INTERPRETIVE
PHENOMENOLOGY
IN HEALTH CARE RESEARCH

GARRETT K. CHAN, PhD, RN, FAEN, FPCN
KAREN A. BRYKCYNSKI, DNSc, RN, FAANP, FAAN
RUTH E. MALONE, PhD, RN, FAAN
PATRICIA BENNER, PhD, RN, FAAN

Sigma Theta Tau International
Honor Society of Nursing®
Sigma Theta Tau International

Copyright © 2010 by Sigma Theta Tau International

All rights reserved. This book is protected by copyright. No part of it may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without written permission from the publisher.

Any trademarks, service marks, design rights, or similar rights that are mentioned, used, or cited in this book are the property of their respective owners. Their use here does not imply that you may use them for similar or any other purpose.

Sigma Theta Tau International
550 West North Street
Indianapolis, IN 46202

To order additional books, buy in bulk, or order for corporate use, contact Nursing Knowledge International at 888.NKI.4YOU (888.654.4968/US and Canada) or +1.317.634.8171 (outside US and Canada).

To request a review copy for course adoption, e-mail solutions@nursingknowledge.org or call 888.NKI.4YOU (888.654.4968/US and Canada) or +1.317.917.4983 (outside US and Canada).

To request author information, or for speaker or other media requests, contact Rachael McLaughlin of the Honor Society of Nursing, Sigma Theta Tau International at 888.634.7575 (US and Canada) or +1.317.634.8171 (outside US and Canada).


Library of Congress Cataloging-in-Publication Data

Interpretive phenomenology for health care researchers : studying social practice, lifeworlds, and embodiment / Garrett Chan ... [et al.].

p. ; cm.
Includes bibliographical references and index.
ISBN 978-1-930538-88-7 (alk. paper)

RT81.5.1584 2010
610.73072--dc22

2010001970

First Printing, 2010

Publisher: Renee Wilmeth
Acquisitions Editor: Cynthia Saver, RN, MS
Editorial Coordinator: Paula Jeffers
Cover Designer: Gary Adair
Interior Design and Page Composition: Rebecca Batchelor

Principal Editor: Carla Hall
Development Editor: Teresa Artman
Proofreader: Linda Seifert
Indexer: Johnna VanHoose Dinse
INTRODUCTION

In 1985, I was a 33-year-old gay man living in San Francisco and a registered nurse who just tested positive for human immunodeficiency virus (HIV). This chapter is a demonstration of how interpretive phenomenology helped me develop a much richer understanding of my own community. Maybe it was because I was a nurse, but gay men who were positive for HIV but without symptoms of acquired immune deficiency syndrome (AIDS) stopped me everywhere to talk with me about the new disease—on the sidewalks in San Francisco's Castro district, at the gym, in bars, and cafés.

People were taking very different stances. Some advocated regular medical monitoring; others warned against assuming a “sick identity.” Some adapted holistic health practices; others focused intensely on the meaning of their own lives. For my doctoral research, I interviewed 17 people whose stories were representative of the hundreds that I had been hearing. This chapter tells how understandings of HIV shaped identities, social relationships, and health practices in my community. Four different orientations to HIV and its treatment emerged in this study, but these four positions are not inflexible or airtight categories; each is constituted and sustained by a dialogue between the stances, and are therefore presented here as a conversation between participants who take different stances. (Benner, 2009)

SITUATING METHOD

The research in this chapter avoided predetermined methods, following Rorty (1982) and Taylor (1989), the ethnography of the illness experience of Benner and Wrubel (1989), and the interpretive ethnography of Geertz (1972/1987). Too often, the literature on qualitative
methods seemed paradigmatically confused—both fleeing from and clinging to logical positivism and a drive toward making truth claims. Interpretive research is neither idiosyncratic nor subjective but rather offers alternative accounts and understandings that open up our worlds and tell those at the margins that they are not alone, and to those in the mainstream that the marginalized are not completely different and "other."

My own research sought a deeper understanding of how a community of urban, HIV-positive gay men was interpreting its antibody status and its T-cell counts in the late 1980s and early 1990s just prior to the availability of protease inhibitors. Patricia Benner encouraged me to "follow the story," which included eliciting stories and experiences from people in the community and writing the best-possible interpretation. During this interpretive work, a religious metaphor emerged that helped me sor: the participants into four major orientations or relationships to the health care system. However, I did not make this metaphor a central organizing framework for my dissertation (Sex, Drugs and T-cells, 1993) or for the book that that came afterward (Mortal Men, 1999). Mostly, I was afraid that the metaphor might upstage the stories themselves rather than serving as a means to understand those stories. Today, I'm more confident that the metaphor has the potential to help health care professionals better understand how people cope with a number of chronic illnesses, and not just HIV/AIDS.

The four major orientations to the health care system offer metaphors for how people orient themselves in relation to the dominant religion in a culture:

- Heretics hold values or adhere to practices that conflict with the dominant understandings of the health care system and the medical model of disease.

- Believers share the values and participate in the practices of the dominant health care system in a culture, just as they might share the values and rituals of a dominant religion.

- Agnostics maintain a distance from both the dominant and alternative medicines.

- Ecumenists seek to integrate values and practices from a variety of traditions in service of health and healing.

A note must be made on the use of quotation marks. When I began the process of writing and rewriting that is central to interpretive work, I took the liberty of rearranging and editing the participant's statements. Part of the interpretive work involved with turning a conversation into a text involves reorganizing the conversation into a story that will be coherent to the reader. Listeners are more forgiving than readers because they can always interrupt to ask questions. I often corrected grammatical errors, eliminated repetitive statements that did not
enhance or emphasize something significant in the story, supplied antecedents when only a pronoun was given, and so forth. Therefore, the use of quotation marks was used in the manner of a fiction writer to offset dialog. As the process continued, I found myself removing much of my own voice in the conversation when it was not contributing to the story, letting the participant speak for himself. My own voice appears in the interpretation and is mostly directed at the reader. Thus, quotations are not verbatim but are always based upon actual statements of the participants.

BEFORE COCKTAILS: WAR AND RELIGION

The 1970s were innocent years of liberation and indulgence: years when Eros taught gay men to celebrate their sexuality and establish relationships. An old photo captured me, two ex-lovers, a recent fling, and my new lover all giggling hysterically at a mechanical bear. Confetti and birthday hats date the event as my 25th birthday in 1977. I had an old T-shirt that lamented, So many men; so little time. Five years later, the god of death arrived and taught us compassion, and how to love through grief.

As a nurse, I spent most of the 1980s and 1990s caring for friends and loved ones with AIDS. Ordinarily, doctors and nurses don’t know their patients as well as I knew many of mine. The long-term loving relationships I had with them made it possible to blend the personal and the professional, and I learned a lot about caring in the process (see MacIntyre, 1996; 1999). But the newly liberated and often still-angry young men in my community were not always easy to understand. Some went to the doctor and did what they were told. Others articulated understandable reasons for not seeking medical attention. Some seemed to stake out ideological positions in response to what I thought were basically biomedical or clinical questions. A few seemed to conflate theories of government conspiracy and corporate greed into explanations for why AIDS existed in the first place, and why there was still no cure. Because this was my community, I wondered whether anyone would be able to comprehend the complexity and variety of our issues and concerns when I was in trouble.

