

Introduction

AIDS and Scientific Knowledge

Brightly colored condoms, arranged in the shape of bicycles, eyeglasses, or flowers: part of an extensive campaign against the AIDS risk, these have been a common sight on billboards in Germany for several years now. An advertising spot presented on the Arte television channel (which defines itself as the cultural television channel of Europe) calls on viewers to "fight together." The spots on German television (distributed by both private and public channels) are about "not giving AIDS a chance." At the beginning of December, the major television and radio stations, advertising companies, and the press reminded the public not only about Christmas and family values, but also about risks, being safe, and not giving viruses any chance to spread. Since December 1st was declared World AIDS Day, the AIDS risk has been featured regularly in the media in the pre-Christmas period. Not that this topic is completely absent from the media in the first eleven months of the year; in fact, the opposite is true. The activities around December 1st are simply an extra reminder to be vigilant, keep up the fight, and not give this deadly enemy any opportunity. And fight it the populace must because these risks seem now to be almost everywhere.

The media have alerted people to "contamination risk," "occupational risk," "technological risk," and "Third World risk." In the 1990s, cases of patient-physician or patient-dentist contamination (Stine 1993, p. 418), and blood bank and organ transplant contamination – to name only a few of the situations highlighted by the media in



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Western Europe and the United States – gained prominence. ¹ The rapid spread of AIDS in underdeveloped and developing countries has also been a major topic. Issues such as "risk factors" and "risk behavior," along with the latest epidemiological trends and "risk groups," old and new, have received media attention. With the advent of a number of epidemiological models, there has been a globalization of "AIDS risk" as well (Mane and Aggleton 2001, p. 23; Maticka-Tyndale 2001); since the end of the 1980s, the AIDS risk topics featured in the press and on radio and television have multiplied and diversified. This public presence of AIDS has been amplified by its being made a subject for novels, plays, docu-fictions, Hollywood-style and French existentialist movies, television medical drama series, votive painting, and avant-garde artworks, among other things (Treichler 1993; Miller 1992).

Reports and articles about "risk behavior" and "factors" in various parts of the world are not a rarity. Tourists and travelers are warned about them when traveling to some region with a "risk pattern." Host countries, when not adopting concrete legislation, are thinking aloud about screening the risks tourists might bring in with them. In 1994, when the organizers of the Tenth International AIDS Conference in Yokohama announced in their preliminary programs² that nobody coming to Yokohama to discuss risk reduction (among other topics) would be denied a visa because of his seropositive status, they implicitly asserted that the exceptional character of the occasion legitimated an exceptional, temporary suspension of risk screening.³

Health institutions have been confronted with the topic of "AIDS risk" from the beginning: the reaction to this challenge has been to enact measures for preventing, screening, coping with, controlling, or minimizing risks. This implies, among other things, increasing the knowledge of various social groups about AIDS risk; inducing overall

- ¹ Cases of dentist-patient contamination have been much publicized in the United States, whereas the theme of blood bank contamination seems to be a European one; the most prominent cases were recorded in France at the end of the 1980s and in Germany in 1993–4. Both events enjoyed a large amount of publicity and have been debated in courts of law.
- ² See, for example, the Advance Program of the Conference, p. 41; also, www.aidsinfobbs.org/periodicals/atn/1993/187.05. Downloaded on May 13, 2004.
- ³ According to reports in German newspapers (Tageszeitung, August 6, 1994, pp. 1, 3; Frankfurter Allgemeine Zeitung, August 6, 1994, p. 7) there were attempts on the part of the organizers to forbid seropositive conference participants from entering Japan.

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behavioral changes supposed to be risk-reductive; increasing the knowledge of public health institutions about individual and collective risks; systematically monitoring these risks in one form or another; preparing healthcare institutions to meet future challenges, according to knowledge about risk; and modifying other policies (concerning insurance and immigration, for example) according to the same knowledge. This broad spectrum of risk-reduction policies has been implemented in many countries.

Many social studies of AIDS operate with and have a concept of "risk" at their core: they describe individual and collective risks, analyze their avoidance, or examine social and behavioral "risk factors." "AIDS risk" has also become an important topic for health economics and for calculating the present and future costs of medical care, research, and drug development. Social security institutions, insurance firms, as well as courts of law, have been confronted with the relationship between AIDS risk on the one hand, and responsibility, care, partnership, and general human rights on the other.

At perhaps a deeper level, "AIDS risk" continues to be a topic for biomedical research. In its basic and applied aspects, research is oriented according to certain criteria of "risk persons," "risk groups," "behavior," and the like. Drug design and clinical trials, as well as clinical and epidemiological studies, constantly operate with notions of risk: at their core is the effort to construct trial groups as homogeneously as possible according to risk criteria. Especially in the United States, this has generated much criticism from activist organizations; counter-trials have become part of an alternative expert culture (Arno and Feiden 1993; Epstein 1992, 1996).

