# HIV/AIDS Denialism Is Alive and Well

# 1

*Every epidemic throughout history has had its "denialists." Some epidemics have been blamed on rats, some on foreigners, Jews, or other disfavored local ethnic groups. Very often, epidemics have been blamed on the people who suffered from them, their illness being seen as some kind of moral failure. Sound familiar?*
Martin Delaney, AIDS Activist, 2000

"Are they still around?" That is what nearly everyone in the United States said, when I told them about this book. They found it difficult to believe that after all these years, anyone still questions the cause of AIDS. Scientists have admittedly found it easy to ignore denialism. We typically dismiss HIV/AIDS denialists as a small group of rogue journalists and unstable troublemakers. Sadly, people who work on HIV/AIDS often fail to realize that denialism is a significant problem because denialists dissuade those affected by AIDS from seeking help. People who are lured to denialism are invisible to AIDS service and treatment providers. Denialism – like stigma, sexism, and homophobia – undermines the fight against AIDS. At the very least, denialism diverts attention and resources from the global AIDS disaster. At its worst, it disinforms affected populations about the importance of prevention, the necessity of HIV testing, and the availability of life-prolonging treatments. At its core, denialism is destructive because it undermines trust in science, medicine, and public health.

In this Chapter, I define HIV/AIDS denialism, focusing on what it is and what it is not. At the start, it is essential to distinguish between denialism and the psychological process of denial, the doubt that patients often express about their medical care, and the important role of dissidence in science. Let us begin by looking at psychological denial, doubt and the difficult patient, and dissidence.

## Denial

In its truest sense, denial is a passive coping response. In psychological terms, denial is an emotional defense mechanism. A nearly universal immediate reaction to trauma, denial involves a subconscious refusal to believe the unbelievable. Denial occurs when we confront something too painful or frightening to face, providing a protective buffer zone, a time and space to assimilate a stressor or trauma into one's sense of reality. Perhaps the best-known account of psychological denial is Elizabeth Kubler-Ross' classic description of how people cope with a terminal illness. In her five stages of coping with death and dying, Kubler-Ross places denial as the first, necessary stage of coping with mortality, exemplified by the reaction, "No, not me." This stage of denial is the time when people want medical tests re-run, when they refuse to return to their doctor, or when they seek to escape reality through alcohol or drugs. The National Cancer Institute describes denial in this way:

> When you were first diagnosed, you may have had trouble believing or accepting the fact that you have cancer. This is called denial. Denial can be helpful because it can give you time to adjust to your diagnosis. Denial can also give you time to feel hopeful and better about the future.[1]

Stanley Cohen, in his classic book on denial, describes the fundamental paradox of simultaneously knowing and not knowing. People must have some awareness of the threat they are denying, or there could be no denial response. Yet denial keeps us from consciously knowing.

Denial is a normal and perhaps universal psychological response to trauma. As a coping mechanism, denial shields our emotions from a harsh reality. People diagnosed with HIV/AIDS, who are experiencing denial, are in the process of coping with the traumatic experience of testing positive for HIV. The same can be true for those close to someone who tests HIV positive – a friend or lover, a parent, a sibling, or a child. Interestingly, those who are in psychological denial are the very people to whom denialists pose the greatest threat. Denial is perhaps best understood as passive avoidance. Though denial can, for a time, serve very well as a way of adjusting to the truth, to making one's peace, it can, when it goes on too long, become maladaptive, keeping us from moving on to active coping strategies.

We should expect anyone who confronts a serious medical diagnosis, such as a positive indication of HIV infection, to respond with denial. Denial should not, however, become a fixed state; rather, it should be a fluid, dynamic process that changes with time. When denial extends for longer than a few months, people are more likely to delay or completely avoid opportunities for medical treatment. The National Cancer Institute states, "Sometimes, denial is a serious problem. If it lasts too long, it can keep

you from getting the treatment you need. It can also be a problem when other people deny that you have cancer, even after you have accepted it."[2] In fact, maladaptive denial is a form of mental illness. Psychiatrists define maladaptive denial as:

> The persistence of a maladaptive mode of experiencing, perceiving, evaluating, and responding to one's own health status, despite the fact that a doctor has provided a lucid and accurate appraisal of the situation and management to be followed. . .[3]

The most extreme case of maladaptive denial is malignant denial, during which people completely ignore their physical condition, with potentially irreversible damage. There are clinical cases in medicine of women who have denied that they are pregnant up until the time they deliver their baby. Denial is a common feature of conditions that are unacceptable to one's self-identity, such as alcoholism, drug abuse, excessive gambling, sexual addictions, and eating disorders. With respect to HIV/AIDS, malignant denial occurs when a person tests HIV positive and continues to expose others to the virus through unprotected sex or sharing injection drug equipment. Avoiding doctors and refusing treatment are also hallmarks of malignant denial.

Malignant denial extends beyond a psychological safety net to ultimately threaten one's health. When malignant, the avoidance of denial permeates into health care and health decisions. Denialist propaganda and the false promises of quackery target those people who are most vulnerable, particularly those whose denial has become entrenched. People in denial are saying "this cannot be happening to me" and denialism responds with a resounding "you are right, it is not happening to you." Denialism feeds on those who are experiencing the very real and humanly understandable state of psychological denial.

An illustrative example of malignant denial in HIV/AIDS may be helpful. Perhaps the most public – even notorious – case involved a woman named Christine Maggiore. After testing HIV positive, she became involved in AIDS activism in Los Angeles. However, she later came to question whether HIV causes AIDS, influenced by the writings of rogue scientist Peter Duesberg and his associates. Christine Maggiore turned her AIDS activism toward denial and, in the course of time, toward what I am calling denialism. Maggiore wrote a book and her husband produced a movie that questions HIV as the cause of AIDS based on her experiences, started an organization around denialism, and has worked to discourage people from getting tested for HIV.