I began my doctoral studies with Patricia Benner (see Benner, 1989) because her work promised to help me develop a richer and more sensitive understanding of my community of HIV-positive gay men. Because I was a nurse, gay men with HIV frequently asked for my opinions on monitoring and treatment decisions, and I felt obligated to offer the most intellectually defensible and individually relevant advice possible. To do this, I had to discover how population-based science intersected with the artful expression of life that varied so much from person to person. I had to take the sidewalk discussions in our community more
seriously. I had to pay closer attention to what HIV meant in individual lives. My research included field notes on casual conversations as well as 17 taped interviews of gay men with relatively asymptomatic HIV.

Metaphors of war and religion were central to the interpretations that I drew from my data and have continued to shape my understanding—not only of people with HIV or AIDS, but of how most people coping with chronic disease relate to the health care system and the professionals charged with ministering to their needs.

Biomedicine has unabashedly taken up the metaphor of war, but the ways in which it takes up the metaphor of religion are less obvious. For decades, scholars from a variety of disciplines have discussed the parallels between Western biomedicine and state religions. The idea that science is the religion of the 20th century is reflected throughout our culture. These parallels are nowhere more apparent than in the medical sciences. Goethe feared that the world was turning into one giant medical institution (cited in Zola, 1984), and Reiff (1979) believed that “the hospital is succeeding the church and the parliament as the archetypal institution of Western culture” (Rieff, 1979, p. 355). That our health care system has taken over many responsibilities that once adhered to the church is clear. Today, the modern hospital supervises our births, our suffering, and our deaths. More importantly, the biomedical industry supervises the production of truth through officially sanctioned research. Like the Catholic Church of the Middle Ages, the biomedical industry has become a monolithic power that structures not only what we understand as “knowledge” but also the way we feel about and understand ourselves in relation to sickness, suffering, and death (Foucault, 1963/1975).

I found that the participants in my study, like most people, orient themselves to the powerful structures in society that define and organize their experiences with pain, suffering, and death in four major ways. Some adhere to the central understandings of medical research centers, hospitals, and the health care industry. These people are the “believers” and are akin to members of a European State Church. The metaphor does not work as well in the United States where there is no single, official church. However, for some European countries (such as Italy, Great Britain, and Norway), the metaphor plays well. For example, the relationship of the Catholic Church to the Italian State is outlined in Article 7 of its Constitution and governed by the Lateran Pacts (1929). In Great Britain, the Church of England is the official church, and the monarch is the head of the Church. And the Evangelical Lutheran Church of Norway is the Norwegian State Church, of which 83% of Norwegians are members (The Church of Norway, 2009). Members of the state church generally share similar notions of truth, values, and understandings about birth, death, pain, and suffering.
Like members of a European State Church, those with strong beliefs in Western medicine share conscious and unconscious ideas about the body, medical science, and illness care that are consistent with dominant cultural understandings. They seek care from licensed professionals and have hope in the products of Cartesian medical science—a science that emphasizes the search for those single causative agents of both health and illness.

The other three religious and medical positions are defined by their relationship to the dominant State Church or health care system.

Those who hold views that are largely antithetical to the dominant medical paradigm can be understood as *heretics*, some because of their holistic thinking and others who cite economic factors rather than objective science as the driving force behind modern medical treatment (see Moss, 2007). In the stories that follow, the heretics are presented first, followed by the believers. *Agnostics* are skeptical of both allopathic and alternative approaches to health and illness. They are not “unsure” like religious agnostics, but generally certain that the longstanding human desire to beat death resulted in both allopathic and alternative medical practices being overvalued. They were often my favorites with a strong sense of their own identities and what seemed to me like immense courage. Finally, there are those like me who take a cross-cultural approach to health care, attempting to integrate ideas and practices from complementary and alternative traditions with Western medicine. They are the *ecumenists*, people who appreciate multiple approaches to healing and who might be inclined to visit a variety of care givers both inside and outside the official health care system.

**The Heretics**

War is the most overt metaphor in modern medicine, and it is employed in response to most diseases. Modern medicine is not alone in this regard. The metaphor of war has signified and guided our response to a number of medical and social problems. Lyndon Johnson started a war on poverty. Richard Nixon declared war on cancer. Retired generals wage a war on drugs. Emmanuel Dreuilhe (1988) wrote a moving book about a war against AIDS fought on the battleground of his own body. Social liberals admonished us to “fight AIDS, not people with AIDS.”

In a culture of war, pacifists are the chief heretics. My friend, Jason, was forever on guard against mucus-producing dairy, cancer-inducing additives, and any chemical that did not make people high. He often spoke of making peace with the virus:
Remember how we always used to say that perhaps the thing to do was to get into harmony with the virus? Maybe we should say, “Okay, Virus, as soon as I die, you’re dead, so we just have to live here together.” I try to be at peace with it. But battling against the thought that I’ll eventually die from AIDS is like swimming upstream. We’re still living in the belief that we’re all going to die from it. The hundredth monkey has not yet thought that HIV is a manageable condition. It’s a mental concept. I wonder how long people would live if they weren’t tested at all. Now I watch my T cells go down, and I think, ub-oh, they might never go back up again. With that attitude, our chances are cut in half. I really believe that getting tested is not for everybody because you have to be willing and able to overcome your fears.”


I wondered how Jason’s battle was going and whether there was anything that might be done to help him. A number of his friends shared the belief that not everyone with HIV would die from AIDS—perhaps not as fervently as Jason did, but with less apparent anxiety. Even so, people were dropping dead all around us, and I was convinced it wasn’t all because of their minds. When I asked Jason how we might create a consciousness of hope without denying the fact that we were living with a deadly virus, Jason jumped into a discussion of support groups that revealed a serious belief in mental powers.

*I don’t think that any of those support groups really work. It’s a bunch of people getting together who feel that they’ve got to somehow struggle to survive. I don’t even want to think about having to survive. Once you get down to the level of finding out you’ve got something, once you start fighting to survive, then you’ve put into existence that there’s something that’s trying to kill you.*

I thought Jason was taking the positive-thinking, mind-over-matter philosophy too far. I told him I figured that chances were greater than 50/50 that I would die from AIDS, and I wasn’t putting anything “into existence” by saying so. He exploded, and we argued for a while.

**J:** Well, that’s just what I’ve been trying to not figure. I can’t understand why you’d want to think that! Because deep down you know that whatever you believe is what you’re creating in your life. So don’t believe that. A million people are HIV positive, and so, far only a tenth of those are sick. If we all believe we’ll eventually die from AIDS, then we certainly will.
RM: I don’t believe I’ll die from AIDS. I’m just saying my chances of dying from it are rather high. What else am I going to die from?

