

## Introduction

---

Looking back on his medical practice during the mid-1980s – a time when the acronym AIDS was widely known but little understood – the dermatologist Alvin E. Friedman-Kien recalled that at the New York Hospital where he worked, not all doctors would see the immunocompromised patients. Selective physicians who turned these cases away knew that Friedman-Kien had a different attitude. These doctors would “walk [the patients] over to my office,” he remembers, “and say, ‘This doctor will take care of you. I don’t see this disease.’”<sup>1</sup> Their resistance toward “seeing the disease” may have been the result of widespread prejudice, anxiety about how this new syndrome threatened medical authority or simply fear of infection. Even though AIDS was certainly not invisible, it could be left unseen.

Friedman-Kien’s account reminds us how difficult it was to see, recognize and diagnose AIDS more than 30 years ago. Very few doctors – most by circumstance rather than intent – had cared for patients affected by the emerging epidemic. The medical profession struggled to recognize the blurred pattern of this new disease and showed hesitation toward its patients. A lack of biomedical information, speculation about the syndrome’s association with sexual identities and bodily practices, and public response structured by a toxic combination of fear, bigotry and blame all obstructed AIDS from being seen within the confines of a straightforward clinic consultation.

Today, it is once again difficult to see AIDS. In the West, full-blown cases are rare. Even if they appear, clinicians are encouraged not to speak of AIDS. They refer to consequences from an unmanaged Human Immunodeficiency Virus (HIV) infection, perhaps even call it *HIV disease*. Three centuries of activism, reforming public and global healthcare and tireless advocacy against stigma, rejection and isolation have all shifted the image of the AIDS epidemic away from many of its original

<sup>1</sup> Ronald Bayer and Gerald M. Oppenheimer, *AIDS Doctors: Voices from the Epidemic* (Oxford: Oxford University Press, 2000), 102.

## 2 Introduction

associations and anxieties. The introduction of HAART (highly active anti-retroviral treatment) in 1995 shifted the experience of AIDS for patients and turned the threat of impending death into a manageable infection with HIV; that is, if life-saving medication is accessible.<sup>2</sup> Our contemporary difficulty in seeing AIDS is very different in kind to that of the 1980s. This book asks how the challenges of seeing the epidemic have changed, and what we can learn about the normalization of a disease from the perspective of its visible and invisible histories.

AIDS is not a disease. It is not a condition composed of an exclusive set of unique symptoms. Rather it is understood as an underlying disposition, an immunodeficiency, that lays the body vulnerable to a series of opportunistic infections that appear in unusually severe and lethal patterns. The syndrome is caused by an HIV infection, as was hypothesized in 1983 and confirmed in 1986. HIV is best described as a retrovirus that slowly depletes the body's defenses against common and normally trivial infections like herpes. In the host, HIV remains mostly invisible within human cells, leading to an asymptomatic stage that is often called clinical latency. An unrecognized and untreated HIV infection will – after eight years, on average, though there is wide variation – leave the patient vulnerable to critical illness. Only then do the emerging patterns of disease suggestive of the underlying syndrome enable a doctor to “see the disease.”

To this end, a small, medically trained minority repurposed one of the nineteenth century’s most powerful empirical instruments of medical classification to assert the profession’s authority. Their collaborative clinical response to the crisis was to create an atlas and reinvent this historical pinnacle of medical taxonomy in the context of an unknown disease. They adapted traditions of medical visualization, including clinical photography to portray AIDS as a disease, geographical mapping of AIDS as epidemic and modeling viruses to picture the infection. The AIDS atlas, first published in 1986, was set up to map out the contours of the syndrome. It promised to establish order where there was little.

This is a book about seeing AIDS in the atlas: It is a book about the challenges of mapping AIDS as a disease through photographs, seeing the syndrome as an epidemic in maps and its identification with the HIV infection in models of the pathogen. AIDS may have been one of the most formidable challenges in history to the medical perspective of

<sup>2</sup> HAART is a combination therapy whose last element, the protease inhibitor Saquinavir, was approved by the Food and Drug Administration (FDA) in 1995. HAART succeeded in suppressing the replication of the virus, leading to a dramatic and at times indefinite extension of the clinical latency of HIV.

