

**Pathologies of Care:
HIV Treatment and Prevention in Turkey**

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Hasan Tankut Atuk

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Acknowledgments

In September 2018, I arrived back at Minneapolis after a three-month long summer research in Istanbul. I was beyond excited for my return because it was time to see the man I met three months ago. After two short months of knowing him, I had to depart for Turkey with a bittersweet feeling, knowing I was leaving something very special behind. I was worried because I was not sure if he would be there when I returned. Two months were indeed very brief to actually know and love someone, yet I missed him every day of that summer. A week after I returned, I was shaken by the news of my HIV diagnosis. I knew that this was the beginning of a new phase of my life, yet I did not have a single clue that it would be full of love. Yet, Nick was there when I got the bad news, and he continues to be there for me to this date. As a lover, as a friend, as an engaged reader, and as a skilled editor, he has contributed to each page of this dissertation. I believe I should thank him before anyone else because I would have never worked as hard as I did if it wasn't for my little queer family. Nick, everything I do, I do to have a tiny house, a garden, and dogs with you.

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I suppose when it comes to love, I was born lucky. I grew up around six wonderful women who taught me how to love and be loved. I never had a strong father figure in my life, for which I am ever grateful. My mother Müjde (meaning good surprise in Turkish), my sister Sumru, my aunts Mukadder and Mualla, my cousin Begum, and my late grandmother Kevser made me the person I am today. Every passing year I see more of them in how I talk, how I react,

and how I do things. Surprisingly, the more I resemble them, the more I find myself. I love them all the same but my sister does deserve a special shout-out. Sumru is literally my hero. In elementary school, I was bullied and threatened by a lot of kids. Until, one day when she showed up at school and twisted this older kid's arm who has been harassing me because I was too girly—the memory is still so vivid that I can almost taste the pistachio ice cream she bought me after she picked me up at the school that day. Even before I noticed, my sister knew I was different and that difference would make me vulnerable. Luckily, she has been my super-girl for the past 32 years. Her superpowers include not only protecting me but also making sure that I am successful. Everything I achieved to this date, every degree, every publication, every grant, is thanks to her. I wouldn't even be graduating from a PhD program today if she didn't pay for my PhD application fees. With the small money that she saved from a fellowship, she made sure I had the chance to pursue my dreams. When I was rejected from all universities I applied the first year and ended up spending nearly a thousand dollars for nothing, she said don't worry, you will apply again next year. Sumru, thank you for being the best sister I could have ever asked for.

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Dedication

To all HIV activists, past and present, and to the positive queer community, the only community I've ever had.

Abstract

This dissertation investigates the ambivalent, elusive, and contradictory nature of care that produces abandonment and harm but dialectically gives rise to vital modes of belonging and carefulness. In Turkey, the number of HIV diagnoses has increased by 620%, and AIDS-related deaths have more than doubled over the last decade. Yet, formal regimes of HIV care block access to testing, condoms, and pre- and post-exposure prophylaxis; impose monogamy as a scientifically legitimate prevention method; deny (health)care to LGBTQI+s and people living with HIV; and refuse sexual health education. This dissertation draws on twenty months of embedded ethnography, public and private archives, medical records, newspaper articles, official government reports, and fifty in-depth interviews with governmental, nongovernmental, medical, and pharmaceutical sector workers. Through the concept of *pathogenic care*, this investigation uncovers how conservative and neoliberal ethics and mechanisms of public health aggravate the conditions of those living with HIV and increase the risk of transmission for others, especially the marginalized, who are socio-immunologically more vulnerable. In other words, this research demonstrates that HIV care has become pathological in Turkey by facilitating a joint epidemic of HIV and *HIVfobi*, i.e., status-based stigma and discrimination. By setting a sterile distance between themselves and the so-called “contagious others,” formal regimes of HIV care create zones of abandonment where particularly queer and trans communities are left vulnerable to HIV transmission and socio-medical discrimination. This study makes three central arguments with important theoretical and public health implications: (1) the Turkish HIV epidemic is not an inevitable result of dissident/terrorist sexualities, foreign lifestyles, or human immunodeficiency virus; (2) public health mechanisms, institutions, and actors in place to provide HIV treatment and prevention have become unexpected vectors of HIV transmission under neoliberal Islam; (3) the fear of medical and social contagion, as well as the aggressive impulse to immunize life against “infectious” others, lie at the center of Turkey’s public health response to the growing HIV epidemic.

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List of Abbreviations

- AIDS:** Acquired Immune Deficiency Syndrome
- AKP/JDP/Ak Parti:** Justice and Development Party
- ARV:** Antiretroviral
- CSR:** Corporate Social Responsibility
- GSS:** General Health Insurance
- GTDM:** Voluntary Testing and Counselling Center
- HIV:** Human Immunodeficiency Virus
- HTP:** Health Transformation Program
- MoH:** Ministry of Health
- NGO:** Non-governmental Organization
- PLWH:** People Living With HIV
- PrEP:** Pre-exposure Prophylaxis
- PeP:** Post-exposure Prophylaxis
- PYD:** Positive Living Association

Introduction: Public Health as an Infectious Technology of Power

If public interventions grounded in such biopolitical procedures as surveillance, screening, testing, contact tracing, 'high-impact prevention,' responsabilization, risk elimination pedagogy, the condom code, the pathologization of risky sex, and the criminalization of HIV through laws requiring the disclosure of HIV infection before sexual contact were actually forms of care instead of forms of regulation, if they really qualified as good medical science, good psychology, or good social policy, we would expect them to be considerably more effective at preventing new HIV infections among queer adolescents and adults than they have proved to be.

—The Biopolitics of HIV Prevention Discourse, Halperin, 2015

Disease may not discriminate, but it helps those who do.

—The City of Plagues, Craddock, 2000

The first official HIV diagnosis in Turkey was given in 1985. Murtaza Elgin, a public figure commonly known as Murti, was suspected to be a queer man who was depicted in the media as the Turkish patient zero. When he died, his body was sterilized with bleach and encased in concrete to prevent transmission of the virus. Like his body, the story of Murti has been buried deep in the history of the country, where it is remembered, if ever, as an anomaly. In Turkey, HIV has never been considered a domestic issue but a peril that only concerns Eastern European sex workers and Western queers, both perceived to be sexual deviants, hence, always-already ill. However, according to recent data, the number of HIV diagnoses in Turkey has increased by 620% since 2007 and the AIDS-related deaths have more than doubled.¹ Among the most cited causes for the nascent epidemic are the lack of knowledge and awareness of HIV; absence of sex education and prevention programs for key populations; insufficiency of test centers; low condom use; stigma and discrimination against PLWH; and conservative cultural values about sex(uality) and sexual health.²

¹ Ayse Gulsen Teker, "AIDS-Related Deaths in Turkey between 2009 and 2018," *Epidemiology and Infection* 149 (July 2, 2021): e191.

² Pinar Ay and Selma Karabey, "Is There A 'Hidden Hiv/Aids Epidemic' In Turkey?: The Gap Between The Numbers And The Facts," *Marmara Medical Journal* 19, no. 2 (2006): 90–97; Sahbal Aras et al., "Sexual Attitudes and Risk-Taking Behaviors of High School Students in Turkey," *Journal of School Health* 77, no. 7 (September 2007): 359–66;

In Turkey, HIV prevention and treatment have become pathological leaving people vulnerable to HIV and subjecting them to myriad yet entwined forms of discrimination once they are HIV positive. In a context where HIV is addressed as a moral issue instead of a matter of public health, formal regimes of HIV care refuse to recognize HIV or those living with the virus; block access to testing, condoms, and pre- and post-exposure prophylaxis; impose monogamy as a scientifically legitimate prevention method; deny services, including in healthcare, to LGBTI+s and people living with HIV; and refuse, even punish, the need for sexual health education. There are four principal actors involved in HIV care: the Turkish state and its Ministry of Health (MoH), health providers, nongovernmental organizations, and pharmaceutical companies. The governmental, non-governmental, medical, and corporate regimes of HIV care in Turkey offer a rich field to explore how an epidemic of a sexually transmitted disease, as well as an epidemic of stigma and discrimination, are co-produced and exacerbated by empty gestures of care.³

The formal regimes of HIV care are indispensable for HIV treatment and prevention, yet their actions are often in contradiction with the realities of public health and needs of people living with HIV. In the name of HIV treatment, the Turkish state offers what on paper is called universal free healthcare, but there exist numerous violations of the right to access health. The Turkish state does provide free antiretroviral medicine, yet its so-called care ends there without an acknowledgement of the fact that medicine is essential but not enough for the biological and social wellbeing of HIV+ people. As such, it fails to protect the fundamental human rights of HIV+ people who are widely denied access to healthcare, work, and housing. In the hands of the Ministry of Health, HIV prevention has also become a harmful gesture of care that leaves marginalized communities vulnerable to HIV and other STIs. In the name of HIV prevention, the Ministry offers monogamy as the only solution to the epidemic—'a fatal advice'⁴—and refuses to

Aygen Tümer, "The Current Situation of the HIV Epidemic in Turkey (türkiye'de hiv epidemiyolojisinin son durumu)."

