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Patient Zero and the Making of a Myth: History as an Archaeology of the Present

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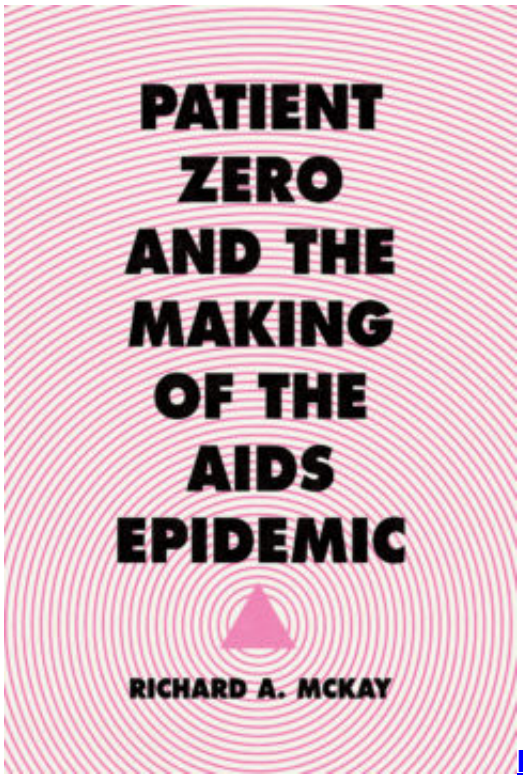

Patient Zero and the Making of the AIDS Epidemic

Richard A. McKay

University of Chicago Press, 2017, 400 pages

> “An innocent he was not. He eventually told health investigators that during the 1970s he’d had some 2,500 sexual contacts with men in Europe, Canada, South America – and in the large centers of gay lifestyle in New York and California. In the later years, he knew he had what he called the ‘gay cancer.’ And knew he was passing it on to others. Criminal? Demented? No one knows. (…) He was only 31 years old when he died, but he’d already earned his own sad brand of medical immortality. Because he was such a

> lethal agent of infection, Patient Zero is to AIDS in America what Typhoid Mary was to an earlier epidemic."
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> – John Lee Clowe, president of the American Medical Association, October 31, 1992, Third Japan/US Health Care Symposium, Kobe, Japan (quoted in (McKay 2017).

How do myths come into being? Why do some myths fade away whereas others become part of history? What roles do myths play in our understandings of the past and our attempts at making the present comprehensible? These questions lie at the heart of Richard A. McKay´s wonderful book *Patient Zero and the Making of the AIDS Epidemic*. It tells the story of Gaëtan Dugas, the Canadian flight attendant, who would become globally-known as the man who gave the world AIDS.

"It started with Air Canada flight attendant Gaëtan Dugas," the German magazine *Der Spiegel* reported on October 26, 1987. "With his airline's flight vouchers in hand, the good-looking man could travel around North America at will and have his fun. In New York, Los Angeles and San Francisco (…) easily accessible sex in saunas and darkrooms wasn't considered indecent. (…) Dugas was the star of the scene. 'I'm the most beautiful,' was his standard response after taking a quick overview of potential sex partners in bars and saunas. A deadly one too." [translation my own] The *Spiegel* article was based on the book *And the Band Played On* published the same year and written by journalist Randy Shilts. It was through this book that Dugas' name first became known to the public, and it was thanks to this book that Dugas would be known as a sociopathic and cynical man, a myth-like status which would haunt his name for decades to come. "Told later he was endangering anyone he slept with, Dugas unrepentantly carried on – by his estimate, with 250 partners a year – until his death in March 1984, adding countless direct and indirect victims," *Time* reported on October 19, 1987. "At least one man indignantly hunted him down. Dugas' charm proved unfailing: he sweet-talked the man into having sex again." The title of the article – ironically, or at least clairvoyantly – was "The appalling saga of patient zero." It was like a self-fulfilling prophecy had already been made.

Dugas became the centre of attention for the US Centres for Disease Control (CDC) in 1982 in their attempt to try to decipher a potential new epidemic. But, as McKay shows, a range of circumstances – among them how the disease clusters were represented, Shilts´ deliberate omissions of information from his narrative, a publisher who needed a good story to market, simplifications by the media, and society´s need for scapegoats in

a situation of much uncertainty, moral panic and deep despair – were all elements which helped turn the story into a myth. McKay compellingly demonstrates, in his historical study based on comprehensive archival material and oral history interviews, that to make this story intelligible, it needs to be interpreted in its historical context.

