The Sounds of Furious Living: Everyday Unorthodoxies in an Era of AIDS

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ABSTRACT

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This dissertation seeks to expand our understanding of AIDS activism by adding to the historical register the stories of individuals who engaged in everyday acts of protest through their endorsement of unorthodox etiological and therapeutic responses to the disease. By focusing on the histories of two poorly understood New York City based organizations – the People with AIDS Coalition (PWAC) and Health Education AIDS Liaison (HEAL) – it both supplements and challenges scholarship which has to date focused predominately on the public protests organized by the AIDS Coalition to Unleash Power (ACT UP). Resisting a common scholarly bias that masks and marginalizes unorthodox, everyday acts of resistance, I map the larger sociocultural currents that gave birth to and sustained their expression amongst individuals living with, responding to, and dying from AIDS in New York City through the 1980s and 1990s. In so doing, I strive to achieve a true social history of AIDS better able to capture diverse expressions of patient resistance than those organized about professional norms and institutional taxonomies. It is my hope that its methodology and conclusions may not only deepen our understanding of the late 20\textsuperscript{th} Century’s most studied epidemic disease, but indeed more broadly inform historical scholarship investigating patient engagement with other infectious and chronic diseases.
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Acronyms

AIDS Coalition to Unleash Power (ACT UP)
Acquired Immune Deficiency Syndrome (AIDS)
Active Lipid 721 (AL721)
AIDS Related Complex (ARC)
Azidothymidine (AZT)
Centers for Disease Control / Centers for Disease Control and Prevention (CDC)
Cytomegalovirus (CMV)
Dideoxycytidine / Zalcitabine (ddC)
Dideoxyinosine / Didanosine (ddI)
Epstein-Barr Virus (EBV)
Food and Drug Administration (FDA)
Gay Activists Alliance (GAA)
Gay Liberation Front (GLF)
Gay Men’s Health Crisis (GMHC)
Health Education AIDS Liaison (HEAL)
Human Immunodeficiency Virus (HIV)
Human T-Cell Leukemia Virus / Renamed Human T-Lymphotropic Virus (HTLV)
Institute of Medicine (IOM)
Kaposi’s Sarcoma (KS)
Lymphadenopathy-Associated Virus (LAV)
National Cancer Institute (NCI)
National Institutes of Health (NIH)
People with AIDS Coalition (PWAC)

*Pneumocystis carinii* Pneumonia (PCP)

Treatment Action Group (TAG)

Joint United Nations Programme on HIV/AIDS (UNAIDS)

Wipe Out Aids (WOA)

Zidovudine (ZDV)
Archives

ACT UP Oral History Project (ACT UP-OHP)
Cornell University Library Rare and Manuscript Collection (CUL-RMC)
Health Education AIDS Liaison Archive (HEAL-A)
Lesbian, Gay, Bisexual and Transgender Community Center National History Archive (LGBT-NHA)
New York Public Library Manuscripts and Archives Division (NYPL-MAD)
New York Public Library, Science Industry and Business Branch (NYPL-SIB)
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Introduction: Acknowledging the Everyday

Images of AIDS activism pervade popular culture, emblazoning in our collective memory a powerful, visceral narrative of the pain and suffering endured by people with AIDS, the transformation of this suffering into anger, and the mobilization of this anger into political action. Photographs of protestors staging die-ins at the steps of the Food and Drug Administration, scattering the ashes of loved ones on the lawn of the White House, and occupying the offices of pharmaceutical corporations have become allegorical illustrations of health activism challenging the policies and practices of those in power. An encyclopedia of gay and lesbian history names the AIDS Coalition to Unleash Power (ACT UP), the organizer of many of the aforementioned protests, the most prominent AIDS activist group of the 1980s and 1990s. Indeed, by some measures, the protests of ACT UP are effectively synonymous with AIDS activism: among the first ten images retrieved through a recent Internet search of 1990s era AIDS activism, nine featured public protests organized by members of ACT UP.

The contributions of ACT UP to the history of AIDS activism and, more broadly, the history of drug research in the United States, have been well documented. By vocally and dramatically demanding access to treatment, typified by ubiquitous demands for “drugs into bodies,” ACT UP was able to facilitate profound changes in the institutional review of drugs by the FDA. However, just as historians have noted that ACT UP’s public protests distracted from

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the organization’s less visible campaigns to secure positions of influence alongside governmental regulators and the leaders of pharmaceutical corporations, they have also masked the heterogeneous nature of AIDS activism through the 1980s and 1990s.⁴

Political scientist James C. Scott has observed that historians and social scientists are apt to focus their attention on “riots, rebellions and revolutionary movements” rather than less violent forms of political action.⁵ For Scott, less visible “everyday forms of resistance” constitute open political actions that are collective in nature, have the ability to exert tremendous influence on the course of history, and ought to be included in the historical record. In the context of AIDS activism, ACT UP’s public protests and disruptions occupy a sphere analogous to the overt forms of resistance typified by Scott’s riots and rebellions.⁶ However, preceding these outward expressions of anger and frustration is a rich history of contestation directed at dominant professional and governmental bodies responding to AIDS. In many cases, this tradition of political action and resistance centered upon challenges to Western biomedical orthodoxy and dominant systems of drug investigation. And it was frequently expressed through avenues of individual treatment and care.

Throughout the 1980s and 1990s, many people – frequently those diagnosed with AIDS or who were believed to be at high risk for developing the condition – actively explored treatment options developed and promulgated by networks operating outside the dominant

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⁴ Some authors would in fact argue that ACT UP’s political aims reflected the interests of a narrow subset of the gay community. Furthermore, as ACT UP was founded in 1987, associations of the organization’s protests with AIDS activism fail to capture the history of AIDS activism in the early-to-mid 1980s. For a discussion portraying ACT UP’s activism as narrowly tailored, see Peter F. Cohen, “‘All They Needed’: AIDS, Consumption and the Politics of Class,” *Journal of the History of Sexuality* 8, no. 1 (1997).


⁶ A complete discussion of ACT UP’s protest methodology is beyond the scope of this analysis. Interested readers may consult Brown, *Replacing Citizenship*; Cohen “‘All They Needed’”; and Gould *Moving Politics.*
Western biomedical model. In some cases, they sought access to chemicals that had not passed the FDA’s testing standards for investigational new drugs. In others, they explored treatment options derived from traditions and practices historically exempted from rigorous federal review, including herbal remedies, mind/body healing, homeopathy and macrobiotics. They at times directly challenged the dominance of particular facets of the biomedical model, such as the roles played by government regulators, pharmaceutical corporations, laboratory scientists and physicians. But, more often than not, they expressed their criticism by silently disengaging from the biomedical model and embracing etiological and therapeutic paradigms that contradicted mainstream biomedicine.7

As these everyday expressions are defined by their variance from accepted, largely hegemonic biomedical practice, I refer to them here under the broad category of unorthodox AIDS activism.8 Movements consistent with this particular type of activism arose out of a deep-

7 One might counter this framing of treatment activism by arguing that Western biomedicine has carved a place for alternative healing styles, subsuming them under the terms “complementary” or “integrative” medicine. However, this professional absorption of unorthodox health practices does not mean that individual patients construe their embrace of alternative, holistic or unorthodox modalities as suddenly part of the mainstream. Furthermore, the historical archive is rife with instances wherein mainstream medicine absorbed or assimilated unorthodox healing systems in an effort to undercut the threat they posed their authority. Consider, for example, the historical experience of osteopathy. Beyond all of this, even if one maintains that the establishment of complementary and integrative models of health constitutes a true embrace on the part of biomedicine for these diverse healing systems, we should consider the role unorthodox AIDS activism has played in facilitating the establishment of these categories.

8 I have chosen the descriptor “unorthodox” as it succinctly conveys a sense of variation from a norm while remaining relatively free from narrow association with particular sectarian practices through history. The terms “alternative” and “irregular,” for example, convey variance from or departure from a norm, but have their own complicated historiographical uses. Terms such as “nontraditional” are ill suited, as they imbue normalized practices with the language of historically validated tradition. Other terms, such as “holistic,” rather ironically have narrower connotations. Some critics have alleged that the use of the word “orthodoxy” to refer to dominant or accepted health practices is pejorative, with at least one claiming that the word is wielded as an insult to biomedicine by AIDS dissidents. See Jeanne Bergman, “The Cult of HIV Denialism,” Achieve: A Quarterly Journal on HIV Prevention, Treatment and Politics, Spring
seated suspicion that Western biomedicine’s approach to conceptualizing and treating disease was flawed and/or incomplete, and the corresponding belief that individuals with AIDS would not find succor through its strategies and tactics. For individuals tapping into this complex and rich tradition, efforts to get “drugs into bodies” in fact contributed to the suffering wrought by AIDS. Unorthodox acts of opposition and resistance are not easily captured in the ephemera of the epidemic, nor do many of their proponents remain to tell their stories. But one finds echoes of their legacy in many places: in newsletters distributed amongst support groups discussing the benefits of herbal medicines in treating AIDS; in recipes meticulously listing instructions for “cooking” experimental egg lipids in Greenwich Village apartments; in information packets circulated in macrobiotic food kitchens explaining AIDS as a consequence of the twentieth century’s reliance upon increasingly processed modes of living; and in articles written by people with AIDS rejecting mainstream clinical treatments such as AZT and defiantly advancing etiological explanations that rejected a role for the Human Immunodeficiency Virus (HIV).

AIDS is perhaps the most studied disease in all of history, attracting the attention of historians, sociologists, anthropologists, biologists, physicians, epidemiologists, ethicists, political scientists, medical geographers and students of countless other disciplines. It has

(2010): 16. I thus appropriate the term “unorthodox” fully aware that there is no straightforward way to characterize or categorize the wide array of healing practices I examine here.

9 We see this tension between unorthodox and mainstream AIDS activists within the structure of ACT UP itself. Many highly vocal members of the group advocated a focus on “drugs into bodies” campaigns while others attempted, largely unsuccessfully, to direct the group’s energies to the exploration of alternative and experimental therapies, such as Compound Q. See, for example, Gould. Moving Politics, 337.

taught us a great deal about the implementation of historically rooted public health practices, the stigmatization of marginalized populations, the interpretation of epidemiologic data, the establishment of lay expertise amidst professional uncertainty, and the organization of highly visible activist groups aimed at expediting drug approval. It is in AIDS that we see perhaps the clearest crystallization of 20th Century treatment activism, the rise of a voluntarist response to disease, and the self-organization of marginalized peoples to respond to a condition many governments chose to ignore. And yet despite all of this, the history of unorthodox AIDS activism remains largely unwritten. The single most authoritative volume dealing with the topic remains Steven Epstein’s influential and insightful *Impure Science* (1996), but neither its specific focus nor its disciplinary approach allows for a broad framing of the intersecting historical currents underlying the diverse manifestations of unorthodox AIDS activism seen in the 1980s and 1990s.

The failure of scholars to adequately explore the complex history of unorthodox AIDS activism carries important consequences for our understanding of the history of public responses to epidemics. In both popular and scholarly formulations, AIDS is credited with almost single-handedly instigating profound change in treatment activism, with AIDS activists operating “at the vanguard of a larger movement for patients’ rights, a movement to revolutionize medical

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research for all diseases.” One recent analysis, for example, credits the social movement that arose to combat AIDS with “creating a roadmap for catalyzing significant public policy change” to be used by patients living with countless other diseases. If we seek to credit AIDS activism with playing such a pivotal role in transforming the role of the patient activist, we must examine all manifestations of AIDS activism, not just those which endorsed or promoted the position of the dominant healthcare system.

Why, then, has unorthodox AIDS activism failed to generate the same level of sustained historical analysis as endeavors which sought to effect change from within mainstream biomedical channels? While many potential reasons present themselves, I maintain that four particular factors warrant scholarly analysis. First, it is easy to construe treatment decisions – an important avenue of unorthodox AIDS activism – as individual and private acts, obscuring their collective dimension. Second, multiple, heterogeneous and seemingly fragmented traditions subsume the broad unorthodox healing movement, posing methodological difficulties for

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13 I do not mean to endorse the notion that AIDS singlehandedly transformed patient activism. Indeed, we should problematize treatments that claim as much, taking into account the important contributions of the women’s health movement, the cancer activist movement, etc.

14 To be clear, my framing of ACT UP as a reformist organization cannot diminish the significance of the emotionally resonant and unapologetically combative protest strategies the group endorsed. However, as Epstein has argued, these strategies ultimately proved successful in granting members of ACT UP a place at the table with government regulators, pharmaceutical corporation representatives and health officials. ACT UP thus effected the most significant change from within the larger biomedical system, a sharp contrast with individuals who espoused unorthodox positions, who would for the most part positioned themselves in opposition to (or were positioned in opposition to) mainstream biomedical power systems. For a discussion of revolutionary and reformist activist traditions, see Steven Epstein. *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley: University of California Press, 1996), 234.
scholars endeavoring to map its contours. Third, patients tended to move between these many traditions, further complicating efforts to identify bounded movements, with committed advocates and sustained campaigns. And finally, particular strands of unorthodox AIDS activism have been radicalized or stigmatized by scholars and the lay public, making sustained, objective scholarly analysis of their origins and development difficult. As I contend that these four factors have impeded scholarly consideration of unorthodox AIDS activism in the past, I shall begin my historical analysis with a brief review of each of them.

Everyday Unorthodoxies: Factors Contributing to the Obscuration of Unorthodox AIDS Activism from Historical Scholarship

The first of these factors – the tendency for scholars to interpret treatment decisions through an individual lens – is anticipated in James Scott’s analysis of everyday forms of resistance. As Scott’s particular interest is in resistance associated with systems of production, he underscores the ways in which seemingly individual acts of protest in this sphere – peasant pilfering, tax evasion, foot dragging and the like – escape the attention of scholars eager to chronicle protest movements. These acts of resistance, administered in silence or within the shadows of individuals’ homes, are easily missed in favor of outward displays of group protest typified by peasant uprisings. If we accept Scott’s arguments, then surely it should come as little surprise that the conduct associated with unorthodox AIDS activism – that is, individual treatment decisions made in response to a disease associated with deeply personal behaviors – would escape the attention of scholars interested in the history of social protest. Indeed, in an era defined by the rise of biomedical ethics and its championing of Kantian virtues of self-
determination and autonomy, it is deceptively easy to interpret therapeutic choices through the lens of the sacred individual.\(^{15}\)

Notwithstanding our 21\(^{st}\) Century fascination with the individual, we must recognize that treatment decisions – and, in particular, the use of treatments deriving from unorthodox healing traditions – fall into a category of action with overt social and political dimensions. In short, as feminist activists have succinctly argued, the personal is political. In the case of AIDS, the individual decisions patients made to look beyond dominant treatment paradigms were predicated upon the existence of networks of people sharing their experiences, examining the strengths and limitations of their perspectives, providing critical information for obtaining and utilizing unorthodox treatment methodologies, and insulating their members from forces of stigmatization and marginalization following their departure from accepted norms. One’s decision to pursue a particular treatment plan therefore must be understood within the context of larger social relationships.\(^{16}\)

However, the collective dimension of unorthodox AIDS activism in fact extends beyond the social forces that sustained its practice and insulated its members from the opprobrium of the biomedical system. Indeed, we might concoct a strained hypothetical scenario involving a lone patient making decisions freely and without reliance upon larger networks of support and legitimization – a hermetic Paracelsus concocting cures in his cloistered closet. Even here, we

\(^{15}\) Interestingly, Tom Koch and Tom Beachamp have argued that biomedical ethicists’ invocation of Kant’s theories was largely instrumental and superficial, and deserves reexamination. As Koch writes, “Raising Kant’s banner, and that of philosophy generally, gave to bioethics a general veneer of historical power and the appearance of analytical rigor. The problem was, however, that asserting the methods of analytic moral philosophy as a basis for practical valuation crossed a firm line between the theoretical and practical in Kant’s writing.” Tom Koch, *Thieves of Virtue: When Bioethics Stole Medicine* (Cambridge: MIT Press, 2012), 119.

\(^{16}\) We might furthermore consider the ways these social systems help facilitate the exercise of autonomy.
must grant that his actions register their effects upon society on the collective level. For, in choosing to pursue an unorthodox healing remedy, this individual exerts a real, measurable effect upon the pool of participants eligible for research trials investigating drugs developed through orthodox channels. In the case of AIDS, we can identify many examples of researchers bemoaning their inability to find enough “pure subjects” – that is, individuals who had not previously used unapproved or untested drugs – for their trials. In this context, the decision to engage in an unapproved or unsanctioned treatment strategy is deeply political.17

A second factor contributing to the elision of unorthodox AIDS resistance from scholarly analysis relates to the movement’s failure to mobilize centrally around one core set of principles or beliefs. Indeed, the list of historically and culturally rooted healing systems giving rise to unorthodox AIDS activism runs the gamut of homeopathy, Chinese medicine, macrobiotics, positive psychology, and Ayurvedic medicine, in addition to diverse interpretations of Western biomedical models that ally themselves with no particular tradition but yet still challenge mainstream theories. Scholars seeking to examine the history of unorthodox AIDS activism are therefore presented with a methodological quandary amenable to two possible solutions. On the one hand, they may cast their nets wide and consider multiple, conflicting strands of unorthodoxy, granting the many contradictions and tensions that exist between these strands. On the other hand, they may focus on one particular strand of unorthodoxy, writing histories of homeopathic responses to AIDS, separate volumes on the use of macrobiotic approaches to combatting the disease, and others aimed at exploring the history of Ayurvedic responses. Both approaches have their own shortcomings. The former, for example, risks reducing complex and

17 Scott touches upon this notion when he posits that a seemingly individual act of resistance – peasant desertion – has real, measurable social consequences for states attempting to conscript armies. Scott, “Everyday Forms of Resistance.”
diverse activist traditions to their simplest common denominator, while in pursuing the latter the historian may produce narrow analyses of minor movements which individually exerted little impact on the course of the epidemic.

Caught between this historiographic Scylla and Charybdis – the ignominious decision of charting a path between the evils of indistinction and irrelevance – I am reminded of observations made by sociologist Rhys Williams, who presciently argues that social movements are seldom neatly bounded, internally consistent, or logical in their organization or actions.\textsuperscript{18} How we define the contours, boundaries, neighborhoods and precincts of these movements is a deeply political process. Scholars must attempt to construct their beginnings and endings using archival sources that have the curious tendency of spilling into one other in boundless overflow while paradoxically revealing themselves to be limited and incomplete. This is to say that it is not always possible to determine where homeopathy ends and macrobiotic activism begins, or where one divides herbal responses to the epidemic from those focused on contrarian etiological framings of the disease. I therefore advocate risking incongruity and indistinction in casting our nets wide, simultaneously considering multiple strands of unorthodox AIDS activism, comparing and contrasting them, uncovering their shared values and common themes.

I should note that my chosen approach to studying alternative health activism is at odds with a deeply ingrained historiographic bias prioritizing the recreation and recapitulation of processes and patterns of sectarianization in medicine. We see this bias in the very organization of the history of medicine – not only is the history of alternative medicine bracketed from the history of regular medicine, but it is furthermore divided into the various and sundry histories of

bounded systems of practice. If we wish to learn about the history of Thomsonian medicine, we consult volumes dedicated to the topic; the same is true of physiomedical medicine, mesmerism, hydropathy, homeopathy, and so on. This historical penchant for organizing healing practices into different philosophical or professional camps should not be viewed as a benign enterprise, for it yokes the individual decisions of patients to histories of professionalization and sectarianization, locating them within a matrix of competing philosophies. To capture a social history of unorthodox healing, we must move beyond methodological penchants for bounded philosophies and ordered heresies and instead train our eyes on the patients – the apprehensive, confused, impressionable, impulsive, demanding, bombastic, emotional, irrational, intelligent and irreverent individuals located at the intersection of these powerful systems of healing.

Focusing on the patient as the primary unit of analysis in historical study poses problems that do not lend themselves easily to systems of historical chronicling or narration. After all, how does the scholar examine the collective mobilization of individuals responding to a fatal condition when they simultaneously employed mutually exclusive etiological and therapeutic methodologies? What are we to make of the young man who experimented with macrobiotics one day and obtained a supply of the immune modulator isoprinosine from a Mexican clinic the next? Or who participated in an AZT trial while secretly taking an experimental egg lipid product? It is all too easy to assume that such behaviors were abrogative and therefore dismissible, or that they proceeded from an irrational desperation, a therapeutic “grasping at straws.” However, to dismiss as a form of organized resistance any individual’s action that is contradicted by his or her later actions is to demand a form of methodological purism seldom
seen in the historic record and unsupported by sociological scholarship.\textsuperscript{19} Furthermore, we must remember that not all decisions made in desperate times are irrational.\textsuperscript{20} The historical archive of unorthodox etiological and therapeutic AIDS activism reveals multiple instances of exacting, scrupulous analyses of theories and claims. The scrutiny expounded in the pages of \textit{AIDS Treatment News} or the \textit{People with AIDS Coalition Newsline} – even the sensational \textit{New York Native} – belies efforts to characterize all of their authors as senseless or irredeemably sensational.

Thus far, I have argued that unorthodox forms of AIDS activism constitute examples of Scott’s everyday forms of resistance in that they are both collective and political in nature. I have furthermore maintained that scholars have omitted or deemphasized these forms of resistance from the larger history of AIDS activism due to their close association with individual treatment responses and to the internal contradictions easily identifiable in their constitutive movements. In short, we might say that unorthodox forms of activism have – in many estimations – failed to satisfy an unstated and unexamined presumptive measure of \textit{collective resistance}. However, if we probe more deeply and examine the ways in which scholars have occasionally engaged or discussed unorthodox forms of AIDS activism, we recognize the results of an altogether separate

\textsuperscript{19} As sociologist Cynthia Fuchs Epstein notes, “[R]eal people are quite capable of vastly contradictory behaviors and transformations that stem from different elements of themselves.” Fuchs advocates moving away from rigid interpretations of identity and instead toward models that recognize the “seeming paradoxes of ‘odd combinations’ of identity elements and subselves, even those ‘mutually irreconcilable.’” Cynthia Fuchs Epstein, “The Multiple Realities of Sameness and Difference: Ideology and Practice,” \textit{Journal of Social Issues} 53, no. 2. (1997), 273.

\textsuperscript{20} In the 1960s, Richard Hofstadter famously analyzed “paranoid styles” within American politics. While I do not wish to subsume all of unorthodox AIDS activism under this rubric, I find Hofstadter’s use of the near fetishistic attempt on the part of activists to factually support their accusations to be very useful for the current historical project. As Hofstadter notes, “One of the impressive things about paranoid literature is the contrast between its fantasied conclusions and the almost touching concern with factuality it invariably shows.” See Richard Hofstadter, “The Paranoid Style in American Politics,” \textit{Harper’s Magazine}, November, 1964.
historiographic bias. This bias does not dismiss such activism because it fails to satisfy an unstated measure of resistance – but instead because of its failure to satisfy a presumptive measure of the everyday.

Readers may find this claim somewhat surprising, for I appear to turn Scott’s argument on its head by claiming that scholars routinely elide from their analysis expressions of activism which are not everyday. And yet this is precisely my argument. I maintain that in the case of particular manifestations of unorthodox AIDS activism, both lay and academic commentators have contributed to a radicalization of resistance movements. This radicalization has had the effect of highlighting fringe aspects of activism and exotifying them to the point that they no longer maintain features of the everyday. As I shall argue, this phenomenon is at play in analyses of unorthodox AIDS activism movements – in particular, so-called AIDS dissidence and denialism – which maintained that HIV was not the cause of AIDS. It is not uncommon among professional scholarship on AIDS dissidence for commentators to dismiss such movements as irrational or radical manifestation of fringe paranoia,\(^\text{21}\) or as the pet projects of rogue professionals.\(^\text{22}\) Lost in this treatment are the ways in which dissidence and denialism grew out of and interacted with diverse unorthodox AIDS resistance movements of the 1980s and 1990s.

The overarching goal of this historical project is to elucidate the forms of unorthodox AIDS activism that arose throughout the 1980s and 1990s, locate them within the larger history of alternative and contrarian health movements, map their contours and connect them to the


\(^{22}\) It is common for authors to presume that dissidence began with or was defined by the pronouncements of rogue scientists, most notable University of California Berkeley retrovirologist Peter Duesberg. Seth Kalichman, for example, has argued that, “HIV denialism starts and ends with Peter Duesberg.” Kalichman, “Denying AIDS,” 175.
broader history of AIDS activism. I intend to redress the aforementioned forces of historical omission that have left unorthodox AIDS activism in the shadows or distorted its complex origins. However, even as I have argued that historical scholarship lacks an explication of this form of activism, some critics may still question the need for my overall project, raising three categories of objection: (i) those deriving from questions of methodology, (ii) those deriving from questions of utility, and (iii) those deriving from questions of professional ethics. I shall pause now to consider each of these objections in turn.

A Consideration of a Methodological Objection

A fundamental methodological objection I must address maintains that, while I have defined a category of protest in terms of its variance from a dominant professional norm, I have failed to explicitly define that norm beyond vague references to the Western biomedical model. This point is entirely valid. The fact that I have been able to proceed thus far in explicating several claims without a formal definition of the dominant model against which unorthodox activism is judged is perhaps a testament to the former’s pervasive reach in society. But an explicit definition is nonetheless necessary. Here, in discussing the Western biomedical model, I refer to a broad network of overlapping professional spheres comprised of licensed clinicians, public health professionals, epidemiologists, basic and applied scientific researchers, representatives of pharmaceutical corporations, and governmental regulators. It is constituted by the standards of practice and explanatory paradigms employed by these individuals in the course of their professional practice, along with the values, judgments, and assumptions underlying these practices and paradigms.  

I intentionally maintain a broad, flexible interpretation of “standards and practices,” including the locations where biomedicine operates (e.g. physicians’ offices, public health clinics, emergency rooms, research laboratories, regulators’ offices, pharmaceutical corporation offices,
tools and approaches of scientific empiricism in matters of medicine, a historical phenomenon with deep roots extending to the Enlightenment (and likely much earlier), and continuing through the late 19th and early 20th centuries, expressed in part through increasing reliance upon scientific tools and frameworks for diagnosing and treating disease.

The Western biomedical model provides an explanatory framework for understanding how illness operates, for developing treatments for illness, and for employing said treatments in an organized, systematic manner. It is sanctioned by the state even as it is an expression of the state’s power; its members are licensed by the state and regulated by sets of standards and practices, which are in large part policed and implemented by representatives of the biomedical system itself. Furthermore, just as it provides socially conditioned responses to the catalogue of diseases it has mapped and tamed (e.g. diabetes, arteriosclerosis, pneumonia), it establishes protocols for addressing diseases it has mapped but lacks the ability to cure (e.g. advanced stage cancers, Alzheimer’s Disease) in addition to new, previously unmapped diseases. Its explanatory and therapeutic framework is pervasive throughout the structures and systems comprising everyday life, from the workplace (e.g. in discussions regarding health insurance availability), to schools (e.g. in institutionalized nurse’s offices and vaccination requirements), to modes of public transportation (e.g. in health screenings at airports and posters on subways). Its hegemonic presence furthermore extends beyond the United States, as Harish Naraindas, Johannes Quack and William Sax have argued: “Biomedicine has penetrated nearly every corner of the globe, so that most adults living in the twenty-first century know what doctors are and the ‘right’ way to
consult them, what injections are and how one makes use of them, what hospitals are and why one visits them.”

A Consideration of Utilitarian Objections

Some critics may accept my responses to the aforementioned methodological challenges while criticizing my larger project on the grounds of what I shall refer to as utility – or the total benefit or good – that one should expect to derive from such an historical analysis. Critics focusing on questions of utility might maintain that the study of unorthodox AIDS activism is unnecessary or unwise for one of several reasons. They might claim, for example, that despite my methodological approach of grouping together different activist traditions under the unorthodox banner, there is no reason to suspect that the aggregate movement enjoyed a high degree of support among individuals. Others might argue that the study of this topic is unwise as its practitioners espoused beliefs that have largely failed to withstand the test of time or exert much influence on the course of history.

These criticisms touch upon issues that transcend the history of medicine and cut to the core of the historical craft. Disputes regarding the incorporation of underrepresented voices in the historical narrative are not new. We might consider, for example, 1970s era efforts to conduct “history from below,” in addition to the postcolonial field of inquiry termed “subaltern studies,” which appropriates Antonio Gramsci’s framing of the subaltern as an underclass upon whom the

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24 Harish Naraindas, Johannes Quack and William S. Sax, “Introduction: Entangled Epistemes,” in Assymetrical Conversations: Contestations, Circumventions, and the Blurring of Therapeutic Boundaries. ed. Naraindas, Quack and Sax. (New York: Berghahn, 2014), 6; Here, in discussing hegemony, I borrow Sara Mills’s formulation of the term: “[H]egemony is a state within society whereby those who are dominated by others take on board the values and ideologies of those in power and accept them as their own; this leads to them accepting their position within the hierarchy as natural or for their own good.” Sara Mills, Michel Foucault (New York: Routledge, 2003), 75.
dominant class exerts its hegemonic influence.²⁵ Suffice to say, historians have actively debated the inclusion of underrepresented, minority and subaltern histories in the historical narrative for some time, and as I shall argue at greater length in Chapter 1, the history of unorthodox AIDS activism is in many ways analogous to these once controversial disciplinary projects. Furthermore, I contend that we must resist any urge to further marginalize or stigmatize activist traditions of the 1980s or 1990s based on the knowledge and experience we enjoy today, for to do so would welcome into our analysis presentism cloaked in the garb of utility.

Other utilitarian objections suffer from the establishment of impossibly high standards for inclusion in the history of activist movements. If we seek to evaluate unorthodox activism by its success in supplanting the dominance of biomedical theory and practice, then it is true, it did not succeed. However, it is a woefully high standard for inclusion in historical narratives if we demand that a movement topple the dominant, hegemonic forces of society. Indeed, is it not interesting and worthy of our attention that segments of the population attempted to undermine or disregard hegemonic systems for organizing and managing their health? That in the context of a highly technologized biomedical era, marked by the promise of molecular biology, biotechnology, genomics, and countless other scientific achievements, we find individuals pulled in the direction of contrarian systems of health and healing?

A Consideration of Ethical Objections

A third criticism of this project does not stem from judgments of relevance, importance or utility but instead deals more seriously with what I shall refer to as matters of professional ethics. Such an objection would maintain that, given the implications of distrust in the dominant biomedical system, any effort to locate 1980s and 1990s era unorthodox health activism

threatens to normalize, rationalize or validate contrarian health movements. While I take this argument seriously, I ultimately reject it as a justification for censoring from the historical record the history of unorthodox AIDS activism. For I maintain that historical analysis offers the opportunity to do much more than inculcate or convert. It ultimately provides a means whereby a society may shed light on aspects of its shared history and origin. A work of history carries with it the potential to change people’s perspectives of themselves and each other, change their minds on matters of great or small importance, or reinforce their ideas and ideologies. These possibilities are no more conceivable in the case of unorthodox AIDS activism than they are in any other historical pursuit. Consequently, what we stand to gain in understanding the histories of unpopular or radical positions far outweighs what we stand to lose.

That this philosophy differs from trends we see in journalism is worth noting. In 2014, for example, the BBC issued guidelines making clear that it no longer felt obligated to air the “marginal views” held by those who espouse unorthodox views on matters of climate change. In response to these guidelines, one journalist opined, “Were every network to start doing what the BBC is, their unfounded opinions would cease to be heard…and maybe, just maybe, they’d all just go away.” While I leave matters of professional journalistic practice to those better versed in the discipline’s history and charge, I strongly contend that such an approach has no place in historical analysis, where our primary concern is not in forgetting, but remembering.

And to those who fear that contrarians wait lurking in the shadows to use this historical analysis to further their own claims, I am reminded of a discussion I had with a member of one of the most controversial contrarian groups considered in my analysis, Health Education AIDS Liaisons (HEAL). When the individual learned of my plan to write a history exploring

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26 Lindsay Abrams, “BBC staff ordered to stop giving equal airtime to climate deniers,” Salon, July 16, 2014.
unorthodox interpretations of and responses to AIDS, he expressed great hope the work would clarify what has been a poorly understood history. And yet, at the same time, he warned, “Please, if you want your work to be taken seriously, begin by making it clear that you don’t agree with any of our ideas. Otherwise you’ll be disregarded and dismissed.” This, perhaps better than any passage, article, letter or bulletin I have unearthed from an archive speaks to the power of radicalization in discrediting contrarian perspectives, and to the hope and potential for historical analysis to move beyond judgment and valuation and to instead illuminate, situate and explain.

A final issue of professional ethics warrants consideration. Any historical examination of contrarian movements will involve the association of particular ideas and practices with individuals, oftentimes those who were diagnosed with AIDS in the 1980s and 1990s and perished from the disease. To the extent that some of these ideas and practices have become radicalized, one might argue that this historical project threatens to besmirch individuals who may no longer defend themselves from the stigma now associated with the movements. This is particularly true for AIDS dissidence, but applies as well to other forms of unorthodox AIDS activism, and indeed appears to have influenced historical treatment of particular individuals, including Michael Callen – one of the most influential people with AIDS through the 1980s and early 1990s. It is therefore appropriate for us to ask whether historians have an obligation to protect the historical memory of individuals from the stigma society now associates with unorthodox movements. My position on this matter is clear: just as we must avoid judging individuals who lived and died in a different time using today’s standards and beliefs, we must avoid efforts to protect the historical memory of activists by ignoring the contributions they made to unorthodox AIDS activism. Just as it is the job of the historian to resist the temptation of interpreting our studies through presentist lenses, so too must we serve as guides to readers,
reminding them of the folly of judging historical figures by the knowledge, standards and 
practices of the times wherein they live.

Having thus defined unorthodox AIDS activism and defended it from several preliminary 
objections, I shall proceed with my larger historical project – namely, to identify the history of 
this complex, multifaceted manifestation of activism, to elucidate the ways in which it changed 
over time, to evaluate the points of intersection and contestation between its constitutive 
components, and to explore its effects on the history of AIDS activism and, more broadly, the 
history of health and medicine in the United States. I focus my analysis largely on the history of 
AIDS activism as it developed in New York City, an epicenter for AIDS through the 1980s and 
1990s. By focusing on New York, this research accomplishes a secondary goal of broadening our 
understanding of alternative AIDS activism beyond the West Coast, where it is most often 
located. Perhaps unsurprisingly, the sources I consult are the writings, publications and 
archives of largely underexplored and unexamined organizations and individuals. They include 
the archives of the People with AIDS Coalition (PWAC) and pages of the PWAC Newsletter; the 
ephemera of one of New York’s earliest self-avowed alternative and complementary AIDS 
treatment groups, Health Education AIDS Liaisons (HEAL), and the archives of controversial

27 Consider, for example, the disagreements between West Coast activists and members of the 
Treatment Action Group (TAG), the latter of whom advocated returning to rigorous FDA testing 
standards. See Steven Epstein, “Activism, Drug Regulation, and the Politics of Therapeutic 
Evaluation in the AIDS Era: A Case Study of ddC and the ‘Surrogate Markers’ Debate,” Social 
Studies of Science 27 (1997).

28 HEAL’s archives remain largely unexplored, having been stored by group members in various 
garages and closets for several decades; Several archives house the remaining editions of the 
PWAC Newsline, a volume consulted in great depth in Chapter 4. All editions cited throughout 
this volume may be found in the NYPL-MAD (People with AIDS Coalition Archives), NYPL-
SIB, or CUL-RMC.
PWAC cofounder and AIDS activist Michael Callen along with those of Greenwich Village physician Joseph Sonnabend.

My overarching goal in elucidating the contours of unorthodox AIDS activism is to establish the context and traditions out of which this activism arose, and to identify the points of contact and interaction between these traditions and the dominant biomedical model. I begin the first section of my analysis in Chapter 1 by examining the history of unorthodox, irregular and alternative health movements to identify themes that have persisted through time, against which we may evaluate contemporary expression of unorthodox AIDS activism. I furthermore maintain that predominant presumptions regarding alternative and irregular medicine – embodied in the very metaphors scholars use to discuss the movements – have limited our ability to understand their longevity and popular appeal. In their place, I advocate an alternate conceptual and metaphorical model better suited for explaining their expressions among members of the public.

In the second part of my project, I focus more narrowly on the context out of which late 20th Century unorthodox AIDS activism grew. Here, I examine the phenomenal transformations in the public’s relationship with and engagement with biomedicine in the mid-to-late 20th Century. In Chapter 2, I examine changing popular perceptions of disease and disease models, exploring discourse taking place among lay individuals seeking to understand and order their lived experience of health and disease. Chapter 3 expands upon this topic by exploring transformations in the public’s perceptions of physicians and researchers, including allegations impugning the character of the nation’s healers and sowing distrust among the lay public. As I shall argue, these changing popular perceptions of disease and health, coupled with the proliferation of public discourse questioning the character and competency of contemporary physicians, formed the soil out of which unorthodox AIDS activism would grow.
In the third and final component of this analysis, I turn my attention to specific expressions of unorthodox AIDS activism through the 1980s and 1990s, focusing on two organizations whose members explored and endorsed etiological and therapeutic strategies that reached beyond and/or challenged the positions of mainstream researchers and biomedical professionals. I begin in Chapter 4 with an examination of the People with AIDS Coalition (PWAC), one of New York’s first and most respected AIDS activist groups formed by and for individuals living with AIDS. As I shall argue, the founders and members of PWAC both direct and indirectly endorsed alternative and unorthodox approaches to healing, viewing them as tools for empowering a membership that had been historically medicalized, marginalized, and maligned. In Chapter 5, I consider the history of an altogether different activist organization formed in New York City during the 1980s, Health Education AIDS Liaisons (HEAL). One of the least studied AIDS service groups, HEAL would, through the 1980s, come to outwardly and vehemently espouse alternative and unorthodox health perspectives, and was, by the 1990s, associated with a dissident and radical “fringe” activism. My analysis closes with a discussion of the significance this historical project carries for our understanding of American public health movements and the professional practice of public health and medicine.
Part I: Irregular and Alternative Medicine in Historical Perspective
Chapter 1

Situating Unorthodox AIDS Activism within the History of Medicine in the United States

“In the early years of the AIDS epidemic, as physicians and public health professionals struggled to make sense of and respond to the “gay plague” that had racked the nation’s largest cities, people turned to history for counsel. In the lofty pages of historical treatments, they hoped to find remedies for a modern plague that many believed was poised to wreak unbounded horrors as it burned its way through the population. If biomedicine could not cure the condition, then perhaps history would offer a salve borne out of past generation’s experiences with fatal infectious diseases. This eager recourse to historical wisdom prompted Allan Brandt to remind readers that history held no simple truths, and would not provide a clear or cogent roadmap for organizing a social response to AIDS. All it could offer were lessons to help structure professional responses to the epidemic in a manner that would, perhaps, avoid the mistakes and missteps of those who came before.”

This practice of mining historical experience with the intent of modeling social responses to epidemics underscores society’s conceptualization of history as a toolkit for aiding and informing our actions, a metaphor whose limitations we must acknowledge. For history does more than provide strategies for approaching problems; it fundamentally structures and influences the ways in which we as a society define, approach, think about and respond to these

problems. Our historical experiences reverberate through time in the terms and metaphors we have developed to discuss diseases, the structures and institutions we have created to respond to them, and the countless avenues through which values, fears, anxieties, apprehensions and uncertainties surrounding matters of health are propagated between generations.

What's more, as social historians have aptly underscored, there is no one historical experience or dominant perspective reverberating through generations that neatly explains the changes witnessed in society through time. That certain ways of conceiving of the world are ascendant at any particular moment is irrefutable, but their predominance typically masks other perspectives, beliefs, hopes and fears whose part in historical change we cannot summarily ignore. By the late 1980s, for example, Western biomedicine had, as several authors attest, established a hegemony over the ways in which powerful institutions and actors within society approached and responded to disease. But the dawning realization that a fatal infectious disease had erupted in New York and Los Angeles, and the concomitant fear that it would spread through the nation, prompted a reexamination of the institutions and disciplines society had entrusted with protecting its health. It was in this context of fear and uncertainty that other voices – those expressing unorthodox and subaltern positions – offered their own interpretations of disease.

AIDS came, then, and the light changed. Now, exposed in the corners and shadows of society was a panoply of subaltern perspectives for conceptualizing and responding to this modern plague. By the mid-to-late 1990s, the light would change once more, as biomedicine reasserted its authority over AIDS in the form of highly effective antiretroviral treatment. The

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31 This discussion parallels similar debates regarding the conceptualization of culture as a simultaneously empowering and constraining force. See, for example, Ann Swindler, “Culture in Action: Symbols and Strategies,” American Sociological Review, April 51 (1986).
32 See, for example, Naraindas, Quack, and Sax, Assymetrical Conversations.
strands of unorthodox AIDS activism that persisted through this time appeared increasingly more radicalized, and the rich history of what was in fact a complex social movement became obscured. How then, can we as historians unearth this longer, richer history?

One way to engage in such a project would be to focus on a particular manifestation of unorthodox AIDS activism and trace the roots of that system through history. That homeopathic remedies were advocated to treat AIDS in the 1980s and 1990s would welcome an historical excavation of the history of homeopathy, tracing its origins to the contrarian philosophy advocated by its founder, Samuel Hahnemann. The same approach may be taken with positive psychology, or herbal medicine, for example, recounting the biographies of idiosyncratic healers, battles for medical licensure, and wars waged between the members of regular and irregular medical societies. However, while such approaches are adept at elucidating institutional histories, I find them lacking in their ability to explain the reasons unorthodox healing systems resonated with the public through US history.

In 1980, just months before word would come of the first diagnosed cases of *Pneumocystis pneumonia* infection in Los Angeles, the Indian poet Jayanta Mahapatra published a collection of poems entitled *Relationships*. In this haunting work, Mahapatra explores identity formation, interpersonal relationships, death and disease – presaging discussions of similar topics in the context of AIDS. To help convey these complex themes, Mahapatra invokes the loneliness of a solitary traveler, “who can sense the brilliant colors of the past / in the ocean’s strange and bitter deeps.” I find the poet’s invocation of this traveler to be of value for informing our study of the history of medicine and health. Indeed, I argue that to better understand the long history of unorthodox health activism in the United States, we must focus our attention on the solitary traveler of medicine – the patient. For it is the patient who registers the long effects of historical
change and contestation in health and medicine, who sits in the crossroads of multiple healing systems, all of which have laid claim to ordering and managing his or her body. By focusing on the patient experience, we may interrogate the explicit and implicit appeals made by the proponents of unorthodox healing systems in their efforts to attract others to their system of healing. In such a manner, we move beyond institutional histories and instead embrace scholarship that interrogates the dynamic position of the frightened men and women who, as Mahapatra evocatively writes, were “caught in the currents of time.”

In this Chapter, I explore the persistence of unorthodox health activism throughout US history, connecting our nation’s earlier experience with irregular healing systems with the contrarian AIDS health movement of the 1980s and 1990s. I begin by reviewing the shifts in historical scholarship of contrarian health movements, noting the transformation in the field shepherded by the social turn in historical research in the mid-to-late 20th Century. Following this brief review, I argue for a more complete embrace of a “history from below” analytical model prioritizing the experience of patients located in the confluence of multiple competing health systems. Finally, I identify four specific historical forces that I argue have helped to sustain and support the appeal of unorthodox systems of healing among members of the public throughout US history.

Understanding Irregular and Alternative Health Practices: An Appeal for a Therapeutic Borderland Model

In her essay A Room of One’s Own, Virginia Woolf remarks that history “often seems a little queer as it is, unreal, lop-sided.”33 Her observation, made in 1929, is no less relevant today

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33 Virginia Woolf, A Room of One’s Own (Oxford: Oxford University Press, 1998), 58; Other historians have invoked this same passage from Woolf. See, for example, Joan Scott, “Women’s History,” in New Perspectives on Historical Writing, ed. Peter Burke. (University Park: Penn
than it was during Woolf’s lifetime. As students of history have come to understand, historical enquiry is, by necessity, both sanctioned and bounded by historically situated values, assumptions, and patterns of understanding. What we think and how we think are linked processes that turn in large part upon when we think, where we think, and who we are. The necessary subjectivities of history are more than mere curiosities – they have direct bearing upon how we conceive of not only our past, but our present circumstances as well. Which groups, individuals, ideas and perspectives we include in historical analysis, and how we discuss them, are matters rife with political tension. For, at the heart of these questions are underlying queries regarding what counts as history and what deserves remembering. Given such high stakes, it should surprise us little that history will always appear queer and lop-sided.

Historical biases and preconceptions are perhaps nowhere more evident than in our historical treatments of minority, fringe and subaltern positions – a broad category into which alternative, irregular and unorthodox health movements have been filed. As historian Norman Gevitz has observed, historical research in irregular medicine was remarkably biased through the first half of the 20th Century, with scholars expressing a thinly – and at times, not so thinly – veiled disdain for contrarian healing systems. It was during these “golden years” of mainstream medicine, when the influence and authority of a dominant medical enterprise was consolidated, that scholarly sources demeaned and derided contrarian health movements as little more than absurdities, or worse yet, manifestations of psychological pathology. The situation would

35 In a 1913 article in the Journal of the American Medical Association, John Benjamin Nichols, MD, wrote of his concern, “When...we contemplate the zeal, enthusiasm, and faith of the
begin to change in the 1950s and 1960s, as scholars intent on crafting social histories of 
forgotten and marginalized groups branched into the study of alternative and irregular health 
movements. Gradually, the tide began to turn, with historians identifying the myriad ways 
alternative healing traditions contributed to the modernization of regular medicine. Irregular 
sects, once decried as the black sheep of medical progress, were suddenly included in the 
extended family portrait of contemporary medicine. Homeopathy, with its appetite for 
infinities, was credited with precipitating the decline of heroic medical measures, 
hydropathy with carving a role for female practitioners in the dominant medical system, and so 
forth.

In this spirit, the latter half of the century witnessed the publication of more sensitive 
histories exploring the origins of alternative healing traditions, resituating our nation’s 
experience with Thomsonian medicine, homeopathy, hydropathy, eclectic medicine, 
physiomedical medicine, mesmerism, and the positive psychology movement, among many 

36 For a discussion of this historiographic turn, see Geoff Eley, “Dilemmas and Challenges of 
Social History since the 1960s: What Comes after the Cultural Turn?” South African Historical 
Journal 60, no. 3 (2008); One of the first works in the history of alternative medicine whose 
approach was roughly consistent with this turn was Walter Wardell, “The Reduction of Strain in 
a Marginal Social Role,” American Journal of Sociology 61 (1955).

37 Martin Kaufman, for example, notes the ways in which regular medicine’s battles with 
homeopathy led to a shift away from heroic medical techniques such as the use of bleeding and 
mercury. Martin Kaufman, Homeopathy in America (Baltimore: Johns Hopkins University Press, 
1971); Susan Cayleff highlights the contributions hydropathy made in terms of establishing a 
place for women in the practice of American medicine. Susan Cayleff, Wash and be Healed: The 
others. However, while these historical treatments refuted the more antagonistic treatments that had come before, they suffered from their own methodological shortcomings. By focusing on the contributions irregular healing systems made to the modernization of regular medicine, scholars maintained an institutional focus, centered upon the roles of the founders of healing systems and their professional exponents. These historical analyses were predicated upon discussions of the philosophical underpinnings of healing systems, the colorful personalities of their founders, and their interactions and contestations with the representatives of regular medicine. As a result, we have histories that elucidate the experiences, first and foremost, of disempowered groups and movements over the experience of patients.

In my analysis of late 20th Century unorthodox AIDS activism and my efforts to connect it to our nation’s earlier history with irregular health movements, I advocate a methodology that reaches beyond such approaches, to one that truly prioritizes the experience of the patient. Such an enterprise moves beyond ordered, fragmented treatments of particular healing traditions toward one that highlights the lived experiences of patients who were caught in the cross currents of multiple traditions. In short, I strive for a methodological approach that satisfies Roy Porter’s injunction for the crafting of histories “from below,” that enrich our understanding of the past not

only by shining light on subaltern groups, but by illuminating the experience of patients whose efforts to combat illness brought them into contact with the proponents of these groups.  

My decision to situate this historical analysis in the tumultuous arenas of intersection and interaction between healing systems calls to mind a metaphor with its own rich and complex usage in contemporary historiography: the borderland. In the mid 20\textsuperscript{th} Century, historians seeking to problematize our understanding of US territories conquered from Spain advocated a shift in methodological focus of these areas, inspired in large part by the writings of early 20\textsuperscript{th} Century historian Herbert Eugene Bolton. Bolten suggested that we conceive of these territories as dynamic borderlands wherein multiple actors engaged in complex exchanges, collaborations and contestations. Through the borderland construct, historians were able to locate power disputes lurking in corners and shadows, identifying expressions of resistance and opposition that, in previous treatments, had been masked.

While historians generally limit their use of the borderland metaphor to geographic areas of overlapping sociological and cultural expression, I find its application to the historical study of unorthodox healing systems illuminating. Throughout American history, individuals have found themselves presented with innumerable traditions and practices laying claim to investigating, surveying, policing, and treating their bodies. Some of these systems have been hegemonic, analogous to the seemingly indomitable empires of Bolton’s histories. Others were less empowered, but nonetheless found ways to exert influence and sway over individuals located in the metaphorical borderlands of these healing systems. If we hope to construct a social history of health and medicine, we must demand more than isolated examinations of these

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40 See, for example, Kelly Lytle Hernandez, “Borderlands and the Future History of the American West,” \textit{The Western Historical Quarterly} 42, no. 3 (2011).
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systems; we must, in short, seek an examination of the experiences of patients living in the borderlands of overlapping systems.

In appropriating the borderland metaphorical construct, I intentionally reject an alternate metaphor commonly invoked in histories of unorthodox medicine: the fringe. Referring to health activist traditions as fringe practices is problematic for two reasons. First, far from underscoring dynamic interaction, it relegates unorthodox healing systems to a far-off, isolated wilderness – a mythical time-out zone where, one imagines, they might ponder their transgressions. Second, the fringe metaphor suggests that these systems enjoyed little more than minority status. Indeed, to be categorized as fringe, to borrow the words of historian Mark T. Hoyer, is to be “categorize[d]… out of existence.” And yet if contemporary measures of the use of alternative and contrarian healing practices are any indication, it would be foolish to summarily dismiss them in this manner. Oft cited surveys by David Eisenberg and colleagues reveal staggering rates of alternative therapy usage by Americans, with 33.8% reporting adoption of nontraditional therapies in 1990 and 42.1% in 1997. Interviews conducted with over 31,000

42 Hoyer focuses on scholars’ treatments of Native American histories and the ways in which academics have exotified and categorized native cultures effectively out of existence – arguing that the only places where such pure identity categories can exist have become museums. For a discussion of Hoyer’s work, see Mark T. Hoyer, Dancing Ghosts (Reno: University of Nevada Press, 1998), xvi.
43 Therapies studied included herbal medicine, massage, megavitamins, self-help groups, folk remedies, energy healing, and homeopathy. David Eisenberg et al. “Trends in Alternative
individuals by Patricia Barnes and colleagues in 2004 reveal even higher rates, with 62% of those surveyed reported using complementary or alternative medicine. And a 2005 Institute of Medicine Report estimates that the number of visits Americans made to complementary and alternative care providers in 1990 (425 million) exceeded the number made to primary care physicians (388 million). Indeed, it would appear, given these statistics, that most of our nation is living in the fringes of society.

Here, I discard the fringe metaphor, with its insinuations of an isolated territory where we file unpopular positions, and instead advocate the use of metaphors implying a state of dynamic interplay and contestation. In borderlands, patients encounter myriad systems of healing, each offering its own framework for explaining and treating disease and each invoking its own arguments and appeals for the patronage of patients. In these borderland areas, the patient simultaneously embodies a position of disempowerment and empowerment. Despite her illness, she is capable, through her allegiance to particular healing systems, of expressing power. I submit that this historical figure, largely absent from our histories of unorthodox healing systems, embodies a role rich with complexity and meaning, and of vital importance to the

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44. This statistic includes individuals who used prayer to treat disease; excluding this practice, over a third of all adults had still employed complementary or alternative healing methods, with the most common being natural products, breathing exercises, meditation, chiropractic care, yoga, massage and diet-based therapies. See Patricia Barnes et al., “Complementary and Alternative Medicine Use Among Adults: United States,” U.S. Department of Health and Human Services DHHS Publication No. (PHS) 2004-1250, Advance Data From Vital and Health Statistics 343, May 27, 2004.
46. The very framing of the therapeutic strategies as “complementary” indeed underscores the ways in which patients positioned in the intersections of healing systems interact with more than one system at a time.
practice of both regular and irregular medicine. I therefore turn my attention to the patient, intent to understand more clearly how and why alternative health systems have flourished throughout U.S. history.

Identifying the Currents Underlying the Popular Appeal of Unorthodox Healing Systems through the 19th and 20th Centuries

The history of irregular medicine in the United States reads as a panoply of miscellaneous isms, each coalescing out of the ether of clinical impotence and uncertainty to propose its own idiosyncratic approach to healing. And each, in time, seemed to fade away, to be replaced by the newest fad, the next idea, the latest system to be peddled by the enterprising entrepreneur. As I have noted, it is easy to become absorbed in a taxonomy of these quaint and peculiar systems. However, I advocate taking a longer view of unorthodox healing systems in the United States, interrogating their sustained appeal through the ages. For, while the precise roster of healing systems has changed over time, at virtually all points of our nation’s history, multiple systems have laid claim to patients’ bodies, sought dominion over their framing of health and asserted expertise in treating their diseases.

Returning to our metaphor, patients have long found themselves in borderland regions demarcated by multiple healing systems, whose names and leaders have changed throughout the ages. In making decisions regarding their health, individuals have moved between these domains of healing, shifting their positions in the complex borderlands constituted by the areas of overlap between these constantly changing systems. What interests me most is not the precise makeup of systems, but rather the movement of people between systems over time. For, even as minority positions were usurped and the dominance of hegemonic systems consolidated, patients
continued moving and shifting their positions within the complex network of changing borderlands.

In this chapter, I task myself with answering a deceptively simple question: What made these patients move? What attracted them away from the hegemonic system to other systems of healing, many of which had earned the opprobrium of dominant leaders of medicine and health? To begin to answer this question, we might first examine the explicit arguments the proponents of unorthodox healing systems have made to support their crafts to understand which were the most persistent through time. We may then expand our analysis, asking whether, in these arguments, they invoked deeper beliefs, suspicions and insecurities stemming from their prior dealings with the dominant healing system. In this fashion, we may continue to expand our analysis, asking at each stage whether the varied unorthodox healing systems that have peppered our history have tapped into deeper anxieties and uncertainties reverberating throughout the nation’s history, linking matters of health and disease to broader societal issues and debates.

The result of such an approach is a nested explication of the broad forces that have underlay the movement of patients from dominant health systems to unorthodox systems. If we conceive of patients as occupying positions in a borderland constituted by overlapping healing systems, then these forces are analogous to currents that have facilitated their motion to different positions within that borderland. The proponents of unorthodox healing systems have tapped into these currents, exploiting them to attract adherents. The current metaphor is particularly compelling in our examination of borderland phenomena, for while the leaders and proponents of unorthodox health movements may have marshaled particular arguments in an effort to influence patients’ engagement with their disease, their arguments generated their ultimate effect in
complex ways. Indeed, currents flow from one another, mutually constitute each other, and generate their most significant outward effects in conjunction with one another.47

Here, I have identified four currents that I argue helped sustain the success of diverse unorthodox healing systems through the 18th and 19th Centuries. The first and narrowest current hews closest to the explicit arguments made by the proponents of unorthodox health systems. It was marked by direct reference to the excesses and immoderations of regular medicine, a legacy carried through history from the heroic practices of the 18th and early 19th Centuries. The second current expands the frame of critique, moving beyond an assessment of particular therapeutic strategies and tapping into deeper apprehensions held by many individuals regarding the uncompromising stereotype of regular or mainstream physicians. Of particular note in this current were beliefs that mainstream physicians derogated or derided patient observations in favor of dogmatically maintained theories. The third current is even broader still, capitalizing on powerful anti-authoritarian impulses that arose at several points in our nation’s history, most notably the 19th Century Jacksonian era. Finally, the fourth current summons much deeper antimodern anxieties stemming from profound transformations witnessed in both micro and macro level relations through the 19th and 20th Centuries.

A word of caution is advised in my presentation of these currents. For, in underscoring their dynamic interrelationships, and the ways in which they flow from and reinforce one another, it is deceptively easy to suggest that we may reduce all four currents to some common or base force. That, upon identifying the broadest of currents suffusing alternative and irregular

47 In adopting the use of currents to metaphorically represent the movement of individuals in the intersections of borderland systems, I attempt to maintain a role for individual agency in addition to structural forces (e.g. the alternative health systems to which an individual is exposed, determined in many cases by their location, gender, race, level of education and socioeconomic status, among many other factors).
healing systems through the 19th and 20th Centuries, we have succeeded in explaining their persistence through time. This is a simplification of my argument. For, while much is to gained by noting, for example, the ways in which antiheroic discourse flowed from antiauthoritarian discourse, much is lost in reducing the former to the latter. My goal is not a systematic reduction of historical forces, but rather an explication of the ways in which these forces exerted their effects on patients caught in the intersection of multiple, competing healing systems. That we can trace a line between antiheroic treatments through antimodern sentiment is certainly interesting, but it does not mean that it is correct or useful to summarily conclude that an individual living in mid-19th Century America sought homeopathic advice because he was responding to the soul crushing effects of modern industrialization. We may conclude that this in some way influenced people’s decisions, but knowing that he would articulate his decision in terms of his fear of heroic medical practice, or his belief that he should be in control of his own body, for example, is in many ways more useful than the neat reduction we may obtain on paper.

Here, too, I believe my chosen metaphor of the current helps in clarifying my meaning. That currents flow from one another is certainly true. However, they do much more than that. For in the intersections and bifurcations of currents, forces collide in unpredictable ways. Subsidiary currents turn back upon their primary channels, currents merge, diverge, and interact in ways that are seemingly impossible to map. In short, in the tumult and turmoil of eddies, we are at the mercy of turbulence. In examining each of the currents, we must therefore recognize that they mutually constitute and reinforce each other in complex ways defying reductionist analyses.

**Enduring Currents: The Shadow of Heroic Medicine**
Historians of alternative and irregular medical sects have rightly noted the distrust, distaste and outright fear many patients expressed toward 19th Century mainstream medical practice. So-called “heroic medicine,” widely associated with the practices of colonial physician Benjamin Rush and his contemporaries, focused on purging, bleeding and blistering to cure the overstimulation believed to be at the heart of disease. Throughout the 19th Century, we identify countless regular and irregular physicians questioning the wisdom of these dominant practices. In 1839, for example, Dr. William Fullerton Cumming, a physician in the East India Company’s service and descendant of the Wolf of Badenoch, wrote of treatment he had received at the hands of his colleagues: “I was largely bled at the arm – had fifty leeches applied to the abdomen, and…in addition to extensive mercurial frictions, I swallowed 215 grains of calomel! True, I recovered, or rather, I did not die; whether in consequence of, or in spite of the above heroic treatment, I will not venture to say.”

Other physicians shared Cumming’s appraisal, challenging the preeminence of ancient philosophies in the practice of regular medicine. In discussing the standard treatment for congestive fever in the Mississippi Valley, for example, a well-respected regular medical periodical included a piece bemoaning the practice of prescribing calomel in the form of R.A.C. pills: “Would to God that Mississippi and Alabama could be relieved of the curse of R.A.C. quackery! Oh! Ye shades of departed worth! Ye ghosts of Hippocrates, Aesculapius, and Galen,

48 The history of the term “heroic medicine” is murky at best, with at least one scholar tracing it to the carnage of Civil War era military hospitals. However, as the cited examples illustrate, the use of the term predated the Civil War by at least a generation, and when it was invoked, it was generally done so in a disparaging manner. Norton M. Hadler. Worried Sick (Chapel Hill: University of North Carolina Press, 2008), 198.
49 The third surviving son of King Robert II the Scotland
50 William Fullerton Cumming, Notes of a Wanderer, in Search of Health through Italy, Egypt, Greece, Turkey up the Danube, and Down the Rhine, Volume I. (London: Saunders and Otley, 1839); See also “Literary Register,” Tait’s Edinburgh Magazine VI (1839), 342.
how long will we yet endure such humbuggery!...Oh! calomel, and R.C.A. pills! Inexorable monsters, who have slain your hundreds, why seek to demolish thousands!” Here, we see clear invocation of the horrors of heroic medicine coupled with distaste for the “humbuggery” of ancient systems of medicine, arguments that will reappear in my later exploration of rational and empirical debates in medicine. The fears of calomel overuse even played a small but instructive role in the US Civil War. In 1863, Surgeon General William A. Hammond, concerned with calomel abuse among the military, issued an order removing the drug from field hospitals. As Ralph B. Leonard has written, regular physicians “rose up in indignation and flooded the Capitol with their vociferous outrage.” The end result of the so-called “calomel rebellion” speaks to the obduracy with which the medical profession demanded its right to prescribe the drug: in November of the same year, Surgeon General Hammond was removed from office and court-martialed.

Distrust and distaste for heroic measures reached their zenith in the writings of Samuel Thomson, the founder of the eponymously named herb-based 19th Century medical discipline. For Thomson, the regular medical system was guilty of committing enormous harm in its recourse to dangerous chemicals – chief among them calomel. Where regular physicians regarded the drug as the “Samson of Materia Medica,” Thomson openly lambasted it as the

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51 The alternate spelling of R.A.C. pills here was either a typographic error or related to the fact that the acronym merely represented the pills’ ingredients (rhubarb, aloe, calomel).
52 E.F. Bouchelle, “Practical Remarks on Congestive Fever,” *Southern Medical and Surgical Journal*, June 1847, 358.
53 The author of the quoted section, Doctor E.F. Bouchelle, made clear that in attacking the prescription of calomel, he meant no disrespect to the esteemed creator of R.A.C. pills, Professor John Esten Cooke: “I respect the Professor; at the same time I am convinced of his delusion.” Ibid.
54 Hammond’s fall from grace among field physicians no doubt provided cover for Secretary of War Edwin M. Stanton to move against the Surgeon General, with whom he had a tense relationship. See Ralph B. Monty Leonard, “The Calomel Rebellion,” *Southern Medical Journal*, 8, no. 5 (1987), 638.
“uncircumcised Philistine of medical science.” For those whose recollection of Old Testament scripture was a bit rusty, he offered a more unambiguous appraisal: the entire mercurial craft, he declared, amounted to little more than “a monstrous bone rotting, tooth destroying, pain engendering, bile vitiating, skin blistering, blood and life destroying system.”

Thomson’s criticisms, coupled with similar attacks by hydropaths, homeopaths, eclectic physicians, physiomedicals and the advocates of countless other hybrid movements, struck a chord among members of the public, several of whom expressed frustration with regular healers’ endorsement of heroic measures over the objections of reformers. We may turn to popular literature for a barometer of these sentiments. In one 1857 work of poetry, the author criticizes the rigidity of regular physicians, satirizing their perspective on therapeutics: “Let others talk of wind or storm / Or speak of Medical Reform / Against their theories I’ll rebel / And stick to good old calomel.” The country’s most revered literary master would even weigh in on this issue. Mark Twain, whose part in the history of alternative medicine we shall explore at greater length later, playfully poked fun at regular medicine in his prose, at one point painting a colorful portrait of a regular physician. He was, Twain explained, “one of them old fashioned industrious kind that don’t go fooling around waiting for a sickness to show up and call game and start fair, but gets in ahead, and bleeds you at one end and blisters you at the other, and gives you a dipperful of castor oil and another one of hot salt water with mustard in it, and so gets all your

56 B.F.W. Stribling, “Fogyism” in *Poems for the Old and Young*. (Beardstown, IL: L.U. Reavis, 1857), 68; The bar for discomfort was quite low at the time. While hydropathy and Thomsonian medicine did not employ high doses of toxic drugs such as calomel, their treatments were not particularly gentle. Thomson relied heavily upon lobelia, an herb affectionately referred to as “pukeweed” and hydropaths regularly submerged themselves in freezing water.
machinery going at once, and then sets down with nothing on his mind and plans out the way to handle the case.”

The turn of the century would witness a remarkable transformation in the standards of regular medicine. William Rothstein has studied the decline of heroic medicine, arguing that measures such as bloodletting and the administration of calomel had faded in large part by the 1860s and 1870s. As Rothstein argues, irregular medical practitioners played a large part in inspiring the abandonment of extreme measures, as regular physicians strove to retain clients despite the popular appeal of irregular medicine’s more prosaic interventions. However, the denouement of heroism was anything but straightforward; calomel, the quintessential heroic drug, was not to be vanquished by the mere threat of homeopathy or promise of germ theory by century’s end. A brief consideration of the history of the drug reveals its appeal persisting through the turn of the century. Indeed, in 1902 – that’s 20 years after Robert Koch identified the bacterium that causes tuberculosis – West coast physician C.W. Kellogg declared, “Calomel without doubt is the most extensively used preparation within the range of materia medica.”

That said, by the end of the first decade of the 20th Century, even calomel was fading into obscurity, with editorials noting that physicians seeking to prescribe it would have to contend themselves with the prejudice and derision of their peers.

While the archetypal excesses of heroic medicine – bleeding, purging, and the administration of calomel – have faded into historic memory, the legacy of heroic treatments

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57 Mark Twain, Tom Sawyer’s Conspiracy, 1897. See Mark Twain, Huck Finn and Tom Sawyer among the Indians (Berkeley: University of California Press, 2011), 157.
persisted in unorthodox AIDS activists movements. Indeed, the long shadow of heroic medicine can be found in articles published through the late 1980s by Michael Callen underscoring the toxicities of high-dose azidothymidine (AZT) treatments, in articles published in the *PWAC Newsline* advocating healing practices that eschewed prescription drugs and instead focused on the body’s “natural” healing abilities, and in circulars distributed by HEAL identifying AIDS as a 20th Century form of “iatrogenic genocide.” Indeed, HEAL’s literature openly advocated the virtues of alternative medicine by plainly declaring, “Most health problems don’t call for heroic medicine.” And for some unorthodox AIDS activists, it was not enough to invoke the specter of heroic medicine; a reminder of its finer details was deemed necessary:

“It took four centuries before medicine finally recognised that calomel (mercurous chloride) couldn’t cure, only kill, and dumped it from its pharmacopoeia. Until then, notwithstanding its manifest poisonousness, doctors had advocated it, some with poetic fervour, as a panacea for gout, headache, menstrual pain, syphilis, and no end of other ailments. No modern doctor…would dream of ladling mercury salts down their patients’ throats nowadays. When is the penny going to drop with AZT?  

How can we explain the sustained potency of heroic medicine discourse into the late 20th Century, long after medicine had shorn itself of the excesses of calomel, bloodletting and similar measures? How is it that the image of the physician – or in the very least his or her therapeutic

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62 The author of the piece, Anthony Brink, was a well-known South African denialist. Brink penned the quoted essay after an earlier piece he had published in *The Citizen* prompted a critical response. The quote, too long to include here, also invokes the historical experience of environmental poisoning with calomel, a connection between the legacy of heroic medicine and the exploration of alternative disease etiologies, to be explored in later chapters. See Anthony Brink, “AZT and Heavenly Remedies,” 1999, Accessed March 20, 2015. 
nostrums – as an instrument of death persisted with such influence into the modern age? While myriad factors likely contributed to the longevity of the specter of heroic medicine, I believe that two are worthy of analysis, particularly given my larger goal of situating the history of unorthodox AIDS activism. The first refers to perceptions among the public of mainstream medicine’s approach to diseases for which it had no cure, most notably terminal cancers. The second relates heroic medical discourse to the history of the patients’ right and biomedical ethics movement.

As historian David J. Hess has argued, while the early-to-mid 20th Century is sometimes regarded as a golden age of mainstream medicine during which nascent biomedicine sought and identified “magic bullets” to cure specific diseases, mainstream medicine’s powers were not complete. Diseases, most notably terminal forms of cancer, defied the successes and achievements wrought in the laboratories of Pasteur, Koch, Ehrlich and their contemporaries. During this period, healing systems such as those developed by Harry Hoxley and Rene Caisse generated a significant popular following. The fear that mainstream medicine was in fact harming patients intensified markedly by the mid-to-late 20th Century; 19th Century allegations of heroic medicine in the form of bleeding and calomel administration gave way to 20th Century equivalents in the form of radical surgery, high dose chemotherapy and radiation.