## Introduction

3

definition and diagnosis, as it seemed so deeply entrenched in social, cultural and political conflict. But endeavors to see AIDS as an object of medical knowledge were informed by long-standing routines of visualization in medicine. These practices and procedures were mobilized in the atlas to continuously separate signs of medical significance from the manifold ways of seeing AIDS as anything other than a medical subject.

What does it mean to see a disease? Scholarship in the history of medicine has developed two modes to address the visibility of diseases, epidemics and infections. The first approach considers seeing disease as a metaphor for representation. Seeing neglected diseases, previously unknown conditions and symptoms whose definition lacked specificity, promises recognition of patients' suffering. "Making visible" is an ethical process of accepting the social structure of sickle-cell anemia, for example, seeing lung cancer as an outcome of smoking, recognizing the mental and physical strain imposed by office buildings or illuminating the backgrounds of rare genetic conditions.<sup>3</sup> AIDS, with its venerable history of stigmatization, neglect, identity politics and social struggle is to historians a recurrent case to demonstrate how deeply seeing enabled the syndrome's representation as a political, social and cultural subject.<sup>4</sup>

A second approach to seeing disease is associated with visualization of a disease as an object of medical knowledge. Visualization here should be understood as the pursuit to identify a disease's cause, classify its appearance and refine its scientific definition. Focus falls on the technical and scientific challenges of visualization, concern for how pictures contributed historically to knowing a disease medically, how pictures have enabled identification and diagnosis and how they have structured biomedical practices.<sup>5</sup> These questions can never be fully disconnected from

<sup>3</sup> Keith Wailoo, *Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health* (Chapel Hill: University of North Carolina Press, 2014); Allan M. Brandt, *The Cigarette Century: The Rise, Fall, and Deadly Persistence of the Product That Defined America* (New York: Basic Books, 2007); Michelle Murphy, *Sick Building Syndrome and the Problem of Uncertainty: Environmental Politics, Technoscience, and Women Workers* (Durham, NC: Duke University Press, 2006); Diane B. Paul and Jeffrey P. Brosco, *The PKU Paradox: A Short History of a Genetic Disease* (Baltimore: Johns Hopkins University Press, 2013).

<sup>4</sup> See, e.g., Sander L. Gilman, *Disease and Representation: Images of Illness from Madness to AIDS* (Ithaca, NY: Cornell University Press, 1988); Roger Cooter and Claudia Stein, "Visual Imagery and Epidemics in the Twentieth Century," in *Imagining Illness: Public Health and Visual Culture*, ed. David Harley Serlin (Minneapolis: University of Minnesota Press, 2010), 169–92; Tara Burk, "Radical Distribution: AIDS Cultural Activism in New York City, 1986–1992," *Space and Culture* 18, no. 4 (2015), 436–49, doi:10.1177/1206331215616095.

<sup>5</sup> The obvious case here is, of course, the history of mental illnesses and their reflection in visualization practices. See, e.g., Georges Didi-Huberman, *Invention of Hysteria: Charcot and the Photographic Iconography of the Salpêtrière* (Cambridge, MA: MIT Press, 2003).

#### 4 Introduction

the politics of a disease's representation, but coaxing this separation is useful to emphasize different modes in the historical analysis of disease visualizations. The first – the metaphorical approach to visualization – tends to presuppose an ethical imperative of radical and indefinite illumination, while the second approach is one of selection, focusing and curation. As I show here, the challenge of seeing AIDS as a disease is inevitably a process structured by principles of stringency, decisiveness and accuracy.