J: You could die of old age, for heaven’s sake. You could never die of AIDS. You could never even contract it. As soon as we find out we’re HIV positive, we just wait until the day that something starts happening to us. More than any other disease, I think you have to have a positive attitude with HIV. You can’t sit around thinking that you’re going to get sick. I think the ones who focus on sickness and dying the least are the healthiest ones to face death. Take Bart. To me, he’s the ultimate example of how to deal with HIV. He’s known he’s been positive for four years, and it doesn’t affect him the least bit.

JM: Why should it? He’s got 900 T cells and is totally healthy.

J: So am I! I’m healthy, too! My doctor says “T cells, T schmells. You’re not a T cell.” What about healthy people who don’t have HIV? How do you know that their T cells don’t go down to 100 when they get something and then go back up to 1,000? They don’t monitor T cells in all those people, so that could be a common occurrence. This is the problem with an unknown situation like this, but we start living in fear and thinking it’s something bad. Like right now, I’m sitting here thinking I have to make some effort in the next two weeks to get my T cells up. I have to start getting my rest. I have to not be stressed. Let me see, maybe I shouldn’t go to work today and rest instead. But if I don’t, then I’ll go in tomorrow and things will be really tense. Then I think maybe I’ll quit my job, but maybe I can’t because it might affect my T cells, and that would mean I’d have to get on AZT [azidothymidine] and I don’t know how I’ll react to AZT. So everything is based around my damn T cells, including building the house in Hawaii! And that’s ridiculous! My doctor says not to worry about my T cells, but I’m getting a lot of outside pressure here. I get barraged with information—from my doctors, from you, and from all of my other friends who love me.

Jason had tried to avoid the numbers game altogether, but after he and his lover succumbed to our admonitions to take the test, retreat was impossible. T cells came to have a number of meanings for him, not all of which were consistent with each other. On one hand, T cells were meaningless and artificial definitions of health. Even though Jason had only 300 T cells and suffered from lymphadenopathy, night sweats, and chronic upper respiratory infections, he didn’t see himself as being any less healthy than Bart, who had no symptoms at all and 900 T cells. On the other hand, Jason thought that T cells were a “good measure of
viral progression,” and he also felt challenged to raise them. He wasn’t the only one who felt this pressure.

Although health professionals did not expect people to raise their own T cells, many felt responsible for doing just that. The sense of personal responsibility for raising one’s T cells was not just confined to people with “holistic” attitudes like Jason’s. In 1995, an old friend came up to me at the gym and asked whether I thought his workout would affect his T-cell count. At first, I thought he was asking whether workouts were good for people with HIV, and I was ready to encourage him to keep it up, but then it became clear he was having blood drawn later in the day. He wanted today’s workout to raise today’s T-cell count. It wasn’t at all uncommon for men in my community to attempt to raise their T cells a few days prior to having them drawn.

Others wanted to know the worst news as soon as possible in order to make treatment decisions at the most efficacious time—whenever that was. This is the rational model. The medical purpose for monitoring T cells is either to facilitate treatment decisions or to document an individual history that might facilitate treatment decisions in the future. However, people don’t always interpret their blood tests within the medical model. Like other lab values, T cells also indicate prognostic probabilities and therefore function as a measure of one’s health, and even of one’s life, taking on a meaning-laden message.

One of the only ways to get out from under the enormous pressure and sense of responsibility for low T-cell counts was to periodically assert that they were meaningless. For men like Jason, T-cell counts tended to function as report cards. The ambivalence these men felt about T cells was similar to that of students who cram or hope for good grades while at the same time maintaining that grades are meaningless. Jason had asserted that testing was not for everyone, and I was already wondering whether the group of us that pushed Jason and his partner into taking the test had done the right thing.

Another group accepted the war metaphor but questioned the strategy, particularly our overinvestment and consequent reliance upon the offensive weapons of medical intervention. To these more holistically minded folk, our preoccupation with advanced weaponry diverted attention from defensive concerns—the health, well-being, and combat readiness of our immune systems; the availability of fresh food and water; and related psychological and environmental conditions. My friend, Damian, related that an experimental medication he was on never produced a change in his T cells:
At that point, I began to think that this had more to do with taking care of myself and less to do with taking that stuff. I cleaned up my act, wasn’t drinking or smoking or doing anything. I was working out and running and taking care of myself—more stringently and more disciplined than I had ever done in my life, and after two months, my T cells went up to over 500.

Another friend, Eric, insisted that instead of waiting for pharmaceutical intervention, we should focus on constructing a balanced life that he defined as

\[\ldots\text{eating well, being happy, getting touched, having sex, feeling good about yourself, feeling good about others. In our society, that’s very hard to do. Instead of putting so much energy into the techno-medical aspect of everything, we need to make this a functional, livable society. We need to stop putting all of our life energy, expertise, intelligence, and care into medicine and work on creating a healthier society, and that means reducing alienation, anger, violence, drug addiction—all those things which cause ill health.}\]

Some argue that medical science is developing a more objective and ultimately more humanistic approach to human problems. Critics like Eric counter that medical authorities have been no less dogmatic in their pronouncements on the causes and treatments of human problems than religious authorities have been, and that the result has been an even greater objectified and dehumanized understanding of life. The power of the medical profession in the lives of everyday people is often experienced without being consciously understood. As a sociologist, Eric understood power dynamics. His analysis of the modern doctor’s office reflected his deep distrust of physicians and is a good example of how many people might experience an office visit.

Think about what happens when you go into a doctor’s office. You are dealing with crucial issues, with life and death. Enter a person who has been given all the magical powers that our society bestows on anybody. They’re almost religious. He is wearing—a usual be, male authority—is wearing a white robe, you know. Wash your hands and stuff like that. The power dynamics are that you’re coming in and asking for divination. You are being told what your status is, what your condition is. You’re nervous because your very integrity as a person is threatened. Then you’re told that you’re near death, and it’s given the full weight that our society can give it.
Eric’s real heresy reflects a distrust of the power and status of professionals that has surfaced throughout history, from the Protestant reformation’s assault on the authority of the Roman church to the Puritan assault on the authority of the English church, to our modern self-help movements that range from 12-step programs to selling homes without real estate agents, writing wills without attorneys, and staging memorial services without funeral directors. Eric distrusts the professional authority, worries about the unequal power dynamic between physician and patient, and advocates for a more-level playing field between patients and their professional caregivers.

*What I personally feel is that the status and the role of doctors and the medical profession need to be reduced to that of a plumber. The general public needs to know more about medical information so that everybody knows enough about common sense medical and health issues to figure things out and make their own decisions. Then go to a mere plumber-type of person, a doctor, to like prescribe the stuff or to set the bone or to do the T cells or whatever. Until the roles become that equal, I think getting involved with the medical world is dangerous.*

Eric’s position may seem extreme, but it shares medicine’s instrumentalist and techno-understanding of the body. In Eric’s world, the priestly and caring activities required by patients should be provided through social services and safety nets with physicians providing simple technical expertise. Illich (1982) did not worry so much about social systems and professional power dynamics but rather that our reliance on professional strangers to manage our pain, suffering, and death was abrogating too much of our essential humanity. That diseases, pain, suffering, and death are not simply enemies to be conquered but rather a central feature of our common humanity is highly unorthodox and overly philosophical in an empirically focused science.