64 I highlight the perseverance of heroic excess discourses in the context of cancer due to the intersections and overlaps between popular understanding of AIDS in the early-to-mid 1980s and popular understanding of cancer. However, the legacy of heroic medicine can be found in discourses surrounding other incurable conditions. The case of childhood autism is particularly interesting, as contrarian activists have cited the purported role of mercury poisoning in causing autism. See, for example, Dan Olmsted and Mark Blaxill, The Age of Autism: Mercury, Medicine, and a Man-Made Epidemic (New York: St. Martin’s Griffin, 2011).
Again, popular literature dutifully registered the potency of invocations of heroic excess. In the late 1970s, for example, *Penthouse Magazine* ran a series of articles by Gary Null extolling the virtues of alternative treatments for cancer and criticizing mainstream medicine’s response to the disease. In these articles, Null accused physicians of advocating treatments that “knife, burn, poison, and, in some cases, kill you sooner than any cancer could.” The same article would go on to claim that, “virtually all conventional anticancer drugs actually caused cancer.”

Lest we think these sentiments were somehow correlated with the readership of *Penthouse Magazine*, I should note that similar beliefs were voiced from a very different disciplinary tradition. For, at roughly the same time, feminist scholars openly questioned the “slash and burn” tactics of oncologists, tying their assessments to efforts to empower women in the context of personal health decisions.

To understand the persistence of heroic medicine discourse into the 1990s, we must also consider the significance of larger institutional and cultural shifts witnessed in the practice of medicine during the mid-to-late 20th Century. Indeed, while this period saw the consolidation of the authority of physicians and the integration of scientific principles and methods for the discovery and application of therapeutic regimens, celebrations of the powers and successes of biomedicine were tempered by realizations that the enterprise was also capable of committing

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66 In commenting on dominant medical responses to cancer, one feminist author noted, “[W]e [doctors] radiated, we lashed, burned, and poisoned I think we’ll look back on this era and think we were totally crazy that we did these barbaric things. Amy Sue Bix, “Engendering Alternatives,” in *The Politics of Healing: Histories of Alternative Medicine in Twentieth Century North America*, ed. Robert D. Johnston (New York: Routledge, 2004), 161; Susan Sontag’s oft cited essay furthermore underscores the frequency with which metaphors present mainstream treatments as dangerous. In summarizing lay framings of cancer, for example, she noted that “patients are ‘bombarded’ with toxic rays” and “chemotherapy is chemical warfare, using poisons.” Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (New York: Picador, 2001), 65.
great harm. It is during this time period, after all, that we find the birth of formal institutional and regulatory frameworks designed to protect the public from the excesses of physicians and researchers. The horrors of Nazi experiments were followed by the revelations of abuse much closer to home – the violations of research subjects in the Tuskegee Syphilis experiments, the aggressive and reckless behaviors of pharmaceutical corporations peddling thalidomide, the Daikon Shield, diethylstilbestrol, and controversies surrounding many other drugs and devices. With the growth of biomedical ethics, patients witnessed the institutionalization of a protective framework designed to shield them from the excesses and abuses of physicians. And with the rise of feminist scholarship in the 1960s and 1970s, the public was forced to consider the deep, institutionally rooted biases and values that pervaded biomedicine, and the ways in which power operated in clinical interactions. From this perspective, the excesses of heroic medicine were not registered in grams of calomel but were instead woven into the very fabric of the biomedical enterprise.

That we should find ties between unorthodox AIDS activism and the patients’ rights movement is no coincidence. Individuals with AIDS forcefully demanded the right to access alternative and experimental drug treatments through the 1980s, frequently invoking patient rights language. Indeed, in New York, frustrations with the policies of the FDA led to the creation of a community drug testing framework completely consistent with the dictates of biomedical ethics; it even included an its own Institutional Review Board.\textsuperscript{67} Furthermore, the

\textsuperscript{67} I should note that the application of the memory of heroic medicine was not straightforward here. For, as activists fought for access to experimental and unapproved treatments, regulators argued that they were falling victim to “quack” treatments that themselves had their own history of directly causing harm to patients.
connections between the positions of AIDS activists – orthodox and unorthodox – and 1960s-1970s era feminism run deep, even if they remain poorly understood.\textsuperscript{68}

The ties between unorthodox AIDS activism and anti-heroic discourse within the domain of cancer treatment also demand careful analysis, particularly given the multiple points of contact between the two diseases. Indeed, the first reports of AIDS labeled it a “gay cancer,” one of its early defining conditions was a rare form of skin cancer, the National Cancer Institute coordinated and conducted a great deal of AIDS research through the 1980s, Dr. Robert Gallo initially theorized that the disease was the result of a cancer-causing virus, and the first antiretroviral developed to combat the condition, AZT, was criticized by activists as a failed cancer treatment. If this evidence of connection and overlap between the conditions is not enough, others abound. A decade after \textit{Penthouse}’s publisher, Bob Guccione, published his series of cancer related articles, his son would oversee the publication of unorthodox AIDS treatment articles in his own publication, \textit{SPIN Magazine}. And Gary Null, the author of the \textit{Penthouse} articles, would carry his allegations of heroic medical excess to his reporting on AIDS treatments, earning fame and infamy as a self-described HIV denialist.

\textbf{Enduring Currents: Distaste for Dogma}

It is easy to trace the invocations of anti-heroic medicine sentiment through the 19th Century, as sectarian practitioners were so assiduous at exploiting it. Harder to identify, but still very important for understanding the appeal of alternative healing systems, was a second current that dealt more broadly with perceptions that regular physicians were rigidly attached to theories of disease causation making it difficult for them to hear the opinions of others. Sectarian authors

\textsuperscript{68} Scholars are only recently beginning to recognize, for example, the contributions made by lesbians (many of whom espoused feminist philosophies) to the history of AIDS activism. See, for example, Gould, \textit{Moving Politics}, page 357, note 17.
frequently discussed this issue using the constructs of rationalist and empirical medicine, but while this distinction is of some value in explaining the support irregular medical sects enjoyed, its scholastic trivialities tend to mask issues that were much more germane to day-to-day living. Simply put, sectarian healers painted regular physicians as a close-minded lot who derogated others’ ideas – ranging from sectarian conceptualizations of the world to the everyday experience of patients – in favor of neat and ordered medical theories. This inflexible attachment to theory, in turn, contributed to arguments that physicians were poisoning their patients through their rigid fixation with unexamined principles.

Historian Richard Shryock has demonstrated that from medieval days through at least the 18th Century, organized medicine was an unapologetically rational endeavor. Medical men generally interpreted disease phenomena through their chosen theories, calling upon the authority of various figures in medicine, ranging from Galen (2nd century A.D.) to Benjamin Rush (18th Century). Through the 18th and early 19th centuries, few medical theories were rigorously tested, with physicians attempting to stretch recently articulated laws of physics beyond their breaking point in an effort to subsume the biological with the physical.  

In opposition to this long history of rational medicine, we find an equally long counterpart in empirical healing, which may be defined as an approach that relied exclusively upon experience in responding to disease. As Shryock has noted, even as rationalism flourished in the learned schools of medicine, medical empiricism was alive and well on the streets. We therefore find a curious juxtaposition of learned men administering treatments based upon the rules of esoteric (and oftentimes very old) theories of medicine, while segments of the population sought recourse in folk remedies and less formal avenues of healing. It was a fascinating time

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indeed, where regular medicine was beginning to professionalize while, as Shryock notes, “even educated men might secure their remedies from the village blacksmith.”

Debates between empirical and rational medicine reiterated historically rooted battles regarding the subordination of everyday experience to academic theory. A treatise penned by a London physician in 1836 addresses the topic rather directly, citing Luther’s invocation that “reason should not be held prisoner by words” in discussing the ways in which clinical theories had a tendency to become doctrinaire over time. Luther’s beliefs resonated through the 19th Century, with many arguing that whereas theories should bend to observable fact, contemporary medicine seemed to invert the relationship. The London physician author noted with exasperation the consequences of such an arrangement: “[O]ur theory, then, becomes our tyrant; and all who work under its bidding do the work of slaves – they themselves deriving no benefit from the result of their labors.”

The precise ways in which this fear of the tyrannical theory – which we might reasonably define as dogmatism – factored into the history of medicine in the United States is difficult to map for several reasons. For one, the meaning and valence of the terms “rationalism” and “empiricism” remained contested through the 19th centuries and indeed shifted in many ways. For example, whereas empiricism was treated with derision in some quarters at the start of the century, at its close, “scientific empiricism” was viewed as an ideal. Even Galen recognized the

70 Ibid. 105.
72 One 1883 medical journal rightly noted that the word “empiricism” had been used without great precision throughout medical history: “[L]et us note that the word empiricism is a much abused word among physicians who deny that they are empiricists. The word means experiment, or a conclusion derived from trial. Empiricism is, therefore, a word which covers in its meaning the expressible basis of the foundation of all sciences – even medical science.” The author goes on to decry that empiricism had become besmirched in its association with “quackery.” Romaine
imprecision of the concepts, arguing that the two approaches to medicine shared more than the proponents of either cared to admit, and that far too much time was wasted in trying to distinguish them from one another.\(^{73}\)

What is of import for my analysis is not a rigid appropriation of rational or empirical labels, but rather the way in which the proponents of unorthodox medicine were able to paint regular physicians as dogmatic and inflexible peddlers of broken theories. Reading the literature of unorthodox healing sects, one cannot help but marvel at the perspicacity with which irregular practitioners presented regulars as elite ignoramuses intent on attacking the contributions of others and ignoring the observations of patients. Sociologist Owen Whooley has, for example, argued that homeopaths intentionally portrayed their medical system as more flexible and amenable to change through empirical observation: “To regulars’ opacity and elitism, homeopaths invited the public to assess competing knowledge claims. They also offered a sophisticated system of medical knowledge and an articulated epistemological program that claimed the scientific mantle through an appeal to empiricism.”\(^{74}\) Irregular physicians’ recourse to personal experience also manifest itself in the clinical relationship. Historian Roberta Bivins has, for example, argued that homeopaths viewed their patients as partners in treatment; whereas regular physicians looked with suspicion on patient descriptions of symptoms, a homeopathic physician would sometimes spend hours on an initial consultation, using his or her patient’s

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\(^{73}\) See Shryock, “Empiricism Versus Rationalism,” 101. “Galen, in comparing the two schools, invoked a plague on both their houses since in the end both commonly used the same remedies. And he added: ‘since empiricism is attacked by some dogmatists as…unscientific, while again the empiricists attack rationalism as being plausible but not true, the result is…[an] argument…elaborated at great length as they refute and defend each other in great detail.’”

experiences as a valuable metric for calibrating treatment. Indeed, Samuel Hahnemann himself observed that the patient’s “own account of his sensations is the most to be trusted.”

That homeopathy was able to claim the mantle of an empirically grounded therapeutic system was remarkable, as Hahnemann’s entire therapeutic model was premised upon a theoretical explication of disease – indeed, he even referred to his guiding principles as laws. Again, we see that what mattered most was not whether a system was rational or empirical, but rather how it was perceived. And irregular medical practitioners – most notably homeopaths – were distinctly gifted at presenting their sects as open-minded and progressive, and regular medicine as outdated and dogmatic. It was, after all, Samuel Hahnemann who introduced the term “allopath” to counterpoise regular medicine in relation to homeopathy while neatly identifying the sectarian theory upon which regular medical practice was premised. This was a brilliant move, and one that infuriated many regular physicians, such as the editor of the *Maryland Medical Journal*, who in 1885 wrote, “There is no word which so grates on the ears of a cultivated and scientific practitioner of the regular school of medicine as the designation, sometimes given to this school of Allopath.” The editor expressed a keen understanding of Hahnemann’s brilliant move, succinctly summarizing the situation:

“It has come to be a fact…that the regular profession has allowed the homeopathic school to apply this term to all who differ with their peculiar dogma without resenting the absurdity of its application. It may be asked, what differences does it make what term is applied to the regular school? The answer appears in fact that the idea expressed by the

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term is deceptive, and classes those thus designated as followers of an exclusive dogma.”

Homeopaths straddled the boundaries of rationalism and empiricism in a manner that was successful at appearing both learned and sensitive to individual observation, imbued with the authority of theory while roughly democratic in application. The sect’s openness to the observations of others was exemplified by its allowance for women to become practitioners and its sanctioning of home health kits that allowed common people to become their own doctors (a later incarnation of Thomson’s approach to healing). But, in truth, homeopaths needed to do very little to appear open-minded, for the attacks regular physicians waged on their system of healing worked wonders in victimizing the group and making allopaths, helmed by the powerful American Medical Association, come across as narrow-minded bullies. Thus it was that at the turn of the century, the Eclectic American Medical Journal of St. Louis could publish an editorial lamenting that, “Regular medicine to-day has more dogma, more prejudice, more intolerance, more irregularity, more empiricism, and more bigotry than any other of the schools.” Optics, it would appear, mattered just as much as methodology, and irregular medical sects were unequaled at exploiting regular physicians’ missteps to make them look bad.

While one might presume that the rise in prominence of European laboratory science and the codification of germ theory would have settled allegations of dogmatic rationalism on the part of regular physicians, the situation was not so straightforward. Indeed, as regular physicians

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77 The case of the Eclectic School is interesting. While professing an openness to different clinical approaches, there remained one school of medicine for which many Eclectics could not hide their contempt: the regular school. The cited quote is from The American Journal, an eclectic medical journal based in St. Louis, MO. “Editorial,” The American Medical Journal XXV, no 12 (1897), 569.
incorporated germ theory into their practice, some worried that the theory itself was itself becoming dogma. In 1888, Dr. J.M. Taylor, former President of the Mississippi State Medical Association and Mississippi State Board of Health, penned an article wherein he worried that germ theory threatened the contributions of the nation’s rural, country physicians, an intrepid lot of healers who rode by day and night “on horseback, in buggies, and on railroad trains, in all seasons, over the hills and through the swamps, carrying, in a pair of saddle-bags or a little handbag, all the medicines, instruments and appliances used by them in the treatment of all diseases and injuries, medical, surgical and obstetrical.”\footnote{78 J.M. Taylor, “Antiseptic Surgery in Country Practice,” \textit{The Medical and Surgical Reporter} LIX, no. 23 (1888): 704.} While Taylor is careful to express his support of the germ in theory, calling it “one of the most beautiful and plausible theories that was ever launched on the sea of medical philosophy,”\footnote{79 Ibid. 705.} he feared that the impotent acquiescence of physicians to the theory unfairly and unwisely derogated the knowledge country physicians had gleaned through their day-to-day practice:

“This beautiful theory supplies a desideratum in etiology long felt, and furnishes an easy solution to many problems which have greatly perplexed the profession for many generations. Immediately after its promulgation, the fertile mind of the discoverer, ever on the alert for something new, was set to work to find some means of killing these microbes, which like the giants that peopled Don Quixote’s brain, cause all the miseries and all of the woes that afflict mankind. Antiseptic surgery, Minerva-like, sprang into existence in full panoply, and has carried the medical profession by storm, with all its boasted modern advancements. So strongly is it endorsed, that it is almost as much as any
ordinary man’s professional scalp is worth to express any doubts of its entire correctness.

In a particularly pointed indictment, Taylor laments the dogmatic application of germ theory across wide domains of medical practice, declaring, “we are not yet freed from the superstition and credulity which have always prevailed in our profession.” Germ theory may be true, he submitted, but it did not mean that the various and varied applications of the theory were appropriate. The profession, in other words, was sacrificing not only experience but practicality for a theory that, while elegant, remained largely untested.

Before connecting this analysis to my larger project regarding unorthodox AIDS activism, I should address a criticism to which my treatment of this particular current is susceptible. I have gone to great lengths to argue for the virtues of a social history of alternative medicine that prioritizes the experience of the patient, and yet the current I have just explicated is supported almost entirely by citation of professional literature. This is a valid critique, but one that I believe points more to the limitations of the historic archive – after all, patients seldom recorded treatises endorsing particular theories for the cause of progression of disease, or reflecting upon the opinions of their physicians. And yet omitting this particular current from our analysis would require a presumption that patients did not engage in such considerations, a presumption I find much more dangerous than granting that they may have. Second, indirect evidence suggests that patients did, in fact, actively devise their own explanations for and understandings of disease. Such was the case in the vast and poorly articulated practice

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80 Ibid.
81 Ibid. 706.
82 It is also worth noting that Taylor’s criticism of the rapid appropriation of germ theory in clinical practice invoked the first current outlined above, with the physician criticizing the use of bichloride of mercury, “a most virulent poison” in surgical procedures to destroy germs. Ibid. 705.
subsumed by the category “folk medicine.” Surely, individuals influenced by folk and home explanations of disease did not surrender their opinions when before a regular physician. Historian Sheila Rothman has additionally noted that through the 19th Century, medical textbooks were written in a style that made them accessible to an educated public, and patients engaged with their physicians in ways that challenged the autocratic stereotype. And finally, popular literature written in the 19th Century provides evidence of the idiosyncratic ways in which patients understood their disease and approached the sick role. An 1883 novel by the author Costa includes a taxonomy of patient types that, while far too long to permit replication here, underscores the fact that patients expressed their individuality in ways both comical and frustrating for medical providers in the 19th Century.

One might grant all that I have argued about the important ways in which regular medicine was associated with dogmatic application of learned theories while quite understandably wondering how this current could possibly have any relevance to late 20th Century health activism. After all, through the mid-to-late 20th Century, scientific empiricism was in ascension. The older distinctions between rationalism and empiricism, difficult to maintain even in their heyday, were relegated to the convoluted pages of dusty medical treatises.

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83 In advocating for the right of osteopaths to practice medicine in New York, Twain cleverly argued that there really were two schools of medicine throughout the state, the regular physicians and the grandmothers, with the public regularly turning to the expertise of the latter in explaining disease. Mark Twain, “Remarks on Osteopathy,” in Mark Twain Speaking, ed. Paul Fatout (Iowa City: University of Iowa Press, 1978), 385.

84 Granted, we can assume that patients with access to medical textbooks were generally well-to-do. The degree to which wealthy patients challenged the received wisdom of regular medicine is well documented. Consider, for example, the fact that in the early 20th Century, John Rockefeller expressed great skepticism with the dogmatic application of allopathic theories, expressing a preference for the homeopathic. Sheila Rothman. Living in the Shadow of Death: Tuberculosis and the Social Experience of Illness in American History (Baltimore: Johns Hopkins University Press, 1995), 7.

However, in several crucially important ways, we find that 1980s and 1990s-era unorthodox AIDS activism featured arguments remarkably similar in tone and content to those waged centuries earlier between regular and irregular medical leaders.

As we shall see in the third unit of this volume, individuals with AIDS openly and vehemently challenged myriad aspects of mainstream AIDS etiological models. In many cases, the advocates of this more radical activist tradition accused mainstream medicine of glorifying particular etiological theories, ignoring criticism of those theories, and derogating observed fact to their chosen theories. This particular manifestation of unorthodox AIDS activism is captured well in the pages of the *Newsline* newsletter published by the People with AIDS Coalition. And no member of the *Newsline* staff expressed it more vehemently than Michael Callen, a highly influential activist diagnosed with AIDS in the earliest days of the epidemic who would go on to live with the condition for an unprecedented length of time, dying in December of 1993. Callen’s criticism of the widespread acceptance of a viral etiology for AIDS was informed by the public positions of his own personal physician, Joseph Sonnabend. Both men criticized the alacrity with which the biomedical profession accepted the viral origin of AIDS. As Sonnabend argued, following the initial 1984 press conference wherein the viral cause of AIDS was announced, “the theory became a fact.”

Callen echoed these sentiments, noting,

“In the weeks surrounding Gallo’s announcement, press accounts would cautiously refer to HTLV-III as the ‘putative’ AIDS virus. Reporters were generally careful to remind readers that the assertion that HTLV-III was ‘the cause’ of AIDS was a hypothesis which

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was yet to be proven. Then, suddenly, the qualifiers disappeared and the caution evaporated. HIV was decreed to be the cause of AIDS. Wait? Did we miss something?87

Through his years writing for the Newsline, Callen would continue to speak out against mainstream medicine’s rapid endorsement of an etiological model of AIDS, going as far as to say that the move was a product of “scientific nationalism” and fit “nicely with most Americans’ unsophisticated notion of germ theory.”88

The historical parallels between Callen’s concern with the rapid acceptance of a viral etiological model for AIDS and Taylor’s aforementioned trepidation with the germ theory’s ascension within the ranks of modern medicine are fascinating. In both cases, the authors based their criticism not on the validity of a given theory, but rather on the speed with which it was codified and operationalized into practice.89 Furthermore, when the FDA approved AZT as the first antiretroviral AIDS drug, Callen and other likeminded activists would focus on its toxicities in a manner reminiscent of Taylor’s discussion of bichloride of mercury.

Further parallels between historically rooted rational and empirical divides in medicine can be found in unorthodox AIDS activists’ recourse to personal experience in explaining and treating AIDS. Michael Callen, for example, famously and vociferously promoted a multicausal model of AIDS, promulgated by Sonnabend. This theory, which I shall revisit in later chapters,

87 Michael Callen, “Why I Don’t Believe that HIV is the Cause of AIDS and Why I Think It Matters at All,” PWA Coalition Newsline 29 (December 1987), 35.
88 Callen is quoted in a letter written by a Mr. Schick. Mr. Schick, “Letter to the Editor,” PWA Coalition Newsline 37 (October 1988), 13. The letter is almost certainly written by Rob Schick, who would later become a regular columnist for the Newsline; Also in 1988, Max Navarre, the editor of the Newsline, wrote, “The medical love affair with AZT is particularly alarming to those of us who remain unconvinced that HIV is ‘the cause’ of AIDS. Every time I hear HIV referred to as the ‘AIDS virus,’ my teeth start to grind.” Max Navarre, “AIDS in ’88 – An Editorial,” PWA Coalition Newsline 30 (January 1988), 16.
89 I do not mean to simplify Callen’s position. As I shall show, he would go on to voice pointed criticism as the viral origin of AIDS, particularly as it became clear that biomedicine was not reversing course in its endorsement of a viral cause of AIDS.
maintained that repeated exposure to a vast array of infectious diseases, compounded by the physical assault of drugs and alcohol, led to the sustained immune deficiency underlying AIDS. Callen relied upon his own personal experience to justify his support of the multicausal model. It was clear to him that his disease followed years of repeated exposures to sexually transmitted disease in the context of his “fast lane” lifestyle:

“I calculated that since becoming sexually active in 1973, I had racked up more than three thousand different sexual partners in bathhouses, back rooms, meat racks, and tearooms. As a consequence I also had the following sexually transmitted diseases, many more than once: hepatitis A, hepatitis B, non-A/non-B hepatitis; herpes simplex Types I and II; venereal warts; giardia lamblia and entamoeba histolytica; shigella flexneri and salmonella; syphilis; gonorrhea; nonspecific urethritis; chlamydia; cytomegalovirus (CMV), and Epstein-Barr virus (EBV) mononucleosis; and eventually cryptosporidiosis.”

The appeal of anecdotal reasoning in the context of AIDS was a powerful approach many unorthodox AIDS activists adopted through the 1980s. While many critics would challenge such reasoning, arguing that larger sample sizes were necessary to reach definitive conclusions regarding the epidemic, activists’ invocation of personal experience resonated with patients seeking validation for their individual struggles. Indeed, the sharing of the anecdotes were, in their own way, an expression of intimacy by a group of individuals whose opportunities for physical connection were rapidly retreating in the face of illness, stigmatization and discrimination. Well respected journalist and lay expert on AIDS John S. James would invoke

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the importance of anecdotal information in drug research when calling upon his readership to personally examine and test an experimental AIDS treatment, AL-721, calling for a “a kind of direct democracy in medical research.”

Enduring Currents: Anti-Authoritarian Sentiment

Broadening our analytical approach even further, we may identify a third current instrumental in supporting the success and appeal of unorthodox healing systems among members of the public. This current centered upon misgivings regarding claims of authority made by an educated few over the lives of others, and was perhaps nowhere more pronounced than in Thomsonian medicine, a popular 19th Century healing practice that advised patients to eschew elite, educated physicians and instead “become their own doctors.” A century before bioethicists would speak of patient autonomy, Thomson, no doubt inspired by pecuniary interests in drumming up support for his proprietary healing system, spoke of the empowerment of patients: “[T]he common people have been found capable of examining, judging, and deciding correctly. Give them the facts, the whole facts, and nothing but the facts. By them, we conquer!” As historians have noted, Thomson’s injunction is best understood within the broader context of the Jacksonian era, a period wherein suspicion of centralized power, be it in the government or professions, was at an all time high. It was in this context that Thomsonian medicine thrived, buoyed by what historian Michael Flannery terms a “pervasive anti-intellectualism that belittled both learning and the learned.”

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93 Ibid. 445.
While Thomsonian medicine, in its purest form, represented a particularly radical departure from the authority of learned men, anti-authoritarianism sentiment could be found across multiple healing sects of the 19th Century, including hydropathy, homeopathy and Eclectic medicine. The anti-authoritarianism of the late 19th Century expressed itself in terms of the public’s opposition to the monopolization of medicine. And here, again, we find that regular medicine’s efforts to respond to the success of sectarian practice merely fueled anti-authoritarian sentiment, as orthodox physicians sought to limit the right of sectarians to practice in many states. As Nadav Davidovitch has noted, by the turn of the century, journals such as *Medical Talk for the Home, Homeopathic Envoy, Medical Liberty News, Journal of Zoophily* and *The Arena* fiercely criticized the authoritarianism of regular medicine, directly invoking the language of monopolies to describe its behavior. Mark Twain would even weigh in on the issue in the final decade of his life. In remarks given before the New York State Assembly, the author defended osteopaths from the bullish efforts of regular physicians to effectively outlaw their practice. Twain testified, “I don't know as I cared much about these osteopaths until I heard you were going to drive them out of the state, but since I heard that I haven’t been able to sleep. Now what I contend is that my body is my own, at least, I have always so regarded it. If I do harm through my experimenting with it, it is I who suffer, not the State.”

Notably, Twain’s statements, which were echoed by many advocates of irregular medicine at the turn of the century, do not turn upon the right of a practitioner to choose his healing craft, but rather the right of the patient to do with his body what he sees fit. This popular expression of anti-authoritarianism expanded the anti-intellectual focus of Thomsonian medicine

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95 Fatout, *Mark Twain Speaking*, 386.
in a way that was compatible with multiple healing systems, including homeopathy, popular among highly educated members of society. This more flexible interpretation of anti-authoritarianism furthermore tied alternative medicine with other early 20th Century activist movements, most notably the women’s health movement. For example, Mary Ware Dennett, well-known birth control advocate and social reformer, served as a Special Lay Representative to the American Foundation for Homeopathy. In this position, she openly resented the “growing medical monopoly” demanded by regulars, arguing that people’s freedom to choose health practitioners was related to their freedom to make personal decisions regarding sexuality and reproduction.\(^96\)

The 1960s and 1970s witnessed a broad anti-authoritarianism on both the macro level (exhibited, for example, in large-scale protests against domestic and international governmental policies) and the micro level (exhibited by challenges to norms regarding interpersonal and sexual relations). The broad current of anti-authoritarianism – and, as noted above, the fear that physicians were capable of causing great harm to their patients – led to the professionalization of biomedical ethics as an adjunct discipline to medicine. By the 1980s and 1990s, biomedical discourse had underscored the importance of informed consent and patient autonomy in matters of health care, replacing older paternalistic models of care. Given this fact, one might wonder how persuasive any argument that turns upon an anti-authoritarian sentiment in explaining the origins of unorthodox AIDS activism may be. For, surely, the authoritarianism of 1980s era medicine, informed and policed as it was by the representatives of biomedical ethics, differed

from the outwardly monopolistic and paternalistic stalwarts of 19th Century regular medicine.\textsuperscript{97}

And yet, a close examination of clinical care through the late 20th Century reveals important institutional and structural expressions of rigidity and authority despite the affirmation of patient autonomy. To appreciate the anti-authoritarian impulse of unorthodox AIDS activism, we must therefore come to understand these expressions of rigidity.

As Barron Lerner has noted, during the 1960s and 1970s, pivotal years in the crystallization of American biomedical ethics and the codification of informed consent and patient autonomy as key principles of care, biomedicine continued to debate how best to respond to patients who disagreed with or disregarded clinical instructions. For mainstream physicians, these patients were “noncompliant,” an interpretation that defined the patient in relation to his/her variance from an accepted standard of care. That this categorization was in direct tension with the tenets of patient autonomy and informed consent largely escaped critical analysis. Lerner, however, has identified this tension, arguing that “calling patients ‘recalcitrant’ and ‘noncompliant’ reinforced the widely held cultural belief that patients who did not follow physicians’ advice were both deviant and deserving of aggressive remedial interventions.”\textsuperscript{98}

\textsuperscript{97} Ron Bayer has noted that, in part as a result of the rise of informed consent and patient autonomy, AIDS was treated very differently than infectious diseases of the 19th Century had been treated. Ron Bayer, “HIV Exceptionalism Revisited,” \textit{AIDS & Public Policy Journal 3} (1994), 16.

\textsuperscript{98} Lerner also cites as evidence of this tension a statement made by Franz Ingelfinger, famed gastroenterologist, editor of the \textit{New England Journal of Medicine} and creator of the so-called “Ingelfinger rule” which stipulated that the \textit{NEJM} would not publish findings that had been published in other journals or by other media outlets. In 1980, Ingelfinger declared, “a certain amount of authoritarianism, paternalism, and domination are the essence of the physician’s effectiveness.” While Ingelfinger would die shortly after the publication of this comment, the Ingelfinger rule had important influence on debates regarding AIDS activists’ demands for scientific findings prior to publication. In 1991, the editor of the \textit{NEJM} wrote that the press’ premature publication of unverified scientific claims regarding the use of cyclosporine and ribavirin to treat AIDS, both in violation of the Ingelfinger rule, had resulted in great confusion and harm. Ingelfinger quote cited in Barron Lerner, “From Careless Consumptives to
Lerner’s arguments underscore, would thus be wise to avoid assuming that the ascension of biomedical ethics in the late 20th Century heralded a wholesale transformation in the deep ways in which physicians conceived of their patients. One informal metric is instructive. A recent search of the National Institute of Health PubMed database polled the number of research articles mentioning the term “autonomy” between the 1960s and 1980s, finding an increase in articles from approximately ten per year in the 1960s to 210 per year in the first half of the 1980s. A similar search of the term “noncompliance” reveals an increase from two per year in the 1960s to a 730 per year at the start of the 1980s.99

Through the 1980s and 1990s, unorthodox AIDS activists explicitly and defiantly refused to comply with the etiological or therapeutic beliefs of mainstream medicine. Be it in the pages of the New York Native, the columns of the PWA Coalition Newsline, or the notes of ACT UP’s Treatment and Data Committee, activists argued not only that they had the right to be their own doctors, but their own researchers and regulators as well. They shared strategies for subverting the requirements of clinical trials, unblinding studies, and engaging in similarly non-compliant behaviors. In their words and in their actions, individuals with AIDS defied the authority of a biomedical model that failed to adequately address their concerns. Furthermore, as was the case with female proponents of alternative healing at the turn of the century, many of the unorthodox AIDS activists – gay men diagnosed with AIDS in the 1980s – felt that it was foolish to comply

Recalcitrant Patients: The Historical Construction of Noncompliance,” Social Science and Medicine 45, no. 9 (1997), 1428.
99 This trend has, for the most part, continued with some minor variation. Between the years 2010 and 2014, approximately 1700 articles including the term “autonomy” were published per year, compared with 4589 including “noncompliance.” Figures calculated using Pubmed’s “Results by Year” feature, accessed on March 21, 2015. PubMed.gov. US National Library of Medicine, National Institutes of Health.
with a medical model that had until very recently denigrated their sexual identity as a medical condition.

While I am principally interested in the ways in which an anti-authoritarian current suffused and supported alternative and unorthodox healing systems through the 19\textsuperscript{th} and 20\textsuperscript{th} centuries, a word on the fate of these movement is warranted. For, what we find both in 19th Century sectarian medicine and late 20th Century unorthodox AIDS activism is that while anti-authoritarian sentiment played an important role in inciting the formation and early popularity of contrarian movements, it failed to sustain them in any meaningful way. In the case of Thomsonian medicine, for example, we see the eventual establishment of medical schools and scholarly journals, directly contradicting the democratic, anti-elitist goals of its founder. In homeopathy, initial attacks on the power and influence of regular medicine gave way to homeopathic medical schools rapidly modifying their practice to gain the endorsement of state standards. And in the case of AIDS, as Steven Epstein has argued, AIDS activists who began by deriding the authority of biomedical researchers and physicians would, over the course of time, transform themselves into “lay experts” who allied themselves more closely with biomedicine than unorthodox activists.\footnote{For a discussion of the creation of lay expertise in response to AIDS, see Epstein, \textit{Impure Science}.}

\textbf{Enduring Currents: Antimodern Sentiment}

The final current I shall examine in my elucidation of the various interrelated forces that have helped to support the appeal of alternative and unorthodox healing systems may be defined as a broad antimodernism sentiment. So-called antimodern campaigns have been launched from multiple berths throughout history; in each case, decriers have surveyed the winds of change and argued that they had caused society to lose its bearings. For these distressed critics, the only
remedy was to look backwards in time to an age that was at once simpler and richer with meaning, aligned with a moral compass that deepened our connections with ourselves, with one another, and with a higher power. My invocation of the term “antimodernity” borrows from Jackson Lears’s discussion of the concept, which he describes as a powerful sentiment pulsing through society in the late 19th and early 20th Century, tied to deep apprehension with the changes wrought through industrialization, urbanization and commercialization. I maintain that an understanding of antimodernism thus construed is of relevance for discussions of the animating force behind diverse irregular healing movements of the 19th Century, and furthermore helps to inform late 20th Century manifestations of unorthodox AIDS activism.

The early-to-mid 19th Century was a period of tremendous change in American society, with many fearing that the nation had lost its moorings in its search for a more mechanized, industrialized mode of living. These changes were registered on both the macro level – in the shifting patterns of commerce as the nation expanded in both size and geographic spread – and the micro level, most notably in terms of transformations in the structure and function of the American family. Critics, in registering this restructuring of life, feared that Americans had come to sacrifice their values for economic and technological growth. One of the most ardent of these critics was a notoriously curmudgeonly preacher by the name of Sylvester Graham. Born in the Connecticut River Valley during George Washington’s second presidential term, Graham’s antimodern fears would prompt the creation of successful and influential popular health movement.

Graham was deeply unsettled by both the excesses wrought by the social changes taking place in the early 19th Century and, most particularly, the transformation of the American family. In response, he introduced a health system focused upon attacks on intemperance in alcohol consumption, the vilification of sexual excesses, and an ardent patronage of vegetarianism. However, his beliefs became most closely associated with a campaign he launched in the 19th Century in response to the fragmentation of means of production and its effects on a product consumed by American families on a daily basis: bread. Whereas bread was once produced by families using wheat they had grown themselves or procured from local farmers, by the mid 19th Century, this process had become impersonal and fragmented, with families purchasing flour that, in many cases, had been prepared hundreds of miles away by faceless farmers and was adulterated with countless additives and preservatives. In short, Graham despised the 19th Century production of what, in modern parlance, we would call white bread.

No single product borne out of modern industrialization attracted greater scorn or animosity from Graham than white bread. For him, it not only heralded the disintegration of the family unit, but it posed direct harm to human health. In its place, Graham would celebrate the virtues of his own “Graham bread,” produced using what he called “family flour.” The student of medicine would likely struggle to find any nostrum throughout all of the history of medicine possessing greater symbolic meaning and significance than Graham’s whole wheat bread. Folded


103 While the vagaries of Graham’s health system are largely forgotten, his name is still attached to a popular bread product: the Graham cracker. As the Graham cracker attests, by the end of his life, Graham had fallen victim to the same systems of commercialization and industrialization he had railed against throughout his life, with his products marketed and sold across the nation. Ibid. 7.

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into its grains were deeply held fears and convictions regarding the place of the family in society, the effects of industrialization and commercialization on the family structure, and the underlying identity – we may even use the word soul – of the American populace. 104

While it is easy to categorize Graham’s health movement as an adjunct system of healing that avoided commenting on core etiological aspects of regular medicine – a 19th Century version of “complementary” medicine – such a formulation would be inaccurate. Graham saw in his system a new framework for understanding all of health and disease. In his view, disease itself was a symptom of widespread, ingrained processes associated with marketplace capitalism, urbanization and industrialization; thus, even a disease such as cholera was largely symbolic of these larger problems. As historian Stephen Nissenbaum notes in his definitive treatment of Graham’s contributions to the history of healing: “The disease itself was nothing; what made it lethal and epidemic were the ‘customs and circumstances of artificial life’ that had reached so deep as to subvert the most basic structure of human need and behavior.”105

104 One can identify parallels between Graham’s attack on the impersonal dimensions of modernity and Max Weber’s theories. This relationship, however, is complex, for while Weber criticized the forces of capitalism, he also attacked asceticism commanded by Puritan teachings, which “descended like a frost” on civilization. See Robert Bocock, Consumption (New York: Routledge, 1993), 8; The health movements inspired by Sylvester Graham and James Kellogg were, in many ways, ascetic – eschewing excess, intemperance, and variation. Furthermore, over time, the health systems of Graham and his contemporaries were absorbed into and fed larger capitalist systems. Nissenbaum notes as much in his conclusion regarding Graham’s lasting contributions to our beliefs about health: “What can be called the physiology of subsistence was born, much like the religion of nature or the cult of domesticity, in an effort to resist and deny the reality of marketplace capitalism. But, like them, it too ended by reinforcing that reality.” Nissenbaum, Sex, Diet and Debility, 135; See also Michael A. Goldstein, Alternative Health Care: Medicine, Miracle, or Mirage? (Philadelphia: Temple University Press, 1999), 139-141. 105 This formulation of disease was roughly consistent with the “seed versus soil” arguments of the day. The appropriation of seed/soil metaphors was generally used to explain the preferential action of particles or germs (the seed) upon a body made susceptible by lifestyle or environmental conditions (the soil). Graham accepted such arguments, but expanded them considerably. See Nissenbaum, Sex, Diet and Debility, 96.
By the late 19th Century, apprehension with shifting social and economic arrangements reached a zenith. In Lears’s formulation of antimodernism, this period witnessed the declining dominance of Protestant culture and a rapidly secularizing worldview. As the nation embraced a culture of rampant consumption, it simultaneously lost its ties to deep moral systems necessary for ordering and extending meaning to day-to-day activities. What’s more, the explanatory frameworks in ascendancy during modernity – vague, liberal Protestantism and sterile positivism – failed to fill the void left by the retreat of deep religious experience. As a result, as Lears argues, society was afflicted by a “hovering soul sickness” which demanded treatment through social organization.\footnote{Lears, No Place of Grace, 142.}

Lears’s treatment of antimodernism is particularly useful in its discussion of the ways in which early 19th Century insecurities regarding rampant social change were expressed in spiritual and religious terms by the end of the 19th Century. Indeed, in late 19th Century antimodernism, we find fascinating efforts to reclaim a religious or spiritual meaning to day-to-day life, expressed both through a recourse to Christian principles in addition to practices as varied as Eastern mysticism. Graham’s healing system also would eventually become interpreted through this spiritual turn in antimodernism. In the 1860s, an intrepid reformer by the name of James Caleb Jackson operated a well-known hydropathic institute in New York State that utilized Graham’s system. The institute attracted the interest of many of the era’s leading figures, including Susan B. Anthony, Frederick Douglass, Clara Barton and, of particular note, Ellen White, the founder of the Seventh Day Adventist religious group. White would eventually incorporate the alternative healing methodologies she learned at the institute into her own
religious philosophy, and time inspired a young firebrand by the name of James Harvey Kellogg to advocate broad change in personal habits to ward against the forces of modernity. 107

The visitation of one of America’s more colorful religious luminaries to Jackson’s institute was more than quirk or coincidence – it speaks to the values shared between alternative medicine and health movements and religious practice. Closely allied with impositions for a return to a pastoral past and celebration of a simpler, more intimate means of existence were efforts to situate men and women in relation to a greater power. Many health care movements of the time shared this interest, invoking some conception of a “vital force,” a medium that bound body and spirit, tying personal health to the worlds of flesh and the world of religions. Such was the case, for example, with American homeopathy, as historian Naomi Kirschmann notes:

“Viewing the cause of illness as the result of a disturbed vital force – affecting mind, body, and spirit – advocates counteracted the fragmentation of individual identity by reinforcing traditional notions of the integral relationship of mind, body, and spirit in healing.”108

The links between antimodern holism, irregular medical sects, and spiritualism were also registered in the reflections of lay individuals during the period. Recall, for example, Mark Twain’s vocal support of irregular healing systems in New York state. In the same testimony before the state legislature wherein he invoked clear anti-authoritarian sentiment, he included pointedly personal reflections that interpreted his childhood experience with hydropathy (the water cure) with latent spirituality:

“I can remember well when the cold-water cure was first talked about. I was then about 9 years old, and I remember how my mother used to stand me up naked in the back yard

107 White formed her own health institute headed by James Harvey Kellogg, whose own beliefs – he once railed against “the artificial conditions of civilized life” – were largely compatible with Graham’s.
108 Kirschmann, No Vital Force, 129.
every morning and throw buckets of cold water on me, just to see what effect it would have. Personally, I had no curiosity upon the subject. And then, when the dousing was over, she would wrap me up in a sheet and then wrap blankets around that and put me into bed. I never realized that the treatment was doing me any particular good physically. But it purified me spiritually. For pretty soon after I was put into bed I would up a perspiration that was something worth seeing….And when finally she let me out and unwound the sheet, I remember how it was all covered with yellow color, but that was only the outpourings of my conscience, just spiritual outpourings.”

At roughly the same time Twain offered these reminiscences, alternative healing movements were directly invoking the language of spirituality to justify their beliefs. Groups such as Boston’s Emmanuel Movement and Mary Baker Eddy’s Church of Christ Scientist unambiguously preached the power of spirituality to cure disease. While underemphasized in the history of medicine, these movements were extraordinary for the popular appeal they held even during the years wherein the germ theory of disease – and plainly material explanations for illness – were most clearly articulated and defended. Indeed, between 1900 and 1925, the same quarter century period that witnessed Robert Koch earn the Nobel Prize for his work on Mycobacterium tuberculosis (1905) and Paul Ehrlich’s discovery of Salvarsan to treat syphilis (1909), Christian Science was the fastest growing religious denomination in the country. The

109 Twain’s testimony was published in multiple sources. One, the World Review, began by declaring, “Mark Twain believes in liberty and wants every fellow given a free hand in his trial in the world.” “Liberty in Healing,” The World Review I (March 9 - August 31, 1901).

110 Whorton. Nature Cures: 123; The Emmanuel Movement was closely associated with the nascent field of psychotherapy. For a discussion of the movement, see Eric Caplan, Mind Games: American Culture and the Birth of Psychotherapy (Berkeley: University of California Press, 1998); In citing the ascendancy of the germ theory of the disease, I do not mean to suggest that it singlehandedly or revolutionarily transformed clinical practice. As historians such as Nancy Tomes have persuasively argued, sanitary reform measures of the 19th Century predated
rise of these spiritual approaches to treating disease, coupled with the broad antimodern turn toward a conception of health that was at once simpler and more satisfying, suggests that historians would do well to interrogate the intersections between religious beliefs and healing practices in the modern era. Historian Roy Porter has suggested as much, arguing, “The religious inputs in medical practice need much further study. Historians have been so concerned with questions such as the secularization of the medical-world view that they have neglected to study the continuing religious motivations for medical practice.”

The dynamic interplay between material and spiritual explanations for disease is well captured by the aforementioned concept which reappears in multiple discussions of alternative healing systems: the vital spirit. A force that helped to unite the material world with the spiritual, the vital spirit served as a bridge between modernity’s focus on the material and pre-modernity’s celebration of the spiritual. While the history of the concept is very old, and beyond the scope of this analysis, it is worth noting that manifestations of it are to be found throughout the history of medicine in the United States, including our early colonial history. As I find the exercise to be

the codification of germ theory and were responsible for tremendous change in both clinical and popular practice. My point here is that religious movements that interpreted health through a spiritual lens, such as Christian Science, grew despite the 19th and early 20th centuries’ codification of a material etiological framework for understanding disease. In this formulation, we would do well to remember that the so-called miasma theory of disease and germ theory disease shared much in common, both contrasting markedly with the spiritualism embodied by Christian Science and the closely related Mind Cure movement. For background on the history of 19th Century sanitary science and domestic hygiene movements, see Nancy Tomes, “The Private Side of Public Health: Sanitary Science, Domestic Hygiene, and the Germ Theory, 1870-1900,” in Sickness and Health in America: Readings in the History of Medicine and Public Health, ed. Judith Walzer Leavitt and Ronald L. Numbers. (Madison: University of Wisconsin Press, 1997).

illuminating for underscoring the longer history of antimodernity and the deeper tensions it attempted to reconcile, I shall close with a discussion of one early expression of the vital spirit. The author of this particular expression happens to be one of the most interesting, if poorly understood, 18th Century figures spanning the practice of theology and medicine: Cotton Mather.

Cotton Mather generally enjoys passing reference in the history of 18th Century medicine, remembered as a Puritan minister who issued recommendations for smallpox inoculation in Boston. While this brief history paints a picture of a practicing minister actively amalgamating scriptural wisdom with medical prescription, this is a woefully simplistic treatment of a complex man living in a time of great change and conflict. Indeed, Mather’s efforts to wade into matters of medicine were met with the opprobrium of leading physicians.112 His experience was characteristic of the fragmentation of American medicine from spirituality, a marked change from the early colonial era when many physicians were indeed ministers. Mather so deeply resented this fragmentation, borne out of the Enlightenment rationalism of Thomas Hobbes and Rene Descartes and their segregation of body and spirit, that he constructed an elaborate theory to countermand it. In his 1724 Angel of Bethesda, the minister conceptualized a mediator between material and spiritual realms. Referred to as the “nishmath-chajim,” a Hebrew phrase translated as “breath of life,” this force has been described by historian Margaret Humphreys Warner as a vital spirit. The nishmath-chajim, present in every person, was acted upon by both material and nonmaterial forces, mediating disease and wellness, and was thus susceptible to the ministrations of both physicians and preachers. Mather devised a fascinating

112 For a wonderful discussion of Mather’s integration of religious and medical systems of thought, see Margaret Humphreys Warner, “Vindicating the Minister’s Medical Role: Cotton Mather’s Concept of the Nishmath-Chajim and the Spiritualization of Medicine,” Journal of the History of Medicine 36, no. 3 (1981).
taxonomy that recognized three physical explanations for disease (the particulate model, the animalcular theory, and intemperate living), and two nonmaterial explanations (sin and mental unrest). Demonstrating a phenomenal command of historical, theological and philosophical learning, and responding to a very real fear that in medicine, mankind was derogating spirit for flesh, Mather thus articulated a mechanism of disease that acknowledged the authority of scientific practitioners while demanding a seat at the table for the inspired preacher.

There is no direct evidence that Mather’s nishmath-chajim influenced later thinkers, but the perseverance of remarkably similar concepts in sectarian medicine is striking.\(^{113}\) A century after the publication of Mather’s theory, Samuel Hahnemann cited a roughly similar concept to explain the function of homeopathic dilutions, roundly ridiculed by many as having been attenuated to such a degree that they lacked any material substance to act on the body. In his explanation, Hahnemann invoked the existence of a vital spirit that governed the physiological functioning of the body, upon which his dilutions acted.\(^{114}\) For historian Robert Fuller, Hahnemann’s description “caught the imagination of many intellectuals seeking innovative

\(^{113}\) To be clear, I do not mean to argue that Mather’s work was singly responsible for the development of similar theories in alternative medical sects, but rather that he summarized a number of prevailing beliefs that were quite old and persisted well past his death. Mather’s own treatise does not appear to have generated great attention among the public. Oliver Wendell Holmes suggested that it was well known while at the same time, disparaging and dismissing its author. Discussing Mather’s involvement in inoculation, he wrote, “In 1721, [smallpox], after a respite of nineteen years, again appeared as an epidemic. In that year it was that Cotton Mather, browsing, as was his wont, on all the printed fodder that came within reach of his ever-grinding mandibles, came upon an account of inoculation as practised in Turkey, contained in the ‘Philosophical Transactions.’ He spoke of it to several physicians, who paid little heed to his story; for they knew his medical whims, and had probably been bored, as we say now-a-days, many of them, with listening to his ‘Angel of Bethesda,’ and satiated with his speculations on the Nishmath Chajim.” See Oliver Wendell Holmes, Medical Essays: 1842-1882. (Boston: Houghton, Mifflin and Company, 1883), 346.

\(^{114}\) See Whorton, Nature Cures, 58.
answers to the perennial question of the relationship of the world of matter to the world of spirit.”

While great attention has been paid to the rise of empirical science in medical practice, epitomized by the much lauded if somewhat overstated contributions of germ theory of disease to the improvements in health through the 19th Century, much less focus is paid to the ways in which society responded to this empirical turn through the proliferation of irregular and alternative health movements conceiving of health through spiritual and religious lenses. These movements provided nexuses wherein the physical and spiritual could coincide, antimodern spaces that helped to remedy Lears’s hovering soul sickness and provide meaning during periods of crisis. They therefore played an important role in facilitating what religious historians refer to as “awakenings,” or phases in social life wherein people examine and reshape their identities and patterns of thought. Historian Robert Fuller has explicitly located several such awakenings in US history, including during the period wherein Thomsonian, Grahamian, and homeopathic healing systems prospered and, of great relevance to our current historic project, in the cultural upheaval of the 1960s and 1970s.

I maintain that in unorthodox AIDS activism, we see powerful recourse to antimodern sentiment, including both efforts to revert to simpler methods of living and to reconcile spiritual and material conceptions of disease. This antimodernism expressed itself in diverse ways spanning the political spectrum. For example, in explaining the origins of AIDS, we find direct invocations of divine retribution exacted against those who had, in the eyes of religious

116 Ibid. 19.
fundamentals, countermanded religious law.\textsuperscript{117} We additionally can locate interpretations of AIDS that describe it as a direct result of the impersonal forces of globalization, urbanization, sexual revolution, and the derogation of intimacy in favor of impersonal sexual excess. Some blamed it on Americans’ increased reliance upon processed, manufactured diets, while others inveighed against the impersonal and bureaucratized transformation of clinical and research science. In some cases, both the cause and purported cures for AIDS were located in the spiritual and mental approach each individual adopted for understanding disease and health. In short, as biomedicine attempted to subject AIDS to its clinical gaze, various segments of the population turned to other distinctly antimodern explanatory frameworks for clarity and guidance.

If ever there were a period rife for an awakening of the sort Fuller discusses, it was the 1980s. After all, AIDS demanded a wholesale reconceptualization of identity, as individuals’ most intimate and personal behaviors – the fabric of identity itself – became exposed for the world to see. And just as individuals with AIDS struggled with their rapid public association with a stigmatized group, society too endured a crisis of identity as it was forced to determine how to respond to the tragedy and fear racking its major metropolises. Out of these crises arose an awakening of sorts, marked by the intense reshaping of the patterns of social life, the ways in which people conceptualized their identities and the ways they came to understand the meaning of a very new, fatal disease.

As we shall see in Part III of this volume, the unorthodox movements that mobilized as part of this broad awakening interpreted disease in broadly spiritual ways. Thus, we find active discussion of the benefits of positive psychology and psychospiritual healing workshops in the pages of the \textit{Newsline}. In HEAL literature, we see arguments that AIDS was a direct result of the

hysteria and paranoia wrought by society’s attack on homosexuals. In explorations of Ayurvedic medicine, Chinese medicine and other Eastern healing systems, we find broad recourse to New Age spiritualism and energy dynamics. These fascinating practices, oftentimes bracketed or dismissed as New Age nonsense, are in fact indications of tremendously important renegotiations of the relationship between the physical and the spiritual within the context of late 20th Century disease and healing.

One final word on the ways in which antimodern arguments sustained unorthodox AIDS activism through the 1980s and 1990s is warranted. My analysis of the late 20th Century manifestations of antimodernism differ from 19th Century arguments in one significant way: the relative emphasis placed on the importance of family in matters pertaining to health. For Graham, the family was the functional unit demanding and deserving protection, and it was through increasing cohesion and meaning in family relations that society would maintain its health. In unorthodox AIDS activism, as a result of the deep stigma attending the disease and the widespread prejudice attached to homosexuality, many individuals living with AIDS could not (or would not want to) strengthen their traditional family connections. And yet I would argue that even in unorthodox AIDS activism, the link between family and antimodernism persisted, albeit in a somewhat different form. For whereas Graham hoped to preserve the family as the primary organizational unit providing love, affection, safety and well-being to society, unorthodox AIDS activists sought to redefine and recreate it. Gay men and their allies established close-knit networks that provided emotional support, distributed material resources and conveyed compassion to those who were ill. In seeking to understand the reverberating effects of 19th Century era antimodernism through the late 20th Century, we must therefore interrogate the shifting and contested meaning of categories such as the family. For in AIDS activism, both
orthodox and unorthodox, we find the establishment of social structures that celebrated a distinctly modern version of the family.

This abbreviated explication of the various currents that have sustained the appeal of unorthodox healing systems throughout US history accomplishes several goals. First, it establishes the deep historical roots of unorthodox AIDS activism, a complex categorization of activism that, for the most part, is either omitted from historical analyses or treated as irrational and radicalized expressions of a fringe minority. Second, by mapping common currents suffusing these movements, it helps to establish their relationship with one another, thereby responding to one of the methodological criticisms outlined in the Introduction. And finally, by highlighting the resonance of these currents among members of the public, it helps explain why it is that individuals have, throughout our nation’s history, moved between systems of healing. It elucidates at least several of the reasons why, despite the magnetic pull of hegemonic healing systems, patients have continued to position themselves between and betwixt systems, resisting straightforward categorization, revealing the complex and conflicting ways they have conceived of and responded to illness.

While much is gained through this approach, we must also recognize the shortcomings of my application of the borderland and current metaphorical constructs. For example, with the exception of my concluding discussion of the role of the family in the context of the antimodern current, my approach thus far has not given adequate consideration to the ways in which the desire for social support and cohesion has facilitated the movement of patients between healing systems throughout history. The degree to which unorthodox healing systems rivaled mainstream healing systems in creating a sense of sharing, belonging and community among its proponents
demands analysis, as does their intersection and interaction with issues of gender, race, and class. Furthermore, in my self-conscious enthusiasm for moving beyond histories of founders and physicians, I ignore the possibility that individuals have been attracted to irregular, alternative and unorthodox systems throughout our nation’s history due in part to the charisma of their leaders. While I would argue that the allure of personality has been overstated in the history of unorthodox medicine, I grant that we must consider its contribution to the sustained appeal of healing systems through the 19th and 20th centuries.

Thus, even as we situate ourselves in the borderlands created by multiple healing systems, interrogating the forces that have pulled individuals between these systems, we must recognize the limitations our own methodological approach introduces. For, even after attempting to correct for the biases and preconceptions that have influenced past historical scholarship on contrarian healing systems, the limitations of our approach soon become apparent. That this is the case – that history will always, as Virginia Woolf reminded us, appear “unreal, lop-sided” – should not dissuade us from the current historical project, but instead challenge us to constantly seek new ways of seeing, of understanding, and of reconstructing our past.
Part II
The Soils of Unorthodoxy

Through the mid-to-late 19th Century, authors writing on the origin of disease would, from time to time, invoke a familiar metaphor to convey their argument, reminding readers that one could not explain the growth of a seed without considering the soil wherein it rooted. Perhaps the most famous exponent of this line of reasoning was a handlebar mustached Canadian baronet who would later achieve considerable fame as a cofounder of Johns Hopkins Hospital. As Sir William Osler once argued – with some literary flourish courtesy of the four evangelists – neither the mighty maple nor the modest microbe could thrive if its seed should fall by the wayside or land upon stony ground. Osler summoned the Parable of the Sower to challenge medical models that focused exclusively on the bounded microbe at the expense of constitutional factors influencing their growth in the human body. Examining the metaphor anew as we approach the centenary of Osler’s death, we find its relevance registered across multiple domains. For just as Osler argued that we cannot understand disease if we do not consider the conditions that subtend its growth, the same applies to unorthodox health activist movements. Indeed, if we hope to understand the growth and articulation of unorthodox AIDS activism through the 1980s and 1990s, we cannot simply cast our gaze directly at the movements, categorizing, anthologizing and pathologizing that which we find. We must resist the urge to isolate our subjects, mounting them to sterile stages so that we may subject them to the magnification and resolution of scholarly microscopy. For as tempting as this may be, it

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118 Nineteenth century invocations of the seed/soil metaphor analogized the seed to the microbe and the soil to the body. Later appropriations of the metaphor would consider broader social and environmental factors as analogous to the seed. Osler invoked the Parable of the Sower in a letter written to his colleague Richard MacDonnell, who incidentally died three months later of tuberculosis. Harvey Cushing, *The Life of Sir William Osler, Volume 1.* (Verlag, Hamburg: Severus, 2010), 348-349.
accomplishes little more than a record of fragmented spectacle, fit for gawking and staring, further fodder to be filed within the “social fringe” entry of our historical register.

In the two chapters that comprise this segment of my analysis, I heed Osler’s injunction, recognizing the need for a richer and more nuanced understanding of unorthodox AIDS activism. Setting the seed aside, I train my attention upon the soil wherein it grew – the conditions and contexts that supported its development, the values and beliefs that anchored its roots. I aim, in a word, to make unorthodox resistance the subject of historical analysis. That we as historians should examine the soil of unorthodoxy is indeed fitting, for as poets have long held, the earth and soil are themselves the silent record of a living history. It was, after all, Thoreau who wrote, “The earth is not a mere fragment of dead history, stratum upon stratum like the leaves of a book, an object for a museum and an antiquarian, but living poetry like the leaves of a tree, which precede flowers and fruit – not a fossil earth, but a living earth.”119 What then, I ask, is the living earth that anchored the growth of a nascent unorthodox AIDS movement? What was the soil of unorthodoxy?

In answering these questions, I begin by examining profound changes in the lived experience with and construction of disease through the 20th Century. In Chapter 2, the first of this segment, I explore transformations in conceptualization of disease from the early 20th Century, when the biomedical model was codified and in ascendance, through the end of the 1970s. In it, I argue that we must closely interrogate the pre-20th Century disease narratives invoked to explain AIDS, recognizing that individuals living with and responding to AIDS

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119 The line, “an object for a museum or antiquarian” appeared in earlier drafts of the work but was replaced in subsequent editions with the phrase, “to be studied by geologists and antiquarians chiefly.” I prefer the initial draft for conveying the sentiment I wish to capture here. Henry David Thoreau, *Walden and Civil Disobedience* (New York: Signet Classics, 1999), 244; See also Robert M. Thorson, *Walden’s Shore*, (Cambridge: Harvard University Press, 2015), 285-286.
interpreted these narratives from perspectives shaped by their lived experience and recent histories. For through the late 20th Century, as a result of both changes in the nation’s disease burden and broad activist movements arising out of potent antiauthoritarian and antiprofessional currents, society embraced constructions of disease and health at odds with those that had attended the rise to dominance of the Western biomedical model. These alternative models and paradigms would persist in the face of a dominant AIDS historiography, and indeed ultimately anchored the roots of a nascent unorthodox AIDS activist movement.

While Chapter 2 documents the proliferation of health models and etiological paradigms that challenged the dominant biomedical system, Chapter 3 focuses instead on changes in the public’s perception of what we might term the character of that system. In it, I consider the development through the 1960s and 1970s of a radical critique by both lay and professional authors communicating deep distrust in a biomedical system perceived by many as having become far too powerful, exerting direct control over life even as it prioritized financial, professional and political interests over patients’ needs. I furthermore argue that the institutional ombudsmen entrusted with the task of policing the biomedical system and responding to allegations of negligence and exploitation largely ignored the deepest expressions of distrust voiced by these radical authors. This disciplinary oversight was most unfortunate, as it blinded scholars to deep-seated fears and anxieties that would go on to motivate social action.

In the final analysis, I intend for this component of my larger argument to convey the foundational anxieties, apprehensions, movements and beliefs that would ultimately contribute to a poorly understood, frequently vilified activist tradition. In so doing, I endeavor to identify connections between stigmatized activist traditions and deeper expressions of disagreement, apprehension and distrust more relatable to modern readers. Armed with an understanding of this
greater lineage of unorthodoxy, I maintain that we are better positioned to understand how individuals positioned themselves in the borderlands of seemingly conflicting and contradictory health paradigms, associating with a past rendered discontinuous through the powers of institutional and professional discourse.\textsuperscript{120}

\textsuperscript{120} My chosen metaphors bear some resemblance to those invoked by Michel Foucault in his development of archaeological and genealogical methods for examining history. That said, my use of the terms is not identical to his, nor do I claim that my argument is Foucauldian in any strict sense of the term. It is more appropriate to say that my work intersects with his in various ways, while departing in others – most notably my focus on expressions of agency by individuals living with, dying from, and responding to AIDS.
Chapter 2
A Broken Model – 20th Century Transformations in the Social Constructions of Health and Disease

"'So my past is homeless now too,' I thought,
And slammed the window on the glimpse I’d caught."
–Charles Barber (ca. 1989)

AIDS has amassed an impressive coterie of experts and authorities who have interrogated its every detail, mapped its epidemiologic and genomic profiles, and investigated its innumerable clinical, social and moral sequelae. Virologists have conferenced with public health professionals, infectious disease physicians have lectured internists, policy analysts have advised governmental officials, and scholars operating in academic disciplines spanning political science, sociology, psychology, bioethics and gender studies have all endeavored to shed light on the late twentieth century’s most famed and feared disease. Analyses and expositions date back to the earliest days of the pandemic, before that which was discussed had been named, when seemingly healthy young men in US metropolises perished from a faceless, poorly understood disease.

It was a time of innumerable questions, when neither the medical nor the scientific gaze seemed capable of taming the disease or identifying its most fundamental methods of action. Its natural history, to appropriate the language of clinical medicine, remained trenchantly and tragically unknown. And yet, even as questions regarding the natural history of the disease – its causative agent, its method of gaining access to and destroying cells, its means of dissemination – were actively voiced by scholars and lay individuals alike, deeper questions reverberated

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through society. Unuttered yet ubiquitous, they reached beyond mechanistic diagrams, immunologic cell counts and genomic guesswork and spoke instead to growing uncertainties and insecurities regarding the state of health and disease in the modern, developed world. How was it, many wondered, that this new disease had descended so rapidly upon the meccas of modern industrialization? Could it be that we were staring through the haze at a disease lifted from the codices of the Middle Ages? What had happened to the progress and promise of yesterday, and to the security society had been bequeathed by the pioneering forefathers of modern biomedicine?

These questions, intimated and implied in the hushed whispers and uneasy stares greeting those suspected of harboring the then unseen and unknown causative agent of AIDS, are the substance of historical inquiry. That this is the case is perhaps unsurprising, for societies have long turned to history for insight and guidance when faced with existential threats, be they from the invisible waves of incurable disease or the armored legions of unstoppable aggressors. Indeed, when the future appears in flux, society turns to the past to find islands of stability and certainty, exemplars upon which it may chart its course, reference points whereupon it may construct a compass for navigating the stormy waters of the present. And yet, despite our age-old propensity for seeking guidance in the past, the precise ways in which men, women and children learn from, appropriate and arrogate history to inform the present remain poorly understood. ¹²²

¹²² This is not to say that scholars have failed to examine how societies conceive of disease. Charles Rosenberg, for example, has identified four stages in what some have referred to as a “pestilential drama”: Progressive Revelation, Managing Randomness, Negotiating Public Response and Subsidence and Retrospection. However, my focus here is narrower in that I seek to examine the ways in which individuals located AIDS within a historical narrative and interpreted the meaning of that narrative. See Charles Rosenberg, Explaining Epidemics and Other Studies in the History of Medicine (Cambridge: Cambridge University Press, 1992); also Philip Strong, “The Pestilential Apocalypse: Modern, Postmodern and Early Modern
Indeed, while we grant that individuals turn to historical memory and example to navigate treacherous times, much like sailors turned to constellations borne out of history and myth to steer their ships, we do not always understand why people summon particular historical memories, or what these memories mean to them.

I maintain that this deficiency in our understanding of the popular use and interpretation of historical memory is particularly acute in the case of AIDS. In the three decades since early cases of Pneumocystis carinii and Kaposi’s Sarcoma were first diagnosed in otherwise healthy gay men living in New York and California, we have amassed a remarkable body of evidence exploring how AIDS has changed the way we think about and respond to disease, how we conceive of privacy in the context of illness, how we investigate and approve drugs, and how we mobilize as a lay society to influence health policy. In short, it has caused us to reflect critically upon what AIDS has meant to the history of medicine. And yet we know relatively little about what the history of medicine meant for people living in the early era of AIDS, or how this history was used, invoked and interpreted. I maintain that to fully appreciate the history of AIDS – including the history of unorthodox AIDS activism – we must answer two interrelated questions: (i) Which strands of historical understanding, stories and narratives did individuals living in the 1980s and 1990s graft onto AIDS in an effort to suffuse it with the depths of meaning only historical knowledge seems capable of supplying? And, (ii) How did these historical narratives intersect with and interact with their lived experience, and with their conceptions of the world shaped by their interpretations of recent history?

In this chapter, I explore each of these questions in sequence, identifying first the dominant historical narratives into which AIDS was assimilated and through which it was

explained. I then address the second question, arguing that those confronted by AIDS interpreted the dominant historical narrative from a perspective indelibly shaped by disease discourse developed through the 1960s and 1970s. As I shall argue, at times, these interpretations would challenge the dominant narrative, producing alternate, “unsanctioned” histories of the epidemic. It is in these unsanctioned pages of the AIDS historiography that we identify many of the underlying principles, perspectives, fears and anxieties that would anchor and fuel unorthodox AIDS activism.

Sanctioned Meaning: Locating AIDS within History

In the earliest days of AIDS, as social commentators, politicians and public leaders struggled to make sense of the sudden suffering and death visited upon New York, San Francisco and soon countless other communities across America, they turned to the metaphors and images borne out of and animated by events of the past. And the past to which they turned was a distant, discontinuous one that reached beyond recent memory and experience. This trend was perhaps best exemplified by journalists’ and commentators’ frequent use of the term “plague” to describe early cases of AIDS. By most measures, the term was little more than an historical artifact, exhumed from time to time by newspaper columnists intent on regaling their readers with harrowing accounts of the black death, cholera, and similar monsters of the past. During the 1980s and 1990s, however, the term enjoyed a resurgence in the popular press. In 1985, journalist David Black published “The Plague Years,” a highly popular, two-part article in *Rolling Stone*, the title of which summoned Daniel Defoe’s 1722 account of the bubonic
Columnists writing in the *New York Times* openly discussed “the plague of AIDS,” wondering whether anything would be capable of stopping it. They contemplated the existence of a “pre-plague” and “post-plague” gay culture, and prophesized a “plague awaiting” the developing world. Furthermore, the trend was by no means limited to New York papers. The term “gay plague,” in fact, was used to describe AIDS in periodicals as far ranging as the *Washington Post*, *Minneapolis Star Tribune*, *Charlotte Observer*, *The Irish Times*, *The Times of India*, Toronto’s *Globe and Mail*, and London’s *Daily Mirror*, *Daily Telegraph*, and *Observer*. Given the ubiquity of the term, it is no wonder that medievalist Steven F. Kruger would lament, “The association of HIV/AIDS with the medieval has been most

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123 The article won the American National Association of Science Writers’ Science-in-Society Award for 1985 and was reissued in a volume published by Picador and Pan Books in 1986. The allusion to the bubonic plague was far more explicit than the title. The article and volume begin with a chapter entitled “Magna mortalatis,” a reference to the term written in 14th Century monastic chronicles to denote interruptions in transcriptions during the years of the bubonic plague. David Black. *The Plague Years: A Chronicle of AIDS, the Epidemic of Our Times* (New York: Simon and Schuster, 1986).


126 Norman Podhoretz, “AIDS Education should be truthful: the disease is a ‘gay plague,’” November 2, 1987, 12A.


persistent in the intractable appellation ‘plague,’ assigned to AIDS even before its current name
had been settled.”

