

### **3. Social science research: understanding and action**

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#### **Introduction**

The Sali Conference was a historical meeting in many ways. It represents a new form of international co-operation between African and European research institutions; it is the first attempt to assess what has been achieved after a decade of AIDS research; and it has brought together a global cast of social scientists, some with extensive experiences from different parts of the world. In addition to promoting co-operation and collaboration among social scientists, it is hoped that the deliberations at this meeting will lead to 'understanding and action'<sup>1</sup> and thereby strengthen research that informs the struggle against AIDS. The theme of the XIIth World AIDS Conference held in Geneva in the summer of 1998 was 'Bridging the Gap'. But in fact, in the North/South divide, there are several gaps to be bridged namely: the gaps in the development of AIDS prevention programmes and access to treatment; and the gaps in collaboration which inhibit the sharing knowledge, skills and experiences. This move to forge a new partnership to fight the epidemic is a direct response to the loud clamour of the dispossessed sufferers to 'own' the epidemic. Some social scientists, particularly anthropologists, have for sometime advocated the practice of involving people in the research agenda by letting them identify the priority problems through information gathering, data analysis and solution suggestions. AIDS is forcing researchers to reformulate their research methodologies and their relationship to those they study. It is no longer research as usual for the consumption of the predominantly North academic community only, the new methodologies and dissemination channels must ensure the sustainability of policies based on social science research.

#### **Tomorrow, AIDS could be cured!**

At every meeting we note once more that AIDS is still a health problem without a cure and we reaffirm our continued struggle against

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<sup>1</sup> This is the motto of the University of Bordeaux based 'Sociétés d'Afrique & Sida' international network of AIDS researchers, which puts out a newsletter by the same name.

the disease. With every new medical discovery, we echo the sentiments of the editorial written during the XIth international Conference in Canada:

*This is no time to jet up on the battle against the disease.*

*Fourteen years ago, AIDS had no name.*

*Today AIDS has no mercy.*

*Tomorrow AIDS could be cured.*

(The Windsor Star, Canada. July 1997).

The new drug therapies, particularly the recent developments in antiretroviral (ARV) treatments, appear to offer real hope to people living with HIV/AIDS (PLHA) of prolonged and disease free survival. Impressive short-term and mid-term clinical results using protease inhibitors and combination therapies respectively have offered hope to many afflicted with HIV. These therapies have raised the possibility, in the developed countries, that HIV/AIDS could and will become a chronic disease treated mainly on the out-patient basis. This will definitely improve the quality of life for the affluent PLHA. The new therapies will for a long while remain mainly a hope for many poor people of the world who cannot afford the costs and would be hard-pressed to follow the strict regimentation required. Even when cures become available in developing countries, it will mainly be affordable to the power and economic elites, the majority of people who are already lining up for vaccine trials will be left as spectators.

Social scientists must actively share their research and theoretical knowledge of the socio-economic and political dynamics in international and national fora in order to influence policies on AIDS prevention. At the moment social science perspectives suggest the need for cautious optimism in connection to ARVs. Take for instance the issues of accessibility and affordability: the combination therapies are prohibitively expensive at \$1,000 to 15,000 per month; the time and discipline required for medication is difficult to observe for many; and securing the support of convenient and efficient medical services is an impossibility in most cases. ARVs are available to a very wealthy minority in developing countries, though some doctors may be prescribing them without sufficient understanding and correct use. ARVs involve a rigorous regime of taking fifteen to twenty tablets a day in order to avoid the emergency of drug resistance. Essential to the therapies is the clinical monitoring of adverse reactions both those felt and experienced by patients as well as those that can only be scientifically evaluated. Long-term clinical outcomes have not been demonstrated. Resistance to triple therapy may occur; and strong viral rebound may occur leading to deterioration when treatment is interrupted.