The adequacy of alternative systems of beliefs and practices to sustain medical heretics through health crises varies. Eric’s distrust of medicine’s authority presents a significant challenge for his health care providers. In the absence of nurturing social services and the presence of symptoms, patients like Eric will feel alienated by physicians who assume the detached nature of a plumber.

Eric and Illich (1982) distrust the doctor-priest, but patients like Jason will embrace any doctor-priest who shares their holistic ideology that can range from thoughts and feelings affecting health to positive thinking raising T cells. For some, these ideas were empowering. For others, these ideas formed imperatives and obligations for self-healing that were often not achieved, deepening a sense of disease as personal failure. They exacted an unachievable
demand for self-control over the body. For Jason, I was concerned about the extent to which his holism might be functioning as a means to cope with abject fear—fear that was not permitted within his mind-body ideology.

Unorthodox views or heresies are neither inherently empowering nor delusional. They are not necessarily instances of enlightened thinking or of denial. The same general idea can function in widely different ways, and it is incumbent upon healers to understand the function of their patients' ideologies if they intend to provide more than instrumental care. As Taylor (1993) notes, conflicting theories often function simultaneously and with different possibilities.

The Believers and the State Church

The best way to understand a dominant paradigm is often through investigating the ideas and practices that develop in opposition to it. The primary alternative to the dominant Western construction of health and illness is loosely identified as holism and provides a framework for practices now referred to as complementary and alternative therapies. This alternative paradigm is not just about ideas, but economic and social power struggles as well. According to Lowenber (1989), holism functions in opposition to the tradition of Cartesian dualism, which is the philosophical foundation of Western medical practice. Although the holistic movement can sometimes romanticize nature, Western medical science tends to see nature—and especially death—as the enemy. Holism struggles to make death acceptable while fully embracing life, and constructs a metaphor of harmony. Western medicine pits life against death and constructs a metaphor of war. The metaphors are oppositional and dualistic rather than interrelated or continuous.

Several men in my study would find the constructs of holism as articulated by Lowenberg (1989) to be closer to their notions of self and world than they would biomedical materialism. Conversely, others clearly embraced the construction of HIV and AIDS that came from the medical establishment. Their ideas seemed less dramatic than Eric's anti-medical stance or Jason's mind-over-matter holism, in part because they are largely consistent with dominant medical understandings and practices.

In fact, the orientations to Western medicine articulated in this study do not seem like ideologies at all. These men are believers but not in the fundamentalist Protestant sense. The "pro-medical" position is more akin to membership in a European State Church that comes with birth or citizenship. Membership has not been renounced to avoid paying church taxes, but beliefs are not world-defining as they are for the truly devout. However, like anyone with a life-threatening illness, these men would resist any limits placed upon receiving medicine's
sacraments. Matthew's and Ron's stories are emblematic of those who looked for Western doctors with an aggressive approach to treatment.

**RM:** Have you done anything in terms of lifestyle changes or anything as a result of being HIV positive?

**M:** I started taking acyclovir four years ago because I thought AIDS was eventually going to be associated with herpes. I'd never had it, so I figured, why bother getting herpes? My doctor said acyclovir wasn't harmful, so I've been taking it since 1986. I've tried various things. I took that mucic you put in the blender, AL-721 (a mixture of lipids extracted from egg yolks thought to inhibit HIV; see Clinical Trials, 2005). I did that for about a year. I've tried various things. I still do acyclovir, and I started AZT two months ago.

**RM:** Your T cells are about 700. How did you decide to start taking AZT?

**M:** . . . from the research coming out. My doctor seemed to think that when you get below 500, you should start AZT. They have an attitude of "when, not if." It's like they're waiting. It's sort of creeping up on you. I figure as long as it's going to be eventual—and they keep telling me that eventually my T cells will drop—I might as well just start it now.

**RM:** Your physician recommended you start AZT with 700 T cells?

**M:** No. He said there's no research, no statistics to show that it does anything, especially for people with more than 500 T cells. The only studies were in the 200 to 500 level. Granted, it was significant, but the sample was so small that he didn't consider it relevant. But I disagree. I know a number of people who are taking AZT and have had dramatic increases in their T cells, which I find strange.

**RM:** Did you just feel like you should be doing something?

**M:** Well, it's not just feeling that I should be doing something. I have this horrible feeling that at some point, we'll find out that we all should have been taking AZT all along, and now it's too late. You should have been doing this two years ago or whatever: I guess I figure I should do something. AZT is all that's out there at the moment that's approved, and it seems to be relatively nontoxic or relatively safe. I had a friend who was just killed by ddI [didanosine]—from pancreatic failure. I don't have those worries about AZT. I had my blood work done again this week, and my red and white cells are fine.
Matthew was a man who thought things through for himself. He generally accepted the medical establishment’s appraisal of the situation: “They have an attitude of when, not if.” However, his decision to begin using pharmaceuticals earlier than his physician recommended was not uncommon. His physician’s research training included concepts of significance and T-cell parameters, but Matthew wasn’t a researcher and was not overly concerned with what seemed like fine points of his physician’s reasoning. Matthew wasn’t interested in AZT because it symbolized hope. Instead, he had a rather pragmatic fear that while waiting for confirmation of a medication’s effectiveness, he might miss the boat. A number of men in my community were anxious to begin taking medicines sooner rather than later. Health professionals often try to weigh potential benefits against potential side effects, but withholding medications from patients who want them can be difficult.

Ron’s story depicts a reversal in the usual state of affairs. Ron describes himself as a “real medical person,” and his response to recommended support groups and meditation was perhaps predictable.

**RM:** We had the test around ’85, and you had it done around ’87. Why did you wait?

**R:** There was no known treatment. They’d just tell you to clean up your act. I always knew that drinking and drugs and late nights were bad for you. I’d already started to clean up my act. But the minute I found out that AZT was available and was effective for treatment, my partner [James] and I decided to go down and take the test. We didn’t want to take AZT unless we were actually positive. But the minute we knew there was some kind of positive action we could take, besides just living a good clean life, then it made sense to take the test. I figured that finding out I was positive wouldn’t be such a disaster since there was something I could do about it. I never had much doubt in my mind. I figured I maybe had a 10 or 20 percent chance of being negative. I wasn’t surprised I was positive. I wasn’t happy about it, but I wasn’t surprised.

