

Understanding HIV/AIDS in Uganda: a Question of Sites and Positions

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Abstract

In this contribution I present and reflect on some recent HIV/AIDS studies in Uganda dealing the multiple challenges that the possibility of ARV treatment is bringing. This research is necessarily 'multi-sited.' We deal with policy and practice at different levels, drawing on case histories, village-level ethnography, observations of clinical practice in town and in the countryside, as well as interviews and some participant observation in NGO and activist settings. Inevitably we draw on our own networks in Uganda and our own experience. In this sense, our research collaboration has involved more than 'following the medicines.' It has also become a matter of learning how to make use of the different positioned experiences of our diverse research team. The methodological significance of multiple positions was not part of our research designs but rather something we came to recognize serendipitously as work progressed. It is still being explored, making this contribution very much a work in progress.

HIV/AIDS, development demands and anthropological practice

In a recent number of Anthropology Today (AT 2005 21/3), Graham Fordham draws attention to the plethora of 'ethnographic' research on HIV/AIDS from Southeast Asia over the last 20 years and notes that the bulk of this work has not been carried out by anthropologists, but by 'researchers from disciplines such as biomedicine, public health, social demography, epidemiology, social geography, social economics and even nursing studies.'

His point is not that anthropology has a prior claim to AIDS-related research but rather that much new research is 'anthropology lite,' misusing ethnographic methods and ignorant of the conceptual framework that created them. Often this research is development-agency driven, linked to donor programs and to monitoring and evaluation processes that the industry spawns.

Fordham urges more commitment to HIV/AIDS research from anthropologists:

Failure to engage with the AIDS epidemic can only result in our discipline being further marginalized in favour of disciplines and organizations which share neither our ontological and epistemological quibbles nor our research methods, our sense of engaged social theory and of critical reflexivity and, perhaps most importantly, our sense of complex and contested social realities.

Fordham seems to question the utility of cross-disciplinary cooperation in this field, where the other discipline contributes neither regional knowledge nor first-hand ethnographic experience. In effect - if you talk the talk, you must also be able to walk the walk.

This is of course polemic, but polemic can have a purpose. Retaining complexity and a sense of contestation is, it seems to me, essential in a field as dominated by mega-projects and donor-interests as HIV/AIDS has become in recent years. How to retain these qualities is the central problem that George Marcus was addressing in his call for a multi-sited ethnography. Fordham's comments can serve as a good place from which to reflect on the continuing methodological impact of George Marcus' ideas in a development context, the focus of this workshop session.

Ethnographic development research, with its mandate to examine the relations between macro-level changes, policy, and people's lives and life conditions, cries out for multi-sited ethnography. In *The Anti-Politics Machine* - to take a now-classic study - James Ferguson moves from the field to the planners office, exploring the way the disconnect between

programmes and local realities is organized. But fifty years earlier, anthropologists were starting to using ethnographic journeys to explore the multiple sites that make up complex social fields - long before the category multi-sited research was named. Gluckman's Analysis of a Social Situation in Modern Zululand, for example, builds not only on the famous bridge but also, and more compellingly, on Gluckman's own ethnographic journeyings across the colour bar.

Marcus' 1995 paper formulated a method for addressing the complexity of the phenomena and processes we study, in the process giving a name to a set of methodological possibilities that are part of the broader anthropological experience. The trope of an anthropological journey from site to site is compelling and useful - and at the same time refreshingly traditional. Anthropology seems to assume a lone researcher; most of those inspired by the multi-sited method imagine an individual ethnographer moving between sites, following people, ideas and things. (Ulf Hannerz provides a recent example.) In development work, by contrast, the researcher is usually part of a team that may include other anthropologists and almost certainly involves people from those disciplines which Fordham accused of doing 'anthropology lite'. Yet our recent experience is that working with a multiplicity of collaborating researchers expands our awareness of relevant sites and multiples our access to them

Building a framework for a multi-positioned ethnography

The significance of multiple positions has emerged in the course of work carried out in Uganda over the last few years by a group of us dealing with HIV/AIDS. Since 1994 anthropologists and epidemiologists at the Universities of Copenhagen and Aarhus have collaborated with researchers at Child Health and Development Centre, Makerere University, in a project we call TORCH for Tororo Community Health. We have been supported by Danida under its Enhancement of Research Capacity programme. In a series of loosely related studies, Masters and Ph.D. students, together with more senior scholars, have followed the interaction between communities and the

changing health system in two districts of eastern Uganda. As anti-retroviral therapy (ART) became a more realistic possibility from around 2000, we took this on as a prime example of interaction and change, involving individuals, families, health workers, NGOs, national policy and international donors.