³ It is important to avoid a categorical reductionism by lumping all four modes of HIV care together. None of these actors have the same role in the emergence of the epidemic and the failure to contain it as much as the Turkish state does, and Chapter 1 will answer why. Later, Chapter 2 will demonstrate why the mistakes made by the nongovernmental HIV organizations should not be compared to the violence and harm inflicted by other actors of HIV care.

⁴ Cindy Patton, *Fatal Advice: How Safe-Sex Education Went Wrong* (Durham: Duke University Press Books, 1996).

implement public health campaigns to increase HIV awareness. It holds prevention synonymous with promiscuity, and it is only concerned with the sexual health of married pregnant women.⁵ Critically, the MoH does not assume responsibility for providing free condoms, pre- and post-exposure prophylaxis, and comprehensive sexual health education either.

Doctors and nurses help blur the fine lines between medical care and medical violence as they widely reproduce HIV stigma and discrimination. Seeking medical help can be very difficult for people living with HIV. When I was doing fieldwork, I postponed my appointment with an infectious diseases specialist for months to avoid what I expected to be a confrontational encounter. Infectious diseases specialists are often criticized for possessing *tanrı egosu*, “god’s ego”, due to their paternalistic and contemptuous attitudes towards their HIV+ patients. The Western idea that patients are an integral part of the treatment process and should be able to express their opinions is not widely accepted among them. Infectious diseases specialists are still key to the holistic treatment of their patients as their letter or phone call is often necessary to convince doctors in other medical branches to accept HIV+ patients. A lot of practitioners refuse to examine or even talk to patients when they find out about their HIV diagnosis through private medical records. Nurses are known for poorly treating HIV+ patients when they are drawing blood or administering medicine. Also, when a patient’s HIV status is revealed, their right to privacy is completely ignored and the hospital staff is informed about them and “the potential health hazard” they present to other patients and the health personnel. Doctors and nurses either loudly announce in front of others that their patient is HIV+ or write and circle the patient’s serostatus on their intake forms.

When it comes to local NGOs and global pharmaceutical companies, HIV care becomes a truly gray area. These actors increase HIV awareness and visibility, provide financial, legal, medical and psychosocial support, yet they have their own financial and corporate agendas. The rapid NGO-ization of HIV care in Turkey poses risks to the wellbeing of the HIV+ community.

⁵ Seda Saluk and Burcu Mutlu, “Cinsellik, Üreme/ Doğurganlık ve Sağlık Politikaları Üzerine Sohbet,” *Kültür ve Siyasette Feminist Yaklaşımlar* 34–35 (2018).

By NGO-ization, I mean the widening governance of HIV care by nongovernmental organizations who have increasingly become dependent on corporate donors that “wield a subtle but nonetheless effective influence on NGOs and their ‘target populations’.”⁶ Because it is easier to find funding for testing and prevention projects, NGOs increasingly target the HIV-negative population and fail to genuinely care for or empower those living with HIV. They also maintain the highly criticized belief that they need to be fighting against HIV instead of HIV-related discrimination. Local NGOs also predominantly provide services to heterosexual and cisgender individuals for they fear retribution from the state and society should their organizations be associated with queer people. The fear of retribution from the state agencies and the financial dependency on the pharma industry passivize civil society and reduce its political willingness and capacity to counteract conservative public health policies.

On the other hand, concerned with increasing the HIV diagnosis throughout the country, the pharma industry reduces HIV care into testing and drug use. Gilead, the original patent holder of the groundbreaking preventive HIV medicine PrEP (pre-exposure prophylaxis), chooses not to introduce the drug in Turkey as the company considers PrEP “too risky” for Turkey’s conservative governance of sexual health. While Gilead contributes to the *pharmaceuticalization* of the field through Corporate Social Responsibility (CSR) projects that serve less the interests of the HIV+ people or those at risk than those of Gilead itself, it refuses to undertake initiatives that would empower PLWH or protect those at risk.⁷ In this context, pharmaceuticalization implies both the increasing understanding of HIV care in terms of pharmaceuticals and the growing influence of multinational pharmaceutical companies in HIV care.⁸ The global leader of antiretroviral manufacture takes a lot of corporate pride in supporting local HIV organizations and researchers, yet it only provides funds for projects aimed at

⁶ Mark Schuller, *Killing with Kindness: Haiti, International Aid, and NGOs* (New Brunswick, NJ: Rutgers University Press, 2012), 8; Sabine Lang, *NGOs, Civil Society, and the Public Sphere* (Cambridge University Press, 2013).

⁷ Tankut Atuk, “Pathopolitics: Pathologies and Biopolitics of PrEP,” *Frontiers in Sociology* 5 (2020).

⁸ João Biehl, *Will to Live: AIDS Therapies and the Politics of Survival* (Princeton, NJ: Princeton University Press, 2007); Stefan Ecks, “Pharmaceutical Citizenship: Antidepressant Marketing and the Promise of Demarginalization in India,” *Anthropology & Medicine* 12, no. 3 (December 2005): 239–54.

increasing HIV testing. The self-serving efforts of the industry to increase HIV testing and drug use play a critical role in the medicalization and depoliticization of the HIV epidemic in Turkey.

Together these four actors create a particular form of Foucauldian governmentality managing bodies, pleasures, and risk, which Cindy Patton calls “national AIDS pedagogy.”⁹ In Turkey, the national pedagogy has four essential pillars: monogamy (Chapter 1), condom use (Chapter 2), drug adherence (Chapter 3), and testing (Chapter 4). According to Patton, these supposedly apolitical public health teachings function as “the means for dividing educational subjects into those who would be formed into citizens through a national pedagogy and those who would be policed or, if they were lucky, ignored as they developed their own dissident safe sex strategies.”¹⁰ The official suggestion of monogamy as a prevention strategy is the result of an ongoing negotiation between HIV’s double meaning as a moral and as a public health problem. Condoms are increasingly recognized for their ineffectiveness as they become largely unpopular as an STI prevention method due to “condom fatigue” and the advancements in pharmaceutical HIV prevention and treatment (condom fatigue; condoms are not preferred among gay men paper). The reduction of HIV care into drug adherence is problematic too provided that the free provision of antiretroviral medicine has been proven in Turkey to be deeply insufficient to care for people living with HIV. Studies have also shown that aggressive testing is not necessarily beneficial when the recently diagnosed are not immediately and successfully referred to psychosocial and medical care.¹¹ Besides, neither testing, nor drugs or condoms can be effective on their own for HIV prevention and treatment unless they are implemented together in a joint effort as steps of a larger national strategy that involves interventions across psycho-social, economic, and medical aspects of HIV treatment and prevention.

This dissertation demonstrates how conservative and neoliberal ethics and mechanisms of public health aggravate the conditions of those living with HIV and increase the risk of

⁹ Patton, *Fatal Advice*.

¹⁰ *Ibid.*, 23.

¹¹ John Blake Scott, *Risky Rhetoric: AIDS and the Cultural Practices of HIV Testing*, 1st edition (Carbondale: Southern Illinois University Press, 2003).

transmission for others, especially those who are already marginalized, therefore, rendered immunologically more vulnerable. Although LGBTQI+ community is blamed for “spreading the epidemic” in Turkey, through the concept of “pathogenic care”, I argue that HIV care becomes pathological in Turkey by paving the way for a joint epidemic of HIV and what HIV activists call *HIVfobi*, i.e., status-based stigma and discrimination. In other words, this dissertation documents the ways in which governmental, nongovernmental, medical, and pharmaceutical regimes of HIV care—i.e, the Turkish Ministry of Health, local HIV organizations, health personnel, and Gilead—leave HIV-negative people susceptible to HIV infection and HIV-positive people defenseless against socio-medical violence. By doing so, it brings to the fore the political, economic, and social mechanisms that create harmful conditions of abandonment and precarity by ethnographically engaging with what Bocci and Backe respectively call ‘tangles of care’ and ‘crisis of care’ in different contexts, and what I would like to think of in terms of pathologies of care.¹² In response to the socio-medical violence enacted by pathogenic care, this dissertation also chronicles the emergence of HIV activism in Turkey as a political mode of care practiced by gay and trans HIV activists through intimate and anti-prophylactic networks of peer support, filling the care lacunae created by public health actors of HIV treatment and prevention.

