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Powerful matter

The role of pharmaceuticals in HIV / AIDS and medicine

Christine Kopp

«As I say to my patients: if something really is a breakthrough, I do not have to study the latest scientific literature to find out about it. First the stock market finds out the company that produces it, and when all of a sudden their shares are rising, then I know something is hot.»

François Neher

In the second half of the 1990s, the symbolically charged field of HIV and AIDS has been dramatically changed. A new generation of antiretroviral drugs, the protease inhibitors, in combination with the already known antiretroviral medication finally provided the opportunity to prevent AIDS and death for many people with HIV. With the broad and rapid changes brought about by combination therapies, many processes characterizing modern medicine became articulated and negotiated through HIV and AIDS.

In the present article, I focus on the power that pharmaceuticals and their producers have both over the experience of sickness and the body and within the health care system as a whole. Using the introduction of new medication into the field of HIV / AIDS as a paradigmatic example, I show how treatment becomes a powerful actor, both hoped for and feared by people with HIV. I argue that the new power of this treatment only partially translates into new authority for the physician, whose work more and more becomes subject to external intervention and control. While medical science gains importance in defining medical practice, pharmaceutical companies increasingly enter and influence the sphere of science.

Methods

This article is based on a research project[1] exploring health care and treatment of people with HIV in Switzerland, as well as on my thesis (Kopp 2001)[2] developed from this project. The project was carried out at the HIV center in the outpatient department of a large university hospital, the Inselspital Bern. The main two phases of our empirical study involved, first, interviews carried out between April and August 1997, shortly after the broad introduction of antiretroviral combination therapies, and, second, a questionnaire survey in January/February 1998 whose results are not included in this article. We conducted semi-structured interviews with eleven 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 eleven of their physicians[3]. According to the inclusion criteria in 1995, all people with HIV we talked to had been infected before 1991, had a relatively favorable course of development and no antiretroviral medication until 1995. They thus not only had a prolonged experience with HIV, giving us the opportunity to talk to «seasoned professionals» (Williams 1984: 176), but their favorable course of development also allowed them a critical distance toward medical treatment. Of the physicians interviewed, eight worked in private practice, one was an assistant physician and two were senior physicians in HIV centers at university hospitals. All the names of our interview partners are pseudonyms.

Further fieldwork took place after this empirical study, that is when I had moved to the anthropology department of the Universität Bern to «write up» my thesis in the classical, though in my case minimal, spatial separation from the field (Clifford 1997). Following up on the themes that emerged in the empirical study 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, and analyzed media coverage, drug advertisements, and discourses in medical journals.

New drugs entering the field

As a consequence of medical powerlessness in the face of a deadly disease and active involvement and interference of people with HIV/AIDS, the early phase of the HIV epidemic was characterized by new approaches to public health. They included a major emphasis on prevention[4] and privacy rights, and a 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).

Medical science and physicians started to describe HIV as a potentially chronic and manageable condition towards the end of the 1980s (Herdt 1992; Treichler 1992). The initial shift toward the chronic model was tied not only to the insight that some people infected were living longer than anticipated, but also to the introduction of the first antiretroviral medication, AZT from *Burroughs-Wellcome* (Fee and Krieger 1993a, 1993b). The more recent and much broader shift toward chronicity and thus toward a «normalization» of the HIV infection (Rosenbrock et al. 2000) began in 1996 with the wide introduction of the protease inhibitors to complement the already used antiretroviral medication.

Combination therapies introduced a «discourse of hope» into the HIV/AIDS phenomenon, a process that has previously been described for the discourse about cancer (DelVecchio Good et al. 1990). How forcefully the discourse of hope entered the AIDS scene may be illus-

[1] I thank the Swiss National AIDS Research Program for financing the project headed by Prof. Hans-Rudolf Wicker of the Institut für Ethnologie, Universität Bern, my colleague Stefan Lang and the physicians Anne Iten, Hansjakob Furrer and Jan von Overbeck for collaboration in the project.

[2] The thesis will be published by Kluwer Academic Publishers in the series «International Library of Ethics, Law, and the New Medicine» (2002). Part of the text is reproduced here with kind permission of Kluwer Academic Publishers.

[3] In addition, we also interviewed their complementary therapists. As I focus here on orthodox medicine, I will not describe our empirical work with complementary therapists.

[4] Dannecker described prevention as «the key word of the forces organizing themselves in the shadow of medical impotence» (1997: 12).

trated by an issue of the German magazine *Der Spiegel* from January 1997. Its cover page shows an AIDS ribbon whose color – red – has turned for the most part green to symbolize hope, with the caption «The AIDS Wonder». The magazine article itself speaks of «the virus of hope going around» (Grolle 1997: 118).