The cluster study: shifting medical paradigms

The book starts in the early 1980s with the CDC's task force on Kaposi's sarcoma and Opportunistic Infections and its quest to try to pin down the causes of a potential new disease. The task force´s main work-tool was contact tracing, meaning that they tried to map the sexual connections between people who displayed various symptoms and diseases in American cities, for instance Kaposi's sarcoma, cytomegalovirus (CMV) infection and pneumocystis pneumonia (PCP). McKay argues that this took place in a time of shifting understandings of disease mechanisms in medicine. The germ theory with Koch's postulates had dominated medicine since the end of the 19thcentury. According to that theory, the goal was to identify disease mechanisms in specific diseases and an important objective was to search for magic bullets in the treatment of disease. Person-to-person disease identification using laboratory tools fitted well into this model. But around the mid-20thcentury, with increasing interest in chronic illnesses and non-communicable diseases, a need for a different, risk-centred and population based, statistical epidemiology appeared. McKay argues, however, that in the field of venereal disease (which was the term in use at the time), the health authorities still used the personal contact model for disease control. One of the task force´s principal investigators had former experience with cluster testing from syphilis control in the 1960s. Not only the patient´s sexual contacts were traced, interviewed and tested but also his or her social network.

"[I]ncorporating a language that was strongly suggestive of detective fiction" (p. 85) these health officials, or detectives in white shirts and dark ties, were on duty to protect the country from the "reservoirs" of venereal disease. McKay writes that it was a long and problematic tradition in the US of associating higher syphilis rates with sex workers and African Americans, not only in the public but also in the medical communities. This cultural mental image of mobile reservoirs threatening the population was in the mid-20th century projected onto new groups, primarily migrant laborers from Mexico working on American farms but also homosexuals. It was with these officials in the early 1980s, that Dugas, and with him many other affected gay men, came in touch, and cooperated by listing their sexual contacts. This information was then used to create maps of affected people and draw connections between them to identify clusters of

unusual diseases. At that time, in 1981 and 1982, the HIV virus was still not identified and the etiological theories in the scientific community, among the health authorities, in the communities and the media, were manifold. In the early years of the epidemic, the incubation period was thought to be much shorter, from nine to twenty-two months, than what was later realized (p. 138). This legitimized the idea that it was possible to visualize accurately the connections between the affected members in the study. However, when, in the late 1980s, it was realized that the incubation period from the contraction of HIV to development of AIDS usually was several years, it became clear that the early attempts of drawing connections between affected people were probably useless; most people had been infected long before initially assumed.

In the earliest drafts of the clusters, Dugas figured as “case 57,” but was later referred to as “Patient O,” where the letter “O” abbreviated “Out-of-California.” By mistake or due to unfortunate circumstances – maybe because of the CDC´s typewriters not distinguishing properly between “O” [the letter] and “0” [the number] – people gradually started referring to this case as “patient 0,” as in “patient zero.” Even though the researchers did not intend to convey the message that patient “zero” was the fountainhead of the epidemic, McKay demonstrates that when the study was published in the *American Journal of Medicine* in 1984*,*“Patient 0” figured in the middle of the cluster diagram with lines to other sexual contacts projecting in a star-like manner, which again gives the impression that he was an originator of the cluster. Furthermore, the media’s usage of charts showing how all affected people could be traced back to this person, helped cement that impression. The first part of McKay´s study thus contributes to our understanding of media´s role in mediating medical research to the public in the late 20th century. On a more fundamental level, his analysis shows how media, researchers, authorities and health professionals are all entangled in the production of scientific facts in modern societies.

Politicization and personification of an epidemic

McKay demonstrates through immaculate archival studies and interviews how Shilts cherry-picked some information and omitted others to paint a picture of Dugas as a ruthless sociopath who deliberately infected other men in the bathhouses. For instance, Shilts wrote that after having unprotected sex with strangers Dugas revealed his Kaposi´s sarcoma lesions adding, “I´ve got gay cancer. I´m going to die and so are you.” (p. 57). It is unclear if Dugas actually ever said this. Marcus Conant, a founder of *the Kaposi´s Sarcoma Research and Education Foundation,* the predecessor of *the San Francisco AIDS Foundation,* was

