**Workshop "Anthropology of ART in Resource-Poor Settings"**

**Aix en Provence, MMSH, April 28th 2006**

# Report

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The workshop was organized by the CreCSS (Centre de Recherche Cultures, Santé et Sociétés) in collaboration with the ASSSR (Amsterdam School for Social Science Research) with the support of the ANRS (Agence Nationale de Recherches sur le Sida).

The objective of the meeting was to bring together social scientists for a discussion on the emerging topic of « Gender and ARV ». The workshop took place in Aix en Provence on the 28th of April from 9:00 am to 5:30 pm in three sessions. 1) Conceptual and methodological approaches of Gender and ART in Resource-Poor Settings, 2) Gender as a key factor for access to care, 3) Social production of gender within ART management.

## 1) Conceptual and methodological approaches of Gender and ART in Resource-Poor Settings

The day began with an introduction by Alice Desclaux on the relevance and the importance of conducting research on "Gender and ART". She first pointed out that the issue is linked to earlier social science research conducted on gender and health. The AIDS epidemic has created a specific context as relations between gender and AIDS were early highlighted by international authorities. UNAIDS as well as the Society for Women and Aids in Africa (SWAA), for example, played a key role in raising awareness regarding sexual inqualities related to the HIV risk and treatment. Very rapidly the term "vulnerability" was commonly used, sometimes becoming the register of the politically correct, but almost systematically referred to the status of women. Largely documented, women's vulnerability to HIV can be described on two different levels : before infection, social and biomedical factors put women particulary at risk, and after infection, social and biological consequences can be more important for women. For example, the use of nevirapine to prevent Mother To Child Transmission (PMTCT) creates viral resistances that can reduce the effectivness of the mother's personal antiretroviral treatment. Yet, several ART programs in Africa have targeted more women than men. This assessment leads to a new set of questions : Is this situation a reflexion of the success of the women's empowerment programs? Are ARV programs favouring women by the "self help group" and "buddy" strategies ? Are men's behaviour influenced by a vulnerability after infection which needs further analysis? Is this stituation specific to HIV or common to other chronic diseases? To this day, anthropological studies have shown that women's role obliges them, in many cultures, to shoulder a heavy care process, usually unrecognized and socially unvalued. Does this involvement give women better opportunities to access treatment than men, usually unfamiliar with care and health services? In this case, could the the "valence différentielle des sexes[1]"be one of the elements which contributes to a better access to ARV for women ? This hypothethic "reversal" of gender hierachy, whether it is solely limited to the issue of AIDS or whether it covers a variety of social aspects, needs to be further investigated with the help of specific and countrybased ethnographic studies.

[1] « Valence différentielle des sexe » is a concept developed by the French anthroplogist Françoise Héritier which refers to the social-structural differences between men and women.

Annita Hardon first projected a short movie (made in collaboration with a selfhelp group of HIV positive women working in one the ASSSR's program in Vietnam) illustrating the challenges that HIV positive women have to face in Vietnamese society. It highlighted the problem of reproduction of discrimination from older women directed toward young women, a model which is particularly common in "patrilineal societies". According to Anita Hardon, we can describe three ways to conduct research on gender and ARV.

The first possibility is to consider ARV as a gendered technology. According to a review made on the Lancet and the JAMA from 2000 to 2004, the study conducted by Anita Hardon's research team shows that although 50% of the participants in clinical trials concerning diabetes, hypertesion, epilepsy and AIDS, are now women, according to the international legislation, bioclinical differences between women and men are rarely analysed. One of the explanations to this result could be the fact that pharmaceutical companies which are funding these trials have little interest in dividing the pharmaceutical market. Philippe Msellati added that for a long time the male body was considered as the best body for clinical research (especially clinical trials) because women and children, referred to as "changing bodies", were considered too difficult to study. Sexual differences are then often disclosed after the introduction of the medicine on a large scale: nevirapine's resistances to ARV treatments were disclosed when the generic form of the medecine was chosen as a key pharmaceutical to prevent MTCT of HIV in Resource-Poor-Settings.

The second way to study gender and ARV can be the analysis of the discourses and practices produced by health institutions. For example, PMTCT programs offer several illustrations of the ways women and men are inequally considered. Resistances to névirapine, which is specifically used during PMTCT, were discussed by the international AIDS authorities only several years after the diffusion of the scientific facts. Moreover, within the PMTCT international recommendations, men are rarely considered as a risk factor in the transmission of the virus to the child. Finally, women are often treated within PMTCT programs but are rarely treated for their own infection afterwards.