Such a medical visualization was encouraged, organized and subsequently archived in the AIDS atlas. It rests on three modes of seeing and thinking through its subject: clinical photographs, geographical disease maps and models of viruses. They combine a practice of mapping AIDS; a practice of visualization that measures, gauges, appraises, calibrates and informs understanding of AIDS. Pictures were cropped, framed, assembled and annotated to produce meanings for a professional audience; this process made the pictures medically legible and tamed the abundant implications associated with immunodeficiency at the time. A medical vision was separated from and cleansed of popular perception, and constantly actualized to keep track of the rapid transformation of AIDS. With each renewal and revision of the atlas from 1986 to 2008, as it transformed into new editions and subsequent series, under changing editorships and in different publishing houses, the consecutive adaptation and refinement of the atlas have left us with a precious set of sources. This series provides us today with the archive of many consecutive medical visions of AIDS.

This study offers a medical visual history of AIDS that looks beyond the strategies of making AIDS merely visible. It unfolds a series of visualizations in which the shifting social appearance of AIDS, the emerging geographical diversity of the epidemic and the microbiological depth of the HIV infection was depicted and presented, curated, arranged, focused and mapped. In this story, AIDS does not become increasingly visible, more brightly lit until we are able to see every facet

Reflections on the productive forces of pictures in medicine is usually scattered among rather general approaches to visual history and "image science." A German collection has reflected on the relationship between pictures and *Gestalt* in medicine, which is perhaps most closely associated with the argument made in this book. W. J. T. Mitchell, *What Do Pictures Want? The Lives and Loves of Images* (Chicago: University of Chicago Press, 2005); Bernd Hüppauf and Peter Weingart, eds., *Science Images and Popular Images of Sciences* (New York: Routledge, 2008); Frank Stahnisch and Heiko Bauer, *Bild und Gestalt. Wie former Medienpraktiken das Wissen in Medizin und Humanwissenschaft?* (Hamburg: Lit Verlag, 2007); Hans-Jörg Rheinberger, "Experimental Systems: Histo-raility, Narration, and Deconstruction," in *The Science Studies Reader*, ed. Mario Biagioli (New York: Routledge, 1999), 417–29.

## Introduction

5

of its enormously complex social, cultural and medical appearance. A moving focus from the patient's body to the geographical distribution to the hidden workings of a virus might suggest increasing the field of sight, extending the depth of focus and revealing unseen truths. But the analysis of the historical layers of pictures of AIDS does not contribute to an increased transparency, and neither has medical sobriety ever achieved to overcome the subject's many faces.<sup>6</sup> Rather, this book pursues the conviction that AIDS has never been liberated from the shadows of doubt, uncertainty and confusion that were associated with the epidemic from its earliest days. Instead, we witness a process of unseeing AIDS. With each new frame, with each new perspective offered by doctors, epidemiologists and scientists, other visions, older versions and past representations move out of focus and into history.

Each time a claim was made about what counted as a real representation of the epidemic, other perspectives were condemned to the archive. In the changing arrangements of useful medical representation, wider questions arise for the history of medicine, such as how visual sources inform and shape the appearance and perception of diseases, epidemics and infections. Furthermore, I ask how the medical visualizations of AIDS engaged with the epidemic's broad social, political issues and cultural implications. How is a medical picture separated from other ways of seeing? Can we ever speak of a medical visualization that is a cleansed picture of the disease, or do we rather see the reassertion of medical authority through successive integration of the political and social questions that emerged with the arrival of AIDS? This leads to the historical outline of this book, which questions how practices of medical visualization that long predate the emergence of AIDS became part of the destigmatization, scientification and, most notably, normalization of AIDS.

The AIDS atlas proposes its own order; the political, epistemological and social implications of this medical order constitute the subject of this book. But such order has been – and remains – under continual strain: There was the emergence of an epidemic that did not fit with established classifications and frameworks in the once supposedly dying field of infectious diseases in the 1980s. There was the sociology of risk associated with the epidemic, which resisted calls for medical rationality and attached notions of infection to sexual identity and the supposed pathology of certain homosexual and urban lifestyles. And there was a rapidly

<sup>6</sup> On the often-misunderstood political risks of transparency, see: Stefanos Geroulanos, *Transparency in Postwar France: A Critical History of the Present* (Stanford, CA: Stanford University Press, 2017).