Maggiore has become the most visible and seemingly one of the most influential denialists in the United States. Her influence clearly must be in part due to the undeniably tragic circumstances of her life. However, it was her own denial that led to the tragedy: She avoided taking preventive action against transmitting HIV to her baby, Eliza Jane Scovill. The girl died of

complications from AIDS at age 3. Maggiore's denial had become literally malignant. And then, in the months following her daughter's death, her stance morphed further into denialism: She set herself to actively misrepresenting and distorting and undermining AIDS science, medical programs, and public health policies. Refuting the report of the Los Angeles medical examiner, Maggiore was assisted by Mohammed Al-Bayati, an AIDS denialist and veterinary toxicologist, who said Eliza Jane actually died of an allergic reaction to the antibiotic *Amoxicillin.* The historical record shows that Christine Maggiore's denial caused harm first to herself, then to her daughter, and ultimately to who knows how many others, clearly illustrating the destructive progression from ordinary psychological denial to malignant denial to denialism.

## Doubt and the Difficult Patient

Just as psychological denial can morph from a reasonable human-coping strategy to something much more dangerous and even sinister, so can doubt and the desire to be an involved and active patient turn from healthy, emotionally understandable, and even helpful impulses to something much less desirable and productive. When people come out of denial and accept their condition, it remains common to question medical decisions and even to doubt one's prognosis. Denial may even recur, to help patients retain hope. So again, we are faced with good motives, or at least emotionally comprehensible motives, providing a possible pathway to denialism.

Patients who ask questions and express doubt in their doctor's recommendations are the same patients who are most engaged in their care and actively participate in medical decisions. Research has shown that patients who actively engage in their care and probe their providers with challenging questions actually survive longer than those who are passive. But self-determined patients might also be difficult to manage, at least by some doctors, and may be particularly vulnerable to false claims and misinformation when exposed to denialists.

In addition to denial, people diagnosed with a serious illness may doubt the value of modern treatments. Doubt can lead to the refusal of treatment even when a person is not in denial. For example, many people with HIV infection believe it is better to wait before starting treatment, keeping as many of their options open for as long as possible. The strategy of delaying treatment paid off for many people who did not follow the recommendation to "hit HIV hard and early," back when doctors thought early treatment was the best plan. New treatments and treatment guidelines for HIV infection become

available with unprecedented speed. In talking with people who have HIV/AIDS and have opted out of taking antiretroviral therapy, I have found some do so because they prefer holistic and natural remedies. In some cases, doctors reject natural remedies, as explained to me by one person who had been living with untreated HIV for over a decade:

> After years of thinking I should get tested for HIV I finally did. I made the decision after a former sex partner died of AIDS. I tested positive and soon after developed a couple of serious infections. Being a naturalist in terms of my health care my entire life, I chose to use herbal remedies to treat myself. But when I became quite ill I went to an AIDS specialist. My natural therapies weren't clearing up the problem, so I wanted to see if a doctor had any solutions. This doctor was totally out of touch with holistic health and healing and was not even open to the idea. The experience confirmed to me that I was on the right track.[4]

When I talk with people who have removed themselves from HIV treatment, they have said that their doctors resent their asking challenging questions. Whether accurate or not, the perception of a closed-minded physician is a likely reason for patients to opt out of care. However, these people, whom I categorize as difficult patients, are usually not in denial about their illness. They clearly recognize their condition and understand their treatment alternatives, but choose something different from the recommendations of their doctors. The difficult patient may, in a few instances, also be doubtful about his or her condition or its severity, but the main focus of their doubt tends to be on the recommended treatments.

Psychological denial, doubt, and the difficult patient do not fall under the general heading of what we will call denialism. However, patients who are in denial, those who doubt their doctor's recommendations, and those who are otherwise dissatisfied with and in some cases resist or decline medical care are the most vulnerable to the false claims of denialists.

## Dissidence in Science

Consensus does not determine the truth, certainly not in science. Science does, however, move through a social process of truth-seeking in which facts are agreed upon. Any single observation or single experiment cannot determine facts in science. To trust an observation, an independent observer must repeat experiments done earlier and arrive at substantially the same results. When many independent observers record the same experimental results with their methods tightly controlled and under strict scrutiny, scientists may consider the observation true. In science, theories lead to questions, just the same as in philosophy. However, it is the accumulation of objective

observations that differentiates science from philosophy. Scientific consensus occurs when independent scientists agree on the body of accumulated facts.

Scientists who hold views outside of the mainstream play an important role in truth seeking. Dissident scientists do not agree with the prevailing theory or do not accept the body of accumulated observations as fact. The importance of dissidence in science is unquestionable, with many celebrated examples throughout history. Revolutions in how we think about our world come from those who move science in new directions. We remember the dissident scientists who changed the way we think. Galileo Galilei changed how we view our universe. Albert Einstein changed how we contemplate space and time. Alfred Wegener changed how we think about the formation of our planet. Charles Darwin changed our view of life. Sigmund Freud changed how we view ourselves. Dissident scientists turn into revolutionaries when their thinking causes science to shift course. Science surely values diverse thinkers, dissent, disagreement, and vigorous debate. How those of us outside of a respective field of science distinguish between genuine dissidence and destructive attempts to undermine the science is a far more complicated matter.

The science of AIDS began in the early 1980s, when there were numerous theories proposed to account for this new disease – most centering on the lifestyle characteristics of the people first diagnosed. After all, the first AIDS cases were among gay men and people who used injection drugs. All of the first AIDS patients had become ill with rare illnesses. The strange clusters of diseases these patients suffered from resulted, scientists soon realized, from a collapsing immune system. Because of the ages and social characteristics of these first patients, it was readily apparent that the cause had to be an environmental agent rather than an inherited gene. It was common for men and women diagnosed with AIDS to have a history of drug abuse, even if they did not inject drugs. One early theory of AIDS stated that drugs were causing the immune system to fail. But soon hemophiliacs, including young children like Ryan White, who would become the icon for the indiscriminant affliction of HIV infection, were found to have the disease in statistically large numbers, so it became obvious that AIDS could not be the result of drug abuse. In addition, blood-transfusion recipients, like tennis star Arthur Ashe, were diagnosed. The medical reasons for the blood transfusions differed too much to consider any one of them the cause of AIDS. In 1984, the virus that causes AIDS was identified and ultimately named Human Immunodeficiency Virus. The only thing that links all of the gay men, drug users, commercial sex workers, hemophiliacs, blood-transfusion recipients, and others who have had AIDS whether they are in Los Angeles, New York, Paris, or Kampala Uganda is that they test positive for HIV infection.

