

COMPTE-RENDU

Atelier AVRIL 2005 (Anglais)

Workshop « Anthropology of ART in resource-poor settings »

Aix-en-Provence, MMSH, 20-22 April 2005

Report

Céline Amiel, Emmanuelle Simon

Workshop organized by CReCSS (Centre de Recherche Cultures, Santé et Sociétés) with the participation of ASSSR (Amsterdam School for Social Science Research), IRD (Institut de Recherche pour le Développement, UMR 145 : Sida et maladies associées).

The aim of this workshop was to share knowledge and approaches on anthropology of ART in resource-poor settings. The topic was focused on adherence in the context of social treatment of AIDS. This workshop took place during three half-days shared in three sessions.

The first session « Approaches of the anthropology of ART in resource-poor settings » was composed of three presentations : Christian Laurent (IRD) : « The needs for anthropological research on the scaling-up of ART in resource-poor settings : point of view of public health », Brigitte Bazin (ANRS) : « The place of social sciences research on ART in resource-poor settings : point of view of National Research Agency on AIDS », Carla Obermeyer (WHO) : « Social sciences research in the context of scaling-up : point of view of WHO ».

As we are entering in the phase of scaling-up of access to ART in resource-poor settings, Christian Laurent proposed to develop researches in anthropology that might analyze, on one hand, the impact of decentralization on adherence, on the other hand, patients' and health care workers' perceptions and uses of decentralization. Several questions were raised : what will be reactions to models of "light" care associated to scaling-up ? Will patients accept follow-up by nurses ? Will decentralized structures providing ART be identified for HIV and therefore stigmatized ? What can be the impact on patients' health care behaviours ? What impact this scaling-up may have on the organization of local health system ?

Observing the international mobilisation about AIDS, Carla Obermeyer suggested to develop projects that will analyze divergent stakes of several international organizations (Global Fund, UNAIDS, WHO, and so on). These institutions, the norms and values carried by these structures, must be studied, and more particularly their articulation (or non articulation) to local structures (PNLS, CNLS, and so on).

Brigitte Bazin presented recent and on-going research projects on ART funded by ANRS. She highlighted the interdisciplinary approach, prevailing in several projects, as a necessary way of tackling ART in resource-poor settings.

The second session « Adherence : an anthropological object ? » was composed of five interventions : Anita Hardon (ASSSR) : « Anthropologizing adherence », Jean-Paul Moatti (INSERM, IFR SHESSAM) : « Public health and social sciences in the clinical research : interest of a multidisciplinary approach », Carla Obermeyer (WHO) : « Connecting professional and lay notions of HIV illness, prevention and treatment », Emmanuelle Simon (CReCSS) : « What do neo-traditional AIDS medicines “tell” about ART in West Africa ? », Alice Desclaux (CReCSS) : « From ideology to methodology, discussion of the conceptual frame to tackle ARV adherence in resource-poor settings ».

Everybody enhanced the fact that anthropology, concerned about implication and application, is linked to a reflexive approach. If the concept of “adherence” and the emergency to lead researches on its “factors” can be obvious for biomedical professionals (and more particularly in the case of HIV/AIDS for which adherence is important), this concept does not make sense so easily for anthropologists.

More generally, it was said that concepts which come from public health, such as the concept of “vulnerable women”, must be questioned, and the impact of their use at field level must be discussed. In a program in Burkina Faso, the labelling “vulnerable women” includes professional and occasional sex workers, and HIV+ women. The aim of de-stigmatizing sex workers on one hand, HIV positive women on the other hand, led to a new label that might have a pejorative content. The lack of critical look on this concept of « vulnerable women » raised a lot of questions from the audience, about, amongst other issues, the impact concerning the perception of the notion of “vulnerability”.