## 6 Introduction

changing geography, deeply tied to the longer natural history of the epidemic, its globalization and its devastating future. And finally, the intricacies of HIV catalyzed the development of a rapidly mounting research industry that reshaped the epidemic into a techno-scientific stream of interventions and innovations.

Looking at the history of AIDS through its configurations in the atlas is an opportunity to reconstruct the normative character of the syndrome at different points over the past 30 years. Visual traditions have shaped the process of normalizing AIDS by supporting the transformation of an old AIDS into a new AIDS. Traditions of medical photography encouraged the historical shift of seeing AIDS beyond symptoms of opportunistic infections and the persons affected by the syndrome. Conventions of medical geography shaped new perspectives on the epidemic's societal impact and its emerging global shape. Routines of visualizing a pathogen iconized the countless abstract and artificial instantiations of HIV. Stripped of obvious pathological connection, the models and technical diagrams of the virus as an inconspicuous submicroscopic entity signal the arrival of a manageable and normalized time of the epidemic.

Since Georges Canguilhem's seminal thesis, we have routinely worked under the assumption that the normal is not the necessary and certainly not always the logical opposite of the pathological. Canguilhem encouraged appreciation of norms associated with the pathological to move beyond an impoverished positivist framework in which health and normality were thought of as one and the same.<sup>7</sup> The healthy, he writes, are not only those without clinical signs and lacking experience of symptoms, but health needed to be understood as more than normal, as "an exuberance that is not limited to and by norms, but indeed constructs them."<sup>8</sup> Diseases, however, present themselves as situations in which humans are constricted by norms, governed by the failure of organs, for example. They are also directed through regimens of treatment, coaxed to adopt therapeutic behaviors, manuals of visitation and routines of living with a disease. Visualizing the disease, and especially portraits of pathogens as images of a disease's most reliable nature, were to Canguilhem vital instruments through which to devise the norms and routines of dealing with a disease. "To see an entity is already to foresee an action," he suggests.<sup>9</sup> Accordingly, as the AIDS atlas offers different norms of seeing

<sup>7</sup> Georges Canguilhem, *On the Normal and the Pathological* (Dordrecht, the Netherlands: Reidel, 1978).

<sup>8</sup> Stefanos Geroulanos and Todd Meyers, "Introduction: Canguilhem's Critique of Medical Reason," in *Writings on Medicine*, ed. Georges Canguilhem (New York: Fordham University Press, 2011), 3.

<sup>9</sup> Canguilhem, *On the Normal and the Pathological*, 40.

## Introduction

7

and thus proposing the shape of the entity of AIDS through time, it predisposes different kinds of actions.

For Canguilhem, the norms of seeing a disease were grounded in the transition from thinking of diseases as poorly differentiated situations of life, to an entity of scientific inquiry that has a qualitative difference to health. “A vulgar hierarchy of diseases still exists today,” Canguilhem wrote in the 1950s, “based on the extent to which symptoms can – or cannot – be readily localized.”<sup>10</sup> This division continues to structure contemporary ways of seeing diseases and its analytical capacity is decisive to the history of AIDS visualization in the atlas. Canguilhem recognized that some diseases were associated with dispositions, malignant excesses of life’s forces, and mutation and monstrous deformation of health and normal physiology. Examples include cancers, endocrine dysfunctions or chronic conditions of deteriorating physiology, such as diabetes. For Canguilhem these conditions, often given the prefix *dys*, can be only incrementally differentiated from the normal condition to which they are seen in quantitative difference: as an excess or deficiency of an otherwise healthy body. Diseases that are defined through constitutive difference are by contrast usually attributed to the presence of an infective organism, or seen in localized causes that exist and persist relatively independently from human physiology. Such an ontology of diseases assists thinking a fully disclosed nature of a disease, which is seen in qualitative difference to human life. The disease agent, from a bacterium to a virus, Canguilhem suggests, appears as a picture that claims to be evil, an entity whose entire figuration is constituted as an antithesis to human life.<sup>11</sup>