Still, not all scientists agreed that the newly identified virus was the sole cause of AIDS. At the time, doctors knew little about HIV and how it destroys

critical immune system cells. Peter Duesberg, a cancer researcher who had mapped the genetic makeup of a virus that is similar to HIV, disputed the predominant theory that a virus was causing AIDS. Duesberg, a respected – some would even say renowned – scientist at the University of California at Berkeley, believed that a single virus could not disable the immune system and cause AIDS. Departing sharply from the overwhelmingly prevalent scientific view, Duesberg said he believed that AIDS must result from drug abuse and other lifestyle factors. And he was not alone in proposing other causes. For example, Robert Root-Bernstein, a well-known and respected professor of life sciences at Michigan State University, proposed that HIV alone was not causing AIDS and that multiple factors must be at play to cause the collapse of the immune system. Well regarded and respected New York physician Joseph Sonnabend was among the first to care for the earliest cases of AIDS among gay men in New York City. He joined with Michael Callen to start the People with AIDS Health Group, one of the first HIV treatment advocacy organizations. Early on, Sonnabend stated that AIDS must have many causes, not a single source. Like nearly all other AIDS dissident scientists, Root-Bernstein and Sonnabend altered their views as the facts of AIDS became clear. In a 2006 statement on his changing views about AIDS, Root-Bernstein said the following:

> Both the camps that say HIV is a pussycat and the people who claim AIDS is all HIV are wrong. . ..[but] the denialists make claims that are clearly inconsistent with existing studies. When I check the existing studies, I don't agree with their interpretation of the data, or, worse, I can't find the studies [at all].[5]

Similarly, Sonnabend clarified his views on AIDS over the years, stating in 2007:

> Some individuals who believe that HIV plays no role at all in AIDS have implied that I support their misguided views on AIDS causation by including inappropriate references to me in their literature and on their web sites. Before HIV was discovered and its association with AIDS established, I held the entirely appropriate view that the cause of AIDS was then unknown. I have successfully treated hundreds of AIDS patients with antiretroviral medications, and have no doubt that HIV plays a necessary role in this disease, a view that I have expressed publicly on several occasions. It is my view that the relationship of HIV to AIDS is of the same nature as that of almost all viruses to the diseases with which they are associated. It is thus similar to the relationship of the Hepatitis A, B and C viruses to clinical hepatitis, or poliovirus to poliomyelitis or the influenza viruses to influenza. In the same way HIV disease, including AIDS, is related to HIV as necessary for disease causation.[6]

Thus, as science moved forward into the 1990s and scientists discovered how HIV causes AIDS, most dissident views faded. Nearly all dissident scientists critically examined the evidence, adapted their views to

accommodate the facts and moved on. Science is after all a forward-moving and evolving enterprise.

But some dissidents did not waver in the face of mounting evidence. They seemed more invested in holding on to the rightness of their initial views than they were in following the evidence, wherever it may have led. In doing so, they turned the corner from dissidence to denialism.

## What Is HIV/AIDS Denialism?

Denialism actively propagates myths, misconceptions, and misinformation to distort and refute reality. A formal definition of denialism that I find particularly fitting comes from a group that tracks denialist activity on the Internet. They define denialism as follows:

> The employment of rhetorical tactics to give the appearance of argument or legitimate debate, when in actuality there is none. These false arguments are used when one has few or no facts to support one's viewpoint against a scientific consensus or against overwhelming evidence to the contrary. They are effective in distracting from actual useful debate using emotionally appealing, but ultimately empty and illogical assertions. Examples of common topics in which Denialists employ their tactics include: Creationism/Intelligent Design, Global Warming Denialism, Holocaust Denial, HIV/AIDS Denialism, 9/11 conspiracies, tobacco carcinogenecity denialism (the first organized corporate campaign), anti-vaccination/mercury autism denialism and anti-animal testing/animal rights extremist denialism. Denialism spans the ideological spectrum, and is about tactics rather than politics or partisanship.[7]

Denialism is the outright rejection of science and medicine. It involves actively contradicting and disregarding medical advice. It is steady state. Denialism is not open to criticism, and it evades modification. Denialism is only open to additional evidence supporting its tenets, and such evidence most often comes from the misuse of science and from pseudoscience. AIDS denialists, often for the sake of personal preservation or recognition, hold fast to old ideas in the face of new evidence.

One of the main features of denialism is a tendency to defend one's position at all costs, rather than to openly consider others' points of view. Proving oneself right seems to take precedence over following the evidence, even when that evidence seems to contradict one's own position and lead closer to the truth. Denialists refute new facts and remain stuck in the past.

A feature of denialism, at least at its root, is the tendency to think of the denialist position as beleaguered, and under attack and in a minority that has to stave off the assaults of the vast wrong-thinking majority. As a

consequence, those involved in denialism often, in the other justifications for their position, declare their strong allegiance to the principle of free speech. Interestingly, then, denialists often set themselves up as plucky underdogs, battling for their right to speak the truth against a tide of misinformation and, as often as not, conspiracies aimed at keeping them silent.