Alice Desclaux has presented an analysis that drew a parallel between the history of ART policies in resource-poor settings and the history of the anthropological thinking on ART,, underlining the dialectical relations between health realities and anthropological postures. She distinguished five periods :

- 97-98 : resistance from public health heads to set up an access to ARV in resource-poor settings. The anthropological approach of adherence is focused on the patient and enhances structural factors of adherence (mainly economic) rather than so-called social and behavioural factors enhancing the patient as responsible for non-adherence.
- 99-01 : following preliminary results of quantitative research showing that the level of adherence can be high in resource-poor settings, programs for access to ART are set up in Africa. Anthropologists move their look from the patient to the relation patient/health services : they show that beyond adherence factors already described in developed countries, some structural factors related to health care institutions are important in resource-poor settings, related to cost of medicines, distribution, etc.
- 02-03 : despite the setting of social care for patients, many patients become “lost patients”. The limit of an anthropological approach that considers only

“cohort patients”; this shows that the look of social scientists must move towards the relationship patient/ ART program.

- 04-05 : the improvement of access to ART and the diversification of “actors” involved in care leads anthropology to focus its analysis on the biomedical health care system and its participants, as “factors” of adherence (including associative networks).

- 05-06 : with the emergence of neo-traditional AIDS medicines, anthropologists re-set emphasis on a “cultural” approach of adherence, that considers adherence in a pluralistic health system taking into account its complexity.

From historical presentations of the concept of “adherence” (Carla Obermeyer, Anita Hardon, Alice Desclaux) and from more descriptive contributions (Jean-Paul Moatti, Emmanuelle Simon), several elements of definition could have been presented. First, adherence is a complex process. A disjoint approach concerning “information” and “adherence” (Carla Obermeyer) or the distinction between the two meanings of the French notion of adherence -adhésion and observance- (Alice Desclaux) have been presented as necessary. Carla Obermeyer has noticed the uselessness of many inventories of beliefs concerning adherence because adherence is also determined by a group of structural and institutional factors : power relations in health relations, gender relations, poverty, therapeutical pluralism, and so on. Alice Desclaux has also noticed the tendency of anthropology to put a look either marked by too much culture (culture as a barrier to adherence) or too little culture (focus on economic and politic). Secondly, adherence is a dynamic and fickle process. Jean-Paul Moatti has pleaded for an empathic approach of “adherence factors” criticizing the idea of “predictive factors” which still shape some decisions for inclusion of patients (qualifications of the adherent-to-be patient : associative, able to manipulate medicines, without noticed previous non-adherence). He has laid stress on the methodological necessity to study long term adherence.

Anita Hardon has proposed to set it in a dynamic process taking into account upstream the types of medicines, its perceptions and uses (ART and “combined” medicines, ART and generics, ART and innovation) and downstream health policies and the devices around these products.

In a similar way, Carla Obermeyer wanted to understand adherence according to the connection with disease, treatment and testing. Finally, for Emmanuelle Simon, since adherence depends on accumulation of experiences and knowledge, it is necessary to try to understand what can be experiences and knowledge accumulated during non-biomedical care itineraries which can interfere with adherence to ART.

Thirdly, adherence can not be reduced to a medically centered concept which contributes to denounce the “deviant” patient. Anthropology must not consider psychosocial approaches too much centered on the patient, and rather focus its analysis on the process of interactions between different actors involved in care (Anita Hardon). Brigitte Bazin has observed that there are few works which enhance the diversity of representations of adherence (definition, required conditions, ability of the patients, and so on) according to the different biomedical workers (nurses, doctors, and pharmacists).

Thanks to these preliminary observations, research leads have been defined : to develop more works taking into account a specific contextualisation to develop comparative analysis between access to ART in resource-poor settings, between various resource-poor settings and between resource-poor settings and developed settings ; to develop some researches at different levels (international, national, local) including an analysis of public health choices regarding ART.