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Within the TORCH network, those who have explicitly undertaken studies of ART include four anthropologists from Denmark, a Ugandan lecturer at Makerere's Department of Social Work and Social Administration with a Ph.D. in anthropology, a Ugandan physician who worked at the Aids Information Centre in Kampala, a Ugandan with a Masters in International Health, a District Director of Health Services with research experience, and a Danish masters student in the sociology of religion. Some of us have carried out long term fieldwork, others have only recently completed doctoral studies. Some have worked mainly in rural areas, others in Kampala. Two are actively engaged in policy formation and health management. We represent different research traditions and bring different research experiences - and different life experiences - to our collaboration.

Increasingly, our work has been inspired not just by working in different 'sites' but also by making analytical use of our different positioned experience. While it would be too much to say that we are managing research collaboration in terms of position, we are starting to draw explicitly on the diversity of positioned experience in the team. This is new

territory for us - perhaps because so many of us come from anthropology, a field with a tradition of individual research. But even in the clinical field, where research teams are the rule, collaboration is generally structured functionally, in terms of research tasks; positioned experience in the field of study is apt to be seen as a potential source of bias. What we are recognizing is that the possibilities for exploring different kinds of sites are far richer when the explorers hold different positions and make efforts to systematically share their experience, understanding and contacts.

Sites and positions in the anthropology of HIV/AIDS in Africa

Brooke Schoepf has provided an excellent critical review of the AIDS literature from Africa. Drawing on Schoepf - and my own Uganda experience - I suggest that Fordham's concerns are reflected in the ways anthropology, development and the HIV/AIDS pandemic have intersected in Africa over the past decades. Three overlapping frameworks or paradigms can be identified. Initially - from the late 1980's at least - there is the concern with simple **cultural causation**. As Randall Packard noted, infection was thought to be based on cultural patterns - dry sex, wet sex, widow inheritance, circumcision, polygyny. Anthropological material, often recycled from older literature, was brought out to illustrate such examples of 'bizarre' behaviour. In effect, sufferers were victims of their own cultural practices. For this sort of explanation, ethnographic examples are rigorously placed and maps of practices are produced. Cultures and customs are objective, 'factual' and undisputed - and there is little effort to trace and connect practice from site to site, from town to village.

The 'victim of culture' notion declines in the 1990's (though it never disappears) and a set of ideas about **power and risk** gain ground. There is an increasing awareness that there are not simply victims but also perpetrators. Studies begin to look more closely at the links between gender, age and power. Drawing on the western AIDS literature, the notion of risk is taken up; debates about risk groups and risk behaviours are also imported and provide useful critical insight. A more sophisticated view of

society and culture comes into play driven, at least in part, by the explosion of AIDS education programs and their need for 'targets.' AIDS programmes and projects also bring Monitoring and Evaluation tools and exercises, community impact studies and the like - the sort of AIDS industry that Fordham describes for Thailand. Ethnography is largely driven by projects and programs; it is overwhelmingly 'development' research (to borrow Ferguson's quotation marks). With the focus on programmes and projects comes an interest in delivery - tracing the journeys of resources and therapy seekers. In particular age and gendered positions are now more important to define, more visible in the agenda. The critical impetus that drives multi-sited ethnography exists (see for example Setel [1999]) - but it is overwhelmed by the urgency of interventions responding to compelling need.

