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# Neither here nor there

## The anthropologist back from the clinic

Christine Kopp

Ethnographies are almost inevitably introduced by a description of the anthropologist's arrival in the field, «the initial reception by the inhabitants, the slow, agonizing process of learning the language and overcoming rejection, the anguish and loss of leaving» (Pratt 1986: 31). This personal narrative takes a somewhat different turn when the field is a large university hospital in Switzerland, just a short walk from the ethnographer's home, and the ethnographer thus cannot rely on the fascination of the exotic when presenting herself to her readers.

I entered the clinic for what eventually turned out to be almost five years of part-time work at the HIV outpatient department in what is probably a paradigmatic way for an anthropologist, that is, by coincidence and connections. I was initially employed as a counselor for the Anonymous HIV Counseling and Testing Center where my work gave me a faint idea of what it must feel like to be a medical doctor. This included the power and responsibility that resulted from the astonishing openness and confidence which

persons coming to take an HIV test brought to me, my clearly defined role, and my duty to tell them what is right and wrong when trying to protect themselves against an HIV infection. As an ethnographer, I was used to asking questions for the sake of my research interests, or in order to fulfill academic requirements. Here, I was asking questions (knowing the desired answers) for the sake of public health. I subsequently went back to the job of research by transferring to two research projects in the field of HIV which had been designed by medical doctors. Assessing and evaluating the research data again confronted me with the different cultures of anthropology and medicine, this time at the level of scientific methods. As can be expected of an anthropologist, I gradually immersed myself in the new culture. The «slow, agonizing process of learning the language» (though luckily not having to overcome rejection) that Pratt describes culminated in my case in the decision to learn biostatistics as part of the language of medical research. An intensive ten-



day course that could be described as a rite of passage revealed some of the basics of a new world of thinking, of expressing meaning and claiming authority and truth. Entering the world of medicine also meant participating to a limited degree in the reciprocity of giving and receiving co-authorship for favors done or alliances established or desired. The furthest this game carried me away from my own field of knowledge was when I became the third author of an abstract called: «CD95 (fas)-expression on CD4- and CD8-lymphocytes of progressors and non-progressors to AIDS» (Harr et al. 1997)<sup>1</sup>.

Partially entering a new community and acquiring a new language meant that a whole genre of scientific literature suddenly made more sense to me, or at times revealed its nonsense, and gave me the keys to presenting our work to a medical audience according to its standards. At the same time it became more difficult to find a common language with anthropologists. As a researcher, I therefore found myself in a somewhat liminal situation as described by Turner (1969: 95): «neither here nor there; he is betwixt and between the positions assigned by law, custom, convention and ceremonial».

A turn back toward anthropology was taken through a proposal to the National AIDS Research Programme that was based upon anthropological premises. The project, which I am currently trying to elaborate into a thesis, was designed and carried out by fellow anthropologist, Stefan Lang, and myself in collaboration with medical doctors, and headed by Prof. Hans-Rudolf Wicker from the Institut für Ethnologie of the Universität Bern. Formally, it was thus affiliated with the Institut für Ethnologie while we continued to work at the Inselspital in Bern, again symbolizing the fruitful and ambiguous balancing act between anthropology and medicine<sup>2</sup>.

Under the project title «Explanatory models of HIV and their relevance for patient care», we explored health care and treatment of persons with HIV outside

the specialized HIV departments in hospitals and clinics. While at least quantitative data is routinely assessed in the clinical setting, very little is known about the situation amongst general practitioners and complementary therapists<sup>3</sup>, an imbalance that our project attempted to correct. Based upon our evaluation, we provided starting points for improving health care around HIV.