In summary, social scientists must impress upon the political and health policy makers, the implications of the social, financial, clinical and ethical implications of providing ARVs. While we acknowledge and celebrate the progress made by medical scientists, our efforts must focus on sex health education as suit the most effective trot in the battle against the epidemic until a cure is found which is accessible to the

majority of PLHA in the world. Effective sex health education must focus not only on the technology of protection afforded by condoms, but must also tease out the socio-cultural and economic nuances that promote its adaptation. In other words, our research must help people and policy makers to translate the public health information on HIV transmission and how to avoid it into knowledge for survival.

### **Social science and AIDS research**

It is obvious that social sciences have an important role to play, but why have not our contributions been in the forefront of combating HIV? HIV/AIDS was from the beginning regarded as a public health issue that would be solved by health education, the technology of condoms and scientific search for a cure. Social science models suggest that the battle against HIV/AIDS must address the social, political and economic milieu in which individuals live and which provide the background for attitudinal changes and behavioural change. The slow incorporation of social science knowledge into mainstream educational policies, put in jeopardy the lives of many people at risk.

Social scientists were late starters in studying AIDS. AIDS medicine has been practised since 1984 and AZT prescriptions written since 1987. The annual HIV/AIDS research industry worldwide is estimated at \$8 billion. But even as late as 1989, social scientists, particularly anthropologists, were included as token members on research projects by scientists who regarded 'culture' as an obstacle to the effective fight against the epidemic. Because HIV is transmitted predominantly through penetrative sex, money and time were wasted on identifying specific cultural practices that increased the risks of HIV transmission.<sup>1</sup> The year 1989 marked a watershed in the involvement of social scientists in AIDS research when the Canadian International Development Research Centre organized a workshop on 'Human Sexuality: Research Perspectives in a World Facing AIDS' to precede the Vth World AIDS Conference. Accordingly, the workshop focused on four areas (IDRC 1989):

- i) to determine how sexuality research differs from other social research;
- ii) to review research on AIDS and sexual behaviour;
- iii) to discuss the major research methodological issues in studying sexual behaviour;
- iv) to recommend strategies for changing sexual behaviour.

But perhaps most important of all, was the workshops focus on notions of power and control relationships:

- who owns research?
- who sets the research agenda?

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<sup>1</sup> African researchers situated the discourse on sexual practices in the distant past or in some rural social customs. Until 1990, when AIDS appeared in epidemic proportions in India and Thailand, some observers claimed a specific African sexuality that explained why the epidemic had spread rapidly in Africa and not in Asia.

- who gets empowered by research?
- what is done with the results?
- what are the implications when one person or a group set out to change the behaviour of others?

These are also the main concerns that are dealt with in this paper.

### **In AIDS research the process is the product**

HIV/AIDS researchers have had to face the issue of commitment. It is true that many have done research, taken it back to their universities and organizations, published books and got recognition and promotion. Needless to say that this will continue to happen, but there has been increasing commitment among researchers to help the people they study. Many anthropologists, for example, increasingly use group methods which I will collectively refer to as Action Research. These methods were developed in the 1980s by advocates of development from below who were frustrated by the failure of institutional and state-centred development policies (Chambers 1983; Cernea 1990). These involve focused group discussions, as a way of involving people in information collection, quick assessment and analysis of problems and suggestions for solutions.

Furthermore, performative methods using drama and role playing can be used to highlight problems, priorities and solutions. These methods make information immediately available for community use. Action research is a process that involves the researchers (as facilitators) and the people (with lived experience and embodied knowledge) in interpreting, reinterpreting or reinventing and changing culture. The people and researchers are partners in the search for knowledge and solutions. This involvement of people in the process of information collection and analysis encourages the translation of information into usable knowledge. In AIDS research, it has been important to transcend what at first sight appear to be cultural obstacles into opportunities for change and human survival.