For people with HIV, treatment brought the potential to challenge the stigmatizing association of the infection with death, and thus to describe HIV as a process with chances of intervention and reversion (Whittaker 1992). The hope that dissociating HIV from death might help to de-stigmatize the sickness was expressed in our interviews by Eliane Dutoit and Simone Peyer, both living with HIV:

«It [HIV / AIDS] has become a little bit, I would say, more accepted in society. The fact that it can be treated helps other people, allows them to think about it. It's a question of people not wanting to associate with this illness, and it allows them to live better with it.» (Eliane Dutoit)

«In the beginning of course everybody was afraid. That's not surprising because we only heard: everybody dies from it. That's not so extreme anymore, but back then, it was somehow a death sentence, and that is what I was told. And everybody was trying to avoid the subject. [...] Now I feel that it goes more towards a chronic disease, with all these therapies, and I actually find that quite positive. I think that way it loses a bit that drastic effect of being lethal and all that.» (Simone Peyer)

Another powerful actor in the body

Treatment not only dissociates HIV from death, but also has a very physical quality. Medication is absorbed by the body, it acts within the body, it affects and alters it. Medication is charged with power that directly works on the body of the person swallowing it, and that is both hoped for and feared by people with HIV. Moritz Pedrini, who did not accept antiretroviral treatment for example, contrasted the power of orthodox medication with homeopathic medication he used and which he described as being «barely traces of matter»:

«The difference is that all the medication I inject is homeopathic medication. *Iscador* as well, these are traces, barely traces of matter, and even the basic matter are plants, of organic origin, mainly [...]. But the drugs from orthodox medicine are incredibly strong preparations and they are measured in high doses, as far as I know, and then I simply don't know what other effects they have. Besides, I also fear that when I feel supported by such powerful substances, it might somehow weaken my vitality and my will to live. That I would not have to fight myself, but could simply rely on medication which will do it all for me. That's not so nice, is it.»

Moritz Pedrini believed that besides having the potential for unpredictable side effects, the drugs as «powerful matter» inside his body would actually weaken his vitality by making his personal fight against HIV unnecessary. The responsibility taken for the infection and the strategies built up to cohabit with the virus and to control its action within the body are, in his view, questioned through treatment and may even be weakened and become obsolete as they are replaced by the effect of the medication. In the case of antibiotics, Jana Seifert described a very similar antagonism between the processes of her body and the processes induced through medication which is swallowed «from the outside»:

«I simply have the feeling that antibiotics stop something inside of me, and it is something synthetic, it is something, yes, something very aggressive, that I swallow from the outside, that interrupts a process inside of me, an important one, I think. The whole production of antibodies afterwards, that's just a good thing the body does, and I just interrupt the process.»

HIV transgresses the boundaries of the body and requires efforts to re-create

integrity, autonomy, and control in the face of the potentially uncontrollable virus within. The medication may receive a similar status as the virus itself, entering the body as an unknown and uncontrollable «powerful» and «aggressive» factor from the outside, acting within the body and altering its workings in unpredictable ways. The body, already polluted from the outside through HIV, is now threatened with pollution again, this time through medication.

While Moritz Pedrini and Jana Seifert describe an antagonism between the activity of the body and of the medication, between inside and outside, self and other, Andrea Meier fears that introducing medicine as an external, «chemical» actor into the body might even blur her very ability to make such distinctions:

«In this uncertainty I simply wouldn't want to take so many chemical things. Maybe then everything really runs out of control, you never know. Now I know why I feel like this, why I feel good or bad, but if I take all that medication, one doesn't know, I don't know anymore, cannot distinguish anymore what I am causing and what the medication is causing, and then I would feel bad anyhow, and that scares me. [...] I already feel scared when I need to have an operation, and I get an anesthetic, and also otherwise, alcohol or drugs or something like that, and my conscience and awareness slip away, and that is somehow scary to me.»

In the description of Andrea Meier, treatment interferes with her perception of her body and her self, it makes it impossible for her to distinguish «what I am causing and what the medication is causing» and therefore questions her identity in ways similar to what she believes psychoactive drugs would do. Forces acting inside of her body, yet beyond her control, undermine her coherent and conscious self. Treatment thus introduces a new dimension into the identity of a person with HIV, built up through long, complex, and often difficult processes. It symbolizes a power that may threaten personal integrity and autonomy. Martin (1996: 105) pointed out in the case of *Prozac* that the medication is «not an animate being like a therapist, exactly, but neither it is an inanimate object like a stone. Once a person has taken Prozac, it is alive in them; simultaneously, the person has ingested a technological device. Together they form a cyborg, part human, part machine.»