**RM:** What was it like for you?

**R:** I think I would’ve been okay, but two things scared me to death. First, they sat me down at the clinic and were so heavy about giving me the results that it scared me. Then they suggested that I go to a support group at Project Inform. That turned out to be the most horrible experience of my life. It was about twenty or thirty people who all sat around and talked about how great life was before AIDS—and that
they would all be dead in a year. So instead of being supported, I ended up cheering everybody up. I felt good about that, but it was a bunch of defeatist people wondering how they were going to tell their parents and worrying that their parents would wind up taking care of them. The whole feeling was death. There wasn’t one person in the group who was thinking that they might live a normal life span. Except for me. My doctor said he wished I hadn’t gone, but the people at the clinic practically forced me to go. They made it sound like it was standard procedure and that it would be really helpful. They made me feel like if I didn’t do it, I wouldn’t be doing everything possible to help myself. The whole testing procedure up to that point was fine.

RM: It sounds like the counselor was too caught up in his own feelings about HIV to appreciate where you were coming from.

R: They could’ve handled it differently. They sat me down like it was the biggest thing in my life and made me feel like everyone they tested in the last several weeks came up negative. I really got the impression that they were singling me out. I sort of went in knowing I was going to be positive. I went out totally broken. A few days later I went back, and they made you do meditation and all that kind of stuff. Then I felt guilty because I’m not into meditation and self-healing and all that stuff. I’m a kind of a real medical person. I would’ve preferred their saying that they’re doing this research and they have this drug and that drug. Even if it wasn’t true, that would have made me feel better. You’re supposed to go like once a week, but I just went once a day. It scared the hell out of me, and I never went back. And from that moment on I felt better and better and better.

Some have argued that medical information is never neutral and that the metaphors surrounding AIDS have been as deadly as the virus. This is an interesting position in light of Ron’s reaction to the HIV test. Ron had approached the HIV test within a context of hope. As a medically sanctioned intervention, AZT provided the impetus and the courage for him to take the test, but that was not the context in which Ron was received by the more “holistically” oriented health care system in his city. Neither the counselor nor the people at the support group shared Ron’s faith and hope in Western medicine. The psychosocial-spiritual interventions they offered in its place were as comforting to Ron as a bottle of AZT would have been to those who believed it was poison. Nonetheless, those who generally trust Western medicine have access to a culturally sanctioned system of care that is mostly alienating for heretics.
The Agnostics

Some of the HIV-positive gay men I interviewed seemed to find heavy anchors in their own self understandings and to resist most forms of intervention, especially early in the disease process. These men clearly understood the limits of Western medicine but were not seeking alternative treatments or philosophies. As with other diseases, those who stay relatively healthy have much more freedom to choose or refuse treatment. Serious symptoms tend to force people into existing structures for care and treatment where dominant cultural understandings prevail. When they got sick, they did what they were culturally prepared to do—visit the doctor.

The freedom from symptoms and the freedom to refuse culturally sanctioned therapies for asymptomatic HIV infection create a degree of ambiguity, ambivalence, and even hostility among some with asymptomatic HIV infection. This is especially true in such cities as San Francisco and New York where health and illness are understood from a variety of different perspectives. Family, friends, and physicians often push different treatments and approaches and sometimes undercut the patient’s choices.

Dick did not begin his story with taking the HIV test, but rather his experience with loss.

The thing that affected me most at the time, probably more than anything that’s ever happened in my life, was the death of Peter. He was from New Zealand, and I met him here in the US through a mutual friend. We became the very, very best of friends. He was the human being with whom I had the closest relationship in my life. It was way more than lovers. It was just this incredible connection in so many ways. I think we sort of had sex once, but it was just kind of peripheral to something else that was going on. We were extremely close. We saw each other every day. We knew everything about each other’s lives. He had boyfriends, and I had boyfriends, and we knew all about and talked to each other about our boyfriends—so we were more intimate with each other than we were with our respective lovers. It would take me more time than is available and more time than I have to try to describe the wonderfulness of that relationship. Experiencing how pure a love between two men can be stands as the high-water mark in my life. I am very fortunate to have had that experience in life with a man. I think if you get one of those, you’re very lucky. If it happens more than once, you’re exceptional.

I am basically a fairly positive person who likes himself and likes his life and is fairly self-confident and enjoys having a good time. Yet the first year after Peter died was
the longest year of my whole life. I was miserable all the time, and life was just black. Then over the period of the second year it got grayer, progressively lighter, and in the last half year or so, I think that I got a bell of a lot happier. Not like I was before, because before Peter died I had a sort of childish innocence based on ignorance. I no longer feel that sort of youthful notion that everything's going to get better as I go along; that I'm in the prime of my life, that I'm going to conquer the world. Now I realize that death happens and things end, but I think that one can know that and be happy anyway.

To draw on an old Catholic metaphor, it's sort of like the fall from grace. Before they got knowledge, Adam and Eve had this sort of blissful ignorance where everything was always perfect and they didn't know anything other. But then they got knowledge, which changed everything and got them thrown out of the good situation they were in. That's sort of what happened to me. Now I know what death is. I have the knowledge of death, so I feel older and wiser. I'm certain that I will never have the innocent quality of happiness I had before I knew of death, but I think it is still possible for me to be happy anyway.

Dick's concise account of regaining a kind of happiness after losing the love of his life suggests Kierkegaard's idea of world-defining commitments, which Kierkegaard (1843/1971) thought were vitally necessary to any rich and full life. Dick's story included a long section where he explained why he could not even imagine a new relationship. For Dick, love was not an abstract concept or a force that somehow attached itself to a beloved object. Love was a particular embodied experience, so when Peter died, love and his way of being in the world died as well.

To avoid commitments like Dick's love of Peter is to avoid life itself, but world-defining commitments come with a price: They must eventually be mourned. Trying to distinguish between the happiness he felt before and after coming to know death was not simply an abstract philosophical issue for Dick. It was about distinguishing who he was as a man who had lived, loved, and mourned. Dick was not alone in this struggle. Freud (1917/1955), Kierkegaard (1849/1983), Becker (1973), and Wilbur (1986) all worked on making sense of mourning and mortality without recourse to overly simple religious or New Age explanations. Dick's sophistication in dealing with his own grief did not mean that he was ready to start contemplating his own mortality on a day-to-day basis, though.
D: If I’ve been gradually dropping T cells over the last few years, I don’t really want to be reminded of that fact or have it verified. I knew I was antibody-positive when I got the test, and after taking it, I was bummmed out for a long time. I suspect that my T cells may be declining. Maybe they are; maybe they aren’t. What I ask myself is, what practical good will it do me to know? What benefit is to be gained? What unpleasantness is to occur? Profit/loss. Let’s look at this the way I look at everything else.

RM: Okay—tell me what the balance sheet shows.

D: And the balance sheet says there’s not a great deal to be gained because if your T cells are going down there isn’t a thing you can do about it. It’s not like it would confirm or deny that I have some disease that can be effectively treated. I could take a highly toxic drug called AZT that will eat my bone marrow and build me the “ill person” Zeitgeist by putting me on this permanent prescription that I’ll never get off. And this would also identify me as an HIV−er to the insurance companies to whom I have to send the AZT bills, which would get me put on the list of people who should be executed or sent to concentration camps or whatever. So all of that is to be lost. And identifying myself as a sick person—both publicly and to myself—would seriously hurt my sense of well-being. I stand to lose that if I get into searching for confirmation that I have some preliminary manifestation of AIDS.