The kind of distorted thinking inherent in denialism can be brought into clearer focus when it is compared to other types of denialism. It is important to note that denialism is a label that no one appreciates receiving. I recognize that it is an emotionally charged term, as expressed by denialist blogger Liam Scheff:

> Denialism is a term, carefully chosen for meaning and emotional response. The term asks the reader to equate those, like myself, who look at "HIV tests" and read that they are neither specific, standardized, or able to diagnose any particular infection, and who therefore question their ethical utility – and those who deny the German/Jewish Holocaust of the 1930s and 1940s. It is not a mistake that the term is used. It is used specifically, to cause anyone with any sensitivity to run screaming from the argument, lest they make the terrible mistake of perhaps falling into "denialism."[8]

Scheff is certainly right that the link to Holocaust denialism means that the word is emotionally charged. Still, I defend my use of the term because I believe it best describes the rejection of objective reality to sustain a flawed, hurtful, and ultimately dangerous belief system. As Scheff points out, deniers and denialists are both terms that describe people who refuse to accept the historical reality of Nazi Germany and the Holocaust. There are also 9/11 denialists and those who deny that man ever walked on the moon. Denialism emerges from defiance against objective historical records or, in the case of AIDS, defiance against established science. Still, those who doubt that the Holocaust or 9/11 ever happened do not identify themselves as "denialists" but rather "truth seekers." The journalist Celia Farber, who has chronicled much of Peter Duesberg's thinking on AIDS, expresses her outrage at those who call her a denialist:

> Attempts to rigorously test the ruling medical hypothesis of the age are met not with reasoned debate but with the rhetoric of moral blackmail: Peter Duesberg has the blood of African AIDS babies on his hands. Duesberg is evil, a scientific psychopath. He should be imprisoned. Those who wish to engage the AIDS research establishment in the sort of causality debate that is carried on in most other branches of scientific endeavor are tarred as AIDS "denialists," as if skepticism about the pathogenicity of a retrovirus were the moral equivalent of denying that the Nazis slaughtered 6 million Jews.[9]

It is plain to see, however, that HIV/AIDS denialists represent just one variant of the broader phenomenon of denialism, sharing common

characteristics with Holocaust Deniers, 9/11 Truthers, and others who refuse to accept an indisputable historical record. At the core of denialism is mistrust – in the case of HIV/AIDS, the mistrust is of science and medicine. Scholars have identified the characteristics of political extremists and fringe groups that promote Holocaust denialism. These same characteristics apply equally well to HIV/AIDS denialism. First, extremist groups hold an absolute certainty that they are the sole bearers of "The Truth." For HIV/AIDS denialists, the truth is that HIV is a harmless virus that cannot possibly cause disease, and that anti-HIV medications amount to nothing more than poison, DNA terminators that can themselves cause AIDS. Second, extremist groups believe that governments are under the control of conspiring forces. In the case of HIV/AIDS denialism, the power of Big Pharma and the medical establishment have corrupted the National Institutes of Health and biomedical sciences in general. A third characteristic of extremists is a hatred for its opponents, often seen as conspiring with their enemies. HIV/AIDS denialists attack the most visible scientists; especially those who are widely exposed in the media as well as those who have publicly debunked their rhetoric. Fourth, extremists deny basic civil liberties to those whose views they see as their enemies. Ironically, denialists censor science by cherry-picking results of research while claiming to be the victims of censorship themselves, and often claiming that their rights to free expression are being systematically thwarted. Finally, denialists, as do extremists, indulge in irresponsible accusations and character assassination. As expected, denialists refer to AIDS scientists and medical specialists as Nazis, the mafia, and murderers.

A paranoid flare that characterizes conspiracy theorists is also apparent among denialists. Suspicious thinking permeates much of denialism. AIDS scientists typically avoid denialists and marginalizing them has likely helped to fuel their paranoia. Actual experiences have reinforced denialists' beliefs that the establishment is conspiring against them. I am sure that some of my own actions in researching this book will be touted as evidence that the AIDS orthodoxy is out to get them. One denialist, on account of his experience at an AIDS conference, offers a typical example:

> Early on it was clear that certain people at the meeting already knew of me. They avoided me. Others, though, initially showed interest when I raised my objections. It was obvious that these problems were not new to them, they had just never discussed them before – or been around anyone who wanted to. However, once these potential allies continued the discussions with people like Markowitz – scientists with status and influence – then they as well avoided me from then on. I found it a lonely business, acting like a scientist at an AIDS conference.[10]

Psychologist Michael Shermer is the leading authority on Holocaust denialism, and he has found that Holocaust deniers' "fallacies of reasoning

are eerily similar to those of other fringe groups, such as creationists."[11] Remarkably, these same personality features that Shermer describe in Holocaust deniers are immediately recognizable among HIV/AIDS denialists. First, denialism concentrates on opponents' weak points without making definitive statements about their own position. In HIV/AIDS denialism, without a shred of credible evidence to the contrary, there is an incessant call for the one study that proves that HIV causes AIDS while not recognizing the thousands of studies that accumulate to irrefutably show that HIV causes AIDS. Even knowing the complexity of HIV and the barriers it poses to vaccines, Peter Duesberg looked me dead in the eyes and said that failure to achieve an HIV vaccine means that an infectious agent cannot be the cause of AIDS. Second, denialists exploit errors made by AIDS scientists, implying that a few errors detected in a mass of work calls into question the entire scientific enterprise. One example I discuss at length in Chapter 3 is a reference citation error in a figure showing the course of HIV disease, posted at the National Institutes of Health AIDS web site. David Crowe, a Canadian journalist, identified the error and used it as the basis for tracing the history of the graph, claiming that the process of HIV-causing AIDS shown in the graph is false. Crowe exploits what amounts to a clerical error to support a conspiracy theory that implicates leading AIDS scientist Anthony Fauci and the National Institutes of Health. Denialists also commonly use quotations taken out of context from prominent mainstream sources to bolster their own position. This strategy is ubiquitous in denialism and includes morphing science into pseudoscience, cherry-picking, and relying on a single study – the so-called single-study fallacy. Denialists warp the findings of a single study to support their views and exploit discrepancies with past research. The fourth flaw in reasoning common among denialists is mistaking genuine honest debate in a given field as a dispute about the existence of the very field itself. Finally, denialists focus on the unknown and ignore the known. They emphasize research findings that fit their views and discount those that do not. For example, in HIV/AIDS, denialists concentrate on side effects of HIV treatments while ignoring the declining hospitalizations and increasing longevity among those who receive treatment.