The question of epidemics has long been a topic of interest for anthropologists. In the *Anthropology of Epidemics*, Kelly and her colleagues provide a summary of the ways in which anthropologists approached and examined the question of epidemics.¹³ According to their thematic outline, the first engagement of anthropology with epidemics have been limited to assessing the cultural appropriateness of containment strategies in the face of an urgent public health crisis. Once the anthropologists discovered the complicated social lives of epidemics that temporally extend beyond the moment of their outbreak, they showed attention towards the social consequences of epidemics in terms of the production of the categories of normal and pathological, clean and dirty, safe and contagious. It was the HIV/AIDS epidemic that changed

¹² Emma L. Backe, “A Crisis of Care: The Politics and Therapeutics of a Rape Crisis Hotline,” *Medical Anthropology Quarterly* 32, no. 4 (2018): 463–80; Paolo Bocci, “Tangles of Care: Killing Goats to Save Tortoises on the Galápagos Islands,” *Cultural Anthropology* 32, no. 3 (August 19, 2017): 424–49.

¹³ Ann H. Kelly, Frédéric Keck, and Christos Lynteris, *The Anthropology of Epidemics* (Routledge, 2019).

the fate of the anthropological exploration of epidemics. Beyond having undeniable social impacts, the AIDS crisis led medical anthropologists, geographers, historians, and social scientists more broadly to consider the historical, economic, and political dimensions of outbreaks across local, national, regional, and global coordinates.¹⁴ This was also the moment in which the political stakes of medical anthropology became obvious, motivating many to openly critique the discriminatory public health models, structural inequities, and necropolitics/thanatopolitics of the pharmaceutical industry.¹⁵ Following this decisive moment, anthropologists increasingly turned their attention towards global health advocacy and activism,¹⁶ as well as the growing rhetoric of biosecurity and how it appropriates and exploits the notion of health threat.¹⁷

By situating itself in the outlined genealogy and by claiming to investigate an ongoing HIV epidemic, this dissertation sustains the premise that there is an HIV epidemic in Turkey. However, this line of reasoning carries two risks of considerable significance: First, the assumption that Turkey is facing an HIV epidemic appears to be a contested fact and it deserves further reflection. Although Sayan and his colleagues assert that increasing numbers of incidence point out an undeniable epidemic—which was dubbed ‘a hidden epidemic’ in 2006 by two public health professors Ay and Karabey—HIV activists suspect the discourse of epidemic is at the same time carefully produced by local NGOs to attract further influx of funds and by the pharmaceutical industry to increase nationwide testing efforts that would ultimately maximize antiretroviral prescription.¹⁸ These criticisms are not always unfounded. In the past, I witnessed

¹⁴ See Ezekiel Kalipeni, Susan Craddock, Joseph Oppong, Jayati Gosh eds., *HIV and AIDS in Africa: Beyond Epidemiology* (Wiley, 2003); Elizabeth Fee and Daniel M. Fox, eds., *AIDS: The Burdens of History* (University of California Press, 1988); Elizabeth Fee and Daniel M. Fox, eds., *AIDS: The Making of a Chronic Disease* (University of California Press, 1992).

¹⁵ Margaret Lock and Vinh-Kim Nguyen, *An Anthropology of Biomedicine*, 1 edition (Malden, Mass.: Wiley-Blackwell, 2010).

¹⁶ João Biehl and Adriana Petryna, eds., *When People Come First: Critical Studies in Global Health* (Princeton, NJ: Princeton University Press, 2013).

¹⁷ Steve Hinchliffe et al., *Pathological Lives: Disease, Space and Biopolitics* (John Wiley & Sons, 2017); Carlo Caduff, *The Pandemic Perhaps* (Berkeley: University of California Press, 2015).

¹⁸ Murat Sayan et al., “Dynamics of HIV/AIDS in Turkey from 1985 to 2016,” *Quality & Quantity* 52, no. 1 (December 1, 2018): 711–23; Pinar Ay and Selma Karabey, “Is There A ‘Hidden Hiv/Aids Epidemic’ In Turkey?: The Gap Between The Numbers And The Facts,” *Marmara Medical Journal* 19, no. 2 (2006): 90–97.

employees of local NGOs expressing disappointment over the conservative numbers of HIV transmission shared by the Ministry of Health because they affect funding opportunities adversely. I also had several conversations with the representatives of the pharmaceutical industry about “tens of thousands of people undiagnosed in Anatolia” who need to be identified and diagnosed immediately.

While “undiagnosed people of Anatolia” can be an epidemiological reality, it can also be a scientific myth produced by actors with varied stakes in the existence of an epidemic. We would like to believe that epidemiology falls in the mythical territory of pure science, independent of the human factor, while even a seemingly simple matter of determining when it is acceptable to call an event epidemic turns out to be an inherently political subject. Maureira and his colleagues contend that epidemiology has historically existed in a gray area between science and politics.¹⁹ According to the authors, through employing mathematical models and containment strategies that were to become essential to the exercise of biopower, epidemiological surveillance played a key role in the emergence of nation states and the consolidation of distinctiveness among European societies in the 18th century. In a similar vein, Reubi suggests epidemiology is not only political, but it shapes global and public health policies in powerful ways as epidemiologists “help make up the world, articulating complex and normatively loaded visions of social life that both enable and constrain action.”²⁰ In other words, epidemiology does not always discover the facts it describes; sometimes, it produces them. It is therefore important not to take the Turkish HIV epidemic as an uncontested fact and to pay close attention to the different stakes involved in naming or not naming an epidemic.

When Ian Hacking wrote about “making up people” he referred to the ways in which science gives rise to new classifications of humans who are then treated like new species with

¹⁹ Marco Maureira et al., “The Epidemiological Factor: A Genealogy of the Link between Medicine and Politics,” *International Journal of Cultural Studies* 21, no. 5 (September 2018): 505–19.

²⁰ Reubi, David. “Epidemiological Imaginaries of the Social: Epidemiologists and Pathologies of Modernization in Postcolonial Africa.” *Medical Anthropology Quarterly* 34, no. 3 (2020): 438–55.

incommensurable differences.²¹ We can interpret similarly the manner in which pharmaceutical industry and civil society conjure epidemiological subjects whose existence will serve varying interests. The works of authors such as Adia Benton and Carlo Caduff invite us to approach the rhetoric of epidemic with extra caution. In *HIV Exceptionalism*, Benton examines how even though HIV prevalence is very low in Sierra Leone, HIV is treated as an exceptional disease because of the international agencies' and authorities' assumptions about the inevitability of post-war "African AIDS."²² She carefully documents how the myth of African AIDS is kept alive by local NGOs, HIV+ persons, and the state to enjoy the uninterrupted influx of global aid. Along similar lines, in *The Pandemic Perhaps*, Caduff unearths how in the early 2000s the US experienced a national panic because of a nascent influenza pandemic, which caused widespread doomsday preparation but has never occurred.²³ Caduff situates the production of an imaginary pandemic at the intersection of the prophetic power of the scientific discourse of microbiologists, the security rhetoric of bioterrorism, and the financial promises a potential pandemic made for the pharmaceutical industry.

The second issue with the uncritical adoption of an epidemic framework has to do with the potential biopolitical mechanisms this would trigger. As Linda Singer astutely noted almost three decades ago in her influential book *Erotic Welfare*, "In order to represent a phenomenon as socially undesirable, be it divorce, drug use, single motherhood, teenage pregnancy, one need only call it epidemic. In doing so, one not only engages in a kind of rhetorical inflation, but also mobilizes a certain apparatus and logic, a particular way of producing and organizing bodies politically. An epidemic is a phenomenon that in its very representation calls for, indeed, seems to demand some form of managerial response, some mobilized effort of control."²⁴ According to Singer, the immediate consequence of naming a situation an epidemic is the emergence of a governmental regime under which the regulatory apparatus of surveillance and discipline

²¹ Ian Hacking, "Making Up People," in *Reconstructing Individualism: Autonomy, Individuality, and the Self in Western Thought*, ed. Heller, Sosna, and Wellberry (Stanford, CA: Stanford University Press, 1986), 222–36.

²² Adia Benton, *HIV Exceptionalism: Development through Disease in Sierra Leone* (U of Minnesota Press, 2015).

²³ Carlo Caduff, *The Pandemic Perhaps* (Berkeley: University of California Press, 2015).

²⁴ Linda Singer, *Erotic Welfare: Sexual Theory and Politics in the Age of Epidemic* (Psychology Press, 1992), 23.

multiply and consolidate, as the previous quote suggests. For Singer, this regime is governed by what she interchangeably calls a “logic of epidemic,” a “logic of contagion,” or a “panic logic.”²⁵ This is an epistemic matrix, put simple, a cultural and social lens through which not only the exchange of bodily fluids but everything regarding sex(uality) is interpreted and evaluated in terms of risk.