AIDS risk is then a topic for (1) clinical and epidemiological research; (2) applied pharmaceutical research; (3) public and health policy; (4) politics, economics, ethics, and law; (5) the social sciences; (6) the media; and (7) the arts and entertainment industries. What these approaches have in common, in spite of their diversity, is the assumption that notions such as "AIDS risk," "risk factors," "risk behavior," "risk groups," and "populations at risk" can be understood because they are ultimately grounded in a body of expert medical knowledge about AIDS. In other words, this body of knowledge about the syndrome, its modes of transmission, and the nature of the infectious agent is taken as reliable ground for specifying other aspects and implications



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of "risk." "AIDS risk" as an issue for expert, scientific knowledge precedes particular (political, juridical, economic) redefinitions of risk. Scientific knowledge determines what "risk" is and what it is not, and how it can be assessed in its various aspects.

The relation of precedence is understood as a logical as well as an empirical-historical one. Its empirical-historical dimension is given by "AIDS risk" initially appearing as a medical issue. Its logical dimension is that "AIDS risk" as a medical topic is necessarily prior to its being a topic for health, insurance, or legal policies. It is hardly imaginable that "AIDS risk" would be referred to without appealing in some way to scientific knowledge. Even mid-1980s televangelists preaching that AIDS was the wrath of God visited upon sinners took care to legitimate their statements by constantly referring to this knowledge (Patton 1985; Treichler 1988b). References to expert knowledge and the experts' presence are constant features of the media's handling of the issue. The idea that this knowledge is a necessary condition (in both the logical and the empirical sense) for analyzing particular aspects of AIDS risk can also be found in historical accounts (e.g., Grmek 1990), as well as in many social studies. They all refer to expert knowledge not only as a source of authority and legitimation but also as the epistemic condition for "AIDS risk."

Scientific Knowledge and Rhetoric

At the center of this book lies the relationship between rhetoric and scientific knowledge about AIDS. In this, I depart from the thesis of AIDS as a "full blown medical and cultural phenomenon" (Sturken 1997, p. 147), which implies that these two aspects are completely separate and brush against each other only at their fringes. I examine here their entanglement at the core of scientific knowledge. There are several social sites where scientific knowledge about AIDS is produced: research institutions, laboratories, clinics, operating theaters, and treatment centers. Moreover, as Steven Epstein (1996) has shown, social movements and alternative organizations are large, significant sites of knowledge production. The study will concentrate on only one such site, one which does not even appear in the previous enumeration; indeed, it does not appear to be a site at all: or, if it is one, then it is very, very flat. It seems to lack the richness, depth, and complexity of the



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lab, the clinic, and the operating theater, and the vigor, determination, and commitment of social movements. It consists of a thousand disparate pieces which circulate constantly, continuously appearing and disappearing in all sorts of places. This site consists of expert articles on AIDS in medical journals; they are what form the core of what is known as medical AIDS discourse. (That a text can be and is a social site is argued at length in the pages to come.)

Seeing journal articles as knowledge-producing social sites may appear paradoxical; after all, a (scientific) text is ultimately merely a vehicle for expressing knowledge produced elsewhere, a means for transmitting knowledge, not an engine that constitutes it. In expressing knowledge, texts may rearrange and reconfigure it according to the logic of literary representation and the canons and conventions of scientific prose (e.g., Gross 1999; Prelli 1989; Knorr 1981). Textual resources, the nature of which is ultimately rhetorical (Fish 1989, pp. 472-3), can perhaps persuade (which is in itself bad enough) but cannot produce knowledge. In other words, a (scientific) text can (more or less successfully) convey its knowledge content to the reader by using rhetorical devices – i.e., it can persuade the reader that something is the case, but its task ends there. Instruments of persuasion may have different forms: coherence and rigor in textual organization and an apparent minimum of rhetoric (as is common in scientific texts) are only two examples of rhetorical strategies. However, such texts remain no more than instruments for transmitting something, or to put it more colloquially, for selling some knowledge content to the reader.

Moreover, isn't rhetoric (that of scientific texts included) contingent upon the skills of the author and, therefore individual, fluctuating, and non-standardizable? Does it not, ultimately, belong to the realm of the literary critic, and exclusively so? To make matters even worse, what about the rhetoric of this text? Isn't it proof of what Woolgar and Pawluch (1985) would call ontological gerrymandering, when a text claims to have something sociologically relevant to assert about the textual (i.e., rhetorical) production of knowledge by pretending not to have any rhetoric – or, if it has, that it is just an innocent means of conveying some external knowledge?