Either through luck or intuition (but I assume it was the former), our research was carried out during the time of the most dramatic changes persons with HIV, doctors and researchers in HIV had faced to date. In the industrialized countries, a new generation of antiretroviral drugs, the protease inhibitors, in combination with the already known antiretroviral medication, were for the first time capable of favorably influencing the course of the infection on a broad level. In short, dramatically fewer people in Europe and Northern America were becoming sick with AIDS and dying. The 1996 11th World AIDS Conference, the first one I personally attended, was characterized by euphoria over the new treatment possibilities. HIV specialists carried the euphoria home to their clinics whence it subsequently trickled down to persons with HIV and into general practices, to be received, revised, rejected, and resisted. Our study thus describes how people with HIV and their doctors, both representing the users' side of the scientific knowledge produced and diffused, are trying to make sense of the sickness and how they struggle to position themselves in the face of ongoing changes. As concepts of the sickness, its care and treatment were constantly changing, as reflected also by the actors involved, we chose to investigate them as ongoing processes.

The study combines qualitative with quantitative data, narration with numbers, providing a configuration that is rather unusual for anthropological research. The methods applied were partly chosen with regard to content, and partly, even though this aspect is usually not mentioned, to strategy. On the strategic level, we wanted to combine the language of

<sup>1</sup> (No, I cannot explain what CD95 (fas)-expression is all about.)

<sup>2</sup> The ambiguity of clinical anthropology has been described amongst others by Singer (1995: 351-370) in a chapter asking: «How critical can clinical anthropology be?»

<sup>3</sup> While our research included also complementary therapists, I will concentrate on our work amongst persons with HIV and general practitioners for my thesis, and therefore in the present paper as well.



<sup>4</sup> Doctors are still mainly male: 88% of our random sample of 542 general practitioners were men.

<sup>5</sup> Atkinson (1995: 148) describes the importance attributed to the doctor-patient interaction as an attempt to keep medical work analytically within comprehensible borders: «Nevertheless, the consultation between patient and practitioner is but one locus of medical discourse. It does not capture the complex organization of modern medicine. Indeed, an obsessive focus on the one-to-one clinical consultation makes the tone of so much medical sociology and anthropology almost nostalgic for a simpler age of medical work.»

<sup>6</sup> As reviewed by Lock (1993).

<sup>7</sup> See for example: Lock and Gordon (1988); Hess and Layne (1992); Lindenbaum and Lock (1993); DelVecchio Good (1995); Casper and Koenig (1996).

<sup>8</sup> The fact that these issues are largely missing in the explanatory model approach has been broadly discussed and therefore is not taken up here.

<sup>9</sup> The contemporary value attributed to the immune system is described on a broad level by Martin (1994), leading her to the conclusion that the immune system serves as the paradigmatic image of the postmodern person, flexibly adapting to a constantly changing environment. Interestingly, in the struggle between virologists and

anthropology with the language of medical research. More important were the reasons with regard to content: The conditions that limit or favor HIV transmission, the representation of the sickness as well as its treatment and care are not subject to disciplinary boundaries (Benoist and Desclaux 1996). We thus tried to overcome these boundaries by collaborating with medical doctors, working within the medical setting, and by combining methods from both fields.

Instead of focusing on the doctor-patient interaction, the more common approach for social scientists analyzing health care, we interviewed persons with HIV and their doctors separately. The reasons for this choice were twofold: firstly, not all persons with HIV are patients, and we wanted to include non-patients as well. Secondly, a decreasing fraction of the work of the doctor is determined by his<sup>4</sup> interaction with the patient. Instead, there are specialist consultations, laboratory results, or economic and political negotiations which gain in importance<sup>5</sup>. As a consequence, medicine moves increasingly away from the patient. It might provide more insight into health care to analyze, say, the interactions between physicians and representatives of pharmaceutical companies visiting them in their offices than to observe the doctor-patient interaction. Our methodological decision was strengthened by the observation that the introduction of the new combination therapies further supported the move away from negotiations between patient and doctor and toward basic science and specialized medicine as the loci of decision-making in HIV care and treatment.

