

INTRODUCTION

Ethnographies are almost inevitably introduced¹ 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 home², 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 physician. 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 physicians. 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 described culminated in my case in the decision to learn a bit of biostatistics as part of the language of medical research. An

¹ The present introduction is a revised and extended version of an article entitled "Neither here nor there: the anthropologist back from the clinic" (Kopp 2000).

² As Gupta and Ferguson pointed out, a main feature of the classical "field" of research is its spatial separation and its distinction from home: "The very distinction between 'field' and 'home' leads directly to what we call a *hierarchy of purity* of field sites. After all, if the field is most appropriately a place that is 'not home', then some places will necessarily be *more* 'not home' than others" (1997: 13, emphases in original). When adopting such a 'hierarchy of purity', then my field has to be characterized as highly impure – which in turn contradicts the very idea of a hospital.

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)³.

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: "neither here nor there; he is betwixt and between the positions assigned by law, custom, convention and ceremonial" (1969: 95). Singer brilliantly describes the ambiguity of clinical anthropology in a chapter asking: "How Critical Can Clinical Anthropology Be?" (1995: 351-370). Facing a rather lonesome position as a social scientist, the anthropologist is driven by the desire to gain legitimacy in the eyes of her colleagues, the medical practitioners, she engages in medical discourse, and her attempts to study the medical arena might turn out to be more difficult than studying the less powerful patients. In a diary entry dating January 29, 1998, I wondered about my role as an anthropologist in a field as political and controversial as HIV/AIDS⁴. The list included: The anthropologist as a foreign body in the clinic – The anthropologist as the advocate of the patient – The anthropologist as a mediator – The anthropologist who herself needs a good physician – The anthropologist who wishes her work was as clear and needed as the physician's. The list of the anthropologist may be extended.

Just when anthropology started to become more exotic than the familiar clinical setting, a turn back toward anthropology was taken through a proposal to the National AIDS Research Programme that was based upon anthropological premises. The project was designed and carried out by fellow anthropologist, Stefan Lang, and myself in collaboration with the physicians Anne Iten, Hansjakob Furrer, and Jan von Overbeck, 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.

³ (No, I cannot explain what CD95 (fas)-expression is all about.)

⁴ HIV stands for Human Immunodeficiency Virus, AIDS for Acquired Immune Deficiency Syndrome.

The project aimed at exploring health care and treatment of people with HIV mainly 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, an imbalance that our project attempted to correct. Based upon our evaluation, we provided starting points for improving health care around HIV (Kopp and Lang 1999; Kopp et al. 1998a; 1998b). While our research also included complementary therapists, I will in the following concentrate on our work amongst persons with HIV and general practitioners.

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, i.e. during the period in between the 11th International Conference on AIDS 1996 in Vancouver and the 12th World AIDS Conference 1998 in Geneva. In industrialized countries such as Switzerland (Egger et al. 1997), 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 reports of people who had resigned themselves to the reality of an early death and now were challenged by the need to develop new life perspectives became popular (Johnson 1997). Meanwhile, people with HIV also feared being redefined from activists to patients (Hirsch 1997). The 1996 11th International Conference on AIDS⁵, 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 per-

⁵ International AIDS conferences, taking place annually from 1985 to 1994 and then changed to a bi-annual rhythm, are a powerful and highly sponsored social enactment of current tendencies and debates in HIV/AIDS research. As Feldman noted, based on fieldwork amongst AIDS doctors: "The experience of *communitas* is not lost forever to my informants but is now integrated into an annual ritual known as the International AIDS Conference" (1995: 183). Besides researchers, also people with HIV populate these conferences as a compulsory, although preferably marginal component which does not always suit the scientists. Treichler cited Robert Gallo complaining about "the amount of diversity" at the 1989 conference in Montreal: "You can't even find the people you want to talk to anymore" (1992: 78). It is probably the social and ritual quality of the conferences that makes them attractive also for fieldwork by social scientists such as Feldman and Treichler. In reviewing science and technology studies, Hess found ethnographic research to increasingly move from the laboratory into a variety of new settings, including conferences. He interpreted this move as reflecting the shift from studying the social construction of scientific facts toward the cultural reconstruction of scientific discourses as they diffuse through scientific and nonscientific communities. In studying the latter, Hess found conferences "a crucial site for ethnographic research. Unlike the laboratory, the conference provides a setting in which the research community is assembled, social and ideological divisions are often clearly evident, and affected publics may also have their voices." (1992: 15). The description similarly reflects my own impression of AIDS conferences.