Holocaust and HIV/AIDS denialism share other common features. For both, millions of people died with the vast majority of Holocaust historians and AIDS scientists confirming the causes. The enormity of human suffering caused by the Holocaust and that of a plague, like AIDS, offers a platform for denialism. Another commonality is that conspiracy theories drive both Holocaust and HIV/AIDS denialism. There are striking similarities in rhetoric, using selected excerpts from credible documents and calling for a debate on matters for which there is universal agreement. Denialist groups of all

types claim mounting controversy and the need for a debate. Both Holocaust and HIV/AIDS denialism have established their own publication outlets, such as the *Journal for Historical Review* for Holocaust denialism and *Continuum* magazine in HIV/AIDS denialism. There are full-length films produced by both movements, *The Truth Behind the Gates of Auschwitz,* produced by David Cole for Holocaust denialism and *HIV=AIDS: Fact or Fraud*, produced by Gary Null and *The Other Side of AIDS* produced by Eric Paulson and Robert Leppo for HIV/AIDS denialism. The major deniers of the Holocaust are knowledgeable of World War II history and are on the fringes of academia, just as the major HIV/AIDS denialists are well versed in the science of AIDS. Denialists of all types seize opportunities by political leaders who express support for their denialism, as has occurred in 2006 by Iran's President Mahmoud Ahmadinejad expressing doubt that the Holocaust occurred and President Thabo Mbeki of South Africa expressing doubt that HIV causes AIDS.

Those we call denialists generally prefer to be called dissidents. Perhaps, behind this preference are the crusading religious and political overtones associated with dissidence. Heretic is another term that may better capture the intent. But still, I preferred the term denialist rather than "denier" because it better represents the psychological process of malignant denial that is inherent in some denialism. Most denialists acknowledge the global AIDS problem but dispute that it is caused by HIV. I therefore use the term "HIV/AIDS denialism" to recognize that most current denialists refute HIV as the cause of AIDS while not necessarily disputing the existence of AIDS itself. A prominent group of denialists referred to as the Perth Group even bolster my rationale by stating the following:

> Let us make it clear that we are not AIDS denialists. That is, we do not deny that in 1981 a syndrome involving a high frequency of KS [Kaposi's sarcoma] and a number of opportunistic infections was identified in gay men and subsequently became known as AIDS. What we are doing and have been doing from the very beginning is to question the accepted cause of AIDS and to put forward an alternative theory for the cause of AIDS.[12]

HIV/AIDS denialism is therefore what Stanley Cohen refers to as interpretive denial. Most denialists do not dispute the objective fact of AIDS. Rather they believe an alternative view of reality. In interpretive denial, the raw facts of events are accepted but given a different meaning from what seems apparent to others. Cohen offers examples where the denier may say, "this was population exchange, not ethnic cleansing" or "the arms deal was not illegal, and it was not really even an arms deal."[13] In the case of HIV/AIDS denialism, the denialists say "AIDS is not caused by a single virus, there may not even be such a virus." Cohen states that word exchanges serve to

reclassify events or objects, such as calling HIV treatments, "toxic poisons," or saying the causes of AIDS are "drugs and poverty."

I did however consider delusion as an alternative term for denialism. The psychiatric definition of a delusion is a false belief based on incorrect inference about external reality that is firmly sustained despite what almost everybody else believes and despite what constitutes incontrovertible and obvious evidence to the contrary. The belief is not one ordinarily accepted by other members of the person's culture or subculture (e.g., it is not an article of religious faith). I considered using the term delusion because the belief that HIV does not cause AIDS is easily refutable by a body of scientific evidence that spans thousands of research findings accepted as fact by thousands of scientists. Yet the belief that HIV does not cause AIDS persists in the face of the evidence, certainly bringing to mind delusional thinking. However, beliefs that HIV does not cause AIDS do not always occur within the context of a psychiatric condition, so the use of the term delusion is not appropriate. Believing that HIV does not cause AIDS can have many motives, none of which may be indicative of a mental illness. HIV/AIDS denialism therefore seems the most accurate descriptive term for refuting that HIV causes AIDS.

In summary, denialism is to denial as activism is to action. Like the activist, the denialist seeks to spread "The Truth" about AIDS. But denialists then cross over from merely informing others of alternative views on AIDS to actively campaigning to persuade people. Chapters 3 and 4 focus on the pseudoscientific basis of denialism and the promotional and persuasive strategies of denialists.

## Suspicious Minds

At its very core, denialism is deeply embedded in a sense of mistrust. Most obviously, we see suspicion in denialist conspiracy theories (see Chapter 4). Most conspiracy theories grow out of suspicions about corruptions in government, industry, science, and medicine, all working together in some grand sinister plot. Psychologically, suspicion is the central feature of paranoid personality, and it is not overreaching to say that some denialists demonstrate this extreme. Suspicious thinking can be understood as a filter through which the world is interpreted, where attention is driven toward those ideas and isolated anecdotes that confirm one's preconceived notions of wrong doing. Suspicious thinkers are predisposed to see themselves as special or to hold some special knowledge.

Psychotherapist David Shapiro in his classic book *Neurotic Styles* describes the suspicious thinker. Just as we see in denialism, suspiciousness

is not easily penetrated by facts or evidence that counter individuals' preconceived worldview. Just as Shapiro describes in the suspicious personality, the denialist selectively attends to information that bolsters his or her own beliefs. Denialists exhibit suspicious thinking when they manipulate objective reality to fit within their beliefs. It is true that all people are prone to fit the world into their sense of reality, but the suspicious person distorts reality and does so with an uncommon rigidity. The parallel between the suspicious personality style and denialism is really quite compelling. As described by Shapiro,

> A suspicious person is a person who has something on his mind. He looks at the world with fixed and preoccupying expectation, and he searches repetitively, and only, for confirmation of it. He will not be persuaded to abandon his suspicion of some plan of action based on it. On the contrary, he will pay no attention to rational arguments except to find in them some aspect or feature that actually confirms his original view. Anyone who tries to influence or persuade a suspicious person will not only fail, but also, unless he is sensible enough to abandon his efforts early will, himself, become an object of the original suspicious idea.[14]

The rhetoric of denialism clearly reveals a deeply suspicious character. In denialism, the science of AIDS is deconstructed to examine evidence taken out of context by non-scientists. The evidence is assimilated into one's beliefs that HIV does not cause AIDS, that HIV tests are invalid, that the science is corrupt, and aimed to profit Big Pharma.