Provided one of the reasons behind the increasing HIV transmission in Turkey is widely considered to be the conservative governance of sexual health, the argument that naming an epidemic can further pathologize sexuality should be taken seriously. Singer’s critique of epidemics as enabling forces of biopolitical technologies also raises ethical questions about the truth claim I make as to the Turkish HIV epidemic and my seeking for further state involvement to mitigate it. Like many other Turkish doctors and public health specialists, I believe naming the situation with HIV in Turkey an epidemic is a necessary step towards holding authorities responsible for taking appropriate public health actions. As an employee of the Ministry of Health’s infectious diseases bureau confirms, “it is important to call this an epidemic because it attracts the state’s attention.” For the same reason, according to her, it is even advantageous to have HIV still listed as a fatal disease instead of a chronic one. In calling for the state's involvement, I am only interested in what Singer calls ‘beneficent’ effects of power. I agree with her that it is possible to demand the state’s engagement without at the same time risking consolidation of disciplinary, biopolitical, and necropolitical mechanisms. As medical anthropologists Hyde and Biehl have observed in China and Brazil, respectively, government cooperation and investment is indispensable for a successful public health response to HIV.²⁶ For an efficacious and efficient public health strategy, though, there needs to be not only an activist state with a strong political will, but a porous one, guaranteeing people’s participation in its decision-making processes.²⁷

²⁵ Singer, *Erotic Welfare*.

²⁶ Sandra Teresa Hyde, *Eating Spring Rice: The Cultural Politics of AIDS in Southwest China* (Berkeley: University of California Press, 2007); João Biehl, “Pharmaceuticalization: AIDS Treatment and Global Health Politics,” *Anthropological Quarterly* 80, no. 4 (2007): 1083–1126.

²⁷ João Biehl, “The Activist State: Global Pharmaceuticals, Aids, And Citizenship In Brazil,” *Social Text* 22, no. 3 (80) (September 1, 2004): 105–32.

An epidemic within epidemic

“What pushes people into loneliness, hopelessness, and depression is not being positive but being perpetually subjected to stigma and discrimination. When we are under treatment, we are not even contagious. We can become parents, we can be friends, teachers, engineers, or surgeons. We can do anything we want, and we deserve to live a good life. We do not suffer from HIV as we suffer stigma and discrimination. Unlike what everyone else thinks, it is not HIV that kills us slowly, it is HIVfobi that takes away our chances of living a good, healthy life.”

These sentences are uttered by a gay man who wanted to remain anonymous for having already been denied employment as a teacher and urgent medical care based on his HIV status. What is observed in Turkey is an epidemic within epidemic as stigma and discrimination can be more harmful and contagious than HIV. The existing law of discrimination does not recognize health, sexual orientation or gender identity among the fundamental rights and freedoms to be protected. The law no. 122 of Turkish Penal Code on hate crimes and discrimination list “language, race, nationality, color, sex, disability, political views, philosophical views, religion, and sect” as grounds on which people should not be discriminated against. Yet, the law is widely criticized by human rights lawyers for its acute inability to protect some of the most disadvantaged groups of the society while establishing religion as the primary category to be protected. As a result, there are no legal or criminal sanctions in place to prevent discrimination based on health status, gender identity, and sexual orientation, resulting in the abandonment of LGBTIs who are subjected to hate crimes and discrimination on the account of all three categories. Queer people living with HIV are especially made vulnerable due to the absence of formal mechanisms that can provide them with assistance when they are not accepted into hospitals, fired from their work, or denied housing and other basic necessities. It is the consensus among local NGOs, HIV activists, and researchers that ubiquitous stigma and discrimination—which is commonly referred as *HIVfobi*, HIVphobia—not only harms HIV+ individuals in vital ways but puts the

public's health at greater risk by preventing persons from getting tested for HIV and knowing their status.²⁸

HIV-positive people in Turkey have been identified as one of the most vulnerable groups, especially when their status is intersecting with other socio-economic precarities.²⁹ The fear of medical contagion is the driving force behind the individual instances of stigma and discrimination, although the fear of social contagion is equally prevalent.³⁰ Lack of information and misinformation are accepted as the root causes of rampant HIVphobia. According to a study conducted with the participation of 1,605 responders that were asked who they would not want to be neighbors with, 84% of the participants chose the answer "homosexuals" whereas 74% marked the answer "people living with HIV/AIDS."³¹ In a more recent and comprehensive study entitled *AIDS Awareness Report* and carried out collaboratively by an NGO, a drug company, a university, and an HIV/AIDS research & treatment center, more than twenty thousand people answered a questionnaire to assess their knowledge of HIV.³² The results revealed that more than 70% of the respondents did not have any information about HIV, its transmission routes, or how to prevent it. A lot of people in Turkey believe that sharing the same food and breathing the same air is a mode of HIV transmission.³³ It is also commonly thought that HIV is a punishment from

²⁸ Deniz Gokengin, "HIV Infection in Turkey: How Close Are We to the Target?," *Klimik Dergisi/Klimik Journal*, June 6, 2018, 4–10; Deniz Gokengin, Sebnem Calik, and Pinar Oktem, "Analysis of HIV/AIDS-Related Stigma and Discrimination in Turkey: Results of the People Living With HIV Stigma Index," *Klimik Dergisi/Klimik Journal* 30, no. 1 (May 8, 2017): 15–21; Fatma Sargin and Safak Goktas, "HIV Prevalence among Men Who Have Sex with Men in Istanbul," *International Journal of Infectious Diseases* 54 (January 2017): 58–61; Sukran Kose et al., "The Social and Health Problems of People Living with HIV/AIDS in Izmir, Turkey," *The Eurasian Journal of Medicine* 44, no. 1 (April 1, 2012): 32–39.

²⁹ Aytül Kasapoğlu and Elif Kuş, "The Role of Gender in the Stigmatization of People Living with HIV/AIDS in Turkey," *Journal of Gender Studies* 17, no. 4 (December 2008): 359–68.

³⁰ Aytul Kasapoglu et al., "AIDS Related Stigma in Social Relations: A Qualitative Study in Turkey," *Qualitative Report* 16, no. 6 (November 2011): 1496–1516.

³¹ Yılmaz Esmer, "Turkey Atlas of Values (Turkiye Degerler Atlasi)," 2012, <https://bau.edu.tr/icerik/1725-turkiye-degerler-atlasi-2012-yayinlandi>.

³² Malhan Simten and Serhat Unal, "HIV/AIDS Farkindalik Raporu (HIV/AIDS Awareness Report)," 2017, <chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.bizimaramizda.org/wp-content/uploads/2021/10/HIVAIDS-Farkindalik-Raporu.pdf>.

³³ Semiha Akin et al., "Turkish Nursing Students' Knowledge of and Attitudes towards Patients with HIV/AIDS," *Journal of Clinical Nursing* 22, no. 23–24 (December 2013): 3361–71; Sukran Kose et al., "The Social and Health Problems of People Living with HIV/AIDS in Izmir, Turkey," *The Eurasian Journal of Medicine* 44, no. 1 (April 1,

God, that HIV+ people should be quarantined, and that HIV/AIDS is the direct result of unapproved gender identities and other ‘foreign and immoral’ cultural elements imported from the West.³⁴

HIV in Turkey is an epidemic of signification in the truest sense of the term.³⁵ During my fieldwork, I would repeatedly ask my friends what they knew about HIV/AIDS. Many middle- or upper-class college graduates would cite the myth of AIDS-infected needles left in the movie theaters’ seats, park benches, bar and McDonald’s restrooms, waiting to come into contact and infect innocent people. Or they would mention the myth of trans sex workers receiving money from the pharmaceutical industry to spread the virus. The widespread lack of information and awareness does not only stem from the absence of national educational initiatives about sexual health. The media is also replete with wrong, unscientific information and othering language. Given most of the Turkish public accesses information on HIV/AIDS through television, NGOs and activists frequently express concern over information pollution and how it contributes to HIVfobi. Once the director of *Pozitif-iz*, Önder, shared his disappointment with the only Turkish movie that used HIV in its main storyline and had a positive protagonist. “Information about HIV is too scant. We don’t know the modes of transmission. While the NGOs’ awareness-raising attempts reach only a few people, the movie *İncir Reçeli* (*fig jam*) is seen by millions. We all know what happened in the movie. All positive characters died. The daughter died, the father died, the mother died years ago. So, the message is clear, HIV equals death.” No matter how much local NGOs try to spread the information that one cannot get HIV by kissing or touching, *İncir Reçeli* depicts dramatic scenes where HIV+ partner cannot touch, hug, or kiss her lover. The only time they kiss happens through a transparent glass barrier. Önder’s anger also originates from the fact that the director of the movie, Aytaç Ağırlar, consulted *Pozitifiz* prior to

2012): 32–39; Eda Yakıt and Anahit Margirit Coşkun, “LGBT Bireylere Yönelik HIV İle İlgili Güvenli Olmayan Cinsel Davranışların Belirlenmesi,” *İnsan ve Toplum Bilimleri Araştırmaları Dergisi* 5, no. 5 (July 1, 2016): 1400.