The image of medication as a counterpole to the body/self and its power is expressed through the attributes for medication used by people with HIV. Medication was described as «chemical» and «synthetic», and as «aggressive» and «powerful matter» which alters, weakens or even suppresses processes of the body/self[5]. Descriptions of artificiality and power entering the body from without as central attributes of orthodox medication seem to be shared also by other patients. In a study among patients of British general practices, Britten (1994: 466) cited a patient describing medication as «an alien force». Britten interpreted the common concerns about «unnatural» medicines among patients in her study as having a double meaning. On the one hand, medicines are perceived as not naturally grown, just as Moritz Pedrini opposed orthodox medication to homeopathic medication which is «of organic origin». On the other hand, they are not natural to the body: also in Britten's study, patients feared that medicines weakened their bodies' own power by damaging the immune system or preventing it from working, just as Moritz Pedrini feared that antiretroviral medication might weaken his vitality and Jana Seifert believed that antibiotics interrupted processes inside of her. The ambiguity of evaluating the power of treatment may also follow a cultural logic of medicines. In their review of the anthropology of pharmaceuticals, van der Geest et al. (1996: 154) link anthropological perspectives on magic, fetishism, or animism to the more recent research on pharmaceuticals as social and cultural phenomena. They point out that the ambiguous meaning of power has always been inherent in medicines: «By definition medicines are

[5] The arguments resemble the second most important reason against treatment (following the fear of side effects) given mainly by gay Australian people with HIV: «These antiviral drugs are very strong poisons. The last thing I need is to add strong poisons to my body» (Gold, Hinchy and Batrouney 2000: 365). More than half of the study's participants confirmed this statement.

substances that have the capacity to change the condition of a living organism – for better or, in the case of sorcery medicines, for worse.»

Knowledge «out there»

While combination therapies brought back the power of curing to HIV/AIDS medicine, they only partially translated into new forms of authority for physicians. Rather, physicians' new power of curing in the field of HIV/AIDS is partially neutralized by broader processes in medicine which increasingly shift the power to generate information and make decisions beyond the sphere of the practicing physician. Data as which to base decisions are produced in the laboratory, and treatment decisions are taken through specialist consultations and based on meta-analyses, systematic reviews and treatment guidelines derived from clinical research.

Authority among physicians is a function of their professional education and institutional location: general practitioners, though having the legal right to prescribe antiretroviral treatment in Switzerland, often feel incapable of managing the increasingly complex treatment regimens and refer their patients to a specialist at an HIV clinic. The knowledge asymmetry between general practitioners and specialists has a potential to create tension and conflicts, as expressed most vividly by Gregor Pfister:

«We general practitioners are not all that stupid. But sometimes that's what the HIV clinics make us feel like. Sure, they have specialized knowledge, but we all used to work in clinics.»

This new medical power thus may put the general practitioner in the paradoxical situation of having his/her professional authority and autonomy undermined, at least in terms of the curative aspects of medical work. A consequence, which might be generalized to the whole health care system under the influence of increased specialization and health technology, is that general practitioners redefine their profession by emphasizing the interaction with the patient, i.e. the caring aspects of their work. This is described by the general practitioner Markus Mader:

«It is absolutely invaluable that you built up trustworthiness in the doctor-patient interaction over time. This is so important for everything to come that I think it is the greatest potential in healing someone. But currently orthodox medicine does not acknowledge this importance. Medicine rather seems to work reparatively, so to speak. When I now, after some ten years, look at the reports of such a clinic, they are sometimes ridiculous to look at retrospectively after four, five years. What does it mean in the life of a patient what a clinician or a team found? It is so relative. And that's why the long-term perspective is much more profound.»

Losing authority to the specialists in terms of treatment competence is being compensated by becoming the expert and advocate of the patient, thus by claiming authority over the complementary key discourse to «curing» in medicine, the discourse of «caring» (Good and DelVecchio Good 1993).