The participants also claimed a real will to develop applied works. The support policy for the research presented by Brigitte Bazin (Cf. session 1) fulfilling interdisciplinary works has been well appreciated by the researchers from ASSSR. However, Jean-Paul Moatti has underlined the limits of this interdisciplinary : he has noticed that interdisciplinarity should begin first amongst social sciences before concerning clinical sciences. Moreover, this interdisciplinarity requires to strengthen concepts, methods, and position on the field. Some presentations, during the third session, which presented surveys flicking between social sciences and clinical research, gave an opportunity to warn young anthropologists about a kind of fascination for public health, biomedicine and clinical sciences.

The third session « Presentation of research projects » included seven presentations :

Sander Leusekamp, ASSSR « Participatory analysis of the development of national ARV treatment plans in both Uganda and South Africa », Céline Amiel, CReCSS « “This medicine is my life”. Real-life experience of ARV treatment in Cambodia », Aryanti Radyowijati, ASSSR « Adherence to HARRT regimens among HIV infected patients in the Dutch health care settings : the patients’ perspectives », Achilles Ssewaya, ASSR « Improving AIDS Medication in Ressources Poor Setting : Factors that Influence Adherence to HAART in Uganda », Sophie Djetcha, CReCSS « Gender and ART in Cameroon », Anselme Sanon, Centre Muraz « Psychosocial factors of adherence and ARV adherence amongst vulnerable women at Bobo-Doualasso (Burkina Faso) », Ann Ferrara, ASSR « Paediatric adherence to ART in Capetown, South Africa ». Most of them were PhD projects that at just began or were going to start.

Two presentations have received our attention ; besides, they sparked off discussions.

Céline Amiel has presented preliminary results of a survey led during two months in two public hospital of Phnom Penh. A consultation department in one hospital was set up by Médecins Sans Frontières. Her fieldwork enhances a relationship between health care workers and patients which appears as asymmetrical and authoritarian. This relation takes place in a context where ART are very difficult to access (the only mean to get treatment for a patient suffering from HIV/AIDS who can not afford medicines is to be registered in an active “file” of a NGO as MSF, MDM, and so on). Brigitte Bazin asked if there any variation between the two health structures observed, and if the observed hospitals reveal some behaviours which can be observed at a national level. Is this relationship really specific to ARV treatment ? Anita Hardon underlined the interest to go on a long term research to better perceive the correlation between this relationship and the national level of access to care. Céline Amiel’s communication which presents rigid and authoritarian positions towards adherence follows Aryanti Radyowijati’s presentation that shows that in Nederland’s, the

interruption of treatment is considered as the result of a rational choice by patients which has to be respected. These two presentations led Anita Hardon to claim again the interest to develop contextualised and comparative researches. This imperative has been also enhanced during the discussions after Sophie Djetcha's presentation.

Sophie Djetcha presented results of a survey led in articulation with a clinical trial about the generic « Triomune » in Cameroon. The trial was led in two hospitals at Yaoundé with a cohort of 60 patients. The survey was held during one year in 2002 with 17 patients. Sophie Djetcha enhanced the masculine vulnerability (and not the female one) showing meaning gaps about adherence after a one-year treatment. According to Sophie Djetcha, women's desire for children and the setting of PMPTCT encourages women's investment in community based organizations and contributes to a better adherence. Concerning men, the improvement of their health would go with a greater social pressure which pushes them to create a family. But they can not fulfil this project and can not even plan to become fathers. On the basis of these results, Sophie Djetcha suggests to implicate more men in PMTCT. Latifa Imane, underlined that opposite observations have been made in Mali : the maternity project is counteracted by the fear of toxicity of medicines. Beyond the importance of leading researches in specific contexts, Latifa Imane suggested to tackle these questions by trying to understand how PVIH associations can be places of inversion of power relationships between men and women.

During the closing session of the workshop, a research network has been set up : NAARPS (Network for the Anthropology of ART in Resources-Poor Settings). A workshop has been also planned at Fall 2005 in Amsterdam, to discuss about anthropological methods to lead researches on access to ART in resource-poor settings.

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