While some authors located AIDS within the narrative of pre-modern disease through
their choice of language, others reinforced this association through the use of images. Consider,
for example, the legacy of editorial cartoonists, who in ways both subtle and direct buttressed the
notion that AIDS was best interpreted as a reconstituted horror of a bygone past. In some cases,
cartoonists yoked AIDS to disease narratives recorded in modern civilization’s origin texts,
summoning fears of biblical scourges from Christian eschatology. This particular brand of
symbolism is on bold display in early cartoons published in Los Angeles and London
personifying AIDS as the four horsemen of the apocalypse. A San Diego cartoon depicted a
student with AIDS shunned by his peers, all of whom wore masks and bore crosses like those
used in the 17th Century to ward off bubonic plague. And a rather stunning cartoon published in
London’s The Daily Mirror depicted a robed figure – presumably God or Moses – descending
upon an orgy of naked men and women with a stone tablet emblazoned with the term “AIDS.”
What’s more, these images cut across social and cultural borders, appearing in countries with
vastly different experiences of AIDS. Consider, for example, the image of the scythe-wielding

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134 Steven F. Kruger, “Medieval/Postmodern: HIV/AIDS and the Temporality of Crisis,” in Queering the Middle Ages, ed. Glenn Burger and Steven F. Kruger (Minneapolis: University of Minnesota Press, 2001), 260; Of note, the term “plague” maintains a fairly narrow, historically rooted connotation, unlike words such as “epidemic,” which as Charles Rosenberg has argued once denoted discrete episodes of disease but through the 20th Century had come to take on increasingly diffuse meanings. Witness, for example, discussions of the epidemics of alcoholism, drug addiction, and automobile accidents. Charles Rosenberg, Explaining Epidemics, 278–279.
136 The cartoons cited here were published during the 1980s and early 1990s. See Forman and Horsey, Cartooning AIDS around the World.
skeleton harassing the sick. Once popularly associated with US and British depictions of cholera, by the 1990s it appeared as part of the AIDS canon in cities as wide ranging as Cincinnati, Ohio; Dallas, Texas; Miami, Florida; Minneapolis, Minnesota; Victoria, Canada; Madrid, Spain; Bonn, Germany; Zagreb, Croatia; San Pedro, Honduras; Lagos, Nigeria; Amsterdam in the Netherlands and Manila in the Philippines.  

(See images at end of chapter).

At roughly the same time journalists and cartoonists analogized AIDS with historical and biblical scourges, conservative social critics deepened the association by explicitly and disdainfully interpreting the condition as an expression of divine retribution. Using the pain and suffering wrought by the disease as an opportunity to rail against the perceived excesses of the sexual revolution, conservatives rained fire and brimstone on the homosexual lifestyle. Ed Rowe, who had directed Anita Bryant’s ministries in the late 1970s, famously condemned gays as, “anti-God, anti-Christ, anti-Bible, anti-moral, anti-life, anti-constitutional and anti-American.” Meanwhile, conservative pastors such as Jerry Falwell maintained that AIDS was “God’s punishment…for the society that tolerates homosexuals.” These attacks, borne out of what Robert Fogel terms the “Fourth Great Awakening” of religiosity in America, yoked AIDS to 3,000 year old biblical narratives while simultaneously subverting a biomedical discourse that

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137 Ibid.
140 Fogel’s description of a Fourth Great Awakening, modeled on the first three awakenings recognized by historians as taking place throughout colonial and US history, is not universally accepted by scholars. However, I believe it is useful in our consideration of the rise of evangelical thought during the 1980s and 1990s in response to AIDS. See Robert William Fogel, *The Fourth Great Awakening and the Future of Egalitarianism* (Chicago: University of Chicago Press, 2002).
left little room for spontaneous acts of celestial wrath. For many public health professionals, religious leaders’ efforts to present AIDS as an extension of ancient scourges meted out by a vengeful god crossed a line. Even Surgeon General C. Everett Koop, credited by some conservatives as a key force in the crystallization of the American evangelical movement, challenged the association of AIDS with the maligned and feared plagues of the distant past, arguing, “Not since the days when people did not understand leprosy and put its victims in chains have we seen such outrageous behavior.”

As journalists, religious leaders and others linked AIDS to historic plagues spanning virtually all of recorded history, and counseled the resurrection of 19th Century public health measures to combat the spread of new cases, historians went to work explaining the origins of these measures. It was in this tradition, for example, that Allan Brandt penned an early article – “AIDS in Historical Perspective: Four Lessons from the History of Sexually Transmitted Disease” – wherein he conveyed the nuanced histories of late 19th and early 20th Century venereal disease campaigns. The same year, historians Elizabeth Fee and Daniel Fox released their own edited volume, *AIDS: The Burdens of History*, in which they too explored the

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143 In the article, Koop was responding specifically to the effects of stigma and prejudice upon the lives of children with AIDS. “Ray Boys’ Treatment Criticized,” *Ocala Star Banner* (Ocala, FL), September 13, 1987; Larry Kramer also compared the public response to AIDS to medieval era abuses: “And, once in [hospitals], patients are now more and more being treated like lepers as hospital staffs become increasingly worried that AIDS is infectious.” See Larry Kramer, “1,112 and Counting,” *New York Native* 59, March 14–27, 1983.
historical origin of infectious disease policies. While these authors set out with the noblest of intentions – to demonstrate the need for nuanced historical analysis that eschewed tempting interpretations born out of presentism or whiggery – in many ways they too contributed to the notion that AIDS could and should be interpreted as a modern expression of a very old phenomenon. The epigraph of *AIDS: The Burdens of History*, which immediately follows a 1930s era syphilis awareness poster depicting a couple menaced by the silhouette of a skull, cogently conveys this sentiment. Quoting the admonition of an early 20th Century physician responding to cases of polio, the editors avow, “We have learned very little that is new about the disease, but much that is old about ourselves.” Indeed, given the extraordinary degree to which actors from across multiple institutions and professions located AIDS within pre-twentieth century plague narratives, we might regard this historical framing as the “sanctioned history” of AIDS, a mapping of the modern disease that was at once descriptive and normative, a guidebook for not only identifying how one could conceive of AIDS, but how one should as well.

The narrative constituted by this historical framing is indeed fascinating. Invocations of biblical rage and retribution from religious firebrands coincided with the widespread

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146 Further evidence for this argument exists in Fee and Fox’s later admission that in locating AIDS within infectious disease narratives, they ignored structural issues of great significance to the lived experience of individuals with AIDS. These became apparent as AIDS transformed into a chronic disease. “Because the history of visitations of plagues was the only history that appeared relevant to the new epidemic, most people ignored the alternative historical models that were available. For example, most of those who used historical analogies avoided the most pertinent aspects of the histories of venereal disease and tuberculosis, emphasizing issues of surveillance and personal control policy and ignoring the problems of housing, long-term care, public education, and the financing of palliative care for people suffering from chronic infections.” Elizabeth Fee and Daniel Fox, “Introduction: The Contemporary Historiography of AIDS,” in *AIDS: The Making of a Chronic Disease*, ed. Elizabeth Fee and Daniel Fox (Berkeley: University of California Press, 1991), 3-4.
appropriation of the language and imagery of historic plagues. As the 1980s progressed, we find scholars framing AIDS in terms of past responses to turn-of-the-century epidemics (e.g. cholera, syphilis), virtually all of which had been conquered through the interventions of modern biomedicine. Witness that, in moving from pre-modern eschatology through 19th Century plague narratives and then the clinical and public health lessons of the early 20th Century, the sanctioned historical framing of AIDS recapitulated earlier histories of disease leading up to the golden era of biomedicine. In the very language individuals used to describe AIDS, in the narratives they appropriated, in the metaphors they invoked, they recreated the rough equivalent of a biomedical passion play, culminating in the miraculous taming of AIDS through the identification of its microbial cause and subjugation to the instruments of clinical medicine. So powerful was the seductiveness of this progress narrative that, for some, society needed only identify the germ cause of AIDS and its vanquishment was but a fait accompli.\textsuperscript{147} Indeed, Margaret Heckler, Secretary of Health and Human Services under Ronald Reagan, fell victim to such reasoning. In 1984, with the announcement of the discovery of HTLV–III/LAV (later renamed HIV) as the cause of AIDS, Heckler predicted the testing of a vaccine within two years, triumphantly declaring, “Yet another terrible disease is about to yield to patience, persistence and outright genius.”\textsuperscript{148}

But alas, things were not as they seemed, for HIV would soon prove itself impervious to the best efforts of physicians and researchers. The biomedical passion play mimitically recycled through the narrative framings of AIDS failed to conclude with the majestic taming of the germ.

\textsuperscript{147} Here we find an example of Michel Foucault’s famous injunction, “Knowledge linked to power, not only assumes the authority of ‘the truth’ but has the power to make itself true.” Michel Foucault, \textit{Discipline and Punish} (London: Tavistock, 1977), 27.

\textsuperscript{148} Heckler’s announcement was widely reported and discussed by scholars. See, for example, Gerald N. Callahan, \textit{Infection: the Uninvited Universe} (New York: St. Martin’s Press, 2006), 222.
The vaccine Heckler had pontificated failed to materialize, even with the intercession of Jonas Salk, biomedical royalty who had helped to codify and ennoble the biomedical passion play in an earlier era. For half a decade, through the late 1980s, the mills of biomedical innovation seemed to grind to a halt. Fields lay fallow due either to a lack of material resources or, far more frightening to consider, a drought of ingenuity. What’s more, even those tools remaining at our disposal – the traditional measures of public health – had lost their purchase among many segments of the public. As Ronald Bayer has argued, society had entered an era of AIDS exceptionalism, when the approaches and strategies employed in the past – name reporting, routine testing, partner notification and selective use of quarantine – no longer seemed relevant or appropriate for combatting AIDS. Indeed, in an era marked by the rise of biomedical ethics, informed consent, the sanctity of privacy and the language of civil rights, traditional public health measures – and by extension, the passion play itself – began to appear anachronistic.

And in this perceived incongruity, this anachronistic erratum, we begin to capture the critically important distinction between the two questions that have served to organize the opening of this chapter. Having identified the historical narratives through which AIDS was explained by journalists, cartoonists, religious leaders, and scholars, we addressed the first of these questions. We now turn our attention to the second, far more nebulous, query, asking what these narratives meant for individuals living with and responding to AIDS in the 1980s and

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149 As one journalist wrote in 1992, “Because of Salk's reputation, people with HIV clamored for his vaccine when it was just a rumor. Once it became available, they scrambled to be included in the nine clinical trials offered nation-wide, including the one here directed by Dr. John Turner of Graduate Hospital.” Mary Flannery, “From The Man Who Beat Polio: Jonas Salk's Aids Vaccine is being Tested Here,” Philadelphia Daily News, July 8, 1992.

1990s. How, indeed, was the light of historical plague refracted and bent as it passed through lenses hewn and carved by personal experience, memories and interpretations of the past?\textsuperscript{151}

Unsanctioned Interpretations: The Meanings of History

For centuries, poets have reminded us of the kaleidoscopic nature of the past, how it changes and morphs, its meanings and lessons obfuscated by the perspectives, opinions, experiences and memories of the beholder. As they have elegantly articulated, yesterday does not sit idle and inert, waiting to be mined by the historians, journalists, policy analysts or leaders of the present. It is instead mercurial and protean, transforming based upon the historically and culturally mediated experiences and perspectives of the beholder. William Wordsworth captured the sentiment nicely when, at the dawn of the Victorian Era, he argued that those wishing to ponder the noble promises of the past toiled in vain, for they would ever find themselves thwarted by “impediments from day to day renewed.”\textsuperscript{152} Nearly a century and a half later, a writer who failed to achieve Wordsworth’s immortality expressed a similar sentiment when he wrote, “‘So my past is homeless now too,’ I thought, / And slammed the window on the glimpse I’d caught.” A young Charles Barber penned these words while attending an AIDS support group

\textsuperscript{151} As Caroline Hannaway has observed, "We also have to consider the general wisdom of how much the study of past epidemics helps in considering AIDS. Has society changed in ways that are going to make such a discussion irrelevant? We historians do not want to think that this is the case, but we should consider the questions." Caroline Hannaway, “Commentary on Workshop 1: Before AIDS: an Overview of Previous US Epidemics to Clarify the Administrative, Scientific, and Social Responses to Mass Disease,” in \textit{AIDS and the Historian}, Proceedings of a Conference at the National Institutes of Health, March 20-21, 1989. NIH Publication No. 91–1584. March 1991, 30.

\textsuperscript{152} The verse reads, “…if my mind, / Remembering the bold promise of the past, / Would gladly grapple with some noble theme, / Vain is her wish; where'er she turns she finds / Impediments from day to day renewed.” From \textit{The Prelude}, a piece Wordsworth began in 1798 and published shortly after his death in 1850.
in the early 1980s. Within three years of having written them, on the anniversary of our nation’s birth, he would die of AIDS related complications.

Armed with Barber’s chilling conjuration of a history bereft of meaning, let us turn our attention once more to AIDS exceptionalism. Through the earliest days of the AIDS pandemic, both scholarly and lay discussions of the disease freely and openly compared it to the plagues and pestilences of the distant past. Be it in the articles gracing the nation’s top newspapers, the cartoons enlivening their pages, the fiery rhetoric issuing forth from the pulpits of the silent majority, or the reasoned analyses filling scholarly journals, society demonstrated a ready willingness to disinter the plagues of the past in an effort to graft meaning onto a very new disease. And yet despite the volume of this historical association, the public proved unwilling to consummate the allusion by answering AIDS using the policies and approaches it had successfully employed in response to these past plagues. Indeed, we might say that mainstream society’s response to AIDS was exceptional not just because it differed from responses to prior infectious diseases, but because it differed from these responses even as the sanctioned history of AIDS sensationally and dramatically described and constructed it in relation to these diseases.

Perhaps the most popular explanation for AIDS exceptionalism holds that the public’s response to AIDS differed from historic approaches to infectious disease largely because of fundamental changes in social conceptualizations of individual rights through the mid-to-late 20th Century. ¹⁵³ This approach, rigorously and persuasively explicated in the literature, is quite popular as it allows scholars to wed analyses of AIDS with the historical rise of gay rights and

AIDS activist groups such as ACT UP. While this explanation warrants serious consideration, we must remain cognizant of its unspoken allure. For in explaining society’s failure to enforce traditional public health measures to combat AIDS, the narrative implicitly justifies avoidable suffering and death as a byproduct of our nation’s progressive embrace of individual rights. This broad historiographic approach, which explains tragedy as a repercussion of social development, shares many characteristics of a progress narrative. Indeed, we might consider it a type of conciliatory progress narrative in that it explains tragedy as the cost of progress. Historians have invoked versions of this narrative to explain resistance to contagionist responses to disease – especially quarantine – dating at least as far back as the Industrial Period.

My aim here is not to disparage the well accepted interpretation of AIDS exceptionalism, but rather to argue that its implicit appeal served to mask other explanations for the changing meaning of historical experience in the early years of the AIDS epidemic. It is undeniably true that individuals interpreted AIDS from a perspective shaped by changing notions of individual rights and liberties. However, we must also consider the possibility that exceptionalism resulted from fundamental transformations in the social construction of disease itself. Indeed, if popular

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155 We find similar invocations of conciliatory progress narratives in arguments holding that decreased surveillance and security monitoring in the modern era, which theoretically places the public at a greater risk, is justified due to society’s recognition of free speech, privacy, etc. as inviolable rights.
156 Sylvia Tesh has argued that anticontagionists “called quarantines ineffective and charged that closing ports was mere mindless bureaucracy. In sum, they argued against contagionism on the grounds that it was inconsistent with the ideals of progress, individualism, and freedom that guided the Industrial Revolution.” Tesh refers to and relies upon Acknerchet’s well know research on the topic. See Sylvia Tesh, Hidden Arguments: Political Ideology and Disease Prevention Policy (New Brunswick: Rutgers, 1996), 16.
conceptualizations of disease and health had changed significantly through the early-to-mid 20th Century, then invocations of 19th Century public health measures would lack appeal. The past, in effect, would be rendered homeless.

For the remainder of this chapter, I examine significant changes in the social construction of disease and health witnessed in the years preceding AIDS. As I shall argue, through the 1950s, 1960s and 1970s, individuals discussed and embraced models of disease etiology that challenged the reductionism that had attended biomedicine’s ascent during the golden era of infectious disease therapeutics. Inspired by broad changes in the national health burden and the rise of widespread, penetrating social activism criticizing fundamental social arrangements, this discursive tradition sought to redefine health and disease as functions of irreducible interrelations between physical, emotional, social and environmental spheres. I furthermore argue that these perspectives persisted through the propagation of sanctioned AIDS histories, challenging dominant AIDS narratives and, by extension, efforts to respond to and treat early cases of AIDS.

A Changing Past: Transformations in Constructions of Disease and Health

“[W]e are, in a sense, at the end of the great era of the battle against infectious disease. We are entering the great era of cold war against chronic diseases for which we do not have biologic cures.”

– New York City Department of Health, 1961

To understand the beliefs, perspectives and aims of unorthodox activists responding to AIDS in 1980s and 1990s era New York City, it is crucially important that we examine the transformations witnessed in the social discourse surrounding health in the first half of the twentieth century. Indeed, as Jeff Goldsmith has argued, this period ushered in a significant

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transition, which he refers to as a paradigm shift, in society’s response to disease. By the 
1920s, analysts noted that cardiovascular disease and cancer had supplanted the contagious 
illnesses of the previous generation as the leading cause of death in the US. As the century 
progressed, each decade seemed to reinforce the notion that, while infectious diseases remained 
an issue in various segments of the population, their significance to the nation’s overall health 
and well being paled in comparison to chronic conditions. The antibiotic revolution of the 
1930s seemed to sound the death knell for the once formidable germ. In the 1950s, the 
National Tuberculosis Association had become the National Lung Association, and by the 1970s, 
the nation’s Communicable Disease Center, which had played an important role in the national 
response to malaria, venereal disease and tuberculosis, was rechristened the Center for Disease 

158 Jeff Goldsmith, “The Paradigm Shift: Transforming from an Acute to Chronic Care Model,” 
Decisions in Imaging Economics (1990). Other authors would use similar language. See, for 
example, Robert E. McKeown, “The Epidemiologic Transition: Changing Patterns of Mortality 
19S–26S; Peter Piot and Shah Ebrahim, “Prevention and Control of Chronic Diseases,” British 

159 Nancy Tomes, “Epidemic Entertainments: Disease and Popular Culture in Early-Twentieth-
Century America,” American Literary History 14, no. 4 (2002): 631; Not even the memory of the 
great influenza pandemic of 1918-1920 seemed capable of altering this transition, a point 
historian Alfred Crosby underscores in deeming the outbreak “America’s forgotten pandemic,” 
See Alfred Crosby, America’s Forgotten Pandemic: The Influenza of 1918 (Cambridge: 
Cambridge University Press, 2003). Tomes disagrees with Crosby’s larger argument but 
concedes that anxieties persisted in “muted and indirect form(s).” See “Epidemic 
Entertainments,” 649-650 n10.

160 It is worth noting that the term “chronic disease” is used in many ways, to refer to many 
different things. We lack a clear understanding of the changing meanings of chronic disease 
through time. Whereas in the past, some authors would define chronic diseases in terms of the 
amount of time they developed in individuals, others referred to as chronic all diseases that were 
not infectious. More recently, many researchers discuss chronic infectious diseases – AIDS as it 
appears in much of the developed world is a prime example. Others speak of “epidemics of 
chronic disease.” Here, in my use of the term, I refer primarily to diseases largely considered 
non-infectious, such as cancer and heart disease.

161 See Nancy Tomes, Gospel of the Germ: Men, Women and the Microbe in American Life 
(Cambridge: Harvard University Press, 1999), 252-255.
Control (CDC) to reflect a mission expanded beyond the parameters of infectious disease. At roughly the same time, Richard Nixon signed the National Cancer Act, viewed by many as initiating the war on cancer, with funding for cancer research increasing from $377 million to $815 million between 1972 and 1976. And in 1979, just months before the CDC’s Morbidity and Mortality Report would disseminate word of a strange new disease visited upon the nation’s cities, researchers who had assembled in Washington for a conference dedicated to developing disease strategies for the 1980s focused the vast majority of their attention on chronic conditions. In fact, the conference organizers made quite explicit their hope that those assembled would successfully replicate the ingenuity of the “glorious age” of infectious disease as they tackled the chronic conditions that would surely define the decade.

And what of the lay public? May we assume that as those located in the nation’s intellectual and political nexus focused their attention on chronic conditions, the same trend was exhibited in discussions had by families across the dining room table? To answer this question, we may turn to the few but informative public opinion polls conducted in the 1960s and 1970s, which offer a fleeting glimpse into the sentiments and concerns of everyday Americans. When we do, we find indirect evidence supporting a transition in lay focus to chronic diseases. In 1973, for example, G. Ray Funkhouser reported in Public Opinion Quarterly that of the top ten issues that dominated the concerns of Americans, nearly half were related in some way, shape or form to chronic disease. Preliminary evidence from newspaper sources further suggests that

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163 Ibid. 65–66.
165 These issues include environmental pollution, smoking, drug use and poverty. The other issues included the Vietnam War, race relations, campus unrest and inflation. G. Ray
journalistic coverage of health related issues may have changed in important ways through the 20th Century. In news outlets such as the New York Times, Los Angeles Times, Amsterdam News and Time Magazine, it appears that coverage of chronic conditions such as cancer increased through the 1950s, surpassing articles explicitly examining infectious disease.

Thus by the 1970s, by both professional and popular measures, national discourse surrounding disease had transformed, with discussions of chronic maladies supplanting earlier campaigns aimed at eradicating the pernicious and pestiferous germ. We might thus conclude that Goldsmith’s paradigm shift construct reasonably captures changes in both top-down political and intellectual discourse and bottom-up social discourse. However, even as we verify Goldsmith’s greater argument, we would do well to question the particular metaphor he invokes.

For in adopting the term “shift,” he suggests that society had moved from one system of conceptualizing disease (the infectious model) to another (the chronic) much like one would shift gears in a car. Having vanquished the infectious maladies of the past, he suggests, society transitioned to a chronic disease model better suited for addressing the infirmities of old age.

This metaphor is tempting indeed, for it suggests that society is capable of transitioning between conceptual models when the circumstances demand it, just as one shifts an automobile to a lower gear when he or she encounters a hill. However, it is woefully simplistic, for disease


While it is beyond the scope of this analysis, one might argue that this transformation in professional and public discourse in part led society to almost universally overlook infectious epidemics of the 1970s, such as the burden presented by hepatitis. To this day, we lack a nuanced or complete understanding of the history of hepatitis in the US.

Goldsmith argues, “Society has been perversely rewarded for its defeat of the past’s most threatening diseases. We added almost 30 years to life expectancy. That’s the good news. The bad news is that we now die of even more horrible illnesses later in our lives. The eradication of infectious disease made it possible for us to die from heart disease, cancer and Alzheimer's.” Goldsmith “Paradigm Shift,” 13.
paradigms are not instruments we as a society exploit when the terrain becomes rough. They are historically contingent, culturally constructed languages for thinking about, ordering, discussing and responding to the physical world. And while they change over time, they do so for complex reasons that take into account myriad factors beyond a society’s epidemiological profile. They are intimately bound together with larger issues touching upon the distribution of power in society, the relationship between the individual and his environment, and the fundamental allocation of burdens and benefits in modern industrial economies. Viewed in this light, it is more appropriate to say that over the course of the mid-to-late 20th Century, society developed an approach for conceiving of and discussing disease that harmonized with changing discourses regarding larger political, social and economic issues.

That we would witness a fundamental change in the language used for defining and responding to disease in post World War II US society is perhaps unsurprising, for the postwar decades brought with them profound apprehension regarding fundamental social arrangements. Feminist critiques of systems and practices inimical to the health of women harmonized with highly publicized exposes of the dangers lurking in the interstices of a society that had become overridden with industrial pollution, occupational abuses and commercialized negligence wrought through an increasingly impersonal consumer economy. The 1960s and 1970s, referred to by many as a period of explicit radicalism and dissidence, witnessed sustained criticism of the perceived excesses and inequalities of American foreign and domestic policies. In 1962, Rachel Carson’s widely influential *Silent Spring* exposed the latent toxicities of pesticides and other chemicals used to “enhance” food production in the industrial world. The same year, Michael Harrington’s *The Other America* exposed the sweeping and tragic effects of poverty throughout the nation. Debates surrounding the detrimental effects of industrial excess and structural
discrimination continued through the 1970s, with the publication of *Our Bodies, Ourselves* in 1970-1971 (re-released in 1973, 1976 and 1979) and extensive reporting on environmental disasters such as the Love Canal tragedy of 1978.

During this period, many well-respected authors who challenged the continued relevance of infectious disease and plague narratives premised their arguments upon a deep-seated apprehension with these greater social and environmental issues. One of the most vocal and influential authors writing in this traditional was the Frenchman René Dubos, a celebrated microbiologist who somewhat ironically had found fame in the discovery of gramicidin, the first clinically useful antibiotic. While Dubos cut his teeth investigating cures for the germ, he would go on to spend much of his life arguing that man’s problems were of an order and scale far greater than the domain of the bacillus. For Dubos, one could not simply magnify and resolve health and disease to its base cellular or molecular dimensions, for it flowed from the deep and complex relationship between the individual and his environment. It was borne in the social and environmental arrangements that many individuals uncritically accepted as the necessary conditions of modern advancement. If Thomas Hobbes had argued that man required society to liberate him from a life that was “solitary, poor, nasty, brutish, and short,” for Dubos he needed protection from a modern structure which entrapped him in a world of “noise, dirt, ugliness, and 

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168 These years do not include French, Danish, Italian, Japanese and British translations and publications of the work.
169 It is a curious irony that in the 1960s and 1970s, perhaps the fiercest proponents of the modern manifestation of Osler’s soil metaphor was one of the 20th Century’s most esteemed soil microbiologist and fathers of the antibiotic revolution. Gramicidin, too toxic for intravenous injection, was used as a topical antibiotic for treating wounds and ulcers in World War II. Some have credited its development with revitalizing interest in antibiotics a decade after the uncelebrated discovery of penicillin. For a discussion of Dubos’s legacy, see Heather L. Van Epps, “René Dubos: Unearthing Antibiotics,” *Journal of Experimental Medicine* 203, no. 3 (2006): 259, and Carol L. Moberg, “Friend of the Good Earth: René Dubos (1901-1982),” in *Launching the Antibiotic Era*, ed. Carol L. Moberg and Zanvil A. Cohen (New York: Rockefeller University Press, 1990).
From 1968 through his death in 1982, Dubos would argue that disease resulted from the untold stresses posed by modern industrialization, and the codification of the modern myth which held that “progress means introducing into our lives everything we know how to produce.”

Dubos did more than merely indict social arrangements permitting inequity and disease. He also criticized a scientific community that, in his view, had failed to adequately address the problem. Modern biomedicine had become fixated on what he termed “the doctrine of specific etiology,” causing researchers to neglect to consider the interactions between man and his larger environment. So enraged was Dubos at the failures of his professional colleagues to address the complex relationship between man and his environment that he began his 1968 Pulitzer Prize winning treatise So Human an Animal by asserting his “indignation at the failure of the scientific community to organize a systematic effort against the desecration of life and nature.” Throughout his work, Dubos – a self-described humanist who had indeed coined the term “humanistic biology” – echoed the views of many who argued that the reductionism of Western science was poorly suited to address the diseases of modern life.

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171 Dubos railed against the constant exposure of children to “pollutants, noise, ugliness and garbage in the streets,” arguing, “This constant exposure conditions children to accept public squalor as the normal state of affairs and thereby handicaps them mentally at the beginning of their lives.” Paul L. Montgomery, “René Dubos, Scientist and Writer, Dead,” New York Times, February 21, 1982.
172 In his 1973 essay, “On the Limitations of Modern Medicine,” John Powles echoes many of Dubos’s ideas, combining them with evolutionary arguments to maintain that degenerative diseases such as heart disease and hypertension were disease of maladaptation arising “because our earlier evolution has left us genetically unsuited for life in an industrialized society.” See John Powles, “On the Limitations of Modern Medicine,” Science, Medicine and Man. 1, no. 1 (1973): 8.
174 Dubos, So Human an Animal.
Some authors, such as historian Charles Rosenberg, would note that the reductionist turn in biomedicine began with the popularization of specificity – the notion that diseases were properly thought of as entities existing outside the unique manifestations of illness in a given person. But it was the adoption of germ theory, Rosenberg argued, that provided the “powerful argument for a reductionist, mechanism-oriented way of thinking about the body and its felt malfunctions.” While this reductionist approach would make possible extraordinary advances in some areas of medicine, including for example drug development and organ transplantation, we nonetheless identify a powerful and trenchant narrative that criticized its side effects. Historian Vijay Kumar Yadavendu gave voice to these deeper concerns with the promise and peril of the germ theory of disease, writing,

“The process of individuation, biologism and reductionism started with germ theory. Through the shifts in epidemiology, the population dimension was reduced first to the individual dimension and finally to the molecular dimension. This effectively obviated the dynamics of interaction between the individual and his/her environment...In the final victory of molecular medicine over public health, the individual is completely robbed of his/her collective identity.”

Thus, to loosely appropriate a term popularized by Michel Foucault, in the postwar period, critics argued that the clinical gaze was both dehumanizing and myopic, reducing

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individuals to lifeless physiochemical reactions while consistently and systematically failing to consider their dynamic relationship with their environment. Many individuals wrote of biomedicine’s myopia, arguing that its practices ignored the lessons laid bare by recent history. And as biomedicine suffered, they argued, so too did its patients. In 1954, example, Ian Galdston, a well-respected spokesman for the New York Academy of Medicine, published an edited volume entitled *Beyond the Germ Theory*, wherein he and eight other authors argued that traditional infectious disease models were insufficient for responding to the era’s chronic diseases. In their place, Galdston advocated etiological models prioritizing the importance of environmental stress, nutrition, and emotions. In 1978, a more unapologetically critical John Ehrenreich lambasted the funds thrown at the stewards of Western biomedicine in the name of the nation’s war on cancer. In the hands of mainstream physicians and researchers, Ehrenreich maintained that society’s investment amounted to little more than “devastating courses of radiation or drug therapy or debilitating radical surgery” despite the fact that the vast majority of cancers were caused by avoidable environmental hazards such as pollution, smoking, food additives, pesticides and radiation. For Ehrenreich, the unchecked pursuit of technology had led medicine down a path that promised little in the way of succor or amelioration of disease. “Scientific medicine,” he wrote, “for all its insights into the molecular mechanisms of carcinogenesis, has simply become unhinged from any fundamentally effective approach to the

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180 Simmering beneath the surface in Ehrenreich’s analysis was a powerful postwar apprehension regarding the unchecked powers of science in medicine, an apprehension that, as sociologist M. L. Tina Stevens has argued, helped motivate the birth of American bioethics. See M. L. Tina Stevens, *Bioethics in America: Origins and Cultural Politics* (Baltimore: Johns Hopkins University Press, 2000), 9.
disease.” Furthermore, many would question whether biomedicine had ever contributed meaningfully to decreases in mortality rates, citing the much-publicized theories of Thomas McKeown. For McKeown and his enthusiasts, this credit went instead to changes in broad standards of living witnessed through the industrial age – an interpretation that complemented the environmental and structural focus we find in the writings of Dubos and Ehrenreich.182

Many students of history will no doubt object to the aforementioned authors’ critiques of germ theory, arguing that it is woefully simplistic to pit germ theory against social and environmental campaigns to address disease. For, as Nancy Tomes has argued, the germ theory in fact gave rise to numerous macro level social reforms in domains that intersected virtually all aspects of life in the late 19th Century, from diet, hygiene and dress, to home life, leisure and courting.183 Michel Foucault made similar arguments twenty-five years earlier when he famously argued that medicine had amassed immense power in its efforts to oversee the air, water, construction and sewage of 18th Century towns.184 While these points are valid, I must stress that

182 John Ehrenreich in fact invoked McKeown’s thesis, arguing that it had been explicated earlier by, of all people, René Dubos! Others have noted that Dubos maintained positions remarkably similar to McKeown’s, albeit without the wealth of demographic data McKeown would bring to the table. See, for example, Peter Conrad, “The Social Production of Disease and Illness,” in The Sociology of Health and Illness, Critical Perspectives, ed. Peter Conrad (Waltham, MA: Worth Publishers, 2009), 6; Later, scholars would highlight flaws in McKeown’s reasoning. See, for example, James Colgrove, “The McKeown Thesis: A Historical Controversy and Its Enduring Influence,” American Journal of Public Health 92, no. 5 (2002): 725-729.
183 Tomes. Gospel of Germs.
184 Foucault addresses this topic in the first of three lectures he gave in October 1974 at the Institute of Social Medicine, Biomedical Center, State University of Rio de Janeiro, Brazil. Later compiled as Michel Foucault, “The Crisis of Medicine or the Crisis of Antimedicine?” trans. Edgar C Knowlton, Jr., Foucault Studies 1 (2004): 5-19; Furthermore, as historians such as Paul Starr have maintained, students of public health had for generations noted the significance of environmental causes of disease. As Starr argued, “Student of public health have long observed, without anyone’s paying much attention, that the effect of environment and behavior on the health of populations is much greater than that of medical care. Suddenly this point is being
my aim in this component of my analysis is to highlight contestations between orthodox biomedical theory and the public perception of the causes of disease. Furthermore, in the case of Tomes’s contributions to the history of medicine, we would do well to heed her greater argument, which is that the gospel of the germ remained ascendant until the close of the first quarter of the 20th Century. At that time, a “new public health” rejected broad Progressive Era reforms in favor of a professionalized health response located in and governed by researchers ensconced in increasingly technologized laboratories. Even if public health professionals had once instrumentalized the germ theory through broad social and environmental campaigns, by the 1920s it had become associated with a scientific discipline that would delve deeply into molecular explanations of disease.

As I have argued, far from a mechanistic shift in paradigms, society’s transition from germ theory based infectious disease models to social and environmentally mediated chronic disease models was itself an expression of more widespread critiques of underlying social, political and economic arrangements. The germ theory, in short, was becoming a creature bound by and trapped within a past rendered anachronistic through the passage of time. During the same years when Robert Koch, Louis Pasteur and their associates aggressively sought out, investigated, chronicled and conquered the domain of the germ, nations such as the United States and Great Britain openly and aggressively pursued imperialist agendas. However, by the late 20th Century, as the New York City Department of Health rather elegiacally declared, society had reached the “end of the battle against infectious disease” and entered the “great era of cold

treated, in influential circles, as if it were a major discovery.” Paul Starr, “The Politics of Therapeutic Nihilism,” Hastings Center Report 6, no. 5 (1976), 24.

185 Tomes, Gospel of the Germ, 241.

186 That germ models of disease are laced with militaristic imagery – a phenomenon bemoaned by Susan Sontag – is no doubt a testament to this imperial legacy.
war against chronic disease.” The Department’s word choice is telling, for in an environment of simmering hostility between former allies, of seemingly intractable conflict incurable through military intervention, the germ theory had lost its luster. The antiauthoritarianism of the 1960s and 1970s, expressed through the social activism movements discussed above and fomented by widespread dissatisfaction with the United States’ failed foray in the Vietnam War, would merely buttress growing fears that the policies and practices effected in an effort to make the nation stronger were in fact causing irreparable harm to its people.\textsuperscript{187}

However, even if we grant the myriad factors that attended the rise of a discursive tradition prioritizing social and environmental models for conceiving of health and disease, we have yet to identify the precise ways in which individuals operationalized these models. What strategies for decreasing morbidity and mortality were to be gleaned from the soaring idealism of René Dubos or the acerbic criticisms of John Ehrenreich? How precisely was society to address chronic disease if it did indeed spring from the relationship between man and his increasingly complex environment? Several avenues of intervention, ranging from the radical to the reactionary, presented themselves. The first counseled an out-and-out, fundamental restructuring of social arrangements to address the inimical byproducts of industrialization, urbanization and market capitalism. However, while we find several significant efforts to effect structural social

\textsuperscript{187} In the opening to a 1974 volume, Philip R. Lee and Milton Silverman would write, “In their awesome power, modern drugs may be likened to nuclear weapons. Their discovery and application marks one of the most exciting chapters in the history of medicine.” See Philip R. Lee and Milton Silverman. *Pills Profits and Politics* (Berkeley: University of California Press, 1974), xiii; For some, science was in fact to blame for global unrest. Charles Rosenberg elegantly expressed this point in the preface to a 1997 volume, noting that, “[I]f the presumed value-free rationality of science could help justify the West’s moral superiority, then opposition to the Cold War implied a willingness to question the authority and social impact of science and the scientific community.” Charles Rosenberg, *No Other Gods: On Science and American Social Thought* (Baltimore: Johns Hopkins University Press, 1997), xii. Rosenberg also cites David A. Hollinger, “Science as Weapon in *Kulturkampfe* in the United States during and after World War II,” *Isis* 86, no. 3 (1995): 440-54.
change through the 1960s – consider, for example, Lyndon Johnson’s War on Poverty – it should come as little surprise that neither the US Congress nor the American Medical Association’s House of Delegates exhibited a hankering to codify Ehrenreich’s radical anti-capitalist invective as law. Thus, wide-scale social and environmental reform offered little in the way of practical, actionable policy guidelines. Instead, through the 1960s and 1970s we find the promulgation of less radical strategies for increasing health that would ultimately refract concerns with socially embedded and environmentally mediated sources of illness through the lens of the individual. Two such strategies bear mentioning here, as they would go on to play important roles in the social response to AIDS through the 1980s and 1990s.

The first of these avenues is generally considered the most conservative in scope. For, while it granted that chronic disease developed as a result of individuals’ interactions with their environment, it located the cause of disease in the unhealthy decisions made by individuals in their interaction with that environment. To the chagrin of many authors, this approach to disease largely ignored the deepest structural inequalities and virtually inescapable sources of harm woven through our society and instead focused on the inability of modern man to manage his own behaviors in a culture that provided ample opportunity for excess.\textsuperscript{188} It was perhaps most powerfully and influentially expressed in the writings of John Knowles, President of the

\textsuperscript{188} In many cases, authors such as John Knowles acknowledged the need for structural reform, even as they recommended changes in personal behavior. See John Knowles, “The Responsibility of the Individual,” \textit{Daedalus} 106, no 1 (1977): 58; Others would resist efforts to make structural inequities the responsibility of the individual. In 1981, Sylvia Tesh would argue, “[W]hat does it mean to hold the individual responsible for smoking when the government subsidizes tobacco farming, permits tax deductions for cigarette advertising and fails to use its taxing power as a disincentive to smoking? What does it mean to castigate the individual for poor eating habits when the public is inundated by advertisements for ‘empty-calorie’ fast foods and is reinforced in present patterns of consumption by federal farm policy?” Sylvia Tesh, “Disease Causality and Politics,” \textit{Journal of Health Politics, Policy and Law} 6, no. 3 (1981): 379-380.
Rockefeller Foundation,\textsuperscript{189} in addition to several state sponsored documents, such as Canada’s 1974 “A New Perspective on the Health of Canadians,” commonly referred to as the Lalonde Report, and the United States’ 1979 Surgeon General Report \textit{Healthy People}. For the authors of these documents, society could not depend upon biomedicine to cure the ailments of the modern age, as its allied professions had become hopelessly wed to a paradigm that had long run its course. Knowles himself underscored this point in radioactive rhetoric apropos to the Cold War era:

“The medical profession hitched its wagon to the rising star of science and technology. The results have been spectacular for some individuals in terms of cure, containment of disease, and alleviation of suffering; as spectacular in terms of the horrendous costs compounding now at a rate of 15 per cent annually. And even more spectacular to some because allocation of more and more men and women, money, and machines has affected mortality and morbidity rates only marginally. The problem of diminishing returns, if current trends continue, will look as large and pregnant to the American people in the future as the mushrooming atomic cloud does today.”\textsuperscript{190}

As one can readily appreciate, underpinning Knowle’s arguments – in addition to the arguments made by Canadian Minister Marc Lalonde and US Surgeon General Julius B. Richmond – were deep economic insecurities regarding the growing expense of healthcare in the context of an increasingly specialized clinical model. In many ways, their arguments extended

\textsuperscript{189} Knowles wrote, “The cost of sloth, gluttony, alcoholic intemperance, reckless driving, sexual frenzy, and smoking is now a national, and not an individual, responsibility. This is justified as individual freedom – but one man’s freedom is another man’s shackle in taxes and insurance premiums. I believe the idea of a ‘right’ to health should be replaced by the idea of an individual moral obligation to preserve one’s own health – a public duty if you will.” Knowles, “The Responsibility of the Individual,” 59.

\textsuperscript{190} Ibid. 58.
the notion of the deviant sick role first introduced by Talcott Parsons in 1951. However, where Parsons’s model focused on the responsibility of the sick to become healthy so that they could once more contribute meaningfully to society, Knowles and his enthusiasts generalized these arguments to the preventative domain, demanding that individuals actively work to remain healthy for the same reason. This extension of the Parsonian model neatly exhibits the characteristics of what Michel Foucault termed the somatocracy – “a regime that sees the care of the body, corporal health, the relation between illness and health, etc. as appropriate areas of state intervention.” We recognize the legacy of this expansive approach to health in public health campaigns that convey a moralistic imperative for people to quit smoking, hold the sugar, cut the fat, abstain from sex, etc.

While this first avenue for conceiving of and responding to chronic disease would attract significant support through the late 20th Century, particularly with those allied with the right wing of American politics, it is not the only interpretation we find. One additional avenue in particular bears mention, as it would go on to influence the history of unorthodox AIDS activism in crucially important ways. Like the Knowlesian perspective, this model granted the complex interplay between the individual and his/her environment in mediating disease, it challenged the wisdom of the reductionism of a highly specialized and technologized clinical medicine, and it located responses to illness in the actions of the individual. However, it differed in one very

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191 Foucault argues that prior to the mid-twentieth century, the state’s involvement in protecting health flowed from a desire to maintain strength, the work force, the capacity to produce, etc. As such, the goals of medicine were nationalistic. He argues that after World War II, and specifically with the adoption of the Beveridge Plan, “health was transformed into an object of State concern, not for the benefit of the State, but for the benefit of individuals.” Michel Foucault, “The Crisis of Medicine or the Crisis of Antimedicine?” trans. Edgar C. Knowlton, Jr., William J. King and Clare O’Farrell. The first of three lectures given by Foucault on social medicine in October 1974 at the Institute of Social Medicine, Biomedical Center, of the State University of Rio de Janeiro, Brazil.
important regard. If Knowles’s argument was premised upon a motivating morality, the second model was predicated upon a metaphysical approach that sought to re-mystify the human body, underscoring the complex interrelationships between the physical, emotional, environmental and social spheres of life. As advocates of this re-mystification professed, these interrelationships were extremely difficult, if not impossible, to reduce. For those who advocated a fundamentally irreducible connection between man and his environment, neither the highly technologized gadgetry of a reductionist biomedicine nor a rigid moralism would secure health. To do so, individuals would have to grant the deep connections between these spheres of existence and implement changes in their lives that acknowledged and acted upon these interrelations.

For some readers, bubbling beneath the surface of this talk of irreducible dynamic interrelationships and blurred distinctions between the physical and emotional realms is a term

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192 Here, I borrow Anthony Weston’s discussion of the metaphysical approach of holistic medicine, which he argued sought to remystify medicine (in contrast to self-care, which sought to demystify it). See Weston, “On the Body in Medical Self-Care,” 69-84.

193 Here, I focus on those who maintained that these interrelationships were irreducible. However, those who advocated a less extreme position, holding that such relationships were extremely difficult to parse out, bear mentioning. Throughout the mid-to-late 20th Century, the multicausal model, a paradigm advocating complex interactions between multiple variables, was popularized within biomedicine and espoused by epidemiologists interested in problematizing the notion of causality. Conceived of using webs, networks or configurations in contrast to simple or linear relationships, this model was quite popular in the years preceding AIDS. For a discussion of support for multicausal models, see the writings of George L. Engel, who would gain fame in the development of the biopsychosocial mode. George L. Engel, “A Unified Concept of Health and Disease,” Perspectives in Biology and Medicine 3, no. 4 (1960): 459-485. See also Elliot G. Mishler, “Viewpoint: Critical Perspectives”; Sylvia Tesh additionally provides a useful discussion of the web-like nature of disease causality. She also reminds us that multicausal models were quite old, and in fact appeared in the works of John Stuart Mill, who argued, “The real Cause, is the whole of these antecedents; and we have, philosophically speaking, no right to give the name of cause to one of them exclusive of the others…All the conditions are equally indispensable to the production of the consequent; and the statement of the cause is incomplete, unless in some shape or other we introduce them all.” See Tesh, Hidden Arguments, citing John Stuart Mill, A System of Logic, published in 1843.
frequently associated with leftist radicalism: health holism. This is no mere coincidence, for the second avenue I consider here is in fact compatible with and frequently denoted by a holistic worldview. In fact, each of the authors whose work I discussed above advocated an approach to health and disease broadly consistent with holistic ideologies. Ehrenreich, for example, explicitly endorsed a “reexploration of more holistic approaches to health and disease” aimed at better understanding how the “body, mind, and environment… interact to produce disease or cure it.”

Dubos, meanwhile, imbued holism with a sense of historic legitimacy in his call for more universal models of health and disease:

> “Clinical and epidemiological studies show that the inextricably interrelated body, mind, and environment must be considered together in any medical situation whether it involves a single patient or a whole community. In a long, roundabout way, scientific medicine is thus returning to the Unitarian concept of disease intuitively perceived by the Hippocratic physicians 2,500 years ago.”

At its core, health holism rejects reductionist approaches to health and disease and embraces the complex interrelationships between physical, emotional, social and environmental

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194 See Ehrenreich, “Introduction: The Cultural Crisis,” 14. Ehrenreich furthermore conceived of the holistic health movement as a component of the civil rights movement. See 13; Ehrenreich wrote, “Modern medicine has been largely based on: (a) the doctrine of specific etiology: each disease is caused by a specific cause; if the cause (e.g. a germ) is present, the person will get the disease, if it is not, he or she will not; and (b) the machine model of the body: the body is conceived of as a machine made up of a group of interacting physical (and chemical) parts; the functioning of these parts is independent of the mind of the organism. These doctrines have provided the underpinnings for much of the advance of scientific medicine. However, their limitations, even in dealing with infectious disease, have become more and more evident. Dubos, Selye, and others have stressed a multiple–cause model of disease, in which body, mind, and environment (including, but not limited to, exogenous microorganisms) interact to produce disease or to cure it; they have called for the reexploration of more holistic approaches to health and disease.” Ibid. 27.

domains. The full array of practices that fit this description is vast and varied, and defies simple or straightforward characterization. However, despite this diversity, we may identify several broad themes common to many expressions of holism. For one, in many of its iterations health holism explicitly or implicitly challenges Cartesian models of mind/body dualism, rejecting reductionism while embracing premodern conceptions of a world wherein the physical and spiritual worlds are bridged. For holistic health practitioners, health and happiness lie in establishing a state of balance and harmony between the many domains of life. It was governed, as one Chicago Tribune reporter wrote in 1976, by “the search for the Certain Something, that elusive state of contentment and inner well-being.”

Second, in advocating a return to the past and challenging the technologism of modern medicine, the movements frequently glorified nature. While Hobbes had argued that man required society to improve his lot, the holistic health reified the individual unpolluted by modern society, the Noble Savage who found health through his connection with a primal mode of life. Third, in holism we oftentimes find a move away from Western modes of treatment in favor of treatment methodologies developed in other societies – frequently developing societies maintaining premodern characteristics, or treatments developed in societies during earlier phases

196 Marilynn Preston, “Mind-body Link and ‘Heal Thyself’ are New Medicine ‘Miracle Drugs.’” Chicago Tribune, September 23, 1976, A3.

197 Some authors have argued that the Noble Savage has long been associated with unorthodox healing strategies, including patent medicine pushers of the 19th Century. Advertisers made ready use of Native Americans, referred to by one advertisement as the “Red Men of the forest” to demonstrate the healing properties of their goods. Arguably, historic unorthodox healing movements such as Thomsonian medicine also relied in part upon this celebration of nature, although Thomsonianism also generated its appeal through nationalist narratives. Jane Marcellus, “Nervous Women and Noble Savages: The Romanticized ‘Other’ in Nineteenth-Century US Patent Medicine Advertising,” Journal of Popular Culture 41, no. 5 (2008): 784-808.
of growth. And finally, the movements generally adopt an antiauthoritarian stance that advocates and celebrates self-care.

Through the 1960s, 1970s and 1980s, myriad health movements sharing one or more of these characteristics spread through the nation, each in its own way attempting to demonstrate how individuals could proactively strive for better health through an understanding and operationalization of the dynamic health model. The list of such movements was legion, running the gamut from herbalism, Chinese medicine, acupuncture and macrobiotic diets to positive psychology, spiritual health and meditation. While these healing systems differed widely in their precepts and the degree to which they emphasized the dynamic interaction between the physical, emotional and environmental, they all provided individuals with a means to intervene to achieve order, balance and stability in their health. Holistic health models enjoyed significant success through the mid-to-late 20th Century, particularly among feminist authors in

198 There is a certain irony in the embrace of non-Western modalities, as it coincided with the broad movement toward a globalized society, facilitated by the very modern institutions and practices the movement largely strove to eschew.


200 Interestingly, the mid-to-late 20th Century popularity of the holistic movement coincided with revitalized interest in models of biology and medicine prioritizing homeostasis. Through the 1960s, 1970s and 1980s many mainstream authors expressed interest in the work of Claude Bernard, who in the 19th Century had originated the theory of homeostasis. Iago Galdston, for example, invoked Bernard to support his environmental stress based model of disease, and in 1980, Elsevier published a 600-page centenary tribute to Bernard. Biological models prioritizing balance and dynamic interaction coincided with the growing understanding of integrated organ systems (e.g. immune, endocrine, nervous). Reductionism was thus tempered by efforts to conceive of organ systems as parts of a dynamic whole. Consider, for example, the cover of the 1984 volume *Stress, Immunity and Aging*, which depicted a brain held in a vice grip bearing the labels “nutrition,” “emotional stress,” “environmental stress” and “aging.” Lightning bolts extend from the brain, sending out immune system cells and antibodies. Edwin L. Cooper, ed., *Stress, Immunity and Aging* (New York: Marcel Dekker, 1984); Historian Mark Jackson has argued that these etiological models resonated in the 1960s-1980s, as broader geopolitical tension revolved around finding balance between major world powers during the Cold War. See Mark Jackson. *The Age of Stress; Science and the search for Stability* (Oxford: Oxford University Press, 2013), 13.
addition to those facing diseases for which mainstream biomedicine could offer no cure. In 1982, a mere month before the CDC would settle upon a name for the immunodeficiency diagnosed among gay men, James S. Gordon – who would go on to chair President Clinton’s White House Commission on Complementary and Alternative Medicine Policy – marveled that holistic medicine had “rapidly emerged as a visible and controversial force in American medicine.”

Some readers may grant the proliferation of holistic health movements through the mid-to-late 20th Century, and may furthermore acknowledge the appeal and influence of Knowlesian arguments underscoring the need for behavioral interventions to prevent disease, but may object to my grouping of both broad movements under the same rubric. Surely, they would maintain, I have engaged in sloppy or surreptitious reasoning in categorizing Knowles’s moralistic calls for responsible living alongside radical holistic health movements associated with left-leaning, crystal-wielding, “masters of doubletalk and weasel wording” quacks. To be clear, I do not mean to argue that the two avenues were identical or that their proponents shared lists of summer reading materials or frequented the same academic conferences. And yet they shared much in common. Both approaches were fundamentally conservative – for example, in empowering the individual to demand and achieve healthier lives. In the case of the moral injunctions found in Healthy People, the Lalonde Report and John Knowles’s writing, this empowerment flowed from the oft-cited injunction *ought implies can*. In maintaining that people had an ethical

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201 For a discussion of the overlap between the women’s rights movement and the holistic health movement, see Amy Sue Bix. “Engendering Alternatives.”


203 See, for example, Kurt Butler, *Consumer’s Guide to Alternative Medicine* (New York: Prometheus Books, 1992). Butler specifically refers to chiropractors in this manner, but his work is marketed as a broad discussion of fringe practitioners, “health pornographers,” and the “quackery mafia.”
obligation to maintain their health and overcome illness, these texts implied that individuals were indeed capable of proactively taking charge of their health, achieving health outcomes that not even a highly technologized medical establishment could achieve. Meanwhile, for proponents of health holism, empowerment flowed from an understanding of the deep connections between the physical, emotional and environmental spheres and the corresponding belief that action in one could effect change in others. In short, in both Knowlesian and holistic approaches to medicine, individuals were empowered to participate actively in their care.

For those readers still skeptical of the overlaps and intersections between Knowlesian and holistic approaches to health, a brief exercise may prove helpful. In 1976, a Chicago Tribune reporter penned an article wherein she quipped, “Of course, curing our own illness just may be the flip side of causing our own illness.”204 I invite the reader to ask him/herself, without reference to the footnotes, which of the two perspectives the author is assuming. Is she invoking Knowles, arguing that individuals must assume responsibility for the ills they had visited upon themselves by their own actions? Or is she speaking to the direct empowerment of the individual through an operationalization of the interrelationships between behavior, environment, emotional and physical health? Is she intimating that individuals are responsible for health as agents liable for its loss, or are they responsible in that they are agents capable of commanding and creating it?

The title of the article – “Mind-Body Link and ‘Heal Thyself’ are New Medicine ‘Miracle Drugs’” – solves the mystery. However, the ambiguity here is far more than a semantic parlor trick. Discussions of health frequently move between the primary and secondary connotation of responsibility, and in so doing transition between holistic and Knowlesian

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perspectives. In 1978, for example, Lewis Thomas, the President of the Sloan-Kettering Cancer Center bemoaned that individuals had with great frequency resorted to “magical” thinking, assuming they could regain health merely by magically deciding to become healthy.205 “Laetrile cures cancer,” Thomas complained, “acupuncture is useful for deafness and low-back pain, vitamins are good for anything, and meditation, yoga, dancing, biofeedback…are specifics for the human condition.”206 The President’s condemnation of unproven holistic and alternative medical techniques seems quite clear. And yet, in an article published in the magazine of the University of California, San Francisco, Joel Gurin questioned the source of this magical reasoning. His answer? “The most prominent source for this view is probably John Knowles, president of the Rockefeller Foundation…[who] has written that, ‘The next major advances in the health of the American people will be determined by what the individual is willing to do for himself.’”207 The polysemy we register in Western conceptualizations of responsibility underscore the lack of clear borders between seemingly disparate systems and paradigms for ordering and explaining health and disease.208

206 Ibid. 462.
207 Joel Gurin, “The Changing Medical Model,” The University of California San Francisco Magazine 1 no. 2 (1978): 11; Additionally, in his 1982 piece, James S. Gordon argues that holistic medical practitioners had begun to focus too much attention on the responsibility of the individual to act to maintain their health. He even cites Marc Lalonde’s report in bemoaning the trend among activist communities. Gordon. “Holistic Medicine: Advantages and Shortcomings,” 548, 551; A similar sentiment appeared in UK and Irish papers. In a 1981 Irish Times article, for example, one author argued, “The paramedical and the medical are getting more united in this concept of responsibility, which is stressed by many unorthodox practitioners too.” Ronit Lentin, “Choosing Not to be Sick,” Irish Times, July 6, 1981, 10.
208 A somewhat more provocative claim might in fact maintain that holistic health activists were, if anything, more wedded to the dominant social order than Knowles’s apologists. After all, Knowles endorsed a model that, in the very least, removed many individuals from the mainstream health economy. Contrast this with the proliferation of health food industries, quasiprofessions purporting to engage mind/body connections, and entire disciplines of health.
Through this discussion, I have shone a harsh light upon the ways in which society projects meaning onto alternative health models, demarcating that which is innocuous from that which is unorthodox. Somewhere between the admonitions of the august John Knowles and his apologists and the holistic health practitioners who rose in prominence during the same period, we draw an invisible line. In so doing, the similarities between movements recede; we see only drastic differences: the conventional versus the radical, the passionate versus the pathological. The history that subtends both of them erodes, leaving behind a narrative that presents one as an extension of orthodoxy and the other as a discontinuous break in historic progress. In drawing lines and erecting walls, we interpret history as cartographers, governed by demarcations and divisions. We blind ourselves to the forces and circumstances that cause individuals to position themselves in the borderland between systems, to move between them, fluently borrowing ideas and merging beliefs in an endless effort to construct meaning.

practitioners in areas ranging from homeopathy to naturopathy and from herbal medicine to crystal healing. Indeed, many of these practitioners in fact defended their right to practice through invocations of the principles of free market economy. Charles Inlander would convey such sentiments when he invoked the theories of Princeton economist Uwe Reinhardt, who wrote, “If organized medicine stops the growth activity of allied health man-power, there are two social costs. One is, of course, that patients will lose access to an alternative provider who often is more accessible and quite probably cheaper. The other social cost, which is not even talked about, is this – you are precluding large numbers of Americans from exercising entrepreneurship in health care.” Quoted in Charles Inlander, Lowell Levin and Ed Weiner, Medicine on Trial: The Appalling Story of Ineptitude, Malfeasance, Neglect and Arrogance (New York: Prentice Hall Press, 1988), 155.

Some readers may argue that during the late twentieth century we identify efforts to integrate alternative with mainstream medicine in the form of complementary care. The complementary care movement is indeed real. However, the movement continues to provoke considerable objection, and its history demonstrates the ways in which integration can transform into assimilation, as was witnessed in the late nineteenth and early twentieth century experiences of homeopathy and osteopathy. Furthermore, complementary medicine is least radical when it provides routes for augmenting mainstream care for chronic conditions; individuals who opt to solely pursue alternative strategies for fatal or infectious conditions continue to provoke discord and disagreement.
Conclusion: A Past Rendered Homeless

Thus, by the late 1970s, we identify a clear and cogent criticism of a reductionist biomedical system, growing out of and interacting with a popular activist tradition targeting the underlying social and environmental inequalities that subtended disease. In the context of growing disillusionment with biomedicine’s ability to address chronic diseases, and inspired by broad social movements underscoring unfair and destructive social arrangements, we witness a transformation in health paradigms. However, we must remember that these changes did not happen overnight, nor did they flow naturally or mechanically from changes in disease demographics. They were instead the result of gradual transformations in the sociopolitical landscape, and the social movements which were both the exponents and products of these changes.

This point is of paramount importance for my larger historical examination of the history of unorthodox AIDS activism. For just as I have argued that society did not instrumentally or spontaneously shift health paradigms in the face of rising tides of chronic disease, it similarly follows that it did not shift back to infectious models in the era of AIDS. As society considered the visitation of a plague upon its cities in the early 1980s, it processed infectious disease narratives through a perspective shaped by the disease discourse of the 1960s and 1970s. Even as journalists wrote of unchecked plague, cartoonists depicted Dark Age horrors, evangelicals preached of the fires of cataclysmal fury, and scholars mined the histories of syphilis and cholera, individuals interpreted the disease through broad behavioral, emotional, social and environmental lenses, challenging the reductionism of the biomedical approach. This enduring lay discursive tradition never fully disappeared, even following the identification of the virus that
causes AIDS. Indeed, it persisted in both the everyday forms of resistance and overt campaigns subsumed under the rubric of unorthodox AIDS activism.

Older models for ordering health and disease die neither noble nor ignoble deaths, but instead persist, resonating at various times with different segments of society. My analysis suggests that unlike Kuhnian models of revolutions within scientific paradigms, and Foucauldian conceptualizations of discontinuous ruptures between historical eras, old models coexist with the new, attracting and repelling individuals who move between them. We find, in other words, that individuals are located in the borderlands of intersecting paradigms, their worldviews shaped by their positions within this broad network of models, systems and traditions. Within such a complex network, binary oppositions of orthodox versus unorthodox, regular versus irregular, and traditional versus alternative lack clear meaning, and indeed blind us to the rich interconnections and interrelations between multiple means of ordering and explaining health and disease.

Foucault would no doubt take issue with my carving out of a domain for individual agency or autonomy in my model, arguing that individuals’ placement within this network of paradigms flows from powerful structural forces operative within society. I grant this criticism and agree that structural forces play an important role in individuals’ placement within the borderland network (such that someone born into a low socioeconomic community may not have the same opportunity to engage with particular paradigms). While I believe that my general argument would stand even in a world completely devoid of individual choice and autonomy, I believe that models presuming a complete lack of agency pose problems as significant as those which presume complete autonomy.
Chapter 2 Images
1980s and 1990s Era Political Cartoons


Image 2.5: Jim Bogrman. *Cincinnati Enquirer.* See *Cartooning AIDS around the World.* Ed. Maury Forman and David Horsey.

Image 2.6: Oto Reisinger. Zagreb, Croatia. See *Cartooning AIDS around the World.* Ed. Maury Forman and David Horsey.

Image 2.7: Humberto de la Torre. *Ya.* Madrid. See *Cartooning AIDS around the World.* Ed. Maury Forman and David Horsey.

Image 2.8: Eyitayo Fatunla. *This Week,* Lagos. See *Cartooning AIDS around the World.* Ed. Maury Forman and David Horsey.


Image 2.16: Fritz Behrent, *De Telegraaf*, Amsterdam. See *Cartooning AIDS around the World*. Ed. Maury Forman and David Horsey.
19th Century Political Cartoons


Image 2.18: Montreal’s Night-Mayor on his Ghostly Rounds. 1875. McCord Museum.


Image 2.20: Frank Bellew. See *Themes in American History*, blogs.baruch.edu
Chapter 3

A Broken Trust: The Changing Character of Healthcare

“What we call Man’s power over Nature turns out to be a power exercised by some men over other men with Nature as its instrument.”

-C.S. Lewis

In the previous chapter, I focused my attention upon fundamental changes in mid-to-late 20th Century conceptualizations of disease. As chronic diseases rose in prominence, various authors and commentators advocated models of disease etiology that took into account the dynamic interrelationship between physical, emotional, social and environmental domains. The highly technologized and reductionist approach to disease which had served biomedicine well during an earlier era of acute infectious epidemics appeared poorly suited for addressing illnesses many argued flowed from the physical and emotional stresses posed by modern society. What was needed, critics alleged, was a reassessment of preventative and therapeutic health strategies, moving away from narrow reductionism and instead empowering individuals to take charge of their own health.

Implicit in these broad health campaigns were appraisals of the social costs of a medical approach increasingly painted as dogmatic and provincial. For authors inclined to hyperbole, the biomedical system was guilty of dehumanizing its patients through its rigid attachment to reductionist responses to disease. However, even those less disposed to such sweeping allegations cast disapproving glances at a medical system resistant to change. In “The Responsibility of the Individual,” John Knowles – himself a physician – spared his colleagues

outright censure, arguing that their rigid attachment to a broken model flowed in part from society’s historic fascination with science and technology. And yet, in the same breath, he delivered a backhanded rebuke of their motives, arguing that they failed to consider new models of disease because the “financial rewards of the present system are too great and because there is no incentive and very little demand to change.”

Thus, in mid-century evaluations of the biomedical model, we recognize a nascent criticism – sometimes mild and diplomatic, other times explicit and condemnatory – of the men and women Americans entrusted with their health. These reproaches would ultimately fuel a more widespread culture of distrust captured in outwardly and unambiguously critical attacks on the perceived failures of physicians, drug manufacturers and governmental regulators to act in the best interest of patients. Launched by individuals located within the medical community in addition to those positioned outside its institutional and professional circles, these biting analyses accused biomedicine and its constitutive agents of squandering the public’s trust through acts of incompetence, arrogance and avarice. Some influential critics would go as far as to allege that these sins had been institutionalized in the very structure of biomedicine, as physicians, drug manufacturers and allied professionals placed personal, professional and political interests over the needs of patients.

As it so happens, during precisely the same period wherein the public voiced these concerns with the character of the healthcare system, biomedicine would witness the institutionalization of an entire professional discipline tasked with surveying its behavior to prevent lapses in justice and fairness, and to ensure that it recognized the inviolable rights of patients. Indeed, biomedical ethics arose to address the sins of the medical system by developing

ordered procedures for adjudicating ethically complex questions arising in medical care and institutionalizing oversight and protection mechanisms to prevent miscarriages in healing. It was, in effect, a professional response to distrust, aimed at shining a bright light into the corners and crevices of biomedical practice. And yet, as I shall argue, bioethics would by and large ignore the broad category of concerns and apprehensions considered here, summarily dismissing them as radical, polemical or seditious. Spurned in professional discourse, these unsanctioned expressions of distrust rooted and flourished in the darkness, resonating with the public, ultimately provoking contentious debate regarding what some considered the unfulfilled promise of bioethical inquiry. To better understand the historic processes whereby some scholars dismissed these critiques as unsanctioned or illicit, we must first consider the institutional routes and avenues through which some apprehensions were sanctified as worthy of study.

A Sanctioned Distrust: the Rise of Biomedical Ethics

As many scholars have argued, bioethics as a formal discipline coalesced in a crucible suffused by the simmering antiauthoritarianism and antiprofessionalism of the 1960s and catalyzed by both startling allegations of abuse committed by research scientists and atomic age insecurities regarding the dangers of an unchecked scientific apparatus.213 Fears that the

213 In a footnote to a 2007 volume, Charles Rosenberg writes, “Although it is conventional to see the bioethics movement as having its late-twentieth-century origins in Nuremberg, it is equally conventional to see it crystallizing as a self-conscious movement in the 1960s as in part a response to those social currents that produced a more general sensitivity to individual rights – of women, of prisoners of sexual and racial minorities – and of an antiauthoritarian skepticism toward credentialed expertise.” Charles Rosenberg, Our Present Complaint: American Medicine, Then and Now (Baltimore: Johns Hopkins, 2007): 184, n10; Authors such as M.L. Tina Stevens furthermore explicitly link bioethics to the antiauthoritarian climate of the 1960s. M.L. Tina Stevens, Bioethics in America, Chapter 1; For a discussion of bioethic’s ties to technological development, see a 2012 piece by Albert Jonsen wherein he reviews several questions posed by new technologies, discussing, for example, a letter written by bioethicists to Pope Pius XII asking for guidance concerning artificial life sustaining technologies. Albert Jonsen, “A History
biomedical system had committed egregious sins against patients and research participants led to a reevaluation of patient protections and a critical analysis of how matters of ethics were adjudicated by physicians and researchers. As a result of the profession’s transgressions, the same physicians who had once held almost mythical status among the public were deemed needing of both scrutiny and oversight.\textsuperscript{214} In the professionalization and deputization of biomedical ethics as a formal discipline, an entire profession arose to provide this oversight.

By locating bioethics within the anti-authoritarianism of the 1960s and underscoring the prominent role it played in ushering in an unprecedented realignment of power in American medicine, scholars present the discipline as an exponent of the larger patient rights movement. In \textit{Strangers at the Bedside}, the first history of the bioethics movement, David Rothman deftly constructs a doublet of interlocking analogies comparing bioethicists to civil rights advocates. He begins by analogizing patients to groups of minorities bound together in a common fight against authority. In their mutual powerlessness, he argues, patients were “at one with women, inmates, homosexuals, tenants in public housing, welfare recipients, and students.” Furthermore, because bioethicists defended patients, they were like the “rights agitators” who fought on behalf of vulnerable parties. It was through such reasoning that Rothman could argue that bioethicists – a group largely comprised of career philosophers – were in fact exponents of civil rights.\textsuperscript{215} For


\textsuperscript{215} Rothman describes bioethicists as, “Ph.D.s, often trained in philosophy, many with a Catholic background, who typically followed conventional life-styles, [who] may not have been personally comfortable with still more left-leaning, agnostic, and aggressive advocates committed to alternative life-styles.” Ibid. 245.
they, like the leaders of interest-based advocacy groups, “looked at the world from the vantage point of the objects of authority, not the wielders of authority.”216

Given Rothman’s framing of the discipline, it would appear that bioethics is in fact dedicated to examining the expressions of distrust relevant to this analysis – probing critiques of the behaviors of a clinical system perceived of as having amassed far too much power. Were this the case, I could give the topic short shrift, happily appending to my greater analysis the history of bioethics, which by now has enjoyed explication by historians,217 ethicists,218 sociologists,219 and attorneys.220 However, as I have argued, while bioethics accomplished a great deal in the way of changing clinical practice, it would ultimately fail to consider the concerns voiced by its discredited detractors. Their apprehensions and objections ran deep – one author would call them marrow-deep – impugning the agents of biomedicine in addition to the invisible institutional, intellectual, technological and economic structures that facilitated their amassment of power.221

Bioethics was and is, by most measures, a fundamentally conservative endeavor. As a branch of applied ethics, it is resoundingly practical in its methodology, positioning itself within the biomedical model and working to modify physician practices so that patients might enjoy and express autonomy. In its scope and aim, it focuses almost exclusively upon what philosopher Anthony Weston refers to as “downstream” problems in healthcare, ignoring upstream

216 Ibid.
217 Ibid; M.L. Tina Stevens, Bioethics in America.
218 Albert R. Jonsen, Birth of Bioethics.
220 Wesley J. Smith, Culture of Death: The Assault on Medical Ethics in America (San Francisco: Encounter Books, 2000).
phenomena giving rise to them. As Hastings Center Cofounder Daniel Callahan has admitted, in the practice of professional bioethics, “the larger and more fundamental human questions that should be engaged are put aside, and the focus is mainly on those issues that lend themselves to some concrete legal or legislative outcomes acceptable in a pluralistic society.” Hewing to this disciplinary approach, bioethics achieved tremendous success. Indeed, in 2005, Arthur Caplan would quip that his field had grown “from a cottage industry of intellectually lonely misfits and malcontents…to a real field that whispers in the ears of Presidents, issues rules to bind the inquiries of Nobel Prize winners, and is consulted by CEOs and media lights for advice and analysis.” Given its meteoric rise, it is perhaps no surprise that some – such as political scientist Albert Dzur, would question whether bioethicists had fallen prey to “institutional capture and neutralization.”