D: So part of me laughs at myself and says, “Honey, you are in heavy denial; you’re trying to preserve this fragile illusion that you’re really not sick or that you really don’t have AIDS, an illusion that’s getting progressively more fragile.” And maybe I am, but that’s what it takes for me to get up every day and keep living. If I start counting T cells, that will probably lead me to start taking medicine. If I start counting T cells and taking medicine, I’m going to become like some hypochondriac old lady who gets worried and obsessed and then wants to talk about it all the time. It’s boring!

D: I want to spend my energy making sure that the quality of my life, however much longer it’s going to be, is as high as I can possibly make it. I do work that I really enjoy. I love being a teacher because I feel like I can start people out doing something that will continue after I’m gone. I may have somebody for only one day, but I may be able to plant some kind of seed or light some kind of spark in them that will make their life better. I think that’s kind of neat. I feel like I’m giving a little something back for all the good things I have taken from living. I’ve bad a
wonderful, marvelous, incredibly lucky life. I’ve met wonderful people and have bad things happen to me that I had no reason to think I deserved. So I want to do those sorts of things instead of sitting around fussing over whether my T cells went up or down.

**RM:** Do you know anybody who is monitoring T cells, taking AZT, and not being a hypochondriac?

**D:** No. One of my friends has been watching his T cells decline for a long time. As a result, he started taking AZT. We were sitting around, and he was describing how much weirder and worse he feels now that he’s started taking a strange and powerful new drug. So, yeah, watch your T cells decline, take AZT, feel weird, get the idea planted in your head that you’re sick, pay too much attention to yourself. It just gets in your way. It gets in the way of doing whatever else you try to do in your day.

**RM:** Okay. Have you been presented with the evangelical medical appeal?

**D:** My friend the doctor tried to give me that. I just buried him last month in New York. So, beat thyself, physician. Yeah, I’ve had people do that and turn around and die themselves. Chinese herbalists—dead. Western medicine—dead. Clean living, bodybuilding, good diet, lots of exercise—dead. Every damn one of them. So anybody can get evangelical in my face about anything they want, and I’ll listen to them and go, “Yeah, okay, fine. Show me a live one, and we’ll talk.”

Dick seemed to reject both biomedicine and the narrative accounts of survival in our community, and his approach seemed needlessly myopic and even deadly. It flew in the face of my rationalism and my idealism. Although Dick had little hope in medicine or New Age holism, he could not wholly abandon hope because he knew that he needed hope to keep living. But his hope was tempered by his experience, which was that HIV invariably led to AIDS and that AIDS invariably led to death. I was concerned that his personal experience with HIV was nonetheless essentially hopeless, at least as far as either alternative interventions or Western medicine was concerned. However, Dick’s hopes were neither about medicine nor prolonging biological life. Dick’s hope was about preserving what was valuable to him in his own life. This is often a difficult position for nurses, physicians, and loved ones to understand—and when they don’t, the patient suffers.
The Ecumenists

Asymptomatic, HIV-positive gay men have found themselves at the intersection of a number of competing approaches to health and illness, including Western biomedicine, traditional ethnomedicines, and a variety of complementary and alternative modalities. At the center of this competition are theories about the immune system: not only the mechanics of its defenses against microbes and cancers, but also its relationship to lifestyle and social issues. In addition to seeing their physicians, people in the HIV-positive community are also visiting acupuncturists, ingesting herbs, and joining gyms. Gay men, especially those with asymptomatic HIV infection, still seek out a variety of approaches to treat it. Even the most medically minded among us were experimenting with things like AL-721—"that 'muck you put in a blender'"—along with their AZT. Nathan, a psychiatrist, embraced both Western and alternative approaches.

I went to see an AIDS specialist who did skin testing. I'd already finished two years of medical school, so I knew what skin testing meant. She kept shaking her head, and the message I got from her was, "You are typical; you are doomed." I didn't have any reaction to the skin tests, and rather than realizing that that was a bad sign, I just totally blocked it out. I canceled my appointment, and the nurse told me I had to come in and have my skin test read. And I just said, "Don't worry, I'm fine. I'm fine." I've never had a case of denial that extreme in my life. I forgot I had ever done the test until a whole year later. It terrified me because it meant I had no immune system. Then one day after I was back in medical school, I was doing skin testing on somebody. All of a sudden I remembered my own skin test, and the result, and I was horrified.

Then in the spring of '87, I went for a routine physical, and my white count came back at 3.9 [low]. My doctor said I had to get tested because this was an indication that something might be wrong, and there was really no excuse not to get tested at this point. So I agreed to go ahead and finally get tested. I felt I really had to face it and was fully prepared for a positive result. What I wasn't fully prepared to find out was that my T cells were only 226. So what happened actually was that I got the results of the T cells before I got the results of the HIV test.

What freaked me out so much was that I wasn't familiar with the numbers, and I really didn't know what they meant. I had just learned about what the ranges were. I had heard that 200–400 was ARC [AIDS-related complex]. So immediately
in my mind, I had ARC. Anything under 200 meant you were vulnerable to opportunistic infections. I didn’t know anything about how T cells could stay in the same place for a long time. Actually, I didn’t know anything. Even being a doctor, I didn’t know anything. So what I thought that meant was that any day I would come down with AIDS. It was like, “Sorry I have to tell you this, but you only have a year to live.”

None of the other doctors knew what they meant, either. I learned about these lab values through my own experience, through what I learned from other people, through watching my own numbers. It wasn’t from having learned it from a textbook or from an article, because even now [1990], nobody really knows.

Then I had my T cells rechecked, and they were 315 a week later. So I learned my first lesson about T cells from that. They could vary 100 points. It didn’t really mean anything necessarily.

Nathan’s comment that “it didn’t really mean anything necessarily” was repeated several times by the men in my study but rarely meant the same thing twice. For Nathan, it meant that he wasn’t necessarily going to get sick and die within the year. His interpretation of the skin testing was not scientific but symbolic. The negative result indicated not a compromised immune system but no immune system at all.

Even physicians occasionally interpret laboratory tests within personal, rather than rational, frameworks. In fact, nobody understands laboratory tests in perfectly rational and abstract terms all of the time. Nor should we. Despite our culture’s having come to idolize the rational over the past 300 years, much of life is lived outside neat rational abstractions in the rather messy world of personal and social meanings and concerns. This is not to say that all personal meanings should be accepted without argument, but rather that personal and social meanings often collide with the rational constructs of health professionals. Nathan seemed to seek some common ground between the personal and social meanings that HIV had in his community and his professional understandings, often by moving back and forth between his feelings and his science. Having no immune system whatsoever was way too dangerous to Nathan’s sense of self, so he “forgot” for a whole year that he had taken the test, which was perhaps the most rational response possible.