The history of AIDS normalization resonates between the two edges of this framework. It exposes how a poorly defined, underlying condition of immune deficiency was deeply implicated in the lifestyle of a subpopulation, before the disease became separated from patient identities and societal mores, and instead was confined to the complex but discrete mechanics of a microbiological agent. Within this history, we find the differentiation of the morphology of a Kaposi’s sarcoma (KS) lesion from the patients’ identity; the diffusion of AIDS as an ecological condition of communities, cities and nations; and the successful separation of a virus from the ways in which it travels, infects and multiplies. This is the history of the sequential mapping of AIDS through clinical photographs,

<sup>10</sup> Ibid., 39.

<sup>11</sup> Canguilhem argues that a rational optimism would need to reject any notion of the reality of evil and rather consider the kind of values that are placed in absolute opposition to what is considered to be health. Ibid., 103.

## 8 Introduction

geographical maps and virus models. In the atlas, we trace how the medical perception of AIDS went from questioning *who* got the disease, to *where* the epidemic was moving, to a fixation about *what* AIDS is.



Inevitably, this is a book about pictures, or rather an AIDS history presented as a visual triptych of photography, mapping and modeling. My inquiry begins when pictures addressed pressing issues about AIDS but follows them as they disappeared or moved to the edge of the frame as new challenges in the epidemic's history demanded new ways of picturing, seeing and thinking about AIDS. Pictures move across history as much as they cross boundaries of knowledge and fields of thinking about AIDS. Photographs linked the clinical imaging laboratory to the politics of activism and AIDS art; maps merged epidemiology with governments' public health communications; virus models bridged the submicroscopic worlds of molecular biology and the human experiences of millions across the globe. These three pictures – photographs, maps and models – do not exclusively belong to one practice, one way of thinking or seeing, but rather embody the relations and connections of an object across boundaries of disciplines and fields.

AIDS provoked the most substantial and extensive crisis to biomedicine in the late twentieth century. The emerging epidemic buried the 1970s utopia of a world without infectious diseases, and submerged medicine into an open-ended stream of politically and culturally charged interpretations of the unfolding crisis, sentencing medical professions to helplessness and passive observation as otherwise healthy, young men died in great distress. With infectious disease doctors unable to define a stable entity causing this suffering, or a discrete disease to fight, the shapes, meanings and dooming prospects of AIDS seemed to develop at an unrelenting pace. Many scholars have argued, that in the early years of the epidemic, medicine was effectively sidelined by other voices.<sup>12</sup> Where pharmaceutical and conservative treatment failed, practices of prevention were devised behind activist picket lines, fortified by a growing corpus of social studies. Assessment of the epidemic's societal impact seemed better articulated through cultural critiques than by public health departments, which were struggling on both sides of the Atlantic with the highly sexualized crisis at hand.

<sup>12</sup> See, e.g., the contribution to this excellent collection of poignant cultural analysis of the epidemic: Douglas Crimp, ed., *AIDS: Cultural Analysis, Cultural Activism* (Cambridge, MA: MIT Press, 1988).

## Introduction

9

Despite previous signs to the contrary, medicine seems to have prevailed. Looking back to a time when those beyond medical profession – patient advocates, activists, historians and social scientists – seemed to have a firmer grip on the questions that mattered (both to persons with AIDS as well as to society's fears about AIDS), the weakness of medicine has been largely forgotten and today seems unthinkable. In an unforeseen twist, the medical profession – from clinicians to lab scientists – not only regained authority, but also AIDS today appears as a crisis more easily attributed to failures of national or international politics and inhumane patent regulations than any failure of medical knowledge or proficiency.