In setting myself the aim of looking more closely at "AIDS risk" in this book, I was confronted with the ways in which rhetoric appears to insinuate itself parasitically into scientific knowledge. For if rhetoric



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is supposed to not have any place in scientific texts, yet invariably insinuates itself into them, how else can it be regarded than as a parasite that lives and feeds on the knowledge content it helps convey to readers? It may successfully persuade skeptical readers; the usual scientific rhetoric of clarity and rigorousness may help convey the message better, but it is still a parasite. Worse still, in this light, do (scientific) texts not actually start to look like parasites on the activities through which scientific knowledge is produced? Do they not live on the richness and complexity of the local production of (scientific) knowledge? If there is something to be said about this, then texts are not the place to look: they may say something about communicating, about transporting this knowledge, about making it available to the public – but not about its production. In the flatness of a (scientific) text, one is confronted with the rhetoric that lives and feeds on the knowledge content and therefore should be rigorously separated from it, but how?

I argue that:

- 1. Texts are not to be viewed as flat, thin conveyors of knowledge, but rather as social "dispositives" (Derrida 1972a, p. 359).
- 2. Rhetoric is not the (more or less sophisticated) form of the knowledge content, meant only to persuade the reader that something is the case, but a social practice producing knowledge.

Arguments contesting the parasitic position of rhetoric with respect to the authorial intention and to content are not new: they have almost become commonplace in the fields of literary studies (De Man 1983; Fish 1989), historiography (White 1985, 1987), anthropology (Geertz 1988), and economics (McCloskey 1998, 1990, 1994). Arguments about the conceptual primacy of writing and texts for the social constitution of meaning are also commonplace in so-called deconstructivist philosophy (e.g., Derrida 1972a,b, 1979; Sarup 1988; Norris 1990). In the field of sociology, the idea that texts should be viewed as social dispositives and rhetoric as a social practice is a matter of debate and dissension. More recently, Actor-Network Theory (ANT) has argued that texts act as "immutable mobiles" (Latour 1999), transporting knowledge across various contexts and disentangling it from local practices. The sociology of knowledge and science has shown the double (local and textual) embeddedness of scientific knowledge (Knorr 1981; Latour and Woolgar 1986), its reconfiguration according to the

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logic of literary representation (Woolgar 1988; Potter 1988), as well as the role played by rhetoric in the constitution of scientific knowledge (Prelli 1989; Gross 1996; Gragson and Selzer 1993; Berkenkotter and Huckin 1995; Ceccarelli 2001; Fahnestock 1999; Halliday and Martin 1993; Montgomery 1996; Myers 1990; Swales 1990). The arguments for rhetoric as a social practice are presented and detailed throughout the study not in a purely theoretical fashion but by means of examining the concrete historical constitution of scientific knowledge about AIDS.

The first argument is this: what would appear to be nothing more than strategies of argumentation actually played a constitutive role with respect to the primary knowledge about the nature of the infectious agent, its means of transmission, and its causal role in the Acquired Immunodeficiency Syndrome. In other words, social representations of "risk" are intrinsic to this knowledge. This means that both the conditions under which it becomes possible to speak about a new syndrome and the concrete forms taken by the scientific knowledge about the syndrome, its causal agent, and its modes of transmission were generated by representations of risk. They played a central part in making the Acquired Immunodeficiency Syndrome the Acquired Immunodeficiency Syndrome - that is, a condition under which old, familiar diseases became new, complex, previously unseen diseases. Moreover, they were central in shaping knowledge about the nature of the infectious agent: something coming out of the environment, a behaviorally determined agent, a gender- or genetically determined predisposition, or a mixture of all of these. Later on, when it was debated whether the French or the American retrovirus was the causal agent, these representations were at the core of the two sides' arguments: both vigorously contended that theirs was the etiological agent because it fit patterns of risk. In shaping medical knowledge about the retrovirus, its effects, and its means of transmission, risk representations also constituted an order of knowledge from which they themselves emerged as secondary and derived, and as feeding on the essential medical knowledge about the syndrome. Risk representations emerged as dependent on whether the causal agent is environmentally or sexually transmitted, spatial location, gender particularities, and membership in certain population segments - i.e., on factors derived from knowledge about the causal agent and how it is transmitted, which, in turn, were constituted by "risk."



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Scientific Knowledge and the World Risk Society

Scientific representations of risk become fully relevant only if we consider them against the broader picture of the world risk society. In the past decade, the notion of risk society has attained a visibility comparable to that attained by the concept of "postmodern society" in the 1980s; intellectual fashions aside, this notion helps us better understand the broader significance and consequences of scientific knowledge about risk.

The sociological concept of risk is usually understood in opposition to the notions of uncertainty and danger. Whereas uncertainty designates lack of valid knowledge about a present or future event, risk implies a set of procedures and techniques through which valid, albeit probabilistic knowledge about the event in question is obtained. Risk emerges when social actors are able to compute the probability of a (natural or social) event, as, for example, when social organizations compute the probability of a technological failure and forecast its consequences (as in the case of electricity grid failures) or compute the rate of spread of infectious diseases (SARS is a good example here).