When Nathan received his first T cell count, he did not rationally choose the meanings that he assigned to his results. Before giving him the result over the phone, his physician asked whether he was sitting down, and Nathan interpreted the result in the context in which it was given. The medical technology to measure CD4 counts (or the levels of T-helper cells,
the primary target of HIV) was available in 1987, but the stories in this project showed that we did not have the experience necessary to make much sense of them. Neither his medical education nor his psychiatric residency did much to reduce Nathan's terror or the symbolic interpretations that grew out of it. So he turned to "alternative things."

**N:** I decided to start researching everything I could possibly do for myself. AZT wasn't a possibility at that time. It was still just experimental. There were really no treatments at that point. I've always been somewhat holistically minded, so within a week after being in a major depression, I was out there doing a whole list of things. First, I started doing complete vitamin therapy," [laughing] "like several hundred dollars on vitamins. I started doing acupuncture, Chinese herbs. I started jogging regularly, meditating, visualization.

**N:** Six months previously, I had started reading A Course in Miracles, which is the first spiritual work that ever touched me in any way. It had been collecting dust in a corner, so I pulled that out again. I started reading things like Louise Hay, Dr. Bernie Siegel, a lot of inspirational things about mind over body. I joined a support group at the Center for Attitudinal Healing, which I attended for fifteen months. [laughing] That was it. Then I took six months off from my residency while I was instituting all of these things. I came out to my supervisor and training director. I told them what was going on, and they were very supportive. So I was given the time off with pay, which was really nice.

**RM:** Jesus! You did it all. What was that like?

**N:** It was empowering. It gave me the feeling that I could have control over this, particularly when I read things from Louise Hay and Bernie Siegel. I also attended seminars and whatnot. I got it into my mind that I'm not going to be a victim of this. I can take charge. I can have control over this. And my theory at the time—it's changed significantly since then—was that if I don't want to die, I'm not going to die. I can will this thing into submission. [laughing] And I needed to feel that at the time. Everything I was doing for it—the meditation, the vitamins, the herbs—made me feel like this was my way of controlling it. As long as I was doing those things, this thing was not going to get me. I felt real positive about that.

**N:** Throughout the first year, I gradually started dropping all the things I had started. I didn't feel like going for acupuncture anymore. The herbs were a pain in the ass—boiling that shit every morning, and the smell was horrible. Not to mention
the expense! All those trace minerals and enzymes; all this shit. Then I started doing AL-721. I did that for an entire year. The only thing it probably did was put weight on me. I finally boiled it down to a multivitamin, multimineral, E and C.

N: But again, all those alternative things were important because they gave me confidence psychologically. I wasn’t just sitting there doing nothing. As time went on, I realized I’m still alive and not getting sick. But I needed to do all those things before to give me a sense of power. When I regained confidence that I wasn’t ready to drop dead, I was able to stop doing a lot of those things.

RM: So what finally convinced you to take AZT?

N: I had a very rigid, puffy, by-the-book internist who said, “You just have to do this.” But the same day I was told I needed to be on AZT, I was told I needed to go on Pentamidine and that I should fill out a durable power of attorney. So I really flipped out. When he gave me the forms for the durable power of attorney, I felt like I was getting a death warrant to sign, whereas a friend of mine immediately filled them out because he said it made him feel much better.

RM: It gives some people a sense of control.

N: Yeah, but that was the same day my ANC [absolute neutrophil count] was 800. My doctor believed in full-strength AZT, and then thought, because of the ANC, that I was in too terrible a state to be on full-strength AZT! I was tied to a schedule of getting my arm stuck every two weeks, an M.D. visit every two weeks, and a once-a-month Pentamidine appointment. I thought I’d never be able to stop thinking about AIDS.

When Nathan started taking AZT, it wasn’t because he found his doctor’s arguments reasonable or convincing. It wasn’t really because he was convinced that it would help. Unlike some of the men I interviewed, Nathan never said that AZT gave him hope. Nathan began AZT to comply with an older gay physician’s insistence, and in the process, was able to let go of some of his denial. He also felt that he had given AZT some of his “power” and that if he stopped taking it, he’d feel very vulnerable and trapped. It made him feel “lousy,” and in a few months, he told his doctor he would rather die than take the full dose of AZT. Nathan called me later that day to tell me how “pissed off” his doctor was.

He was so pissed off that he dictated his notes right in front of me. He turned on the Dictaphone and said, “Patient refuses to take 500 mg as recommended. Will only
take 300 mg even though I told him there is no evidence that 300 mg... blah, blah, blah—as if life waits for evidence. You know, I never thought the AZT did much at all. There never was a bump in my T cells.

A couple of years later, Nathan had two T-cell counts in a row that were below 200. “I got terribly depressed. I thought this is it. It’s inevitable. There are two of them now.” He started Prozac, and his T cells went back to above 200. On the advice of his new physician, Nathan stopped the AZT. He tried two new antivirals. DDC (dideoxycytidine) gave him canker sores, and ddl gave him diarrhea. Two months later, his T cells went up a bit more. For the next few years, Nathan stayed away from antivirals altogether. When protease inhibitors were available in 1996, he started taking what was known as “the cocktail”—generally three different antiretroviral medications. In 2005, he became impressed with Harold Foster’s work and added selenium, NAC (N-acetylcysteine), glutamine, and tryptophan.

CONCLUSION

While Nathan went back and forth between Western and alternative medicine, the playing field for the holistic and biomedical positions is hardly level. Western medicine isolated HIV and defined AIDS. Western biomedical understandings have dominated public discussions, shaped the structure of HIV and AIDS services and research, and became the credo of almost every major AIDS organization. A century ago, Robert Koch (1878/1880) and Claude Bernard (1865/1957) took different positions on the relative role microorganisms played in human diseases. Koch focused on microbes, whereas Bernard argued that microbes were everywhere and that health was dependent on the human terrain or milieu intérieur.

Some gay men with asymptomatic HIV heeded Bernard’s warning against the “single minded fervor of the microbe hunters,” especially because the early drugs used to fight HIV were often both ineffective and dangerous. Some of these men focused on stress reduction, drug and alcohol use, nutrition, exercise, and meditation. Others developed fantasies about being able to control their HIV and T-cell counts with right living and right thinking, becoming examples of the “blame-the-victim” critique that Western medicine has leveled against the holistic health movement. Some, like Nathan, took an ecumenical approach.

However, the vast majority of gay men embraced Western medicine. We grew up in a culture informed by the notion that diseases are caused by single, identifiable, and measurable agents. People who accepted the dominant, medical construction of AIDS understood that the illness was caused by a chance encounter with a virus. The religious and political right,
however, construed the epidemic as the scourge of an angry God or the consequences of an immoral agent—“the wages of sin is death” approach.