Action research when done well, allows power in the research situation to be shared and encourages people to explore ways behavioural change can best be achieved. This seems to be the ideal solution to issues pertaining to power relations because both the researchers and the people benefit. However, the issue of who sets the agenda and who gets empowered by research still remain problematic. It is important to ask two questions: who locally benefits from action research and who benefits from collaborative research between North and South scholars. Often the pressure to get quickly data for immediate use leads to local leaders dominating the discussion fora and thus silencing the people whose views remain unheard (Pottier 1997). In many situations giving voice to the people leads to the rise of professional spokespersons who may start out as articulating the 'we' position but soon change to the 'I' stance so as to boost their prestige. This is particularly true of non-governmental organizations where the

power to speak is dominated by the founders or other leaders who are regularly contacted by researchers and AIDS agencies for expert advice. Vested interests are created as the same people are seen by outsiders as community spokespersons and are paid per diem to attend local, national and international fora. Clearly in this the benefits of AIDS research are predominantly accrued by the spokespersons.

On the issue of who benefits from collaborative research, it can be said that Northern researchers have been at best reluctant colleagues of African researchers. In Africa our financial poverty to fund research has meant that most of the researchers and many of the budgets for AIDS research and intervention come from the North. This is true of other types of research as well. Since funding is always tied to specific research agenda, many researchers don't feel free to do as they please. Crewe's description of the day to day dynamics in foreign aid funded projects, is instructive. It is planners in donor agencies who make the important planning decisions. "They hire advisers to write very short reports or tell them what to do verbally" (Crewe 1997: 61). These advisers and expatriates impart technical, managerial, marketing, business and social-scientific wisdom through assistance and training and it is called 'indigenous capacity building'. This 'expert' assistance takes \$7-8 billion of donor money a year (*ibid.*). Indigenous capacity building fails because the expatriate advisers use many strategies to assert their perceived superiority over 'local'. They quote recent publications (which are often difficult to obtain locally), refer to their work in other countries, contradict locals and generally dominate meetings with their speeches. Thus expert superior knowledge is asserted by constant reiteration development jargons and methods as well as ability to use the latest technologies such as computers (*ibid.*: 74-76). The situation is not different in AIDS research. As Michel Foucault (1980) noted, knowledge is power. Collaboration between researchers must be seen in the general context of international geo-political co-operation, whether in trade or cultural exchanges. Organizations and individuals compete fiercely to dominate the AIDS agenda in different African countries. It is not a surprise, for instance, that the names that have dominated the United Nations Global AIDS programme often reads like a roll-call of those who worked in Zaire during the 1980s. Often when Northern researchers have their gaze fixed on the prize of being AIDS experts, they act unscrupulously, minimizing the contributions and appropriating the intellectual labour of Southern colleagues. In fact many feel that they put such labour and see no obligation to acknowledge it. Nonetheless, some Northern scholars do acknowledge local contributions and even credit locals with co-authorship. However, the distances between Northern and Southern universities, where the resources for analysis and writing are located, encourage the marginalization of African intellectual efforts. We must re-examine and strive to change the prevalent intellectual division of labour whereby Africans are 'research assistants' who collect data and are debriefed by Northerners who process the data. The neo-colonial

mentality that sees African scholars as our man or woman in 'Banga Banga' undermines the social science contribution of Africans. The writing and analytical capacity of African scholars must be promoted so that they too enjoy unqualified professional prestige as AIDS experts.

The research styles of researchers show the degree of their commitment to those who are suffering. This is illustrated by the two examples below. The first incident took place in 1990 in Kinshasa, Zaire, during the Vth International Conference on AIDS and STDs in Africa. When a social scientist who was working with a medical research team was asked why people whose blood samples were taken in their project were never informed of their serostatus, and why it took two years for the results to become available, she replied: "I am paid to do research and not to interfere. It takes two years for refereed articles to come out in journals". The question here is whether in the days of AIDS this attitude of research as usual for the consumption of the academic community is ethically acceptable? Should researchers study the natural history of AIDS without the intervention of counselling or education? Is it acceptable to deprive the people and policy makers the results of research until they are presented at international meetings or appear in journals? These questions are worth pondering as desperate people line up for vaccine trials.