Yet the new power that treatment brings remains partial also for the specialist. Knowledge and competence do not simply leave the domain of the general practitioner to be placed in the hands of the specialist. They also, as illustrated by the new status of treatment guidelines, more radically slip out of the control of the practicing physician. Treatment guidelines are produced and published with the aim of helping physicians to base their decisions on evidence from basic and clinical research, and thus to reach goals as diverse as improving the quality of health care (the main aim of HIV treatment guidelines in Switzerland), reducing malpractice claims against physicians, or cutting health care costs (DelVecchio Good 1995; Woolf 1992). The key term around which this trend crystalizes is «Evidence-Based Medicine», a movement that aims

at further integrating external evidence into the physician's work. With meta-analyses, systematic reviews and evidence-based guidelines, Evidence-Based Medicine provides the methods and tools for a new step in the rationalization of medical knowledge. While the experience of the individual physician in patient care is explicitly acknowledged as a basis for implementing the data provided by Evidence-Based Medicine, the proponents of Evidence-Based Medicine just as explicitly question and challenge the common idea that individual expertise and competence increase with experience. In fact, if expertise and competence are defined as the «knowledge of up-to-date care» (Sackett et al. 1997: 9) according to the standards of Evidence-Based Medicine, then increasing experience leads to decreasing expertise and competence in clinical practice.

Basic to such an argument is a redefinition and, most importantly, a relocation of medical knowledge. What is defined as legitimate knowledge is increasingly dissociated from the person of the physician and allocated instead somewhere «out there» in the world of science where acquiring it is primarily a matter of methods. With the increasingly sophisticated methods of data gathering (i.e. the double-blind controlled clinical trial) and processing (i.e. meta-analyses and systematic reviews), medical science gains further terrain and legitimacy as the source of medical knowledge. This position does not always seem appropriate in the eyes of physicians involved in the care of individual patients:

«I think this Evidence-Based Medicine abstracts in a certain sense from individual destiny, and that cannot always be allowed. It is a general statement for a general population, but not for the individual. And I would always like to let the individual decision depend also on other factors than the ones known to be useful.» (Markus Mader)

The formal codification of medical knowledge through Evidence-Based Medicine may also be used to enhance external surveillance and control of medical practice and physician performance. It is a common concern amongst physicians that their freedom «to let the individual decision depend also on other factors than the ones known to be useful» is increasingly being restricted. They worry that decisions that seem appropriate for the individual patient but may not be in accordance with Evidence-Based Medicine, become illegitimate and that the «art» of medicine, the personal knowledge of the physician, will become further limited. In an editorial on Evidence-Based Medicine, a general practitioner asked: «Of course the meta-analysis leaves me the freedom of medical decision-making. Nice. But: for how long?» (Altorfer 1997: 561)

University-industry connections

While medical science gains importance in the contest to define medical practice, pharmaceutical companies increasingly enter the sphere of medical science by crossing and blurring the boundaries between the commercial and scientific domains of medicine. As Rabinow (1992) has pointed out for the United States, scientists increasingly represent the interests of pharmaceutical companies. The Patent and Trademark Amendment Act passed by the US Congress in 1980 and intended «to prompt efforts to develop a uniform patent policy that would encourage cooperative relationships between university and industry, and ultimately take government-sponsored inventions off the shelf and into the marketplace» (1992: 172), facilitated this shift. As a consequence, according to Rabinow, the 1980s saw an increased movement across the university-industry boundary. This movement was supported by economic ties such as sponsorship for research and personal ties as scientists became formally integrated into the biotechnology industry. Companies

also took on the symbols of universities by incorporating libraries, organizing conferences and seminars, and hiring scholars to mimick the features of a university.

One of the effects of such strategies is that pharmaceutical companies increasingly establish themselves as an important source of information on disease and treatment for the physician. An HIV specialist at a university hospital, for example, described the pharmaceutical industry as one of the sources of information for his department. When asked how he and his department gained knowledge on treatment, he answered:

«I must say that for the moment I have so many other things going that I cannot primarily inform myself. We have interns who are on the Net. Well, we have connections to the industry. X, who is presently in charge of the HIV center, sits in the committees that write these guidelines. I read what is being published, although that is all a year out-of-date.» (Luca Granges)

Another mechanism by which pharmaceutical companies impose their products on medical practice is the clinical trial. Koenig (1988) pointed to the irony that the very process which is considered central to evaluate new therapies rigorously and scientifically, that is to say the randomized controlled clinical trial, contributes to the routinization of a treatment in the hospital setting while it is still experimental. At the HIV outpatient department where I worked, new drugs entered the office shelves through clinical trials, to be given out to the study participants. Once the trial was finished, patients could often stay on the drugs without having to pay for them until they were officially approved by the state and thus reimbursed by health insurance companies. Through this practice, new drugs are recognized and used even before official approval, and the clinical trial which prolongs the time for a drug to get on the market is at the same time also a central element in establishing it on the market before it officially enters it.