interviewed by both Shilts and McKay. He recalls being told that the phones of the foundation's hotline would "*literally* light up" with callers who reported a man with a French accent having sex in the bathhouses. After sex he would tell his lovers that he had gay cancer. Since the hotline´s call statistics have been aggregated into monthly totals and because McKay has been unable to find any reference to problematic persons with Kaposi´sarcoma in the organizations records from that period, McKay concludes that this claim cannot be further interrogated. McKay argues that it is quite possible that Dugas did not make any effort to hide his Kaposi´s sarcoma lesions from his lovers and that he might have talked about them freely, believing not to be infected by a contagious disease. Shilts was a struggling journalist who needed this story not only for his own success but also because he desperately wanted to raise awareness of a manifest societal crisis. Himself a gay man seeing his friends fade away, Shilts was convinced that people needed to start changing their lifestyle, but also wanted to highlight the Reagan administration´s political ignorance and inaction. McKay shows that the story would never have obtained its myth-like status without the book publisher´s promotion strategy of focusing on the flight attendant as *the person* who brought AIDS to the US. The media´s uptake and wide circulation of this narrative solidified the idea that the epidemic could actually be traced back to one person´s "irresponsible" and "hedonistic" lifestyle – to "The Monster Who Gave Us AIDS" as one newspaper article tellingly claimed (p. 198). For instance, McKay shows how the CBS program *60 Minutes* in November 1987 used a sexy, shirt-less photo of Mr. Dugas, and through a sequence of photos which successively zoomed in on his eyes to an extreme close-up, hammered home an image of the personification of the epidemic. Still, an aura of mystery was preserved: look closely into his eyes, what do you see?

The story eventually kept on living its own life far away from its country of origin. In an article in one of Norway's biggest newspapers on September 19 1992, Dugas was described as the man who "was tied to most cases of the AIDS in North America in the beginning of the [19]80s." The story later appeared in legal discussions in the US where it would be used as an argument for criminalization of HIV transmission. But in the chapter "Ghosts and Blood,"McKay also demonstrates how the story not only became embedded in, but was also mobilized in, various examples of what he calls "AIDS work" in Canada through the 1990s. Here McKay juxtaposes the history of the Krever Inquiry and the role "Patient Zero" played in these hearings with Canadian LGBT and HIV/AIDS activism and how activists challenged the myth of "Patient Zero" exemplified by the making and reception of the film *Zero Patience*. The Krever Inquiry was a commission established by the Canadian Government in 1993 to investigate the Canadian blood system scandal where approximately 2,000 Canadians were infected with HIV and 30,000 with hepatitis C virus

through transfusions of blood and blood products (McKay refers to slightly different figures). The insistence on treating both the political-judicial Krever Inquiry and activist art work together as examples of "AIDS work" – examples which might at first sight appear unrelated – enables McKay to analyse how the myth continued to haunt Canadian society on various levels. McKay also highlights how activism, art, medical research and public hearings are not qualitatively unrelated phenomenon, but rather different examples of the politicization of HIV/AIDS.

Presentism

A central part of the myth of "Patient Zero" is that Dugas deliberately infected other men and intentionally decided not to listen to the advice of health care workers to change his behavior. However, as McKay shows in probably the book's most beautiful chapter, this assumption is deeply presentist and unhistorical, because it takes present knowledge of HIV/AIDS as the frame of reference. Based on the scarce scientific knowledge at that time – the many medical theories, uncertainty and contradictory media reports – what could be expected to be known about the situation, about potential transmissibility and how to stay healthy or protect yourself and your lovers? From the earliest reports – the CDC published its first report of PCP infection among five young men in LA in June 1981, on July 3 of that year the New York Times published the news article "Rare cancer seen in 41 homosexuals," and two months later an article appeared in *The Lancet* about eight cases of "Kaposi's sarcoma in homosexual men" – it took three years before the cause of AIDS was identified (the HIV virus was first referred to as HTLV-III). How gay men navigated in this ethically complicated landscape of personal uncertainty, grief and deep despair, amongst rumours, discrimination and political ignorance must be seen in the light of the historical context of LGBT liberation in the 1970s and 1980s and the fear many gay men had of their newly acquired freedom being taken away from them. Not least, the sex culture needs to be understood not just as a leisure activity – for many gay men, having sex, making love, was understood as what being gay *was.*

McKay delivers a convincing argument for Dugas himself supporting a multifactorial etiology for his illness. According to this theory, there was no single cause of the new disease, like a new infectious agent, but the body's immune suppression was a result of recurrent venereal diseases (now referred to as sexually transmitted infections, STIs), unhealthy lifestyle or the use of drugs including "poppers" (amyl nitrites). Seen from this perspective, it becomes comprehensible why many saw the question of whether to use condoms or reduce the number of sexual partners was more a matter of protecting oneself and one's own health (by avoiding

recurrent sexually transmitted infections for instance) than avoiding passing on a potential infectious agent.