A third way to study the issue is to analyse the use of the pharmaceuticals themselves. Are data related to men's and women's side effects to ARV sufficiently documented? What are women's real and reported body effects? Does the willingness to enter in an ARV treatment program vary from men to women (to stay alive, to protect the lives and/or the education of children, to carry on present activities, to carry on sexual activity). A variety of new investigations can be conducted out of the gender and ARV issue.

Based on an anthropological study related to circulation of money within the couple in Burkina Faso, Anne Atanné dicussed the potential impact of these social norms on the access to ARV. Many ethnographic examples show the importance of gift and counter-gift within the husband-wife relation and in the inter-personal and inter-family relations. In Burkina Faso, women often consider marriage as a way to enhance their social status. More over, it is socially stated that it is the man's task to financially support his wife or wives. Women's financial autonomy usually takes place out of the couple relations, particularly during community ceremonies where gift and counter-gift practices are carried out between friends and relations. Taking into account the economic reality which makes access to ARV dependent on financial aid, it seems relevent to question if HIV positive women have a network of financial help which is more efficient than that of men. This reflexion helps to open up new research on the vulnerability of HIV positive women. The AIDS epidemic could increase women's gift and countergift activities outside the couple in order to finance treatments. Discussion then focused on the fact that the epidemic could weaken or change the social construction of the couple in Burkina Faso and therefore alter the social sex relations, like the relations between generations.

2) Gender as a key factor for access to care

Pascale Hancart opened the second session whith a presentation based on an anthropological study conducted on a free access to ARV programs for women in Namakal,

South India. She first emphasized the importance of discrimination among HIV positive women in India and described the "victim and defendant" status of the infected women in the country. The Indian government set up a PPTCT (Prevention of Parent to Child Transmission of HIV) program, emphasizing the role of men. However, PMTCT strategies are generally inefficient and HIV care unequally distributed throughout the country. Pascale Hancart presented an analysis of the ARV access program she studied, focusing on the key role of NGOs to recruit participants. She also pointed out that the gathering of HIV positive women in a clinical context provided them with an opportunity to come out of isolation and thus to create social bonds. According to Anita Hardon, Pascale Hancart's intervention confirmed the interest to pursue resarch on PMTCT with a gendered study approach and also called for further investigation of women's access to HIV health care outside the PMTCT programs. According to Philippe Msellati, the decentralization, suggested by Pascal Hancard as a way to improve PMTCT and HIV care in India, is limited in its application. He suggested that discrimination among HIV positive patients was difficult to avoid, especially in the Indian context in which discrimination seems to be an important issue, if one considers the fact that the village nurse would personally give the ARV's to the patients.

Based on an anthropological study conducted on "the search for therapy, the social networks and the experience of People Living With HIV (PLWHIV) in Burkina faso", Blandine Bila presented a dicussion on the relation between gender and access to ARV. In this country, ARV programs target a larger number of women and this sex differential is also effective regarding the use of HIV/AIDS organizations. The study shows that men are experiencing difficulties disclosing their status, talking about their disease but also in going to the health care structures and to the medical consultations. As in the burkinabé society, it is socially stated that misfortune, and *a fortiori* AIDS, comes from women, she pointed out that "seropositivity in men" could be socially nonsensical. Indeed, the disclosure of one's infection represents a social risk for a man as it indirectly implies his incapability to protect himself. Men's seropositivity may indirectly refer to the inability of the man to preserve his descendants. More over, it is usually perceived as a failure that may weaken a man's social status in his familiy and in society. The men interviewed during this study often expressed their fear of exclusion which would result from discloser. The study shows that the AIDS empidemic can lead men to be vulnerable because of their social status' obligations. It leads them to hide their disease from others and from their partner. This situation sometimes causes men to adopt a high risk behaviour, to avoid HIV labelled institutions or even to adjust or to postpone their ARV treatments. A variety of strategies exist : a man interviewed in this study pretended he had an affair with an HIV positive woman working in a local HIV NGO in order to avoid specific tasks that she was doing for him (collecting medicine and food, participating in the positive group activities). He was, thus, able to acess HIV/AIDS labelled institutions without major social risks. According to P. Msellati, this situation is recurrent in Ivory Coast where men are not supposed to be sick and as a result, some of them adopt a conscious denial of their disease.

3) Social production of gender within ART management

Discussing the representations that patients of the Trimomune© cohort in Cameroon were developing regarding their medicines, Sophie Djechta opened the third session. The study shows that the fact that Triomune© is a generic medicine doesn't seem to be significant to the patients. Paradoxically, although Triomune© is a combination of molecules created by an Indian pharmaceutical company, patients consider the medicine as a western product. The packaging of Triomune® in a hermetically sealed box is associated with good quality (as opposed to street medicines which are usually sold per unit without any packaging). The analysis of patients' perception of Triomune® shows significant differences between men and women regarding the way they take medicines. Women often take their medecines in public (sometimes their children even remind them of the exact time to take the treatment) whereas men usually hide the drugs and take them in secrecy. Regarding side

effects, women often mention lipoathrophy and sometimes evoke changes in their menstrual cycles. Men have usually little to say about the side effects. Then, Sophie Djechta remarked that periods of nonadherence were more frequent with male participants, and that they were also more attracted by traditional medicines when they considered that Triomune® was unadapted or ineffective.