sons with HIV and into general practices, to be received, revised, rejected, and resisted. By the 1998 12th World AIDS Conference in Geneva, researchers had been sobered of hopes that the new drugs might cure the infection, and a more pessimistic discourse around drug resistance, treatment failure, and the inaccessibility of the new drugs to most people with HIV living outside of Europe and Northern America was predominant. Possibly this more pessimistic discourse was anticipated and accentuated by our interview partners and the people responding to our questionnaire who to some degree looked at the developments from the margins. Most of the physicians worked outside the specialized HIV centers, and people with HIV not only looked back over a prolonged experience with their infection, but their favorable course of infection also allowed them a critical distance toward medical treatment⁶.

The research thus captures a crucial moment of transition in HIV/AIDS brought about by the introduction of new treatment options. As the image of HIV was changed from a lethal to a potentially chronic disease, people with HIV and their physicians, both representing the users' side of scientific knowledge, were trying to make sense of the sickness and struggled to position themselves in the face of the ongoing changes.

While I develop my work from a central moment in the history of HIV/AIDS, I do so not only through the eyes of mainly rather critical study populations, but also from a geographically marginal perspective. Switzerland is not precisely a global center of HIV/AIDS research. While at least in biomedical research it gained considerable reputation through the Swiss HIV Cohort Study SHCS (Francioli 1999; Ledergerber et al. 1994), little anthropological research in this field is generated here. There are some disadvantages to this fact, most notably a relative isolation as a researcher. Yet the perspective from the margins may to some degree also support the researcher in keeping, like her interview partners, a critical distance towards the changing trends – both in biomedical and in anthropological research.⁷

The study combines, as outlined in chapter 1, qualitative with quantitative data⁸, narration with numbers, providing a configuration that is rather unusual for anthropological research. The methods applied were partly chosen with regard to content,

⁶ For a detailed description of our study populations, see chapter 1.2.

⁷ For further reflections on the role of the "field" in contemporary research and on the relationship between the global anthropological center and its periphery, see chapter 7.

⁸ For a discussion of such a combination, see Bryman (1988). One of the rare anthropological examples involving such a combination is Lock's research on the menopause in Japan and the United States (Lock 1993b).

and partly, even though this aspect is usually not mentioned, to strategy⁹. On the strategic level, we wanted to combine the language of 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 physicians, working within the medical setting, and by combining methods from both fields.

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 that 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 narrow¹⁰. Theories of the body and its role in constructing self and sickness as well as research into science and biomedicine as a social and cultural system¹¹, 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.

While many themes as well as part of the underlying concepts changed during the course of this research in accordance to what our interview partners told us, we stuck to the belief that studying HIV and health care from an anthropological perspective cannot be limited to the patient and her perspective of illness, giving her the status of the subjective, the irrational, the non-compliant, the unpredictable factor that distorts medical objectivity and health care, thus implicitly assuming that medicine would be so easy if physicians just did not have to deal with patients. Instead, we treated people with HIV and physicians equally, interviewing both and asking the same type of questions. Not surprisingly in the light of an increasing body of research on biomedicine, we found that the "problem patient" might be the physician himself¹², and his non-compliance may be just as rational as the one of his patients.

Instead of focusing on the doctor-patient interaction, we interviewed people with HIV and their physicians separately. The reasons for this choice were manifold:

⁹ According to Rouse, networks of scientific communication "shape both what needs to be said and what vocabulary and technical resources can be appropriately utilized" (1992: 11).

¹⁰ As Kleinman himself commented: "Clinically the explanatory model approach may continue to be useful, but ethnography has fortunately moved well beyond this early formulation" (1995: 9).

¹¹ Part of this research cumulated in the "science wars" fought between researchers from the social sciences and scientists over the authority in science (Fujimura 1998).

¹² Physicians are still mainly male: 88% of our random sample of 542 general practitioners were men.

The New Era of AIDS

HIV and Medicine in Times of Transition

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