Through the second half of the 20th Century, various critics would contend that bioethics had effectively gone astray; they argued that in transforming itself into an expression of the power of biomedicine, it had lost the ability to understand how that power operated. Feminist scholars were among the first to voice their dissent, arguing that in focusing on the promulgation of universal concepts of individual agency and informed consent, bioethics turned a blind eye to structural abuses that dictated and defined the patient experience. What good was informed

223 Daniel Callahan, “Bioethics and Policy – a History,” in *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns*, ed. Mary Crowley (Garrison, NY: The Hastings Center, 2008), ix-x,
225 Albert W. Dzur also quotes Charles Bosk, who argues, “By assimilating bioethics, organized medicine was able to defang this other, broader challenge.” Cited in Albert W. Dzur, *Democratic Professionalism: Citizen Participation and the Reconstruction of Professional Ethics, Identity and Practice* (University Park, PA: Pennsylvania State University, 2008), 212.
consent, feminists asked, if as a result of their social circumstances, individuals were poorly equipped to exercise it? Furthermore, they argued that in focusing on enhancing the clinical experience, bioethicists failed to consider the structural causes of health and disease in addition to the ways in which the clinical experience itself could be harmful. Feminist Christine Overall gave voice to these concerns in a sharply worded rebuke of bioethical practice wherein she invokes the work of Ivan Illich, a fascinating character whose name had by the 1970s become shorthand for polemical attacks launched at the US healthcare system. Writing in 1996, Overall commented,

“What Ivan Illich calls the ‘ethical status of medicalization’ – that is, the gradual incursion of medicine into, for example, sexuality, reproduction, disability, the emotions, nutrition, childhood, old age, and dying – is seldom recognized as an issue within bioethics. Nor are the marketing of infant formula and bottle feeding, the effects of environmental degradation on health, the drugging of athletes, or physicians’ widespread participation in the certification of defiance, incompetence, and insanity recognized as such.”

226 Christine Overall, “Reflections of a Sceptical Bioethicist,” *Philosophical Perspectives on Bioethics*, ed. L.W. Sumner and Joseph Boyle (Toronto: University of Toronto Press, 1996), 166-167; In the introduction to the inaugural issue of the *International Journal of Feminist Approaches to Bioethics*, Mary C. Rawlinson argues that many bioethicists dismissed the rise of feminist bioethics, arguing that feminists tackled issues already considered by mainstream bioethics, or that their efforts merely constituted a special interest discipline centered upon women’s health issues. Similarly, Philosopher Laura M. Purdy has noted that, “Analyses sensitive to gender and other markers of disadvantage often have been rejected as uninteresting, bad scholarship, biased, ideological, or ‘political,’ thus having no place in a serious intellectual endeavor like bioethics.” See Mary Rawlinson, “Introduction,” *The International Journal of Feminist Bioethics* 1, no. 1 (2008), 1; Laura M. Purdy, “Good Bioethics Must Be Feminist (And Allied Liberationist) Bioethics,” *Philosophical Perspectives on Bioethics*, ed. L.W. Sumner and Joseph Boyle (Toronto: University of Toronto Press, 1996): 144.
In ignoring the structural correlates of health, disease, and healthcare decision making, bioethics failed to seriously consider the rich discourse developed through the 1960s and 1970s interrogating the construction and operation of power in society. Interestingly, while the writings of Michel Foucault would go on to profoundly influence academic disciplines such as history, anthropology and sociology, they had relatively little effect on the practice of bioethics. Indeed, in 2003, scholars Arthur W. Frank and Therese Jones analyzed American bioethics from a Foucauldian perspective, concluding that the French theorist would have adjudged it “yet another practice of power” which located individuals in a rigid hierarchy even as it purported to empower them.227 By the late 2000s, bioethicists had begun to recognize their failure to adequately problematize power in their disciplinary approach. Writing in the Hastings Center Report in 2010, Bruce Jennings would admit,

“Bioethics lives in the shadow of great structures and practices of power, and yet, it has not been notable for its contributions to an understanding of power. Indeed, the narrative that bioethics has fashioned for itself has been mainly a liberationist romance: a quest narrative in which the individual, seeking autonomy, struggled against limitations, constraints, and inhibitions imposed by forces from the outside.”228

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As Rothman’s framing of the discipline underscores, bioethicists and their apologists presumed that by granting all individuals – the rich, the poor, the homosexual, the heterosexual – autonomy, they were redressing structural inequalities. And yet, as feminists and Foucauldians had long noted, giving individuals a voice in their care does little to change structural deficiencies, biases and prejudices in the biomedical system, nor does it address the systematic abuses arising out of the fundamental arrangement of clinical care.229

At the same time that the proponents of bioethics fielded criticism from feminist and Foucauldian scholars, they found themselves faced with unsettling reinterpretation of their disciplinary history. In 2000, historian M. L. Tina Stevens challenged the canonical narrative of bioethics, arguing that the discipline had sacrificed its radical origins in 1960s era antiauthoritarianism and antitechnologism for an accommodationist posture that ultimately served the interests of physicians and researchers.230 In effect, Stevens argued that bioethics had tailored its campaigns to satisfy the demands and requirements of clinical medicine in its embrace of an increasingly reductionist, technologized model of care.231 Stevens’s explosive

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229 Medical sociologist Renee Fox would indeed raise many of these points. In Strangers at the Bedside (pp. 245), Rothman dismisses her structural critiques, arguing that bioethicists transcended such problems by recognizing individuality across class (and, while he does not explicitly say it, one can reasonably argue he means gender, racial and sexual orientation lines as well). Needless to say, his response fails to satisfy the core of a feminist critique which held that bioethics, in its ardent endorsement of patient autonomy and individual rights, ignored the ways in which autonomy and rights were constructed and operated for women, homosexuals, those lacking adequate housing and the other “objects of authority.”


231 Stevens cites, for example, a 1972 Hastings Center Board of Directors meeting wherein those assembled “reached an informal conclusion: the institute should make an effort to elect more members with a pro-technology bias.” I must stress that I am not interested in supporting or refuting Stevens’s claims. Rather, I find the debate to be illuminating, in particular as it elucidates underlying biases in the practice of bioethics. Stevens Bioethics in America, 61; For an
work provoked the ire of Albert Jonsen, who in a sharply worded review published in the
_Hastings Center Report_ argued that her interpretations were “driven less by the context and
evidence than by her fundamental ideology as a historian, namely, that all historical analysis is
nothing more than the record of power seeking to perpetuate itself.”

Stevens’s response, also published in the _Report_, disputed the bioethicist’s claims while simultaneously delivering a
backhanded rebuke, congratulating Josten on his 1998 work _The Birth of Bioethics_ by calling it
“informative history from a Whig perspective.”

While the many attacks Jonsen directs at Stevens’s work are fascinating and deserving of
further analysis, I am far more interested in the points on which the two scholars agreed. Of
particular note is a broad structural critique Stevens levels at bioethics, similar in some ways to
Christine Overall’s argument, cited above, which held that bioethics excluded from its analysis
so-called radical appraisals of the healthcare system. Interestingly, in his acerbic review of
Stevens’ work, Jonsen in fact agrees that bioethicists had engaged in the systematic elision of
radical positions from their analysis. What’s more, he ardently defends the practice, once more
invoking everybody’s favorite archetypical radical, Ivan Illich, to demonstrate his point:

“I cannot imagine how the radical critics whom [Stevens] idolizes could ever have
participated in this sort of public discourse. They could verbally demolish the social
institutions that they accused of domination, but they had no means of actually revising
or rebuilding them. They stood outside and shouted. Illich’s slashing dissection of

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additional discussion of Stevens’s work, and a criticism of her conclusions, see Ruth Macklin,
“The New Conservatives in Bioethics: Who Are They and What Do They Seek?” _Hastings
Center Reports_ (January/February 2006).

232 Albert R. Jonsen, “Beating up on Bioethics,” _Hastings Center Report_ (September-October
2001): 42.

modern medicine and health care offered no alternative except the exhortation that people should take care of themselves.”

Jonsen therefore dismisses radical critiques, painting authors such as Illich as polemicists intent on destroying that which biomedicine had built while offering nothing of value in return. In his barbed refutation of an historian, Jonsen thus demonstrates that bioethics declared no dominion over the vast arena of biomedicine defined by self-care. If radicals were intent on destroying that which biomedicine had assiduously constructed, then they would receive little support – or acknowledgment – from bioethics, a field which indeed had become an allied profession within biomedicine. Somewhat ironically, the discipline of applied ethics that had constructed its authority upon the bedrock of patient autonomy would in fact recognize limits to that autonomy. Those who questioned the legitimacy of the biomedical system writ large, or who advocated unorthodox approaches to healing that rejected its authority, simply

234 Jonsen. “Beating up on Bioethics,” 44, emphasis added. I should note that while Jonsen goes out of his way to note that Illich’s analysis were too radical for serious consideration, Stevens herself failed to seriously consider Illich in her text. Thus, in effect, Jonsen critiques Stevens for ignoring Illich while defending his discipline’s decision to ignore him.

235 I suspect that Illich’s work was branded polemical for two reasons, both of which are suggested by H. Jack Geiger’s New York Times discussion of Medical Nemesis. First, his target audience was the general public, avoiding and eschewing the practitioners, ombudsmen and sentries of medicine. As Geiger wrote, “The ultimate target of his blame is not the professionals but the rest of us – all of us, at once eager consumers and the passive slaves of industrialism, and, therefore, the willing participants in our own dehumanization. He wants us – the world’s biggest medical-care users and spenders – think about our implicit beliefs in salvation through science and immortality through medical care.” H. Jack Geiger, “Medical Nemesis: the 20th Century’s Leading Luddite Turns to Medicine,” New York Times May 2, 1976; Chase Madar similarly argued, “This is perhaps the lasting appeal of Illich’s work: while colossally learned, it is subversively attuned to everyday needs.” Madar “The People’s Priest”; Furthermore, Illich’s writing was not marked by objectivity or disciplined academic detachment; he instead spoke in outrage.
went too far. Throughout history, authors have often ascribed radicalism to the rapacious freedom seeker who would use his autonomy to destroy the very system that had granted it to him in the first place. Consider, for example, discussions of the immigrant poor arriving on the shores of the nation in the early 20th Century. Addressing the Carnegie Institute in 1919, banker Otto H. Kahn would argue, “They have become drunk with the strong wine of freedom. Brooding in the gloom of age-long oppression, they have evolved a fantastic and distorted image of free government. In fatuous effrontery they seek to graft the growth of their stunted vision upon the splendid and ancient tree of American institutions.”

My goal for the remainder of this chapter is to shine a light on those who had become drunk with the strong wine of freedom, identifying and describing several popular expressions of apprehension and ambivalence with the dominant, orthodox biomedical system in the years preceding AIDS. One might achieve this end by focusing specifically on those authors deemed radical by the biomedical system – in short, the Ivan Illichs of the world. However, focusing directly and exclusively on Illich’s arguments severs radical invective from the historical discourse which gave rise to it, further reinforcing Jonsen’s claim that Illich “stood outside and shouted” at the biomedical system. And yet, as I shall argue, Illichian radicalism grew out of and was itself expressive of concerns common through society in the mid-to-late 20th Century. In short, Illich’s theories, like the unorthodox AIDS activism they later fueled, had roots in earlier social movements and campaigns, not all of which were deemed radical. Just as I have argued

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236 See, for example, Allan Parachini, “Medical Iconoclast Attacks the ‘Holistic’ Path,” *Los Angeles Time*, April 15, 1986.
elsewhere in this analysis, if we hope to understand the radical firebrand, we must therefore strive to apprehend the discourses that anchored and fueled him.

In the following two sections, I therefore chart the incubation of a deep and resonant distrust communicated among the public regarding the content and character of mid-to-late 20th Century orthodox healing. The first section of my analysis examines concerns that the biomedical orthodoxy was itself directly injurious to the public’s health as a result of its increasing recourse to a rapidly growing armamentarium of potentially dangerous drugs. In it, I explore widespread fears through the 1960s and 1970s holding that the nation was in fact overmedicated, identifying three different categories of drugs whose history contributed to substantial distrust in the biomedical system. Following this analysis of the effects of the pharmacologic revolution on public perceptions of medicine, I turn my attention to changes in social perceptions of the competence and character of the physician through the 1960s and 1970s. I ultimately argue that the period would witness a proliferation of criticism aimed at the nation’s healers not seen since the sectarian battles of the late 19th and early 20th centuries.

Only after having established the greater context of distrust and apprehension shall I turn my attention to the structural critique Illich launched in Medical Nemesis, examining his analyses of clinical, social and cultural iatrogenesis. I also consider the similarities between his critique and those of another rabble-rouser whose attacks would enjoy a different fate among scholars – Michel Foucault. In the final component of the chapter, I discuss the popular extensions of Illich’s analysis, demonstrating the impact it exhibited on the growth of the self-help movement and, by extension, unorthodox approaches to healing. And I reconsider the failure of professional bioethicists to address his critiques, arguing that in dismissing them as destructive expressions of
radicalism, scholars failed to understand and appreciate the profound distrust he articulated and the culture of self-help he inspired.238

The Overmedicated Society

In 1980, Louis Lasagna, a clinical pharmacologist well known for penning a modern adaptation of the Hippocratic Oath, edited a 600-page volume dedicated to examining controversies in clinical care. In the opening line of his Introduction, Lasagna identifies overmedication as one of the great fears of the era. “Few topics in medicine elicit such passions in the hearts of physicians,” he writes, “as the question, ‘Are we an overmedicated society?’”239 The first two essays of the volume focused exclusively on the topic, with subsequent chapters contributing to the discussion in ways both direct and indirect. In a piece entitled “The Politics of Medication,” John P. Morgan attests to the popular media’s enthrallment with the issue, noting that everyone from high school groups to alcoholism counselors to reporters from *Time Magazine* and *Gentlemen’s Quarterly* had approached him to discuss the nation’s epidemic of overmedication.240 “Everyone seems to know that we are an overmedicated society,” Morgan observes, “and one imagines editors of publications small and large, common and arcane, swallowing benzodiazepines while rushing to meet a deadline with an article on the overmedicated society.”241

Ardent criticism of society’s overreliance upon prescription drugs saturated both lay and professional publications in the years preceding AIDS. In 1980, Philip R. Lee – a former

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238 I should say, my goal here is not to criticize orthodox medicine but rather to underscore criticisms voiced through the 1960s and 1970s.
Assistant Secretary for Health and Scientific Affairs under Lyndon Johnson who would later serve as the first President of San Francisco’s Health Commission during the AIDS epidemic – noted with alarm that since 1950, the nation had witnessed a three-fold increase in the number of prescriptions dispensed by community pharmacies, discount stores and physicians.\textsuperscript{242} For many authors, the biomedical industry, and by extension society in general, had become dependent upon pharmacological solutions to everyday problems, seeking “a pill for every ill.”\textsuperscript{243} Lee’s comments echoed alarming research conducted by John M. Firestone, who in 1970 would argue that in the US, the volume of the US drug business had grown by a factor of 100 through the 20\textsuperscript{th} Century,\textsuperscript{244} and a startling report issued by The Consumers Union Report holding that in the US, 20,000 tons of aspirin were consumed per year (almost 225 tablets per person), while in England every tenth night of sleep was induced by a hypnotic drug and 19 percent of women and 9 percent of men took a prescribed tranquilizer during any one year.\textsuperscript{245}

It is impossible to locate a single, unifying “overmedication discourse” operative through the 1960s and 1970s, for the topic intersected numerous anxieties and insecurities common to the era, harmonizing with concerns voiced by individuals located on both the left and the right of the political spectrum. To say that society was overmedicated was to indict a vast array of social institutions and professionals, ranging from pharmaceutical corporations and governmental regulators to physicians. Correspondingly, throughout the 1960s and 1970s we identify several

\textsuperscript{243} Lasagna, “Introduction,” 3.
overlapping overmedication discourses, each in its own way questioning the nation’s growing reliance upon a biomedical industry increasingly painted as broken. In some cases, these discourses centered upon sensational revelations of drugs with demonstrably debilitating side effects making their way onto the market. In others, they focused opprobrium on more commonly prescribed medications believed to pose their own risks to the population. I maintain that each discursive tradition utilized its own conceptualizations of risk and harm; to appreciate the full measure of overmedication fears, we therefore must consider each of these conceptualizations.

The first category of drugs I shall discuss here is, in many ways, the most recognizable, its story indelibly inscribed in the history of drug regulation. Through the 1960s and 1970s, several authors published shocking exposés arguing that the biomedical system produced and administered an armamentarium of drugs whose toxic side effects far outweighed their utility. One of the most vocal and influential critics in this tradition was Morton Mintz, a Washington Post investigative journalist who in 1967 published a volume sharply critical of drug development and regulation in the United States. What its title sacrificed in brevity it more than gained in brass, plainly making clear its author’s opinions of biomedicine: *By Prescription Only – A Report on the Roles of the United States Food and Drug Administration, the American Medical Association, Pharmaceutical Manufacturers, and Others in Connection with the Irrational and Massive Use of Prescription Drugs that May be Worthless, Injurious, or Even Lethal.* In it, Mintz provides an encyclopedic breakdown of the toxic drugs for which the pharmaceutical industry had sought, and in some cases received, approval. In addition to

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thalidomide, the archetypical drug whose history is closely associated with drug regulation reform, Mintz tells the harrowing tails of chloramphenicol (an antibiotic associated with aplastic anemia), flexin (a muscle spasm remedy associated with liver damage), MK-665 (an oral contraceptive associated with breast cancer), dimethyl sulfoxide (an industrial solvent touted as a wonder drug and later associated with ocular conditions), and many other famed and feared formulations. A decade after its publication, Ivan Illich would extoll Mintz’s analysis as a masterpiece that had “done more than any other book to change the focus of the U.S. discussion of medicine.”

It is difficult to make it through Mintz’s analysis without experiencing some measure of trepidation in the nation’s drug testing, review and administration machinery. Surveying statements made by leaders in biomedicine, including testimony given before Estes Kefauver’s 1957-1963 Senate Committee investigating the nation’s health industry, Mintz paints a picture of widespread neglect. The reader encounters, for example, a deeply concerned pathologist whose years of experience conducting autopsies led him to conclude that pharmaceuticals were killing patients, contributing to what he called “a sort of involuntary euthanasia.” We similarly learn of analyses conducted by a well-respected statistician holding that three quarters of published biomedical studies drew conclusions unsupported by their data. And we read an FDA Commissioner’s shocking concession that “the hand of the amateur” was evident far too often in drug testing data submitted to his office for review. Furthermore, for those readers unimpressed with concerns voiced by biomedical researchers and regulators, Mintz invokes the memory of one of the era’s most beloved champions of the public’s health. His project, he makes

247 Illich, Medical Nemesis, 67.
248 Mintz, By Prescription Only. 107.
249 Ibid. 160.
clear, is to be read as an extension of the mission undertaken by the late Rachel Carson, the acclaimed and beloved conservationist whose name had become synonymous with efforts to protect the public from toxicities wrought through modern industrialization. Mintz wastes no time underscoring the connection – on the second page of his preface, he prints comments Carson made roughly a year before her death:

“The problem I dealt with in Silent Spring is not an isolated one. The excessive and ill-advised use of chemical pesticides is merely one part of a sorry whole – the reckless pollution of our living world with harmful and dangerous substances. Until very recently, the average citizen assumed that ‘Someone’ was looking after these matters and that some little understood but confidently relied upon safeguards stood like shields between his person and any harm. Now he has experienced, from several different directions, a rather rude shattering of these beliefs. Almost simultaneously with the publication of Silent Spring, the problem of drug safety and drug control, which had been simmering in the press for many months, reached its shocking culmination in the thalidomide tragedy.”

Narratives invoking the international and national experience with substances such as thalidomide tended to focus on the establishment of more comprehensive regulatory mechanisms to protect the public. The goal, in short, was to catch the bad apples before they slipped through the regulatory net and into the hands of unsuspecting consumers. In devising solutions for culprits such as the teratogenic thalidomide, these narratives deflected attention from larger social arrangements permitting an overreliance upon medication – in effect, they lost the forest

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for the trees. Furthermore, inherent in these narratives was a certain optimism, not in the biomedical system as it existed, but in our ability as a society to make it better through more scientific knowledge, more information, and more oversight. What society needed was a certain “Someone” to protect it from those who out of negligence or malice would cause it harm. In some iterations, that Someone was constituted by the consumer rights movement – indeed, Ralph Nader penned a glowing review of *By Prescription Only*, which its publisher wisely printed on its back cover. In others, they were embodied in the fiery tenacity of heroized professionals – sentries in the mold of Frances Oldham Kelsey.\textsuperscript{251}

In sum, social discourse surrounding the first category of drugs intersected with issues pertaining to overmedication, but generally sacrificed probing analyses of entrenched, disciplinary failures in favor of isolated examinations of bad drugs, heroic regulators and the recalibration of mechanisms designed to adequately screen drugs before they entered the pharmacopeia. Somewhat ironically, it is in moving from infamous and reviled “bad drugs” to those of lesser toxicities that we better appreciate 1960s-1980s era social discourse surrounding the dangers of overmedication. Take, for example, the second category of drugs considered here, constituted by medications of questionable clinical efficacy that offered no clear benefits and lacked the discernible toxicities of the first class, while still exposing patients to some theoretical risk of harm. It is all too easy to dismiss this second class of useless medications as a minor concern in comparison with drugs of clear and demonstrable toxicity. Or, alternatively, to conflate the two categories into one, noting for example that legislators addressed the second category of drugs in the same hallmark legislation – the Kefauver-Harris Amendment signed by

\textsuperscript{251} As a 1963 article in the *Journal of New Drugs* read, “If the thalidomide experience is to make a lasting contribution to drug safety, it will be through the recognition of the importance of the Dr. Kelseys to the nation's health. These are the people we need more of: trained and responsible scientists in government, in industry and in the profession.” *Journal of New Drugs* 3 (1963): 149.
President Kennedy in 1962 – that addressed the first.\textsuperscript{252}

However, focusing narrowly on legislated fixes blinds us to the effects pharmacologic duds would have on popular discourse surrounding medication. For through the 1960s and 1970s, as people contemplated the existence of useless drugs already on the market, we identify expressions of far more diffuse, insidious conceptualizations of risk. Perhaps, some wondered, \textit{all drugs} posed some level of harm. Unlike the dangers of thalidomide – discernible through more transparent testing standards and rigorous regulatory oversight – these harms appeared virtually unknowable, exacting their effects through complex pathways, facilitated through the dynamic interaction of multiple agents in any one person; augmented by the constitution, lifestyle and environment of the patient; and resultant from the gradual accumulation of drugs in the human body.\textsuperscript{253} In short, while many had once assumed that ineffective drugs posed harm mainly to the purse, some began to question their effects on the person as well. Morton Mintz expressed this concern well in the opening line of his chapter dedicated to ineffective pharmacologic products. \textquote{Ineffective drugs can be dangerous drugs,} he wrote. \textquote{There is no fact more crucial to an understanding of why we have wasted our money and our health.}\textsuperscript{254} This expansion of the notion of risk to include unknowable offenses corresponds with a similar extension of interpretations of risk witnessed in tort law in the early-to-mid 1960s.\textsuperscript{255}

\begin{itemize}
\item \textsuperscript{252} The Kefauver-Harris Amendments strove to avoid the approval of ineffective pharmacologic drugs by requiring manufacturers to demonstrate the safety \textit{and} efficacy of new products.
\item \textsuperscript{253} See Inlander et al., \textit{Medicine on Trial}, 123.
\item \textsuperscript{254} Mintz, \textit{By Prescription Only}, 37.
\item \textsuperscript{255} In February of 1986, the Department of Justice\textquotesingle s Tort Policy Working Group on the Causes, Extent and Policy Implications of the Current Crisis in Insurance Availability and Affordability issued a report wherein it noted the substantial rise in malpractice cases through the 1980s. While many causes of this increase are considered, of particular interest here were changes witnessed in the early to mid 1960s wherein the \textquote{twin pillars} upon which tort law had been based – deterrence and compensation – were rejected in favor of \textquote{more enlightened theories based largely on concepts of societal inductance and risk spreading.} The report cites a 1982 New
\end{itemize}
The consumer rights movement would also focus widespread attention on the theoretical risks of useless medications. Through the 1970s, several critics accused the FDA of failing to adequately implement the provisions mandated by the Kefauver-Harris Amendments, arguing that many ineffective and potentially dangerous drugs remained on the market. In 1980, Sidney M. Wolfe, Christopher M. Coley, and Ralph Nader’s Health Research Group published an immensely influential volume chronicling these failures, entitled *Pills that Don’t Work: A Consumers’ and Doctors’ Guide to Over 600 Prescription Drugs that Lack Evidence of Effectiveness*. In their opening argument, the authors forewarn, “Neither you nor, in some instances, even your doctor realizes that one out of every eight prescriptions filled – 169 million prescriptions costing over $1.1 billion in 1979 – is for a drug not considered effective by the government’s own standards.”256 The book meticulously lists 607 drug products deemed ineffective or unsafe, explicitly counseling patients to refuse doctors’ advice if they should be prescribed one of them.257 It also lists what it considers the “Top 30 Less-than-Effective Prescription Drugs,” which it notes were recently among the top 200 drugs prescribed in the US.

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257 The book reads as a help manual for navigating the health system, at one point listing common questions and providing answers. It reads, for example, “Is it all right for patients to challenge doctors who prescribe drugs listed in this book?” The answer: “Certainly. You will be doing yourself and the doctor a favor. By refusing to take such a drug, you will protect yourself from the needless risk of a bad reaction from a drug found not to be effective. You may also help the doctor because he or she too wants to avoid any bad reactions.” Ibid. 3.
The authors fashioned the book as a self-help manual of sorts, aimed at decreasing the degree to which patients turned to physicians for the treatment of minor ailments, hoping to in the process, “lessen the very dangerous gap between what the doctor knows and what the patient knows.”

Despite its encyclopedic structure and at times dry review of FDA policies and judicial pronouncements, the book was a phenomenal success. After Phil Donahue aired an hour-long conversation with one of its authors, sales skyrocketed. In November of 1981, Ray Walters of the New York Times observed, “To date, the book has sold 280,000 copies and the end isn’t in sight.” All said, it remained on the Times’ trade-paperback bestseller list for six weeks in a row and inspired the publication of a sequel investigating over-the-counter medications. Maintaining the self-help format of its predecessor, the volume told individuals which drugs to avoid and directed them to alternative, low toxicity treatments they could administer on their own. In these volumes’ pages, we identify a nascent tension regarding the wisdom and necessity of government sponsored regulatory reform. Some authors, such as Peter Temin, would argue that the appropriate response to the broken healthcare system was the empowerment of patients and corresponding dissolution of regulations concerning the purchase of potentially dangerous substances; historian Charles O. Jackson, on the other hand, harshly criticized such free

258 Andrea Pawlyna, “Readers Learning more about ‘Pills that Don’t Work,’” The Baltimore Sun. December 27, 1981; As author Sidney Wolfe observed, many individuals wrote to the publisher asking to purchase two copies of the book – one for themselves and the other to educate their physicians. One letter, for example, read, “[P]lease forward a copy to our pediatrician at the following address, since $6 is cheaper than an office visit for an ineffective prescription.” Allan Parachini, “A Prescription Dilemma: ‘Pills that Don’t Work,” Los Angeles Times, February 20, 1981.

259 Joel Kaufman, Over the Counter Pills that Don’t Work (New York: Pantheon Books, 1983).

260 In his 1980 text, Temin would endorse the “sacred right to self medication.” As it so happens, Peter Temin was the brother of Howard Temin, who in 1975 shared the Nobel Prize with David Baltimore and Renato Dulbecco for the discovery of reverse transcriptase, the enzyme that facilitates HIV’s replication. Peter Temin, Taking Your Medicine: Drug Regulation in the United States (Cambridge: Harvard University Press, 1980).
market positions, arguing for increased oversight for the good of the public.\textsuperscript{261}

The refraction of health issues through the consumer rights movement relocated the nexus of power in health decisions from the physicians’ office to the individual’s home. The best consumer, Nader intoned, was the educated consumer; correspondingly, the healthiest patient was s/he who more judiciously assessed the costs and benefits of taking any given medication. As physicians lacked the ability to navigate patients through the minefield that was the modern healthcare system, patients would have to take the lead, making health related decisions in the absence of clear information. Thus, in the tale of ineffective drugs – seemingly insignificant duds when compared to behemoths such as thalidomide – we uncover an interesting social phenomenon bearing resemblance to the precautionary principle operationalized in population level environmental policy debates through the 1970s and 1980s.\textsuperscript{262}

The final category of drugs I shall consider here comprises highly controversial psychotropic agents marketed and administered in large numbers through the 1960s and 1970s. Some may argue that this third category may be subsumed by the first; however, I maintain that the separation is both justified and useful. For unlike the drugs in the first category, many biomedical professionals conceived of the benefits offered by psychotropic agents as largely outweighing the harms they posed; indeed, they were incredibly successful, immensely popular, and resoundingly effective in producing their desired outcomes. Furthermore, unlike the other drugs thus considered, all of the agents in this third category effected biophysiological changes in the body. Finally, and perhaps most importantly, psychotropic agents provoked a rich public

\textsuperscript{261} Jackson in fact reviewed Temin’s work alongside \textit{Pills that Don’t Work} and found the latter to be the superior text. Charles O. Jackson, “A Difficult Pill to Swallow,” \textit{Reviews in Medical History} 9, no. 4 (1981): 516-520.

\textsuperscript{262} While it is beyond the scope of this analysis, a similar phenomenon may contribute to the decisions of anti-vaccination activists to withhold vaccination for themselves and their children.
debate articulating constructions of risk and harm unique from the other two categories.\footnote{For a detailed analysis of the rise of overmedication discourse pertaining to psychotropic drugs, see Susan Lynn Speaker, “Too Many Pills: Patients, Physicians, and the Myth of Overmedication in America, 1955-1980” (Ph.D. Dissertation, University of Pennsylvania, 1992). Throughout my research, I have benefited greatly from the various sources Speaker cites in her analysis.}

Several scholars have documented the phenomenal boom in production of medicinal psychotropics witnessed during the latter half of the 20th Century. As Nicolas Rasmussen has noted, through the 1960s, many physicians readily prescribed amphetamines to patients presenting any of a wide variety of symptoms of emotional disquietude. In short order, despite their powerful effects, amphetamines had become first-line treatment options, with one estimate holding that in 1969, enough pharmacologic amphetamine was produced to supply each American with 50 ten-milligram doses of the drugs.\footnote{See Nicolas Rasmussen, “America’s First Amphetamine Epidemic 1929–1971,” \textit{American Journal of Public Health} 98, no. 6 (2008): 974–985.} Furthermore, what amphetamines had done for low energy and depression, benzodiazepines would do for anxiety. In 1960, Hoffman-La Roche introduced Librium, the first benzodiazepine, later supplemented by Valium in 1963; both largely replaced anxiolytic drugs such as Miltown, popular in the 1950s. Benzodiazepines became phenomenally popular among clinicians, in many cases supplanting amphetamines as go-to medications in the clinical armamentarium. A 1979 Institute of Medicine conference report declared Valium the single most prescribed drug in not only the US, but the entire world. Rounding out the national list were Darvon, a powerful painkiller later removed from the market, and Librium, Valium’s analog.\footnote{Gerald L. Klerman, “Policy Issues on Provision of Mental Health Services in Primary Care Settings: A Federal View,” in \textit{Mental Health Services in General Health Care, Volume I: Conference Report} (Washington, D.C.: National Academy of Sciences, 1979): 39; Darvon, deemed by some individuals to be “the worst drug in history,” was later pulled from the market. See Allison Gandey, “Physicians Say Good Riddance to ‘Worst Drug in History,’” \textit{Medscape Medical News}, (February 2, 2011).} As several authors noted with alarm, given the remarkable
degree to which individuals sought recourse in psychotropic agents, it appeared that the nation had descended into an age of anxiety, a period famously articulated by poet W.H. Auden in his Pulitzer Prize winning eclogue of the same name.

It was perhaps only a matter of time before a nation ensnared in an age of anxiety would express anxiety with the skyrocketing national prescription rates of amphetamines and benzodiazepines. Growing realizations that medicinal psychotropics could become habit forming transformed national conversations surrounding the agents; the same drugs once depicted in saccharine pharmaceutical advertisements promising to transform overworked housewives into cheery, optimistic go-getters were soon associated with social unrest and crime. Despite these concerns, however, the biomedical industry expressed reluctance to decreasing its use of the agents – which as some critics maintained, were being given out like cough drops. We thus find a clear tension between discourses celebrating the drugs as panaceas and those indicting them as poisons. In 1984, for example, a text on adult psychopathology noted that the drugs were widely considered safe by physicians and lay persons alike, this despite reports from the Addiction Research Foundation – cited in the same text – arguing that minor tranquilizers had become a major cause of drug related toxicity.266

For some critics, mood-altering drugs presented a harm that transcended discussions of individual side effects; for they appeared to threaten the very fabric of social relations, robbing from individuals cohesive, community building experiences wrought through struggle and perseverance. Throughout the period, we find multiple, histrionic pronouncements of the mass

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medication of the American people. The nation, many feared, had lost its nerve, flocking to the medicine cabinet at the slightest sign of disquiet or strife. While these concerns harkened back to earlier fears regarding 1950s era anxiolytic drugs,\textsuperscript{267} the tenor of conversation was far more sensational. One claim that would eventually make its rounds in the scholarly literature was dramatically conveyed by psychiatrist Peter Tyrer, who in 1973 forewarned, “Sales of benzodiazepines are increasing in geometrical rather than arithmetic progression, and if the trend continues total tranquillisation of the population will soon be achieved.”\textsuperscript{268}

While Tyrer’s analysis may appear cut from the pages of a science fiction novel, he both tapped into and expressed concerns reverberating through society at the time. For in evaluations of the nation’s growing appetite for psychotropic drugs, we find a powerful moralism invoking individuals’ responsibility to uphold the values and principles that defined American life. Arthur Gordon, a well-respected editor of \textit{Good Housekeeping}, \textit{Cosmopolitan}, and \textit{Guidepost} magazines, implored individuals to reject mood-altering pills and “return to values of duty, obligation, and responsibility.”\textsuperscript{269} Similarly, newspaper columnists such as the author of a 1975 \textit{Los Angeles Times} article investigating the perils of Valium articulated the perception that psychotropics robbed individuals of opportunities for demonstrating both self-reliance and a willingness to face the world’s problems.\textsuperscript{270} The same columnist would in fact compare Valium to \textit{soma}, the dystopian cure introduced by Aldous Huxley in his 1932 novel \textit{Brave New World}:

\textsuperscript{267} In the late 1950s, for example, the \textit{Philadelphia Tribune} reported, “If sales of the new tranquilizing drugs are any indication, the entire nation is sitting in the anxious seat.” “Anti-Worry Pills Posing Great Peril,” \textit{Philadelphia Tribune}, February 26, 1957, 8.
“euphoric, narcotic, pleasantly hallucinant, [possessing] all the advantages of Christianity and alcohol and none of their defects.”

To its critics, individuals turned to drugs like Valium when they could no longer accept the world as it existed, and no longer found succor in the values that had been inculcated through institutions such as religion. Psychotropics drugs therefore represented a failure of both collective will and the traditions and institutions many argued were foundational to our nation’s values. Leslie Farber neatly conveyed this antipathy in a 1966 _New York Times Magazine_ article wherein he bemoaned, “It was only a question of time before man, in his desperation, would locate a divinity in drugs and on that artificial rock build his church.”

Interestingly, while in some analyses, psychotropic medications provided individuals an opportunity to cede control over their lives and engagement with society, for others they represented tools of oppression, used to subjugate segments of the population. Feminist authors, for example, argued that pharmaceutical corporations aggressively marketed psychotropic drugs to women – in 1979, then Representative Barbara Mikulski, speaking on behalf of the Congresswomen’s Caucus, note that 60 percent of psychotropic drugs, 70 percent of antidepressants, and 80 percent of amphetamines were prescribed to women. In 1963, Betty Friedan famously described the use of medications to address “the problem that has no name” – the lingering dissatisfaction many women experienced with the sharply delineated social roles they were expected to accept in the postwar years. For Friedan, in taking “tranquilizers like cough drops,” housewives interpreted what was in fact a broad social problem through a narrow

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271 Ibid.
clinical lens, accepting personal responsibility for their own oppression.\textsuperscript{274} Feminist concerns would eventually find expression in the popular press, with articles exploring the use of psychotropics among women appearing in the \textit{New York Times, Newsweek, Good Housekeeping} and \textit{Time} magazine. And, in 1966, a relatively obscure group of traveling feminist troubadours would spread Friedan’s message to the masses in a piece of popular faire. Famously invoking the dangers of Valium use, the group intoned, “Mother needs something today to calm her down. / And though she's not really ill, / there's a little yellow pill. / She goes running for the shelter of a mother's little helper.”\textsuperscript{275}

Thus, through the 1960s and 1970s, we locate a rich discursive tradition questioning the biomedical system’s reliance upon pharmacological treatments. In highlighting the harms posed by highly toxic drugs such as thalidomide, the theoretical harms posed by drugs of low efficacy, and the social harms posed by powerful psychotropics, authors expressed reservation with biomedicine’s core methods of treatment. Within a remarkably short period of time, we find the development within society of discourses questioning the magic bullets Paul Ehrlich had prophesied at the turn of the century. This reconceptualization of biomedical treatment would contribute to a gradual loosening of the patient’s tie to the Western biomedical system and resultant embrace of self-help and unorthodox healing strategies, much as 19\textsuperscript{th} Century fears regarding heroic medicine led individuals to embrace alternative healing systems. Also contributing to this loosening of ties were fundamental transformations in perceptions of the


\textsuperscript{275} Keith Richard and Mick Jagger, “Mothers Little Helper,” The Rolling Stones, Released July 2, 1966. The song peaked at #8 on the Billboard’s Singles Charts in 1966. At the end of the song, the mother dies of an overdose.
modern physician, with many authors questioning the competence and character of the nation’s once venerated healers. It is to this transformation in the public perception of the orthodox healer that I now turn.

A Fall from Grace: The Rise of Post-War Critiques of the Physician

As Susan Lynn Speaker has compellingly argued, through the 1950s and 1960s overmedication discourse generally centered opprobrium on the sins of the pharmaceutical industry, with congressional hearings investigating both the monopolistic practices and lax testing standards of the nation’s drug producing behemoths. By the 1970s, however, the public’s reproach expanded to include other professionals and institutions constitutive of the larger biomedical system, including most significantly the venerated and beloved physician. The link between patient and physician was far stronger than that which bound him to drug manufacturers; indeed, the doctor/patient bond had in fact been lionized, romanticized and celebrated as a core component of Western medicine. From the omnipotent and sacerdotal physicians portrayed in the 1950s television series *Medic*, to the humane and compassionate *Dr. Kildare*, to the dependable, morally grounded *Ben Casey*, physicians were viewed as heroic figures expected to connect with patients, know what was right for them and to fight for it.276 However, by the late 1960s and 1970s, many authors began to question both the ability and the resolve of physicians to achieve these ends. As Speaker has argued, the period witnessed a fundamental transformation in the social perception of orthodox healers – indeed, examining articles published in the 1970s, she concluded that a paltry ten percent presented physicians as

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capable and proficient authorities.\textsuperscript{277} The nation, it appeared, had begun to question both the competence and the character of its healers.

Critiques of physicians’ competence abounded in popular discussions through the 1970s, with authors arguing that doctors had lost the ability to shepherd patients through an increasingly bureaucratic biomedical system. The tone of attacks would, at times, slide into unabashed mudslinging, with some critics labeling physicians the “dupes of pharmaceutical companies’ marketing departments.”\textsuperscript{278} Few possessed an aptitude for slinging mud surpassing that of Edgar Berman, surgeon and personal physician to Hubert Humphrey who turned his acerbic wit on his own profession in 1976.\textsuperscript{279} His volume – the cover of which includes a bolded disclaimer warning “Your Doctor May be Hazardous to Your Health” – portrays physicians as incapable of recognizing or addressing the absurdities of their craft.\textsuperscript{280} In a characteristically sardonic style that would, from time to time, land him in hot water,\textsuperscript{281} Berman asks, “[I]s it the doctor’s fault

\textsuperscript{277} This is a jaw-dropping claim, which Speaker makes in the context of discussions of perceptions of overmedication in the 1960s and 1970s. To my knowledge, she does not discuss her methodology for calculating the figure. I am less interested in the specific ration she suggests than I am with its demonstration of a growing distrust in clinical practice. Speaker, “Too Many Pills,” 53.


\textsuperscript{279} Interestingly, Humphrey presided over Senate hearings investigating the FDA’s failure to comply with the Kefauver-Harris Amendment. A trained pharmacist, he had worked as a young man in his family’s farmer drugstore, which had generated some acclaim for selling patent medications promising to cure the ailments of people and pigs alike.


\textsuperscript{281} Berman was a controversial figure who famously asserted that women were unable to hold leadership positions due to their “raging hormonal imbalance.” A self-declared chauvinist, his apologists would argue that his vitriol was satirical – while his fears of the biomedical system’s failures were quite real. See, for example, Judy Klemesrud, “A Surgeon and Author Explains His Chauvinism,” \textit{New York Times}, August 22, 1982.
when he gives a patient MER 29 to lower cholesterol (by the same wonderful people that gave us thalidomide) and it causes cataracts? Was it not on the best advice of a detail man who has a college education with an A.B. degree in Urban Studies? If you can’t trust a multibillion-dollar industry like pharmaceutical firms, whom can you trust?”

Berman was not alone in his unsettling suspicion that physicians had become locked into a detrimental system of care controlled by corporate interests. Revisiting the chapter Philip R. Lee penned on overmedication, we find a review of clinical practice that, while notably less incendiary than Berman’s, was no less insightful. In a brief discussion involving what he terms the “symbolism” of prescription practices, the measured and dispassionate Lee suggests that physicians overprescribed drugs because they had been conditioned to believe that they were necessary components of clinical care. If this were true, then doctors were not capable of challenging overprescription trends because the body of knowledge and practices they brought to bear upon human illness, and by extension their legitimacy as professional healers, were all premised upon the provisioning of pharmacologic agents. In discussing the symbolic meaning of prescription, Lee cites a stunning claim Edmund Pellegrino made in a 1976 speech given before the American Association for the Advancement of Science. “[I]t is prescribing which makes a clinical situation legitimately medical,” Pellegrino deduced. “In its absence, [the physician] may regard the patient’s problem as a personal or social matter outside the domain of

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283 This limitation on physician behavior strikes me as either an expression of or in some way reminiscent of Pierre Bourdieu’s conceptualization of habitus. As he explained, “The habitus is not only a structuring structure, which organizes practices and the perception of practices, but also a structured structure: the principle of division into logical classes which organizes the perception of the social world is itself the product of internalization of the division into social classes.” Pierre Bourdieu, *Distinction: A Social Critique of the Judgement of Taste* (London: Routledge, 1986).
medicine entirely.”284 Lee and Pelligrino’s fears dovetailed nicely with arguments made by health economist Charlotte Muller, who in 1971 argued that physicians relied upon prescriptions to designate the end of a clinical encounter and to express compassion and concern to patients.285 For some authors, these concerns reverberated in the context of overmedication fears, with one 1960 Science Newsletter writer maintaining, “It is the doctors who need those tranquilizers, not the patient. Perhaps general practitioners are doling out the calming pills to relieve their own anxieties which develop when they do not know what to do for a patient.”286

Several authors would go further still, suggesting that physicians’ tendency to overmedicate extended beyond the prescription of drugs to include other clinical interventions as well. The problem, it appeared, was a cultural one – professional practice favored activist physicians, who were inclined to intervene forcefully even when intervention was not indicated. Perhaps one of the most well respected authors to engage this topic was sociologist Eliot Freidson, who famously wrote on what he termed the “bias toward illness in everyday practice.”287 Physicians, he argued, were inclined to a certain degree of clinical activism or

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284 Edmund Pellegrino, “Prescribing and Drug Ingestion: Symbols and Substances,” Paper delivered at the American Association for the Advancement of Science Annual Meeting. February, 1976. Cited in Lee, “America is an Overmedicated Society,” 1980, 6. As a bioethicist, Pellegrino was concerned with the changing character of health care and committed to articulating the virtues that defined medicine and underpinned the doctor/patient relationship. However, he had little stomach for attacks on the health care system he viewed as radical or destructive, frowning upon Illich’s 1976 Medical Nemesis. For a discussion, see Robert J. Barnet, “Ivan Illich and the Nemesis of Medicine,” Medicine, Health Care and Philosophy 6 (2003): 273-286.


287 While Freidson argued that this bias pervaded standard practice, it was provoked and exacerbated by the work of “moral entrepreneurs” – physicians who strove “to create in the
interventionism, causing them to recommend treatments or procedures even when none were indicated. To support his claims, Freidson recounted the results of a 1934 study investigating pediatricians’ tendency to recommend tonsillectomies. The study began with 1,000 children, 611 of whom previously had their tonsils removed. A group of physicians was asked to review the 389 children with intact tonsils, and they deemed 174 (45%) of the group in need of tonsillectomies. The researchers then took the remaining 215 children with presumably healthy tonsils and presented them to a new group of physicians, at which point 99 (46%) were selected for the same procedure. The remaining 116 children were presented to a third group of physicians and, once more, roughly the same percentage (44%) was identified as needing surgery. Freidson thus concluded that, “Like the teacher who gives a certain proportion of failing grades no matter what the over-all quality of his class, so the physicians studied were inclined to remove a certain proportion of tonsils no matter what the range of signs observed.”

Not all critics would share the same measured, scholarly detachment from the issue. Three years after the publication of Freidson’s *Profession of Medicine*, Louise Lerner, affiliated with the left-leaning Health Policy Advisory Center, would argue, “the doctor is trained and expected to be an activist, to engage in active intervention rather than passive observation. And what we get is

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Some authors would in fact argue that physicians’ propensity for resorting to aggressive surgical or pharmacologic interventions stemmed from their fundamental inability to truly understand an increasingly complex, technologized pharmacopeia. As Michael G. Michaelson argued in a sweeping 1971 *New York Review of Books* piece, everyday physicians were ill-equipped to evaluate new medical devices and treatments and were thus inclined to buy almost anything, “the flashier it looks and sounds, the better.” Citing Harry F. Dowling’s damning 1970 work *Medicines for Man*, Michaelson suggested that physicians were effectively under the dictatorial control of the pharmaceutical industry, incapable of challenging its hegemony. For philosopher and religious scholar Jacob Needleman, the problem ran deeper still. Physicians, he maintained, had glorified science to the point that they were no longer capable of or willing to question it. In a beautiful passage printed in his 1985 epistolary volume entitled *The Way of the Physician*, Needleman addresses an unseen doctor:

“[In the past,] it was not science you believed in, it was man. But today it is science you believe in and science, great as it is when it is good, is less than man, far less. When science was new to you, you believed in using it — but you were so very careful about it. You were always watching, looking, never taking anything for granted when you used

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289 Louise Lander, *Defective Medicine* (New York: Farrar, Straus, Giroux, 1978): 38. Cited in Inlander, *Medicine on Trial*, 201; John Ehrenreich would later argue, “The picture of the medical system that emerges from Freidson’s description is that of some vast, expansionist, and itself uncontrolled regulatory apparatus…The ranks of the ‘sick’ swell, but there is no way that this army of ‘deviants’ can turn against the social order; each marches to a separate drummer, and submits to his or her own medical ‘management.’” Ehrenreich, “Introduction: The Cultural Crisis,” 47.

290 Others would argue that patients were under the spell of science. John C. Burnham, for example, cites a comment made by popular author Evelyn Barkins in 1952: “Most patients are as completely under the supposedly scientific yoke of modern medicine as any primitive savage is under the superstitious serfdom of a tribal witch doctor.” See John C. Burnham, “America’s Golden Age: What Happened to It?” *Science* 215 (19 March 1982): 1475.
the methods and the instruments of science. You were an observer and your eyes were in your heart as well as your head. But now science is no longer new for you. You no longer put it to the test when you act. More important, it no longer puts you to the test. It has swallowed your mind.”

It is interesting to note that in the above mentioned analyses of clinical incompetence – be it Freidson’s, Pellegrino’s or Needleman’s – we identify a movement toward victimizing the physician. Doctors may make poor decisions, overmedicate their patients, employ methodologies for recommending surgical procedures reminiscent of elementary school rubrics, but yet the moral outrage one might expect to find directed at them is tempered. Indeed, many discussions of clinical incapacity and inability suggested that physicians made poor decisions because they had become entangled in the same broken system as patients. In such framings, they too were susceptible to the avarice of a pharmaceutical system bloated with power. In other cases, their errors are explained as the consequence of an entrenched system of reasoning which taught them to believe that what they were doing was in fact good medicine.

This explanation of clinical failure is fascinating, for it is in fact a *structural* defense impugning the underlying cultural practices subtending clinical care. However, through the 1950s, 1960 and 1970s, victimization narratives would come under fire for two reasons. First, in defending physicians by assailing the professional institutions and practices that gave them meaning, the narratives conceded the very structural problems that motivated radical critiques in the first place. And second, as one might readily intuit from several of the authors thus considered, by the 1970s many critics directly challenged the notion that physicians were indeed

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innocent bystanders in a broken system, arguing instead that they had directly and intentionally contributed to the problem. The issue, these critics maintained, was not merely one of competence, but of character. And while an exhaustive review of the factors attending transformations in social constructions of the character of physicians is beyond the scope of this analysis, three contributing factors deserve mention, as they would anchor late 20th Century unorthodox health activist movements. They included, (i) the proliferation of critiques associating physicians with self-interested businessmen who systematically prioritized profit and efficiency over patient care, (ii) the perception that professional organizations such as the American Medical Association had squandered the trust society had placed in it through gratuitously self-serving political campaigns, and (iii) allegations that medicine systematically harmed disempowered subpopulations through the selective provisioning of excessive or injurious care. I shall briefly consider each of these issues in turn.

In mid-twentieth century discussions interrogating the failings of clinical medicine, several authors invoked a metaphor whose meaning resonated with readers of the period: the highly efficient but coolly impersonal assembly line. To many, medicine had engaged in a Faustian bargain of sorts, sacrificing its connection with patients for efficient service defined by

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I do not separately consider here the defense for physicians that would justify the harm they caused patients as a function of their acquiescence to the demands of an increasingly vocal patient population, for I believe it is merely a further expression of the cultural and structural arguments considered above. We furthermore must question any argument which recognizes the autonomy of patients only to impugn them for the actions of those in greater positions of power and prestige; Also, as I noted earlier, reconceptualizations of risk through the 1960s would contribute to significant increases in the number of medical malpractice suits in the latter half of the 20th Century. This increase was likely both characteristic of and contributive to the transformations in social conceptions of the physician at the time. For further discussion regarding the rise of medical malpractice suits, see J.C. Mohr, “American Medical Malpractice Litigation in Historical Perspective,” *Journal of the American Medical Association* 283, no. 13 (2000): 1731-7.
an increasingly specialized and fragmented clinical model. The problems with clinical medicine were so well known that, in 1957, an attorney writing in the *Journal of the American Bar Association* would warn his colleagues to resist making the same mistakes physicians had made in embracing a model defined by rampant specialization. “Today’s patients often feel like a piece of machinery on an assembly line,” he wrote, “with one man to put the rivets in the head and another to tighten the screws in the elbow. The doctor frequently doesn’t even know their names.”293 One might be tempted to argue that here, as in the cases cited above, the physician is conceived of as a victim in a bureaucratic system, analogous to the immigrant cogs in the industrial machine. However, the attorney’s admonishment belies such an interpretation, for he wrote to implore his colleagues to resist making the same *decisions physicians made*. Indeed, the notion that physicians were complicit in the rise of assembly line medicine appeared in popular literature through the 1950s and 1960s. A 1954 *American Magazine* article, for example, laid bare the irony of a clinical profession which demanded that patients recognize the “high priesthood of medicine” even as they processed bodies “on an assembly-line or chain-store basis, as if they were running a mass-production manufacturing or retail business.”294

By all accounts, specialization was in vogue by the mid-twentieth century. Of the 271,000 physicians working in the US in 1969, all but 58,000 limited their practice to specialties,295 quite a transformation from the 1930s, when general practitioners outnumbered specialists by a factor of five to one.296 Furthermore, far from a phenomenon that swept up

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unwilling and unsuspecting physicians in its wake, specialization seemed driven by the professional and financial interests of medical practitioners. By assigning physicians to specialized domains of expertise, biomedicine granted healers dominion over a narrow range of increasingly complex technological and pharmacological innovations. As wielders of such nuanced knowledge, specialists watched as their salaries rose. A 1951 report issued by the US Department of Commerce would in fact suggest that the growth of specialization had been a key factor in the transformation of physician income through the 20th Century.297 For historian Rosemary Stevens, the most concerning aspect of the specialization of American medicine lay in specialists’ failure to work collaboratively with one another, recognizing the complex ways in which disease and health were constituted. The illustrious specialists, she bemoaned, opted to “take the stand of isolationism, surveying with jaundiced eyes and outraged complacency the social facts of medicine in the second half of the twentieth century.”298

By the 1970s, critiques of physicians’ complicity in producing and sustaining the nation’s broken health care system became much more explicit. Let us reconsider, for example, the attack launched by surgeon Edgar Berman. While it is possible to locate in his argument a critique of the underlying culture of medicine, Berman pulled few punches in his discussion of the role physicians played in making it that way. Indeed, the volume’s title alone – *The Solid Gold*...

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298 Rosemary Stevens, *American Medicine and the Public Interest*, 421-422; Susan Lynn Speaker (1992) echoes this sentiment: “[W]ith seeming abandon, physicians used new drugs, new procedures and diagnostic testing, increasing the cost of even basic health care. But beneath the bottom line of dollar costs, Americans, according to public opinion polls, complained just as much about the social price, that is, the growing complexity and impersonal nature of modern medicine. The growth of medical knowledge, technology and specialization, while enabling better treatment, also encouraged ‘the fragmentation of the patient into body parts, each with its own practitioners.’” Susan Lynn Speaker, “Too Many Pills,” 111.
Stethoscope – pithily conveys Berman’s belief that physicians regularly sacrificed patient care for financial gain. As Berman explains it, the once sacrosanct doctor/patient relationship had been sacrificed on the altar of industrial efficiency:

“It happened the moment the computer found out that any time over nine minutes and thirty-three seconds spent with a patient is a bad investment. Every minute over that figure costs the average M.D. a minimum of 9 percent on the bank loan for his wife’s new mink and the wall-to-wall carpet yet to be installed. How much rapport can be built up in a ten-minute contact in a cold cubicle, with a patient who’s waited for four hours with no lunch and a doctor who has twenty more bodies to probe before dinner? Even to remember what each looked like last time around is a triumph in this revolving-door routine.”

While one might dismiss Berman’s critique as the venomous vituperations of a noted curmudgeon, his contemporaries expressed remarkably similar concerns. In 1979, for example, the esteemed Yale psychologist Seymour Sarason discussed a survey he had conducted among premedical students. In the survey, he asked the participants what satisfaction they expected to receive from their careers in medicine. While he thought nothing of their answers at the time, he was later struck with the realization that in their discussions of the allure of high income, travel, interesting work and high social status, none of the respondents spoke of an interest in helping patients:

“[I]t dawned on me one day that I could not recall a single interview during which the student had said – spontaneously or in regard to any question or discussion in the hour or more long interview – that he or she had chosen medicine to help people, to contribute in

299 Berman, Solid Gold Stethoscope, 12.
some selfless or idealistic way to the betterment of society, to put any form of personal aggrandizement secondary to service to others and to the improvement of a larger scheme of things…there was a subliminal part of my thinking that did expect that some of these students, at least one or two, would describe themselves in relation to a medical career in idealistic terms. None had, although there had been ample opportunity for them to do so.  

For some, the naked self-interest exhibited by physicians merely confirmed an observation made by the sharp-witted George Bernard Shaw half a century earlier. Writing in the preface to his 1907 play *The Doctor’s Dilemma*, the polemicist quipped, “That any sane nation, having observed that you could provide for the supply of bread by giving bakers a pecuniary interest in baking for you, should go on to give a surgeon a pecuniary interest in cutting off your leg, is enough to make one despair of political humanity.”

The transformation of the image of the American physician from a priest-like healer into a self-interested businessperson was further facilitated by a controversial 1975 Federal Trade Commission ruling requiring that the American Medical Association lift the ban on advertising it had implemented in the mid 19th Century. The issue provoked profound disagreement within the medical profession, with several fearful that such an act would further tarnish the clinician’s reputation. In a 1976 article in the *New England Journal of Medicine*, editor Franz J. Ingelfinger

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argued that in differentiating mainstream physicians from hucksters and quacks, the ban had preserved patients’ trust in regular medicine. Noting that medicine had endured a powerful deprofessionalization movement and precipitous decline in the confidence of the public, Ingelfinger argued that for clinical medicine to survive, its leaders had to continue to fight open advertising among physicians. “If the FTC has its way, and doctors succumb to hucksterism,” he wrote, “no one need worry any longer about deprofessionalization. The process will have run its full course, for what better way than advertising to annihilate trust and confidence, what more effective means to convert medical practice into a purely commercial enterprise?”

Writing thirty years after Ingelfinger’s warning, Nestor D. Tomycz would confirm all that he said, revealing that in demanding the lift of the ban, FTC Chairman Michael B. Pertshuk admitted his intent to treat medicine as a business which responded to the same marketplace influences as other industries. The effort appears to have succeeded. For, as Tomycz argues, “If American medicine has lost some of its prestige in the last few decades, perhaps it is because the best advertisement for physicians was the original decision not to advertise.”

While the increasingly specialized, fragmentary, and impersonal nature of clinical care threatened to undermine the relationship between physician and patient, a second powerful critique arose through the 1950s, 1960s and 1970s contending that physicians sought to trade on the sacred doctor/patient bond to sway public opinion on key pieces of national health

304 Ibid. 27.
legislation. A central player in debates surrounding this topic was the American Medical Association, which throughout the mid-to-late 20th Century launched myriad campaigns opposing universal health care platforms. The AMA had in fact long attracted the criticism of many authors who argued that its petty political maneuverings tainted medicine, linking it to lesser trades. John C. Burnham has argued that public opprobrium with the physician group dated back to before World War II, and further deepened the association between the physician and the dishonest businessman. To support his argument, he cites a 1943 *American Mercury* column wherein Waldemar Kaempffert declared organized medicine’s social outlook to be “scarcely distinguishable from that of a plumber’s union.”

One of the most apoplectic critiques of professional medicine’s meddling in national debates regarding universal health care is found in a 1951 article penned by historian Bernard DeVoto in *Harper’s Magazine.* In it, DeVoto describes AMA literature he had received in the mail urging him to voice his opposition to the compulsory health insurance plan debated in Congress at the time. In a piece dripping with venom, DeVoto decries the AMA propaganda, which he argues cheapened the image of the noble, self-sacrificial family doctor by suggesting that the nation needed his protection from not only infectious ills, but the perils of “political enslavement” as well. The historian’s attack is cogent and cutting, impugning everything from the AMA’s poorly disguised antisocialist invective to the hubris of a profession feverishly grasping at the reins of power even as it failed to, in his opinion, adequately treat the nation’s epidemic of chronic disease. But most of all, he argues that physicians had foolishly sullied the

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307 DeVoto 1951, pp. 57.
precious bond between healer and patient:

“Your ad speaks of the trust between physician and patient, so noble it says here, so sacred, so certain to be destroyed by what the propaganda calls socialism. But I do not like any kind of solicitation that trades on prestige or on such fears and hopes as illness necessarily involves, and I will not tolerate political solicitation in a relationship of trust. Solicitors who call at my house must use the back door.”

The AMA’s efforts to derail public health legislation persisted through the late 1950s, 1960s and 1970s, with various authors decrying their deceptive and manipulative disinformation campaigns. Richard Carter’s *The Doctor Business*, published in 1958, presented a stinging attack on the AMA and was in fact identified by one writer as a key exponent in changing public perceptions of physicians. In the 1960s, Richard Harris would meticulously chronicle the AMA’s efforts to derail landmark Medicare legislation, published first as a series of articles in the *New Yorker*, and later as a bounded volume. Similarly, in 1971 Michael G. Michaelson published a review of nine volumes critical of medicine published between 1967 and 1971.

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308 Ibid.
many ways, the review constituted its own, tenth addition to the series, with Michaelson making clear his revulsion with the state of American healthcare, arguing for more democratic, patient driven care.\textsuperscript{312}

While the first two factors thus considered impugned the character of physicians by arguing that they were self-interested businessmen who sacrificed the doctor/patient relationship for personal, professional or political gain, critiques flowing from the final factor were perhaps even more nefarious. For they maintained that contemporary medicine systematically harmed particular subpopulations through the selective provisioning of injurious care. In these critiques, physicians were seen as possessing phenomenal power, which they wielded in a deeply biased manner to dictate and define the lived experiences of their patients. Indeed, exponents of this interpretation of clinical care would argue that, far from a benevolent institution, medicine exerted tremendous social control over the population, assuming a power previously reserved for religious and legal institutions.\textsuperscript{313}

As Susan Lynn Speaker has noted, social control theory had been cited in discussions of medicine – in particular psychiatry – as early as the 1960s, most notably in the writings of R.D. Laing and Thomas Szasz. The antipsychiatry movement Laing and Szasz would inspire maintained that psychiatry pathologized normal states of being, coercing individuals – frequently those disempowered and economically dependent upon others – to accept care they did not want.

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\textsuperscript{312} It is worth noting that John Knowles would become embroiled in the AMA’s campaign against social medicine. Early in his presidency, Richard Nixon sought to appoint Knowles as Assistant Secretary of Health, Education and Welfare for health and scientific affairs, but the AMA blocked the move by operating through Senator Everett Dirkson, who challenged Knowles’s support of universal healthcare. For a discussion of the topic, see Dean Kotlowsky, “The Knowles Affair: Nixon’s Self-Inflicted Wound,” \textit{Presidential Studies Quarterly} 30, no. 3. (2000): 443-463.

\textsuperscript{313} See, for example, Zola. “Medicine as an Institution of Social Control.”
or need. In effect, Szaszian critiques were themselves an expression of the overmedication phenomenon discussed earlier. However, whereas the aforementioned critics interpreted the overutilization of pills and invasive surgical procedures as structural signs of an irrational system or the effects of systematized self-interest, Szasz saw the diagnosis and treatment of mental disorders as a potent effort to medicalize that which society did not understand or like.314

Throughout his career, he would argue that psychiatry medicalized countless states that were not true diseases, including homosexuality, hysteria, depression, schizophrenia, pedophilia, sexual perversions and drug addiction.315 A highly controversial figure, he argued that psychiatrists wielded a power to subjugate and suppress individuals on par with slavery, and in fact would throughout his career argue that Americans were tasked with “abolishing psychiatric slavery.”316

While the antipsychiatry movement directly and stridently accused physicians of coercing patients, it was not alone in accusing medicine of policing and controlling the bodies of the dejected, despised and disempowered. As noted earlier, the feminist movement would accuse mainstream physicians of practicing a deeply sexist medicine, registered in their overmedication of women with psychotropics, frequent recourse to unnecessary gynecologic procedures, and the medicalization of natural (that is to say, unavoidable) stages and phases of women’s lives. The first edition of Our Bodies, Ourselves would in fact cite Carter’s The Doctor Business in arguing that one third of all hysterectomies conducted in a leading hospital were performed on women

315 See, for example, a collection of Szasz’s essays published as The Medicalization of Everyday Life (Syracuse, NY: Syracuse University Press, 2007); See also review of his work by Jeffrey Poland, Metapsychology Online Review 12, no. 35, (2008) http://metapsychology.mentalhelp.net/poe/view_doc.php?type=book&id=4438
who suffered from no disease or deformity.\textsuperscript{317} While the authors of the Boston Women’s Health Collective granted that financial interest played a role in these unnecessary procedures, they argued that women were specifically targeted as a result of the operationalization of deep and trenchant sexism throughout medical practice.\textsuperscript{318} In the face of such potent critiques, physicians would find little succor in victimization narratives. Invoking language which had appeared in \textit{Fortune Magazine}, the Collective argued, “[T]he doctors created the system. They run it. And they are the most formidable obstacle to its improvement. It is the doctor who decides which patients will be treated, where, under what conditions, and for what fee; who will enter the hospital, for what therapy, and for how long; what drugs will be purchased and in what quantities.”\textsuperscript{319} Indeed, the feminist framing of the character of mainstream physicians underscores the complex ways in which apologists and critics mobilized structural arguments to support their aims. Biomedical sympathizers, for example, would cite structural factors to exonerate physicians from responsibility for harms wrought by biomedicine, while at the same time ignoring the structural critiques of “radical” detractors. Similarly, feminists would lament biomedicine’s failure to explore structural factors influencing health outcomes while

\textsuperscript{317} The authors cite figures published by Carter \textit{The Doctor Business}; See Boston Women’s Health Collective, \textit{Women and Their Bodies: A Course} (Boston: Boston Women’s Health Collective, 1970): 183. This was the initial name of \textit{Our Bodies, Ourselves}.

\textsuperscript{318} Indeed, they inquire of the reader, “How many remunerative testectomies do you think are done?” Boston Women’s Health Collective, \textit{Women and Their Bodies}, 183.

\textsuperscript{319} Here, they cite Dan Cordtz, “Change Begins in the Doctor’s Office,” \textit{Fortune} (January 1970): 84; Michaelson echoed many of these feminist critiques in his 1971 piece, questioning the frequent recourse by physicians to hysterectomies and mastectomies. He additionally argued that “pregnancy and childbirth are now treated by male doctors as routine diseases; the medical hierarchy is exclusively male-dominated; many hysterectomies and even mastectomies are performed without sound medical reasons; labor is too often induced, especially in the case of poor and black women, by oxytocin—an unsafe procedure when unnecessarily done—so that the woman will deliver at the doctor’s convenience.” Michaelson, “The Coming Medical War”; Ehrenreich (1978) would discuss similar issues, considering allegations of structural racism directed at orthodox medicine through the late 1960s and 1970s by Black and Latin liberationists. Ehrenreich, “Introduction: The Cultural Crisis.”
disregarding the ways in which physicians were themselves subject to these same entrenched, structural forces.