³⁴ Unal Ayrancı, “AIDS Knowledge and Attitudes in a Turkish Population: An Epidemiological Study,” *BMC Public Health* 5, no. 1 (December 2005): 95; Yılmaz Esmer, “Turkey Atlas of Values (Türkiye Değerler Atlası),” 2012; Naim Nur, “Turkish School Teachers’ Knowledge and Attitudes toward HIV/AIDS,” *Croatian Medical Journal* 53, no. 3 (June 2012): 271–77.

³⁵ Paula A. Treichler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*, 1 edition (Durham, NC: Duke University Press Books, 1999).

the release of his film. Even though the association provided Ağırlar with a detailed explanation of the factual mistakes in the movie and how they can drive fear and stigma, deleterious both for public health and HIV+ persons, the director moved on to releasing the movie without any revision. His defense was that art should be free from factual concerns.



Figure 7: A still from the film *İncir Reçeli* where the protagonists kiss through a glass barrier at a bus stop.

Rejection, exclusion, abandonment, being subjected to gossip, verbal abuse, threat, and aggression in the hands of the family, friends, and partners are some of the primary shapes HIVfobi takes in social life. Due to its sexual transmission, HIV is considered “a bad person’s disease” and the fear of social and medical contagion overdetermines many formal and informal relationships.³⁶ As an activist friend said during a social gathering at my apartment, “People consider us as dangerous, risky, and contagious. HIV is not just any virus; it implies sexuality and queerness. That’s why everyone sees us as monsters or half-dead, half-living, death spreading zombies.” I was struck by his metaphor of death spreading zombies because it is an

³⁶ Kasapoglu et al., “AIDS Related Stigma in Social Relations.”

ingenious sociological observation. For deviating from the statistically maintained definition of normality—i.e., being HIV-negative, healthy, noninfectious—HIV+ persons are registered as anomalous threats to the moral health of the social body as well as the physiological health of the general public. Although not all anomalies are pathological, as Canguilhem noted,³⁷ the wall of stigma and fear built around HIV causes those living with the virus to be seen as a pathological anomaly, destructive to the healthy functioning of a body, both biological and social. An anomaly is easily translatable into an abnormality too. Being HIV+ not only implies a deviation from the norm/al; it also implies a perversion, an irrevocable departure from the ideal, average, ordinary, healthy and noninfectious state of existence.

The low level of HIV awareness should not be taken as a sign of ignorance among just lay people. Studies demonstrate that nurses and doctors do not have sufficient, up-to-date, or correct information about HIV and AIDS either.³⁸ Turkish infectious diseases and public health specialists recurrently share concern over students finishing medical schools without having learned HIV's transmission routes. This can hold some light into why HIVfobi takes place most blatantly and frequently in healthcare settings, where the fear of contagion is intensified.³⁹ The recorded cases of violation of HIV+ persons' rights from 1985 to 2021 reveal that an overwhelming majority of cases consist of discrimination at hospitals and clinics, followed by workplace and social life.⁴⁰ The denial of treatment and examination and the disclosure of patients' HIV status to third parties are the most common problems faced at healthcare facilities.⁴¹ Discriminatory practices in health facilities toward PLHIV include but are not limited to refusing to provide treatment, keeping clients waiting longer, or referring clients unnecessarily to other health facility staff or facilities; gossip and verbal abuse, such as scolding and name

³⁷ Georges Canguilhem, *On the Normal and the Pathological* (Springer Science & Business Media, 1966).

³⁸ V. Duyan, F. Agalar, and I. Sayek, "Surgeons' Attitudes toward HIV/AIDS in Turkey," *AIDS Care* 13, no. 2 (April 2001): 243–50; Ozlem Koseoglu Ornek, Fehmi Tabak, and Birgul Mete, "Stigma in Hospital: An Examination of Beliefs and Attitudes towards HIV/AIDS Patients, Istanbul," *AIDS Care* 32 (May 25, 2020): 1–7.

³⁹ Duyan, Agalar, and Sayek, "Surgeons' Attitudes toward HIV/AIDS in Turkey."

⁴⁰ Pozitif Yasam Dernegi (PYD). "The Reports of Rights Violations (Hak Ihalleri Raporlari)," <https://pozitifyasam.org/raporlarimiz/>.

⁴¹ Gamze Senyurek, Mustafa Volkan Kavas, and Yesim Isil Ulman, "Lived Experiences of People Living with HIV: A Descriptive Qualitative Analysis of Their Perceptions of Themselves, Their Social Spheres, Healthcare Professionals and the Challenges They Face Daily," *BMC Public Health* 21 (May 12, 2021): 904.

calling; marking the files or clothing of patients living with HIV or isolating clients in separate waiting areas or wards when there is no clinical need to do so; forcing clients to be tested for HIV or tuberculosis without their consent, without adequate counseling, and without providing the results of the tests to the client; disclosing the HIV status of clients to other health staff, family members, or other people without the consent of clients; excessive use of barrier precautions, such as using gloves or face shields for routine tasks that do not involve the handling of bodily fluids.

When it comes to HIV-related discrimination in the workplace, cancellation of contract by the employer, the unlawful requirement of an HIV test for job applications, violations of privacy, and discriminatory attitudes at the workplaces are the most common problems.⁴² In Turkey, a prospective employee must provide a clean bill of health to prove they do not have a communicable disease. Existing regulations do not require the person to get tested for HIV, yet the occupational physicians usually demand an HIV test without the knowledge or consent of the employee. Sometimes, if the person is a male who did not complete the mandatory military service, the workplace demands to know the reason for their failure to serve in the army as well. Normally, the bill of exemption should suffice for bureaucratic purposes, but occupational physicians can insist on knowing the details of the exemption since they suspect it's either because the person is gay or HIV+, both of which count as reasons to be exempt from the service.⁴³ Once the physicians unlawfully find out about someone's HIV status, they are obliged by law to respect the privacy of the information and not allowed to share it with the employer. Yet, due to the unsounded fear that an HIV+ person could be a risk for the entire workplace, occupational physicians inform the employers about what they believe is a potential health threat. Many people living with HIV are either fired from their jobs when their status is revealed or not hired at the first place. Because regulations do not allow someone to be denied a job because of their chronic health condition, most employers find other performance-based excuses to terminate the contract. Such forms of discrimination not only violate the fundamental human

⁴² Pozitif Yasam Derneği (PYD), "The Reports of Rights Violations (Hak İhalleri Raporları)."

⁴³ T. Atuk, "Comrades-in-[Each Other's]-Arms: Homosociality, Masculinity and Effeminacy in the Turkish Army," *Men and Masculinities*, August 1, 2019.

right to decent work but also might cause disruption in treatment because of the loss of health insurance.⁴⁴

Pathogenic Care

Biopolitics implies a hierarchy with the immunized at the top and the de-munized, who will be excluded from any act of immunological protection, at the bottom.

—Paul B Preciado, 2020

Care is ambivalent, elusive, and contradictory. It produces abandonment and harm, but also gives rise to alternative forms of belonging and carefulness. There is no unique word in Turkish to translate ‘care’—it can mean service, nursing, or attention among other things. The semantic richness of the word itself points out the necessity to approach care not as a predetermined category but a fluid notion that acquires meaning and direction in everyday practices, ordinary encounters, and political imaginations. Han agrees that we should resist the urge to fix the meaning of care in time and space to be open to its being diffuse and untamable. STS scholars too approach care as a ‘slippery word’ and choose to focus on the “ambivalent rhetorics and practices taken up in its name.”⁴⁵ Similarly, in their introduction to the special issue on *Unsettling Anthropologies of Care*, Cook and Trundle invite their reader to embrace the ambiguity and instability of care. The authors advocate for an “analytic approach to care that questions care as either morally suspect or morally virtuous and instead allows for the compromised, shifting, and ambiguous dimensions of care practices to take center stage.”⁴⁶ Regardless of its definition, however, in the hands of the Turkish state, humanitarian NGOs, Ministry of Health, military, health personnel, and police, care has often implied a certain

⁴⁴ Hülya Özkan Özdemir et al., “The Determinants of Employability of People Living with HIV/AIDS in Turkey,” *American Journal of Industrial Medicine* 63 (October 3, 2019): 1–7.

⁴⁵ Aryn Martin, Natasha Myers, and Ana Viseu, “The Politics of Care in Technoscience,” *Social Studies of Science* 45, no. 5 (October 1, 2015): 625–41.