Various denialist rhetorical techniques speak to suspiciousness, such as morphing science into pseudoscience, using overly technological terminology, and cherry picked research findings. All of these devices are employed in the service of self-perpetuating beliefs. As noted by Shapiro, the suspicious person "does not pay attention to the apparent facts, but, instead he or she pays sharp attention to any aspect of them or their presentation that lends confirmation to his original suspicious idea." The suspicious person constructs a subjective world based on "significant" clues with a complete loss of appreciation for the context. Shapiro also discusses the suspicious person as having encapsulated delusions, limited in content and type. Encapsulated delusions fit what we see in denialism, where a person can be grounded in reality in nearly every facet of his or her life and yet have a circumscribed entrenched belief system that is not reflective of reality and not refutable by facts.

The insights offered by Shapiro are that denialists are not "lying" in the way that most anti-denialists portray them. The cognitive style of the denialist represents a warped sense of reality for sure, explaining why arguing or debating with a denialist gets you no where. But the denialist is not the evil plotter they are often portrayed as. Rather denialists are trapped in their denialism. From the denialists' perspective, AIDS is a battle ground to play

out a sense of good versus evil, with evil being the government scientists, medical establishment, and drug companies. To suggest otherwise would be to just as easily turn the denialists' inverted world right-side up.

Psychologically, certain people seem predisposed to suspicious thinking, and it seems this may be true of denialism as well. I submit that denialism stems from a conspiracy-theory-prone personality style. We see this in people who appear predisposed to suspiciousness, and these people are vulnerable to anti-establishment propaganda. We know that suspicious people view themselves as the target of wrongdoing and hold persecutory ideas. Suspicious people also tend to be overly independent in their thinking and even in their interpersonal relationships. The source of this independence is of a pervasive unwillingness to trust others. Suspiciousness is also commonly characterized by a fear of homosexuality, or even homophobia. A sense of divisiveness brings the suspicious thinker to carve the world into us and them. The distrust of suspicious-thinking people can reach an extreme to which even indisputable objective evidence to the contrary of their beliefs is dismissed and countered. It is then that suspicion buys into conspiracy theories and the suspicious thinker can be called a denialist.

## Why AIDS? Why Now?

It is not surprising that AIDS has attracted the attention of pseudoscientists, conspiracy theorists, and suspicious thinkers. AIDS has always been a hot political issue, embroiled in controversy by its very nature. Much of what fuels denialism stems from the political and cultural heritage of the disease. There is clearly extreme social conservative support for denialism, with prominent conservative web sites offering a home to denialist writings. For example, the *American Journal of Physicians and Surgeons* presents itself as a legitimate scientific journal and offers an outlet for articles on topics with a politically conservative bent. It also provides an outlet for denialist writings and uncritical reviews of denialist books. An affiliated organization, *The Semmelweis Society International*, honored denialists Peter Duesberg and Celia Farber for their exposing the truth about HIV not causing AIDS. Political Libertarians have also jumped to endorse the rights of denialists, particularly with respect to freedom of expression issues, and without apparent consideration of the harm caused by much of denialists' speech. Ignoring and misrepresenting AIDS science does not help anyone. The populations most affected by AIDS are also among the most marginalized, including gay men, racial minorities, drug users, and the inner-city poor – all are favorite targets of the extreme socially conservative right.

The fact that HIV is transmissible between persons also feeds fear, attracting people prone to paranoid thinking. Irrational fears of germs and contagions as well as obsessions with homosexuality and conspiracies are paramount in paranoia. It is no wonder that a widespread sexually transmitted virus that is prevalent in gay communities would attract the interest of the paranoid personality. The AIDS fatigue factor also appears to open the door to denialism. Public health education campaigns have dwindled over time, with new generations not being educated about AIDS. There is also growing complacency in response to HIV/AIDS, especially as HIV infection becomes a medically manageable disease (Appendix A presents a timeline of HIV/AIDS denialism).

The Internet also plays a critical role in the rise of denialism, offering fringe groups access to a global audience. Pseudoscience on the Internet is easily confused with legitimate science. People living with HIV/AIDS often seek answers by searching the Internet. Many denialists attribute their awakening to reading the facts about AIDS on the Internet or in life stories of denialists published online. Among denialists, none is known better than South Africa's former President Thabo Mbeki, who became involved in denialism by surfing the Internet.

Denialism is also at least partly an outgrowth of a more general anti-science and anti-medicine movement. There is public distrust against the US Food and Drug Administration and the pharmaceutical industry. Every time there is a recall of approved medications, as happens all too often, public trust is eroded. Campaigns against teaching evolution in favor of creationism, now referred to as Intelligent Design, remain as commonplace today as ever. Conservative political groups have called the peer-review process into question, further heightening suspicions toward science and medicine.

Scientists are generally good at communicating with each other, but often fail to communicate effectively with the public. Public health agencies also fail to provide useful and accurate science-based information on HIV/AIDS, undoubtedly playing an important role in the rise of denialism. Unfulfilled promises and predictions made by scientists and politicians through press conferences and media interviews also raise suspicions about AIDS science. AIDS pseudoscientists and denialists have seized on failed scientific predictions in making their point that science is a fraud. In some cases, denialists distort predictions, stating them in more certain terms than they were originally intended. In other cases, denialists selectively pick from partially fulfilled predictions to buttress their case.

Table 1.1 summarizes predictions that denialists commonly point to as proof that HIV does not cause AIDS. Denialists ask the question, "With all of the money and all of the attention poured into AIDS research, why have these predictions not panned out?" As shown in the table, most of the predictions

