDS: for example, it achieved the opening of an AIDS ward, carried out a project testing needle exchange, and demanded improving the situation of women prisoners. Nevertheless, the strain of a variety of intersectional crises, a lack of success, and the death and burnout of leaders led to the slow death of ACT-UP/LA between 1992 and 1997 when the account of the organization was finally closed. ACT UP/LA emphasized direct action and even refused available funding in order to stick to its values. This distinguishes ACTUP/LA from action groups which made compromises and became partners of the pharmaceutical industry or governmental entities.

Roth provides a nuanced account of a significant organization that should be of interest to every one interested in gay and lesbian studies, health activism and gender studies. In addition, she makes significant contributions to social movement scholarship more generally. She highlights the importance of place for activist communities, engages with the challenges of coalition-work employing an intersectional perspective, and addresses the relationship between different types of activism. Activists varied in their view on the benefits and appropriateness of insider and outsider activism. Some of them carried out service work, advocacy and direct action simultaneously, others successively. Roth’s analysis makes clear that ACT UP/LA had long-lasting impact, not least on the biographies of those who survived and continued their activism in a variety of public, private and third sector organisations.

*The AIDS Industry – Behemoths, Butterflies and Brokers*

In contrast to direct action groups such as ACTUP/LA, the AIDS industry comprises vast sums of funding and provides many job opportunities. It is estimated that in 2016, US$ 19.1 billion were made available for the global HIV response in low and middle-income countries.1) These sums are provided – and spent – by donors including multi- and bilateral aid organisations, governmental and non-governmental organisations, international foundations and academic institutions, contractors and faith-based organisations. In their book *A Fraught Embrace: The Romance and Reality of AIDS Altruism in Africa* Ann Swidler and Susan Cotts Watkins refer to this group of donors as ‘behemoths’ which they juxtapose with ‘butterfly’ altruists: individuals and small informal groups driven by the urge to provide help usually supporting a village, school or orphanage. What behemoth and butterfly altruists share is their dependence on brokers who create the connection to villagers. The aid chain between head offices of the behemoths and the village level provides multiple, but precarious job opportunities.

Swidler and Watkins compare the relationship between altruists and brokers to a romance which is characterized by hope, dreams, and disappointment. The authors recognize the transformation of self and others as the essence of romance: donors dream of protecting AIDS affected communities by transforming them and this dream is reciprocated by the brokers. These brokers serve as guides and cultural interpreters, translate the policies of international AIDS organisations into national policy strategies, process funding proposals, monitoring and evaluation reports, and implement donor dreams on the ground. They comprise cosmopolitan, national, district and interstitial elites (volunteers in villages). These groups vary in education – ranging from post-graduate degrees obtained at international and national universities, to secondary school. Depending on their educational credentials, they are much closer to the international donor community than to the villagers. In fact, interstitial elites who are closest to the beneficiaries of aid interventions tend to be unpaid.

Swidler and Watkins make a convincing case for paying more attention to the role of brokers in aid encounters which so far have been largely ignored. Except for the interstitial elites who work unpaid in the villages in the hope of accessing education and network opportunities, the work of brokers is mostly carried out in offices where reports are created and processed, including occasional field visits. The jobs of the brokers might be better paid than in the public sector, but they are also more precarious, dependent on the latest strategy promoted in the AIDS business. Though the buzzwords of the aid sector (empowerment, reliance etc.) are changing, the emphasis of the AIDS industry (and much development) lies on training. Swidler and Watkins explain the donor preference for training (rather than providing material support) with the fact that it is cheap and ‘sustainable’, i.e. the trained villagers are expected to spread newly learned practices and knowledge.

Swidler and Watkins are highly skeptical whether the training teaches villagers anything new and useful and whether it actually contributes to the treatment and prevention of HIV and AIDS. Moreover, they note that the efforts to ‘fight stigma’ and the focus on orphans might even be counter-productive if not harmful. They contrast donors’ and brokers’ view of the empowerment of sex workers and the role of harmful cultural practices. They argue that in order to assess the impact of donor interventions rigorous longitudinal studies and randomised control trials are needed. However, neither donors, nor brokers are interested in learning that their efforts have little impact as this would undermine the AIDS industry and the jobs that it is creating at various levels of the aid chain. In fact, Swidler and Watkins suggest that by providing material support the amateur altruists might make a bigger impact on villagers’ lives than the professional aid system.

They focus on Malawi, one of the poorest countries of the world, a donor darling due to its high prevalence HIV+, the fact that it is very rural, small and peaceful and that it allows international agencies and altruists to work unconstrained. Swidler and Watkins acknowledge that Malawi is not archetypical. Nevertheless, they refer to Africa instead of Malawi in the introductory and concluding chapters of the book rather than acknowledging the diversity of African societies (and their urban areas). For example, Fassin (2007) brilliantly analyses the initial rejection of the Western epidemiological model and associated AIDS prevention and treatment by South Africa’s president Mbeki on the background of colonialism and apartheid. However, Swidler and Watkins’ perceptive analysis of the role of brokers makes an outstanding contribution to the understanding of aid encounters of other African and developing countries, not just in the context of the treatment and prevention of AIDS.In fact, it very nicely complements Autesserre’s (2014) analysis of the practices, habitus and narratives of international interveners in peacebuilding efforts. Both, the study of the AIDS industry and ‘Peaceland’ are relevant for the analysis of North-South encounters in development, humanitarianism and human rights work.