Thus, through the 1950s, 1960s and 1970s, critics launched impassioned attacks on the practice of biomedicine, impugning the competence and character of the once venerated and beloved physician. In my brief analysis, I have identified multiple intersecting narratives presenting physicians as puppets of avaricious pharmaceutical corporations, rapacious entrepreneurs willing to sacrifice patient health for personal gain, opportunistic propagandists prepared to trade patient trust to further political agendas, and an empowered nobility eager to recapitulate patterns of oppression and subjugation. In some cases, these critiques of clinical competence and character were tempered through the invocation of victimization narratives, which spared the healer at the expense of the larger institutional and cultural system through which s/he amassed power. However, in the aggregate, both condemnation and victimization narratives sullied the reputation of orthodox medicine.320

In challenging the character of both healer and healing system, these critiques would

320 I must note that my discussion of the public framing of biomedicine challenges the common perception that physicians enjoyed tremendous respect through the mid-to-late 20th Century. Critics may, for example, highlight opinion surveys and polls indicating that members of the public rated physicians quite high on prestige indices. However, as William A. Gamson and Howard Schuman have argued, prestige surveys likely mask what is in reality a complex relationship between members of the public and professions. Their research, for example, demonstrated that, “It is the very people who rank the occupation of physician at the top of the prestige hierarchy who tend to show relatively more hostility toward doctors when the questioning shifts to concrete matters of occupational performance...ambivalence may be the characteristic attitude of those who accord them the highest prestige.” To underscore the difficulty of interpreting prestige surveys, they furthermore point to a 1922 study conducted by Jacob Feldman wherein "doctors were described as rapacious, pompous, arrogant, inconsiderate, and so on ... at a time when... the medical profession was supposedly accorded nothing but deification by a grateful populace.” William A. Gamson and Howard Schuman, “Some Undercurrents in the Prestige of Physicians,” *American Journal of Sociology* 68, no. 4 (1963): 463-470.
reject resolution through the empanelment of oversight committees or the application of rights
based ethical paradigms. Extending autonomy to its logical conclusion, they counseled self-care
and resolute suspicion with the biomedical orthodoxy, in the process earning the opprobrium of
an emerging professional discipline purportedly built upon the archetype of the autonomous
man. Impassioned and impolitic, stimulating and seditious, they were indeed the radical rabble-
rousers who endeavored to achieve Rothman’s maxim of looking at the world from the vantage
point of the objects of authority – and in so doing, argued that it was the wielders themselves
who posed the greatest threat to health and well-being.

Of all of the radical rabble-rousers of the 1970s, few possessed the capacity to attract the
attention generated by Ivan Illich, both in the years he wrote and, as the Stevens/Jonsen debate
makes abundantly clear, in those that followed.\footnote{I have chosen to focus my analysis here on Illich’s work, as he was perhaps the most famous and infamous of antimedicine critics, likely surpassed only by Thomas Szasz. However, Illich is more relevant for our current study due to his broad critique of medical practice in comparison to Szasz’s narrower focus on psychiatry. Among Illich’s compatriots in his discussion of medicine as a form of social control, E. Richard Brown names Barbara and John Ehrenreich, Irving Kenneth Zola, John Ehrenreich, Waitzkin and Waterman, Thomas Szasz and the classic works of Talcott Parsons. See E. Richard Brown, \textit{Rockefeller Medicine Men} (Berkeley: University of California Press, 1979): 270, n103.} Indeed, we recognize in Illich’s analysis many
of the objections to clinical medicine outlined above. However, Illich’s work was especially
controversial for his detailed analysis of the ways in which medicine served as a form of social
control that systematically \textit{and unavoidably} harmed patients. His writings earned the opprobrium
of many scholars of medicine, Jonsen included, and it is not difficult to see why. For Illich’s
critique was expansive and exacting, cutting a rift that was at once broad and deep. In his
impassioned review of medical failings, he anathematized the medical system for structurally
disempowering patients and, in so doing, causing them harm. He covered a vast array of topics,
and admittedly failed to articulate a consistent or easily summarized position on many of them.
In his far-reaching analysis, he was furthermore prone to occasional acts of histrionics, penning statements destined to attract the condemnation of more orthodox readers.\(^{322}\) He indeed was a provocateur, who endeavored not only to shed light on the failings of an immensely powerful system, but to offer recommendations for wresting from that system individual freedom and autonomy. In sum, he offered a powerful and important critique of the biomedical system – one that scholars, including bioethicists, would ignore at their own peril.

The Prophet of Cuernavaca: Ivan Illich’s Radical Dissent

Referred to by one contemporary author as a “quasi-mythical being,” Ivan Illich was, by virtually every measure, one of the most fascinating critics of modern medicine.\(^{323}\) The child of a German Jewish mother and Croatian father, he was a true polymath and polyglot who throughout his life would speak German, Italian, French, Serbo-Croatian, Greek, Latin, Spanish and English. After earning graduate degrees in history, philosophy and theology, he was ordained a Catholic priest and, while expected to move up the ranks in the Holy See, requested instead an assignment at a parish in New York’s Washington Heights. As journalist Chase Madar has noted, his time in the Manhattan community would go on to influence his anti-authoritarian outlook: “The experience of tending to immigrant parishioners as they got flashfried in urban modernity left a lasting impression of the grotesque inadequacy of large-scale, rationally administrated institutions in dealing with basic human needs.”\(^{324}\) Recognized for his unique intellect, Illich was

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\(^{322}\) One favorite paroxysm held that, “Among murderous institutional torts, only modern malnutrition injures more people than iatrogenic disease in its various manifestations.” Illich, *Medical Nemesis*, 26.

\(^{323}\) Chase Madar. “The People's Priest.”

\(^{324}\) Ibid.
soon sent to Puerto Rico to serve as the vice rector of the Catholic University in Ponce. Once there, he made waves among church leaders, refusing to accede to the indoctrination of missionaries and, under a pseudonym, espousing controversial views on topics such as contraception. He was summarily sent to Cuernavaca, Mexico to prepare North American Catholic church workers to serve in Latin America but, true to form, opted instead to establish an ecclesial community supporting grass-roots lay initiatives and attracting independent thinking priests and nuns who had been expelled from other South American churches. A career firebrand, Illich soon fell out of favor once more with church superiors; this time, however, as Harvard Professor of Divinity Henry Cox has explained, “it appeared that Brer Rabbit had finally reached the briar patch.” Summoned before the Sacred Congregation for the Doctrine of the Faith in Rome, Illich was severely chastised and in 1969 requested a release from his priestly vows.

Through the 1970s and early 1980s, Illich penned several works critical of the systems and structures that had come to define and organize modern society. He advocated a disestablishment philosophy, arguing that the very systems man had invented to enhance his life—education, transportation, and medicine among them—effectively disabled him from acting on his own. Through their pernicious and malignant spread, these systems became “radical monopolies,” destroying individuals’ abilities to act freely and independently in an increasingly

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325 There is some disagreement regarding Illich’s move to Puerto Rico. Harvard Professor of Divinity Henry Cox argues that Illich left after falling out of favor with Cardinal Spellman, whereas Chase Madar and Todd Hartch argue that the Cardinal in fact sent Illich to Puerto Rico recognizing his potential (only later to regret the move). See Henry Cox, “Appreciation: A Prophet, a Teacher, a Realistic Dreamer,” National Catholic Reporter (December 20, 2002); Todd Hartch, The Prophet of Cuernavaca: Ivan Illich and the Crisis of the West (Oxford: Oxford University Press, 2015).


327 Cox “Appreciation.”
regimented world. “Ordinary monopolies corner the market,” he wrote, “radical monopolies
disable people from doing or making things on their own…Intensive education turns autodidacts
into unemployables, intensive agriculture destroys the subsistence farmer, and the deployment of
cosmopolitan’s self-control.”328 For a period, the world was bewitched by
Illich’s controversial ministrations. As Madar has noted, “His books were bestsellers, his lectures
jammed auditoriums, his essays appeared in the New York Review of Books (back when it was
radical, fun, and widely read) and even the square-john Saturday Review.”329

In 1975, Illich would turn his attention to the state of the modern medical system,
penning the expansive and deeply divisive Medical Nemesis: The Expropriation of Health. In it,
he argued that the biomedical health care system was in fact responsible for a great deal of
human suffering, indicting it on three counts of iatrogenesis, or physician induced harm. The first
and most visible category of harm, clinical iatrogenesis, is the most recognizable to a modern
audience, and in fact subsumes many of the harms considered earlier in this chapter. Included
within its purview were the dangers posed by exposure to toxic, useless, and addictive drugs, in
addition to unnecessary and potentially dangerous medical procedures. Had Illich ended his
argument here, his critique would have been one of the many articulations of the failings of the
biomedical system to adequately police the production and administration of care. However, he
felt very strongly that clinical iatrogenesis was but a symptom of deeper harms wrought by an
incredibly powerful medical system. Demonstrating his penchant for romantic and allegorical
imagery, he argued, “[A]ny charge against medicine for the clinical damage it causes constitutes
only the first step in the indictment of pathogenic medicine. The trail beaten in the harvest is only

328 Illich, Medical Nemesis, 42.
a reminder of the greater damage done by the baron to the village that his hunt overruns.”

Illich’s second and third categories of iatrogeneses together form his most damning critique of contemporary medical practice. In his formulation of social iatrogenesis, Illich rails against the medicalization of life, wherein much of everyday experience is subsumed under the authority of the physician. As he wrote, “Once a society is so organized that medicine can transform people into patients because they are unborn, newborn, menopausal, or at some other ‘age of risk,’ the population inevitably loses some of its autonomy to its healers.” Social iatrogenesis constituted a category of harm that was at once deeper and more pernicious than clinical iatrogenesis, for it occurred invisibly, in the diffusion of the medical system into all areas of life. In cultural iatrogenesis, Illich expanded upon the consequences of social iatrogenesis, arguing that as a result of the proliferation of an increasingly hegemonic health system, individuals lost the ability to conceive of health and illness in a manner unique to their own lives and experiences. Both forms of iatrogenesis therefore multiplied disabling dependence, allowing the professional autonomy of the physician to render individuals unable to process or order their lives, and unwilling to independently endure states of being deemed abnormal, deviant or disabled. In Illich’s worldview, when this happened, individuals ceded control over their lives to professionals, who in turn rendered them illiterate in the language used to describe

330 Illich, Medical Nemesis, 40.
331 Ibid. 78.
332 One can recognize elements of cultural iatrogenesis in Illich’s description of social iatrogenesis and vice versa. However, one rather poetic distinction was highlighted by R. Smith, who noted that while we may conceive of social iatrogenesis as harm wrought through the medicalization of life, cultural iatrogenesis arises through the medicalization of death. Quoting Illich, Richard Smith notes, “[O]urs is a morbid society, where ‘through the medicalisation of death, health care has become a monolithic world religion…Society, acting through the medical system, decides when and after what indignities and mutilations he [the patient] shall die…Health, or the autonomous power to cope, has been expropriated down to the last breath.” See Richard Smith. “Limits to medicine. Medical Nemesis: the Expropriation of Health,” The Journal of Epidemiology and Community Health 57 (2003): 928.
their own bodies.\textsuperscript{333} Correspondingly, both suffering and healing outside the traditional biomedical patient role were deemed deviant.\textsuperscript{334}

For Illich, the fundamental problem with contemporary medicine was its misuse of scientific achievement to strengthen the growth of industries and professions instead of enhancing and facilitating personal growth.\textsuperscript{335} While branded a Luddite by his contemporaries,\textsuperscript{336} Illich’s expressed concern was not in technology in itself, but rather the weaponization of technology to suppress individuality and autonomy. In his view, the public had been taught to conceive of the technologized orthodox system for ordering and explaining health and disease as the only legitimate system. They were therefore blinded to the harms wrought by inimical social arrangements, and furthermore rendered incapable of perceiving the dangers posed by the medical system itself. Channeling the 1960s era feminist arguments we visited earlier, Illich maintained that in disempowering patients, biomedicine, “exempt[ed] them from the scene of political struggle to reshape the society that has made them sick.”\textsuperscript{337}

Illich’s indebtedness to feminist and consumer rights advocates is quite clear, for he freely cites their arguments throughout his volume. However, while he would write approvingly of their activist initiatives, he simultaneously made clear that many of their arguments were too accommodationist for his taste. This was particularly apparent in his discussion of Nader’s work enhancing public awareness of the dangers posed by clinical medications. Praising the consumer

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\textsuperscript{333} Illich would call the disempowering biomedical jargon “bureaucratic gobbledygook,” \textit{Medical Nemesis}, 41.
\textsuperscript{334} Ibid.
\textsuperscript{335} Illich wrote, “The medical and paramedical monopoly over hygienic methodology and technology is a glaring example of the political misuse of scientific achievement to strengthen industrial rather than personal growth. Such medicine is but a device to convince those who are sick and tired of society that it is they who are ill, impotent, and in need of technical repair.” \textit{Medical Nemesis}, 9.
\textsuperscript{336} Geiger, “Medical Nemesis,” BR1.
\textsuperscript{337} Illich, \textit{Medical Nemesis}, 33.
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rights movement, he nonetheless argued, “Unless it disabuses the client of his urge to demand and take more services, consumer protection only reinforces the collusion between giver and taker, and can play only a tactical and a transitory role in any political movement aimed at the health-oriented limitation of medicine.”

No, Illich made clear that the problems he unearthed would find no resolution in consumer reports or empaneled review boards, as noble as such initiatives may be. The only solution was, he believed, a recapture of a culture of self-care society had lost in the institutionalization of a highly powerful biomedical system. In truth, Illich made no effort to disguise his embrace of self-care – in the very opening of *Nemesis*, he raucously called for the “laicization of the Aesculapian temple…leading to a delegitimizing of the basic religious tenets of modern medicine.” His arguments were no doubt quite difficult for the modern clinical audience to endure. For as he saw it, medicine could not fix the problem because it was the problem; only the layperson could effect a cure. By rejecting the excesses of a modern biomedical system and redistributing its powers into the hands of the individuals, Illich hoped to establish a community of self-care wherein individuals determined for themselves what constituted disease and how it should be addressed; reaffirmed their ability to identify structural and environmental determinants of health; freed themselves from the harms wrought through biomedicine’s vainglorious attempt to commandeer science to eradicate suffering; and developed the capacity for embracing birth, death, and the innumerable sequence of successes, setbacks, triumphs and tribulations bound between both extremes.

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338 Ibid. 236.
339 Ibid., 4.
340 Ibid. 62; As Illich argues, “Deprofessionalization of medicine means the unmasking of the myth according to which technical progress demands the solution of human problems by the application of scientific principles, the myth of benefit through an increase in the specialization
Despite his popularity during the early-to-mid 1970s, by the end of the 20th Century, Illich’s works had faded from memory, and in 1989, *New York Times* book reviewer Anatole Broyard would comment that he took special delight in purging Illich’s volumes from his library.\(^{341}\) How was it that a man who had rattled and enraged the keepers of orthodoxy, filling auditoriums and penning popular columns, faded so precipitously from memory? Several possible explanations present themselves. One might argue, for example, that by the 1980s, the antiauthoritarian and anti-institutional sentiment that had anchored and fueled Illich’s work faded in the face of a new conservatism. However, it is far too simplistic to paint Illich as the liberal agitator whose works soured in a conservative climate. For in truth, Illich was a liberal to conservatives and a conservative to liberals; far more than an ecclesiastic nomad, he was an intellectual one too, passionately expressing views that in one way or another estranged him from both poles of the political spectrum. In rejecting biomedical orthodoxy and advocating self-care, for example, he alienated himself from the bioethicists and clinical authorities who dismissed him as a radical firebrand intent on dismantling the modern health care system while offering very little in its place. At the same time, to liberal audiences, he was viewed as a conservative advocate of the free market principles famously espoused by Milton Friedman. Writing in the *New York Times*, H. Jack Geiger would express such misgivings, arguing that Illich’s volume began with a socioeconomic bang but ended in political whimper, valorizing free will and individual enlightenment while ignoring the need for more radically progressive economic redistribution.\(^{342}\) “It is all the more disappointing,” Geiger argued, “that from Illich’s

\(^{341}\) Madar, “The People’s Priest.”

\(^{342}\) Geiger, “Medical Nemesis.”
cocoon of apparent radical humanism there ultimately emerges no bright butterfly of revolutionary change but rather, in a curious inversion, a caterpillar of petty conservatism."

In the final analysis, through his deeply contrarian invective, Illich offered unto society a prism through which it might view, raw and naked, the dangers posed by the institutions that had come to dominate everyday life. His arguments concur, to a point, with the celebrated critiques of Michel Foucault – indeed, Illich directly states his indebtedness to the French scholar in his chapter discussing the invention of disease. However, Illich would incontrovertibly part ways with Foucault in his exposition of recommendations for responding to the dangers posed by institutions. Surveying the individual and social ills wrought by modern medicine, he identified an antidote in the reclamation of the autonomy of the individual. Interestingly, much like the perspective assumed by bioethicists, his approach assumed a romanticized – and perhaps naïve – valorization of free will, a harkening to the past that, as Geiger noted, was roughly Rousseauian. Indeed the radical polemicist dismissed by many as irredeemably destructive would ultimately express an abiding faith in the capacity of the enlightened man, freed from his iron cage, to once more claim control over his health.

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343 Ibid.
344 Geiger argues that, “There are echoes here of Rousseau’s Noble Sage: the paradise we have lost was the one within us; it was whatever enabled us, on our own, to make life feel whole and coherent, even if painful. We have traded it in for compulsory survival in a planned and engineered hell, an anesthetized existence in a world turned into a hospital ward, a ‘managed maintenance of life on high levels of sub-lethal illness.’” Historians have noted that Rousseau did not actually use or popularize the term “noble savage,” but Geiger’s larger point remains. Ibid.
345 Interestingly, while Illich’s belief in the transformative abilities of the free will were considered contrarian and divisive, they enjoy a long tradition in the literature and were not always considered radical or contrarian. In 1985, Jacob Needleman would give voice to them in his aforementioned work exploring the promise and perils in medicine, writing “[T]he part of the human psyche that is most centrally involved in the cure of illness, namely the attention or will, is not understood in the contemporary era…Nowadays, the only patients who discover will-power in themselves are those who, through mere chance or through their own exceptional
Herein we identify what was perhaps the underlying reason for Illich’s slow slide into obsolescence – for just as he was an ecclesiastical nomad, so too was he an intellectual one. He was, in the final analysis, a German Jewish Roman Catholic Priest deeply suspicious of institutions, a traditionalist harking back to a purer and simpler past, and an optimist who saw in man the capacity to free himself from the servitude of pernicious institutions. He cited Foucault while embracing autonomy and valorized free will while alienating bioethicists. He was that rare individual who spoke myriad languages but was seldom understood; who was versed in innumerable traditions but had no home.

Ivan Illich’s theories may have faded from the literature, his structural critiques forgotten as departments of history, philosophy, sociology and anthropology enthusiastically embraced Foucault’s works while assiduously mapping the origins and influence of civil rights movements in health and medicine. However, the shadow of Ivan Illich is cast long, rendering itself whenever discussions of a broken medicine impugn institutional orthodoxies. In some cases, it is the anointed leaders of medicine who grant his influence – so it was that, in 2003, a former editor of the British Medical Journal would observe that the closest he had ever come to a religious experience was listening to Ivan Illich. Perhaps even more significant was Illich’s impact on the development of a robust self-help and alternative medicine movement. Speaking at a 1980 conference dedicated to the rise of self-care, Yale University Professor of Public Health Lowell S. Levin credited Illich with challenging conventional beliefs and raising public awareness

character development, see with objective horror both their own situation and the total helplessness of their doctors, and, having no taste whatever for self-deception, find that there is no place to go but ‘up’ – that is, inside themselves, where they chance to find the existence of a truly higher psycho-psychical energy that carries them through either what is called a ‘miraculous’ cure or an honorable death.” Needleman, Way of the Physician, 138.

regarding the dangers of an ineffective and harmful biomedical model. Many authors, including historian of alternative medicine James C. Whorton and holistic medicine advocate David Kopacz, credited Illich with catalyzing the American holistic health movement. And in his commemoration marking Illich’s death, Henry Cox, Professor of Divinity at Harvard University, went so far as to declare him a prophet of alternative medicine.

The synergy between Illich’s work and the alternative and holistic health movements is easy to understand, as each in its own way embraced a model of self-care and resistance to orthodox healing methodologies. Even as leading columnists purged their libraries of Illich’s texts, his beliefs resurfaced wherever unsanctioned expressions of distrust breached the surface of biomedical practice. When faced with inescapable apprehensions regarding the competence and character of their healers and healing system, the public would disinter the prophet of Cuernavaca and his radical critiques. So it was in the early 1980s as gay men living in US metropolises endeavored to process, respond to and cope with the visitation upon their cities of a disease which cast into the clinical gaze intensely stigmatized facets of their private lives while offering little in the way of succor or salve. In this caldron of fear, suspicion and distrust, we find leaders such as Michael Callen, whose would play a key role in the development of unorthodox AIDS activism, openly finding inspiration and guidance in Illich’s work.

In dismissing Illich as a radical detractor, professional scholars such as mainstream bioethicists summarily disregard the long history of distrust that anchored and fueled his

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348 See, for example, Whorton, Nature Cures, Chapter 11; David Kopacz, Re-humanizing Medicine: A Holistic Framework for Transforming Your Self (Winchester, UK: Ayni Books, 2014); See also Parachini, “Medical Iconoclast.”
350 Chambre, Fighting for Our Lives, 33-34.
Bioethics in effect constructed a rigid border around orthodox biomedicine, claiming it as its sovereign domain while ignoring the wilderness that lay outside its walls. In so doing, its practitioners blinded themselves to the popular consequences of unsanctioned distrust, and to its potential to do more than destroy, but to produce. To the ways it prompted individuals to explore alternative systems and practices of healing, seamlessly moving between them irrespective of the borders bioethics policed. It is in these movements and repositionings that we find self-care, that phenomenally important expression and manifestation of autonomy whereby individuals claimed for themselves a sovereign sphere over which no authority – clinical, legal, or sacerdotal – could claim dominion.

Interestingly, in ignoring Illich’s analysis, bioethicists also deprived themselves of a powerful critique of the alternative and holistic health care movements they perceived as challenging biomedical orthodoxy. A decade after publishing Medical Nemesis, Illich penned a short, oft overlooked article in the Bulletin of Science, Technology and Society wherein he once more exhibited his unparalleled ability to alienate the very communities who would rally around his cause.351 Lamenting the health movements his work had inspired, he argued that health holism had in effect replaced orthodox medicine with alternative systems of control that taught individuals how to conceive of their bodies, to strive for health, and to combat illness, ultimately failing to effect the fundamental changes he believed were necessary.352 An explication of his

352 Allan Parachini. “Medical Iconoclast”; Interestingly, Irving Kenneth would express remarkably similar concerns in 1972, writing, “The change of medicine’s commitment from a specific etiological model of disease to a multi-causal one and the greater acceptance of the concepts of comprehensive medicine, psychosomatics, etc., have enormously expanded that which is or can be relevant to the understanding, treatment and even prevention of disease. Thus it is no longer necessary for the patient merely to divulge the symptoms of his body but also the
misgivings with health holism was not forthcoming, for while he agreed that Nemesis was properly seem as a popular rabble-rouser, he adjudged his more recent reflections on holism to be “very delicate, [and] not necessarily for mass consumption.”

Whether he feared that a detailed explanation of his concerns would be received as support for orthodox medicine is impossible to ascertain, for Illich would die in 2002 without further expounding on the topic. Even in death, he would consummate the mythical air Madar identified in his analysis of his work – for Illich would die of cancer after refusing, over the course of several years, to excise a tumor that had appeared on his face, fearful that the surgery would interfere with his ability to speak.

It is regrettably easy to dismiss the immensely complex man that Illich was – and the rich, multifaceted traditions and movements out of which his beliefs grew – through the ascription of radicalism. And yet, when we do, we blind ourselves to a valuable perspective through which individuals perceived and interpreted their worlds. Fears, anxieties, apprehensions, and distrust cut across political spectra and defy categorization on rigid binaries purporting to demarcate the appropriate from the inappropriate, the sanctioned from the unsanctioned, the orthodox from the radical. They would furthermore motivate individuals to challenge received wisdom, question power dynamics, and explore alternative healing methodologies, moving among and between disciplines and paradigms, positioning themselves symptoms of daily living, his habits and his worries.” Zola, “Medicine as an Institution of Social Control.” 493.

He playfully wrote “necessarily” in parentheticals. To my knowledge, he never further elaborated on his concern with the holistic health movement. Parachini, “Medical Iconoclast,” 1986.

Through his illness, Illich chewed opium to address his pain and referred to his tumor as a symbol of his irrefutable mortality. See Madar, “People’s Priest.”; See also a summary of Illich provided by his publisher, Marion Boyars: “Ivan Illich,” accessed 20 June 2016, http://www.marionboyars.co.uk/AUTHORS/Ivan%20Illich.html
in the borderlands of the greater healthcare landscape, drunk on the strong wine of freedom.
Part III  
The Emergence and Growth of Unorthodox AIDS Activism

As the previous two chapters demonstrate, while the late 20th Century witnessed the ascendance of a modern biomedical juggernaut exerting tremendous influence over daily life, interwoven between promises of pharmacological panaceas and biotechnological benedictions were lingering doubts regarding the state of the nation’s healthcare system. Critics pointed to a number of factors – the rise of a highly technologized, pharmaceutical driven clinical model; the elaboration of an outsized role for the state as scientific entrepreneur; and the unfettered promulgation of a culture that glorified and heroized the search for cures – as signs not of a healthy therapeutic renaissance, but rather a system gone awry. Some scholars would go further still, arguing that the nation’s healthcare system had become institutionalized as a massive, impersonal, profit-driven bureaucracy, a health denying behemoth Barbara and John Ehrenreich famously dubbed the “Medical Industrial Complex.”

This lingering distrust and disillusionment would in fact catalyze the development of robust, as yet poorly understood, unorthodox health activist campaigns through the 1960s and 1970s. From the dissemination of alternative health advice by the Boston Women’s Health Collective, to resurgent interest in New Age therapeutic methodologies, to the polarizing popularity of nontraditional cancer therapies, a host of health activist movements arose in the postwar years to challenge what some deemed a biomedical hegemony. In advocating their contrarian perspectives, unorthodox activists tapped into the same currents of

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355 For a discussion of the rise of the modern biomedical system, see Viviane Quirke and Jean-Paul Gaudilliere, “The Era of Biomedicine: Science, Medicine, and Public Health in Britain and France after the Second World War,” Medical History 52, no. 4 (2008): 441-452.
antiauthoritarianism, antidogmatism, antimodernism and antiheroism that had attended the rise of irregular medical sects through the 19th and early 20th Centuries. These currents of resistance are indeed among the few constants to be found in our nation’s long experiment with healing, having endured eras of bloodletting heroics, antibacterial animus, and biotechnological breakthroughs.

So too would they persist in the age of AIDS. And yet few analyses of AIDS activism explore linkages with these enduring currents of resistance – an oversight all the more conspicuous given the propensity authors demonstrate for framing AIDS as a regression to the pestilences and plagues of yesteryears. Indeed, even as authors construe AIDS as a clinical anachronism, they interpret AIDS activism as a watershed moment in the postwar patient rights and gay rights movements. We thus observe the effects of two contradictory biases – one which projects onto AIDS a very old narrative, and a second which interprets the social movements it engendered as decidedly modern. Such framings of the disease are indeed attractive, for they pair the tragedy of regression narratives with the promise of progress narratives. However, they are woefully misleading, severing both the disease and the activist response it engendered from their historical moorings. AIDS activism, the focus of our current historical project, was very much a product of earlier protest movements, with its proponents tapping into thematic currents that had attended the rise of myriad protest movements through the ages.

In this third component of my larger project, I identify several important expressions of AIDS activism that directly and indirectly intersected the nation’s long history of alternative healing practices. I focus my analysis on two largely overlooked New York City based activist initiatives, with Chapter 4 dedicated to the campaigns of the People with AIDS Coalition (PWAC) and Chapter 5 focused on the works of Health Education AIDS Liaisons (HEAL). Often overshadowed in AIDS scholarship by organizations such as the Gay Men’s Health Crisis (GMHC) and AIDS Coalition to Unleash Power (ACT UP), PWAC and HEAL strove to empower individuals living with AIDS to claim ownership over their disease and their bodies. Their activism was neither the loudest nor the most visible amongst AIDS organizations, and yet by promoting unseen, everyday acts of resistance among their members, they played a pivotal role in empowering those affected by AIDS. As we shall see, each organization in its own way encouraged its members to challenge biomedical orthodoxies, thereby laying the foundation for a rich, robust engagement with alternative healing systems.

In the archives of both HEAL and PWAC, we find tales of heroism and heartbreak, of unalloyed courage and unallayed despair, of selfless sacrifice and selfish avarice. The groups’ apologists included amongst their ranks individuals who summoned tremendous personal energy to organize a robust activist movement even as their bodies collapsed under the burden of their illness. So too do they include charlatans and frauds peddling useless and at times dangerous wares. For this reason, some may argue that an exhumation of unorthodox AIDS activism serves as little more than a cautionary tale warning against the credulous embrace of health quackery by individuals futilely grasping at straws. And yet, were we as historians to so easily dismiss these individuals’ stories, we would commit an offense remarkably similar to that which mobilized their activism in the first place, treating them as victims twice disempowered – first by virtue of
their disease, and then by virtue of their desperation. I present my historical project as an antidote to this scholarly bias, an attempt to locate expressions of agency in a setting of tremendous social, political, and clinical disempowerment.
Chapter 4
Everyday Unorthodoxies and the People with AIDS Coalition (PWAC)

“I listen to the sounds of furious living
within and without.”
-Tony J. Giordano (circa 1984)\textsuperscript{359}

Out of the AIDS epidemic arose a powerful health activist movement many authors credit with fundamentally transforming the relationship between patient and healer.\textsuperscript{360} Echoes of this activism resonate in the public memory, coalescing around the riotous chants and impassioned pleas of protestors beseeching action by government researchers and pharmaceutical corporations. We may trace these echoes to precise loci of protest – the streets of Greenwich Village whereupon ralliers unfurled hand painted banners demanding “drugs into bodies,” the meeting halls of medical conferences wherein protestors interrupted biomedical leaders to demand the reframing of AIDS as a national priority, and the offices of FDA officials wherein people with AIDS staged vast die-ins.\textsuperscript{361} In our shared reminiscences – transmitted through lived memory, oral history, journalistic reporting and faded photographs – we recall AIDS activism as an exercise in overt resistance staged in the public arena. Whether demonstrators marched on Washington, besieged St. Patrick’s Cathedral or stopped traffic before federal office buildings, they expressed their impassioned views in fora chosen to maximize public exposure.


\textsuperscript{360}It is not uncommon for AIDS activists and scholars alike to identify the AIDS epidemic as a watershed moment in patient activism. Noted activist Peter Staley, for example, says of AIDS that, “It was the very first time in history where a patient group, from an illness or disease, showed up and demanded to be heard, to the bureaucrats in Washington.” Amy Goodman, ““How to Survive a Plague”: As ACT UP Turns 25, New Film Chronicles History of AIDS Activism in U.S.,” Interview with Peter Staley and David France, March 23, 2012, Accessed July 10, 2016. http://www.democracynow.org/2012/3/23/how_to_survive_a_plague_as

\textsuperscript{361}A die in was a form of protest where individuals lay in place, simulating their deaths.
While popular protests echo loudest in our historical memory, to summarily reduce all AIDS activism to such vocal demonstrations ignores a vast array of resistance that remained largely hidden or shielded from the public sphere. The location of action and expression for this activism was neither the streets of New York City nor the fields of the National Mall, but rather the bodies of men and women living with and dying from AIDS. Where public protestors would claim as tools a compendium of bolded banners and rancorous chants condemning federal bureaucracies, activism located on the scale of the body registered resistance through individuals’ decisions to claim ownership over their disease, questioning the etiological and therapeutic paradigms of mainstream biomedicine. It was manifest in the actions of the young man who eschewed antiretrovirals and turned instead to soy lecithin solutions he religiously mixed in his East Village apartment, or the person who rejected pharmacological cures to instead pursue a treatment plan grounded in herbal nostrums. These individuals’ acts of protest, effected before medicine cabinets each morning and facilitated by underground networks, are no less examples of everyday forms of resistance than the private protests of peasant farmers famously explicated by James C. Scott.

It is admittedly more difficult to identify and examine everyday expressions of resistance in comparison to, say, overt and explicit street protests and riots. And yet we stand to learn a

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362 Steven Epstein presciently notes that PWA activism was staged at the level of the body. In his well-crafted *Impure Science*, he quotes an introduction PWA Jim Eigo gave during a conference presentation. “We in the communities most touched by AIDS have learned that the ultimate site of this struggle is the body,” Eigo observed. “So here I am, my own and my only audiovisual aid. There will be no ‘next slide.’” Epstein, *Impure Science*, 21.

363 Scott, “Everyday Forms of Resistance,” 33; Some would in fact critique the tendency for the mass media to highlight public acts of protest over these every expressions of activism. In a 1990 article published in the People with AIDS Coalition’s *Newsline*, Ed Sikov wrote, “It rankles me that the newspapers and magazines focus on ACT UP’s media stunts to the exclusion of the day-to-day efforts of literally thousands of PWA Coalition and GMHC volunteers, then, in the same breath, criticizes ACT UP for being outrageous and drawing so much attention. Ed Sikov, “Have You Heard What They’ve Been Saying about You?” *PWAC Newsline* 55 (May 1990): 33-34.
great deal by doing so. Let us consider, for example, the history of gay men living in New York City through the 20th Century – a cohort of obvious relevance to the history of AIDS activism. Popular conceptions of the gay rights movement identify demonstrations such as the Stonewall Riots as watershed moments in the expression of resistance and opposition to sexual norms. However, if we look beyond such protests, we find that long before the first glass was shattered outside the Stonewall Inn, individuals who engaged in homosexual interactions – be they in private bedrooms, downtown bathhouses, or the dark of Central Park – expressed their opposition to gendered orthodoxies through their everyday actions effected at the level of the body.364 As we shall see, far from marking the end of these expressions, the AIDS epidemic catalyzed fascinating transformations in private acts of protest, with individuals claiming ownership over their bodies in an effort to quell a disease increasingly attributed to sexual liberation.

Although I have presented everyday expressions of resistance as private acts, they were in fact sustained and supported by a fascinating array of underground networks and communities. In the case of 1960s-1970s era sexual liberation, for example, we find the establishment of institutions (e.g. bathhouses) and cultural practices (e.g. nonverbal means of communicating interest) that enabled gay men’s acts of resistance and facilitated their empowerment. During the first decade of the AIDS epidemic, we similarly recognize the development of underground groups that assembled with the aim of empowering individuals to assert control over the treatment of their disease. These organizations would, through anonymous publications and

364 Michael Helquist, for example, observed, “For gay men, sex, that most powerful implement of attachment and arousal, is also an agent of communion, replacing an often hostile family and even shaping politics.” Quoted in Dennis Altman, AIDS in the Mind of America, 7; See also George Chauncey, Jr. “Gay Men’s Strategies of Everyday Resistance,” in Major Problems in the History of American Sexuality, ed. Kathy Peiss (Boston: Houghton Mifflin Company, 2002): 356-366.
support groups, encourage individuals to reject the external ordering of their bodies, defy mainstream biomedical ministrations, and claim expertise over their own healing. Among the first and most successful of such organizations was New York’s People with AIDS Coalition (PWAC).

The PWAC remains woefully understudied within scholarship on the AIDS epidemic. In fact, historians appear torn in their descriptions of the group’s core mission, with some categorizing it as a service organization in the mold of GMHC while others argue that it was a direct action protest group more similar to ACT UP. In truth, it defied such rigid binaries, as it was concerned neither with linking individuals to support services nor with taking to the streets to demand action. It instead sought to empower individuals by encouraging them to claim ownership and expertise over their bodies, in so doing transforming 1960s-1970s era cultures of bodily resistance into forms more appropriate for a decade defined by suffering and disease. In a poem he penned while hospitalized with AIDS, poet and PWA Tony J. Giordano may have most eloquently captured the linkages between 1960s and 1980s era expressions of bodily activism. Reflecting back upon his freewheeling past and gazing forward into a painfully precarious future, Giordano discerned from both directions the harrowing sounds of “furious living” – the furor of individuals demanding and commanding lives of resistance and protest.


This chapter tells the history of furious living in the era of AIDS, of the empowerment attained by impassioned and intrepid individuals who lived with and perished from AIDS in America’s great metropolis. I divide my analysis into three units. In the first, I examine the foundational texts that motivated the creation of the PWAC, arguing that these core documents established the organization’s allegiance to a culture of radical empowerment and connection to alternative health activism. In the second unit, I move on to an examination of the main print publications produced by PWAC leadership: the PWAC Newsline (1985-1993), the dual volume Surviving and Thriving with AIDS collection (1987 and 1988), and Michael Callen’s Surviving AIDS (1990).\footnote{Technically, the 1990 text Surviving AIDS is not a PWAC publication. It is an independent volume Callen issued after leaving the organization. However, given Callen’s outsized influence in the PWAC, and the thematic similarities between it and the publications produced under the aegis of PWAC, I have included it here.} I argue that these documents shared a common goal of encouraging contributors and readers to reject the teachings of biomedical professionals and claim responsibility for their own healing. As a result, they fomented deep distrust in biomedicine, with editorials and essays frequently invoking many of the themes that have historically subtended alternative and nontraditional health movements. By indirectly engaging the history of unorthodox health activism in this way, the documents ultimately set the stage for contributors to directly endorse unorthodox etiological and therapeutic responses to AIDS. The third and final unit of the chapter reviews these direct points of intersection and engagement in greater depth.

It is important to note at the outset of my analysis that the PWAC was truly heterogeneous in terms of the positions, beliefs and initiatives embraced by its members. Some advocated unorthodox philosophies while others allied themselves more closely with biomedical orthodoxies. Perhaps even more importantly, many individuals did both. The group famously lacked internal consistency – but then, it was seldom its goal to establish homogeneity of thought
or action beyond its shared interest in empowering individuals with AIDS.\footnote{Whether or not the PWAC remained this open minded throughout its history is difficult to say. The group endured tremendous turnover among its leadership, as individuals perished from AIDS. There is evidence of increased rigidity over time, however. For example, Callen, an outspoken critic of mainstream medicine, reports pushback from the board toward the end of his tenure at the organization. See, for example, Letter from Michael Callen to Bill Case, July 30, 1989, \textit{Latest Newsline Crisis} (1989), Folder 99, Michael Callen Papers, LGBT-NHA.} In describing the \textit{Newsline}, for example, one PWAC cofounder famously commented, “AIDS is full of non sequiturs and incomplete thoughts and so is the \textit{Newsline}.”\footnote{Jane Rosett, “A Tribute to Michael Callen,” \textit{PWAC Newsline 47} (September 1989): 5.} As I shall argue in greater depth in the third unit of this chapter, we should view this heterogeneity not as a sign of diluted unorthodoxy, but in fact an example of the borderland model in action. Rather than claim citizenship in the kingdom of biomedicine, or any of the myriad alternative sects dotting the landscape, individuals moved between them in overt and covert ways. The history of the PWA movement traces these movements – of the ways people organized amidst tremendous fear and uncertainty to contest received wisdom, share hopeful remedies, and reject the external ordering of their bodies – in short, to live furiously.

\textbf{A Bill of Rights, A War Bulletin, and the Birth of the People with AIDS Coalition}

As sociologist Susan Chambre has chronicled, by the early 1980s, myriad professional and lay groups had organized on both coasts to provide support services for those diagnosed with AIDS and to raise funds for basic biomedical research studying the condition.\footnote{Chambre, \textit{Fighting for our Lives}, 2006.} In many cases, the earliest of these groups assembled informally in living rooms and kitchens, convened by individuals – mostly gay men – who had been diagnosed with AIDS.\footnote{Among the earliest groups formed were People with AIDS San Francisco, New York’s Gay Men with AIDS, and New York’s Wipe Out AIDS, the forerunner to HEAL. See Michael Callen and Dan Turner, “A History of the PWA Self-Empowerment Movement,” in \textit{Surviving and Thriving with AIDS: Collected Wisdom, Volume II}, ed. Michael Callen (New York: People with AIDS Coalition, 1988): 288-293.} In 1982, the city’s first
professional AIDS service group, the Gay Men’s Health Crisis (GMHC) was founded. While renowned for its support services, by 1983 GMHC would attract complaints by some who viewed the organization’s attitude toward patients as broadly patriarchal, and at times patronizing. As two prominent AIDS activists would later note, “New York PWAs and PWArcs began to express frustration at attending GMHC forums where those of us with AIDS would sit silently in the audience and hear doctors, nurses, lawyers, insurance experts, and CSWs tell us what it was like to have AIDS…The ‘real experts,’ we realized, weren’t up there.”

This concern with the health service community’s victimization of AIDS patients dramatically came to a head in June of 1983 at a national Gay and Lesbian Health Conference held in Denver. In the midst of conference proceedings, a group of 14 men living with AIDS – many from California and New York – stormed the stage to read prepared comments asserting their right to participate in the national AIDS discourse. Their opening statement would eloquently and emotionally give birth to the PWA movement: “We condemn attempts to label us as ‘victims,’ a term which implies defeat, and we are only occasionally ‘patients,’ a term which implies passivity, helplessness, and dependence upon the care of others. We are ‘People with

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372 PWArCs were people with AIDS-Related Complex, a prodromal syndrome used to differentiate individuals with HIV infection from those who had developed full-blown AIDS. The diagnostic category is no longer used.
374 The proceeding was the Fifth National Lesbian/Gay Health Conference, sponsored by the National Gay Health Education Foundation, American Association of Physicians for Human Rights, and the Gay and Lesbian Health Alliance of Denver.
375 Michael Callen and Dan Turner listed the following PWAs in attendance: Bobbi Campbell, Dan Turner and Bobby Reynolds from San Francisco; Phil Lanzaratta, Artie Felson, Michael Callen, Richard Berkowitz, Bill Burke, Bob Cecchi, Matthew Sarner and Tom Nasrallah from New York City; Gar Traynor from Los Angeles; a man named Elbert from Kansas City; an unnamed individual from Denver; and Michael Helquist, the partner of Mark Feldman, who had died of AIDS related complications just prior to the conference. See Callen and Turner. “A History of the PWA Self-Empowerment Movement.”
By the end of their protest, the group had enumerated 17 core principles – remembered today as the Denver Principles – outlining the rights of those living with AIDS. Half a decade after the conference, activists Michael Callen and Dan Turner registered the moment’s lasting effect on the PWA movement: “[I]t simply hadn’t occurred to those of us in New York who were diagnosed that we could be anything more than the passive recipients of the genuine care and concern of those who hadn’t (yet) been diagnosed. As soon as the concept of PWAs representing themselves was proposed, the idea caught on like wildfire.”

Given the prominent role they played in shaping the public response to the epidemic, it is unsurprising that scholars and activists alike remember the Denver Principles as a cornerstone of AIDS protest. Or that a leader of the AIDS movement would, in 2005, refer to them as “the Magna Carta of AIDS activism, our Declaration of Independence, Constitution and Bill of Rights rolled into one.” What is surprising, however, is how we choose to remember them. Consider, for example, the first six principles, intended to shape the behavior of health care professionals. The result of active compromise between East and West coast activists, this set of principles in fact captured positions rightly viewed as unorthodox. Representatives of California, for example, successfully lobbied for a provision (Principle 5) advocating the holistic treatment of patients, while those from New York secured a plank (Principle 2) recognizing the diversity of opinion

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378 Sean Strub, “What's Wrong With Our Movement.” POZ. December 5, 2005. Excerpted from speech delivered December 1, 2005 at the National AIDS Memorial Grove in San Francisco. Straub is a long-term survivor of AIDS, the founder of POZ magazine, and was a member of ACT UP.
surrounding the etiology of AIDS. And yet many contemporary discussions of this foundational PWA text ignore these intersections by literally eliding the first six principles from the historical register. In reproductions published by ACT UP New York and the Joint United Nations Programme on HIV/AIDS (UNAIDS), for example, both organizations redact without comment the first six principles. Where once there were 17, the groups list only 11, even as they ensure readers that they remain “as relevant and powerful today” as when they were first drafted. The historical elision of provisions directed toward health care professionals is all the more remarkable when one recalls that the Denver Principles were first announced in a conference of assembled physicians! While it is difficult to ascertain the cause for this elision, its consequence is far easier to assess, for it severs the PWA activist movement from the unorthodox principles that once formed its foundational base.

Following the Denver Conference, the eight east coast PWA attendees returned home to form “PWA – New York,” the City’s first PWA organization. The group would register some success – producing, for example, the first safe sex posters to appear in New York bathhouses – but soon disbanded following internal dissension, the death of many founders, and hostility from professional service organizations such as GMHC. In its wake, several of its leaders formed the People with AIDS Coalition (PWAC), an organization that would persist for nearly a

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382 Ibid. See also Callen and Turner, “A History of the PWA Self-Empowerment Movement.”
With a budget approaching one million dollars by the early 1990s, the PWAC differed from ACT UP, which it predated, in that its leaders shied away from public expressions of protest, endeavoring instead to empower individuals to effect changes in their conceptualizations of and responses to their disease. It was well regarded for hosting discussion and support groups but exerted greatest influence through its print publications, including the two-volume collection of essays entitled *Surviving and Thriving with AIDS* and, even more importantly, its monthly *PWAC Newsline* newsletter. First distributed in June of 1985, the *Newsline* began as a sixteen-page resource long-time editor Michael Callen described as a “breathless war bulletin from the front lines,” and included essays, reflections, interviews, letters, poems and cartoons written by and for PWAs. By the late 1980s, the publication had burgeoned into a 48-page resource distributed monthly to 14,000 individuals in hospitals, private homes, offices and correctional facilities throughout the city, state and nation.

Both the *Newsline* and *Surviving and Thriving with AIDS* were living documents airing diverse, contradictory and controversial perspectives aimed at helping PWAs find order and

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385 The naming of the New York based PWA organization is somewhat confusing. PWA – New York was the first group, which closed relative soon after launching, to be succeeded by the PWA Coalition (PWAC). A successful organization with an impressive reach, the PWAC would eventually endure significant financial hardships by 1993 and soon after closed its doors, to be replaced by the People with AIDS Coalition of New York (PWAC/NY). This chapter focuses exclusively on the work of the PWAC (1985-1993).

384 Griffin Gold, the President of the PWAC, underscored this point, as captured in Board of Directors notes: “A number of the Board would like more political action. Gold explained that the Coalition can only allocate 20% of its budget for political advocacy, if it wishes to maintain its tax-exempt status.” PWA Coalition Board of Directors Meeting Notes, 21 October 1987, Box 65, Folder 3, Board of Directors Minutes, 1987, June-Dec., Michael Callen Papers, LGBT-NHA.


386 Navarre, “AIDS in ’88;”; Many PWAs living outside of major cities noted that the *Newsline* was their primary source of information.
meaning in the midst of profound uncertainty, and reclaim their health in a setting of widespread resignation. The texts bore some resemblance to publications produced by the feminist health movement, particularly the Boston Women’s Health Collective’s highly popular 1971 text *Our Bodies, Ourselves*. This was no accident, for Michael Callen – the indefatigable cofounder of PWAC, editor of the *Newsline* and *Surviving and Thriving with AIDS* and author of *Surviving AIDS* – credited the feminist health movement with motivating PWA activism. In his brief history of PWA activism, Callen observes, “We felt that we had a right to tell our own stories, to control to a greater extent who said what about us. Our experiences were a reaffirmation of the feminist principle that the personal is indeed political.”

And yet it is incorrect to argue that PWAC activism flowed directly from the women’s health movement, for the urgency and severity of the AIDS epidemic hewed and shaped PWAC initiatives in profound ways. Indeed, many PWAs, who remained painfully stigmatized and isolated by both their health status and sexuality, would view the *Newsline* as nothing short of a lifeline. Through the early 1990s, it existed as one of precious few fora wherein individuals could engage their conditions as both anonymous readers and contributors, sharing strategies for survival and wresting control over their disease narrative from a medical industrial complex viewed as hegemonic, a government viewed as negligent and a mainstream media viewed as sensationalist. Callen and other PWAC leaders would in fact argue that this level of engagement

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387 Michael Callen, “People with AIDS-New York: a History,” March 18, 1984, Box 6, Michael Callen Papers, LGBT-NA.
388 As Susan Chambre notes, “One caregiver commented that, ‘GHC gave me the bureaucratic cold shoulder because my lifemate hadn’t been ‘officially diagnosed’… [The] *PWA Coalition Newsline* was my lifeline, my sole source of information and human contact with other living, vibrant gay human beings wrestling with the implications of this vile epidemic and their own mortality.” Susan Chambre. *Fighting for Our Lives*, 38.
was crucial to the long-term survival of PWAs, with one group leader observing, “You cannot underestimate the therapeutic value of feeling like a soldier in the war against AIDS.”

It is easy to interpret these calls for engagement as benign expressions of the patient rights movement – appeals for the education of individuals so that they could participate in healthcare decisions as informed, autonomous agents. Such a framing, however, sterilizes what was in fact a far more complex and contentious activist tradition. Leaders such as Callen – who would exert tremendous influence over PWAC publication discourse – viewed biomedicine not as a symphony strengthened by the addition of patients’ unique vocal registers, but rather a cacophony that had fallen badly out of tune. This fundamental critique, which simultaneously celebrated the power of the individual while repudiating the legitimacy of the mainstream biomedical model, was in fact one reason GMHC leaders initially viewed PWAC activism as unacceptably radical. For in many regards, the group’s activism bore less in common with the patient right movement’s Kantian individualism than it did Illichian anti-institutionalism. A radical repudiation of health bureaucracies, it located hope not in systems of ennobled expertise but rather in individuals’ power to direct their own care. As Callen would write, borrowing the words of democratic socialist Michael Harrington, to support PWA activism was “to sense the seed beneath the snow; to see, beneath the veneer of corruption and meanness and the

391 Of Michael Callen, Joseph Sonnabend once commented, “[H]e embodied a sort of confrontational activism that I understand and respect – not the collaborationist kind. It starts with the importance of self-reliance and not depending on experts. I mean, you can’t do without them, but you can’t trust them either.” Sean O. Strub, “The Good Doctor,” POZ Magazine (July 1998): 109.
commercialization of human relationships, men and women capable of controlling their own destinies.”  

Callen would vigorously maintain this philosophy through his editorship of the *Newsline*, consistently arguing that PWAs possessed both the capacity and the right to engage therapeutic and etiological debates on their own terms. He evidenced his position most clearly in his support for the newsletter’s *Medical Matters* section, wherein PWAs openly debated the wisdom of mainstream biomedical practice.  

Throughout its run, the column attracted criticism from some readers who accused it of sanctioning almost guerilla style attacks on mainstream biomedicine. Unflinchingly committed to the principles of PWA empowerment, Callen rejected their critiques, oftentimes invoking the language of the Denver Principles in his rejoinders:

“[R]equiring that articles by PWAs/PWArcs who happen not to be medical experts be censored or fact-checked by so-called medical experts runs contrary to the basic philosophy of the Newsline…The PWA self-empowerment movement was born out of a general distrust of expert-ism. One of the founding principles of our movement states that we PWAs are, in one sense, the *real* experts about AIDS; we demand to be included in all decision-making processes [with] full and equal credibility as other so-called experts.”

So committed was Callen to this principle that in a 1986 *Newsline* column, he recommended that PWAs speaking publicly about their condition first recount their medical histories, “much in the

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392 This quote from Harrington appears in Callen’s archived notes from his publication of *Surviving AIDS*. Analysis of AIDS activism typically focus on the power and privilege of gay male activists, many of whom were white and middle class. Less attention is paid to those – like Callen – who identified as socialist. Callen’s political philosophy no doubt contributed to his distrust of immensely powerful pharmaceutical behemoths. For an example of class based analyses in AIDS activism scholarship, see Cohen, “‘All They Needed.’”

393 The *Medical Matters* section was inaugurated in May of 1989, but in many ways it simply grouped under one section controversial opinions that had appeared in the *Newsline* since its inception.

way that other experts list their credentials.” Other Newsline authors would take this call for PWA engagement further still, transforming individuals’ right to challenge experts into an obligation to do the same. In a 1986 Newsline column entitled “How to Talk to Your Doctor,” PWA Bob Herman, for example, suggested that patients who refused to challenge received wisdom and instead passively followed the advice of physicians were “choosing not to heal” themselves.

Through the 1980s and 1990s, numerous Newsline and Surviving and Thriving with AIDS contributors heeded Callen’s call for open engagement with their disease, penning articles critical of the ennobled experts entrusted with the nation’s health. Their critiques betrayed a fundamental distrust and disillusionment with institutions and individuals perceived of as wielding power in AIDS research and policy, including the National Institutes of Health (NIH); the Food and Drug Administration (FDA); pharmaceutical corporations; mass media outlets; and political figures on the local, state and national levels. Ranging far and cutting deep, they impugned virtually all aspects of the mainstream response to the epidemic, from (i) the ways biomedical leaders discussed AIDS, to (ii) how they organized their research efforts, (iii) theorized the disease’s etiology and pathology, and (iv) developed cures to address the suffering it wrought in its wake. They waged, in short, a full-scale offensive against the orthodox response.

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395 Michael Callen. PWAC Newsline 18 (December 1986): 32; Steven Epstein would identify a similar phenomenon when he argued that AIDS activism resulted in in “the multiplication of the successful pathways to the establishment of credibility and diversification of the personnel beyond the highly credentialed.” Epstein. Impure Science, 3.

396 In this same piece, Herman argues, “Doctors are not the demigods that we were brought up to believe they are.” Bob Herman, “How to Talk to Your Doctor,” PWAC Newsline 17 (November 1986): 26-28; Herman was furthermore known for traveling to Paris to obtain the experimental drug HPA-23. He died of AIDS related complications in 1986. See Jeff Jarvis, “Desperate American AIDS Victims Journey to Paris, Hoping that a New Drug Can Stave Off Death,” People 24, no. 7 (August 12, 1985), and Sandy Rovner, “After Ten Years…Where We’re Headed,” Washington Post (June 19, 1990).
to the epidemic, in the process casting serious doubts on the capacity for mainstream biomedicine to better the lives of those living with the disease.

In the second unit of this chapter, I explore these four broad domains of dissent and protest in greater detail. I argue that, in articulating a broad and deep distrust of biomedicine, PWAC contributors tapped into and expressed the same core themes of anti-authoritarianism, anti-dogmatism, anti-heroism and anti-modernism that have historically subtended alternative and irregular health activism throughout our nation’s history. As a result, they would ultimately support PWAs’ direct engagement with these activist traditions, a point to which I turn in the third and final unit of the chapter.

Disputed Words: Challenges to Universal Fatality Narratives

“What shall we do with Max? He will not face the facts. He insists he’s alive. And continues to thrive. What shall we do with Max?”

- Max Navarre (1988)

Many scholarly analyses of AIDS activism focus predominately upon discussions of the anger and frustration pervading the gay community in the first decade of the epidemic. That this is so is unsurprising, for as sociologist Deborah Gould has argued, the most famous expressions of AIDS activism – including the protests of ACT UP – harnessed shared sentiments of anger and rage to mobilize highly public activist responses. By the late 1980s, protestors had begun taking to the streets in record numbers, staging vast die-ins to remind the general public that,

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398 Gould argues that, “One of the most significant aspects of social movements is that they are sites for nurturing counter-hegemonic affects, emotions, and norms about emotional display.” Gould, *Moving Politics*, 41.
absent active intervention by an apathetic government, they were fated to perish from their
disease. One can craft near endless histories of AIDS focused narrowly upon such expressions of
fury, bringing to bear compendiums of faded photographs capturing the bodies of protestors
forcing the general public to gaze upon the face of death and suffering.

As compelling as such histories may be, they are but one part of the larger story of AIDS
activism. To capture the full range of AIDS protest, particularly that which was communicated
on the pages of PWAC publications, we must temporarily set aside rage and wrath to consider
other emotions which helped organize and catalyze acts of resistance. When we do, we come to
understand that perhaps one of the most important and oft ignored emotions subtending AIDS
activism was hope – an abiding faith in the capacity of individuals to survive with their disease.
As we shall see, PWAC leaders such as Michael Callen and Max Navarre argued that
empowerment was predicated upon awakening among individuals a belief that they could indeed
survive their condition. For these authors, hope was more than a cheerful or optimistic
disposition; it was itself a prerequisite for survival. What’s more, it was under siege.

Through the 1980s, Callen deemed the print media ground zero in an unrelenting,
mainstream assault on PWAs’ capacity for hope. In one 1986 Newsline piece, for example, he
complained, “Every time I pick up the paper, I choke on that boilerplate paragraph about AIDS
being ‘invariably 100% fatal.’”399 In a column published a year later, he similarly condemned
reporters’ practice of framing AIDS as “uniformly, inevitably, ineluctably, always, without
exception…fatal.”400 Callen fiercely commit himself to challenging these macabre
caracterizations, dedicating his 1990 text Surviving AIDS to finding and interviewing long-term

400 Michael Callen, “Beating the Odds: More Thoughts on Surviving AIDS,” PWAC Newsline 26
survivors of AIDS to prove that it was indeed possible to persevere through the condition.\textsuperscript{401} In his text, he surveys the ubiquity of universal fatality narratives, demonstrating the ways in which they reached beyond sensationalist headlines to influence visual representations of the condition as well. In one passage, for example, fellow PWAC cofounder and photographer Jane Rosett recalls submitting photos of PWAs for a spread in a major news magazine only to have the editor reject them for being “too healthy looking.” Dumbstruck by the man’s response, Rosett replied, “That was the point.”\textsuperscript{402}

Most analyses of AIDS activism ignore these condemnations of universal fatality narratives, no doubt because they appear minor in comparison with other more weighty topics, such as funding for drug research. Indeed, it is easy to dismiss Callen’s critiques as nothing more than petty semantic quibbles – the call for the use of politically correct designations to describe those suffering from illness. However, for both Callen and fellow PWAC editor Max Navarre, they were about a great deal more. Less than a year before his death, for example, Navarre would write, “Does anyone consider the impact of [the] cult of the victim? Does anyone realize the power of the message, ‘You are helpless. There is no hope for you?’ I’m not immune to the reinforcement of hopelessness that surrounds me. That reinforcement causes despair, and I

\textsuperscript{401} Callen estimated that 10-15\% lived long term, or longer than three years. In \textit{Surviving AIDS}, he furthermore took to task mainstream reporters for promulgating universal fatality narratives. Of one news outlet, for example, he comments, “The editor underscores his contempt for the concept of an AIDS survivor by putting the word ‘survivors’ in quotes, as if to say ‘of course, they’re not \textit{really} going to survive AIDS, but we’ll call them survivors just to humor them.’” In other cases, he interviews reporters from the \textit{New York Times} and the \textit{Wall Street Journal}, who admit that whitewashing AIDS as universally fatal had become standard journalistic practice. See Callen, \textit{Surviving AIDS}, 53.

\textsuperscript{402} In another instance, Callen tells of allowing a \textit{Newsweek} photographer into his home to capture his image for a magazine spread on PWAs, only to have the correspondent reject him – and his body – for not having visible Kaposi’s Sarcoma (KS) lesions. When the photographer arrived, he scoffed at Callen’s appearance, shrieking, “Where are your lesions? I need someone with lesions,” before storming out. Ibid. 56.
believe that despair kills people with AIDS as much as any of AIDS’ physical manifestations.”  

Similarly, in his opening to *Surviving AIDS*, Callen would observe, “A common thread that has run through my AIDS activism has been a passionate belief that hopelessness kills. This is why challenging the myth that everyone dies from AIDS has become an obsession.”  

Both Callen and Navarre thus argued that the purveyors of universal fatality narratives – including a mainstream media and the biomedical leaders who influenced it – were fundamentally incapable of championing the survival of PWAs, for they forestalled its possibility. Their views of hope and hopelessness were not romantic, but rather radical, blurring distinctions between physical and symbolic forms of violence.  

For this reason, their positions resonated with the supporters of attitudinal healing movements, as we shall see in the third unit of this chapter.  

While PWAs criticized news outlets for fomenting fatalism, they also challenged the authority of biomedical leaders for fueling the fire with far too many unsophisticated assessments of the disease. In the second volume of *Surviving and Thriving with AIDS*, for example, Callen criticizes New York City Health Commissioner Stephen Joseph for stating that the proportion of long-term PWAs was greater than he “would have intuitively expected it to

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404 Callen, *Surviving AIDS*, 10; Callen would also argue, “Admitting the possibility of survival means that people around us may have to suffer the disappointment of our hopes along with us in a new way. If death from AIDS is not inevitable, then each death is uniquely painful. And each struggle to survive is uniquely empowering.” Ibid. 69.  
405 Sadly, even the most rigorous analyses of AIDS activism tend to overlook unorthodox health activism as expressions of protest. Steven Epstein, for example, argues that gay men were well positioned to engage in discussions of symbolic violence due to their socioeconomic privilege: “Drawn often from the ranks of those with significant cultural capital, AIDS activists have both a greater inclination and capacity to participate in the construction of social meanings and challenge the purveyors of ‘symbolic violence.’” While Epstein comment is no doubt correct, he fails to capture the ways in which unorthodox health activism helped broaden individuals’ discussion of symbolic acts of violence. It was a result of this unorthodox activist tradition that members of PWAC and HEAL – not all of whom were highly educated – could contribute to this discourse. For Epstein’s discussion, see *Impure Science*, 22.
be.” Callen’s response to the Commissioner’s quip was unequivocal: “What the hell does that mean? In New York City, 15% of us have survived five or more years. Shouldn’t the City’s own Health Commissioner have known that? And is it enough for him and others to now say, ‘Oops! Guess we were wrong about 100% mortality?’ Is there no one to hold accountable for the lie and its harmful effects on PWAs?”

In the same publication, Joseph Sonnabend, Callen’s outspoken physician and an influential leader in the PWA movement, suggested that mainstream biomedicine’s fatalism derived from its exaltation of laboratory science over the experiences of community physicians who were in the trenches working with PWAs.

Sonnabend would frequently rail against the inordinate power and influence afforded academic/research physicians, whom he viewed as distant professionals ensconced in their labs, lacking necessary clinical experience with patients.

Just as Callen, Navarre and Sonnabend accused the mainstream media and biomedicine with robbing PWAs of the hope requisite for survival, so too did they express frustration with the City’s acclaimed AIDS service organizations. In the short poem opening this section, for example, Navarre conveys a common frustration voiced by long-term PWAs who felt neglected.

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407 Sonnabend singles out Anthony Fauci, who argued that patients presenting with PCP as the first manifestation of AIDS should be expected to live 36 to 40 weeks. “His statement demonstrated an astonishing discrepancy between the experience of many community physicians who treat AIDS patients on a day to day basis and those whose focus is primarily on research rather than patient management.” Joseph Sonnabend, “More Thoughts on Preventing Pneumocystis Pneumonia,” Surviving and Thriving with AIDS: Collected Wisdom, Volume II, ed. Michael Callen (New York: People with AIDS Coalition, 1988): 65.

408 Sonnabend’s critique of mainstream biomedical practice was emblematic of larger power struggles in the construction of biomedical knowledge, and mirrors the previously discussed historical debates between rationalists, who hung their hats on abstract theories, and empiricists, who relied primarily upon experience wrought through trial and error. For Sonnabend, the empirical experience of community physicians was, in the 1980s, derogated to the rational models of laboratory scientists.
by AIDS service organizations fixated on universal fatality narratives. Callen would put an even finer point on the matter, arguing that GMHC – the City’s crowning service organization – actively promulgated universal fatality narratives to elicit greater public support and funding. In *Surviving AIDS*, for example, he recounts with horror an early encounter at a GMHC event:

“Once, after giving my ‘hope speech’ during a public forum organized by the Gay Men’s Health Crisis, I was angrily pulled aside by a gay man who worked in the GMHC Education Department. He begged me to stop saying that AIDS might not be 100 percent fatal. Shocked that a gay man would make such a request, I asked for reasons. He gave three: (1) efforts to persuade gay men to practice safer sex might be undermined because they would ‘take AIDS less seriously’; (2) it was bad for fund-raising; and (3) it would make lobbying for increased federal funding more difficult. ‘After all, he said, ‘if not everyone who gets it dies, then maybe AIDS isn’t really the crisis we’re being told it is.’”

West Coast based PWA Stephen Pieters reported similar pushback when he triumphantly announced to members of the AIDS Project Los Angeles that he had gone into remission. There, a group representative quietly asked him not to share his story, arguing, “it’ll be real bad for fund-raising that it gets out that people are doing well.”

For Callen and Navarre, such mainstream practices were not just politically incorrect, they were in fact health denying. Their positions were indeed anti-authoritarian in nature, but the

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409 Callen, *Surviving AIDS*, 62; Cass Martin would echo Callen’s comments in the *Newsl ine*, writing, “The expectation is that the moment you test HIV antibody positive, you are one of the living dead awaiting only the formality of your cremation. Sadly, most AIDS organizations are in collusion with this world-view as, in order to become respectable and acceptable to the bodies which fund them, they have made pacts not to have activist elements within their structure and, further, to publicly disengage themselves from such activity.” Cass Martin, “The Necrophiliacs of AIDS” 75 (April 1992): 18.
precise form of anti-authoritarianism they embraced ran far deeper than challenges to particular
drugs or clinical trial standards. For they in fact impugned mainstream society’s – and
mainstream biomedicine’s – basic ability to frame the disease and give voice to the epidemic.
Through their *Newsline* and *Surviving AIDS* commentaries, these authors would encourage
PWAs to project their voices, their ideas and their perspectives onto AIDS discourse, supplanting
a biomedical framing they viewed as not only misguided, but dangerous.

Armed with this understanding of 1980s era critiques of mainstream fatalism discourse,
let us now move into more familiar terrain, briefly mapping PWA engagement with biomedical
professionals’ early efforts to research AIDS and develop drugs to treat its symptoms. As we
shall see, PWAs expressed concern with virtually all aspects of the mainstream biomedical
research response to the disease, betraying grave distrust and disenchantment with the
commitment and competence of leading biomedical professionals.

**Disputed Actions: PWAC Activism and Allegations of “Fourth or Fifth Rate” Science**

Many scholars have by now recounted the history of PWA discontent with the low
number of clinical trials organized in response to AIDS and researchers’ failure to develop
treatments for the condition until half a decade into the epidemic. The history of PWA protests
surrounding these issues is well known – both because it inspired the most popular public forms
of AIDS protest and also because it makes for compelling histories, peopled as it is by
phlegmatic Presidents, sanctimonious senators and dispassionate bureaucrats. PWAC
publications would air these complaints as well, with authors lamenting a research response that
appeared woefully underfunded to address the suffering at hand.411 However, by focusing

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411 Nathaniel Pier, the PWAC leader whose comments we visited earlier, in fact took to
comparing AIDS research trials to Santa Claus, noting that, “you see them represented
everywhere, but they do not really exist.” Nathaniel Pier, “Open Letter to Mr. Jim Gottlieb
exclusively on top-down research funding issues, or the truancy of national leaders, we blind
ourselves to an even more radical critique logged in the pages of PWAC publications, as authors
expressed growing concerns that the biomedical research system itself was broken. For these
authors, society could not solve the problems with its mainstream research response merely by
procuring additional research dollars. It had to instead acknowledge the shortcomings of the
biomedical system writ large, and the failures in both character and capacity of the individuals
entrusted with safeguarding the nation’s health.

Through the 1980s and early 1990s, many individuals writing in the Newsline would
express concern with the acumen of the mainstream professionals tasked with researching and
treating early cases of AIDS. Community physician Joseph Sonnabend made little secret of his
feelings toward professional researchers, arguing that they lacked a real understanding of the
needs of those living with AIDS, and furthermore had badly fumbled early efforts to study the
condition. In a 1991 Newsline interview, for example, he told of the earliest days of the epidemic
when it first became known that the disease was linked to disorders of T cells. As the field of T
cell subtyping was still relatively new, Sonnabend tracked down a pioneer in the area, certain
that he would be among many professionals who had called the researcher for council. He was,
needless to say, shocked to learn that his was in fact the first AIDS related call the man had
received – this despite the fact that, as a community physician, he lacked the resources, prestige
or clout enjoyed by major academic researchers. Experiences such as this one would indelibly
flavor Sonnabend’s opinion of professional biomedical practice, causing him ultimately to
conclude that, “the caliber of people who’ve gone into the field of AIDS research is abysmal.”

(Chief of Staff for Representative T. Weiss), September 14, 1988,” in AIDS Patient Care
Michael Callen, Sonnabend’s long-time patient, echoed these concerns, arguing that a mixture of incompetence and complicity had forestalled the free expression and testing of ideas among researchers. Writing in the second volume of *Surviving and Thriving with AIDS*, he addressed the matter head on, declaring, “[W]hat’s going on in terms of AIDS research – or should I say, what’s not going on in terms of research – is a form of passive genocide… I think that the caliber of science that has been brought to bear on the problem of AIDS is fourth or fifth rate at best.”