On a theoretical level, we quite crudely took as our point of departure the «explanatory model» approach developed by Kleinman (1980) in his milestone book on medical anthropology, an approach which has been used over and over in applied research in the field of medicine. It may hardly be surprising that this point of departure soon proved to be too narrow. Theories of the body and its role in constructing self and sickness<sup>6</sup>, as well

as research into science and biomedicine as a social and cultural system<sup>7</sup>, broadened my view of our research topic. Most importantly, they helped me understand the intense negotiations over boundaries, power, competence, and control addressed by our interview partners<sup>8</sup>. These negotiations take place on different levels which may be sketched out only roughly here.

For the person afflicted by the sickness, the physical boundary of the body has been violated, as the virus is often experienced as an outside invader. Its embodiment circles around re-establishing personal integrity, autonomy, and control in the face of the potentially uncontrollable virus, the «ghost» as one person put it, within the body. Organizing the experience of disruption brought about by the infection through boundary work and developing mechanisms to control the outsider from within draws largely on the notion of pollution and the cultural reactions to it as developed by Douglas (1966). The immune system, as the body's network for distinguishing between self and other and for organizing rejection, integration and adaptation, receives symbolic value as the physical expression of the struggle for integrity and control<sup>9</sup>. This struggle is also carried over into the health care process, where it becomes highly accentuated when the question whether or not to take antiretroviral treatment arises. Treatment may threaten the integrity and autonomy achieved in a long personal process of incorporating the sickness<sup>10</sup>. On a physical level, the medication receives a status similar to the virus itself, entering the body as an unknown factor from the outside and acting unpredictably within the body (as one woman said: «Maybe then everything really runs out of control. If I take all that medication, I cannot distinguish anymore what I am causing and what the medication is causing, and that scares me.») On the social level, treatment means highly increased dependence on the health care system, including its practitioners and the technical devices that produce, for example, the laboratory data which largely guide treatment.



While much research focuses on asymmetry and dependence between patient and practitioner, our interviews showed a formal analogy between the situation of patients and general practitioners: the latter seem to be just as anxious about re-establishing boundaries and keeping independence and control as their patients are. The boundary they defend runs between general and specialized medicine, between individual expertise and clinical science. Large-scale initiatives in medicine aiming at an increased integration of the results of clinical trials into the daily work of the general practitioner, represented by an approach called «Evidence-Based Medicine» (Sackett et al. 1997), cause fear and resistance amongst a portion of general practitioners<sup>11</sup>. The issue is further accentuated in HIV care through the need for specialized knowledge to initiate and monitor the highly complex treatment regimes. Some practitioners refuse to do «cook-book medicine» (the cook-book being the official treatment guidelines written by specialists interpreting clinical trials), which they perceive as negating their own expertise and experience. Others complain about the asymmetric relationship with specialists (to put it in the words of a general practitioner interviewed: «We as general practitioners are not all that stupid. But sometimes that's what the HIV clinics make us feel like.») As stories about losing patients to the HIV clinics after referring them for specialist consultations indicate, the struggle between generalists and specialists also entails concrete economic implications along with the struggle about knowledge, competency, and ultimately power, which in turn characterizes medicine as a whole.

As I recently moved my office from the HIV department to the anthropology department, again separated only by a short walk, I have gained just enough yet not too much distance from medicine to reflect about its working and its power. To shape these preliminary reflections into a thesis, however, I still have a somewhat longer way to go.

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immunologists within basic science on HIV / AIDS over who adequately defines the sickness, immunologists have recently regained some territory.

<sup>10</sup> As Lock (1993) notes, in the face of independence as a high cultural value, loss of autonomy through sickness may produce contradictions in individual embodiment. Regaining autonomy in relation to HIV may thus reduce such contradictions, an achievement all the more important when a sickness is as stigmatized as HIV.

<sup>11</sup> The widespread reluctance toward Evidence-Based Medicine is commonly articulated in terms of the non-congruence of clinical science producing numerical data from large populations and the work of the practitioner directed at the individual patient and his/her specific situation, known as «the art of medicine». The symbols of science and art in medicine, going back to Aristotle (Wieland 1993), may hide «much that is not very scientific nor very artful» (Gordon 1988: 258).



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