

CHAPTER 3

TRANSLATING MEDICINE TO ORDINARY PEOPLE

"Cautious skepticism is simply what any sensible person is inclined to exercise when dealing with professionals who have the kind of power that doctors have over their patients' lives."
(Durant 1995)

ANDREA MEIER: A BALANCING ACT

For the first time now I was really profoundly moved by this treatment decision. So far I always thought: I feel well, and that's the most important, I feel well now, and I don't think that far into the future, and the past, that's over, I can't change that anymore, it is how it is. And a treatment decision is always oriented toward the future, you start planning: What could happen? That really got me, really for the first time, how shall I say, almost pulled me down, because there are all these abstract figures, CD4 figures and viremia and tablets, so many tablets, and traveling so many times to the HIV center, and I might not get anything out of it. Maybe, maybe not. And then I thought that somehow this is much worse for me than when I just think: I am feeling well, and maybe I do not know too much. In addition, I planned to go hiking in France and to take a language course in Spain this summer, and then I just do not want to organize my whole life around this medication. For I see that somehow I would place my hopes too much on the medication instead of on myself, and for the moment that's an imbalance to me. That's why I now just thought: not for the moment, in fall I might think about it again.

Actually it was good now to really think about it, because it did indeed get closer again. Also with all these people – family and friends – around me. I intensely talked to some twelve people about it, just to hear how others would deal with something like that, how they see it. That was a good thing, also just to know that all these people are around, no matter what happens. And that was actually what was good for me, this very basic reflection: What is the matter with my life? What will I still do and what do I want now?

I thought for a long time about going into psychiatric treatment. I mean, treatment, just talk to someone, since I was confronted with so much, and all these people that know me, they are emotionally affected, want the best for me and don't really know either. And it was a big thing in my family, and so I thought, somehow I should talk to someone not so involved, who can speak objectively. I had already looked for addresses,

but then I dropped it again. I also contacted physicians, called the "Aids-Hilfe", all the things that I had never done before, looked everywhere for information, and everybody was a bit at their limits. My general practitioner was helpful, he could really tell me that there were so and so many tablets, and different complicated combinations, these tablets in the morning, these at noon, these in the afternoon, and that was what I had to expect. I think that's very good about him, he doesn't just say: now you have to, and do this, and watch out. Instead, he really tries to tell me as he knows me I have been rather cautious about medication and always tried it with nutrition and things like that, and therefore he would suggest to think it over. I just prefer this way to someone trying to put pressure on me, saying: now you have to. Because then I don't understand why I do something, whose opinion it is. As far as I am concerned, a physician doesn't have to tell me what I have to do, he has to inform me. Although, it actually means more than providing information, it also means, somehow, translating medicine to ordinary people. We somehow have a relationship that made me realize he is interested as well, and he passes on what he knows, and that's quite good.

I have been with him since, yes, since 89. I went there as I suspected – well, it was a complicated story – as I suspected that I might have been infected. He has been involved in my care since the very beginning. And he also knows my partner, and all these conversations are always quite personal. When I just used to go there once a year to be monitored, I found that it was of no use for me, and he didn't know anything more to do (laughs). Then I thought that I might have to talk to someone who is less concerned with the medical side of it. But now I have given up that idea, since now, somehow, I found that medicine is again an issue now, and you can't neglect that anymore, nowadays. I mean, I can't just go into the woods and say goodbye, I have nothing to do with the world anymore. That's why I think it is good for me now.

Back then, when I went less to the physician, laboratory values didn't mean anything to me, I didn't want to know how many cells and things like that, because it didn't mean anything to me. Although now, with the perspective of medication, laboratory values are, yes, important. You are almost a bit forced to it. Except if you were just to say no to everything, that of course is another possibility. I'm of course always a bit in conflict, I also always think: in earlier times, it was like this or like that, but I mean, we live now, in 1997, and science and medicine came to this point, and we are all involved in it, in one way or another. You can't just say no to everything, because then you can't live in this world anymore. Somehow it is also a way of being realistic, with these laboratory values. If indeed these CD4 values were dropping now, then I certainly would try it with these drugs, there somehow is a glimmer of hope, that's clear. I somehow just thought that I will still wait a bit, and I just monitor it more regularly. It is after all a balancing act, because you should not wait until they really drop, then it is simply too late. It is not easy if you have to make these decisions that suddenly give you the feeling: you might fall ill. Death might be close.

The introduction of combination therapies profoundly influenced the interaction between patients and their doctors. As a consequence of medical powerlessness and active involvement and interference of persons afflicted, the early phase of the HIV epidemic was characterized by new approaches to public health. They included a

major emphasis on prevention⁶⁸ and privacy rights, and collaboration between people affected, social movements, public health officials, medical professionals, and political parties. These approaches are commonly described as "HIV exceptionalism" (Bayer 1991; Rosenbrock et al. 2000). The state of exceptionalism also left its traces on the doctor-patient interaction. In the situation of medical impotence, physicians who had to offer little in the face of a deadly disease were confronted with well-informed and active patients, above all gay men. While activism tended to empower patients, the relative inability to act tended to reduce physicians' authority since "in the absence of medical power, it was difficult to be arrogant" (Bayer and Oppenheimer 1998: 5). To some degree, the combination of bottom-up activism and therapeutic impotence leveled off the inequalities inherent to the doctor-patient interaction and entailed what Bayer called "a new, more 'democratic' style of medicine" (ibid.: 5).

The "patient as expert" became a key rhetoric to grasp the new doctor-patient interaction: "In this sense, the doctor-patient relationship is not a simple relationship between an expert and a relatively uninformed layperson but, in a real sense, a meeting between experts" (Walker and Waddington 1991: 129). André Favre similarly described the relation with his patient as actually dissolving the doctor-patient relationship (which is therefore implicitly described as being asymmetric by definition) by being an exchange on an equal level. In his description, though, such an interaction is not characteristic for all encounters with HIV patients:

"He always challenged me, in a pleasant way. He was always up to date, sent me sometimes articles to have a closer look at something (...). With him, it is indeed closer than with other {HIV patients}. That somebody knows so much about it – he actually knows more than I do – does not apply to the others. Therefore it is very interesting with him, it is really on one level, it is not the doctor speaking with the patient, but it is indeed one level, the whole exchange. Therefore it is very pleasant."

Conventional wisdom holds that with the shift from HIV "exceptionalism" toward "normalization" through treatment, the expert position of the HIV patients is attempted to be undermined and power to be reclaimed by physicians: "It is more than probable that medicine will try to push its virulent claim to power in the field of AIDS at the expense of those groups they so far, like it or not, had to cooperate with due to their own powerlessness" (Dannecker 1997: 17). Impotence is to be shared, power to be kept. While there is, of course, some truth to this argument, I prefer to draw on the approach of Kaufman (1988), who argued that the dichotomy between medical power on the one hand and patient autonomy on the other fails to grasp the assumptions about the boundaries of medical authority (and, I may add, patient autonomy) that are held by patients and practitioners alike.

⁶⁸ Dannecker described prevention as "the key word of the forces organizing themselves in the shadow of medical impotence" (1997:12).

The New Era of AIDS

HIV and Medicine in Times of Transition

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