Finally, towards the end of the 1990's, an external shift in the donor and biomedical worlds - coupled to the anti-globalization movement and the targeting of pharmaceutical multinationals as 'perpetrators' at another level - changed the research agenda again. At last there was something to do, ARV medicine to demand and later to deliver. The years after 2000 mark the increasing availability of antiretroviral therapy in Uganda. The anti-globalist critical agenda was bearing fruit and the price of antiretroviral medicines (ARVs) had begun to fall as copy preparations were gaining ground. Major players - the Global Fund, the United States PEPFAR (President's Emergency Plan for AIDS Relief) and many others - were taking elephantine steps in an already well-fertilized field of donor activity. It was possible - at least from cosmopolitan centres - to imagine a time when ART would be far more generally available and AIDS would become another treatable disease. But the genie of power and politics was well and truly out of its bottle and studying the sites of power and the pathways to it became compelling policy research. In this new context, more voices are beginning to be heard, and beginning to be listened to. More players seem to be joining the game.

Treating AIDS where elephants walk

This latest phase in the AIDS agenda is the context for our recent work. From the point of view of the 'ordinary' communities and individuals in rural eastern Uganda, where we have worked for a number of years, ART is only now, in 2005, becoming known as a demotic possibility. ARV medicines - also still poorly understood - are for 'those city people', 'those big men', those 'who know Europeans', for those who have money. Certainly ART was not a thinkable therapeutic possibility in 2002 when our group of TORCH-affiliated researchers began a modest collaborative project designed to identify key social issues involved in 'Treating AIDS' (the title of the paper published in 2004). That paper became the first of a series of collaborative studies, some of which are now published while others are still underway.

following channels

In 'Treating AIDS' we placed our localized experience of HIV/AIDS treatment (mostly from eastern Uganda) in a broader social, economic and political context. However we sought to retain our grounded viewpoint. What might the expected increase in access to ARV medicine mean for therapy seekers? Would the awareness of a treatment possibility change attitudes towards disclosure? What about cost, what about dependency, what about the definition and meaning of AIDS? There were - there are - important issues of gender, power and meaning here.

Our starting point was the very evident unequal access to ART in Uganda. By 2003 perhaps 10,000 people were taking ARV medicine - but 157,000 should have been receiving them (according to the Uganda AIDS Commission). But unequal access is not very meaningful without a context: where were ARV medicines in Uganda? How did they flow? What sorts of social lives did they live?

This initial research strategy was necessarily multi-sited: in Marcus' terms, we 'followed the things' (medicines) identifying four broad channels through which ARVs flowed once they entered Uganda.

1. Donor-funded treatment and research programmes providing free ART for perhaps 4000 people.
2. Gazetted treatment centres - hospitals and in particular the Joint Clinical Research Centre - offering fee-for-service treatment.
3. Private physicians who treat patients discretely - for a fee.
4. Personal networks that 'facilitate' individual access to ARVs, often without medical supervision. This 'help' may be free or at reduced cost.

Our next step was to identify a series of dilemmas arising from unequal access to medicine and treatment. We reviewed the lottery of donor-funded research projects, where living in the 'right' parish or sub-county can mean access to treatment and services. Inclusion in such projects, at times literally arbitrary, is more often determined by residence and the sample size deemed appropriate for the research project.

We interviewed staff at gazetted treatment centres and visited hospital wards. At the national hospital, Mulago, ART was not offered in 2003 'because most people cannot afford it'. Hospital staff told us that they did not want the spectacle of the lucky ones going to the dispensary window of long life.

On our ward, we use the "blanket sign" in order to decide whom to inform about where they can go to buy ARVs. Our patients bring their own bed linen. You check the blanket, the bed sheets, how the patient and family are dressed, whether they are wearing shoes or rubber slippers. Do they bring a nice thermos flask, a basket of food with a crocheted cover, a radio? Do they ask for a private room? Or is the patient using old sheets, or maybe a woman's gown because they can't afford a blanket. On the bedside table, is there only a plastic mug with the cold porridge provided by the hospital? It's not fair to suggest treatment costing 60,000 shillings a month to someone who has not been able to afford sheets at 8,000 shillings in the past five years.