**Table 1.1** Predictions in the history of AIDS science, their use by denialists and evidence-based status

| Historical prediction | HIV/AID denialist myth | Scientific fact |
|---|---|---|
| HIV causes immune deficiency by killing CD4/T-cells. | HIV does not kill cells. HIV=AIDS theory says that HIV programs cells to commit suicide. | HIV does kill CD4/T-cells in the laboratory and in the body. The specific systematic loss of CD4/T-cells only occurs with HIV infection and is the cause of AIDS. |
| HIV will spread rapidly throughout the heterosexual population. | In 1987, there were predictions that one in five Americans will have AIDS within a decade. | HIV did not spread as originally predicted. We later learned that there are multiple strains of the virus that are spread more easily in different ways. The virus responsible for the US epidemic is more easily spread by anal sex, whereas the African strain is more easily spread by vaginal sex. |
| AIDS will devastate Africa. | Even the most AIDS-burdened countries of southern Africa continue to experience population growth. The population of Africa has increased more than 300 million since AIDS began. | AIDS has devastated and continues to devastate southern Africa. Countries such as Botswana have experienced negative population growth that can only be explained by HIV/AIDS. |
| There will soon be a cure for AIDS. | In 1984, Gallo predicted a cure for AIDS in the next 2 years. Now it is likely that a cure will never be found. | HIV/AIDS is becoming medically manageable with antiretroviral medications, and one day, there may be a cure. However, today there remains no cure for HIV/AIDS. |
| A vaccine to prevent HIV infection will soon be available. | In 1984, Gallo predicted a vaccine in 2 years. All vaccine efforts have failed, and there will not likely be a vaccine because HIV+ people already have HIV antibodies. | Robert Gallo never predicted an HIV vaccine within 2 years, although others in the US Public Health Service did. HIV rapidly mutates, is genetically diverse, and harbors in the |

**Table 1.1** (continued)

| Historical prediction | HIV/AID denialist myth | Scientific fact |
|---|---|---|
| | | immune system, proving to be evasive to preventive vaccines. There may never be an HIV-preventive vaccine, certainly not for several years to come. |
| HIV will be spread primarily through sexual transmission, needle stick injuries, and sharing injection drug equipment. | Only 1 in 1000 unprotected sex acts with an HIV+ person transmits HIV, even a constant number of cases could not be sustained in this way. Only 1000 needle stick transmissions have occurred. Injection drug users who use needle exchanges are more likely to test HIV positive than those who do not use clean needles. | The claim that HIV is not spread through vaginal intercourse is false. The modes of HIV transmission identified in the early 1980s have proved correct. Many needle exchange clients are HIV+ because they only started injecting safely after they were infected, in order to protect others from the virus. |
| HIV will be present in high quantities in people with AIDS. | HIV is proved to barely be found in AIDS patients. | HIV is present in high quantities in people with AIDS. In fact, the highest levels of HIV in the blood occur when a person has developed AIDS. |
| People who do not have HIV antibodies will not get AIDS. | AIDS does occur in people who do not have HIV antibodies, but they are not classified as AIDS. | There are other causes of immune suppression, such as cancer chemotherapy and malnutrition, but there are no other causes of the selective depletion of CD4 T-cells that results in the syndrome we call AIDS. |
| AIDS will develop within 5 years of a person getting HIV infected. | A prediction made in the mid-1980s has had to change repeatedly and is now at 10 years. No one really knows, and this | The natural history of HIV in causing AIDS is now known to occur over an average of 10 years, which can be substantially |

**Table 1.1** (continued)

| Historical prediction | HIV/AID denialist myth | Scientific fact |
|---|---|---|
| | estimate creates a conundrum when the first AIDS cases among people in their early twenties are considered. | extended with antiretroviral therapy. |
| AIDS does not discriminate. | AIDS remains contained in risk groups in the United States and Europe – gay men and injection drug users. Mostly men have AIDS in these countries. Even more damning is that different risk groups have different AIDS-defining conditions. | HIV/AIDS occurs in subgroups because of patterns of risk behaviors and networks of people who carry and transmit the virus. Different risk groups get different AIDS-defining conditions simply because of differences in exposure to those other disease-causing agents. |
| Anti-HIV medications will stop HIV infection. | The annual mortality rate of HIV+ people being treated is much higher than those not treated. People who are treated are much more likely to die of cardiac failure and liver disease than they would have from AIDS. | We remain hopeful that antiretrovirals will one day eradicate HIV from the body. This would be a cure for HIV/AIDS. Today, HIV treatments slow the virus and extend years of life, but the medications do not stop the infection. People with HIV/AIDS are also more likely to die while on treatment because the treatments are typically not started until late in the disease process. |
| Commercial sex workers will be decimated by AIDS. | Prostitutes are not at risk for AIDS, unless they inject drugs, and there are virtually no clients who have contracted AIDS from a prostitute. | This myth is proved wrong by countless medical studies of sex workers in the United States, Africa, Asia, and elsewhere. Sex workers who have never injected drugs contract HIV and have infected subsequent sex partners. |

Note: Failed AIDS predictions adapted from R. Culshaw (2007). *Science Sold Out.*

made by AIDS scientists are supported by subsequent evidence. Some predictions, however, reflect the limited knowledge about AIDS in the 1980s. Still others, particularly predicted cures and vaccines, failed to appreciate the complexity of HIV infection.

Denialism has taken hold as a troublesome social phenomenon. Like its siblings – AIDS stigma, homophobia, and racism – denialism is more than an irritant, more than a handful of rogue scientists, and more than a bunch of crackpots on the Internet. Denialism creates confusion between pseudoscience and science, and between fraud and medicine. Denialism also provides political cover for policy makers, including presidents, whose political and economic interests often outweigh their interests in public health. Unlike most other problems in the fight against AIDS, however, denialism has been neglected by researchers and activists – perhaps because those who follow the denialists are invisible to us. Or perhaps because we have focused on what have seemed like more pressing problems. Or perhaps because the default strategy has been to ignore denialism and hope it will go away – or to believe it has already gone away. Clearly, the strategy of denial in response to denialism has failed.

## Who Are the Denialists?

Not surprisingly, there is a list of denialists or "AIDS Rethinkers" posted on the Internet. Over 2700 people listed are described as "Very serious, concerned, and highly educated people from every corner of the globe." The purpose of the list is to rebut those who say that "only a handful of scientists doubt HIV's role in AIDS."[15] What is obvious is that the list of Rethinkers is a definitive directory of denialists. What is not so obvious is that it also serves as a means for denialists to see who has been vetted and cleared for insider communication.