A more holistic approach to AIDS would have included psychosocial and behavioral issues, such as the rampant promiscuity, alcoholism, and drug use in the gay community, but the battle lines had been drawn. The religious and political right proclaimed our guilt and picketed our funeral services, while the biomedical establishment insisted that the virus was morally neutral and would infect whomever it could. The cause of AIDS became a black-or-white issue: a blame-the-victim mentality parading as personal responsibility, or a blame-the-virus mentality parading as hard science. Given those choices, it is no surprise that most people with HIV felt more comfortable with the latter.

When the scientific establishment did address psychosocial and behavioral issues, it was almost always within a viral framework. Researchers seemed to conclude that studying behavioral issues that were not directly related to contracting HIV (and the social structures that sustained them) might be construed as being homophobic or blaming the victim. The viral framework had the distinct advantage of appearing objective, amoral, and nonjudgmental, and most humanists and academics opted for the “HIV is the cause of AIDS” equation.

Over time, however, as people accumulated more experience living with HIV, the assumption that the virus held all the cards seemed too simplistic, disempowering, and unduly pessimistic. In addition to pursuing traditional holistic approaches to sustaining health (e.g., nutrition, exercise, acupuncture, herbs, and micronutrients), many gay men started reappraising specific social structures and practices in their community. The gay liberation movement had forced gay men out of the closet and into a world where they were compelled to develop new identities and ways of understanding themselves. That all this gay liberation and gay identity construction took place within a largely hostile and homophobic culture immersed in its own narcissism and hedonism has not been fully appreciated. A sexuality and sensuality that had been repressed and restrained throughout adolescence (and for eons) suddenly exploded.

Not all practices that develop around liberation movements are valorous or healthy. Some take a serious toll. The idea that some of the behaviors associated with gay liberation contributed to the decimation of gay men's immune systems continues to be both psychologically untenable and economically unprofitable. It is far more comforting for patients and far more profitable for the medical industry to attribute the entire epidemic to a chance encounter with a virus.
Yet the notion that lifestyle might affect who remains asymptomatic and who progresses to AIDS has been part of the conversation among gay men with asymptomatic HIV for well over two decades. This hasn’t been an easy conversation. The major “party boys” did seem to drop dead first, but lots of us knew men who had lived cleaner lives but were already dead. Thus, questions about the effect that drugs, alcohol, stress, depression, and promiscuity might have on disease progression persist in the gay community, both consciously and subliminally. These questions aren’t simply attributable to unresolved feelings of guilt, self-loathing, or internalized homophobia. Although emotions often accompany such questions, rational minds will pose them independently. But the questions have been hard to answer.

Science does not know how people with asymptomatic HIV can prevent their conditions from turning into AIDS. Even the fine print on the pharmaceutical advertisements admits that we don’t know whether antiviral medications will prolong the asymptomatic period. We also don’t know whether reducing stress, abstinence from drugs and alcohol, eating right, exercising, or meditating will prolong the asymptomatic period. Some studies show that cigarette smoking hastens and some micronutrients slow progression to AIDS, but these conclusions are not uniform. After all this time, we don’t even know whether condom use between HIV-positive partners will prolong life. And even though science has not answered these questions definitively, people with asymptomatic HIV answer them every day, within the contexts of their own lives, experiences, and beliefs.

Whereas most of the top AIDS researchers gave lip service to the existence of “co-factors,” the role that these and other non-HIV-related factors might play in the progression of HIV to AIDS has not been systematically investigated, although some progress is being made. The war against AIDS has mostly involved a single strategy: Seek out the virus wherever it may be lurking and kill it. The single-minded focus on the virus is not confined to the medical establishment. When Rotello (1996) suggested that 2,000 or more sexual partners per decade may not be a biologically sustainable norm in any community, many accused him of being homophobic. Nonetheless, the views of dissident and often marginalized academics and community leaders who suggest that other factors besides the virus should be considered are seriously entertained by many gay men living with HIV. Foucault’s work (1963/1975; 1975/1979; 1976/1979) on the relationship between scientific truths and the structures of power that develop and sustain them has inspired serious thinkers to reconsider the biomedical construction of HIV/AIDS. Those who have lived with asymptomatic HIV infection over the past two decades have had to chart their courses between these larger cultural arguments about health, microbes, and disease.
On the surface, comparisons between religion and medical science can seem strange, but
the struggles between religious and medical authorities are over the same turf—the nature of
reality or truth. One prescribes the methods required to investigate objective reality; the oth-
er prescribes the rituals required to understand revealed truth. However, big differences exist
between modern medicine and the modern church. In the Western world, rejecting modern
religion is increasingly possible (Taylor, 2007), but it is as hard to walk away from modern
medicine as it was to walk away from the church of the Middle Ages. The sacraments of
health care can be witheld, as they frequently are in the United States, but the importance
of health care cannot be denied. Nonetheless, heathens and heretics have never been com-
pletely extinguished, and the AIDS dissident movement always intrigued me.

Over the past two decades, I came to appreciate that being a nurse is somewhat like be-
ing a nun. Nuns are told what to profess by a religious hierarchy, whereas nurses obtain their
doctrine from an industrial or academic one; yet, the truths perpetuated by our religions and
sciences are far more orderly than the real world in which people live—worlds of crisis, cha-
os, and ambiguity. Nuns and nurses tend to live closer to the people than do their more pow-
erful priest and physician counterparts, and both nuns and nurses often wind up mediating
relationships between their neighbors and the larger powers that govern modern life. Nuns
now offer communion, and nurse practitioners dispense medications. Both minister to pa-
riishioners and patients in ways that used to be the singular province of priests and physicians.

Today, many nurses act as apologists or even evangelists for the medical status quo. Many
nurses—especially those in academic positions—demonstrate a deep reverence toward the
modern systems charged with developing scientific knowledge. They are contemptuous to-
ward the “n of one”: the anecdote, the individual patient. Other nurses, though, revere the
sanctity of specific human lives in addition to statistical data based upon populations and
aggregates. Our challenge is to remain simultaneously respectful and skeptical of both posi-
tions.

Healing care requires an understanding of particular patients and population-based sci-
ence. If we approach everyone as if they were members of our own church—if we fail to
distinguish between heretics, believers, agnostics, and ecumenists—we miss the mark. If we
cannot comprehend why our most compliant patients might also visit the alternative clinic
down the street, we must struggle to enlarge our concept of the population we treat.

Aristotle’s (330 B.C.E/1994) concept of the virtuous mean can be helpful here: Aristotle
postulated that human virtues can be found between their two opposing vices (and it has
always been easier to identify pathological states than healthy ones). Aristotle’s most famous
example is perhaps the virtue of courage falling between the vice of cowardice and the vice of recklessness, and a bit closer to recklessness than cowardice. In health care, the virtue of healing can be found between the vices of shamanism and scienticism. The most sensitive healers will move away from one vice or the other depending upon their own tendency to favor one over the other, their institution's tendency to favor one over the other, and the patient's beliefs and orientation to health and the health care system.

References


A#v=onepage&q=&f=false