⁴⁶ Joanna Cook and Catherine Trundle, “Unsettled Care: Temporality, Subjectivity, and the Uneasy Ethics of Care,” *Anthropology and Humanism* 0, no. 0 (2020): 1.

amount of pain and dispossession in Turkey for disabled veterans,⁴⁷ queer refugees,⁴⁸ Kurdish and political prisoners,⁴⁹ urban precariat,⁵⁰ and ordinary citizens.⁵¹ To this date, missing from the anthropological explorations of care has been an account of HIV care in Turkey or the Middle East. Including in academic discussions, Muslim-majority countries have been depicted as socially immune to HIV due to the alleged prophylactic function of Islamic values. This form of scientific Orientalism has only helped authoritarian governments to deny and invisibilize the existence of not only the virus but those living with it. What an investigation of HIV care at the intersections of Islam, neoliberalism, and authoritarianism reveals is that care mechanisms do not suddenly or unexpectedly turn against those they are meant to serve. Instead, they are all along capable of causing harm as they were never meant to “care about,” recognize a need for care, or “care for”, take responsibility to meet the needs of those who are deemed unimportant, unworthy, and unsafe.⁵²

The theoretical and ethnographic richness of care has been capturing the interests of medical and cultural anthropologists for more than a decade now.⁵³ Among the first objects of

⁴⁷ Salih Can Açıksöz, “Sacrificial Limbs of Sovereignty: Disabled Veterans, Masculinity, and Nationalist Politics in Turkey,” *Medical Anthropology Quarterly* 26, no. 1 (March 2012): 4–25.

⁴⁸ Elif Sari, “Lesbian Refugees in Transit: The Making of Authenticity and Legitimacy in Turkey,” *Journal of Lesbian Studies* 24, no. 2 (April 2, 2020): 140–58; Mert Koçak, “Who Is ‘Queerer’ and Deserves Resettlement?: Queer Asylum Seekers and Their Deservingness of Refugee Status in Turkey,” *Middle East Critique* 29, no. 1 (January 2, 2020): 29–46.

⁴⁹ Serra Hakyemez, “Margins of the Archive: Torture, Heroism, and the Ordinary in Prison No. 5, Turkey,” *Anthropological Quarterly* 90, no. 1 (2017): 107–38.

⁵⁰ Alize Arıcan, “Behind the Scaffolding: Manipulations of Time, Delays, and Power in Tarlaş, Istanbul,” *City & Society* 32, no. 3 (2020): 482–507; Alize Arıcan, “1237, or Dying Elsewhere,” *Current Anthropology* 62, no. 1 (February 2, 2021): 110–16.

⁵¹ Hayal Akarsu, “Citizen Forces,” *American Ethnologist* 47, no. 1 (2020): 27–42.

⁵² Joan C. Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (Psychology Press, 1993).

⁵³ Annemarie Mol, *The Logic of Care: Health and the Problem of Patient Choice* (Routledge, 2008); Janelle S Taylor, “On Recognition, Caring, and Dementia,” *Medical Anthropology Quarterly* 22, no. 4 (2008): 313–35; Evelyn Nakano Glenn, *Forced to Care: Coercion and Caregiving in America* (Cambridge, MA: Harvard University Press, 2010); Laura Lynn Heinemann, “For the Sake of Others: Reciprocal Webs of Obligation and the Pursuit of Transplantation as a Caring Act,” *Medical Anthropology Quarterly* 28, no. 1 (March 2014): 66–84; Carina Heckert, *Fault Lines of Care: Gender, HIV, and Global Health in Bolivia* (New Brunswick: Rutgers University Press, 2018); Sandra Teresa Hyde, “‘Spending My Own Money, Harming My Own Body’: Addiction Care in a Chinese Therapeutic Community,” *Medical Anthropology* 36, no. 1 (January 2, 2017): 61–76; Felicity Aulino, *Rituals of Care: Karmic Politics in an Aging Thailand* (Ithaca, NY: Cornell University Press, 2019); Ciara Kierans, *Chronic Failures: Kidneys, Regimes of Care, and the Mexican State* (New Brunswick: Rutgers University Press, 2019); Sandra Teresa Hyde and Laurie Denyer Willis,

the critical query were ‘care practices’⁵⁴—or ‘practicalities of care’⁵⁵—and the ethics of caregiving.⁵⁶ Initially, care was studied closely in ‘spaces of personal relationships’⁵⁷ or clinical settings.⁵⁸ This interest in the everyday modes of care encouraged others to attentively examine the emergence of local, familial, and community-based networks of care. Elders, family member, and grassroots organizations are shown to replace the formal networks of care when they fail or become harmful.⁵⁹

Care can operate as an ‘armed love’ where repressive measures are instituted in its name by humanitarian agencies.⁶⁰ It can produce enduring conditions of harm when it is motivated by profit-driven neoliberal ethics,⁶¹ and may become murderous in the hands of a colonial state.⁶² When it involves rehabilitating drug users, care can become “criminal, perverse, or self-defeating.”⁶³ It can also simultaneously involve compassion and brutality for homeless women who use drugs.⁶⁴ Or care may imply extreme violence in rape victims’ experiences with forensic

“Balancing the Quotidian: Precarity, Care and Pace in Anthropology’s Storytelling,” *Medical Anthropology* 39, no. 4 (May 18, 2020): 297–304; Lauren Cubellis, “Gestures of Care and Recognition: An Introduction,” *Cultural Anthropology* 35, no. 1 (February 12, 2020); Zoë H. Wool, *After War: The Weight of Life at Walter Reed* (Durham, NC: Duke University Press, 2015).

⁵⁴ Annemarie Mol, Ingunn Moser, and Jeannette Pols, *Care in Practice: On Tinkering in Clinics, Homes and Farms* (Bielefeld, Germany: Transcript, 2010).

⁵⁵ Jeannette Pols, “Washing The Citizen: Washing, Cleanliness And Citizenship In Mental Health Care,” *Culture, Medicine and Psychiatry* 30, no. 1 (March 2006): 77–104.

⁵⁶ Arthur Kleinman, *The Soul of Care: The Moral Education of a Husband and a Doctor* (Penguin, 2019).

⁵⁷ Emily Yates-Doerr, “The Weight of the Self: Care and Compassion in Guatemalan Dietary Choices: Care and Compassion in Guatemalan Dietary Choices,” *Medical Anthropology Quarterly* 26, no. 1 (March 2012): 136–58.

⁵⁸ Julie Livingston, *Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic* (Durham, NC: Duke University Press, 2012).

⁵⁹ Angela Garcia, *The Pastoral Clinic: Addiction and Dispossession Along the Rio Grande* (Berkeley: University of California Press, 2010); Clara Han, *Life in Debt: Times of Care and Violence in Neoliberal Chile* (Berkeley: University of California Press, 2012); Vincanne Adams, *Markets of Sorrow, Labors of Faith: New Orleans in the Wake of Katrina* (Durham, NC: Duke University Press, 2013).

⁶⁰ Miriam Iris Ticktin, *Casualties of Care: Immigration and the Politics of Humanitarianism in France* (Berkeley: University of California Press, 2011).

⁶¹ Adams, *Markets of Sorrow, Labors of Faith*.

⁶² Lisa Stevenson, *Life Beside Itself: Imagining Care in the Canadian Arctic* (Berkeley: Univ of California Press, 2014).

⁶³ Garcia, *The Pastoral Clinic*.

⁶⁴ Andrea M. López, “Necropolitics in the ‘Compassionate’ City: Care/Brutality in San Francisco,” *Medical Anthropology* 39, no. 8 (November 16, 2020): 751–64.

nurses,⁶⁵ and the way violence of care “is lived and experienced enfolds many different temporal moments in ‘the everyday’.”⁶⁶ Finally, care can simply become harmful when it marginalizes vulnerable communities it contends to protect by reifying them as racially risky groups.⁶⁷

Nonetheless, representations of care, patient activism, and HIV in the Middle East have been largely missing from academic discussions. In other contexts, scholars explored the intertwined relationship between harm and care and called attention to the inherited paradoxes (HIV) care is predicated on.⁶⁸ Yet they have paid little attention to the ‘pathogenicity’ of care. By looking at the ways in which the regimes of care render HIV more pathogenic, this dissertation conceptualizes care as part and parcel of the problems it seeks to alleviate. In doing so, it will further destabilize the onto-epistemological separation of harm, abandonment, and care. I seek to show that socio-medical abandonment is not only caused by neglect and rejection but also empty gestures of care, such as the ones undertaken in the name of preventing HIV and treating HIV+ citizens in Turkey. In other words, zones of abandonment and harm are not always results of lack of care⁶⁹—sometimes precarity is produced by the ambivalent absent-presence of mechanisms put in place to provide care. Therefore, this dissertation explores care as an inherently paradoxical practice that resists simple definitions of biopolitics that cannot account for its complexity. As Aizura incisively noted in *Mobile Subjects*, “[t]he key is understanding that incoherence, mutation, and contradiction are central to governmentalities and biopolitics.”⁷⁰

⁶⁵ Sameena Mulla, *The Violence of Care: Rape Victims, Forensic Nurses, and Sexual Assault Intervention* (New York ; London: NYU Press, 2014).