Attacks on the acumen of biomedical researchers were joined by lingering doubts – consistent with the narratives of distrust chronicled in Chapters 2 and 3 – that avaricious and self-serving pharmaceutical corporations had hijacked the nation’s biomedical research apparatus. Many authors contributing to the *Newsline* would underscore these fears, arguing that the federal research and drug testing bureaucracy was designed to profit pharmaceutical corporations, not heal patients. In 1987, for example, the *Newsline* published a statement from PWA activist Marty Robinson, who argued that the FDA had “hidden behind a guise of cautious scientific detachment” in failing to prevent the excessive profiteering and delay by big pharma. And in a second *Newsline* piece, a former NIH lab director openly admitted that researchers structured their clinical trials primarily to benefit pharmaceutical manufacturers, not PWAs. But perhaps the sharpest rebuke to appear in the *Newsline* came from well-known West Coast AIDS advocate John S. James, who argued that pharmaceutical companies’ obsession with developing high tech, expensive and toxic therapies was costing PWAs their...

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lives. “The commercial forces driving AIDS treatment research favor high-tech, patentable options, the very ones which take the longest to develop,” James wrote. “Simple, available, off-the-shelf treatments, already well known in human use, could be applied much more quickly; but these kinds of treatments have little commercial potential.”\footnote{Ibid. 36.} In his view, no matter what evidence PWAs marshaled in support of potential remedies, if they derived from a plant, a health food or a commonly available chemical, they had virtually no prospects of seeing the light of day due to the monopolistic hold big pharma exerted on biomedical research. In James’s vivid contrast opposing natural plant-based and nutritional healing modalities with pharmacological agents, we recognize a nascent strand of anti-modernism, pitting the simple and the natural against the manmade and artificial.

Through the mid-to-late 1980s, Michael Callen used his editorship of the Newsline to cultivate a chorus of PWA criticism questioning the capacities and character of mainstream biomedical research. The resulting tenor of protestation and dissent would reach such levels that some readers felt compelled to pen letters to the editor defending the legitimacy of biomedicine. In one such letter, published the same month AZT was approved, a contributor urged other PWAs to accept on faith that mainstream researchers operated with a “certain degree of sophistication” and were thus indeed capable of quelling the growing epidemic.\footnote{If the author’s defense of biomedicine was full-throated, it was also admittedly quite hoarse. Indeed, he granted that some researchers – in particular, the highly controversial Robert Gallo – may have been “execrable human beings,” but they deserved respect nonetheless. Stewart Frankel, “Letter to the Editor,” \textit{PWAC Newsline} 21 (March 1987): 19.} Callen – who regularly published pieces critical of his own perspectives – printed the letter while appending to it a full-throated rebuke. “It remains my view,” he wrote, “that the gay community’s (and the media’s) unwillingness to demand the best science – it’s ‘willingness to assume on faith, at least
 provisionally, a certain degree of sophistication among AIDS researchers’ – is costing us our lives.”

In addition to impugning the commitment and capacities of mainstream researchers, PWAs writing in the Newsline and Surviving and Thriving with AIDS took issue with biomedicine’s insistence upon gathering “clean” or “pure” data, a topic explored in great detail in Steven Epstein’s 1996 volume Impure Science. Rigid entry requirements for clinical trials, such as rules forcing PWAs to forego the use of unapproved therapeutic treatments before or during trials, and to submit to placebo randomization, effectively forced individuals to choose between their regimens of self-care and the potential promise of new experimental agents. Both literally and figuratively, they demanded that PWAs submit to systems of control, while simultaneously asking that they prioritize statistical power over individual expressions of power. In their design and administration, they attempted to contain PWAs within neatly bounded and bordered domains, proscribing the turbulent movement between systems characteristic of the borderland model.

For many PWAs, the request was simply too bitter a pill to swallow. Michael Callen, for example, would overtly counsel PWAs to avoid federally sponsored trials. “The federal government’s track record of unethical, poorly designed trials speaks for itself,” he wrote in the conclusion to Surviving AIDS. “Don’t be willing to die for the supposed greater good of the greater numbers. Besides, a government trial is likely to be so poorly designed and executed that the data will end up being worthless anyway.” Navarre voiced similar concerns in the second

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419 In particular, see Epstein, Impure Science, 256-258.
420 Callen, Surviving AIDS, 199; Callen expressed a similar sentiment in a 1987 Newsline piece wherein he wrote, “When one federal researcher passionately implored me to beg PWAs in treatment trials to stay off all other medications to insure [sic] the data from trials was ‘clean,’ I
volume of *Surviving and Thriving with AIDS*, noting, “I question the advisability and
effectiveness of gay people sacrificing themselves on the altar of science in the hope of
preventing the onset of symptoms. Is that really the responsibility of the gay community?"\(^{421}\)

However, perhaps the greatest resistance to systems of control was to be found in
individuals who feigned deference to scientific authority while simultaneously working to
undermine that authority. One rather remarkable 1989 *Newsline* article captures this dynamic,
relaying in vivid detail the efforts one anonymous PWA undertook to gain entry into a clinical
trial of the experimental drug ribavirin, which he had previously procured at great personal
expense from Mexico. The trial had fairly rigid entry requirements, accepting only PWAs with
T-4 cell counts below 600. Concerned that his high titer would prohibit his enrollment, the man
took actions to effectively cheat his way into the study. What’s more, when finally enrolled, he
violated the protocol by pursuing a dosage schedule more in line with his self-care regimen. A
fascinating expression of both PWA stratagem and atonement, and an articulation of everyday
expressions of resistance effected at the level of the body, it warrants extended reproduction
here:

\[\text{“In order to try to lower my T4s a little, I went out the night before [my pre-trial test],}
\]
\[\text{partying and barhopping with friends with little sleep. It didn’t work. My T4s were 680.}
\]
\[\text{Another appointment was made for me to try again a few days later. This time, I stayed}
\]
\[\text{out the entire night before, and with NO sleep at all (I am not advising this!), my blood}
\]

\(^{421}\) Max Navarre, “‘Newsline Editor Max Navarre Responds,” in *Surviving and Thriving with
was taken again. The result was 630. I was accepted anyway…Then it dawned on me that although there was some difficulty in recruiting for this program, there are so many people with ARC who could benefit from free ribavirin. So I cheated to get into this study. Also on my mind was the fact that I could be fucking up the results which may or may not jeopardize (again?!) the approval of this beneficial and life-saving drug by the goddamn FDA. I felt very guilty and had very mixed emotions about what I was doing. But I would be saving myself and family a lot of money since the medication was costing a fortune…When I got in the study I cheated; I began to stockpile Ribavirin. I continued with my 5-days-on/5-days-off schedule even though the protocol required that I take it every day. I now have enough Ribavirin to last me through November. My doctor commented once that I seemed to have lower blood levels of Ribavirin than others and I laughed and denied selling it on the street…It’s just a goddamn shame that one has to cheat, lie and who knows what else to obtain what you need to live. May God bless our government”

As this brief analysis makes clear, PWAs engaged in a rich, multilayered critique of biomedical research practice through the 1980s and 1990s, calling into question the competence and character of both mainstream researchers and the broader biomedical research paradigm. Their impassioned arguments challenged the authority of not just individual researchers, but entire systems and cultures of practice. What’s more, they exercised this resistance through both words and actions, fomenting distrust through emotionally charged opinion pieces while subverting clinical trial protocols to procure unapproved agents and pursue individualized systems of self-care. Interestingly, by questioning the capacities of mainstream researchers and

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research paradigms, and advocating that PWAs pursue their own programs of self-care, PWAs engaged in a form of activism that was, in some ways, even more radically disruptive than protests staged in the public arena. For by steadfastly endorsing expressions of self-empowerment, they ultimately robbed the biomedical system of the one resource it desperately required to conduct its business: controlled bodies.

**Disputed Thoughts: HIV, AIDS and the “Unholy Holy War”**

Of all the topics discussed in the pages of PWAC publications, few were as controversial as debates surrounding the theoretical and etiological models biomedical leaders adopted to explain AIDS. In both his authorship and editorship of the *Newsline, Surviving and Thriving with AIDS*, and *Surviving AIDS*, Michael Callen was renowned – and in some cases reviled – for fiercely contesting the claim that HIV caused AIDS, and for maintaining an editorial policy receptive to critiques of orthodox etiological theories. While his was in many ways the loudest, others would contribute their voices to the opposition of the so-called “killer virus” model, including members of HEAL, who wrote into the *Newsline* expressing their support for the firebrand editor. As a whole, this culture of opposition and resistance would censure biomedicine for uncritically accepting the HIV etiological model, replacing falsifiable knowledge with unquestioned dogma, and failing to heed the fears and concerns of those who questioned its legitimacy.

Interestingly, despite this rich culture of engagement and protestation, most scholarly treatments of AIDS activism largely ignore the role PWAs played in so-called “dissident” or “denialist” etiological debates, focusing instead on the contributions made by rogue scientists such as University of California, Berkeley retrovirologist Peter Duesberg. It is difficult to

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423 Callen, in fact, famously refused to print the term “AIDS virus” in the *Newsline*, and actively edited contributors’ letters to omit the expression.
determine the ultimate reasons for this elision, but we may posit several possibilities. Some scholars, I maintain, exhibit a paternalistic defensiveness toward the memory of PWAs, perhaps striving to protect them from the stigma now attached to HIV dissidence. Such expressions of benevolent paternalism may, for example, explain the whitewashing of Michael Callen’s activism found in the works of Marita Sturken.424 Others may simply presume that scientists are the only legitimate experts to consult in scientific disputes, even when said experts have been denounced or renounced by their colleagues. Whatever the cause, the effects of this bias are quite clear. For it has led to stunningly bald scholarly assertions, which reduce a complex social movement into neat questions of scientific accuracy and legitimacy. In one 2009 volume dedicated entirely to unorthodox etiological AIDS debates, for example, an academic psychologist summarily discounts the role PWAs played in contrarian etiological activism, arguing that, “HIV denialism starts and ends with Peter Duesberg.”425

There is, of course, a certain irony to be registered in scholarly analyses of unorthodox AIDS activism that recognize as legitimate only those expressions of resistance originating from within the hallowed halls of biomedicine. For, as we will recall, it was precisely a discomfort with “expertism” that motivated the editorial policy of PWAC publications – and, more broadly, inspired the drafting of the Denver Principles in the first place. Indeed, suggesting that PWA expressions of dissidence grew out of or depended upon Duesberg both misrepresents the

424 In one rather stunning example, Sturken cites the 1993 Canadian film Zero Patience, wherein Callen appears as “Miss HIV,” an anthropomorphized version of HIV. Sturken claims that Callen scolds other viruses who wish to claim cofactor status in causing AIDS, while lamenting that nobody understands her. This summary mischaracterizes Callen’s boldly dissident diatribe in the film. In his cameo, he in fact argues, “Despite all the research, despite billions of dollars, not one reputable scientist has proven absolutely and conclusively that I disabled people’s immune systems.” He furthermore ends his segment by singing, “Tell a story of a virus, of greed, ambition and fraud, a case of science gone bad.” For Sturken’s summary, see Marita Sturken, Tangled Memories, 251.
425 Seth Kalichman, Denying AIDS, 175.
chronology of etiological activism and recapitulates the systematic disempowerment of PWAs against which individuals like Michael Callen railed. However, even more importantly, in equating HIV dissidence with the pronouncements of Duesberg and his academic acolytes, we take what is in fact a multifaceted tradition of resistance and reduce it into a purely scientific disagreement debated according to the traditions and standards of modern biomedicine. As we shall see, PWA engagement with etiological disputes reached beyond questions of viral titers or statistical power analysis, interrogating instead the full measure of the power biomedicine wielded over the ill. Throughout the 1980s and early 1990s, authors writing in the Newsline and Surviving and Thriving with AIDS – inspired and encouraged by Michael Callen – asked probing questions regarding the power of experts to dictate truth, the power of a theory to influence individuals’ lived experience of their disease, and the power of PWAs to both define and respond to their condition on their own terms.

For Callen, across virtually all domains, the HIV etiological model fundamentally disempowered PWAs. On the most basic level, its rapid ascent from questionable hypothesis to received truth, a phenomenon Steven Epstein chronicles in Impure Science, smacked of that

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426 As a matter of historical chronology, the claim is easily refuted, as PWA engagement with unorthodox etiological arguments predated Duesberg. In fact, the very first issue of the PWAC Newsline – published two years before Duesberg entered the debate – featured an article wherein Callen questioned the public’s uncritical acceptance of the viral etiological theory. Callen would write, “I do not believe that LAV/HTLV-III ‘causes’ AIDS. It may – or may not – play some role, but the notion that AIDS spreads like syphilis or gonorrhea or like a common cold is patently absurd. It has been my experience and my observation that AIDS is a complicated disease to develop. It seems clear to me that AIDS is certainly not a one-shot deal.” Michael Callen, “Media Watch,” PWAC Newsline 1 (June 1985): 7; Duesberg’s first article on the topic would not appear until 1987. Peter Duesberg, “Retroviruses as Carcinogens and Pathogens: Expectations and Reality,” Cancer Research 47, no. 5 (1987): 1199–1220.

427 Epstein conducted an article review and found that the number of unsubstantiated claims made by scientists regarding the etiological role of HIV in AIDS increased greatly from 1984-1986. Furthermore, while authors would initially write in to journals to protest the claim that a single virus was destroying individuals’ immune systems, such letters largely stopped post 1984.
most pernicious exponent of expertism: dogma. The situation was, in many ways, a perfect storm for controversy: a new theory developed by a famously controversial American researcher, and announced with much fanfare by an administration widely deemed negligent, was rapidly codified by a media establishment viewed as sensationalist. Callen argued that in catalyzing and condoning this process, biomedicine had branded itself into something far worse than fourth or fifth rate science – it had become, in effect, religion masquerading as science. Writing in the Newsline in 1986, the editor argued, “Regarding the virtual non-debate about the etiology of

In his analysis of this consolidation of scientific certainty, Epstein cites Paula Treichler, who in her own work argued, “By repeatedly citing each other’s work, a small group of scientists quickly established a dense citation network, thus gaining early (if ultimately only partial) control over nomenclature, publication, invitation to conferences, and history.” See Epstein, Impure Science, 81-84.

In one PWAC Newsline piece, Callen railed, “How, I ask myself, did we fall into the shorthand of calling HIV the ‘AIDS virus’ and when and how did the term ‘HIV Disease’ creep into usage? Doesn’t anyone else remember how “appropriately” skeptical the press was about Gallo’s announcement about HTLV-III? Everyone seemed to smell the same rat…In the weeks surrounding Gallo’s announcement, press accounts would cautiously refer to HTLV-III as the ‘putative’ AIDS virus. Reporters were generally careful to remind readers that the assertion that HTLV-III was ‘the cause’ of AIDS was a hypothesis which was yet to be proven. Then, suddenly, the qualifiers disappeared and the caution evaporated. HIV was decreed to be the cause of AIDS. Wait? Did we miss something?” Michael Callen, “Why I Do Not Believe that HIV is the Cause of AIDS,” 35, emphasis in original.

In the late 1980s, Robert Gallo was under investigation for purportedly misappropriating a sample of LAV (later renamed HIV) from the French and claiming to have isolated it himself. See, for example, John Crewdson, “The Great AIDS Quest: Science under the Microscope,” Chicago Tribune, Nov 19, 1989, Special Section; Gallo was a frequent target of both Callen and other PWAs, who found him to be overly confident and dismissive of PWA activism. In one PWAC Newsline article, for example, Callen tells of his efforts at a conference to push the National Cancer Institute researcher to discuss other potential causes of AIDS. “When I persisted with my questions, he got nasty and said words to the effect that he didn’t know what I’d done for people with AIDS, but he was busy saving lives and questions like mine were a waste of his valuable time. In other words, by questioning the religion of HIV, I’m killing people.” Michael Callen, “Montreal AIDS Conference: A ‘Major Stressor Event,’” PWAC Newsline 46 (July/August 1989): 44, emphasis in original.
AIDS, HTLV-III\(^{430}\) has become a matter of faith – almost a religion. To question its central role in AIDS is heresy.\(^{431}\) He would carry his profound distrust and distaste in biomedicine’s uncritical embrace of the killer virus etiological model for the remainder of his life. Seven years after the Newsline piece, in one of the last letters he penned before his death from AIDS related complications, Callen reflected, “Naïve poor Midwestern boy that I was, I thought this battle would be fought according to the rules of science. It came as quite a shock to discover that the true discourse of AIDS is theological. There are received truths; papal bulls (papal bullshit, more like it), and various sects and denominations who launch jihads against one another. It’s an unholy holy war.”\(^{432}\)

In addition to believing that the killer virus etiological theory wrapped religious precept in the garb of scientific objectivity, Callen worried that the public would use the theory to further stigmatize and disempower PWAs. He disagreed fiercely with the leaders of mainstream AIDS organizations who argued that a narrative centered upon a specific germ would diffuse some of the spotlight that, through the early 1980s, remained sharply focused on gay men’s sexual practices. He instead maintained that viral narratives merely made matters worse by allowing

\(^{430}\) Along with LAV, HTLV-III was an early designator used to describe the virus later renamed HIV. The French team, led by Luc Montagnier, used the former term while Gallo’s lab used the latter.

\(^{431}\) In the same piece, Callen approvingly cites Sir Karl Popper’s falsification principle, juxtaposing Popper’s beliefs with mainstream AIDS research. Michael Callen, Newsline. 15. September 1986. 24; In his personal papers, Callen would write, “I’ve come to a BAPTIST CONVENTION and asked to consider the possibility that god doesn’t exist.” This is almost certainly an effort to explain how he felt trying to question the HIV model. Interestingly, Callen scribbled his notes on back of HIV dissent articles. Handwritten Notes, Box 8, Community Research Initiative, 1989, Michael Callen Papers, LGBT-NA, Emphasis in original.

\(^{432}\) Letter from Michael Callen to Neville Hodgkinson of the Sunday Times of London. July 17, 1993, Box 8, Unfolded Correspondence, 1993, Folder 237, Michael Callen Papers, LGBT-NA; In an article in his short lived AIDS Forum publication, Callen similarly argued, “Anyone unwilling to genuflect before the god of HIV…will most likely be denied research funding.” AIDS Forum, 1.1, January 1989, 1, Box 11, AZT, Folder 320, Michael Callen Papers, LGBT-NA;
conservatives to cast gay men as vectors threatening to infect mainstream America with their malady. Writing as early as 1985, he noted with alarm new expressions of discrimination enabled by the virological model, with parents in Queens, New York protesting the admission of children with AIDS into classrooms and small towns in America passing ordinances requiring antibody testing for food handlers. “As many gay activists are only now beginning to realize,” he wrote, “we’ve painted ourselves into a very dangerous corner by our uncritical acceptance of the simplistic and unproven hypothesis that LAV ‘causes’ AIDS.”

Callen’s critique of the HIV etiological model in fact flowed from his ardent support of an alternative etiological theory first proposed by Joseph Sonnabend in 1983. Revised several times through the 1980s, the multifactorial theory viewed AIDS as the consequence of repeated infections with known sexually transmitted pathogens coupled with other environmental factors that, over time, wore away individuals’ immune systems. The multifactorial theory was never particularly popular among AIDS service organizations or protest groups such as ACT UP, almost certainly because its focus on the sexual and recreational practices of gay men bore too

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433 Michael Callen, “Media Watch,” PWAC Newsline 5 (October 1985): 10; Callen’s concerns with the ability for the killer virus theory to foment panic harkens back to the first edition of the Newsline, wherein he criticizes New York Native and Advocate articles recommending that people with AIDS air dry dishes and boil sheets that had come into contact with bodily fluids. In the second edition, he critiqued a now famous Life Magazine cover intoning, “Now No One is Safe from AIDS.” Approximately two years later, he criticized ACT UP for attempting to provoke and profit from the notion that AIDS was poised to spread into the general population. See Michael Callen, “Media Watch,” PWAC Newsline 1 (June 1985): 7; Michael Callen, “Media Watch,” PWAC Newsline 2 (July 1985): 3; Michael Callen, PWAC Newsline 23 (May 1987): 28. 434 Sonnabend would argue, for example, that “The repeated infections with CMV, the reactivation of EBV, exposure to multiple allogeneic semens and infection with other sexually transmitted pathogens result in an accumulation of effects that interact either addictively or synergistically to result in a switch to a self-sustaining condition.” He first formulated his theory in 1983. See Joseph A. Sonnabend, Steven S. Witkin and David T. Purtilo, “A Multifactorial Model for the Development of AIDS in Homosexual Men,” circa 1983, 5, Box 11. Sonnabend [Joseph A., writings] Folder 306, Michael Callen Papers, LGBT-NA; Joseph Sonnabend, “Acquired Immunodeficiency Syndrome: Opportunistic Infections and Malignancies in Male Homosexuals” Journal of the American Medical Association 249, no. 17 (1983): 2370.
close a resemblance to the condemnations of the religious right. The mainstream viral etiological model was in many ways more palatable, as Raymond Keith Brown argued in *AIDS, Cancer and the Medical Establishment*. “A single disease agent that just happened to have emerged within the gay community,” Brown argued, “absolves its members from individual or collective responsibilities for containing or controlling the spread of AIDS.” And yet, despite this, Callen would maintain that the multifactorial theory was the only etiological model that explained reality, arguing that he had failed to meet a single PWA who refuted his belief that AIDS resulted from the constant barrage of infections over time.

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435 Callen would, for example, admit, “You’ve got George Bush saying it’s a disease of behavior, and that’s what we believe it is. We’re saying it neutrally; he’s being moralistic.” Anne Christine D’Adesky, “The Man Who Invented Safe Sex Returns,” *Out* (Summer 1992): 33; Similarly, on coauthoring the first safer sex manual with Michael Callen and Richard Berkowitz, Sonnabend commented, “[I]n those days, GMHC hated us because we spoke about promiscuity and used words like *sperm* and *rectum* in public.” Sean O. Strub, “The Good Doctor.”


437 In addition to citing interviews with other PWAs to support his support for the multifactorial model, Callen would refer to his own experience, chronicling a seemingly interminable list of sexually transmitted diseases he had contracted prior to developing AIDS. A 1992 *Newsline* article, for example, quotes him as stating, “By the age of 27… I had over 3,000 different sexual partners. Not coincidentally, I’d also had: hepatitis A, hepatitis B, hepatitis non-A, non-B; herpes simplex types I & II; syphilis; gonorrhea; non-specific urethritis; shigella; entamoeba histolitica; chlamydia; fungal infections’ venereal warts; cytomegalovirus infections; EBV reactivations; cryptosporidium and therefore, finally, AIDS. For me, the question wasn’t why I got AIDS, but how I had been able to remain standing on two feet for so long…If you blanked out my name and age on my pre-AIDS medical chart and showed it to a doctor and asked her to guess who I was, she might reasonably have guessed, based on my disease history, that I was a 65-year-old malnourished equatorial African living in squalor…I believe that a small subset of urban gay men unwittingly managed to re-create disease settings equivalent to those of poor Third World nations and junkies.” As a result of his personal experience and his interviews with other PWAs, Callen firmly supported the multifactorial etiological model. Writing in the *Newsline*, he commented, “I remain convinced – based on my own experience and my conversations with other gay men with AIDS – that AIDS is a the [sic] result of a constant barrage of infections over a period of time. I guess I’m a rabid multifactorialist, I just don’t buy this crap about one ‘unlucky’ sexual encounter causing AIDS.” See Carola Burroughs, “AIDS and Cofactors: A Homeopathic Perspective,” *PWAC Newsline* 74 (March 1992); Michael Callen. “Media Watch,”
Sonnabend’s multifactorial model was very much a product of its time, expressive of significant shifts in the public experience of disease witnessed through the early-to-mid 20th Century. As we will recall from Chapter 2, in the decades preceding AIDS, the developed world witnessed a fundamental shift in the overall burden of disease, with chronic conditions replacing infectious diseases as the primary cause of morbidity and mortality. During this time, professionals and the lay public alike came to interpret intransigent chronic diseases such as cancer through multifactorial models. That some PWAs would interpret AIDS through a chronic lens is perhaps unsurprising, for it suggested the possibility that they could survive long-term with the disease. Interestingly, most histories of AIDS activism fail to recognize the inherent empowerment of the chronic disease model. In the impressive 1992 volume *AIDS: the Making of a Chronic Condition*, Elizabeth Fee and Daniel Fox in fact paint chronicity as a failure of sorts. As they argue, “[T]he idea that AIDS would become another killer chronic disease, like heart disease, cancer, and stroke, has been unpalatable because it adds to the already overwhelming financial and organizational problems of health policy.”

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438 In *Surviving AIDS*, Callen explicitly invoked chronic diseases to explain the multifactorial model, musing, “With heart disease, people understand that genetics, diet, exercise, and other factors conspire to determine whether or not one will suffer a stroke. But for some reason, most people abandon any notion that getting sick is a multifactorial process once an infectious agent is involved.” Callen, *Surviving AIDS*, 13, n7; Similarly, Callen would argue, “A multifactorial model suggests that multiple exposures to infectious and non-infectious immunosuppressive factors conspire, over time, to produce AIDS. A useful disease model would be heart disease: one wouldn’t ask which particular pat of butter caused a heart attack. Clearly cholesterol builds up over time.” Michael Callen, “Can Women Transmit AIDS?” in *Surviving and Thriving with AIDS: Collected Wisdom, Volume II*, ed. Michael Callen (New York: People with AIDS Coalition, 1988): 226.

Callen offered at least two additional supports for his belief that the multifactorial theory empowered to PWAs. For one, he maintained that by forcing PWAs to examine high-risk behaviors, the theory made it easier for communities to identify the structural roots of discrimination that had ultimately led gay men to seek out risky sexual interactions in the first place. But perhaps most importantly, Callen believed the theory empowered PWAs directly by suggesting they could reverse the course of their disease by making real and lasting changes to their behavior. In rejecting the notion that an unlucky sexual encounter could transmit a killer virus, the model replaced chance with agency, preserving a role for individual action in both preventing and treating the disease. Reflecting upon his support of the model in Surviving AIDS, Callen would admit, “Whether or not Joe’s multifactorial theory of AIDS ultimately proves to be correct, discovering a different way of thinking about AIDS at such a crucial turning point in my life provided a framework for me to justify believing that I might survive my disease. It was a life raft that kept me afloat in a sea of doom and gloom.”

Even Rob Schick, a Newsline columnist famously critical of Callen’s positions, admitted, “We’d like to believe that AIDS is

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440 In a 1983 letter sent to the editor of New York Magazine, for example, Callen argued, “Society’s irrational and insidious hatred of homosexuality has forced too many of us into the ghetto of the bathhouse circuit...That so many gay men continue to seek refuge from our homophobic society in such disease-polluted places is perhaps the saddest observation about AIDS that I can make.” Letter from Michael Callen to Editor Ed Kosner of New York Magazine, June 15, 1983, Box 1, Folder 8, Joseph Sonnabend Papers, NYPL-MAD; What’s more, in 1992, the notoriously private Sonnabend would admit in an Out Magazine interview that his concerns with structural dimensions of illness were shaped by a young adulthood spent in South Africa during the rise of the pro-apartheid Afrikaner National Party. The experience also made it difficult for him to join groups of any kind, be it the National Party, the gay activist community, the Reagan-Bush medical establishment, or the “HIV camp.” D’Adesky, “The Man Who Invented Safer Sex Returns,” 31.

441 Callen, Surviving AIDS, 6.
caused by Michael’s proposed ‘fane lane’ urban lifestyle because we could change that lifestyle ourselves. As Michael himself points out, belief in HIV is disempowering.”

Schick’s admission is fascinating, for it grants that the mainstream HIV model was disempowering because it provided fewer opportunities for PWAs to engage their condition and effect their own cures, a topic to which I shall return in the third unit of this chapter. The multifactorial model, in contrast, allowed PWAs to explain their disease in terms of long-term behaviors and to derive power by accepting responsibility for making changes to that behavior. In so doing, it inverted the bromidic aphorism, variously attributed to Luke the Evangelist, Voltaire and Winston Churchill, which holds that great power brings with it great responsibility. For Callen, the power requisite to survive AIDS came from owning one’s body and one’s past, a point he underscored in the closing of Surviving AIDS. “[T]he survivors I interviewed took responsibility for their own healing, and this expressed itself in a number of ways,” he noted. “Many voiced strong opinions about the need to acknowledge some personal responsibility for life-style choices, both in terms of getting sick in the first place and in terms of getting well.”

As we have seen, in Callen’s championship of unorthodox etiological models, he invoked the same resistance to dogmatism that had attended the rise of alternative and nontraditional healing movements. And, indeed, as we shall see later, elements of the multifactorial model appeared in various PWAC contributors’ embrace of specific alternative healing systems. The model, however, would fail to generate traction among the biomedical community, with

mainstream research efforts consistently organized entirely about the mainstream viral etiological model. Correspondingly, most drug research through the 1980s and early 1990s focused upon developing antiretroviral agents to target HIV. The first of these agents to receive FDA approval, azidothymidine (AZT), generated considerable concern among many in the PWA community. It is to these concerns that we now turn.

Disputed Cures: Curses, Cures and the “Promiscuous Use” of AZT

In the previous sections, I identified myriad ways in which individuals contributing to PWAC publications expressed positions rooted in antiauthoritarianism, antidogmatism, and antimodernism, three of the themes identified in Chapter 1 as common to historic expressions of alternative and nontraditional health activism. By the late 1980s, with the approval of AZT, these publications would additionally feature arguments evocative of the fourth and final theme identified earlier: anti-heroism in the domain of therapeutics. In the final section of this unit, I argue that PWAs invoked themes of anti-heroism in two distinct ways. I begin with an analysis of PWA discourse regarding the drug’s toxicities and attendant claims that biomedical researchers failed to adequately vet it prior to its approval. I then consider broader complaints with the biomedical system’s narrow pursuit of magic bullet cures targeting HIV.

Granted expedited review and approval by the FDA in 1987, AZT stoked remarkable controversy in the pages of the Newsline and the second volume of Surviving and Thriving with AIDS. Much of it centered upon the drug’s noted toxicity, and the fact that the NIH had ended the AZT clinical trial early after initial results strongly suggested that it prolonged the lives of PWAs.444 As early as 1986, a Newsline article would plant seeds of doubt in discussions of the drug, warning readers that dangerously little was known about its toxicity beyond the two-week

444 For a discussion of the trials, see Epstein, Impure Science, 198.
mark. By 1987 and 1988, the tenor of criticism increased markedly, with PWAC cofounder Paul Lande flatly declaring it “morally negligent, if not criminally negligent, to push AZT without carefully explaining how little is known about it.’’ Meanwhile, Newsline editor Max Navarre bemoaned what he termed the “medical love affair with AZT,” which led physicians to prescribe it even to those with few symptoms of AIDS. Navarre would, in fact, pair his concerns regarding PWA desperation with the historic insecurity that racked the gay community as a result of their marginalization from mainstream society. As he argued, the rush of PWAs to take potentially dangerous drugs such as AZT “sounds to me like more dyed-in-the-wool, gay community lack of self esteem: we don’t count, so why not throw ourselves to the wolves? Why not sacrifice ourselves on the altar of ‘progress.’”

As early as 1986, several Newsline contributors had begun to air specific concerns with AZT’s untoward side effects. In fact, in the same article that announced the initial AZT clinical trial results, the editorial issued a stern warning: “Anecdotal reports of serious side effects – particularly bone marrow suppression – abound. The Coalition knows of several individuals who

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447 Navarre would argue, “Certainly, the current fashion of prescribing AZT to virtually anyone with a few symptoms has contributed greatly to the trends towards AIDS-it is. The medical love affair with AZT is particularly alarming to those of us who remain unconvinced that HIV is ‘the cause’ of AIDS. Every time I hear HIV referred to as the ‘AIDS virus,’ my teeth start to grind.” Max Navarre, “AIDS-it is,” in Surviving and Thriving with AIDS: Collected Wisdom, Volume II, ed. Michael Callen (New York: People with AIDS Coalition, 1988): 45.
448 Max Navarre, “Some Thoughts on Experimental Drugs,” PWAC Newsline 22 (April 1987): 18; The PWAC’s unrelenting critiques of AZT would in fact provoke discord with other AIDS service organizations; the leader of Project Inform, for example, at one point issued thinly veiled critiques of the PWAC when he questioned the “New Yorkers who have so effectively convinced thousands of people around the country that AZT is a poison.” Letter from Martin Delaney to Mathilde Krim, September 21, 1989, Box 7, Compound Q Frenzy, 1989, Folder 210, Michael Callen Papers, LGBT-NA.
had to drop out of the trials due to side effect.” The drug’s early history as an experimental anti-cancer agent, coupled with the fact that it inhibited DNA synthesis, did little to bolster its reputation among skeptical PWAs and their advocates, and in 1989 Joseph Sonnabend definitively declared the drug “incompatible with life.” But it was Michael Callen who would launch the most sustained critique of what he termed society’s “promiscuous use of AZT.” In article after article, the PWAC cofounder and Newsline editor indicted and imprecated the drug, referring to it as “Drano in pill form,” and arguing that prescribing it to combat AIDS was like “swatting a fly with a thermonuclear warhead.” So vociferous was he in his negative appraisals that his detractors would in fact take to calling him an “AZT terrorist.”

To support his claims, Callen would turn to the interviews he had conducted with long-term PWAs, arguing that the overwhelming majority of individuals who had beaten the odds to survive for longer than three years had refused to take AZT, a point he reiterated in both Surviving AIDS and Surviving and Thriving with AIDS He would note, for example, that well-

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450 Sonnabend’s quote, in fact, comes from the first edition of the HEAL Quarterly 1, no. 1 (Fall 1989): 3. Copies of all available HEAL Quarterly articles found in HEAL-A.; Callen similarly critiqued the expectation among researchers that PWAs would take AZT long-term, arguing, “The idea that individuals should take chemotherapy every day for the rest of their lives is completely unprecedented.” See Callen, Surviving AIDS, 212.
454 Callen would also note that physicians had angrily approached him saying that their patients had refused to take AZT based on his suggestions. See Callen, “AIDS 201,” 3; Michael Callen, “Newsline Policy on Medical Matters,” 53.
455 Callen, Surviving AIDS, 27; Michael Callen, “Surviving and Thriving with AIDS,” 137.
known PWA and activist John Lorenzini steadfastly refused to take the drug,\textsuperscript{456} and quoted a second PWA, AJ Roosevelt Williams, who flatly argued, “You can’t cure anyone with a poison, and AZT is obviously a poison.”\textsuperscript{457} Many of these contributors who eschewed AZT would furthermore pursue regimens of self-care featuring alternative therapeutic components – a topic we will explore in greater detail in the third unit of this chapter. Williams, for example, would reject the antiretroviral agent in favor of mainstream drugs such as Bactrim and aerosolized pentamidine, alongside nontraditional healing approaches including garlic pills, germanium, food grade hydrogen peroxide, egg lipids and visualization.\textsuperscript{458}

Concerns with AZT’s toxicities were, as one might expect, closely linked with trepidations regarding the methods and motives of pharmaceutical corporations. As I noted in the previous section, many PWAs viewed the pharmaceutical industry as a vastly powerful corporate behemoth that systematically put corporate profits before the needs of PWAs. In the early years of the epidemic, the leaders of Burroughs Wellcome, the corporation that developed AZT, did little to assuage these concerns. In 1987, for example, former PWAC Executive Director Michael Hirsch penned a letter to Burroughs Wellcome requesting information regarding the drug’s clinical trials, eager to evaluate the many controversies surrounding its approval. The pharmaceutical giant replied with a letter so nakedly paternalistic in its stance toward PWAs that an exasperated Hirsch submitted it for publication in the \textit{Newsline}. “[I]t can be difficult, and in some cases ill-advised, to provide complex scientific information directly to the news media or the general public,” the letter argued. “As a pharmaceutical company, we feel it is very important

\textsuperscript{456} Callen, \textit{Surviving AIDS}, 119.
\textsuperscript{457} Ibid. 110.
\textsuperscript{458} Ibid. 111; Other articles similarly discussed the refusal of many long-term PWAs to take AZT. See, for example, Buzz Wolf, “A Long-Term Survivor Speaks Out,” \textit{PWAC Newsline} 46 (July/August 1989): 30; Marcus Boon and Kate Hunter. “Dr. Joseph Sonnabend Takes a Look,” 30.
to preserve the integrity of the patient-physician relationship. This relationship is a critical one and a very important way for patients to get answers about their individual condition and experiences." The response underscores the chasm dividing pharma’s conceptualization of benevolent expertise and the PWA empowerment movement’s celebration of radical engagement. Joseph Sonnabend, for one, would rail against such casual disempowerment of PWAs by biomedical researchers seeking to shield them from information on the grounds that it might be confusing. “There is nothing worse than treating people like cattle,” the community physician argued, “giving something which is presented with conviction only for the purposes of maintaining order or lack of confusion.”

For some PWAs, the biomedical fascination with AZT stemmed from a mainstream professional culture that had come to glorify the search for cures and, in the process, lost sight of the actual needs of PWAs. Callen, for example, argued that the biomedical research apparatus had become fixated on the “Nobel-prize winning prospect of curing” AIDS as opposed to engaging in the “unglamorous, labor intensive task of KEEPING PEOPLE ALIVE.” Editor Bree Scott-Hartland echoed similar sentiments in a 1992 interview wherein he rejected John Ehrenreich’s well-worn metaphor describing clinical therapeutics. “People are screaming for a magic bullet,” Scott-Hartland lamented. “Their energy would be better spent learning to live with the disease. We don’t all die within six months. There are people who have lived with

460 Cass Mann and Stuart Marshall, “HIV – Questions Not Answers,” Positively Healthy News 3 (March 1989); Callen also argued that the GMHC’s decision not to distribute the second volume of Surviving and Thriving with AIDS to its clients stemmed from its leaders’ beliefs that the diversity of opinion it presented and endorsed would confuse and overwhelm PWAs. Memo from Michael Callen to PWAC Board, January 16, 1989, Box 6. GMHC (1989-1990), Michael Callen Papers, LGBT-NA.
AIDS for ten years and are still thriving.” In fact, for PWAs who were dying of unglamorous opportunistic infections largely ignored by researchers, the word “cure” had become a curse, a point underscored by a 1989 Newsline article penned by a representative of Boston’s AIDS Watchdog Group. “While the old-boy researchers at Harvard play Star Wars with pie-in-the-sky antiviral strategies, people are dying from infections that need not kill them,” its author argued. “‘Looking for a cure’ is a phrase that has little meaning in the here and now…‘Cure’ is a useless word; in fact, it’s a deadly word.”

As we can see, much like questions pertaining to the etiology of AIDS, the debate amongst PWAs regarding AZT was about much more than a single drug, touching instead upon fundamental issues cutting to the core of patient empowerment. In their critique of pharmaceutical corporations’ motives and practices, PWAs displayed the same trademark anti-authoritarianism we have seen woven through the other three loci of resistance thus considered. We also recognize anti-dogmatism, particularly amongst authors who critiqued AZT out of a firm belief that research had not sufficiently demonstrated the relationship between HIV and AIDS. And, most noticeably, we recognize expressions of anti-heroism centered upon the known and unknown toxicities of AZT, and the belief that the search for magic bullet cures was costing PWAs their lives. These fervent appeals to anti-heroism would provoke diverse responses in the Newsline. Michael Callen, for example, used his critiques of AZT to encourage PWAs to instead engage in their own explorations of less toxic drugs and agents – both conventional and alternative. Others, however, would express even more radical positions. The controversial

464 Larry Kramer would voice similar concerns. In a 1987 letter, Kramer asked Dick Thompson of Time Magazine whether he was aware that “87% of all NIH protocols in existence and being planned for the next five years are still only for AZT?” He furthermore listed drugs that no NIH
New York Native reporter John Lauritsen, who in 1986 coauthored a text explicating a multifactorial toxin-based etiological model for AIDS, argued in a September 1989 Newsline article that the only solution to AIDS was to be found in foreswearing the use of all drugs – recreational and medicinal – in favor of a “healthy lifestyle.”

Few topics elicited as rancorous a debate within the pages of the Newsline than those centered upon the fortune and folly of AZT. In the publication’s January 1990 volume, for example, readers encountered an anti-AZT article followed immediately by a pro-AZT article, which was rebuffed by an anti-AZT article, only to be countered by another pro-AZT article!

It was in no small part a consequence of Callen’s personal critiques of mainstream biomedical protocol was studying: Ampligen, AL 721, Colony Stimulating Factors, Ribavirin, Imuthiol, Anatabuse, Foscarnet, DHPG, Fusidic Acid, Carrisyn. Michael Callen would fiercely advocate the use of one mainstream drug (aerosolized pentamidine) and one alternative (AL721, or egg lipids). He believed that mainstream medicine’s celebration of magic bullets forestalled critically important research into aerosolized pentamidine, an agent which created Pneumocystis carinii pneumonia. And his support of egg lipids would lead him to cofound the People with AIDS Health Group, the City’s first buyers’ club dedicated to making available low cost, low toxicity agents to PWAs who sought to pursue their own treatment plans. Letter from Larry Kramer to Dick Thompson of Time Magazine, December 3, 1987, Box 4, CRI Press (1987-1988), Folder 105, Michael Callen Archives, LGBT-NA.

466 Lauritsen would argue, “If ‘AIDS’ is caused largely by toxins, what is an appropriate treatment? Not still another drug, but freedom from toxins. Long-term survivors, almost without exception have avoided toxic chemotherapy (like AZT) and are repairing their bodies through a more healthy lifestyle” exercise, good nutrition, rest and stress reduction, and avoidance of harmful substances (including cigarettes, alcohol, heroin, cocaine, MDA, quaaludes, ethyl chloride, poppers and all other ‘recreational drugs’).” See John Lauritsen, “The Case Against AZT,” PWAC Newsline 47 (September 1989): 58.
467 This back and forth appeared in Issue 51 (January 1990) of the Newsline. Marc Colter penned the initial article critical of AZT; Rob Schick replied in support of the drug, prompting a rebuttal from John Lauritsen and a rejoinder by Rob Schick; By the late 1980s, Schick had become increasingly frustrated with those who attacked AZT, at one point writing, “Truth is, the people who say AZT is no good don’t know science from a hole in the ground. They’re the same ones who can’t admit AIDS is caused by HIV. They won’t face up to the harsh truth that they’re in a fringe group which has been dangerously wrong all these years.” See Rob Schick, “The Crazy Case Against AZT,” 49 (November 1989): 35 and related letters in same volume.
practices, coupled with his ardent support for PWAs’ open contestation of received truths, that the *Newsline* would continue to air critiques of AZT years after the drug’s approval. However, lest we presume that “AZT terrorist” Callen single-handedly orchestrated the anti-AZT perspective, it is worth noting that similar pieces aired in the *Newsline* even after the profane and prolific editor left the publication in September of 1989.

In sum, the *Newsline* and *Surviving and Thriving with AIDS* volumes were lively, contentious publications airing impassioned perspectives penned by contributors committed to questioning the practices, principles and pronouncements of mainstream biomedical professionals. They both would serve, in effect, as safe harbors wherein PWAs could engage their condition on their own terms, articulating a wide array of questions, theories, hopes and fears, and sharing strategies, ideas and practices for defining and responding to their disease. For Jane Rosett – one of only two PWAC cofounders to survive to see the close of the 1980s – Callen’s vigorous defense of editorial diversity was in fact the only factor that made the group a true coalition.\(^{468}\) She had early on wondered whether the PWAC was indeed a true coalition, as it was founded almost entirely by gay white men who met weekly in the city’s Gay and Lesbian Community Center. “[I]f, as a publication we are a coalition,” Rosett observed, “it is all thanks to Michael Callen’s commitment to create and maintain varied editorial content.”\(^{469}\)

In some ways, then, the PWAC’s core identity was rooted in the varied perspectives of contributors engaging and debating the four topics explored in this unit. The source of rancorous debate and disagreement among PWAs, they constituted loci of resistance around which individuals organized their own responses to the epidemic, rejecting the efforts by others to

\(^{468}\) Callen was the second PWAC cofounder to survive to see the early 1990s. Among PWAC cofounders, Rosett was unique in being a woman and not having AIDS.

define their conditions or order their bodies. Through their engagement with these issues, PWAs expressed positions and opinions that invoked themes of resistance that have long attended alternative and nontraditional health activism, including anti-authoritarianism, anti-dogmatism, anti-modernism anti-heroism. They in turn established a forum supportive of and conducive to PWAs’ *direct* embrace of alternative and nontraditional healing systems. In the final section of my analysis, I turn my attention to these direct points of intersection, examining the diverse healing practices and traditions whose tenets found expression and support on the pages of the *Newsline, Surviving and Thriving with AIDS*, and *Surviving AIDS*.

**Embracing Unorthodoxies: PWAC Contributors’ Embrace of Alternative Health Systems**

Both *Surviving and Thriving with AIDS* and the *Newsline* regularly featured columns, letters and advertisements embracing a wide array of alternative health modalities, ranging from herbalism and homeopathy to macrobiotics, chiropractic, acupuncture, yoga, biofeedback, Ayurvedic medicine, Orthomolecular medicine, crystal curatives and attitudinal healing. The very first edition of the *Newsline*, in fact, featured an article entitled “Acupuncture as an Alternative” wherein PWAC cofounder David Summers explored the benefits of Chinese medicine while criticizing organizations such as GMHC for neglecting such nontraditional healing systems.470 Similar articles would appear through the close of the first decade of the epidemic, seemingly unfazed by advances in biomedical research and drug development. Indeed, if anything, PWA engagement with nontraditional healing systems *increased* in frequency and intensity following the approval of AZT, a trend that distinguishes the history of unorthodox

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AIDS activism from earlier alternative health movements such as homeopathy, which declined in influence following the development of antibiotics.\(^{471}\)

The diversity of alternative healing systems invoked and supported by PWAC contributors may prompt one to question whether it is indeed possible to treat unorthodox AIDS activism as a single topic of analysis. An easier approach, no doubt, would be to chronicle the healing modalities mentioned on the pages of the *Newsline* and *Surviving and Thriving with AIDS*, treating each as a separate bounded system of practice. However, such a strategy is unsatisfactory for two reasons. First, individuals advocating diverse alternative healing practices in PWAC publications in fact shared a common script, embracing the same themes of dissent and opposition we explored in the previous unit. Critiques of dogmatism, heroism, reductionism and fatalism established a certain degree of coherence and allegiance between otherwise dissimilar healing traditions, thereby increasing their appeal and insulating their proponents from criticism. And second, as I shall argue in the final component of this unit, individuals living with AIDS seldom limited themselves to one bounded system of alternative health practice, but rather actively moved between diverse systems as they saw fit. Consequently, instead of viewing alternative healing traditions as rigidly enumerated philosophies, it is perhaps more appropriate to conceive of them as tools PWAs wielded in their efforts to claim responsibility for and ownership over their disease. As such, they harmonized with the PWAC’s underlying mission of empowering individuals to conceive of and respond to AIDS on their own terms.

A cursory review of the unorthodox healing modalities advocated on the pages of PWAC publications underscores there many areas of overlap and synergy. For example, the advocates of guided visualization, yoga, hypnosis, biofeedback, and the teachings of Louise Hay and the

AIDS Mastery all shared the same concerns with fatalistic narratives Callen railed against as editor of PWAC publications. In a 1986 Newsline column, for example, HEAL member Tom Cunningham expressed grave concern with the “conspiracy of hopelessness” surrounding AIDS, facilitated by a victim narrative promulgated by mainstream researchers and the popular press. Similarly, in the second volume of Surviving and Thriving with AIDS, self-hypnosis instructor Gail Spindell argued, “If you imagine yourself with three months to live, how does that help? Instead, imagine yourself well. There is a blurry line between fantasy and reality…the body and the mind make little distinction between the real and the imagined” Many authors writing in support of nontraditional health modalities would furthermore invoke antimodern and antiheroic arguments, eschewing pharmaceutical agents in favor of herbal and nutritional strategies they deemed more natural.

However, perhaps the single most important link uniting diverse alternative health systems was their shared view of orthodox biomedicine as rigidly reductionist and stubbornly dogmatic. The supporters of alternative health systems would in fact articulate a robust critique of the killer virus etiological model, and indeed the germ theory writ large, painting both as woefully simplistic and outmoded. In one 1989 Newsline column, for example, Tom Herman extolled the virtues of homeopathy while lambasting biomedicine’s reliance on the germ theory of disease. “To a homeopath,” Herman observed, “to say a sore throat is caused by a streptococcus germ is like saying that a murder is caused by a bullet – true in a way, but the most important part is left out. Our modern obsession with ‘causative’ agents may be the legacy of the

so-called Pasteurian model of disease.” This tactic of acknowledging the legitimacy of germ theory while denigrating it as one-dimensional has roots in the early 20th Century, when the supporters of irregular medical sects recognized that they could no longer paint germ theory as wholly fallacious. These individuals, like those writing in the *Newsline* three generations later, argued that their chosen health systems enriched a germ theory based clinical model by identifying and treating other dimensions of health and disease. Their embrace of a multidimensional health model was, in effect, an expression of multifactoriality – a model which, as we have seen, found support in publications edited by Michael Callen and influenced by Joseph Sonnabend. Those writing in the 1980s and early 1990s would, however, vastly expand upon Sonnabend’s multifactorial model, arguing that AIDS resulted from irreducibly complex interrelationships between stressors spanning environmental, behavioral, interpersonal, emotional and even spiritual domains. Their articulation of multifactoriality was, in short,  

476 In his draft notes for *Surviving AIDS*, Callen quotes at great length from George M. Engel, who argued, “An important aspect of many concepts for disease has been the tendency to ascribe disease to a ‘bad’ influence, usually something external which gets into the body. This theme characterizes most primitive and prescientific views of disease and has reappeared repeatedly in various guises in the scientific era.” Authors writing in support of irregular healing traditions would invoke similar arguments through the early 20th Century, holding the germ theory of disease to be antiquated. In one rather colorful 1916 newspaper editorial, for example, a chiropractor hold that bacteriology is of no more use to his clinical practice “than a whipsocket would be in an automobile or a smoke stack to an aeroplane.” For Callen’s Engel reference, see Notes, Box 7, Folder 195, “Surviving AIDS,” 1988, Michael Callen Papers, LGBT-NA; For the 1916 reference, see Ogden, *The Examiner*, October 1, 1916, cited in “Confessions of a Chiropractor,” *Journal of the American Medical Association* 68, no. 9 (1917): 732.  
477 In 1988, for example, Michael Ellner penned a letter supportive of Callen’s editorship of the *Newsline*. “I am writing to support Michael Callen’s skepticism regarding HIV a the ‘cause of’ AIDS…It is my opinion that it is implausible that HIV causes AIDS even if it’s proved that there’s a germ factor in AIDS. Modern medical research has yet to prove a single cause in any illness – and yet we are to believe HIV causes this very complex syndrome. Multifactorial views apply to all disease and quite frankly the germ view has never held water.” Michael Ellner, “Letter to the Editor,” *Newsline* 37 (October, 1988): 11-12.
holistic in design. As we shall see, a shared affirmation of health holism would ultimately band together extraordinarily diverse healing traditions, increasing their influence and insulating them from criticism.

Many PWAC contributors openly acknowledged their allegiance to holistic health models, as was the case in Alex Idavoy’s aptly titled 1992 piece, “Holistics 101: An Alternative Beginning.” In it, Idavoy boldly dismisses mainstream biomedicine for relying upon reductionist pathological models and toxic cures, and instead posits health holism as a more enlightened etiological and therapeutic paradigm. “Since holistic medicine holds that the physical, emotional and spiritual are interconnected, there could be a myriad of explanations [for AIDS],” he writes. Included among these explanations were “chronic malnutrition, long-term abuse of over-the-counter as well as illegal drugs and alcohol, long-term exposure to environmental toxins, sexually transmitted diseases, exposure to immune-suppressive vaccines, even unresolved psychological trauma and/or long-term locked up emotions.” In his framing of AIDS, we register a synthesis of both Sonnabend’s and Lauritsen’s multifactorial models, augmented by vague psychological and emotional sources of illness. This holistic articulation of multifactoriality is particularly interesting when we recognize that it appeared a full ten years after Sonnabend introduced his multifactorial model, during a period in which two antiretrovirals (AZT and ddI) had already secured FDA approval and a third (ddC) was looming on the horizon.

Readers may profess a certain exasperation with Idavoy’s conceptualization of health holism, as he lists a vast array of stressors underlying AIDS while making little effort to

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478 As Carola Burroughs writes, “From a holistic health perspective, and particularly from the standpoint of homeopathic theory, nearly all disease is multifactorial, because it involves the interaction of elements which are hereditary, environmental, and behavioral.” Burroughs, “AIDS and Cofactors,” 17.

reconcile these variables into a single, unifying conception of etiology or pathology. For these
readers, health holism may thus appear less panacea than pastiche, failing to offer a logical or
coherent plan for responding to disease. However, such a reading misinterprets the meaning and
significance of the holistic health construct. Many PWAC contributors treated holism not as a
remedy for AIDS, but rather as an antidote for a broken biomedical system that had become too
dogmatic and reductionist to adequately address their disease. Consequently, the same features
that befuddle and bewilder modern audiences in fact differentiated holism from the mainstream
system it sought to undermine. Its expansive explication of nebulousy interacting variables
defied reduction, while its openness to near constant emendation by individuals positing ever
more physical, emotional or spiritual causes for AIDS protected it from allegations of
dogmatism. It was thus a broadly philosophical rejoinder that capitalized on the uncertainties and
ambiguities of AIDS, coupled with the distrust and disenchantment of those who questioned the
wisdom of mainstream biomedical responses. The model was extraordinarily powerful,
particularly as those who invoked it seldom incurred any real obligation to defend all of its
constituent healing systems. Instead, they merely carved out a subset of variables and elected
their chosen alternative healing system – homeopathy, macrobiotics, attitudinal healing, etc. – as
most capable of acting upon these variables to restore health.

Health holism was thus a vessel of sorts, grouping together alternative health practices
bound by their distrust for a mainstream biomedical model deemed dogmatic, heroic and
reductionist. The term was sufficiently loose and open-ended that authors could invoke it to refer
to all manners of healing practices. Alan Burns, for example, construed holistic healthcare as
including macrobiotics, vitamin therapy, herbology, Reiki, and the visualization therapies of
Louise Hay and the AIDS Mastery,\textsuperscript{480} Michael Hirsch used the term to refer to Reiki, Transcendental Meditation and yoga;\textsuperscript{481} Bob Lederer used it in conjunction with acupuncture, herbalism, nutritional supplements and spiritual healing;\textsuperscript{482} Peter Dvarackas invoked it while discussing Chinese medicine and acupuncture;\textsuperscript{483} and Alex Idavoy argued that it subsumed homeopathic, Ayurvedic, traditional Chinese, and orthomolecular healing systems.\textsuperscript{484}

In voicing their support for holistic health practices, these PWAC contributors echoed the organization’s underlying mission, suggesting that PWAs were capable of self-organizing to challenge the dictates of a hegemonic biomedical orthodoxy, claiming ownership over their disease and responsibility for their healing.\textsuperscript{485} Some supporters of alternative healing systems would paint this reclamation of responsibility in a vaguely moral light, as when an Executive Director of the PWAC penned a Newsline letter defending the practitioners of one particular alternative healing system by arguing that they were “working hard at taking responsibility for their own well-being and quality of life.”\textsuperscript{486} At the same time, the publication plainly

\textsuperscript{480} Alan Burns, “H.E.A.L.,”
\textsuperscript{482} Bob Lederer, “Holistic Treatments”
\textsuperscript{484} Alex Idavoy, “Holistics 101.”
\textsuperscript{485} For example, a 1988 Newsline contributor would argue, “While conventional medicine continues to search for a ‘magic bullet’ and ignores or rejects alternative treatments as ‘quackery,’ holistic medicine teaches us that the true source of magic is within our own bodies already, waiting to be tapped.” Carola Burroughs, “Mechanisms of Holistic Healing,” \textit{PWAC Newsline} 39 (December 1988).
\textsuperscript{486} Hirsch would elsewhere argue that holistic methods allowed PWAs to, “[take] a more active role in the treatment of their medical condition by adopting sound nutritional practices, by employing methods to reduce both generalized and illness-related stress, by examining and redirecting negative thought patterns, and by releasing depressing and dis-empowering emotions
underscored a belief that this reclamation was fundamentally empowering. Three months after publishing the aforementioned letter, for example, the Newsline’s editorial staff renamed its monthly alternative health column “Holistic Approaches,” arguing that the title conveyed a sense of PWA self-empowerment. In their announcement, they quoted the Holistic Medical Association’s definition of holistic medicine as “a system of medical care which emphasizes personal responsibility, and fosters a cooperative relationship among all those involved, leading towards optimal attunement of body, mind, emotions and spirit.” Interestingly, we would do well to note that this framing of holistic medicine as empowering sharply contrasts with stereotyped characterizations of alternative and holistic medical supporters as quacks and their patients as dupes.

While it is beyond the scope of this analysis to review the many alternative health movements PWAs embraced through the 1980s and 1990s, one in particular bears special mention. Referred to by PWAC leader Michael Hirsch as “the most popular and most simple holistic approach used by PWAs/PWArcs,” it was epitomized by the visualization and attitudinal health methodologies promoted by Louise Hay and AIDS support service Northern such as fear and internalized homophobia.” Hirsch, “Holistic Health Care,”: Volume II. 122. See also Letter from Michael Hirsch in response to Paul Lande. Newsline. 8. January 1986. 8.

This may have been the result of a general Newsline editorial policy, which cautioned individuals against celebrating “chauvinistic” healing systems that purported to solve all problems PWAs encountered. See, for example, “Alternative Therapies: Managing Editors’ Note.” Newsline. 10. March 1986; Some PWAs furthermore expressed concern with the power PWAs invested in alternative curatives. In one Newsline piece, for example, Max Navarre worries that his friends and colleagues had turned one particular homegrown agent – AL721 (egg lipids) into a veritable symbol of self-empowerment: “...I think because of this home grown quality, egg lipids have themselves emerged as a symbol of self-empowerment. We have confused the product with the motivation behind the product’s availability. And how shocking when self-empowerment fails. When the home grown treatment is as fallible as that offered by the big boys, when there does one turn?” Max Navarre. “Editorial.” 25. July/August 1987.

Lights Alternatives. The attitudinal health movement, inspired by the late 1970s/early 1980s volumes *Getting Well Again* and *Love, Medicine and Miracles*, taught PWAs that they could use their minds to influence their course of illness. Hay, for example, famously argued that PWAs could secure their health by acknowledging and rejecting feelings of self-loathing and internalized rejection, while the Northern Lights Alternatives AIDS Mastery workshop taught participants to “find inner peace and come to understand the meaning of their lives” as a step in effecting their own cures. The systems were far more radical than benign entreaties to optimism, for they indeed argued that one could harness his or her mind frame – through, for example, visualization exercises – to influence the disease process.

Perhaps more than any other alternative healing system, attitudinal health modalities embodied a radical allegiance to the view that PWAs possessed the innate capacity to heal themselves. In one 1987 *Newsline* column, for example, PWA Steven James summarized what he referred to as the “personal power” PWAs derived from visualization, arguing of his own treatment regimen that, “There was a satisfaction in knowing that I was using my own willpower

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490 These texts would provoke controversy for, among other things, arguing that individuals living with cancer could affect their disease by visualizing “their white-blood cells as armies attacking and annihilating their tumors.” See Louis Weisberg, “‘Incurable’ Patients Work At Healing Themselves,” *The Philadelphia Inquirer*, June 12, 1988, L1; Bernie Siegel, *Love, Medicine and Miracles* (New York: HarperCollins, 1988); O. Carl Simonton, Stephanie Matthews-Simonton, and James L. Creighton, *Getting Well Again: A Step-By-Step Self-Help Guide to Overcoming Cancer for Patients and Their Families* (Los Angeles: JP Tarcher, 1978); These positions are reminiscent of quite old philosophies harkening back to the 19th Century irregular healer Phineas Quimby, who was in turn inspired by mesmerists. Quimby, for example, advocated a visualization approach to healing cancer. See Whorton. *Nature Cures*, 279.

491 Weisberg, “‘Incurable' Patients”; Sally Fisher furthermore argued, “If we see illness as a warning signal that there is something not working about our lives or as a symptom of a deeper issue, then we can aid and nurture our healing progress. If one has cancer, it is necessary to release the past and allow the resentments to dissolve in order to heal and prevent further complications.” Sally Fisher, “Creating a Climate for Health.” “AIDS Mastery and Visualization Workshop.” Box 2. Folder 4. PWAC Archives. NYPL-MAD.
to do something to further my own health. Others would focus on the attitudinal health movement’s ability to develop within PWAs a capacity for self-control – a fascinating concept linking together notions of empowerment and morality. In the second volume of *Surviving and Thriving with AIDS*, for example, PWA Michael Hirsch argued that visualization exercises “advocate that one take more control over one’s life, that one re-examine one’s self-image and attitudes about one’s world, and that one forgive oneself and others for the past.”

The attitudinal health movement ultimately purported to help PWAs wrest control over the conceptualization of and response to their disease from a biomedical orthodoxy viewed as fatalistic, dogmatic and heroic in its impulses. It was one of the most radical expressions of PWA activism, and as such provoked ardent debate among PWAC contributors, with some deriding leaders such as Louise Hay as charlatans and others praising them for empowering individuals to assume a direct role in their own healing. However, while it is easy to cast attitudinal healing as a radical manifestation of PWA empowerment, we should not construe this to mean that only

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492 Steven James, “Visualization in Healing,” *Newsline* 20 (February 1987): 38. Emphasis in original; Elsewhere, James argues, “Personal power is probably the key factor in healing, and to me having personal power means developing the singleness and strength of purpose, of vision, and of will to transcend circumstances which, outwardly, might seem overwhelming. It requires not only an assertion of faith, but hard work and perseverance.” Steven James, “Reflections on Healing, Honesty and Personal Power,” in *Surviving and Thriving with AIDS: Hints for the Newly Diagnosed, Volume I*, ed. Michael Callen (New York: People with AIDS Coalition, 1987).


494 In *Surviving and Thriving with AIDS: Collected Wisdom*, Hirsch offered powerful reflections on the value of holistic health models: “While AIDS/ARC has introduced an inordinate amount of grief and loss into our lives, at the same time, a more holistic approach to our personhood and our physical health has afforded man the opportunity or create a deeper sense of self love, a profound renewal of personal spirituality, and a newfound commitment to such essential humanistic values as brotherly love and charity. For many, a more holistic look at oneself and one’s health has provided these persons with the drive and the inner resources to keep forging ahead in their struggle to live with AIDS.” Hirsch, “Holistic Health Care for AIDS,” 123.

radical PWAs embraced the health movement, or alternatively that attitudinal healing modalities were the only systems embraced by its most enthusiastic supporters. For, in truth, PWAs actively combined and mixed diverse healing strategies, rationalizing their own linkages and synergies between wholly distinct therapeutic modalities. In fact, the AIDS Mastery taught individuals that visualization and meditation could help them better understand which complement of non-attitudinal healing strategies would work best for them.\footnote{Weisberg, “‘Incurable' Patients.”} And even Louis Nassaney, perhaps the most ardent proponent of Louise Hay’s methodology, admitted to Michael Callen that he combined attitudinal health modalities with other unorthodox and orthodox healing systems.\footnote{Callen, Surviving AIDS, 99.}

This active mixing and melding of disparate healing systems was almost certainly the rule rather than the exception among individuals responding to AIDS in the 1980s and early 1990s. In the first volume of Surviving and Thriving with AIDS, Steven James in fact reports employing unorthodox healing strategies to modulate his use of mainstream medications. As he explains, “I have used alternative methods such as Applied Kinesiology, or muscle-testing to determine the precise dosage of Bactrim [a mainstream antibiotic] which seems to be optimal for my body. I also take herbs and vitamins, and I follow a diet low in red meat, white flour, and sugars.”\footnote{James, “Holistic Approaches to AIDS,” Internal parentheses removed for ease of reading.} Michael Callen’s near-decade long effort to identify long-term survivors of AIDS further corroborated the notion that PWAs actively moved between different healing systems. Many of the PWAs he interviewed for Surviving AIDS reported pursuing hybrid approaches, with one swearing by Bactrim and macrobiotics,\footnote{Identified in Callen’s Surviving AIDS as Ron (no last name given). 159.} another egg lipids and AZT,\footnote{Identified in Surviving AIDS as Gary Mackler, 175.} and Callen himself reporting use of high dose acyclovir, Itraconazole, egg lipids and homeopathic doses of
Furthermore, in a 1988 *Newsline* article entitled “My Doctor and My Chiropractor,” PWA Larry Peck discusses his use of conventional therapies administered by his physician combined with alternative therapies – including body manipulation, kinesiology, herbal/flower remedies, homeopathic treatments and natural nutritional supplements – prescribed by his chiropractor. Interestingly, while Peck credits his mainstream physician with helping him overcome an early bout with *Pneumocystis pneumonia*, he portrays the orthodox therapeutic model’s focus on fatal viruses as inherently disempowering when compared with unorthodox approaches that identify a curative role for personal intervention.502

As this brief analysis reveals, the history of PWA engagement with alternative health activism was neither a neat nor ordered affair. AIDS simply posed far too many uncertainties, ambiguities and non-sequiturs to yield a protest tradition bounded or ordered by rigid categories or domains. In my rendering of this history, I have chosen to treat the divergent paths individuals charted in response to AIDS – the mixing and melding of different systems, the synthesizing of responses borne out of seemingly mutually exclusive activist traditions – as expressions of empowerment rooted in PWA cultures of dissent and protestation. Other scholars examining the same sources might reach an entirely different conclusion, telling of desperate individuals investing their time and resources engaging therapeutic modalities lacking rigorous scientific support. Where I speak of agency and empowerment, these scholars might identify quackery and chicanery. And yet I believe something critically important is lost in such dismissive framings of

501 Callen, *Surviving AIDS*, 75. Callen’s reference to homeopathic doses of Naltrexone is interesting, for Naltrexone itself constitutes a mainstream medication which, when employed to treat AIDS, was viewed as both unorthodox and holistic. For a discussion of the drug, see Neenyah Ostrom, “Enhancing Immunity,” *New York Native*, 18 Sept 1989.

502 “My doctor figures that such lifestyle changes may not hurt,” Peck writes, “but are not very significant as long as I carry deadly HIV in my body.” Larry Peck, “My Doctor and My Chiropractor,” *Newsline* 38 (November 1988): 37-38.
unorthodox activism, for historical scholarship has taught us that some of the richest, most
complex and nuanced expressions of activism are effected by the weak, the marginalized and
disempowered among us. For these individuals locate, within the limits of the restrictions
imposed upon them from without, a space of relative freedom wherein they may find and express
their voices. Their stories deserve to be told, and their expressions of agency recognized.

Conclusion: Quacks, Dupes and the Empowerment of PWAs

The PWAC’s activism was neither the loudest nor the most visible form of protest
organized in the 1980s and 1990s in response to AIDS. Rather than taking to the streets to
demand changes in the federal research response, it sought to empower PWAs by encouraging
them to claim ownership over their bodies and responsibility for their conditions. Through its
celebrated print publications, it fostered a level of radical engagement among its readership,
fomenting deep distrust and disillusionment with the ennobled systems and professionals tasked
with responding to the growing epidemic. In pursuing its overarching aim, it cultivated a rich,
multilayered discourse that invoked and intersected many of the same themes that have
historically subtended alternative health activist movements throughout US history.
Consequently, it created a forum and community receptive to direct engagement with these
movements.

In addition to capturing important linkages between PWA protest and historic
expressions of alternative and nontraditional health activism, this analysis challenges several
commonly held perceptions regarding the workings of power within communities facing
disruptive or lethal diseases. For one, as noted above, it rebukes a persistent scholarly bias which
summarily dismisses as quacks the proponents of alternative therapeutic modalities. While it is
certainly true that some of the advocates of nontraditional healing systems engage in chicanery
and quackery, there is no reason to suggest that their presence somehow negates the willful actions of individuals who eschew orthodox biomedical practice. The “quack” and the “dupe” are static, outdated tropes which by their very nature deny the possibility for empowerment for those who look beyond orthodox biomedicine for treatment. My analysis of PWAC activism suggests that many individuals who turned to alternative healing traditions through the 1980s and 1990s did so out of a conscious and avowed belief that these nontraditional systems were more inherently empowering than orthodox biomedicine. Many of these PWAs exhibited a profound personal investment in their diseases and eagerness to explore potential healing strategies. Just as they refused to be construed by physicians and researchers as disempowered patients waiting for their bodies to give way under the burden of their disease, so too would they no doubt reject historical framings painting them as the victims of quackery or deception.