*Global Sisterhood?*

Women’s empowerment plays an important role in the AIDS industry and development and humanitarianism more broadly. Moreover, many aid workers are women. AIDS is rarely mentioned in de Jong’s book *Complicit Sisters: Gender and Women’s Issues across North-South Divides*, but as Swidler and Watkins note, HIV and AIDS prevention and treatment has been incorporated in the portfolios of aid organizations large and small. The women portrayed in de Jong’s study worked on reproductive issues, health, development, peace and trade, political leadership and participation, sex work and migration. Three groups of women are introduced: women working for international organisations with offices in Geneva and Brussels, women working in other European capitals engaged in international work, and women in European cities who work with women who migrated to the Global North.

Like the altruists discussed by Swidler and Watkins, the women interviewed by Sara de Jong want to ‘do good’ by supporting women in or from the global South. De Jong considers them ‘complicit sisters’ because their “normative engagement with other women across North-South divides is itself embedded in the inequalities and power relations they seek to address” (p. 1). Sara de Jong’s study of women working in international, national and local projects links the previously discussed books in multiple ways. De Jong’s study bridges the ‘North-South’ divide by looking simultaneously at activists in the Global North who are working with migrants and those working for organisations that focus on women in the Global South. These linkages are quite self-evident for the activists working in European women’s networks. However, these connections are rarely noted in the academic literature that usually focusses either on migration or on development. Also, the author combines a discussion of the international women’s movement with an analysis of the aid system. Finally, de Jong skilfully integrates feminist, postcolonial and development critiques and employs an intersectional perspective on activism and altruism.

De Jong contextualises the work of the women in the history of transnational feminism and international development. This backdrop is important in order to distinguish between different generations of women who vary in their feminist views and work trajectories. De Jong analyses women’s self-understanding and sense of responsibility and notes that many overlook how privilege and marginalization are related. It is therefore not surprising that she notes that the women fail to question power imbalances between themselves and their local partners. In this respect, de Jong study complements Swidler and Watkins. Even more, it deepens the analysis of encounters in the aid chain by explicitly addressing power differences. De Jong adds a further dimension to the analysis of the romance between altruists and brokers by exploring how feminist aid workers invoke notions of sisterhood. She identifies four interdependent building blocks for creating real – rather than projected – solidarity which involve: an intersectional perspective on inequality that acknowledges that women in all regions of the world experience structural inequalities; drawing on experiences of marginality without generalizing any one experience; recognizing that identity, position and status are shifting; and that solidarity is a process. Such efforts could be the basis for overcoming colonialized logics and racialized cultural expressions that underpin the desire for Otherness and ‘civilising’ interventions. It is important to note that de Jong observes these postcolonial articulations of Othering not just in the international development programmes, but also in the projects for migrants in the Global North. Her combined interest in development and migration is highly original, much needed and relevant for a wide range of disciplines including gender, post-colonial, development and migration studies. It also links the previously discussed studies that look at these regions separately.

*Longitudinal qualitative data and positionality*

Roth’s study draws on a remarkable richness and depth of data. She combines ethnographic data collected in the early nineties with retrospective interviews and archival data. Roth is thus able to combine a multitude of perspectives as she took part in meetings and protests of ACT UP/LA and is able to contrast the recollections of founders and members of the organization with her own experiences and field notes as well as with archival data. Swidler and Watkins also draw on remarkably rich and complex data that they collected over the course of roughly twenty years. Their data includes “motel ethnography” (p. 16) conducted during trainings and workshops, 147 interviews with donors, brokers, civil servants, and expatriate staff, gray literature, systematic survey data collected between 1998 and 2010, and 1200 diaries written by local ethnographers between 1998 and the present.

Such a longitudinal qualitative studies are rare and especially in the current funding regime that focuses on research priorities and predictably impact unlikely to be encouraged. Whereas Roth’s data allow her to capture change over time, the description of the aid encounters by Swidler and Watkins appears remarkably static and ahistorical. Compared to these studies, the data on which de Jong draws is narrower: her study is based on twenty-one semi-structured interviews that were carried out between 2007 and 2008. However, these interviews yield rich data which de Jong analysed with great skill and depth. Roth and de Jong not only share an intersectional perspective, they both reflect on their positionality, that is how their gender, ethnicity, sexuality, academic status, and engagement in activism shaped the encounters with the activists and altruists they studied. Such reflections are largely absent from Swidler and Watkins’ account.

*Concluding comments*

Each one of these studies makes an important contribution to the understanding of activism and altruism, a combined reading enhances the impact of these studies even further. It highlights the need for partnership among activists and altruists to overcome dominance of those with more access to power and resources. The next world AIDS conference is taking place in Amsterdam in July 2018, 15,000 participants are expected. Scholarships will support the participation of those with limited resources. Hopefully the proceedings will offer instances of practiced solidarity rather than being dominated by the perspectives of donors.

**Notes:**

1. <https://www.avert.org/professionals/hiv-around-world/global-response/funding#footnoteref3_q10w5um>.

**References:**

Autesserre, Severine (2014) *Peaceland. Conflict Resolution and the Everyday Politics of International Intervention*. Cambridge University Press.

Fassin, Didier (2007) *When Bodies Remember. Experiences and Politics of AIDS in South Africa*. Berkeley: University of California Press.

1. Benita Roth and I are not related, however I know her and Sara de Jong's work since a long time and had the pleasure and privilege of reviewing their book manuscripts. [↑](#footnote-ref-1)