⁶⁶ Alyshia Gálvez, Megan Carney, and Emily Yates-Doerr, “Chronic Disaster: Reimagining Noncommunicable Chronic Disease,” *American Anthropologist* 122, no. 3 (2020): 640.

⁶⁷ Thurka Sangaramoorthy, *Treating AIDS: Politics of Difference, Paradox of Prevention* (New Brunswick, NJ: Rutgers University Press, 2014).

⁶⁸ Sangaramoorthy, *Treating AIDS*.

⁶⁹ João Biehl, *Vita: Life in a Zone of Social Abandonment* (Berkeley: Univ of California Press, 2013); Elizabeth A. Povinelli, *Economies of Abandonment: Social Belonging and Endurance in Late Liberalism* (Durham, NC: Duke University Press, 2011).

⁷⁰ Aren Z. Aizura, *Mobile Subjects: Transnational Imaginaries of Gender Reassignment, Perverse Modernities* (Durham: Duke University Press, 2018),168.

HIV has not become a global pandemic because of the deviancy of gay men or cultural backwardness of people from Africa or risky behaviors of African-Americans. As Jason Hickel argues, high HIV prevalence in Swaziland “is less a biomedical condition than a symptom of neoliberal market policy” and for that reason “the burden of behavior change should lie not with HIV patients but with the architects and beneficiaries of the prevailing economic order.”⁷¹ In a similar vein, Adam Geary explains the risk of HIV infection for African-Americans not based on the so-called risk behaviors but “the violent intimacy of the racist state” that renders an entire population vulnerable to HIV by wearing them out physically, mentally, and, most significantly, immunologically.⁷² As such, epidemics are not individually caused by so-called risky behaviors, communities, or microbes; rather, they are made relationally in an ever-shifting assemblage of social, political, economic, and historical forces. What creates risk for the individual, public, and global health is not so much viruses or microbes as it is the structural and systemic factors that transform otherwise harmless microscopic entities into pathogenic forces to be reckoned with. The concept of pathogenicity as developed by Hinchliffe and his colleagues signals that “disease is always a matter of more than pathogens alone,”⁷³ given microbes and viruses always exist(ed) among us, but they don’t always cause diseases. That is, they are not necessarily pathogens, for certain conditions have to be met for them to turn infectious. Such conditions can vary

⁷¹ Jason Hickel, “Neoliberal Plague: The Political Economy of HIV Transmission in Swaziland,” *Journal of Southern African Studies* 38, no. 3 (September 1, 2012): 513.

⁷² Adam M. Geary, *Antiblack Racism and the AIDS Epidemic: State Intimacies* (New York: Palgrave Macmillan US, 2014).

⁷³ Steve Hinchliffe et al., *Pathological Lives: Disease, Space and Biopolitics* (John Wiley & Sons, 2017): xvi.

significantly from racism⁷⁴ and authoritarianism to poverty, from privatization of drug patents to unethical drug trials,⁷⁵ and from colonialism to neoliberalism.⁷⁶

At times, the conditions necessary for a virus to become more infectious are created and sustained by the very mechanisms established to prevent its transmission. By narrowly focusing on microscopic agents as the origins of epidemics, we miss the crucial role public health policies and technologies play in the emergence and continuation of public health outbreaks. I call this kind of care pathogenic, on the one hand, because it increases the pathogenicity of HIV in Turkey by blocking people from being informed about sexual health, using protection, getting tested, knowing their status, and using medicine—all the necessary precautions to prevent new transmissions. As I will discuss in the next chapter, free or low-cost access to state-of-art antiretroviral medicine is relatively easier in Turkey compared to many other “developed” and “developing” countries. Notwithstanding, not enough precaution is taken to prevent new HIV transmissions. This is a governmental modality that substitutes, or rather complements, the famous “make live, let die” logic of contemporary biopolitics with the logic of “make live, let infect/be infected”. In the words of Angela Garcia, then, pathogenic care can “enhance, remake, and sometimes reduce the life possibilities.”⁷⁷

On the other hand, HIV care has not become pathogenic solely due to its acute failure to prevent new HIV transmissions. I use the term pathogenic also to attract attention to how People

⁷⁴ Cathy J. Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*, 1st Edition (Chicago: University of Chicago Press, 1999); Tankut Atuk and Susan L Craddock, “Social Pathologies and Urban Pathogenicity: Moving towards Better Pandemic Futures,” *Urban Studies*, May 1, 2022, 00420980221079462; Francisco Ortega and Michael Orsini, “Governing COVID-19 without Government in Brazil: Ignorance, Neoliberal Authoritarianism, and the Collapse of Public Health Leadership,” *Global Public Health* 15, no. 9 (September 1, 2020): 1257–77; Paul Farmer, *Infections and Inequalities: The Modern Plagues, Updated with a New Preface*, Updated edition (Berkeley: University of California Press, 1999); Paul Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor* (Berkeley: University of California Press, 2003).

⁷⁵ Paul Farmer, *Infections and Inequalities: The Modern Plagues, Updated with a New Preface*, Updated edition (Berkeley: University of California Press, 1999); Paul Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor* (Berkeley: University of California Press, 2003).

⁷⁶ Didier Fassin, *When Bodies Remember: Experiences and Politics of AIDS in South Africa*, First edition (Berkeley: University of California Press, 2007); Hickel, “Neoliberal Plague.”

⁷⁷ Garcia, *The Pastoral Clinic*, 10.

Living with HIV (PLWH) are left defenseless against socio-medical violence by the so-called caring institutions and actors. The absolute disenfranchisement of HIV+ citizens, stripping them of all privileges provided to HIV-negative people, and abandoning them with no means to protect themselves against harm reminds the reduction of *homo sacer* into the status of bare flesh that deserves no protection.⁷⁸ Infection with a virus is sufficient enough ground to cancel one's legal, medical, and social rights who, after all, do not deserve them for being a threat for the rest of the society. We must understand that the production of *homo sacer* is instrumental to the protection of others who cannot sacrifice but may exterminate bare lives. In *Sacrificial Limbs*, Açıksoz makes a critical intervention in Agamben's theorization of bare life by calling attention to how "[t]he production of some bodies as *homo sacer* always depends on the sacralization of others in the name of whom the former can be rendered killable."⁷⁹ The marginalization and debilitation of HIV-infected bodies is intimately related to the sacralization of HIV-free bodies who will ensure the social and biological reproduction of the nation, even when it means help eradicating potential biological threats who cannot be sacrificed—because their blood is infected and not worthy as a sacrifice—yet shall be “beheaded” or “burned alive” as angry crowds once demanded in Turkey when HIV disclosure was being publicly discussed.

The symbolic division of society as the sacred and worthy ones, on the one hand, and unholy and ungrievable ones on the other coincides with the production of the categories of normal and abnormal. In *Ordinary Genomes*, Taussig observes that “[b]iopolitics operates most powerfully through its delineation of the contours of the normal.”⁸⁰ She also calls attention to the volatility of the category normal for it is constantly threatened by its constitutive outside, abnormal. The perpetual pressure to firmly establish the boundaries of normality necessitates the continual disavowal of those who deviate from the normal. Biopolitics establish normality through governance technologies such as *state-istics*, producing “normal distribution” and

⁷⁸ Giorgio Agamben, *Homo Sacer: Sovereign Power and Bare Life* (Stanford, CA: Stanford University Press, 1998).

⁷⁹ Salih Can Aciksoz, *Sacrificial Limbs: Masculinity, Disability, and Political Violence in Turkey* (Univ of California Press, 2019), 10.

⁸⁰ Karen-Sue Taussig, *Ordinary Genomes: Science, Citizenship, and Genetic Identities* (Duke University Press, 2009), 10.