Eileen Moyer offered several coments which opened a set of new directions in research. If one considers stigmatization among thin people in Africa, could lipodytsrophy be considered as a sort of "socially positive" side effect of ARV ? Does the gender of the counsellor have an impact on access and adherence to ARV among women and men? No matter how important the impact of women's dependency on their husbands is on the access to ARV, the gender and ARV topic can also be observed outside the couple. Based on an anthropological study in South Africa among street men, Eileen Moyer highlighted the fact that a majority of the young men interviewed did not know of ARV. Some of them had never even heard of it. Pursuing the fact that the gender and ARV topic shouldn't hide other realities, the discussion gave an opportunity to the participants to have a direct reflection on the emerging topics of the workshop.

Saskia Walentowitz briefly presented the outcome of the study of Emmy Kageha who couldn't participate in the workshop. As a research assistant on a study on the socio-behavioural factors of breastfeeding transmission of HIV in Kenya, Emmy Kegaha analysed the gendered issues that appear during the counselling sessions. Saskia Walentowitz described how in Kenya counsellors did not often help the women talk during the sessions. This fact needs to be highlighted by women's social status in Kenya which can be described by an expression collected during the fieldwork : " *In Kenya women have to be seen, not to be heard*". Moreover, many counsellors are expressing their diffuculties to cope with patients of the other sex. This observation was confirmed by several participants who gave a set of ethnographic examples to improve the discussion. The impact of gender on relations between counsellor and patient and, moreover, on relations between the health care providers and the patients is another way to do research on the issue of gender and ARV.

Based on the study she is currently leading in Kenya on the Kesho Bora project, Saskia Walentowitz presented a part of her ethnographic work, giving special emphasis to a theoretical hypothesis. Given the fact that in Kenya the number of PMTCT sites is continuously increasing, she questioned the reasons why, beyond economical and institutional factors, PMTCT sites are not yet a channel for HIV positive women to access ARV treatments. She first reminded the "ambiguous nature" of women as "life givers" who are also considered then as "death givers" according to French gender theorist Françoise Héritier. Several ethnographic elements show that HIV positive women are pushed to feel guilty when they think about childbearing. Moreover she pointed out an often heard opinion saying, like this local actor of PMTCT management, that: "*As soon as they get on ARV, women get pregnant in Kenya*". Based on a structuralist approach, Saskia Walentowitz developed the hypothesis that ARV medicine might unconsciously be perceived as an anti-anti-oral-contraceptive that permits HIV + women to give life. This "symbolic reason" could be an obstacle to think PMTCT as an entry point for Kenyan women to access ARV. The discussion that followed focused on the need to conduct research on the symbolic aspects of ARV, in combination whith other factors (especially biological factors) in order to avoid over-interpretations. Other theoretical issues such as the status of PLWHIV whose rights to procreate are not respected were discussed. This subject opened a debate on the ways to combine theory and ethnographic data.

Based on the quality of the workshop's dicussions, Alice Desclaux concluded on the need to pursue ethnographic research on "Gender and ARV" in order to "reread" feminists' theoretical studies. Workshops organized by the NAARPS help researchers to improve their

personal analysis on the one hand, and offer an opportunity to think together about new and innovative research issues on the other hand. These discussions will be further developed for the next workshop in fall, and during future meetings, more particularly at the “AIDS impact” symposium in July 2007 in Marseille.

Workshop participants:

**Attané Anne** : In charge of research, IRD
**Bila Blandine** : PHD student in anthropology, CreCSS
**Desclaux Alice** : Professor in Anthropology/ director of the Centre de Recherche, Cultures, Santé et Sociétés (CreCSS)
**Djetcha Sophie** : PHD student in anthropology, CreCSS
**Hancart-Petitet Pascale** : PHD student in anthropology, CreCSS
**Hardon Anita** : Professor in Anthropology/ Director of the Amsterdam School for Social Science Research (ASSSR)
**Moyer Eileen**. : Post doctorate student in Anthropology, ASSSR
**Msellati Philippe** : Epidemiologist, IRD
**Ouvrier Ashley** : PHD student in anthropology, CreCSS
**Walentowitz Saskia** : Teacher and researcher in Anthropology at the Bern University (Switzerland)

Mis en forme : Anglais (Royaume-Uni)