My analysis furthermore suggests that, far from pledging allegiance to a particular bounded system of therapeutic practice, PWAs frequently moved between systems in an effort to craft a response that resonated most with their experiences and beliefs. The holistic health construct facilitated this movement, as it grouped countless, seemingly incompatible healing systems under a common rubric. Consequently, the history of AIDS era engagement with alternative health modalities diverges in key ways from the so-called sectarian medical battles of the 19th Century. It demonstrates that as scholars continue to examine alternative and unorthodox health activist movements, we should focus not on the bounded and ordered philosophies which delineated each system of thought, but rather on the messy, muddled and chaotic movement of individuals who passed between their permeable borders.

This chapter focuses primarily on written publications appearing between 1985 and 1993, as this was in many ways the zenith of PWAC activism. Beginning in the early 1990s, the
PWAC would endure tremendous financial difficulties owing to a decrease in contributions and increase in real estate prices in Chelsea. The group declared bankruptcy in 1993 and officially closed, only to be revived later under a different name. By the mid-1990s, much had changed in mainstream PWA care as well, with physicians and researchers generally acknowledging the missteps taken with early AZT use. New classes of biomedical therapeutics – most importantly protease inhibitors, first introduced in 1996 – drastically improved the lives of PWAs while avoiding the toxicities of high dose AZT. It is difficult to assess the persistence of everyday expressions of activism or the importance of the borderland model of action during these years. However, I anticipate that future historians will come to find that even in eras of biomedical triumph, individuals find ways to loose themselves from the moorings of orthodoxy and explore the borderlands between healing systems – to communicate through everyday actions effected at the level of their bodies a fervent desire to live furiously.
Chapter 5
Patient Heal Thyself – The History of Health Education AIDS Liaison (HEAL)

“The younger swam but the yielding waves
Denied help; they were not supported,
They swallowed and sank, ceased thereafter
To appear in public; exposed to snap
Verdicts of sharks, to vague inquiries
Of amoeboid monsters, mobbed by slight
Unfriendly fry, refused persistence.
They are nothing now but names assigned to
Anguish in others, areas of grief.
Many have perished; more will.”
-W.H. Auden (1947)503

In the previous chapter, we examined the history of the People with AIDS Coalition (PWAC), chronicling its members’ endorsement of unorthodox etiological and therapeutic paradigms for describing and responding to the nascent AIDS epidemic. Inspired by the firebrand activism of leaders such as Michael Callen, the group doggedly questioned mainstream biomedical practice, arguing that PWA survival was predicated upon individuals’ willingness to directly engage their disease. We also discussed the tendency for contemporary scholars to elide from the historical record the group’s most unorthodox, alternative and radical activism, thus recapitulating uncontroversial formulations of the patient empowerment movement. This historiographic abridgement is most evident in recreations of the Denver Principles that omit references to unorthodox resistance and in scholarly discussions of Michael Callen’s activism that excise his most contrarian beliefs.

While this scholarly sanitization of AIDS activism has resulted in a woefully myopic picture of the PWAC, it has virtually blinded students of history to the initiatives of a second health activist group founded in the earliest days of the AIDS epidemic. Forged in the same

AIDS Liaison (HEAL) pursued a much more open, avowed embrace of nontraditional health modalities, with its literature explicitly extolling “alternative, complementary, non-toxic, natural and holistic approaches to living with AIDS and staying healthy if at risk.”\(^{504}\) One of the earliest AIDS support groups of any kind organized in the city, HEAL in fact predated ACT UP – which scholars have studied quite extensively – by five years. What’s more, it would remain active for an astonishing two decades, with its mission and reputation undergoing profound transformation as its leaders pursue an increasingly unorthodox activist agenda.

Given its remarkable history, one might reasonably expect HEAL to have earned its place within the late 20\(^{th}\) and early 21\(^{st}\) Centuries’ robust body of historical and sociological AIDS scholarship. And yet by nearly every measure, its story remains obscured, appearing today as little more than an anomalous aside or fringe curiosity relegated to the footnotes of scholarly works. An OCLC WorldCat search for “Health Education AIDS Liaison,” for example, reveals a grand total of seven entries – five cataloguing fragmented copies of the group’s self-generated informational packets and newsletters, one pointing researchers to a polemic written by a HEAL member, and one identifying a science fiction novel whose author had donated royalties to the organization. On the rare occasion when one comes across reference to the group in the index of a scholarly piece, it generally points him or her to the slimmest of paragraphs listing HEAL as one of several early AIDS groups.\(^{505}\) Others summarily dismiss the grassroots organization as an

\(^{504}\) *Information Packet*. Undated. HEAL Archive. In many formulations of group literature, the term “complementary” appears in parentheses alongside the word “alternative.”

exponent of a radically dissident fringe inspired by the denialist perspectives of rogue retrovirologist Peter Duesberg.\textsuperscript{506}

The following chapter seeks to redress this dearth in scholarship, exhuming HEAL’s history so that we may add its unique voice to the record of AIDS activism. Exhumation is indeed an apt descriptor for the methods brought to bear in my research process. For, as the abovementioned Worldcat search makes clear, one does not merely happen upon HEAL’s archives in the card catalogues of regimented reading rooms within public libraries. No central repository houses the group’s collected ephemera; a grassroots organization through and through, by the early 2000s its leaders had consigned surviving group documents to whichever members’ apartments could house them. My research took me far from the august archives of major academic institutions and into the dusty closets of East Harlem apartments and bedraggled berths of Long Island garages, where boxes of HEAL literature sat, in many cases untouched for the better part of a decade.

The research undertaken to draft this chapter thus marks the first time in many years that these sources have, quite literally, seen the light of day. It is my hope that in analyzing the newsletters, news clippings and group correspondence I cite, the reader may share in the excitement I experienced upon first sifting through this forgotten archive. And yet a word of caution is warranted, for raw and unfound archives pose unique historiographic challenges affecting historians’ ability to reconstruct the past. While I was fortunate to review thousands of pages of documents, countless pieces of correspondence and literature have no doubt been lost to time. Furthermore, many surviving documents lack authors or dates, oftentimes necessitating an approximation of their origins. In general, the group’s later initiatives enjoy greater

\textsuperscript{506} See, for example, Kalichman, \textit{Denying AIDS}. 
representation within the archive, likely a consequence of HEAL’s increased focus on print publications post-1990, and the fact that those individuals who eventually housed the archives came to positions of power at roughly this time. To redress this imbalance, I have conducted supplementary oral history interviews with two group leaders, Gene Fedorko and Michael Ellner, and have additionally consulted independent interviews compiled as part of the New York Lesbian and Gay Experimental Film Festival’s ACT UP Oral History Project.

In this chapter, I seek to convey to the reader the complex, multifaceted and deeply rich holistic health activism embraced by HEAL throughout its two decade existence. As we shall see, the transformations witnessed in the group’s membership and mission through the 1980s, 1990s and 2000s reveal a dynamic organization in a near constant state of flux. From its earliest years, group members explored and advocated a wide array of alternative health paradigms, ranging from macrobiotics and herbalism to chiropractic and positive psychology. Interestingly, despite its unorthodox philosophy and members’ willingness to openly question the pronouncements of biomedical professionals, through the early 1990s the group enjoyed the respect of the City’s larger AIDS service organizations. And yet by the mid-1990s, the winds had changed – the same group once lauded as a nontraditional resource for individuals seeking to engage their disease on their own terms had become derided as a dissident organization spreading dangerous misinformation. In the first section of this chapter, I briefly review HEAL’s

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507 Interviews with Michael Ellner were conducted in November of 2009 in conjunction with coursework completed under the mentorship of Mary Marshall Clark, Director of Columbia University’s Center for Oral History Research (“Oral History, Methods and Theory,” OHMA 4015G, Call Number: 81598). Interviews with Gene Fedorko were conducted in the Fall of 2016 in conjunction with a research project which was approved and granted exempted status by Columbia University’s Institutional Review Board (“Oral History Interviews: Alternative/Dissident AIDS Activism,” Protocol Number: AAAN8600).

508 These interviews focus specifically on the history of ACT UP, but are useful insofar as several early HEAL leaders eventually became active in ACT UP. See ACT UP Oral History Project, a program of MIX, the New York Lesbian & Gay Experimental Film Festival.
early history as an alternative and complementary health activist group, demonstrating its synergistic relations with other more mainstream AIDS support groups. I then juxtapose this early history with the group’s eventual embrace of contrarian and dissident perspectives, arguing that HEAL’s turn toward dissidence resulted in part from the radicalization of two core holistic health principles underlying its alternative health activism.

The Consonant Contrarians: HEAL’s Early Years

A quintessentially grassroots organization, HEAL boasts an early history that is, in many ways, the stuff of historical lore. Cofounded by a prominent gay rights activist just two weeks after GMHC opened its doors, HEAL was among the first groups to meet in New York’s newly inaugurated Lesbian and Gay Community Center. Operating on the thinnest of budgets, the support group initially assembled weekly in one of the Center’s broken-down bathrooms, the toilets of which had been removed from the walls to create a makeshift discussion space. From this most humble beginning, HEAL created a safe space wherein members – by and large gay men – could discuss alternative and unorthodox responses to the strange new disease that had racked their community. Indeed, the group’s earliest meeting space captures well its relationship with the larger AIDS activist community – proponents of contrarian holistic health philosophies, HEAL members embraced a model of patient engagement that nonetheless resonated with the larger PWA empowerment movement. They thus enjoyed a place – albeit one somewhat out of sight – in the larger network of AIDS service providers.

While HEAL would become known for its embrace of health holism, it is important to stress that its founding in fact had less to do with ardently promoting holistic health paradigms than it did with more broadly nurturing individuals’ hope in their capacity to survive their

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509 Interview with Eugene Fedorko, Interview 144, Conducted by Sarah Schulman, August 25, 2012, 7, ACT UP-OHP.
condition. As noted in Chapter 4, the earliest days of the AIDS epidemic were fraught with anxiety and uncertainty, particularly within gay communities agonized by the deaths of many of their members. As one longtime HEAL president would later note, the period signified nothing less than the “Dark Ages” of gay society, wherein paranoia and dread shook already ostracized outsiders to their core.\textsuperscript{510} It was into this crucible that gay novelist Larry Kramer injected his now famous \textit{New York Native} articles stridently alerting gay men to the crisis that had arrived at their doorsteps. Intentionally incendiary, Kramer sounded a death knell that would reverberate throughout gay communities. “If this article doesn't scare the shit out of you, we’re in real trouble,” he wrote in March of 1983. “If this article doesn’t rouse you to anger, fury, rage, and action, gay men may have no future on this earth. Our continued existence depends on just how angry you can get.”\textsuperscript{511}

For Jim Fouratt, a well-known gay rights activist who had served as an active member of the Gay Liberation Front (GLF) and participant in the Stonewall Riots, this type of fatalistic hyperbole exacted a heavy toll. In his estimation, liberal media outlets had, in their efforts to cultivate a politically propitious fury amongst gay audiences, written off individuals diagnosed with AIDS as fated to die. “This was at the height of the AIDS hysteria,” Fouratt would later reflect. “Even the gay newspapers, all they could talk about was death, death, death. And I remember thinking it was just an awful environment in which to be diagnosed and in which to be concerned about being sick because it was so negative.”\textsuperscript{512} The situation was, of course, far worse amongst the more conservative media outlets, many of which had \textit{literally} adopted

\textsuperscript{510} Ibid.
\textsuperscript{511} Kramer, “1,112 and Counting.”
\textsuperscript{512} Michael Callen, “Jim Fouratt: Unsung Hero,” \textit{PWAC Newsline} 18 (December 1986): 36; In his ACT UP interview, Fouratt also argued, “The only message you got was death…there was no hope at all.” Interview with Jim Fouratt, Interview 066, Conducted by Sarah Schulman, November 28, 2006, 36, ACT UP-OHP.
apocalyptic language to argue that AIDS was the equivalent of a modern day biblical plague.\textsuperscript{513}

Indeed, wherever one looked, AIDS eschatologies abounded, with both liberal and conservative outlets dismissing PWAs as hopeless sacrifices in larger moral or political wars.

In 1982, less than a month after Kramer cofounded GMHC, Fouratt organized his own support group with a decidedly different focus. Originally named Wipe Out AIDS (WOA), the group strove to shift the tone and tenor – what Deborah Gould would call the “emotional habitus” of AIDS activism – from one of despair to one of hope.\textsuperscript{514} Shortly after its inception, WOA changed its name to Health Education AIDS Liaison (HEAL), which members found more directly linked to the organization’s mission of engendering and promoting self-empowerment.\textsuperscript{515} From its earliest years, the group adopted holistic health paradigms as tools for helping PWAs claim ownership over their disease, turning first to the macrobiotic diet popularized by Michio Kushi in the 1970s and 1980s. Within their first year, HEAL leaders broadened their focus, using weekly meetings and print publications to introduce PWAs to homeopathy, Reiki, chiropractic, herbalism, acupuncture, attitudinal healing, and countless other unorthodox health systems.\textsuperscript{516} Rather than emphasize any one healing paradigm, discussion

\textsuperscript{513} See, for example, Thomas L. Long. \textit{AIDS and American Apocalypticism}. State University of New York Press, 2005.

\textsuperscript{514} Gould defines the emotional habitus of a group as, “the socially constituted, prevailing ways of feeling and emoting, as well as the embodied, axiomatic understandings and norms about feeling and their expression.” Deborah Gould. \textit{Moving Politics: Emotion and ACT UP’s Fight Against AIDS}. University of Chicago, 2009, 10; Fouratt would argue that HEAL first formed to challenge universal fatality narratives with discourse centered about hope. “[W]e tried to set up a group that gave some sort of hope…You’ve got to have hope…You just can’t deal with death.” Jim Fouratt Interview, ACT UP Oral History Project. 36.

\textsuperscript{515} Interview with Jim Fouratt, ACT UP Oral History Project. 35-36.

\textsuperscript{516} One 1985 advertisement in the PWAC Newsline, for example, explained, “HEAL (Health Education AIDS Liaison) is a group whose goal is to provide support and information regarding natural ways of self-recovery…In its efforts to explore the natural methods of health improvement and maintenance, HEAL has sponsored presentations that have included acupuncture, homeopathy, herbology, meditation, visualization techniques, polarity therapy,
coordinators tasked themselves with providing avenues and approaches whereby individuals affected by AIDS could directly engage their condition on their own terms, nurturing a hope that they could indeed survive their diagnosis. Group facilitators made clear that they possessed no cure-alls or panaceas, and promised only health-affirming strategies for individuals seeking to “stave off the specter of death” by focusing on strategies for healthful living.\textsuperscript{517}

Given the fraught relations between mainstream biomedicine and unorthodox health movements through the 20\textsuperscript{th} Century, readers may be surprised to learn that many mainstream AIDS activists viewed HEAL’s early work as uncontroversial. However, we would do well to recall that through the mid-to-late 1980s, orthodox biomedicine remained largely impotent against AIDS. In this setting, orthodox gatekeepers lacked sufficient social or political capital to decry alternative remedies as quackery. As one HEAL leader would pithily remark of the early 1980s, “No one had anything, so nobody objected.”\textsuperscript{518} Furthermore, HEAL literature went to great pains to make clear that unorthodox health interventions were best viewed as \textit{complementary} to mainstream medical therapeutics. One early informational packet, for example, counseled its readers, “If you have any one of the 29 diseases which are included in the Acquired Immune Deficiency Syndrome, HEAL advises that you follow the best procedure to treat it, which may well include prescription drugs…Once your prescription medicine has done the job, HEAL can supply suggestions on how to rebuild your immune system.”\textsuperscript{519} In a 1986

\textsuperscript{517} Interview with Eugene Fedorko, ACT UP-OHP, 7-8.
\textsuperscript{518} Interview with Michael Ellner, conducted by Matthew Kelly on November 2, 2009 as part of research for Columbia University course “Biopolitics in the 20\textsuperscript{th} Century,” Professor Matthew Connelly (Course number: HIST 9310 G, Call Number 26847).
\textsuperscript{519} “Medicine: When to Use It.” \textit{HEAL Comprehensive Information Packet}. HEAL-A. This informational packet is undated but was likely penned in the mid-1980s.
PWAC Newsline article, HEAL leader Alan Burns reiterated this sentiment, explicitly stating that “the holistic therapies discussed at HEAL do not rule out medicine.” In fact, we might say that early HEAL activism openly embraced and advocated a borderland model of healing (see Chapter 1). Rather than attempt to persuade individuals that unorthodox therapeutics were superior to an ineffectual or dangerous mainstream practice, HEAL leaders conceived of PWAs as autonomous agents capable of independently and proactively moving between orthodox and unorthodox healing systems. In this patient-focused empowerment model, no one therapy, professional or system alone possessed the power to save PWAs from their disease.

HEAL’s early focus on PWA empowerment harmonized well with the initiatives of the PWAC, with both groups decrying universal fatality narratives and striving to cultivate amongst PWAs a belief in their capacity to persevere through their diagnosis. Through the 1980s, the leaders of both groups in fact contributed opinion pieces to each other’s newsletters and publications. One 1986 PWAC Newsline article, for example, features HEAL leader Tom Cunningham condemning the “conspiracy of hopelessness” pervading mainstream biomedical discourse, a position echoed by multiple PWAC columns at the time. And in 1989, PWAC cofounder Michael Callen penned a piece in HEAL’s Quarterly Bulletin wherein he identified several traits shared by long-term survivors of AIDS. HEAL leaders were only too happy to

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520 The article continues, “[H]olistic medicine simply insists that the whole patient be considered, including physical, spiritual and mind issues, and that drugs should not be administered unless proven save and necessary.” Alan Burns, “H.E.A.L.,” 21.

521 Within Burns’s article, Cunningham is quoted as stating, “I just can’t stand this victim mentality – you know, ‘AIDS victim,’…You never see ‘cancer victim’ or ‘heart victim’ – the government, the medical establishment, and the media have built a conspiracy of hopelessness around this disease. It infuriates me.” Ibid.
point out that the first two items in Callen’s list plainly underscored the frequency with which long-term survivors sought recourse in alternative and holistic approaches to healing.\footnote{522 The first entry on Callen’s list recognized that long-term PWAs actively experimented with alternative healing approaches. The second entry specified, “Most or all had used approaches such as shiatsu massage, acupuncture, or visualization. A clear majority were involved with groups such as Louise Hay, or AIDS Mastery or Metaphysical Alliance.” Michael Callen, “7 Very Important Qualities,” \textit{HEAL Quarterly} 1, no. 1. Fall 1989. HEAL-A. This article additionally appeared in printed HEAL’s Information Packet, circa 1994 on file at UT-TFRBL.} 

The support HEAL enjoyed from its more mainstream colleagues extended beyond leaders’ joint publication in group newsletters. In the late 1980s, as HEAL endeavored to secure funding for its burgeoning services – which by then included weekly meetings, dinners and an informational hotline – it sought and obtained letters of support from other prominent AIDS service groups. In one such letter penned in 1988, the Executive Director of the PWAC declared, “I find the basic philosophies of HEAL to be consistent and complementary to our own – namely, that all people need to [be] allowed to be responsible for their own lives and health. The right to retain control over how their bodies are treated and to choose alternative healing methods is fundamental to PWA Coalition’s philosophy of self-empowerment.”\footnote{523 Letter from William Case, Executive Director of PWAC to Frank Russo, Executive Director of HEAL, 27 June 1988, HEAL-A; Similarly, a letter from the PWAC’s Deputy Executive Director observed, “The importance of your programs is exemplified by the daily requests we receive, on our Hotline, for services such as you offer.” Letter from Christopher L. Babick, Deputy Executive Director of PWAC, to Gene Fedorka [sic], President of HEAL, June 24, 1988, HEAL-A} Even the GMHC – known as one of the most orthodox and mainstream of AIDS service organizations – voiced its support, with one representative writing, “[HEAL] provides information on alternative therapies for AIDS-related illness, a necessary balance to the Western-medicine options touted by most other hotlines, and does so in a responsible manner.”\footnote{524 Letter from Bruce Woods Patterson, MSW, Hotline Coordinator, to HEAL, July 31, 1992. HEAL-A.} Perhaps most remarkably, the strongest
word of endorsement came not from an AIDS service organization, but from a New York City Department of Health agency, with the Director of the City’s official AIDS hotline declaring,

“On behalf of the counselors and supervisors here at the Department of Health’s AIDS Hotline, I would like to commend you for HEAL’s continued and invaluable contributions to all those living with HIV disease…Many of our clients request information regarding the non-traditional and holistic approaches that are not routinely studied by the medical community. HEAL’s explorations of alternative therapies and other approaches to healing has met these clients’ needs…You continue to remind us all of the importance of empowering those living with HIV to investigate different therapies wherever and whenever possible.”

For HEAL leaders, the most prized and cherished testimonials penned in support of the group’s work came not from other service organizations but rather from current and former HEAL members. These letters, anonymized versions of which appeared in the group’s informational packets, tell of PWAs wracked with despair who found in HEAL the will necessary to continue fighting. In one letter, the author reflects, “[W]hen I walked into the doctor’s office for a routine physical, I wasn’t ready for the diagnosis of ARC I received, or the doctor’s encouraging words: ‘There’s nothing you can do…come back in three months.’ Finding HEAL has made me feel as good as I did before I saw the doctor.” A second handwritten letter tells the story of a young man who, upon receiving an HIV positive test result, mailed his diplomas to his parents in preparation for death. He credited a chance encounter with a HEAL

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526 HEAL Information Packet, circa 1994, 1, UT-TFRBL.
pamphlet with transforming his life. “I read it page by page, line by line. Making notations, writing down questions for the next meeting…I went from a basket case to a human being again.”\textsuperscript{527} And yet another individual would write to thank HEAL for freeing him from victimhood, referring to the group’s unorthodox services as “balm to my troubled soul.”\textsuperscript{528}

HEAL would remain a largely uncontroversial voice within the larger AIDS service community through the late 1980s and early 1990s, even as mainstream biomedicine concretized its conceptualization of and response to AIDS. The growing focus within professional circles on viral AIDS etiologies – propelled by Health and Human Service Secretary Margaret Heckler’s 1984 announcement of the discovery of HTLV-III/LAV – strained a holistic paradigm that challenged reductive, unicausal etiological models. However, as it would be another three years before the viral model bore therapeutic fruit, holistic health advocates found sufficient space wherein they could promote their unorthodox philosophy without contradicting mainstream practice. What’s more, while seldom acknowledged by scholars, not every member of New York City’s gay community agreed with the viral etiological AIDS models. Through the mid-to-late 1980s, for example, the \textit{New York Native} – the same outlet that had published Larry Kramer’s call to arms at the start of the epidemic – actively promulgated a wide array of contrarian and unorthodox etiological AIDS theories.\textsuperscript{529}

\textsuperscript{527} Letter from HEAL Member, Feb 8, 1989, HEAL-A. Sender’s name intentionally redacted.  
\textsuperscript{528} HEAL Information Packet, 1.  
\textsuperscript{529} One can dedicate a full volume to exploring the \textit{Native}’s research into myriad unorthodox AIDS theories through the late 1980s. Suffice to say, the outlet would become quite controversial in due time. One reader, for example, would write to the newspaper’s editor in 1987, commenting, “I find nothing wrong with the reports in the \textit{Native} on alternative theories and treatment for AIDS. However, the presentation of [editor] Ortleb’s pet theories is shockingly irresponsible, yellow journalism at its worst, the ravings of a lunatic.” “Letters.” \textit{New York Native}, April 6, 1987, 6.
HEAL’s holistic health activism assumed a more outwardly confrontational stance in 1987, when the FDA granted expedited approval of azidothymidine (AZT), the first antiretroviral developed to treat AIDS. While group leaders had previously endorsed the use of mainstream therapies for opportunistic infections, many could not bring themselves to support AZT. HEAL President Gene Fedorko, for example, noted that HEAL members who took the drug suffered tremendously for little apparent gain: “[P]eople would come to our meetings with black fingernails, vomiting, and diarrhea. [AZT] had no effect on T-cells increasing whatsoever.”

In the PWAC’s *Surviving and Thriving with AIDS* – a volume we consulted in Chapter 4 – one recently diagnosed PWA recalled attending a HEAL meeting only to feel overwhelmed and “freaked out” by the group’s stridently anti-AZT platform. And on at least one occasion, HEAL members engaged in an overtly public act of protest, “zapping” a conference of physicians assembled by AZT manufacturer Burroughs Wellcome to challenge what they deemed pharma’s stranglehold over the medical profession.

While HEAL’s early critiques of AZT were at times strident, they were not in fact enough to brand the group as outwardly dissident or dangerous. Indeed, the representatives of the PWAC, GMHC and New York City Department of Health all penned their letters of support for HEAL years after AZT’s approval. To understand HEAL’s continued support by mainstream organizations, we must recognize that AZT remained a deeply controversial drug through the late 1980s, with numerous lay and professional publications questioning its cost-benefit ratio, particularly given its substantial toxicological and financial tolls. What’s more, although

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530 Interview with Eugene Fedorko, ACT-OHP, 8.
532 Fedorko argued that Burroughs Wellcome was guilty of “whipping up all these doctors to prescribe AZT and giving them these lovely soirées with these fancy canapês.” Interview with Eugene Fedorko, ACT UP-OHP, 28.
individuals disagreed when it came to AZT’s relative benefits, everyone agreed that it was no panacea. In a setting of continued morbidity and mortality, many PWAs viewed HEAL’s advocacy of alternative therapies to be of vital significance to the PWA empowerment movement. Indeed, even those who would come to question HEAL’s later activism conceded the positive contributions the group made in challenging mainstream etiological and therapeutic parochialism. In his 1996 Out Magazine article, for example, AIDS activist Bob Lederer harshly critiqued the group’s mid-1990s era work while acknowledging that, in its earlier years, HEAL had provided “an important antidote to the widely accepted simple-minded one-bug/one-drug line.”

To be clear, I do not mean to paint a rosy-eyed picture of the early interactions between HEAL and more mainstream AIDS service organizations, for points of disagreement did at times drive rifts between group members. As groups such as GMHC grew and professionalized, they dedicated increasing attention to the promotion of research into biomedical cures for AIDS. For some of their leaders, HEAL’s pursuit of alternative therapies and critiques of biomedical orthodoxies were a bothersome distraction. When Eugene Fedorko suggested to GMHC that macrobiotics were preferable to AZT regimens, he encountered rigidity and dismissal from Executive Director Richard Dunne. “I could tell immediately that he was hostile to the idea of macrobiotics…we didn’t click,” Fedorko recalled. Both Fedorko and Fouratt furthermore reported similar resistance from ACT UP’s lauded Treatment and Data Committee, particularly…

533 Bob Lederer, “Curb Your Dogma,” POZ. June 1, 1995. This article was included in one of HEAL’s Comprehensive Information Packet (circa 1996), along with an expansive letter written in response by HEAL President Michael Ellner, challenging several of Lederer’s critiques. HEAL-A.

534 Interview with Eugene Fedorko. ACT UP-OHP, 10.
when HEAL challenged ACT UP’s efforts to secure greater access to AZT and, later, the second antiretroviral approved by the FDA, dideoxyinosine (ddI).  

Interestingly, some of the disagreements we find between HEAL and GMHC stemmed from broad class-based differences in the two groups’ membership bases. HEAL, in Fedorko’s opinion, had been comprised of artists and free spirits – a creative group of nonconformists who were “clever in putting together a regimen and a belief system to at least get them through the near future in a healthy way.” This population differed markedly from that of GMHC, which he argued had been created by and for “the bourgeois white boys,” or ACT UP, which he believed contained its own highly vocal “white pro forma contingent.” In his estimation, these more mainstream groups represented a shirt-and-tie “homocracy” – a society of professional homosexuals that viewed itself as superior to HEAL’s free spirited homosexual proletariat.

535 For Fedorko’s comments, see Ibid. 18-19; Fouratt would argue, “Every time a new drug would come down the pike ACT UP’s Treatment and Data would get all excited and people would get all excited. And for someone like me who thinks about side effects, and long term, and quality of living, and all that sort of stuff that’s as important as taking the new drug. ACT UP got the inside path to access to that drug. And Keith [Haring] and Ethyl [Eichelberger] both got it. And they got it in large dosages when they found out later that that was lethal. And Ethyl Eichelberger committed suicide and Keith died. Now am I saying that ACT UP caused that? Or ACT UP’s Treatment and Data people caused that? No I don’t say that, but I think that it has to be said that that is what happens when you don’t step back a moment and say, what are we putting into our bodies? ...When a person is desperate and you’ve got Larry Kramer screaming, ‘Drugs into bodies! Drugs into bodies! If you don’t want to do this, then you’re not helping!’ And all that sort of stuff. And the doctors who don’t believe in giving choice to their client...who say, ‘You take this, you take AZT or you’re not my patient.’ This is awful.” Jim Fouratt. ACT UP-OHP, 54.

536 Interview with Eugene Fedorko, ACT UP-OHP, 9.

537 Ibid 19.

538 Fedorko commented, “[He] was a representative of the homocracy and white AIDS establishment and political pandering.” The “homocrat” is a pejorative term for professional homosexuals, who made a living representing gay causes. Ibid. 10; In a 1986 interview conducted by Michael Callen and published in the PWAC Newsline, Jim Fouratt argued that professional AIDS service organizations were the successors to the Gay Activists Alliance (GAA), an organization founded in 1969 by individuals concerned with the Gay Liberation Front’s radical activism. For Fouratt, the GAA’s reticence to challenging pervasive social
Fedorko’s bifurcation of the AIDS service landscape based upon class is indeed fascinating, particularly as he associated HEAL’s alternative health activism with a nonprofessionalized lower class, thereby challenging a prominent scholarly bias which locates alternative health movements within the bourgeoisie.539

We thus have arrived at a fairly organic and, on the whole, accurate encapsulation of HEAL’s early relationships with more mainstream biomedical and activist organizations. While differences between membership bases would at times bubble over, through the 1980s and early 1990s, HEAL remained a well-respected member of New York’s larger AIDS service community. AIDS was simply too big – and too intractable – of a problem to allow any one group to claim a monopoly over good ideas. What’s more, all of the major AIDS service organizations by the mid-1980s had been forced to develop strategies for collaborating through differences of opinion, for their own members often shared wildly divergent perspectives on AIDS. As the epidemic raged on through the late 1980s and 1990s, and it became clear that Fedorko’s Dark Ages would not yield to a Renaissance of curative therapeutic innovation, many PWAs could make a legitimate claim to the benefits of a multifocal, multifaceted activist response.

inequities such as racism and classism yielded a simplistic “If it’s gay, it’s ok” organizational philosophy. He fiercely critiqued this perspective, arguing that the gay lifestyle was itself shaped by societal oppression, and would level similar charges against orthodox AIDS organizations through the 1980s. See Michael Callen, “Interview by Michael Callen with Jim Fouratt,” PWAC Newsline 18 (December 1986): 37-38, and Interview with Jim Fouratt. ACT UP-OHP; For a discussion of the divide between professional and radical activists, see Benjamin H. Shepard, “The Queer/Gay Assimilationist Split: The Suits versus the Sluts,” Monthly Review 53, no. 1. 539 Homeopathy, for example, has been referred to as the “aristocracy of quackery,” and “the quackery of the drawing room.” See Whorton, Nature Cures, 68; A 2010 study published in Pain Medicine furthermore argued that alternative medicine therapies usually attract individuals with higher education levels and income. See S. Khady Ndao-Brumblay and Carmen R. Green, “Predictors of Complementary and Alternative Medicine Use in Chronic Pain Patients,” Pain Medicine 11, no. 1 (2010): 16-24.
And yet at some point in the early-to-mid 1990s, mainstream groups’ tolerance for HEAL’s unorthodox activism reached its breaking point, with the holistic health group eventually becoming radicalized and ostracized from its institutional peers. The same group that had once robed its support for holistic health paradigms in the language of therapeutic complementarity would vehemently denounce the biomedical mainstream. Even the most cursory examination of HEAL’s mid-1990s era literature plainly underscores this transformation. One 1996 HEAL informational packet, for example, decries the mainstream viral etiological model and antiretroviral drugs it yielded, arguing that, “as far as ‘AIDS’ goes, we have been subject to the most heinous and genocidal fraud in medical history.”

A second column went further still, arguing that biomedical professionals had intentionally misled the public in their response to AIDS. “By 1987,” the author argued, “we became aware that the public was being intentionally misled about the causes, size and very nature of AIDS…We could not in good conscience ignore the emerging connection between all those nice AIDS doctors and all those dead AIDS patients.”

In perhaps the clearest sign of the group’s departure from its earlier embrace of therapeutic complementarity, it would by the mid-1990s stamp its literature with a new slogan pithily conveying its radical condemnation of biomedicine: “Fire your doctor.”

To date, no scholarly work has chronicled HEAL’s remarkable transformation from a consonant-if-contrarian health activist group to a flagrantly radicalized, stigmatized and ostracized dissident organization. As I noted at the start of this chapter, our AIDS historiography

541 Undated, untitled document from HEAL Archive, HEAL-A.
includes virtually no works analyzing the group’s early history as a broadly complementary health support group. What’s more, the rare analyses that mention HEAL at all generally reduce the group to its mid-1990s era dissidence. If this elision were not bad enough, these same scholars go a step further, dismissing HEAL’s dissidence by presenting it as a byproduct of the firebrand activism of University of California retrovirologist Peter Duesberg.\textsuperscript{543} The author of one recent scholarly work on AIDS dissidence, for example, briefly mentions HEAL within a section entitled “AIDS Activism Meets Denialism.” Demonstrating a profound lack of understanding of the group’s history, it suggests that HEAL existed as a bounded activist organization which, at some point in its history, veered into the orbit of Duesbergian denialism only to become irrevocably trapped within its gravitational pull.\textsuperscript{544}

There is a certain degree of irony to be registered in such reductions, for they treat Duesberg – a man who, we will recall, argued that HIV was insufficient to cause AIDS – as a necessary and sufficient cause of the larger dissidence movement. And yet HEAL did not exist as a consonant and complementary therapeutic movement only to become infected by Duesberg’s dissidence in the late 1980s. In fact, as I shall argue, the transformations witnessed in HEAL’s activism by the early-to-mid 1990s were themselves a consequence of a radicalization of the same holistic health principles the group endorsed through the 1980s. HEAL was thus neither infected, corrupted nor bewitched by the Berkeley retrovirologist, but instead came to embrace

\textsuperscript{543} Duesberg was a nationally acclaimed member of the scientific community who stridently announced his belief that HIV was harmless, and that the root cause for the disease was to be found in the specific behaviors and exposures of different risk groups. Thus, for example, his supporters maintained that long-term exposure to immunosuppressive substances by injection drug users and repeated exposure to STDs by homosexual men were in fact the primary cause for immune breakdown. See, for example, Duesberg’s \textit{Inventing the AIDS Virus} (Washington, D.C.: Regnery, 1996).

\textsuperscript{544} Kalichman. \textit{Denying AIDS}, 138-141.
its own expression of AIDS dissidence as a result of the radicalization of its operating principles.\textsuperscript{545} AIDS activism, in short, did not “meet” AIDS denialism; it helped give birth to it.

In the second section of this chapter, I explore this radicalization of health holism, arguing that it resulted from HEAL’s embrace of increasingly unorthodox interpretations of two core holistic health principles. The first of these principles, which I term the multifactoriality of health and disease, is quite similar to the theory of multifactoriality we discussed in Chapter 4. Many PWAs viewed the principle as broadly empowering when applied to AIDS therapeutics, as it posited an ever-increasing number of avenues whereby they could strive to bolster their health. However, as we shall see, by the mid-1990s, a small faction within HEAL expanded the group’s holistic multifactorial discourse to explicitly include questions of AIDS etiology, at which point it came head to head with a mainstream biomedical community that had rallied behind a viral etiological model. This move would ultimately expose HEAL to many of the same criticisms Joseph Sonnabend and Michael Callen endured in their endorsement of multifactorial etiological models as discussed in the previous chapter.

In the third and final section of the chapter, I explore HEAL leaders’ radicalization of a second holistic health principle, which emphasizes the intrinsic interdependency of the physical, psychological, social, environmental, and spiritual domains of life. As in the case of holistic multifactoriality, the principle of interdependency proved broadly empowering to PWAs when applied to questions of therapeutics. However, a faction within HEAL would in time radically expand it to consider questions of disease etiology. This radicalization ultimately led these

\textsuperscript{545} I should note that I do mean to suggest that dissidence spontaneously proceeds from health holism, nor do I argue that early members of HEAL were “dissident” – a term that through the 1980s lacked the meaning ascribed to it today. I instead argue that in HEAL’s activism we may recognize broad positions that, when distilled into radical philosophies, correlate with the later AIDS dissidence movement.
leaders to pursue a number of incendiary positions, contributing toward HEAL’s conspiratorial rejection of mainstream biomedical practice.

**The Radicalization of Health Holism: A Divisive Multifactoriality**

To understand HEAL’s eventual turn toward a radicalized health holism, it is essential that we first discuss the holistic health movement out of which its early outreach grew. This is no easy task, for over the course of the past 30 years, myriad professionals and lay individuals alike have adopted the term “health holism” to connote a wide variety of beliefs and practices, and as a result no single, authoritative definition of the movement exists. In his 2016 volume *To Fix or to Heal: Patient Care, Public Health, and the Limits of Biomedicine*, sociologist Joseph E. Davis argues that at its core, health holism embraces “a systematic concern with the whole organism, a focus on the interconnected effects of the larger physical or social environment, and attention to population-level variation.”

Interestingly, as Davis has sagely noted, virtually all premodern health systems qualify as holistic based upon this loose definition, and indeed advocates of health holism frequently frame their beliefs as a return to an idealized and bucolic past. However, it is erroneous to suggest that the holistic health movement as we know it today is

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premodern in origin, for it was deliberately developed and promulgated as an antipode and antidote to modern biomedicine. Where biomedicine has come to rely upon increasingly advanced diagnostic and therapeutic technologies, holism invokes a simpler past; where biomedicine seeks to reduce disease to its constituent causes, holism speaks instead of the irreducible links between the mind, body, and environment; and where biomedicine dehumanizes patients through an increasingly profit driven, hyperspecialized bureaucracy, holism claims to humanize individuals.

There are many factors underlying the modern holistic health movement’s rapid growth during the mid-to-late 20th Century, including the broadly countercultural foment of the 1960s and 1970s which contributed to the public’s growing disenchantment with and distrust in the biomedical care system – a topic addressed in great detail in Chapters 2 and 3. While it is impossible to review all of these factors here, one particular issue warrants revisitation. By the mid-20th Century, the groundswell of therapeutic successes biomedicine logged had begun to dry up, with intractable chronic conditions replacing infectious diseases as major sources of morbidity and mortality in the developed world. The same magic bullet approach that had successfully treated conditions such as pneumonia, enteric diarrhea and tuberculosis proved largely ineffectual against cancer, heart attack and stroke. As many lay and professional commentators had long intuited, these diseases stemmed not from infection with single inciting agents, but rather from a nebulous and difficult to parse web of interconnected biological, behavioral, social and environmental variables. The holistic health movement flourished in

549 As one analysis of health holism published in 1989 would note, the movement argued that human disease was far more complicated than linear “cause and effect” relationships suggested, with health and disease resulting from the complex interaction of myriad variables. See Kristine Beyerman Alster, The Holistic Health Movement (Tuscaloosa: University of Alabama Press, 1989): 61. Interestingly, Alster’s piece is very critical of the holistic health movement.
these years, developing complex, multifactorial models for conceiving of and responding to chronic disease while – in the case of conditions such as cancer – resisting the feared and in many cases futile heroic interventions advocated by mainstream biomedical professionals.\footnote{Holistic health activism through the second half of the 20th Century dealt heavily with cancer treatments, with the 1950s witnessing the rise of the Hoxey herbal tonic, the 1960s the rise of Krebiozen, and the 1970s laetrile and the Therapeutic Touch.}

Some readers may find it difficult to understand how a movement that grew to prominence during the mid-20th Century’s era of chronic disease could find a foothold amongst individuals facing AIDS. For it is by now almost cliché to discuss AIDS as the century’s great anachronism – a terrifying epidemic that lurched society from the limbo of chronicity back into the hell of infectious plagues. And yet our tendency in the developed world to divide AIDS history into an era of infectious disease (1982-1996) and an era of chronic disease (1996-present) blinds us to a wide array of activist traditions organized in the earliest days of the epidemic.\footnote{Elizabeth Fee and Daniel Fox chronicle this transformation in their 1991 volume \textit{AIDS: The Making of a Chronic Condition} (University of California Press); More recent articles published in the world’s leading medical journals have heralded “the end of AIDS” as a result of HIV infection’s transformation into a chronic condition. Steven G. Deeks, Sharon R. Lewin, and Diane V Havlir, “The End of AIDS: HIV Infection as a Chronic Disease,” \textit{Lancet} 382, no. 9903 (2013): 1525-1533.}

For those diagnosed with AIDS through the early 1990s, life did not map neatly or cleanly onto an infectious disease narrative. The prevalence of Kaposi’s Sarcoma (KS) among PWAs, for example, led many early journalists to speak of AIDS as a “gay cancer,”\footnote{Joe Wright, “Remembering the Early Days of ‘Gay Cancer,’” \textit{All Things Considered}, National Public Radio, May 8, 2006.} a term that would become common in gay communities in the earliest months of the epidemic.\footnote{Altman, \textit{AIDS in the Mind of America}, 35.} What’s more, through the 1980s, our nation’s federal AIDS research apparatus remained intimately interwoven with its cancer research apparatus. Early on, the National Cancer Institute (NCI) took a lead in AIDS research, with Robert Gallo – the NCI scientist who would become the face of US
research efforts – strongly asserting that AIDS was caused by a human leukemia virus (HTLV-III) related to two retroviruses he and his team had previously implicated in human cancers.  

As interesting as these points of intersection between early AIDS cases and chronic disease discourse may be, even deeper connections appear when we consider the overarching principles and philosophy of the larger PWA empowerment movement. To appreciate these linkages, we must first recognize the profound ambiguity which attends most professional and scholarly uses of the term “chronic disease.” There are indeed few concepts used as often in the modern biomedical lexicon that remain as poorly defined or delineated. The websites for many state departments of health throughout the nation avoid defining the term entirely, speaking instead of chronic conditions by way of example. The Department of Health for Illinois is one exception to this rule, although even it rather vaguely defines a chronic disease as one that “persists over a long period of time.” The US National Center for Health Statistics is somewhat more precise, defining as chronic those diseases lasting three months or longer, while another recent work suggests that chronic diseases have a duration “measured in months and years, not days and weeks.” This ambiguity is of great significance to early AIDS history,


556 “A chronic disease, as defined by the U.S. National Center for Health Statistics, is a disease lasting three months or longer. About 40 million Americans are limited in their usual activities due to one or more chronic health conditions.” “See About Chronic Diseases,” National Health Council, Rev 7/29/2014, accessed Sep 26, 2016.


557 The source, published in the peer-reviewed journal Radiology, also notes that chronic diseases are oftentimes progressive in nature and are not self-limiting. James H. Thrall, “Prevalence and
for as we will recall, the PWA empowerment movement arose out of an ardent desire to challenge universal fatality narratives and argue instead that PWAs could survive long-term with their condition. To say that AIDS was an infectious disease pre-1996 is thus to prioritize epidemiological history over social history, thereby obscuring the lived experience of countless PWAs who fought tirelessly to reframe their condition through a chronic disease lens. It was amongst these PWAs – and not the epidemiologists – that health holism, a movement more commonly associated with chronic conditions such as cancer, established an ardent following.

As Davis and others have argued, a key component of the mid-20th Century’s holistic health movement was its shift away from modern biomedicine’s penchant for reducing disease to unicausal cellular or molecular origins. Instead, holistic health practitioners argued that conditions such as cancer resulted from the complex, additive effects of numerous variables. HEAL would embrace a similar conceptualization of therapeutic multifactoriality – arguing that AIDS resulted from the additive effects of myriad forms of antigenic assault spanning virtually all domains of life (a topic we shall revisit in the next section of this chapter). It is important to note that this early embrace of multifactoriality was not, in fact, borne out of a dissident contrarianism. Instead, group leaders believed that multifactorial AIDS models yielded a wider array of therapeutic interventions PWAs could embrace in their efforts to gain control over their bodies and their disease. In commenting on the wide assortment of variables HEAL leaders identified as relevant for the development and progression of AIDS, the group’s Executive Board


member Andrew Cort exalted, “This is good news! If there are many factors involved in illness, then there are many things which can be done to regain and/or maintain health. We do not have to wait for a ‘magic bullet,’ we do not have to count on just one treatment. Instead, we can deepen our own personal responsibility toward all aspects of our health and well-being.”

Consistent with this belief, HEAL literature abounded with explorations of a dizzying variety of alternative health modalities, ranging from macrobiotics, herbalism and chiropractic, to hypnotherapy, Reiki and attitudinal healing.

Interestingly, while many would see in HEAL’s early embrace of multifactorial disease paradigms a vehicle for PWA empowerment, by the mid-1990s the situation had changed considerably. A review of the archive reveals that at approximately this time, a small faction of HEAL members under the leadership of longtime member Michael Ellner shifted the group’s


560 Similar appeals to individuals’ sense of personal responsibility reappear throughout the archive. A 1988 HEAL Newsletter article penned by Dr. Raymond K. Brown, author of AIDS, Cancer and the Medical Establishment, argued that PWAs who survived the longest were “those taking an active role in shaping their health program, rather than passively waiting for their doctor’s next instruction.” Several HEAL information packets produced through the 1990s warned PWAs not to place all of their faith in mainstream doctors, intoning, “You must learn to count on yourself! Your greatest help will come from personal responsibility and self-empowerment.” And in the very first edition of the HEAL Quarterly, an article by Michael Wayne Miles directly coopts the language of mainstream biomedicine to advocate holistic self-empowerment: “Self-empowerment is becoming aware of your options, alternatives and choices you have in your life and your health. You get involved and take responsibility. Because you believe in yourself and your ability to take care of yourself, this is your magic bullet.” See Raymond K. Brown, HEAL Newsletter 1, no. 2 (March 1988): 2, HEAL-A; “Introduction,” HEAL Comprehensive Information Packet. circa 1996, HEAL-A; Michael Wayne Miles, “Self-Empowerment is the Magic Bullet,” HEAL Quarterly 1, no. 1 (Fall 1989): 3, HEAL-A.
multifactorial discourse. Whereas members previously had invoked multifactoriality as a means to an end – that is, the promulgation of an ever-increasing number of avenues for therapeutic intervention – Ellner instead viewed it as an end in itself. As such, he presented the paradigm as a legitimate etiological philosophy worthy of activist support. It appears that this turn toward a rigid etiological multifactoriality was in part a response to the consolidation of mainstream biomedicine’s support behind a rigid notion of viral unicausality. Indeed, throughout the 1980s, acclaimed and controversial AIDS researcher Robert Gallo betrayed little patience for activists who challenged the notion that HIV was both necessary and sufficient to cause AIDS, which in turn inspired Michael Ellner and his colleagues to challenge mainstream unicausal models all the more strongly.561

Once Ellner and other proponents of multifactorial etiological AIDS models had dethroned HIV as the *sine qua non* of AIDS, they were forced to identify a set of variables cumulatively capable of causing the widely feared disease. Relying upon lay, informal analyses of HEAL members, Ellner argued that AIDS resulted from the additive effects of severe antigenic stresses amongst gay men, specifically identifying repeated infections with sexually transmitted agents, persistent recreational drug use, and long term use of antibiotics as the main culprits. Ellner’s holistic paradigm, much like Sonnabend’s multifactorial model, thus implied that PWAs had, prior to diagnosis, endured a veritable onslaught of self-inflicted immunologic assaults. In increasingly inflammatory language, the group’s literature transformed PWAs from the unlucky victims of an equal opportunity virus into the willful participants of their own demise.

561 Early in the epidemic, Gallo famously rejected multifactorial models, arguing that HIV “kills like a truck” and dismissing talk of cofactors as “cock and horseshit.” “Gallo Rethinks HIV,” *SPIN* (July 1988): 97.
The sexual practices of gay men garnered particular attention in HEAL informational packets by the late 1980s and early 1990s, with one such packet naming “repeated traumatic sex acts and multiplicity of sexual partners engaging in anal sex” as a major factor underlying AIDS.\(^{562}\) Michael Ellner was perhaps the most vocal HEAL leader to blame gay male promiscuity for AIDS, arguing that nearly all of the PWAs he met in HEAL meetings had engaged in frequent and extreme acts of sexual intercourse through the 1970s and 1980s. “They were looking to live wild and high and die young and beautiful,” he argued, “having sex in numbers that I don’t think were ever possible historically because you didn’t have so many people in the same place.”\(^{563}\) HEAL advisor Frank Buianouckas echoed many of Ellner’s arguments, in some cases invoking PWAC cofounder Michael Callen’s medical history to argue that as a result of repeated infections with STIs, the immune systems of many gay men had come to resemble that of a “65-year-old equatorial African living in squalor.”\(^{564}\)

While Ellner presented his multifactorial arguments as more intrinsically empowering than unicausal viral models, many gay men would hold them to be not only disempowering, but blatantly homophobic. Such accusations deeply pained the heterosexual HEAL member, a self-described “child of the 60s” who prided himself on his fervent support for gay rights and sexual liberation.\(^{565}\) In Ellner’s view, his embrace of multifactoriality in fact protected the hard won victories of sexual liberation by challenging the notion that a single unlucky act of sexual intercourse shared between two men (or between a man and a woman) could transmit a virus and cause AIDS. However, by rejecting a primary causal role for HIV, Ellner bore the tremendous

\(^{563}\) Interview with Michael Ellner, conducted by Matthew Kelly, November 2, 2009.
\(^{565}\) Interview with Michael Ellner, conducted by Matthew Kelly, November 2, 2009.
burden of enumerating gay sexual practices which he thought were sufficient to transmit the crippling immunodeficiency associated with AIDS. Consequently, in order for the self-proclaimed child of the 60s to protect the sanctity of sexual intercourse itself, he was forced to paint PWAs as having engaged in profligate, promiscuous and extreme acts of sexual excess. Consider, for example, a response Ellner gave in a 1994 episode of *Tony Brown’s Journal* when asked which gay male sexual practices were capable of causing immune collapse:

“I would think it would have a violent atmosphere around it; be very, very brutalizing to the person – the receptive partner, in this case. And I think another component would be volume, the number of partners; that anal sex, in and of itself, is not what’s the danger. It’s if you have a number of exposures, and continuous exposures, and a lot of antigenic assaults on your health, that really is the danger.”

While Ellner would identify promiscuity as one important variable underlying AIDS, he and likeminded HEAL contributors also focused considerable attention on recreational drug use amongst gay communities. Ellner was especially fond of *New York Native* journalist John Lauritsen’s claims that AIDS was caused in part by gay men’s use amyl nitrile inhalants (“poppers”). The two activists collaborated frequently – Lauritsen penned columns in HEAL publications, he and Ellner appeared together on *Tony Brown’s Journal*, and at one point

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569 “AIDS Psychology: Interview with Michael Ellner and John Lauritsen.”
Ellner described Lauritsen as capable of “walk[ing] on water.” Other HEAL contributors echoed the claim that recreational drug use amongst gay communities underlie AIDS, with one 1995 HEAL “white paper” published by controversial physician Robert Willner rather sensationally claiming that 96% of gay men surveyed had used nitrile inhalants, 90% used marijuana, 60% amphetamines, 55% cocaine, 50% Quaaludes and 50% lysergic acid (amides of which form LSD). The implication that such drug-induced stresses – and not HIV – underlie AIDS was quite clear.

By the 1990s, HEAL would expand its discussion of the immune burden of drugs to include more explicit attacks on mainstream pharmaceutical agents. Willner, for example, argued that the use of “street drugs” and medicines such as AZT together “correlate virtually 100% with the development of AIDS in Europe and the United States.” And a HEAL Info Page circulated amongst members pointed to the use of prescription medicines, over-the-counter remedies, and adulterated street drugs to argue that PWAs had turned their bodies into a “human toxic dump site.” Some would furthermore link promiscuity with pharmacological stressors by arguing that gay men in the 1970s exposed themselves to numerous STIs, which they in turn treated with copious amounts of antibiotics, resulting in a vicious cycle of immune degradation. And while

570 Interview with Michael Ellner, conducted by Matthew Kelly, November 2, 2009.
571 An ardent opponent of the HIV etiological model, Willner in fact injected himself with the blood of an individual diagnosed as HIV positive blood on several occasions between 1993 and 1995, declaring “I will repeat the process of sticking myself with the blood of an HIV positive person on television in every city of the world until this genocide stops.” See “Doctor Injects Himself with HIV+ Blood,” POZ, February 1, 1995; For Willner’s discussion of recreational drug use among gay communities, see Robert E. Willner, “A Call for the Truth about AIDS: A White Paper on the Viral-AIDS Hypothesis,” January/February 1995, 9, HEAL-A.
573 “Is AIDS a New Disease?” HEAL Info Pages, circa mid-1990s, HEAL-A.
the group’s literature primarily maintained a gay male focus, its occasional forays into discussions of AIDS amongst heterosexual drug using populations were no less incendiary. In one astonishingly sensational HEAL article, Frank Buianouckas described this particular subpopulation by invoking images of “drug addicts shooting up in dank abandoned buildings, living off Captain Crunch, if they have any money left after they have bought their dope, cigarettes and booze – otherwise they exist on sugar packets stolen from wherever possible.”

As HEAL discourse would become increasingly dominated by Ellner’s focus on multifactorial antigenic assault brought upon by recreational drug use, medicinal drug use, and promiscuous sex, the notion that PWA empowerment was predicated upon individuals reclaiming responsibility for their lives took on blatantly moralistic undertones. By the 1990s, some would begin to suggest that those who sought magic bullet solutions to AIDS were looking for quick fixes to avoid engaging in a holistic examination of the sources of imbalance and stress in their lives.576 In one early 1990s article appearing in a HEAL informational packet, for example, Lese Dunton argues, “Some people will never allow themselves to stop and look, and they will die…The concept that you’re responsible for everything that happens to you – some people resist that greatly.”577 Similarly, in the aforementioned episode of Tony Brown’s Journal, Ellner’s attempt to explain the controversy surrounding lifestyle modification campaigns suggests a level of judgment toward PWAs. “I think [PWAs] don’t want to hear that message,”

577 Lese Dunton. “Getting beyond AIDS.”
he commented. “They want a pharmaceutical solution. They’re not looking to change their lives. What they’re looking for is, ‘Give me a medicine, so I can go back and do these behaviors.’”

By the early 1990s, Ellner and others within HEAL would sharpen their critiques of pharmaceutical solutions, arguing even more forcefully that the biomedical system itself was directly contributing to AIDS. Two important medical advances catalyzed this radicalization of the multifactorial model. The first was an acknowledgment on the part of the FDA that the initial dosage regimen for AZT had been too high, prompting it to decrease the recommended dose from 1,200 mg to 600 mg. While many in the AIDS community saw this as a triumph, Ellner and his compatriots took it as evidence that AZT was indeed toxic, and that it had furthermore contributed to the immune degradation amongst PWAs – a position Duesberg also strongly advocated at the time. It additionally led the group to disseminate conspiracy theories claiming that Burroughs Wellcome had known of AZT’s toxicity issues but ignored them to insulate their earnings, further isolating HEAL from mainstream activists.

The second issue that contributed mightily to HEAL’s radicalization ultimately precipitated the dissolution of HEAL’s greater membership and drove a wedge between the group and the PWAC. Through the 1980s, PWAC cofounder Michael Callen waged a tireless

578 “AIDS Psychology: Interview with Michael Ellner and John Lauritsen.”
580 As Ellner argued, “[Burroughs Wellcome] sat on those studies and these people were lied to…The battle cry was, ‘We don’t care if they kill us, we want access to life saving drugs just in case’…Desperate people make desperate decisions, and these people were very desperate. Being an outsider and not being directly at risk, I could watch the consequences of AZT and I was among four or five people tops who were protesting it at the time. And all of us were shouted down, and that was about when HEAL began to fall from grace. And that’s when people started to accuse us of being political.” Interview with Michael Ellner, conducted by Matthew Kelly, November 2, 2009.
battle to convince biomedical leaders that asymptomatic PWAs could prevent the contraction of AIDS related conditions through the prophylactic use of medications. Attributing his long-term survival to Sonnabend’s decision to treat him prophylactically with agents such as Bactrim and aerosolized pentamidine, Callen fought tirelessly to convince the FDA that his approach could save lives, finally achieving success in the early 1990s. For Michael Ellner, who viewed mainstream biomedical treatments as intrinsically dangerous and one of many factors contributory to AIDS, the prophylactic use of such powerful medicines amongst asymptomatic PWAs was anathema to health.581 Through the 1990s, he engaged in a bitter critique of prophylaxis and in some cases directly criticized Michael Callen, who died of AIDS related conditions in December of 1993. In a 1993 video aired on Manhattan’s cable news network, for example, Ellner commented that as a result of Callen’s prophylactic drug use, “He didn’t even look human for the last six or seven months” of his life.582 Another like-minded author would in 1997 invoke the “pathetic” figure of Michael Callen, “the AIDS ‘survivor’ 12 years after diagnosis, defying the pronouncements of the authorities that salvation lies in AZT but preaching the false gospel of ‘prophylactic’ use of antibiotics, holding up his sandwich bag of pills, 56 of which he took every day.”583

581 As he would explain in a 2009 interview, “I had had rooms full of people say they thought preventive antibiotics made them sick in the first place. And now they were being told if you take them you wont get PCP pneumonia and the drugs were Bactrim and aerosole pentamidine and it was like insanity. Well, every AIDS group was pushing them vigorously as this was the thing to do. And because I was leading the meetings, I was able to say anything I wanted. And so I challenged it.” Ibid.
583 This source is in fact a highly laudatory column appearing in the alternative medicine publication, which glowingly reviewed a dissident text featuring articles by Michael Ellner, John Lauritsen, Casper Schmidt and others. Elizabeth A. Ely, “Read at Your Peril,” Review of The
While HEAL’s multifactorial health activism had endured a great deal of criticism, Ellner’s attempts to invoke it to condemn the use of prophylactic treatments proved the last straw for the group’s longstanding members, many of whom resigned in protest by 1992. Among the defectors was Eugene Fedorko, who we will recall joined the group at its inception and once served as President. In a 1995 interview with AIDS activist Bob Lederer, Fedorko intoned, “HEAL’s message that all Western medicine is bad – and particularly not to take antibiotics – is horribly oversimplified. Sure, there are toxicities to consider and counteract. But the big killer infections like Pneumocystis carinii pneumonia (PCP) can’t be treated with less than antibiotics or the person will die.” As Fedorko’s comments suggest, as the group pursued an increasingly isolated, radicalized rejection of mainstream medicine, it ostracized itself from other unorthodox health activists. HEAL member Tom DiFerdinando would underscore this point in a 1997 article wherein he lambasted the unorthodox AIDS community for acquiescing to a mainstream unicausal etiological model. In his opinion, the larger alternative health community had come to use HIV as “an unspoken and socially sanctioned closet door behind which one can hide…absolv[ing] themselves of responsibility as a participant in their environment or situations.”

584 Ellner explained that the remaining members included Cliff Goodman, Alan Burns and Tim Pedifer. Of Pedifer, he observed, “Unfortunately, he took the early preventative antibiotics and they killed him in my opinion, which really pushed my resolve to challenge it. In other words, members of HEAL did take the treatment and it was not a pleasant thing to watch. They did believe that it was the answer.” Interview with Michael Ellner, conducted by Matthew Kelly, November 2, 2009.


586 Elsewhere in the article, DiFerdinando – who was by this point HEAL’s Executive Director, argued, “The alternative community is well aware that the microbe theory of disease has more of a political, economic and emotional function than a medical one and, particularly with catalytic books like Ivan Illich’s Medical Nemesis, had long since rejected it. But then with the advent of
Thus, as activists rigidly embraced multifactoriality as an alternative to a mainstream, unicausal viral paradigm, they came to ostracize not only their own members, but the larger biomedical and alternative health communities. We could in fact end our discussion here, having successfully mapped one route whereby a subset of HEAL members pursued a radicalized conceptualization of holism. And yet to do so would paint an incomplete picture of what was in fact a deeply complex movement. For HEAL’s turn toward radical holism was a function of far more than a focus on the additive effects of self-inflicted stressors such as recreational drug use, medicinal drug use and repeated exposures to sexually transmitted infections. Its leaders would in fact adapt a second holistic health principle – the notion that all variables underlying health and disease are intimately interdependent – to arrive at startlingly radical theories regarding the etiology of AIDS. It is to this second health principle that we now turn.

The Radicalization of Health Holism: From Holistic Interdependency to an Isolating Dissidence

In the previous section, we explored HEAL’s endorsement of an increasingly rigid multifactorial AIDS etiological model, which led leaders to argue that immune breakdown resulted from the cumulative effects of a wide array of antigenic stresses. While this analysis sheds light on one aspect of grassroots holistic activism within the larger AIDS movement, it is important to emphasize that health holism is in fact defined by far more than an additive immune overload conception of multifactoriality. Indeed, when we speak of holism, most readers likely conjure a New Age movement which emphasizes the irreducible wholeness of the individual.

Underlying this aspect of holistic practice is a fervent belief in what I shall refer to as the holistic ‘infectious AIDS’, they all suddenly jumped right back into the ‘deadly virus’ roller coaster. All of a sudden its [sic] the new exception, and viruses are in vogue again because our government scientists, corporate media and conventional medical community say so.” See Tom DiFerdinando, “This is a Challenge,” September 12, 1997, HEAL-A.

We might consider, for example, the fact that Joseph Sonnabend famously promulgated a multifactorial etiological AIDS model but was not himself an acolyte of health holism.

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interdependence of an individual’s physical, psychological, emotional and spiritual beings – and the irreducible linkages between these domains and larger social/environmental domains. As health scholar Michael H. Cohen has observed, the holistic philosophy “attempts to account for patients as whole persons, exercising autonomous choices and seeking health in terms of a larger pursuit toward an irreducible, unified, physical, emotional, mental and spiritual wholeness.”

By the late 1980s and early 1990s, Michael Ellner’s vocal HEAL faction had come to yoke its activism to an increasingly radicalized philosophy of holistic interdependency. This turn toward a broader and more far-reaching holism ultimately ostracized key members of its membership base and marginalized HEAL from the biomedical community.

Some readers may find it surprising to learn that HEAL’s descent to a dissident and divisive radicalism stemmed in part from its embrace of an interconnected, interrelated worldview. After all, this same presumption of interdependence between physical, emotional, environmental and spiritual spheres has conferred upon the larger holistic health movement an aura of New Age, “flower child” free-spiritedness, complete with entreaties to inner harmony and world peace. For many, holistic interdependency was the language of idealistic hippies and high-flying health gurus who spent their time, in Frank Zappa’s immortal words, “jiving

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with that cosmik debris," finding connections between their bodies, their minds and the larger universe. Of all of holism’s facets, it may seem strange to consider that this one in particular played such an important role in the group’s turn toward rancorous contrarianism, for we oftentimes dismiss it as the calling card of an inebriated, idealistic and innocuous fringe.

However, our assumptions regarding holistic interdependency are largely without merit. For one, a review of 1970s and early 1980s era mainstream literature plainly belies the notion that interdependency was a dialect spoken only within the confines of hippie communes. We must recall that this was, after all, the dawn of the era of globalization, and countless authors had begun to conceive of a world wherein technology, commerce and information transfer collapsed the boundaries that once divided different peoples, cultures and societies. For these commentators, a globalized world was one defined by interrelation and interconnection; correspondingly, the early-to-mid-20th Century’s fixation with specialization, segmentation, atomization and rigidly mechanistic etiological models began to appear startlingly anachronistic. In his bestselling 1982 text The Turning Point, for example, acclaimed author Fritjob Capra argued:

“[W]e are trying to apply the concepts of an outdated world view – the mechanistic world view of Cartesian-Newtonian science – to a reality that can no

590 The song aptly captures the speaker’s frustration with health gurus: “With the oil of Aphrodite, and the dust of the grand wazoo / He said you might not believe this, little fella / But it'll cure your asthma too / And I said look here brother / Who you jiving with that cosmik debris? / Now what kind of a guru are you, anyway? / Look here brother, don't waste your time on me.” See Frank Zappa, “Cosmik Debris.” Apostrophe (’) Album, 1974.

591 The International Monetary Fund notes, “The term ‘globalization’ began to be used more commonly in the 1980s, reflecting technological advances that made it easier and quicker to complete international transactions—both trade and financial flows. It refers to an extension beyond national borders of the same market forces that have operated for centuries at all levels of human economic activity—village markets, urban industries, or financial centers.” International Monetary Fund Staff. “Globalization: A Brief Overview,” International Monetary Fund Issues Brief 2, no. 8. May 2008.
longer be understood in terms of these concepts. We live today in a globally interconnected world, in which biological, psychological, social, and environmental phenomena are all interdependent. To describe this world appropriately we need an ecological perspective which the Cartesian world view does not offer.”

If holistic interdependence was indeed a dialect, it was one many people by the 1980s had come to understand, which helps explain HEAL’s early success in appealing to both PWAs and the leaders of major AIDS service organizations. Much as we saw in the case of the multifactorial health model, the group’s early endorsement of holistic interdependency was linked directly to its wide-ranging therapeutic initiatives. While the group pursued an impressive array of initiatives, by far the most important avenue for therapeutic interdependency within HEAL posited deep, irreducible linkages between the physical, emotional and psychological domains. Largely a result of Michael Ellner’s activism, by the early 1990s HEAL had come to enthusiastically argue that physical, somatic illnesses such as AIDS could be treated through interventions aimed at modulating individuals’ psychological or emotional states. Ellner, whose own alternative health training was in the field of hypnotherapy, strongly believed that the mind played a crucial role in AIDS prognosis, and through the 1980s held myriad workshops advocating the use of “hypnoimmunotherapy” to heal PWAs through treatments directed at the mind. HEAL also organized many communal Reiki and attitudinal healing seminars,

593 They included the 1989 HEAL Quarterly column “Change Your Health by Changing Your Thoughts,” HEAL Quarterly 1, no. 1 (Fall 1989), HEAL-A; “The Turning Point: A Creative Healing Workshop” with Dr. Andrew Cort and Michael Ellner, No Date. HEAL-A; an advertisement for a seminar entitled “Tapping Your Psychospiritual Possibilities: Understanding
introducing members to healing traditions such as the AIDS Mastery and Louise Hay’s therapeutic approach, both of which we discussed in Chapter 4.\(^5\)

Had HEAL maintained its emphasis on holistic therapeutics, we likely would remember it today as a relatively benign, idealistic exponent of the early integrative medicine movement. The strongest accusation scholars would level against it likely would be allegations of fringe quackery similar to the ones that greeted Louise Hay’s psychotherapeutic AIDS activism.\(^6\)

However, just as we saw in the previous section, by the 1990s Ellner and his colleagues had shifted the group’s discourse away from questions of therapeutics, and instead toward questions of AIDS etiology. It was this foray into the realm of etiological theory that ultimately radicalized the group and catalyzed its ostracization from the larger biomedical, PWA and AIDS service communities. It furthermore earned it an opprobrium far more radioactive than health quackery – that of AIDS dissidence.

As HEAL shifted its focus toward holistic interdependency as a means of explaining AIDS etiology, Ellner’s non-Cartesian view of the irreducible linkages between the body and the mind began to take center stage. The hypnotherapist would by the 1990s advocate an increasingly radical etiological model holding that AIDS could result from emotional and

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5. One HEAL informational packet includes a *New York Native* article written by a PWA who used guided meditation, Louise Hay and visualization tapes. Dunton, “Getting beyond AIDS.”

