

CHAPTER 1

METHODS AND STUDY POPULATIONS

"People with HIV/AIDS are a vulnerable group that should be protected from researchers."¹³

1.1. METHODS: NARRATIVES AND NUMBERS

Anthropologists doing research in the field of medicine are still rather surprising for their research subjects. While psychologists have a clearly defined role within medicine, anthropologists remain, at least in Switzerland, undeterminable, even more so for the physicians than for the patients, as I may illustrate by a passage from my interview with the general practitioner Jonas Ender:

"On the one hand there are components like in any malignant progressive disease, but where you somehow never really know what is actually going on. (...) I have this patient with a Polycythaemia vera who... – are you a physician or a psychologist?

ck: Neither nor. An anthropologist, social scientist.

An anthropologist? – Well, I'll have to stop speaking in technical terminology then. Okay, that is somehow a semi-malignant blood disease which can also develop over ten, fifteen years. Well, the blood produces too many red blood corpuscles."

At times, being an anthropologist in medicine became tiresome since it required continuous justifications and explications. Yet the indeterminable status of our profession also bore the advantage that we seemed to be open enough to our interview partners to allow different meanings, attitudes, and explanations to be elaborated on with us. Thus, while we were not clearly positioned in terms of professional background, our connection to the HIV center at the outpatient clinic of a large university hospital did position us in terms of institutional affiliation. On a national level, the HIV centers represent the sources of biomedical knowledge from where it flows to the peripheries of smaller hospitals, general practitioners, patients, and the public.

¹³ Quoted from Ambrose Rachier, 12th World AIDS Conference, "Bridging Session: Ethics and Science", July 1, 1998.

HIV centers therefore occupy a position of power which is both acknowledged and resisted.

Most of my knowledge of the biomedical aspects of HIV/AIDS and its treatment is based on my working within the HIV center, attending rounds, conferences and further education, reading journals and articles passed amongst the team members, and discussing new developments. Based on this fieldwork, I analyze in some chapters of this book how knowledge is produced, established and diffused in medicine through scientific articles and social events, mainly conferences.

Working in an HIV center also influenced my implicit understanding of medical work and of HIV care and treatment. Institutionally, I was closer to the initial enthusiasm about the new combination therapies and the so-called "aggressive" approaches to treatment than the doubts and reluctance I encountered when interviewing general practitioners and people with HIV. When I focus in this book on HIV care provided by general practitioners, I am thus doing so by peering over the boundary between specialized and general medicine. It might be because of the very fact that I kept going back and forth between specialized and general medicine that I increasingly became aware of their struggles over where the boundary is to be drawn and how much autonomy and competence is attributed to each side.

The main two phases of our empirical study involved first interviews and second a questionnaire survey. Further fieldwork though took place after this fieldwork, i.e. when I had moved to the anthropology department to "write up" this text in the classical, though in my case minimal spatial separation from the field (Clifford 1997). Following the themes that emerged in the empirical study into various directions involved data gathering using methods quite different from those that initially characterized the research. Instead of merely writing up, I followed discussions in Internet newsgroups, analyzed media coverage, drug advertisements, or discourses in medical journals. As I remained almost "naturally" connected to these sources, it seemed to make little sense to limit my analysis to the data gathered in the initial research process.

In the first phase of the empirical study, we conducted semi-structured interviews (Britten 1995b; Kiefl 1991) with people with HIV from the Long-Term Survivor Cohort recruited for a former interdisciplinary study on long-term survival (Kopp et al. 1999) and with their health care providers¹⁴. Physicians tend to be surprised, if not doubtful, when a study is based on interviews and thus attributes ana-

¹⁴ Health care providers, as mentioned in the introduction, included orthodox physicians and complementary therapists. As I focus here on orthodox medicine, I will not describe our empirical work with complementary therapists.

lytical status to narratives. Nevertheless, in contradiction to the language of medical science dominated by populations and numbers, the language of medical practice is also based on individuals and narratives, as represented by the medical anamnesis and the medical history (Good 1994; Mattingly 1998)¹⁵. The narrative though not only holds a weak position in medical research, but also a somewhat ambiguous position in medical practice. With increasing possibilities to look into the body and to extract data from it, i.e. through visual methods or laboratory tests, the narrative receives the status of an unreliable subjective account of what is really going on in the body, an account to be verified, modified or rejected through the objective data provided by biotechnology. Despite this unreliability, the narrative provides a main starting point for the clinical investigation (Hydén 1997), and, after all, an evaluation whether diagnosis and treatment are considered to be effective.

The questions we put together for the interviews covered definition, etiology and course of HIV/AIDS, sources of information on HIV/AIDS, living with HIV or working as a physician with HIV patients, health care, doctor-patient interaction, antiretroviral treatment and compliance/adherence. We discussed the interview questions with anthropologists, a senior physician at an HIV center, a complementary therapist, a general practitioner and an epidemiologist, and subsequently revised the questions based on their feedback.

We conducted a total of eleven interviews with people with HIV and eleven interviews with their physicians. Of these 22 interviews, 13 were conducted by myself and the remaining nine by my colleague Stefan Lang. 18 interviews were held in Swiss German, three in French, and one in English. My colleague and I each tried to interview the same persons with HIV we had already interviewed in the prior project and therefore already knew personally. Each of us subsequently interviewed the physicians caring for the persons with HIV we had interviewed.

The names of our interview partners are pseudonyms. While the mix of names of Swiss German, French, and other European origins should indicate the variety of the people we talked to, they do not represent the origins of the individual interview partners. To further grant our interview partners anonymity, I changed some of the personal attributes of the interview partners.

The interviews lasted between 30 to 90 minutes and were tape-recorded. Interview partners who wished so received a tape and/or a transcript. The interviews initially were transcribed fully and verbatim in their original language, although the

¹⁵ The case history as a classic form of presenting medical knowledge provides a middle level between the work with the individual patient and medical science. It represents the standardized way in which individual patient cases are recounted, reflected upon, and generalized.

The New Era of AIDS

HIV and Medicine in Times of Transition

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