The time it takes for a drug to be officially approved by the state («drug lag») is a factor prolonging the time it takes a drug to become profitable. In the United States, the requirements for drug approval through the Food and Drug Administration (FDA) were stiffened in 1962 (Bodenheimer 1985) to the point that it may take years for a new drug to be approved. Through a joint effort, people with HIV/AIDS and the pharmaceutical industry have dramatically reduced the drug lag for HIV medication. While people with HIV are motivated by the need to have access to the new therapies before it is too late, pharmaceutical companies enhance their profits by reducing the time before which they are allowed to sell their new products. Antiretroviral drugs have set new records in approval time: in the United States, the drug *Norvir* produced by *Abbott* was approved within only 72 days, a record that the company *Merck* broke only a few days later with the approval of *Crixivan* within 42 days (Johnson 1997). Fast drug approval not only means economic benefits for the pharmaceutical companies, but – like a company's rising shares, as François Neher points out it in the quote introducing this article – it also becomes a symbol for the power of the drug. Without commenting on the symbolism of the approval time or denominating the drug mentioned, which seems to be *Crixivan*, Schulz (1998: 139) cited a patient describing the new drug combination prescribed by his physician: «There is another substance, something absolutely new has been added. They have approved it in America within 42 days.»

The power released

The power that people with HIV attribute to medication has its striking counterpart in the commercial presentation of medication, which often focuses on a discourse of power. The position of power that pharmaceutical companies increasingly claim is thus reflected in their advertisement. When pharmaceutical

companies advertise their drugs as powerful, they also represent their own power, just as the power of magic reflects the power of the magician and vice versa. The power attributed to the product and the power of its producers are mutually reinforcing.

In the case of the new antiretroviral drugs, the protease inhibitors which led to the highly increased efficacy of combination therapies, power was a common metaphor to describe this efficacy. Two different pharmaceutical companies for example, *Agouron Pharmaceuticals Inc.* and *Roche Laboratories Inc.*, advertised their protease inhibitors with the metaphor of power. *Agouron* described *Viracept* as «powerful and easy to live with», a slogan visualized through the opposition of a wild bear showing its teeth and a friendly teddy bear[6]. *Agouron* thus created the ambiguous image of medication as a savage, yet tamed and domesticated, animal allowed to exercise its power within the body without hurting or destroying it. The advertisement text explains the ambiguous imagery by underlining the power of the medication in fighting HIV, while refuting two common fears about medication, namely the difficult treatment regimen and the possible side effects.

More than *Agouron* even, *Roche* relied on the imagery and metaphor of power when introducing *Fortovase* as an «improved formula» of their earlier protease inhibitor *Invirase*, which was known to be poorly absorbed by the body. Both *Invirase* and *Fortovase* are based on the substance *Saquinavir*. While *Saquinavir* is presented as «the promise of power», visualized by a female javelin thrower attempting to throw her javelin, *Fortovase* is «the power released», the javelin thrower releasing her javelin[7].

Pharmaceutical companies stand on firm grounds in their self-confident claim for power. The history of medicine shows that patients have had faith in drugs for longer than they have had faith in physicians. According to Trostle (1988), physicians gained their monopolistic power and thus also their control over pharmaceuticals only in the twentieth century. In the light of physicians' eroding authority and autonomy, and the increasing power of globally organized pharmaceutical companies, it is increasingly possible that they will lose this monopoly power again, and pharmaceutical companies seem to be among the main actors ready to step into this position of power.

[6] *a&u America's AIDS Magazine* 45(7), July 1998: 7-9.

[7] *POZ Magazine* 37, July 1998: 113-117.

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Abstract

The role of pharmaceuticals in HIV / AIDS and medicine

The article focuses on the power that pharmaceuticals and their producers have both over the experience of sickness and the body, and within the health care system. Based on an empirical study carried out in the field of HIV / AIDS medicine shortly after the introduction of combination therapies, it is argued that the power of this new treatment, which is both hoped for and feared by people with HIV, only partially translates into a new authority for physicians who increasingly lose power to actors beyond their control. Data on which decisions are based are produced in the laboratory, and treatment decisions are taken through specialist consultations and based on meta-analyses, systematic reviews, and treatment guidelines derived from clinical research. While medical science thus gains authority to define medical practice, pharmaceutical companies increasingly enter the sphere of medical science by crossing and blurring the boundaries between the commercial and scientific domains of medicine. In the light of physicians' eroding authority and autonomy and the increasing power of globally organized pharmaceutical companies, this article argues that pharmaceutical companies are about to take over portions of physicians' monopolistic power.

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