The second incident took place in 1992 during the VIIIth International Conference on AIDS at Amsterdam, Holland.<sup>1</sup> A person living with HIV/AIDS (PLHA) posed a question to an expert who had just presented a paper on her home town. As the expert asserted his superior knowledge in answering her, it became obvious that his 'knowledge' was not grounded in what was actually taking place. This case raises the problem of 'instant experts', and competition for professional prestige. Commonly, this is done by visiting a country and writing reports after talking to expatriates who 'know what is going on'. Alternatively, the researchers consult locally based non-governmental organizations to help locate research assistants. The assistants are told what to do after a safari tour of the research area. The researchers give partial payment and return home or move on to check on the half a dozen or so international AIDS projects they are operating. The research assistants sit down and write reports from what they know without the benefit of research. The employing researchers often pay up even while complaining that the reports are poor work. Nonetheless, elegant reports come out and are quoted by more expatriate experts. These short cuts to research have undermined the impact social science research could have had by now in combating AIDS.

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<sup>1</sup> This meeting was historical because it marked the beginning of the struggle for what I call 'epidemic ownership'. For the first time non-governmental organizations sponsored many PLHA to attend an international meeting. ACT-UP, the New York based gay activist group, held many memorable demonstrations. African PLHA were inspired enough to form an association and hold a meeting in 1994.

In an apparent struggle to own the epidemic, one constantly hears local spokespersons dismiss social science research with 'we know it all because we know the culture' assertions. As the saying goes, the proof of the pudding is in the eating. Why has it taken so long to curb the spread of HIV if local experts are so knowledgeable? It is perhaps time we educated Africans admit that we do not automatically know what the poor, the peasants and the less educated think: we need to talk with them. If we want to really know what is going on; to identify what are the contested meanings, which are the areas of resistance and how information, such as that on AIDS prevention, can be translated into knowledge for survival, we must do research away from our offices and desks and we must listen to what people are saying not what we think they are saying. This requires humility and patience to realise that getting worthwhile data is a time consuming process and that things are not often what they appear to be at first sight. We should to use our 'double consciousness' (DuBois 1961) as insider/outsider by virtue of being native and educated to interpret the social, cultural and political nuances of words and action. As 'natives' we may have the advantage of recognizing speech patterns, tone and silences, and body language. We may also hold positions on issues. However, as trained social scientists we should be able to use the theoretical and analytical tools to present studies encompassing different perspectives of the problem. The perceived wisdom from anthropology is that if we stay long enough with the people it may be possible to solve puzzles over contradictions between words and action (Obbo 1995).

The relationship between the theories and models we take to the field to guide our research and the actual information we collect sometimes raises ethical concerns. Data should help us modify, refine or confirm our models: it may even generate new theories. However, this is often not the case. Below are two examples where square pegs of theory and model were rammed into round holes of data. In a project in which I spent eleven months of intensive participant observation interviewing and living among the people, conflict arose over how data was being interpreted to fit the pre-research model. In the final model which depicted what happens to families at different stages during the process of coping with the epidemic, AIDS was privileged as the cause of girls being out of school. The fact that the area had always undervalued girls education because of general poverty, the predominance of pastoral culture and the cultural practices that overemphasized the competence of girls in the performance of domestic chores, were ignored. These factors pre-date the AIDS epidemic. Girls had never stayed in school because their involvement in domestic chores meant that they missed school so often that they were unable to keep up with school work. They dropped out of school because they were ashamed to repeat a year with younger classmates; and no one pressured them to persevere. What concerned the guardians and parents was their indispensable labour contributions and the eventual bridewealth they would command as skilled home managers.