Archaeology of the present

I do not read McKay's book as a mere defence manifesto for Gaëtan Dugas or as a simple attempt to debunk a myth. No doubt, as McKay underlines, Dugas continued to have many sex partners and lovers after he got ill. More precisely, I think we should regard McKay's work as an encouragement to open up and unpack the past to the present by following the many loose threads, insecurities, inconsistencies and lacunae in what the past has left us. One of the book's biggest achievements is that we are constantly reminded – by its approach to historical material, integrating archival material, newspaper articles, oral history interviews, art and media material – how representations of the past (truths, tales, or myths) have their own history which continues to live in the present. Digging through the strata of historical material, staying open and reflexive to the temporalities of the archive, it becomes clear that the historian's excavations are not simply direct, objective observations or windows to the past. Rather, looking at history writing as an *archaeology of the present* reminds us that archival practices – what was conserved, what was not – are inseparable from historical power structures: some histories were found important enough to be kept for later generations, others were deliberately neglected, and some material has by chance forever disappeared (Geissler and Lachenal 2016).

In an article published in *Nature* in 2016, researchers – among them Richard A. Mckay – once and for all settled the question of whether Gaëtan Dugas brought HIV to the US: he did not. Serum samples from the late 1970s from cohorts of men who had sex with men in New York and San Francisco were serologically screened. Positive samples were then picked for HIV-1 viral genome sequencing with subsequent molecular clock phylogeographic analysis. The findings provide strong evidence for the US epidemic originating from the Caribbean epidemic; the virus was probably introduced to the US around 1970. The study is a powerful example of how tools from natural science, when combined with the historical tools of contextualization and source criticism, can be used to write biohistory (Worobey et al. 2016).

It would take 15 years, from the first organized efforts of trying to identify the cause of the new disease, until an effective therapy was presented in 1996. With highly active antiretroviral therapy (HAART) began a new chapter in the history of HIV/AIDS, which radically changed the face of the epidemic, at least for people living in high-income countries with universal

health coverage. In many places around the world, HIV now has become a chronic disease. The HIV epidemic of the first two decades of the 21st century is primarily one of the sub-Sahara countries, Central Asia and Eastern Europe, where HIV is still spreading rapidly, mainly due to lack of harm-reductive measures, testing services and effective treatment. Children, women, sex-workers, transgender people and men who have sex with men (MSM) are at particular risk. In the US, African American and Latino MSM are disproportionally affected.

In many gay communities, HIV is still shrouded in shame. AIDS profoundly changed gay men's lives. Most sexually active gay men have at some point in life encountered the fear of contracting HIV. When AIDS brought death into gay men´s lives the condom became a barrier between life and death. The use of condoms, which became the major HIV prevention strategy for gay men, activists and gay organizations, however, also became a way of demonstrating responsibility. Maybe showing responsibility has been a way of compensating for having non-heterosexual sex, a way of staying morally respectable in a heteronormative society? Maybe, when men on various hook-up apps describe themselves as "clean,"meaning free from STIs or HIV, this could partly be seen as wanting to distance oneself from a "tainted history"? AIDS is a historic wound in gay culture.

Pre-exposure prophylaxis (PrEP), HIV-medicines taken prophylactically to reduce the risk of HIV infection, has radically changed HIV prevention among MSM in many high-income countries (though in the US, access to and uptake of PrEP among African American and Latino MSM is much lower than in the white population). Taken correctly, PrEP almost eliminates the chance of contracting HIV. Still, many in the gay community have been skeptical of PrEP, leading people to shame publicly, online or on hook-up apps those who choose this strategy to protect themselves. The emergence of the term "Truvada-whore" (Truvada is the registered trademark for one drug used as PrEP) is the most obvious example of this. The reasons for skepticism surely are manifold; the worry of STIs becoming more prevalent if PrEP replaces condoms, medicalizing gay men's bodies, and unwanted side-effects are all important questions. Still, maybe the HIV/AIDS stigma in the gay communities sticks deeper and partly needs to be seen in a historical context. McKay brilliantly discloses how the questions of responsibility, moral and how to have sex in an epidemic were negotiated in the early years of the AIDS epidemic. In this ethically and politically complicated landscape, a simple narrative of one man's irresponsibility and ruthlessness was born and was able to thrive. To identify the myths and the "Patient Zeros" of our time, history provides a powerful tool.

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