Analogously, at a basic level the notion of danger presupposes an undesirable (natural or social) event occurring with a lack of social knowledge about its causes, concrete shape, and consequences. By contrast, risk implies a set of tools and procedures through which knowledge about the causes, shapes, consequences, and means of prevention of undesirable events is gained. In both pairs (risk/uncertainty and risk/danger), the concept of risk is grounded in tools and procedures through which unknown events are made into an object of analysis and valid expert knowledge is gained. This body of knowledge enables social actors and institutions to devise paths of action, maintain trust, make decisions, and prevent or reduce the consequences of undesirable events.

It follows, then, that expert scientific knowledge plays a central role with respect to risk. At the macro-social level, however, the picture becomes more complicated. Roughly speaking, we encounter two main theories about how risk works at this level: a systemic approach promoted mainly by Ulrich Beck (1992), Scott Lash (2000), and Niklas Luhmann (1990), and an anthropological one promoted by

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Mary Douglas (1992a, 1985) and Aaron Wildawksy (Douglas and Wildawsky 1982).

Beck's argument is that processes of social modernization (individualization, industrialization, the penetration of technology into all spheres of social life, and the expansion of capitalist exchanges) bring with them not only benefits, but also undesirable effects (e.g., technological failures, epidemics, economic recession, and environmental destruction). Once these are recognized, science is called upon to analyze them and devise countermeasures. Scientific knowledge lies at the core of modernization processes, and the solutions it provides are inescapably scientific: analysis and knowledge will be used to counteract the undesirable effects of modernization. But there is no guarantee that these measures designed to counteract risks will not, in turn, have undesirable side effects. This, in fact, happens in many cases. The social consequences, argues Beck, are manifold: late modern societies learn that total indemnity from risks is impossible. They have to reflect constantly upon the social consequences of the decisions taken at the collective, institutional, and individual level; risk society implies then a stage of advanced modernization, where society "disenchants and then dissolves its own taken-for-granted premises" (Beck, Bonss, and Lau 2003, p. 3).

Another consequence is that risk groups occupy a prominent place in the social fabric: they are defined by their exposure to undesirable events *and* by their means for reducing exposure (Scott 2000, p. 35). This is evident in the process of biomedicalization, among others, where the health state of individuals is comprehensively monitored on a mass level with the help of standardized risk-assessment tools (Clarke et al. 2003, p. 172).

Yet another consequence is that, due to globalization processes, risk society becomes world risk society: undesirable events can no longer be geographically contained but rather unfold on a planetary scale. Epidemics such as SARS (which surfaced simultaneously in several cities on two continents) and AIDS are cases in point.

There are, however, still more implications: developed societies learn that the total management of undesirable effects is impossible, but in this process they are confronted with the fears and anxieties of their citizens. A major social institution that should alleviate fears and



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restore trust is science itself, because undesirable effects cannot be managed without scientific expertise. The increased need for expertise in all domains of social life gives rise to a class of "professionals of representation, simultaneously oriented towards their constituency (social reality, the citizenry) and their professional rivals (fellow scientists and politicians)" (Pels 2000, p. 7). Several levels of dialogue have to be maintained in the social management of risks: a dialogue among experts/scientists, as well as dialogues between the general public and scientists, and between policy makers and scientists. In many cases, group interests intervene in this dialogue and can shape it in decisive ways (Brint 1994, p. 18).

The maintenance of social order also requires trust in social institutions, which in turn requires the ability of these institutions to account for events. This implies, among other things, that responsibility is assumed and blame is ascribed. The notion of risk intervenes in this process: Niklas Luhmann (1990, pp. 10, 23; see also Nelkin and Gilman 1988) argues that causes of undesirable events can be attributed either to one's own social institutions (and they become risks) or to external entities (natural and supra-natural forces, external enemies, and radically different societies), in which case they become dangers. "Risk" is not only a tool for assessing the probability of undesirable events, but also a device for attributing responsibility, maintaining trust, and ensuring social order.

In a similar line of argumentation, Mary Douglas (1967) sees risk as a cultural component of social order: social cohesion, she argues, is determined by the degree of internal and external cohesion of social groups, among other things, as well as by the categories with which these groups operate. In making use of categories such as pure/impure, safe/unsafe, social groups establish paths of individual and collective action and, at the same time, trace the boundaries of their social world. From this perspective, risk appears as one of the categories with the help of which social actors make sense of their world: it is used for defining responsibility, placing blame, establishing accountability, and maintaining trust. At the same time, risk is a device with the help of which fundamental distinctions between society and nature are established: we talk about risks generated in our own society, but we talk about dangers coming from nature or from other societies perceived as radically different (e.g., in the case of terrorism).