6. Here, again, we see the curious inadequacies of the fringe epithet, for Hay established widespread notoriety by the late 1980s. Her 1988 text *You Can Heal Yourself* sold over 35 million copies, and she appeared on programs such as the *Oprah Winfrey Show* to discuss her work with PWAs. Mark Oppenheimer, “The Queen of the New Age,” *New York Times Magazine*, May 4, 2008; At the same time, the Internet is replete with online message boards decrying Hay’s therapeutic approach as chicanery and quackery. See, for example, “Louise Hay is a Dangerous Quack,” *Spirituality is No Excuse*, January 24, 2014, accessed September 20, 2016 [https://spiritualityisnoexcuse.wordpress.com/2014/01/24/louise-hay-is-a-dangerous-quack/](https://spiritualityisnoexcuse.wordpress.com/2014/01/24/louise-hay-is-a-dangerous-quack/), and “Quack Watch,” Discussion thread on *POZ Forums*, February 28, 2015, accessed 20 September 2016, [http://forums.poz.com/index.php?topic=57962.0](http://forums.poz.com/index.php?topic=57962.0).
psychological trauma sustained by gay men. This flagrantly unorthodox theory is fascinating, as
in it Ellner positions the mind as a conduit which effectively translated socially mediated
structural and symbolic forms of violence onto the body. AIDS thus became the fault of larger
society – or, more precisely, the systems and structures of power within society – which
imprinted themselves on the body through the intercession of the mind. Students of public health
may recognize somewhat surprising overlaps between Ellner’s embrace of holistic
interdependency and the fields of social epidemiology and social medicine. Both, for example,
challenge reductive and atomistic conceptualizations of disease, viewing illness instead as the
results of complex webs of causation. While Ellner’s embrace of holistic interdependency
diffs from social epidemiology in key regards – including, for example, his defiant disregard
for Cartesian dualism – the two models both provide languages which allow individuals affected
by disease to impugn larger structural forces that so often escape serious biomedical inquiry.

It is worth noting that Ellner was far from the first who would position the mind as a
nexus linking bodily disease with structural violence. In 1956, for example, acclaimed
anthropologist Margaret Meade penned a *New York Times* column wherein she discussed the
popular notion holding that social change begot anxiety amongst members of the public, which
in turn begot disease. “This is what we have arrived at with all our vaunted progress, our great
technological advances, our great wealth,” Meade wrote. “[E]veryone goes about with a burden
of anxiety so enormous that, in the end, our stomachs and our arteries and our skins express the
tension under which we live.”

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596 For a discussion of social medicine, see Dorothy Porter, “How Did Social Medicine Evolve,
To be clear, Meade’s essay is meant as a support of the progress witnessed in the Age of
Anxiety, hence the essay’s title; The notion that structural factors can cause anxiety and that
a special role in registering the stresses of society onto the body, be it amongst 19th Century neurasthenia patients or mid-20th Century populations racked by Meade’s anxieties.\textsuperscript{598} Indeed, one might surmise that, if anything, anxiety’s perceived role as translator of social stresses has only increased through the 20th Century. Our is, after all, the era poet W.H. Auden famously defined the “Age of Anxiety” in his Pulitzer Prize winning 1948 eclogue of the same title. The quote opening this chapter captures well Auden’s perception of a society brimming with unease. Written some three decades before the dawn of the AIDS epidemic, the words are all the more remarkable for the ways in which Auden – himself a closeted homosexual – eerily portends the anxieties of the AIDS epidemic. “They swallowed and sank, ceased thereafter / To appear in public; exposed to snap / Verdicts of sharks, to vague inquiries / Of amoeboïd monsters, mobbed by slight / Unfriendly fry, refused persistence. / They are nothing now but names assigned to / Anguish in others, areas of grief,” he wrote. “Many have perished; more will.”\textsuperscript{599}

Ellner’s early interest in the role the mind played in the development AIDS led him to a radical theory first proposed by Casper G. Schmidt in a 1984*Journal of Psychohistory* article entitled “The Group-Fantasy Origins of AIDS.” This piece – published in an obscure journal and all but ignored in AIDS scholarship – exists as one of the earliest dissident etiological AIDS treatises. Described by Ellner as a Renaissance man, Schmidt had relocated to New York from his native South Africa to open a psychoanalytic practice, and is credited with articulating a

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\textsuperscript{598} For a discussion of neurasthenia, see for example, Julie Beck, “‘Americanitis’: The Disease of Living Too Fast,” March 11, 2016. *The Atlantic.*

holistic critique of HIV before the virus was named. In his 1984 article, he wrote, “Against the grain of monoetiological thinking and an unconsciously held Cartesian dualism, I posit that AIDS is a bio-psycho-social disorder. I argue that a sequence of group psychological events in the U.S. has shamed – and mercilessly so – the homosexuals and the drug addicts, giving rise to an epidemic of shame-induced depression.”

In Schmidt’s bio-psycho-social model, AIDS was itself an example not of an infectious disease spread by germs, but rather a “contagious form of psychological disturbance…spread by suggestion.” The fascinating and openly unorthodox perspective argues that AIDS represented a crystallization of the entrenched symbolic violence promulgated by the Moral Majority against gay men through the 1970s and early 1980s. As Schmidt saw it, gay men had become the scapegoats of a shamed and penitent society, the “whipping boys” of a “sadistic” New Right who self-righteously condemned its members to death as a means of reinforcing its own sense of virtue and sanctity.

Needless to say, Schmidt’s theory is profoundly provocative, flying in the face of not only mainstream biomedical theory but also the theories we today associate with AIDS dissidence. In the language of our outdates metaphor, it exists in the margins of the margins – the

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600 We have very little information regarding Schmidt’s life, as he died of AIDS related conditions in 1994. One might theorize that Schmidt’s experience in South Africa was similar to Sonnabend’s, who attended medical school when the pro-apartheid Afrikaner Party came to power. Years later, Sonnabend would note that the experience had left him “unable to join groups of any kind. I’m totally suspicious of the demagoguery…I’m distrustful of not speaking to the simplicity of one’s original motivation…Even today, I’m not able to join the Party, as it were…The Party is not the National Party, but gay activists, the ‘HIV camp,’ the Reagan-Bush medical establishment – any group that has, in his view, politicized and distorted otherwise apolitical issues of common sense or health.” See D’Adesky, “The Man Who Invented Safer Sex Returns.”


602 Ibid. 12. Brief parenthetical omitted.

603 Ibid. 41, 50-51.
fringe of the fringe. “The Group-Fantasy Origins of AIDS” is furthermore noticeably thin on the types of support modern audiences have come to expect from etiological models, with most of Casper’s evidence loosely appropriated from non-AIDS related epidemiological studies and, in some cases, anthropological research of pre-industrial societies.\textsuperscript{604} In place of mechanistic discussions of disease pathways, for example, Schmidt cites the shaming taboos of New Guinean tribal societies, practices which he argues carried the capacity to cause death. He in fact acknowledged this glaring shortcoming in his model, promising to publish a companion article dedicated entirely to matters of pathology and biology in the bio-psycho-social paradigm. However, he would die of AIDS related conditions in 1994 before completing or publishing the piece.\textsuperscript{605}

Setting aside for a moment the flaws and shortcomings of Schmidt’s model, his 1984 article is profoundly interesting as an expression of applied social theory. For the bio-psycho-social paradigm presents us with a world where deep, structurally mediated inequities directly yield fatal infectious disease through their work on the human psyche. In this frankly frightening worldview, power is made flesh, as individuals plagued by trenchant sources of symbolic violence experience emotional trauma which in turn causes a breakdown in their somatic organ


\textsuperscript{605} It is impossible to surmise why Schmidt did not write the article in the decade that passed between publication of “The Group-Fantasy Origins” and his death. He may have found his argument too difficult to defend, or alternatively may have changed his position on the question of AIDS etiology. However, the latter possibility is refuted by claims Ian Young makes in \textit{The AIDS Cult} wherein he states that Schmidt remained committed to his group hysteria AIDS paradigm until his death. Ian Young, “The Psychohistorical Origins of AIDS: An Interview with Casper Schmidt” (Provincetown: Asklepios, 1997). Originally published in \textit{The Journal of Psychohistory}, Summer 1984.
systems. Schmidt’s world is thus one where the gaze of the empowered, the hate of the oppressors, and the invisible inequities of the enabled majority act directly on man, yielding crippling immunodeficiency. We know very little of Schmidt’s history or background, for he has been all but forgotten by scholars. However, it is interesting to note that the psychoanalyst penned his works during roughly the same time period that Michel Foucault and Pierre Bourdieu first articulated their microphysics of power and symbolic power theories.

While it is incorrect to argue that any AIDS activists completely endorsed Schmidt’s biopsychosocial model, many of Ellner’s supporters within HEAL supported the psychoanalyst’s larger thesis. New York Native journalist John Lauritsen, for example, granted that psychological effects could indeed influence AIDS, arguing that gay men regularly “experienced terror, owing to the war waged against gay men by the Moral Majority.” Indeed, the HEAL archive is rife with articles claiming that the stress and anxiety placed upon gay men by an uncaring and discriminatory society played a direct role in AIDS, with many authors listing chronic stress amongst the variables impugned in multifactorial AIDS etiological models. However, no

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606 Kalichman, to his credit, cites Schmidt’s early article as predating Duesberg as an expression of dissidence. However, beyond passing citations, he does not seriously consider or incorporate non-Duesbergian activism into the history of AIDS dissidence and denialism. See Kalichman, Denying AIDS, 25-26.
608 Furthermore, Lauritsen would argue that gay men’s use of recreational drugs was itself a product of symbolic violence, with oppression forcing gay men to engage in underground practices, and conservative hatred teaching them that their lives did not matter. Schmidt would also touch upon these topics in the arena of sex, arguing that social shaming caused gay men to remove themselves from groups and engage in a “libidimization of the retaliatory fury with inappropriate sexual excitement.” See John Lauritsen, “The Risk – AIDS Hypothesis,” and Schmidt, “The Group-Fantasy Origin of AIDS,” 34.
609 See, for example, “AIDS is the result of many co-factors in one’s life. Co-factors can include nutrition, multiple infections, self-image, spirituality, will to live, substance abuse, exercise, rest, stress and much more.” Michael Wayne Miles, “Self-Empowerment is the Magic Bullet,” HEAL Quarterly 1, no. 1 (Fall 1989), HEAL-A; A HEAL information packet furthermore argues,
single individual was influenced more by Schmidt’s theories, or did more to modify and apply them to his own AIDS outreach work, than Michael Ellner. The HEAL leader very strongly believed that AIDS resulted in part from mass psychological trauma sustained by members of undesired subgroups within society. In a 2009 interview, for example, he focused on the fatalistic hysteria pulsing through society through the 1980s. “[I]t occurred to me because I was trained in hypnosis, that the power of suggestion and the level of hysteria was enough to make someone ill, possibly kill them, if they really got caught up in it.”

Through the 1980s and 1990s, Ellner would adapt and modify Schmidt’s bio-psycho-social paradigm, incorporating it into a broad, multifactorial etiological AIDS model which impugned a wide array of factors, as we saw in the previous section. While he continued to recognize Schmidt’s emphasis on homophobia, Ellner would follow Michael Callen’s footsteps in arguing more specifically that it was the anxiety wrought through AIDS universal fatality narratives that in fact caused the most harm to PWAs. In one article published in the 1980s, Ellner extolled, “We have been led to believe that HIV is synonymous with AIDS, and that AIDS equals death. The hopelessness these beliefs engender is as damaging to the immune system as any virus.” Ellner would come to espouse a complex theory holding that AIDS resulted from anxiety over universal fatality narratives in addition to hysteria over anti-gay

“...There is much evidence that ARC and AIDS are multifactorial problems and that HIV may simply be a co-factor: other germs, histories of drug abuse, other chronic infections, poor nutrition, environmental poisoning and intense, chronic stress may each be equally important as a cause and equally necessary to treat.” In its list of factors underlying AIDS, the same source includes, “histories of medical and ‘recreational’ drug abuse, chronic infections, chronically poor nutrition, environmental poisoning and intense, chronic stress” HEAL Information Packet, 3, UT-TFRBL, 3.

Ellner would also argue, “[I]t was impossible not to be impressed by the hysteria in the early ‘80s.’ Everywhere I turned, I was getting, ‘Always fatal, always fatal, always fatal.’” Interview with Michael Ellner. Conducted by Matthew Kelly, November 11, 2009.

Michael Ellner, “Don’t be Scared to Death,” HEAL Information Packet, UT-TFRBL.
stigma, which together yielded a “trance state” wherein PWAs uncritically accepted mainstream theories and practices.\textsuperscript{612} He would by the mid-1990s refer to this state as the “AIDS Zone,” which he described as “a virtual community center where everyone either goes to die or is encouraged to die; an ideological framework within which expression of the crisis mentality is not only sanctioned but also actively encouraged.”\textsuperscript{613} For Ellner, the only way to escape the AIDS Zone was to break free of the cultural hypnosis wrought through the “hidden, spontaneous, accidental and unrecognized forms of power of suggestion” which held that “HIV=AIDS=DEATH.”\textsuperscript{614}

As mainstream biomedical professionals coalesced around the HIV etiological model and developed antiretrovirals such as AZT and ddI to respond to it, Ellner intensified his critique of the AIDS Zone. In his opinion, physicians and PWAs alike had become entranced by the HIV=AIDS=DEATH paradigm, and by perpetuating the notion that the only viable response to AIDS was treatment with dangerous antiretrovirals, had themselves contributed to the spread of immune deficiency. One 1990 HEAL article provocatively titled “Psychological Genocide: the Push for AIDS Testing” fiercely decried mainstream calls for individuals to consent to HIV blood tests by invoking language remarkably similar to Schmidt’s. “The framing of AIDS as

\textsuperscript{612} Students of the history of medicine will no doubt identify shades of Mesmerism in Ellner’s theories, and indeed hypnotherapy traces its origins to late 18\textsuperscript{th} and early 19\textsuperscript{th} Century German physician Franz Mesmer’s belief system. In at least one instance, HEAL literature directly invokes Mesmer. See Tom DiFerdinando, “Psychosocial Tension and the Lure of the AIDS Zone,” Presented at First International Meeting of Integral Psychosomatic Medicine, Sao Paolo, Brazil. May 3, 2006. HEAL-A.

\textsuperscript{613} DiFerdinando, “Psychosocial Tension and the Lure of the AIDS Zone,” 4,

\textsuperscript{614} Ellner would continue, “I believe that anytime a person accepts information (regardless of the source) without evaluating it, that person is open to cultural self-hypnosis and all the associated hypnobehaviors (trance logic, positive and negative hallucinations, etc.)” Michael Ellner, “Cultural Hypnosis’ and Questioning the HI-Virus.” \textit{HEAL Quarterly} 1, no.3. (1991), Reprinted for ACT UP’s National People of Color AIDS Activist Conference, March 24, 1991, HEAL-A; Many later pieces of HEAL literature prominently featured bolded, crossed out “HIV=AIDS=DEATH” logos.
universally fatal, and HIV=AIDS,” Ellner argued, “is like a shaman bone pointing and causing death.” 615 Through the 1990s, Ellner and his supporters continued to fiercely condemn biomedicine’s killer virus model and the antiretrovirals it wrought, arguing that the PWA community was “being terrorized by the HIV dogma,” itself an expression of biomedical tyranny. In his view, all of society had become entranced into accepting the notion that PWAs were helpless victims in need of pharmacological intervention; by accepting this fatalistic worldview, they surrendered power to a dehumanizing medical system. Consider, for example, an article Ellner penned in 2000 expanding the borders and contours of the AIDS Zone:

“If you’re HIV+ your part is to get sick and die; if you are a doctor your role is to test for an antibody, make healthy people sick and sick people die, and then blame a virus; if you’re a gay AIDS activist your role is to insure that unproven treatments get into everyone’s body and that everyone wear a condom as if everyone’s at risk; if you’re an AIDS organization your role is to deliver HIV+’s to the pharmaceutical ovens and silence anyone who questions the insanity; and if you’re not in any of these groups your role is to wear a red ribbon, a latex condom and act like you care. AIDS works because everyone has something to do. It all serves to keep us all from looking at what’s truly going on in the world. The rampant death and subsequent social cleansing artificially absolves everyone of the repressed tension generated by the preexisting social conditions.” 617

616 Tom DiFerdinando, “Dirty Words: The AIDS Fraud in Context,” HEAL Basic Information Packet, no date, HEAL-A.
Thus, in the most radical expansion of the interdependent holistic health model, biomedicine itself represents a form of tyranny blinding individuals to the deep, structural origins of disease. For Ellner, by giving everyone a scripted role, the biomedical response to AIDS forestalled their engagement with the world while creating the impression that they were making progress against the disease. Medicine’s magic bullets thus served as a rough equivalent to Marx’s famous “opium of the people,” palliating their pain while robbing them of the incentive to organize for broad structural change.

This outwardly oppositional stance, complete with allegations of genocide on the part of physicians, incontrovertibly alienated HEAL from the larger PWA community. The same group that began in the 1980s by welcoming diverse therapeutic responses to AIDS had, by the mid-1990s, completely rejected narrow therapeutic efforts. In time, group leaders would not only challenge biomedical interventions, but harshly judge PWAs who pursued them. Such was the case in a volume penned by HEAL Executive Board Member Andrew Cort in the early 1990s, wherein he wrote that “personal salvation by itself is a fantasy masquerading as an accomplishment.” In Cort’s view, by failing to acknowledge the broadly holistic underpinnings of AIDS and instead buying into pharma’s toxic treatments, PWAs had squandered their opportunity for meaningful, life and world changing empowerment.618 Thus, in HEAL’s radicalization of the holistic health paradigm, we find the group’s ultimate rejection of the

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618 Cort continues. “When health care is concerned only with combating disease and symptoms, it allows us to engage in the dangerous illusion that we can keep doing everything wrong (to ourselves, to each other, to the planet) and that we will somehow ‘get away with it.’ As long as scientists find a cure for heart disease, we can keep on eating badly. As long as scientists find a cure for cancer, we can continue to pollute the environment.” Andrew Cort, *Our Healing Birthright: Taking Responsibility for Ourselves and Our Planet* (Inner Traditions, 1991): xiv. This text received a favorable review in an undated *HEAL Quarterly* article. HEAL-A.
borderland health model, with group leaders critiquing PWAs *themselves* for adopting mainstream therapeutic modalities.

And so we arrive at the ultimate irony of HEAL’s mid-1990s era embrace of holistic interdependency. While individuals such as Michael Ellner sought to underscore broad, structural sources of violence, they would ultimately express their activism in baldly reductive, individualistic terms. Within HEAL columns, for example, it is the PWA who incurs a personal moral obligation to challenge larger systems of structural violence by rejecting mainstream biomedical nostrums. As we saw above, HEAL activists in fact faulted those who failed to do so, accusing them of shirking a responsibility to engage their lives and their disease. Thus, what began as a model focused upon fundamental inequities, structural violence and symbolic violence devolved into a harshly critical assessment of PWAs’ willingness to stand up to these entrenched systems of inequity and violence. Interestingly HEAL’s story in some ways echoes the history of the social epidemiology and social medicine movements of the early-to-mid 20th Centuries. For they were also defined by efforts to identify the fundamental social correlates of health and disease, and by the late 20th Century they too had become reduced to initiatives focused upon modulating individual risk behaviors. It is ironic indeed that HEAL’s embrace of a radically interdependent AIDS etiology yielded a moralistic activist campaign that, like contemporary biomedicine, focuses so heavily upon individuals’ obligations to pursue healthy lives. These thematic overlaps further suggest that the orthodox and the unorthodox are not nearly as dissimilar as our outmoded fringe/mainstream metaphor would have us believe.

By the mid-to-late 1990s, with the group’s core gay male membership base abandoning HEAL, Ellner and his colleagues pursued an increasingly radicalized and ostracizing dissident
activism. Interestingly, although the period would mark the decline of the New York group’s membership, it also saw the consolidation of HEAL’s influence in the nascent AIDS dissidence movement. By the mid-1990s, as the Internet facilitated grassroots organization across large distances, a number of independent and autonomous grassroots HEAL chapters had taken root in Arizona, California, Florida, Michigan, Minnesota, New Hampshire, Oregon, Vermont, and Washington, as well as in Argentina, Australia, Canada, England, and Mexico. In a 2009 interview, Ellner claimed that at one point approximately 23 autonomous HEAL chapters were in operation throughout the world, making HEAL an early hub of the dissident movement. Perhaps the most successful splinter group was HEAL Los Angeles, formed in 1995 by Christine Maggiore, who would go on to play a significant role in the US AIDS dissident movement.

HEAL’s New York activism also persisted, even as the group shrank to include little more than Ellner, Buianouckas and a handful of their supporters. Through the late 1990s, HEAL aired its views on an international stage, with Ellner penning articles in the UK’s dissident Continuum

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619 It is important to note that Ellner did not necessarily welcome the dissident label affixed to HEAL’s later work. Describing the group’s efforts to define their movement, Ellner recalled, “[W]e were looking at different words and we were thinking of ‘rethinkers.’ We were thinking of ‘critics.’ We were thinking of ‘analysts.’ I’ve always been one who doesn’t like labels, but if you want to call me a dissident, I’d much prefer that to being called a denialist, which is an ugly, unfair term.” Interview with Michael Ellner, conducted by Matthew Kelly. November 11, 2009.

620 For mention of HEAL chapters in Arizona, Australia, Argentina, Canada, Detroit, England, Minnesota and New Hampshire, see Christine Maggiore, What if Everything You Thought You Knew about AIDS was Wrong? 4th Revised Edition (Studio City, CA: American Foundation for AIDS Alternatives, 2000); for HEAL chapters in Florida and Oregon, see “Re. Survey,” email from chrism@cogent.net to cory@direct.ca. October 1998. HEAL-A; for the Seattle group, see “HEAL Seattle Group Now Forming,” HEAL/Seattle 2, no. 1 (Spring 1995), HEAL-A; for the New Hampshire group, see “Notice from Dr. M. Dennis Paul, President, HEAL of New Hampshire.” April 19, 1995, HEAL-A; for the Vermont chapter, see PWAC Newsline 37 (October 1988).
Magazine, and for a period of time it hosted its own public access cable television show in Manhattan.

By the early 2000s, HEAL’s activism had all but ceased. Christine Maggiore died of AIDS related conditions in 2008, and though Ellner would continue to espouse contrarian perspectives beyond 2010, the group as a functional unit atrophied. By this point, the dissident movement had become firmly associated with Peter Duesberg, who published numerous articles and volumes throughout the 1990s and early 2000s, several of which HEAL members cited in the group’s literature. Given Duesberg’s prominence and his resultant ability to marshal other renegade scientists to his cause, his work would soon become synonymous with the AIDS dissident or denialist movement. And yet, as we have seen, the modern dissidence movement also traces its origins to the grassroots activism of groups such as HEAL, who came to embrace openly unorthodox positions as a result of a radicalization of holistic health principles.

Interestingly, while Ellner would through the 1990s frequently invoke Duesberg’s contributions to dissident discourse, by the late 1990s and early 2000s, the HEAL leader began to express concern with the degree to which dissidence had transformed into an internal battle waged within the borders of biomedicine. For, unlike HEAL, Duesberg and his colleagues did not seek to supplant all of biomedicine with a radically holistic health paradigm, but rather to

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622 One advertisement for the “HEAL this Week” television program noted that it aired every Friday on Channel 17 of Manhattan/Paragon Cable. It also describes HEAL as “the only major AIDS organization not bought off by pharmaceutical, corporate or government interests.” HEAL-A.
underscore AIDS researchers’ failures to satisfy biomedicine’s own standards. This divergence troubled the longtime HEAL president, who in 2009 decried,

“I think that a lot of the people involved in the dissident movement now have a certain level of integrity issues. I think they’re invested in maintaining biotechnology, maintaining molecular biology and just making HIV, AIDS an isolated situation. It’s not isolated. There [are] problems with that whole branch of science and that ties into cancer research as well. They’re all interconnected.”

For Ellner, the transformation of dissidence from an emotional problem into an academic one was deeply disturbing. He longed for an AIDS dissidence defined not by the language and tools of biomedicine, but rather by a radically contrarian holistic health model which challenged Western biomedicine writ large. And yet by 2010, that dissidence had become a thing of the past, its support eroded not only by advances in mainstream biomedicine which made AIDS largely treatable within the developed world, but by the redefinition of dissidence itself as an expression of Duesbergian denialism.

Conclusion: Remembering HEAL

As this analysis underscores, HEAL was a fascinating, complex and controversial group whose organizing goals and principles changed over the course of a changing epidemic. Respected and lauded as a member of the larger AIDS service community through the 1980s, by the mid-1990s it had become isolated and radicalized, replacing a complementary therapeutic focus with a divisive and contrarian etiological philosophy. This turn was not, as some scholars have suggested, simply a result of the group’s infection with Peter Duesberg’s theories. Instead, Duesberg would spend a great deal of time, for example, arguing that HIV failed to satisfy Koch’s postulates. See Peter Duesberg, “HIV is Not the Cause of AIDS,” Science 241 (July 1988): 514-517.

Interview with Michael Ellner, conducted by Matthew Kelly, November 2, 2009.
HEAL’s dissidence stemmed at least in part from a radicalization of the principles of multifactoriality and interdependency which underlie the holistic health model. Historians of health and medicine would do well to heed HEAL’s history, for it demonstrates the complex ways in which alternative health movements – and more specifically holistic health movements – become radicalized in the face of controversial, incurable, poorly understood diseases.

Nothing about HEAL’s history is straightforward, and readers cannot be faulted for experiencing a certain exasperation with the principles Ellner and his compatriots endorsed through the 1990s and early 2000s. For those accustomed to neat and ordered disease paradigms, or etiological and pathological models which observe internal consistency, HEAL’s activism is no doubt frustrating. The same individuals who impugned gay male promiscuity as a primary cause of AIDS also blamed the medical community’s prescription of AZT, while simultaneously arguing that a broad and undefined anxiety bubbling within the gay community as a result of homophobia and AIDS fatalism somehow underlie the condition. And yet, where some find only confusion and internal inconsistency, others will find a phenomenally rich activist tradition that witnessed a profound transformation as its members pursued an increasingly radicalized and oppositional stance toward mainstream biomedicine. It is my contention that by remembering forgotten grassroots activist groups such as HEAL, we stand to learn a great deal about not only unorthodox health movements, but orthodox health movements as well. For, as this analysis suggests, these grassroots groups oftentimes reflect principles and philosophies which reverberate throughout the mainstream.
Conclusion
Listening to and Learning from the Sounds of Furious Living

“For causes less sublime they fight;
Each breath becomes a victory.
Although the next they faintly flee
Those bloodless battlefields of white,
Leaving their bodies on the sheet
Like standards fallen in retreat.

For many battles won may be
But lost the war in their despite;
Ends solemn efforts do requite
Nor fame their simple bravery.

No laurel makes their temples bright,
None honor them on bended knee –
They lived and die in infamy,
Alone and solaced of the night.”

-Bob Carver, Jr. (1986)

Throughout this volume, I have endeavored to shed light on hitherto unexamined facets of PWA activism, focusing specifically on the initiatives undertaken by two of New York City’s earliest grassroots AIDS organizations – the People with AIDS Coalition (PWAC) and Health Education AIDS Liaison (HEAL). As I have argued, by appending to the historical register the contributions made by these organizations’ intrepid members, we arrive at a far more nuanced representation of the history of AIDS activism. The picture that emerges not only adds to our scholarly understanding of the AIDS epidemic – it in fact challenges broad assumptions regarding patient responsibility and empowerment in the domain of health and disease. Indeed, our descent into the subaltern to unearth so-called “fringe” grassroots activism ultimately

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625 Bob Carver, Jr.’s poem “A New Song in Plague Time” appeared in a 1986 volume entitled a hundred LEGENDS, a collection of art, photographs, poetry, prose, music and other media created by 127 people with AIDS. The volume was copublished by Northern Lights Alternatives, the creators of the AIDS Mastery Workshop, whose work we explored in Chapters 4 and 5.
exposes the hidden ways we as a modern, technologized society respond to disease – and, perhaps just as importantly, how we marginalize, radicalize, and ignore these same responses in our historical scholarship. As such, *The Sounds of Furious Living* offers lessons and admonishments both for the healers we entrust with keeping us well and the scholars we task with studying the history of healing.

In this concluding chapter, I undertake a brief distillation of these lessons, striving to articulate concrete ways my analysis may inform the practice of both healers and historians of healing. In the first and most substantial component of the chapter, I explore the volume’s challenge to historical scholarship investigating alternative healing systems. Positing my analytical approach as an important contribution to social historical research conducted “from below,” I urge historians of health and medicine to take from it a recognition of the diverse ways individuals facing disease demand and command power. In the second component of the chapter, I briefly consider how this analysis may directly inform the practice of public health and medicine, arguing that many of the same lessons articulated in the first section apply equally well to those we entrust with preventing and treating illness. I close by reflecting more broadly upon how this volume may inform society’s response to the lay public’s engagement with topics transcending healthcare and medicine – including, for example, matters of importance to the practice of science, politics, history and numerous other domains.

**The Sounds of Furious Living – Lessons for the Practice of Historical Scholarship**

As I have argued, this analysis significantly challenges and expands upon our understanding of the history of AIDS activism by appending to historical scholarship the unsung stories of everyday acts of resistance effected at the level of individuals’ bodies. As important as this may be, the lessons it offers in fact transcend AIDS scholarship, as they encourage historians
to more closely interrogate their framing of the sick role itself, particularly as it pertains to patient engagement with unorthodox healing modalities. In this regard, my project contributes to a long history of historiographic critique aimed at refining the analytical lenses through which scholars refract the history of health and medicine. I present its methodology as an important extension of an historical turn David Rosner and Susan Reverby famously advocated in their 1979 volume *Health Care in America: Essays in Social History*, wherein they wrote of the pressing need to move historical practice away from celebratory chronicles of the accomplishments of ennobled physicians. In their new social history of public health, Rosner and Reverby transformed the patient – that humble nonentity who had for so long served as the object of medicine – into the rightful subject of historical analysis.\(^{626}\) Several years later, Roy Porter made his own contribution to this historiographic discourse, advocating a “history from below” which prioritized the perspectives of patients over that of biomedical experts.\(^{627}\)

At roughly the same time Rosner, Reverby, Porter and their colleagues strove to shine the light of historical enquiry on individuals prior literature had overlooked and neglected, a second group of scholars tasked themselves with writing histories of health movements academic historians had systematically marginalized.\(^{628}\) Thus, beginning in the mid 20\(^{th}\) Century and continuing through to the present day, we find the proliferation of historical volumes looking anew at healing systems as wide ranging as homeopathy, hydropathy, chiropractic medicine and


\(^{627}\) Porter, “The Patient's View.”

\(^{628}\) As Roberta Bivins has argued, “At least until the advent of social history, histories of alternative medicines also struggled to overcome the frequent conflation of these practices with ‘quackery’ – a conflation profoundly influenced by the dismissive hostility of established medicine to systems that were simultaneously cosmologically heretical and economically competitive.” See Roberta Bivins, “Histories of Heterodoxy,” in *The Oxford Handbook of the History of Medicine*, ed. Mark Jackson (Oxford: Oxford University Press, 2011).
Thomsonian Medicine. Where Porter advocated a history from below, we might say these historians promoted histories from “the fringe.” For these authors, like the social historians following in the footsteps of Rosner, Reverby and Porter, endeavored to hone an historical craft that replaced laudatory hagiographies of biomedical leaders with more nuanced analyses of the disempowered, forgotten and marginalized.

And yet, despite these clear similarities, the historical literature exploring alternative and irregular healing systems has in many cases failed to embrace social history’s prioritization of the perspective of individual patients. As I argued in Chapter 1, even those histories of subaltern health movements written in the latter half of the 20th Century frequently remain beholden to institutional and professional taxonomies developed by the founders and leaders of those healing systems. Thus, the result of historians’ efforts is a scholarly tradition that, while seeking to capture the experience of the forgotten, merely substitutes one group of professionals for another – with scholars crafting bounded histories of homeopathy, hydropathy, chiropractic medicine and so forth. By organizing their analyses around professional and disciplinary sects, these well intended authors in fact blind themselves to the ways in which individuals living with and dying from disease defied such neat and ordered sectarian divisions.

With an eye toward redressing this pervasive historiographic bias, I have advocated the appropriation of a borderland construct for the crafting of social histories of health and disease. In this model, historians conceive of patients as individuals capable – within the limits of certain important constraints – of locating themselves within and between multiple lay and professional systems of healing, existing in the nebulous borderlands formed between bounded medical sects. When faced with disease – be it acute, chronic, infectious, non-infectious or of unknown length, duration or origin – individuals within these borderlands selectively adopt etiological models and
therapeutic modalities from each system, generating hybrid practices whose unique formulations defy rigid classification. What’s more, we recognize that within this complex and tumultuous frontier of healing, patients remain capable of moving between systems, borrowing from and experimenting with different tenets, theories and therapies as they see fit. This conceptual model is in fact consistent with evidence compiled by David Eisenberg, Patricia Barnes and the Institute of Medicine, all of whom argue that individuals frequently borrow from both orthodox and unorthodox healing systems, creating their own healing amalgams.\textsuperscript{629} No one healing system thus holds complete dominion over those individuals who at any given moment endorse or adopt its principles – no walls immure, no laws define and no citizenship delineates. To creatively appropriate a term Steven Epstein famously utilizes in his explication of AIDS activism, the borderland model ultimately demonstrates the preponderance of acts of so-called “impure” healing – whereby individuals selectively appropriate tenets and practices from both orthodox and unorthodox health systems.\textsuperscript{630}

As this analysis has demonstrated, the borderland model does more than underscore the complex hybridizations of healing systems common amongst individuals and communities affected by disease. It in fact helps researchers identify and define expressions of agency effected by members of these same communities. For as we have seen, the ways in which individuals


\textsuperscript{630} As I note earlier, this volume borrows from and builds upon the methodological approach Epstein embraced in his volume \textit{Impure Science}. However, whereas Epstein’s focus remains primarily on PWAs’ engagement with orthodox scientific principles – be it in the form of ACT UP members participating in the construction of orthodox scientific knowledge or Duesberg’s efforts to counter orthodox biomedical knowledge with contrarian arguments borne out of different orthodox biomedical principles – this analysis focuses instead on PWA empowerment through engagement with unorthodox healing sects.
locate themselves in the borderlands of overlapping healing systems – the strategies they employ in experimenting and allying with diverse healing traditions – are themselves important articulations of self-empowerment. Thus, by examining individuals’ engagement with different healing modalities and philosophes, historians of medicine will move one step closer to accomplishing a true social history of health and disease attuned to what Michel Foucault famously termed the “microphysics of power.”

What, then are the specific lessons historians may take from this reconceptualization of patient empowerment? First, by interpreting individuals’ movements within and between healthcare borderlands as expressions of agency, we challenge a prominent bias which assumes that those who embrace the tenets of alternative medicine have been tricked or hoodwinked into doing so. It is indeed difficult to speak of alternative medicine without conjuring images of opportunistic quacks shamelessly preying upon desperately naïve dupes. Students of the history of medicine are well acquainted with these colorful charlatans who lurk in the fringes of society, capitalizing on desperation to peddle their useless wares. And yet histories of unorthodox health movements focused upon the role of the quack are no more histories “from below” than accounts of orthodox medicine focused upon the part played by the physician. In short, missing from evaluations of quackery, deception and gullibility are the perspectives and beliefs of the patients who seek alternative care.

That historians, through their lopsided appropriation of quackery narratives, have blinded themselves to the true perspectives of patients is rendered apparent through a brief consideration

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631 Steven Epstein provides a succinct and informative definition of Foucault’s microphysics of power, describing it as, “the dispersal of fluxes of power throughout all the cracks and crevices of the social system; the omnipresence of resistance at every site; and the propagation of knowledge, practices, meanings, and identities out of the deployment of power.” Epstein, Impure Science, 4.
of two hypothetical scenarios. Suppose, for example, that after an intense and personally meaningful review of treatment options, an individual chooses to visit a homeopath for care. And suppose further that orthodox biomedicine soundly rejects the benefits of that homeopathic treatment – as it does. To call this patient the victim of quackery is to reject her engagement and instead evaluate her behavior based upon the tenets of an orthodox professional healing system (and, more specifically, that healing system’s appraisals of the tenets of a rival unorthodox healing system). Surely this framing of healthcare decision-making contradicts the stated goals of social historical analysis. Let us now contrast this hypothetical patient with a second individual who blindly follows the prescriptions and pronouncements of his orthodox biomedical physician, taking his allotted medications at the assigned times without truly understanding what or how or where or why they work. Even if this individual recovers from his disease, would we rightly say that he was empowered? Or, alternatively, should we consider him naïve – a gullible dupe, of sorts, cajoled into health by an unquestioned biomedical orthodoxy? As this brief exercise demonstrates, it is only when we sit amongst the disempowered that we find just how limiting our conceptions of empowerment are.

While this volume challenges stale representations of quacks and dupes, so too does it dispute the notion that a social history of unorthodox health activism reads as an interminable struggle between marginalized irregular sects and a hegemonic biomedical profession. For through the pursuit of a history from below, we recognize that individual patients – without whom the practice of orthodox and unorthodox medicine would be rendered impossible – in fact intimately weave together different healing sects. Indeed, while it is true that PWA activists such as Michael Callen argued that biomedicine’s systems and methods of knowledge production had become dogmatic and dangerous, even in his most vociferous attacks we identify a palpable
belief in the potential biomedicine carried to contribute meaningfully to treating AIDS. A similar phenomenon presents itself within HEAL, where leaders such as Michael Ellner fiercely condemned biomedicine while, in the same breath, invoking the tools and language of biomedicine to make their case. That Peter Duesberg – the University of California molecular biologist and member of the National Academy of Sciences who vociferously argued that HIV failed to satisfy Koch’s Postulates and other standards of contemporary biomedical practice – generated such fervent admiration amongst HEAL’s unorthodox leaders neatly underscores this phenomenon.

We might say, in short, that even the most impassioned advocates of unorthodox healing waged two simultaneous battles – one against the hegemony of orthodox systems of knowledge production and the other against the hegemony of the unknown itself. The pressing need to stanch the suffering visited upon their communities led patients to creatively engage that which they condemned, all in an effort to glean knowledge amidst tremendous uncertainty. The historical account that emerges from our analysis is admittedly far less neat and ordered than enumerations of professional battles waged in the pages of competing medical journals, or manifest in sensational campaigns fought on the floors of state legislatures. But historians of both regular and irregular medicine would do well to heed its lessons. For we cannot truly capture the history of health or disease without placing ourselves in the shoes of the humble.

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632 This complex expression of self-empowerment was in fact anticipated by Michel Foucault in his enumeration of movements which arise in opposition to the oppression and suppression of peoples. Such movements, he noted, “are an opposition to the effects of power which are linked with knowledge, competence, and qualification: struggles against the privileges of knowledge. But they are also an opposition against secrecy, deformation, and mystifying representations imposed on people.” See Michel Foucault, “The Subject and Power,” Critical Inquiry 8, no. 4 (1982): 777-795. The reader will note that this article was, in fact, published a mere weeks before the CDC used the term “AIDS” for the first time.
patient who betrays precious little concern for the bounded borders and regimented battle lines the leaders of medical sects patrol.

Our exploration of everyday forms of resistance in the era of AIDS furthermore demonstrates that individuals’ engagement with and hybridization of diverse healing systems is motivated by far more than those systems’ formal etiological models or therapeutic modalities. As we saw, many PWAs explored alternative healing systems due to deep frustration with the ways orthodox physicians and health officials framed and discussed AIDS. Michael Callen, for example, railed against the universal fatality narratives he identified in mainstream biomedical AIDS discourse, arguing that such framings of disease were inherently and innately disempowering for PWAs. This belief that language carried with it the potential to empower or disempower individuals in turn motivated entire unorthodox healing approaches – with advocates of Louise Hay and the AIDS Mastery, for example, arguing that psychoemotional stress could itself cause or contribute to AIDS. Even seemingly innocuous issues such as healers’ designation of AIDS as an infectious or chronic disease themselves became contested facets of narrative construction. For the terms communicated messages of hope or desperation, and thus influenced individuals’ migrations within a complex health borderland. Healthcare decision-making, and thus patient empowerment, are therefore the products of a complex calculus whose contributing variables transcend a healing system’s enumerated theories or treatments. Consequently, historians hoping to understand the full range of patient empowerment, particularly as it relates to everyday acts of resistance expressed through individuals’ movement between healing systems, must consider these factors in their analyses.

The histories of the PWAC and HEAL additionally counsel scholars to look anew at patients’ conceptualizations of personal responsibility in the arena of health and disease.
Scholars have long noted that patients express feelings of responsibility and culpability for illness, a phenomenon no doubt rooted in longstanding interpretations of disease as divine punishment for sin. However, in our examination of these two largely forgotten unorthodox health activist groups, we find evidence of a complex reinterpretation of responsibility facilitated by the term’s multiple meanings. When conservative factions within the public argued that gay men with AIDS incurred *moral* responsibility for their disease, many of these men translated this moral responsibility discourse into *causal* responsibility discourse. We saw this, for example, in the proliferation of multifactorial etiological models amongst members of both HEAL and the PWAC, which argued that drug use and unprotected sex with multiple partners had caused AIDS. PWA activists such as Michael Callen in turn engaged in a second transformation of this responsibility narrative, translating causal *etiological* discourse into causal *therapeutic* discourse. Thus, just as PWAs claimed responsibility for causing their illness, so too did they claim a responsibility for effecting its cure.

This complex, two-part translation of responsibility discourse generated a profound sense of empowerment amongst PWAs, who argued that direct, unorthodox engagement with their healthcare could itself bring about healing. It correspondingly minimized the significance of the mainstream biomedical “killer virus” model, which some PWAs viewed as forestalling their reclamation of moral (and thus causal) responsibility for illness. One might in fact argue that in moving between and hybridizing different healing systems, PWAs engaged in a complex, secular act of atonement facilitated by the multiple meanings connoted by the notion of responsibility. As it has long remained common for both the general public and health professionals alike to saddle the sick with moral culpability for their disease, this topic deserves further attention in historical treatments of health and medicine.
I have thus far argued that the borderland model allows historians to identify expressions of empowerment articulated by individuals living with and dying from disease. As illuminating as this exercise has been, we must remain wary of applying the borderland model in a manner that reduces what is in fact a complex microphysics of power. For patients do not act as absolute free agents charting courses through the healthcare borderland. In truth, the paths they take are inescapably influenced by numerous constraining variables which collectively increase or decrease their likelihood of moving away from or toward different healing systems. Socioeconomic status, for example, likely plays a role in facilitating individuals’ abilities to experiment with different healing strategies, as only certain individuals may possess the resources necessary to research and experiment with certain healing systems. Future research may furthermore elucidate the ways in which membership in particular racial or cultural groups facilitates or inhibits individuals’ likelihood of moving between healing systems. The membership of PWAC and HEAL both suggest, for example, that the avenues for empowerment the groups advocated were more easily accessible to gay white men. Historians may

633 That said, this should not be taken to mean that only members of a privileged socioeconomic class embrace unorthodox healing systems. As we saw in Chapter 5, the members of HEAL included many individuals who viewed themselves as less socioeconomically privileged than those in leadership roles within GMHC. Furthermore, the PWAC’s Newsline, a rich resource advocating unorthodox etiological and therapeutic models, was circulated within communities of socioeconomically underprivileged individuals. Copies, for example, made their way to US prisons, which in turn prompted the publication’s editors to create a column featuring the correspondence the group received from prisoners with AIDS.

634 I should note that both HEAL and PWAC made efforts to reach out to members of minority racial groups. Michael Callen, for example, actively sought the perspectives of minorities (both gay and otherwise) to include in the Newsline. And within HEAL, openly gay African American PWA Cliff Goodman led discussion groups in Harlem and published articles seeking to appeal to African American readers. In one of his articles, Goodman proudly identified himself as, “a 32-year-old, Gay man of African descent, born in the southwest Bronx…and raised in North Central Harlem. I am a veteran (peacetime, 1976–1979 U.S. Army – Korea/Germany), a college dropout (Lehman College, Bronx) a Buddhist, a Hypnotist, a member of NA/AA. I’m also poor, HIV+, but sexy and happy!” Interestingly, while Goodman rose to a position of leadership within
furthermore find that, somewhat paradoxically, subgroups within society who have experienced systemic marginalization and disempowerment are, by virtue of underground networks and cultures sustaining everyday forms of resistance amongst their members, better positioned to experiment with diverse healing systems. It is the difficult and exciting job of the historian to interpret and apply the borderland model in a manner that identifies sources of structural constraint while simultaneously articulating avenues for agency and empowerment within these constraints. In that historians have risen to this challenge in the past, ascertaining expressions of individual empowerment in the context of tremendous suffering and oppression, we who seek to examine the history of healthcare and medicine are no doubt capable of the same.635

As we can see, our analysis of the PWAC and HEAL underscores several important lessons historians of health and medicine may apply as they seek a more refined and revealing chronicle of society’s efforts to heal itself. However, hidden beneath these neat and ordered lessons is a far more radical question which may exert profound influence on the way we as historians approach our craft. For throughout this volume, I have identified potent and passionate expressions of self-empowerment. In many cases, these expressions brought PWAs into engagement with diverse healing modalities which contemporary biomedical professionals argued lacked proof of efficacy, and away from healing approaches these same professionals certified as life sustaining. This was the case, for example, amongst PWAs who resisted calls to

HEAL, he experienced resistance even within its fairly open community, at one point writing, “There was some concern from an associate that I should ‘tone down’ the language of this editorial! He felt that it was ‘too emotional’ for you to understand and he had the nerve to ask me will I ‘move it to the back’ (people of color section) of the HEAL newsletter.” Cliff Goodman, “The Fall of the House of AZT: An Afro-Centric View,” Comprehensive Information Packet, 1991, HEAL-A.635

accept prophylactic antibiotics or antiretrovirals well into the 1990s, instead embracing alternative, holistic and contrarian healing systems that lacked clear evidence of efficacy. In our analyses of power, how do we as scholars reconcile expressions of empowerment borne out of individuals’ engagement with their healthcare with the disempowerment which results from their development of preventable disease? In short, what relationship should we recognize between patient empowerment and patient health?

On the surface, the relationship between health and power seems fairly straightforward. Few, for example, would argue with the claim that a society is empowered by virtue of the enactment of policies and practices positively impacting the health of its members. Correspondingly, we grant that a society riddled with preventable death and disease is, in some fundamental way, disempowered. Health, in these formulations, serves as either a prerequisite or proxy for power, and policies which improve the health of the community are viewed as intrinsically empowering. And yet in our analysis of everyday forms of resistance amongst individuals facing AIDS, we find the expression of an altogether different type of power. Here, power is manifest through individuals’ direct engagement with their care – a power borne out of praxis, which itself frequently brings patients into contestation with orthodox norms and practices. Whereas our first formulation assesses power as a function of a definable and measurable outcome – the health status of individuals or communities – the second is more nebulous, arising out of one’s interaction with his health or disease.

The importance of both conceptualizations of power and empowerment are rendered apparent through simple thought experiments of the sort popular within ethical analyses. We might imagine, for example, a society that decrees health by fiat – endorsing policies that coerce, stigmatize and shame individuals with the goal of improving their health status. Even if such a
society achieved maximal health outcomes, drastically decreasing morbidity and mortality rates, few would conceive of it as one that truly empowers its members. Conversely, let us consider a community whose health authorities warn of a coming epidemic of disease, counseling its members to take specific precautionary measures to safeguard their health, but whose members – through a process of genuine engagement and contestation – choose to ignore the authorities. If the entire community is, as a result, decimated by an easily preventable disease, we may understandably ask whether its members were truly empowered in any meaningful sense of the word.

While these hypothetical scenarios may appear contrived or fantastical, they in fact mirror very real contemporary issues in public health practice. It is not uncommon, for example, to find health public campaigns utilizing shame, stigma or blame to inspire individuals into making healthy life choices, with recent authors noting the implementation of such tactics in campaigns targeting tobacco use, obesity, and alcohol consumption amongst other behaviors and conditions causally associated with disease. The types of policies these sources

cite are admittedly a far cry from the totalitarian health regime considered in our hypothetical scenario, but they nonetheless raise similar questions. If we as a society truly value an open and free engagement with health, then to what extent can tactics that emotionally coerce individuals in order to improve their health truly empower them? And what of our second hypothetical scenario – the community whose expression of empowerment leads its members to deny, ignore or resist state efforts to protect them from a coming epidemic? Virtually this same issue arises with great frequency amongst communities of “vaccine deniers,” who vehemently argue that the harms wrought through vaccination outweigh its benefits. If these individuals’ pursuit of a direct engagement with their healthcare leads them to make decisions which systematically endanger themselves through exposure to easily preventable disease, should we consider them empowered?

As these two scenarios suggest, genuine empowerment seems to require a balancing of consequentialist and non-consequentialist reasoning. And yet, in many instances, scholarship tasked with examining public health practice from historical, ethical, or sociological lenses fails to adequately capture this dynamic – with most giving short shrift to the non-consequentialist form of empowerment arising out of engagement. As we saw in Chapter 3, bioethicists have largely ignored expressions of self-empowerment manifest through individuals’ embrace of self-care – testified, for example, in Albert Jonsen’s stinging disparagement of Ivan Illich’s scholarship. Other scholars working both within and outside of the domain of bioethics systematically disempower patients through the uncritical importation of “patient non-compliance” language to describe individuals who, in defying their physicians’ pronouncements, stray beyond the bounded borders of biomedical practice.

What’s more, those sources that do recognize a role for empowerment borne out of active public engagement with matters pertaining to healthcare unfortunately present woefully simplistic or idealistic caricatures of the public. In 2003, for example, the Institute of Medicine (IOM) published a report advocating the reframing of public health in a manner recognizing the critical role lay individuals play in health practice. In its endorsement of a so-called “intersectoral public health system,” the IOM hits all of the right notes in celebrating the benefits of lay engagement in healthcare. “The concept of a public health system,” the Institute wrote, “describes a complex network of individuals and organizations that have the potential to play critical roles in creating the conditions for health. They can act for health individually, but when they work together toward a health goal, they act as a system – a public health system.”

And yet, beyond granting a seat at the health intervention table for non-professional members of communities, the intersectoral model fails to engage in a real discussion of power in the context of public health campaigns. For one, when organizations like the IOM speak of patient engagement, they import an assumption – sometimes stated and other times implied – that engagement is necessary as a means of facilitating the public’s embrace of public health initiatives, and consequently improving health outcomes. Thus, consequentialist reasoning creeps once more into our analysis of power relations, and empowerment is again correlated with health. The value of engagement for its own sake largely escapes consideration.

641 A similar phenomenon presents itself in scholarly critiques of public health campaigns utilizing shame in an effort to improve individual and community health. Many authors, for example, portray these campaigns as ill advised by arguing that they fail to achieve their stated health outcomes. Lacking from most analyses is any real consideration of the benefits of empowering the public as an end in itself. See, for example, Rebecca Puhl. Shame Campaigns: Do They Work?
To speak of power in the context of the public’s relationship with public health and clinical professionals requires that scholars move beyond merely celebrating the public in the abstract, and instead examining the complex ways in which its members engage their disease and their health. The analysis this approach yields is admittedly far messier than neat expositions of synergistic health models. For people do not valuate information according to the same rubric embraced by public health professionals, and instead – as we saw in the context of PWAC and HEAL activism – creatively amalgamate healing paradigms and practices in ways that defy the principles set out by biomedical professionals. The paths they chart in the healthcare borderlands are themselves borne out of complex, historically mediated interests, apprehensions and fears surrounding a wide array of issues. Distrust in the pharmaceutical enterprise, disenchantment with mainstream medicine, antiauthoritarian sentiments arising out of geopolitical events, anti-heroism, anti-dogmatism, and anti-modernism are, for example, just several of the currents which have influenced PWAs’ changing allegiance to different healing practices. In short, if we choose to recognize as empowering individuals’ active engagement in healthcare decision-making, then we must come to terms with the fact that their engagement will be on terms they – and not biomedical leaders – set. Correspondingly, it may very well lead them to challenge, defy and stray from accepted clinical and public health practice.

This reassessment of empowerment in the context of healthcare decision-making not only counsels a reframing of those patients who embrace unorthodox healing systems, but also of those who embrace orthodox biomedicine as well. Earlier, in my repudiation of the widespread scholarly appropriation of quack tropes, I posited two hypothetical scenarios describing circumstances wherein patients pursuing unorthodox health modalities appeared more self-empowered than those pursuing orthodox modalities. As it turns out, research investigating
patient responses to orthodox AIDS treatment regimens provides compelling evidence suggesting that similar scenarios indeed present themselves in real life. In a 1997 study published in the *Journal of General Internal Medicine*, for example, Meredith Smith and colleagues analyzed reasons underlying PWAs’ failure to adhere to treatment regimens utilizing the antiretroviral zidovudine (ZDV), a later designation commonly used to refer to AZT. The authors’ examination of factors influencing patient decision-making paints a rather startling image of an engaged and empowered “non-compliant” group contrasted with a highly impressionable compliant group:

“Among individuals offered ZDV, those accepting it have been shown to view: the drug as being highly beneficial to their health, be highly susceptible to other people’s opinions, and possess great confidence in the ability of ‘powerful others’ to affect health outcomes. In contrast, those declining ZDV have been shown to be: highly internally motivated; concerned with possible disruption of their current lifestyle (e.g., intravenous drug use); fearful of potential ZDV-related side effects or toxicity; resentful of ZDV distribution and pricing policies; and likely to deny having any need for treatment.”

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*Meredith Y. Smith, Bruce D. Rapkin, Anne Morrison, and Sandra Kammerman, “Zidovudine Adherence in Persons with AIDS: The Relation of Patient Beliefs About Medication to Self-Termination of Therapy,”* *Journal of General Internal Medicine* 12, no. 4 (1997): 216–223. Within the quoted passage, the authors cite the following studies:

What, then, are we as scholars to make of this analysis? How should we interpret the power differential evident between the “highly susceptible” individuals who accepted ZDV and the “highly internally motivated” ones who refused it? How do we reconcile this data with the verified benefits of ZDV treatment – particularly following dosage reductions in the early 1990s? By shining our light on the forgotten individuals who, as PWA Bob Carver Jr. wrote, “lived and die in infamy, alone and solaced of the night,” we illuminate a tremendously complex world peopled by both furiously lived lives and tragically premature passings, of empowerment borne of engagement yielding disempowerment borne of death. It shall fall to those of us who claim a part in the study of the history of health and disease to examine these histories conducted from below to understand more fully the workings of power amongst those living with and dying from disease.

The Sounds of Furious Living – Lessons for the Practice of Public Health and Medicine

Throughout this chapter, I have endeavored to enumerate ways in which the study of everyday forms of resistance amongst PWAs may help inform and enrich historical scholarship. And yet readers likely have already surmised that the issues I raise – including, most importantly, my challenge to scholars’ conceptualization of the relationship between power and health – transcend the historical craft. Indeed, I argue that many of the same lessons and questions I have already identified prove equally valuable in informing the practice of medicine and public health. That both healers and historians of healing may jointly benefit from an application of the same lessons may itself point to important synergies and similarities between the practice of medicine and the practice of history. For at the heart of our historical enquiry has

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been an effort to see patients – to recognize and respect the myriad forms of power they command and articulate in the midst of suffering and disease. By refracting the study of health and healing through a social historical lens, we have – in a small way – empowered countless individuals whose contributions to history have remained unrecognized for far too long. We may not have healed them in the same way physicians heal the sick, but by empowering them as historical entities, we have – in a tangible and very real way – changed them for the better.

I contend that the unique ability social history possesses to register the significance of individual patients, to create a deep understanding of their perspectives and practices, and to locate within those practices important expressions of self-empowerment, in fact rivals in significance the many contributions made throughout the mid-to-late 20th Century by biomedical ethics. To be clear, bioethicists have made tremendously important contributions to the reimagining of the doctor/patient relationship and the lionization of patient autonomy which defines contemporary rights-based ethical analysis. However, their tendency to view healing through the eyes of the healer – a practice no doubt influenced by their close professional association with schools of medicine and public health – all too often blinds them to the tremendously complex contestations for power which define the patient role. For this, we must turn to the tools of social history, whose methodological approach is far better attuned to recognizing and analyzing self-empowerment borne out of expressions of self-care.

Let us then ask how our larger social history of everyday acts of resistance amongst PWAs may guide and inform biomedical practice. The topic is admittedly vast and deserving of more probing an analysis than space allows in the final pages of this volume. However,

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643 I should note that although I focus exclusively upon lessons of relevance to orthodox health professionals, these same lessons apply equally to any individual – mainstream or alternative – whose practice is bounded by a set of professional standards, assumptions, values and systems of knowledge production.
broadly stated, I contend that like historians, physicians and public health professionals would benefit tremendously from an appreciation for the ways in which patients migrate between different healing systems and the reasons underlying their migrations. By virtue of the tremendous energy health professionals invest in becoming experts in bounded systems of knowledge, they run a high risk of interpreting lay behavior as expressions of similarly bounded systems of knowledge production. And yet as we saw earlier, just because we recognize the existence of formal schools of biomedicine, homeopathy, naturopathy, chiropractic, herbal medicine, and countless other health practices does not mean that patients responding to disease pledge or ally themselves with any one system. By inquiring into patients’ creative amalgamation of healing systems – asking how and why they pursue their chosen avenues for healing – physicians may come to see and, by extension, understand them more clearly. And by understanding their patients, they will better position themselves to treat them well, in all meanings and senses of the phrase. In the very least, the exercise may encourage physicians to move beyond notions of non-compliance by focusing less on the distance patients stray from mainstream biomedical practice and more on the complex landscape of intersecting theories and practices they choose to explore.

To be fair, over the past thirty-to-forty years, some progress has been made in this arena, particularly in mainstream medicine’s institutional embrace of so-called “complementary medicine.” The complementary health movement resulted from a growing realization on the part of physicians that patients had come to embrace unorthodox healing modalities in surprisingly high numbers. By calling such health modalities complementary, these physicians sought to link them to mainstream practices, thereby suggesting a synergy between different healing systems. However, we must be careful not to construe the mere existence of complementary health
discourse as proof that mainstream medicine sufficiently recognizes, understands, or appreciates the expressions of power articulated by individuals in their migrations within the healthcare borderland. Indeed, the complementary health movement as embraced by mainstream physicians bears much in common with historical efforts by regular physicians to subsume homeopathic and osteopathic practice into mainstream medicine. In both cases, orthodox professionals welcomed irregular health systems into their fold by subjecting those systems to the legitimizing apparatus of mainstream biomedicine (e.g. double blind clinical trials, epidemiological review.) This method of accepting the unorthodox by way of the orthodox is decidedly not the chosen avenue through which many lay individuals hybridize or amalgamate orthodox and unorthodox healing systems. Indeed, as we saw throughout this volume, many individuals embrace unorthodox health systems as a result of deep distrust or disenchantment with orthodox biomedicine. Their complex and contentious motivations for migrating within the healthcare borderland are not only missed by the invocation of a complementary health movement – they are effectively rendered invisible by it.

In addition to shining light on individuals’ migration within and between different healthcare systems, this volume may help physicians understand how their actions and inactions influence this movement. For example, as we saw earlier in this chapter, the narratives health officials adopt in their discussions of disease exert profound influence over individuals’ embrace of orthodox and unorthodox healing systems. Countless PWAs, for example, echoed Michael

644 James Harvey Young, for example, recounts conflicts between early leaders of the National Institute of Health’s Office of Alternative Medicine (later the National Center for Complementary and Alternative Medicine and then the National Center for Complementary and Integrative Medicine) who challenged mainstream efforts to embrace alternative healing modalities by subjecting them to double blind clinical review. See James Harvey Young, “The Development of the Office of Alternative Medicine in the National Institutes of Health, 1991-1996,” Bulletin of the History of Medicine 72, no. 2 (1998): 279-298.
Callen’s ardent condemnation of mainstream universal fatality narratives, invoking these same narratives to explain their support for unorthodox healing philosophies. I contend that neither clinical nor public health officials sufficiently interrogate their narrative framings to consider the effects they have on patient behavior. Far too often, language becomes a tool wielded in the struggle to effect positive health outcomes. Such was the case, for example, amongst mainstream biomedical leaders’ efforts to portray AIDS as universally fatal as an effort to increase funding dollars for AIDS research. Lost in this noble aim was the fact that painting a disease as ineluctably fatal sacrifices those living with it for the benefit of those at risk for developing it. And a people who have lost faith in a health system’s commitment to healing them have no reason to yoke themselves to that healing system, no matter how storied its past or virtuous its intent.

We have also seen that health officials’ proliferation of moral responsibility narratives may, through the translation of these narratives into causal responsibility discourse, engender individuals’ migration within and between healthcare borderlands. If future research demonstrates that this translation of moral culpability narratives also applies in the context of other chronic and infectious conditions, it demands serious consideration by those who organize and implement public health campaigns. For it would mean that health policies which seek to improve health outcomes by blaming, shaming or stigmatizing individuals – a tactic that, as we have seen, has become increasingly popular in the late-20th and early-21st Centuries’ efforts to address “lifestyle” diseases – may in fact engender a wide array of unorthodox lay responses. The systematic disempowerment of individuals through stigmatization discourse, in other words, may lead to the proliferation of everyday acts of resistance which simultaneously empower these individuals while undermining the intent of the inciting public health policies.
This brief application of historical lessons to healthcare practice has focused primarily upon narrowly identifying ways in which an increased appreciation for patient empowerment may inform healthcare professionals’ efforts to treat and prevent disease. However, its true potential to challenge clinical and public health practice transcends these rather uncontroversial recommendations. For just as our examination of everyday acts of resistance amongst PWAs posits difficult-to-answer questions for scholars tasked with studying the social provisioning of healthcare, so too does it raise difficult queries for those who provide that care. If we accept this volume’s claim that individuals express their engagement with their bodies and their health in part through migration within and between healthcare systems in ways that bring them into contestation with orthodox biomedical tenets, then we must ask ourselves whether the legitimate aim of public health and medical practice should be to facilitate this process of engagement or, alternatively, to increase the likelihood that people will embrace orthodox health interventions. Should health professionals endorse policies that facilitate patient engagement and correspondingly increase the likelihood of migration between healing systems, or should they instead pursue those that maximize patient compliance in a manner most likely to improve the health of the population? How do we balance empowerment borne out of engagement against empowerment borne out of improved health outcomes? If we ultimately decide that public health and medicine should remain wedded to improving health outcomes, then who – if anyone – do we vest with the authority to check its broad powers should it unduly constrain or violate individuals’ engagement with their bodies, health and disease?

These questions cut to the core of public health and clinical practice, and are not easily adjudicated through recourse to the same ethical principles scholars typically invoke in our analyses of bioethical and public health controversies. It may be tempting, for example, to strain
this debate through the sieve of the harm-to-others principle – arguing that public health professionals ought to empower individuals’ engagement in their health only insofar as that engagement does not harm others. However, this neat conclusion largely begs the question: What does it truly mean for a policy to help or harm others? The question in turn invites even more questions, all of which present no neat or simple answers. What are the metrics by which we evaluate the social goods public health and medicine are tasked with rendering? By what standards of ethical accounting do we compute the goods and harms wrought through policies that maximize health at the expense of true engagement, or vice versa? Do we help others by empowering them to become autonomous agents directing their care, or alternatively by keeping them healthy? Is the answer to be found in a balance between the two?

I do not purport to have developed concrete answers to all of these questions. However, I suspect that in applying the lens of social history to public health and medical practice, we shall come to recognize the need for health policies to not only respect, but facilitate, individuals’ active engagement with their healthcare. This will require the development of a new culture for thinking of and speaking of patient empowerment – one that may occasionally yield positions or principles that chafe against the consequentialist philosophy which has long driven public health – and, the bioethics revolution notwithstanding, clinical – practice. For in celebrating the form of self-empowerment which arises out of individuals’ migration within a complex borderland system, we will in effect move away from a clinical and public health ethic premised upon informed consent models, and toward one that values and promotes informed engagement. How we maximize not only health but empowerment in the context of a truly engaged public is an issue that demands careful consideration by those we entrust with healing society in addition to the scholars we entrust with scrutinizing our healers.
The Promise and Peril of Furiously Lived Lives: Beyond Healing

This chapter has focused exclusively upon questions of lay empowerment in the context of healthcare decision-making, counseling scholars and health professionals alike to develop a more refined approach for balancing expressions of empowerment deriving from individuals’ engagement with their health against those that derives from improved individual and public health outcomes. However, as fruitful and revealing as this analysis has been, it merely scratches the surface of a much larger issue, the reach of which extends far beyond matters of health and disease. For just as individuals command and express empowerment through their engagement with unorthodox healing systems, so too do they express shifting allegiances to unorthodox perspectives in disciplines as wide ranging as science, politics, history and journalism, among countless others. People, in short, engage with their world on a variety of levels and in a multiplicity of ways – and yet their very engagement at times generates considerable consternation on the part of those entrusted by society with ensuring its health, safety or well-being. Examples of this phenomenon abound in modern society, and indeed have provoked significant debate in recent years. We might consider, for example, the case of the lay individual who ardently and vehemently expresses resistance to the notion that human activity has played a role in the warming of the planet.

What are we to make of this level of engagement and self-empowerment? The easy response to the question, of course, is to argue that the aforementioned individuals is not truly informed in her engagement with scientific issues such as Global Warming. We may argue, for example, that she has been manipulated into rejecting mainstream scientists’ pronouncements by political and industrial forces intent on maintaining the status quo. However, we should not be so quick to undo the hypothetical scenario simply because it asks too hard a question. For if the
stated individual fervidly disputes our notion that she has been deceived or manipulated, we are left with an uncomfortable query: To what extent may individuals legitimately derive power through the rejection of codified systems of knowledge production society relies upon for the generation of truth – and for the implementation of social policies premised upon that truth?

This issue, while inspired by hypothetical scenario, in fact cuts to the core of very real dilemmas facing society, particularly as public distrust and disenchantment with the scientific process appears to be at an all time high. One recent Pew Research Poll found marked discord between lay and professional perspectives on a wide variety of scientific matters. Take, for instance, beliefs concerning human contributions to Global Warming. Whereas 87% of scientists argued that humans contribute to global climate changes, only 50% of the lay public concurred. Similarly, although 88% of scientists argued that genetically modified foods are safe for human consumption, a mere 37% of the public agreed. Even in the case of a topic many treat as largely settled – the theory that humans descended from apes – we find a significant delta between scientific support for the principle (98%) in comparison to lay support (68%). Collectively, these data point to a fairly remarkable division between expert and lay opinion. If we assume for a moment that many or most of the individuals who disagreed with these scientific principles did so out of a sense of engagement or conviction, and assume furthermore that important social policies turn upon the acceptance of these scientific positions (a circumstance plainly true in the case of Global Warming), then we are left once more with the same dilemmas we encountered in our analysis of everyday expressions of health activism. Namely, to what extent would we say that the dissenters are empowered?

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For some authors, these data point to a larger and deeper problem – a sign that society has entered a period defined by a celebration or glorification of obliviousness. A 2015 article in the *Washington Post*, for example, argued, “America risks drifting into a new Age of Ignorance. Even as science makes unparalleled advances in genomics to oceanography, science deniers are on the march – and they’re winning hearts and minds more successfully than the academic experts whose work they deride and undermine.” The phenomenon may, in fact, transcend matters of scientific truth and touch upon the pursuit of verifiable truths of all varieties. Within the past year alone, we have witnessed a contentious debate regarding the proliferation of sensationalized news stories disseminated primarily on social media outlets designed to allow the lay public to directly engage their world. How do we reconcile the individual who actively engages his world through the dissemination of these sensationalized stories? What’s more, how do we compare him to the individual who absents himself entirely from any dialogue or discourse surrounding world events, but who acquiesces to those interpretations of events consistent with orthodox systems of knowledge production and verification? Which of the two is more engaged, informed, or empowered?

Much work remains to be done before we may answer the many questions this analysis raises. For one, historians must commit ourselves to further examining the avenues through which lay individuals seek and attain empowerment – both in the case of healthcare decision-making and otherwise. The same level of analysis rendered in this examination of PWA activism is necessary for the other expressions of contrarian resistance reviewed in this closing segment. In our analyses, we must seek to elucidate the different variables which conspire to influence

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individuals’ migration between orthodox and unorthodox positions, paying particular attention to the roles played by historically mediated distrust and disenchantment with empowered orthodoxies. It is only by employing the tools of social historical analysis in this way that we may understand how power operates amongst communities embracing contrarian and unorthodox perspectives. And it is only with this understanding that we may hope to one day develop a morality of empowerment capable of addressing the difficult questions our society today faces.
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