The second case is that of a poor sick man living alone whom my colleagues happened upon when they were doing reconnaissance

research. The researchers tried, with the help of a research assistant from another part of the country, to interrogate the man. A crowd had been attracted by a white Land Rover with 'British AID' written on one of the doors, the two white men and a non-local African man. The crowd appeared to be interpreting what the man was saying to the strangers without either side really comprehending what was being said. But this man ended up as a perfect candidate for the model slot where abandonment was required. The man in question had come to Buganda during the 1940s and 1950s Banyarwanda migration to southern Uganda. Many of these men worked as agricultural labourer for Baganda coffee farmers (Richards 1973). Some eventually returned to Rwanda, others became assimilated in the host culture through ties of marriage and patron-client relationships, but still others lived as squatters or tenants. Most of the latter had limited social interactions with the host population because they never mastered the local language, they usually remained poor and unmarried; and were despised. They often drank too much after work. But they survived because there were always local people who did not entirely marginalise them: they visited them when ill. The man in the model was a marginal Munyarwanda in Buganda, and he had a fever and was found by the researchers sunning himself outside a hut that was on the edge of the forest. However, he was neither abandoned by his family, nor was he suffering from AIDS. In summary, these contrived examples lessen the impact that social science could have in the formulation of effective policies. Local policy makers merely laugh when situations that are attributed to AIDS actually are widely known to have preceded the epidemic.

### **Social sciences and the study of sexual risk**

*"The heart has its reasons which reason knows nothing of"*  
(Blaise Pascal, 1669)

This quote suggests humility when dealing with human motivation and action because most things people do are not and need not be rational according to the laws of logic. Human sexuality has proved such a complex and contested area requiring that social scientists be humble before the facts. Our tasks are to reveal the social, economic, political and historical structures which influence the seemingly personal decisions of hearts.

Since the predominant mode of HIV transmission is through sexual intercourse, how much has social scientist contributed to sex research. At the 1989 Ottawa IDRC workshop, social scientists doing AIDS research acknowledged that "The AIDS epidemic caught us ill prepared to answer basic questions about people's sexual behaviour. Efforts to fill this void have not always been based on sound methodological footing. Unfortunately, we are in the unfortunate position of playing catch up" (Zenner 1989: 88; see also Bolton 1992). It was an admission that "Major concerns in the lives of people

revolve around their sexuality. Human sexuality is a pleasurable activity; it dominates fantasy; it both establishes common bonds and identifies gulfs between people: and it occasionally conceives new life” (Cantania 1989: 48).

In the late 1990s, anthropologists doing research on AIDS have focused on culture, sex and sexual risk. The studies reveal a complex picture in which human sexuality is on the one hand a cultural construct and on the other a source of culture and yet not under its aegis. The emphasis here is on both culture and human agency and the symbolic economy of sex. To date the most informative research on sexuality has been realized on homosexuals and bisexuals in Europe, Latin America and North America (Parker 1991; Henriksson *et al.* 1995). This has been due to the grassroots efforts of the affected communities and the commitment of anthropologist to do intensive participant observation research among other things. Hard studies of sexuality among African groups are non-existent and most analyses have not gone beyond looking at polygyny, promiscuity and sex work. Homosexuality has not received the research attention it deserves because of political phobia and the way some researchers have combed ethnographic monographs and uncritically lumped together all same sex activities and associations as homosexuality. Likewise researchers working mainly in West Africa have analysed ethnographic studies on African societies and concluded that the rapid spread of AIDS can be explained by an African sexual system (Caldwell *et al.* 1989). African sexuality was seen as a product of lineage concerns with descent and reproduction that reduced the conjugal bond to emotional poverty. This we are told is a recipe for promiscuity. This selective analysis of ethnographies that were never focused on the study of sexuality, needless to say leaves out contradictory evidence and is hampered unfamiliarity with linguistic nuances.

AIDS has revived network studies to map out the routes through which HIV is spread, and to help explore the dynamics of power relations in communities, in families, and between men and women (Hunt 1989; Obbo 1993a). Unexamined, normal everyday movements, other than going to the bar or market, can reveal unexplored networks that put people at risk for HIV infection (Obbo 1997). Sexual networks also have the potential to be used as HIV prevention networks, especially among the youth (Obbo 1995).