This book searches for an answer to the question about how medicine regained this control over the epidemic, in terms of administering care as well as managing the disease's social and cultural repercussions. Was medical authority reinstalled after an initial period of shock and despair by finding systematic and rigorous treatment regimens to deal first with opportunistic infections, then with social attitudes and false conceptions, to arrive finally at a techno-scientific pharmaceutical solution? Or should we take a step back and ask if medicine after the AIDS crisis was still the same compared to what it had been before. In other words, is this a history of medically guided integrating, adapting, appropriating and sustaining criticism that were posed to the medical professions by patient-cum-activists, social scientists, historians and policy advocates?

The answers lie in the larger history of visualizing disease, far beyond the history of AIDS after 1981. Photographs of patients were in circulation almost immediately after the invention of photography in the mid-nineteenth century, geographical mapping had a decisive impact on perceptions of epidemics as measurable and manageable entities, while the visualization of pathogens was not just a result of laboratory medicine but essential to the transformation of microbes into agents of infectious disease. The long nineteenth century and its characteristic push for modernization, the introduction of scientific practice and mounting political regulation of medicine shaped visualization practices into powerful and spectacular instruments of medical classification.<sup>13</sup> To make sense of AIDS, to stake the importance of a medical vision, the tradition of these practices mattered. Clinical photography, medical

<sup>13</sup> See, e.g., John Harley Warner, "The History of Science and the Sciences of Medicine," *Osiris* 10 (1995), 164–93; Steven Sturdy and Roger Cooter, "Science, Scientific Management, and the Transformation of Medicine in Britain c. 1870–1950," *History of Science* 36, no. 114 (1998), 421–66; Michael Worboys, *Spreading Germs: Disease Theories and Medical Practice in Britain, 1865–1900* (Cambridge: Cambridge University Press, 2000).

## 10 Introduction

geography and pathogen visualization had become routinized practices with agreed-upon conventions. They each had unique and extensive capacities to render signs and patterns into objects of medical significance. The atlas of AIDS harnessed this history of visualization and the abundant visual culture of AIDS to distill and present a stringent and accurate medical form.

My analysis encourages a perception of AIDS pictures as moving objects claimed by different protagonists at different times to articulate various ways of seeing and understanding the epidemic.<sup>14</sup> The book reaches from opinions about what is significant within a photograph or map, to the associations that are expected when one sees a suffering person, a moving geographic distribution or the outline of the virus. Motives, shapes and figures have no inherent medical nature, but can be made medically meaningful. To look at pictures as objects characterized by an interpretative flexibility, we can point beyond the historical analysis of the political and rhetorical oppositions that structured so much of AIDS history. Instead, the pictures provide a historical archive of the obstacles and complexities that were referenced across activism, medicine and politics. A source and a starting point of problematization practices, pictures lead us to an archive of strategies and tactics employed to make sense of AIDS.<sup>15</sup> They encourage us to reflect on the three central embodiments of a disease that modern medicine has made available: the individual body in the clinic, the diseased space in epidemiology and the pathogen in microbiology.<sup>16</sup>

### Histories of AIDS

Photographs were the earliest images of AIDS. Since 1981, cameras – on the streets and in the clinics – captured the mysterious appearances of unusually severe infections on what the Center for Disease Control

<sup>14</sup> For the original discussion on boundary objects, see John R. Griesemer and Susan Leigh Star, “Institutional Ecology, ‘Translations’ and Boundary Objects: Amateurs and Professionals in Berkeley’s Museum of Vertebrate Zoology, 1907–39,” *Social Studies of Science* 19, no. 3 (1989), 387–420. For a recent discussion of the continued relevance of the concept and beyond, see Geoffrey C. Bowker et al., *Boundary Objects and Beyond: Working with Leigh Star* (Cambridge, MA: MIT Press, 2016).

<sup>15</sup> This only hints at the extensive discussion of problematization as a method of historical research, which Foucault repeatedly compared to a kind of diagnostic perspective onto the archive, comparable to the clinician’s gaze. See, e.g., Michel Foucault, “Polemics, Politics and Problematisations,” in *Ethics: Subjectivity and Truth*, ed. Paul Rabinow and Robert Hurley (New York: New Press, 1997), 111–19.

<sup>16</sup> Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception* (New York: Pantheon Books, 1973), 9.