Illness and treatment is a social affair in Uganda, but that does not make it unproblematic. We learned that any fee for service could be critical, whatever the channel. In rural Uganda, where many families first eat in the late morning, making up a fire and preparing food so that a patient could take ARV medicine upon waking, could be a considerable burden. The

expenses - ' for feeding' - and the effort involved in daily care continued under 'no fee' treatment. Meeting such demands was a dilemma for the patients and families we spoke with and observed. Ugandans know that the practice of relatedness is made visible in giving and receiving assistance and wealthier (or simply less poor) family members regularly take on obligations for the school fees and care of orphans or the emergency medical needs of kin. ART however is different: families have already been burdened by attempts to care for 'their person' - and often there is more than one affected person. Difficult choices were shared with us: to keep a child in school or to pay for medicine for a sister or brother. Painful and poignant choices were made at many levels, from households to larger kin groupings and family associations: to help this relative with medicine and deny help to that one. We met with PWAs who rejected ART because of the additional burden it could place on their families, often already caring for other AIDS patients. And we recorded stories of suicides attributed to a kind of altruism.

Dilemmas of access, we heard, are also dilemmas of secrecy and status. Those with money can choose their channel of access, paying for privacy and discretion. This in turn can have implications for families; a husband may treat himself 'privately' leaving his wife to wonder about the many medicines whose labels she cannot understand. Secret access to medicine and treatment is of course also political on a larger stage. Ugandans seem not to resent wealth and advantage as such, but people object to secret consumption and selfish unwillingness to affirm relations with others. Major Rubaramira Ruranga, an outspoken AIDS activist and long-time AIDS survivor, is highly critical of current Ugandan AIDS policy and the unwillingness of the country's leaders to press for the resources to make ARV medicines generally available. For him this is an issue of equity - without help the poor will never be able to afford such medicines. But he also stresses a pragmatic point: with public access to treatment, people will be more willing to be open about their own HIV status—and openness is the key first step towards behavioural change. The misuse of public trust and public resources is not in

itself so unexpected (it is “just politics”, after all). Worse than the cheating are the hypocrisy and the hiding which have become commonplace among HIV+ elites. AIDS, for Rubaramira, is truly a crisis in Uganda and secrecy is the behaviour that encourages the continuation of the pandemic.

sites and positions

These are just a few examples of positions along the channels where ARV medicines flow. They are points where dilemmas are recognized and formulated by actors who are socially (and at times physically) placed. What makes this sort of presentation more than a collection of anecdotes is that there is a design, a method to the methodology. George Marcus speaks of

... chains, paths, threads, connections, or juxtapositions of locations in which the ethnographer establishes some sort of literal, physical presence, with an explicit, posited logic of associations or connections among sites that in fact defines the arguments of the ethnography.

Marcus uses the metaphor of the chase: follow the people, the thing, the plot or story or allegory, the life or biography, the conflict. In our project 'following' the medicines did turn out to be a way to link the lifeworlds of Ugandans to the ways that ARV medicines were transacted in 2003-3. It was a method suited to the political and global nature of 'access'. It was productive because we pushed ourselves to move on from localized ethnography and engage with social issues on a broader scale and then to return to the very local problems of placed and positioned people - to the 'blanket test' and what it says about a particular social situation.

In research and analysis we moved from site to site. While the logic that connected our sites was often left implicit, the juxtaposition of sites was deliberate, designed to illustrate dilemmas of access and inequality for actors. In retrospect though I think that what proved most productive as ethnography was the complexity of the connected social worlds that emerge. Actors, embedded in social contexts, bear our ethnography. Their interaction with ARV medicine serves to objectify solidarity, hope and

concern, power and ignorance, selfishness and altruism. Within families, the idiom of caring is expressed through medicines - and thwarted by poverty. Nurses on wards and counsellors carrying out PMTCT testing juggle professional indifference with sympathy and concern. At more global levels, activists, pharmaceutical representatives, clinical administrators and donors all make the necessary compromises that will allow for some access and some justice in an unjust world.