In addition to network research and analysis, anthropologists have found that there is a symbolic economy of sex that hinder the practice of safer sex. Because homosexuals were the first group to be severely afflicted by AIDS, they have not only been pioneers in sex research and education but they invented the concept of ‘safer sex’. Despite the success rate with condom use among homosexuals, researchers report a retrogression to unsafe sexual behaviour because young homosexuals regard AIDS as an adult problem, and some men regard condom use as a nuisance to the intimacy of feeling their partners sperm inside them when they have anal sex (Henriksson *et al.* 1995: 172). In Uganda, I found that sex workers fail to use condoms with ‘special’ male friends partly because of the intrinsic intimacy they associate with

semen inside them (Obbo 1993b). Before dismissing people's behaviour as irrational, it is important to understand what they regard as intrinsic to their sexuality: what gives them pleasure and what they regard as intimacy.

It is also important to pay attention to the intersection where gender and cultural terms inform the construction of each other. For example, the majority of sex workers do so by economic necessity but at the same time they hold romantic notions that puts them at risk. Many engage in unprotected sex because they are preoccupied with getting marriage. They live in a milieu in which everyday gender ideology regards women as socially worthy only when they marry and have children. The ideology of wifehood and motherhood divides women into the binary categories: 'good women' who are virgins before marriage and sexually monogamous when married; and 'torse women' who are sexually 'promiscuous'. Women increase their marriage chances if they appear to be virgins and monogamous. Sex workers by having unprotected sex are declaring their monogamy. Over four-fifths of African women are infected by their single partner: their husband. Often women fail to negotiate safe sex because suggesting condom use implies sexual promiscuity on their part as well as distrust of their partners. The negotiating powers of economically dependent women is weak and so they get infected rather than risk social criticism or being thrown out to starve. The complex motivations influencing behaviour must be addressed at many levels in order to motivate behavioural changes. This is the political ecology of gender relationship which must be deconstructed and used as an opportunity for change (Schoepf 1995).

In conclusion, the networking gendered by this meeting among us will foster co-operation and consolidation of our research efforts. We are poised at the crossroads of understanding and action.

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Christine OBBO, *Social science research: understanding and action*

*Summary* — Research, theory and application are interconnected in the days of AIDS when the understanding gained from research must generate action. AIDS research has focused attention on two areas of tension: between long term and short term objectives of research; and between researchers and researched. The dynamics of research have weakened the contributions of social science research to the AIDS epidemic solutions. At issue is the ownership of research. To date, AIDS has benefited the scientists, officers of AIDS agencies and their fellow traveller social science experts rather than the people who are suffering. But we are on the threshold of networking and collaboration which should promote understanding and action.

*Keywords:* research • researchers • action • people living with HIV/AIDS  
• networking • AIDS agencies.

Christine OBBO, *La recherche en sciences sociales : la compréhension et l'action*

*Résumé* — La recherche, la théorie et l'application sont liées en temps de sida, où la compréhension acquise par la recherche doit engendrer des actions. La recherche sur le sida s'est concentrée sur deux pôles de tension : d'une part entre les objectifs de recherche à long terme et ceux à court terme, d'autre part entre les chercheurs et leurs "objets" de recherches. Les dynamiques de recherche ont affaibli les contributions des sciences sociales aux solutions à la pandémie du sida. En fin de compte, l'enjeu est la propriété de la recherche. Jusqu'à nos jours, le sida a profité aux scientifiques, aux agences concernées par le sida et à leurs confrères voyageurs-experts en sciences sociales, plutôt qu'à ceux qui souffrent. Mais nous sommes parvenus au seuil d'un travail en réseau et d'une collaboration qui doivent promouvoir la compréhension et l'action.

*Mots-clés :* recherche • chercheurs • action • personnes vivant avec le VIH/sida  
• travail en réseau • agences concernées par le sida.