Few on the list actually have any scientific credentials, and those who do are key figures in denialism. In late 2007, there was also a movement among antidenialists, such as the aidstruth.org group, to verify the names on the list. Antidenialism activists started contacting people on the list to ask whether they were aware that they were listed as AIDS Rethinkers. These contacts resulted in some listed members becoming outraged and asking to be removed, I suppose by a process of unvetting. Names started being blacked out from the list with the explanation that the "Names removed due to fear and intimidation." I spoke with a retired public health researcher who had coauthored a paper with a denialist and ended up on the list. He told me that he was surprised that he was listed as an AIDS Rethinker and insisted that he be removed, stating that

he did not want to be associated with the group. Others threatened to sue Rethinking AIDS if they were not removed. AIDS Rethinkers would have us believe that people are asking for their names to be removed because they are scared of being associated with people who question HIV as the cause of AIDS, victims of a conspiracy to persecute and censor AIDS dissidents.

It is essential to realize that denialism is not a solely US phenomenon. There are denialist groups on every continent, and their work appears in every medium. Televangelists, such as Ken Greene of Greenville South Carolina, see AIDS as the wrath of God placed upon those who sin. Minister Greene has preached about the sins of homosexuality, and he is the founder of African Harvest Ministries, where he claims documented proof that he has cured people of AIDS by performing miracles. In Ethiopia, more than one in four people with HIV/AIDS who are given treatments stop taking their medications because their spiritual leaders have told them to drink holy water instead. There are gay activist groups, most notably the now defunct ACTUP San Francisco, who view AIDS as a product of government conspiracies against the gay community. Denialism has also emerged from deranged and disgruntled university professors who turn to pseudoscience as a platform to gain attention. There are also unscrupulous entrepreneurs who rely on pseudoscience to sell fake cures. There are untrained scientist wannabes for whom denialism is only one facet of a personal mission against the medical establishment. There are also sensationalist journalists and Internet bloggers who sell AIDS denialism as a good conspiracy story. Among denialists are heads of state that have turned away from AIDS science in favor of denialist views. Other heads of state have even invented potions that they claim to cure AIDS (Appendix B provides a brief synopsis or who's who among denialists).

In all of its forms, denialism is inextricably intertwined with AIDS pseudoscience. AIDS pseudoscience propagates denialist myths through unregulated and non-scientific communication outlets, particularly books, magazines, and the Internet, as well as the exploitation of non-peer reviewed avenues within scientific outlets, such as letters to editors and commentaries.

Denialists are not just a few renegade crackpots looking for attention. Internet postings suggest thousands of people to at least question the science behind HIV as the cause of AIDS. There are support groups for people who have tested HIV positive and refute their medical diagnosis. In 2007, there were "AIDS dissident" science conferences held in Paris and Berlin. An online AIDS dissident encyclopedia style web site AIDS Wiki boasts over 70,000 visits, and the Alberta Reappraising AIDS Society web site claims over a million visits. The proliferation of denialist writings through multiple media outlets does more than distract AIDS scientists; it undermines countless efforts to save lives.

## Why We Should Care About Denialism

Denialists cause me less concern than people who desperately search for information about AIDS and stumble on their web sites and books. If no one paid attention to the denialists, they would be little more than an amusing blip in the history of AIDS, and I would not have written this book. Unfortunately, denialists are responsible for a significant amount of death and suffering. Faced with a life-threatening illness, people diagnosed with HIV infection will undoubtedly search for hope and cures, with the casual onlooker unable to distinguish between pseudoscience and science, between bogus quackery and genuine medicine. The credibility gap becomes fuzziest in claims found on the Internet, in books, and in the popular press. Pseudoscience also creeps into the mainstream through letters to scientific journals and publication outlets with limited review.

Consider this example of credibility creep in AIDS pseudoscience; it comes from a review of a book by Henry Bauer, a science professor at Virginia Tech University who claims HIV does not exist. Bauer's book *The Origins, Persistence and Failings of HIV/AIDS Theory* claims to prove that HIV cannot cause AIDS. William F. Shughart is the editor of a peer-reviewed professional journal in economics and political science, *Public Choice,* the outlet of the Public Choice Society; Shughart, included the following:

> The epidemiology of AIDS in Africa is different. Its signature diseases there are "not the same as the characteristic AIDS diseases in Europe and North America." As a matter of fact, because diagnosing AIDS in Africa does not require a positive HIV test, "deaths from causes that have beset Africans for a long time" may simply have been reclassified as AIDS-related. Nevertheless, mortality rates from all causes have not risen sharply in Africa. Fear-mongering about an AIDS "epidemic" in Africa plausibly reflects naked self interest: "the world has been generous with help against AIDS while not generous with help against ordinary poverty and malnutrition." Bono, call your office.[16]

Accepting the content of Henry Bauer's book as credible is a mistake that anyone who knows nothing about AIDS could make, I suppose. But the nonsense of this book is readily apparent to anyone with even a basic understanding of the HIV/AIDS epidemic or basic principles of epidemiology. Nevertheless, when a journal editor publishes a positive book review, he creates an impression of credibility for Bauer's ill-conceived thesis.

Ultimately, denialism promotes distrust in the diagnosis and treatment of HIV/AIDS. Why get tested when the results are invalid? Why receive treatment when the virus is harmless? Why earmark more money for treatment programs in Africa when mortality rates there are more or less the same as they have always been? Merely raising these questions refutes AIDS science,

fosters a sense of personal denial, and interferes with treatment options and policy decisions. Denialism can cultivate maladaptive and even malignant denial in people who have tested HIV positive. Denialism has influenced people who make policy, teach students, and lecture to the public at large. These are the fundamental harms caused by propagating denialism and the basis for my sense of urgency in writing this book.

Denialism has a definite political dimension. Denialists can influence government policies on HIV testing, HIV prevention, and HIV/AIDS treatment. Policies such as banning people with HIV from entering the United States, prohibiting access to sterile needles and syringes, insisting on abstinence for prevention, banning condoms in prison, and interfering with access to HIV treatments are examples of how denialism has caused unknown amounts of suffering. Denialism can also cut off millions of dollars in resources from much-needed programs. Thousands or tens or hundreds of thousands of people have not gained access to HIV treatments and thousands or tens or hundreds of thousands of babies have needlessly been born with HIV infection – and denialism has helped that failure, that turning away from the truth, happen. To not understand how destructive denialism can be is to have one's head in the sand.