reflexivity and research collaboration

George Marcus reminds us that, in multi-sited research, 'the traditional privileged self-identification as "ethnographer"' is 'effaced'. This can mean that 'the ethnographer's shifting affinities, affiliations with, as well as alienations from, those with whom he interacts at different sites constitutes a distinctly different sense of "doing research."' Our first 'treating AIDS' study was a joint ethnographic effort made complicated - and enriched - by the 'shifting affinities' of three anthropologists and a medical doctor. Michael and Susan Whyte have worked in eastern Uganda off and on for over 30 years, Lotte Meinert lived and worked in Kampala before and after carrying out dissertation research in eastern Uganda for a year, and Betty Kyaddondo was trained as a physician and draws on professional clinical experience in different HIV/AIDS contexts. Most case material is from long-term, sited ethnography carried out for other purposes. That is, we drew on experiences of families we had known earlier as they began to deal with AIDS. Some of the cases came not from research efforts, but from ordinary interaction with colleagues, family and friends in Kampala. Research specifically for this project - mainly interviews and some direct observation - was usually cooperative, involving two or sometimes three of us. This was not an attempt to 'control the data' but simply reflects the excitement we all felt as the project developed. The opportunity to talk to a drug rep specializing in ARVs or to meet the person in charge of a major research programme providing treatment to hundreds of people was something intriguing to be shared. Fieldnotes were written up and distributed as soon as possible after interviews and observations, and discussed constantly.

What Marcus calls 'a different sense of doing research' was certainly part of our experience - though I think with a different difference. As collaborators we contributed experience gained over many years in Uganda (for one of us, a lifetime). Put simply, we knew different things from different positions and, compared at least to some research teams working with HIV/AIDS issues, we all knew quite a lot about the empirical worlds that we were studying. Personal and professional links - in some cases going back for decades - could be mobilized in order to facilitate an interview or an introduction. Our joint network became a significant research tool: there was always one of us who knew someone, who knew someone, who could providing an opening onto a research site.

Collaborative research - at least in our version - involved more than sharing contacts. We used our different experience to reflect on other differences: professional status, age, gender and, of course, European/Ugandan. We shared earlier written work (texts, notes and headnotes) turning some significant part of our 'collective' knowledge into a framework for reflecting both on our data and on our own role in 'producing' it. All the anthropologists, for example, had been taken up and positioned in local families and clans and, over the years, had developed extensive networks of 'fictive' kinship links. Kyaddondo's own kinship identity was obviously of a different order, yet our experience allowed us to achieve a degree of mutual understanding of what was involved in family and kinship roles, and what that might mean to actors seeking therapy or making a decision about medicine or revealing HIV/AIDS status.

Beyond 'anthropology lite:': Ethos, position and multi-sited research

The research carried out in the TORCH project since 1994 has been shaped by the political commitment of our cooperating partner, CHDC, to community-level applied research. For CHDC, improving community health is very much a matter of building capacity - and not only the capacity of academic researchers pursuing higher degrees. Health workers from the

districts have been a part of research from the beginning. They have been encouraged to develop their own projects, given support and at times additional training. District health teams identify needs for operational studies and request support from TORCH/CHDC. In this sense, CHDC was operating in a multi-sited framework before TORCH cooperation began; the Danish input has built on this pre-existing awareness of the politics of health development - and learned much from the experience of core CHDC staff.

TORCH has also built very much on the ethos of CHDC, a commitment to teamwork, to openness and to 'listening to the community.' This commitment starts with a personnel policy based in mutual respect: the CHDC family comes together not just to celebrate an advanced degree earned, but also to support any colleague, whether the director or the driver, who has lost a close relative. Stiff professional hierarchy is discouraged at the office and, most particularly, in the field; everyone in a research team is encouraged to 'be social' and to develop links to the communities and institutions they work with.

This is an ethos that builds community - and TORCH became a part of this expanding community. CHDC staff are aware of what they are doing - and what they have achieved; 'cooperative spirit' is no less valid for being instrumental. When planning projects or identifying potential collaborators, CHDC (and TORCH!) teams review 'our' family of contacts: who is in the district health team just now? where is that good Woman Representative in the local council? when did we last work with that DDHS? who do we know who works with counselling these days?

I stress ethos and community here because it has become a methodological resource, a basis for not just for facilitating collaborative research but also a tool for reflection and analysis. In our work, it has been the precondition for transforming collaboration as a functional division of labour into collaboration as a joint exploration of the complexity of a social field, a domain of action. Exploration often proceeds within the now-traditional

development methodology framework - key informant interview, focus group and PRA - but it is also inspired by explicit reflection about the links between researcher and subject. Collaboration as multi-positioned fieldwork is not, we submit, 'anthropology lite.'

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