“standard deviation” as a means to understand and govern the population.⁸¹ Australian historian of science Alison Bashford wrote about public health as *a technology of power* that consolidated the whiteness and racial purity of Australia by erecting ideological lines between pathological, contaminated others and the white nation.⁸² Those who do not fall into the category of normal are marked as *deviants* whose abnormality is considered not as a result of artificially small margins of error, but as a result of being a marginal error that needs to be corrected. If identification of the error is the first task of modern biopolitics, its correction is its second, and it is done using the same techniques in place to extend and improve the lives deemed deserving by bell curves. To put it simply, when protection, testing, and drugs are promoted—that is, when “the power to govern is presented as the power to heal”⁸³—it is done so to regulate sex, sexuality, bodies, and pleasures, rather than to promote healthy publics. As Craddock meticulously demonstrates in *The City of Plague*, once a disease is associated with deviancy, it becomes a tool of social control that facilitates the surveillance and governance of so-called risky individuals and communities in the name of public health.⁸⁴

Given both the visible harms and benefits of care, it is a difficult task to determine whether care belongs to the domain of necropolitics or biopolitics. This difficulty mainly stems

⁸¹ Michel Foucault, *Security, Territory, Population: Lectures at the Collège de France 1977--1978*, First edition (New York, NY: Picador, 2007). In his lecture series entitled *Security, Territory, Population*, Foucault addresses the emergence a new form of power in the 18th century. He is particularly concerned with the question of security: security not of the territory or society but of the population. The particular way in which the question of security arises in the 18th century according to Foucault is the epidemics. The dangers of leprosy, plague, and smallpox necessitate both a new way of understanding the subjects of a state and a new technique of addressing their needs, as well as ruling them. Disciplinary power, which takes the individual as its target, is no longer viable to be able to effectively respond to epidemics that put everyone’s *lives* at danger. The new technique, therefore, arises in this context with the purpose of regulating the life of the population. In another series of lectures, *Society Must Be Defended*, Foucault writes, “What we are dealing with in this new technology of power is not exactly society (or at least not the social body, as defined by the jurists), nor is it the individual-as-body. It is a new body, a multiple body, a body with so many heads that, while they might not be infinite in number, cannot necessarily be counted. Biopolitics deals with the population, with the population as political problem, as a problem that is at once scientific and political, as a biological problem and as power’s problem.”

⁸² Alison Bashford, “Quarantine and the Imagining of the Australian Nation,” *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 2, no. 4 (October 1998): 387–402.

⁸³ Catherine Waldby, *AIDS and the Body Politic: Biomedicine and Sexual Difference* (Routledge, 2003), 5.

⁸⁴ Susan Craddock, *City of Plagues: Disease, Poverty, and Deviance in San Francisco* (Minneapolis, MN: U of Minnesota Press, 2000).

from the extent to which necropolitical governance of death is integral to biopolitical governance of life, and vice versa. For Banu Bargu, who compares Turkey to a necropolitical laboratory where a wide repertoire of violence is in the making, necropolitics is the permanent other of biopolitics. Building on the intellectual lineages of Foucault, Agamben, and Mbembe, Bargu calls attention to a “necropolitical undercurrent that, sometimes loudly and at other times silently and subtly, flows below the surface of Turkey’s political regime.”⁸⁵ The analogy of undercurrent is an apt way to understand necropolitics according to Bargu because necropolitical violence often remains in the shadows of democracy and it does not always resurface in the form of obvious death-making. Hence, saying care can be necropolitical does not mean it actively and willfully engages in the act of killing, although it is recorded to be murderous in certain instances.⁸⁶ “There are also other, more subtle modalities of violence that operate not to kill or to injure but to render (some) lives unliveable, through the infliction of a myriad of psychic, symbolic and epistemic infringements and harms alongside the threat and deployment of deadly force.”⁸⁷ The conceptualization of necropolitics as a biopolitical modality of governance that does not only take life but also undermines it through various actions—or inactions—may be the key to understanding the inherent paradoxes of care.

Should we follow a different genealogy of biopolitics, a rather unpopular one in the North American academic circles, we can assert that beyond being each other’s permanent, significant others, biopolitics and necropolitics are two faces of the same coin. According to Italian philosopher Roberto Esposito, both life making and life taking are intrinsic to the operation of the biopolitical dispositifs—in fact, it is often the preservation of life itself that requires the elimination of others who are deemed risky and contagious. For Esposito, we must deconstruct the concept of biopolitics to resolve the tensions it is built on and re-imagine it in terms of modern civilizations’ “most intimate essence”, that is immunization.⁸⁸ The main tension

⁸⁵ Banu Bargu, “Turkey’s Necropolitical Laboratory: Notes towards an Investigation,” in *Turkey’s Necropolitical Laboratory*, by Banu Bargu (Edinburgh University Press, 2019), 1.

⁸⁶ See Lisa Stevenson, *Life Beside Itself*.

⁸⁷ Bargu, “Turkey’s Necropolitical Laboratory,” 2; Also see Lauren Berlant, “Slow Death (Sovereignty, Obesity, Lateral Agency),” *Critical Inquiry* 33, no. 4 (2007): 754–80.

⁸⁸ Roberto Esposito, *Bíos: Biopolitics and Philosophy* (U of Minnesota Press, 2008), 55.

he identifies in Foucault's theorization is expressed in the form of two questions: "Why does a politics of life always risk being reversed into a work of death?" and "How is it possible that a power of life is exercised against life itself?."89 Put simply, Esposito is concerned with how the destructive and productive aspects of biopolitics come together in a single framework. He criticizes (a) Foucault, for not making a decision on whether biopower is the power *of* life or power *over* life, (b) Agamben, because he reduced biopolitics to the production of unworthy and ungrievable lives, (c) Hardt and Negri, since their biopolitics is overdetermined by the productive possibilities of the multitude.

In order to resolve the paradox of biopolitics and understand the true nature of the relationship between life and politics, Esposito guides us towards what he names the immunitarian paradigm. When biopolitics is revisited from the perspective of immunization, we are not only able to bridge the theoretical gap between the affirmative and negative interpretations of biopolitics. We can also grasp the extent to which the logics of preserving and undermining life are not self-contradictory or mutually exclusive. "Only when biopolitics is linked conceptually to the immunitary dynamic of the negative protection of life does biopolitics reveal its specifically modern genesis" writes Esposito in an attempt to establish immunity as the defining paradigm of contemporary life.⁹⁰ "The point is that wherever you look, what is happening in the world today, from the individual to the social one, from the technological body to the political one, you will find the question of immunity placed at their intersection."⁹¹ The presupposition that modernity is defined by a necessary yet destructive need to protect life at all levels and at all costs requires serious consideration. And to do justice to Esposito's thinking, we should take a step back and set the context by defining what *immunity* is and how it is related to *community*.

⁸⁹ Esposito, *Bíos*, 8, 39.

⁹⁰ Esposito, *Bíos*, 9.

⁹¹ Roberto Esposito, *Terms of the Political: Community, Immunity, Biopolitics*, trans. Rhiannon Noel Welch (Fordham University Press, 2013), 60.

To define both terms, Esposito resorts to their original meaning in Latin and their shared root *munus*. *Munus* is a task, a duty, but also a gift that might be only given rather than received. We are bonded to and bound by others through an unpayable debt and community is the relation that allows us to break through our individual boundaries to become more open and vulnerable so that we can perform our duty towards others. The nature of this primitive duty is not clearly described by Esposito, nonetheless, by considering how he situates care at the basis of community, it is not hard to imagine that our debt has something to do with how we provide care for others. On this matter Esposito writes, “the duty of community (providing yet not conceding, that there is one) is not to liberate us from care but instead to protect it as the sole thing that renders community possible.”⁹² If community is what binds people together, immunity, emerging simultaneously, is both what separates them from each other and frees them of their duty. Immunity is the relation that protects individuality, sometimes at the cost of the individual. “Whereas *communitas* opens, exposes, and turns individuals inside out, freeing them to their exteriority, *immunitas* returns individuals to themselves, encloses them once again in their own skin.”⁹³ The immunitary logic is to conserve and defend the self from external threats, which is necessary to some degree yet self-destructive when taken beyond a certain threshold.

According to Esposito, modernity coincides with biopolitics taking a definitive immunitarian turn. What characterizes the present moment of local and global politics is the result of immunization becoming more than an individual phenomenon and transforming into a socio-political one, affecting collectives and operating at institutional levels. “Everywhere we look, new walls, new blockades, and new dividing lines are erected against something that threatens, or at least seems to, our biological, social, and environmental identity.”⁹⁴ Where social and political relations are overdetermined by the immunitarian paradigm, preventing contagion, symbolic and biological, becomes key to the preservation of life. Nazism is the main example Esposito uses to explain what happens when immunization is taken to the extreme and the protection of the Aryan race requires the extermination of Jews and many others who were

⁹² Esposito, *Terms of the Political*, 25.

⁹³ Esposito, *Terms of the Political*, 39.

⁹⁴ Esposito, *Terms of the Political*, 59.

considered contagious threats to the purity of German blood. What mattered to the Nazi regime was “inhibiting, preventing, and fighting the spread of contagion wherever it presents itself, using whatever means necessary.”⁹⁵

Although the thanatopolitics of the Nazi regime lays bare the consequences of the fear of contagion, it still represents an extreme case and should we focus too much on the totalitarian politics of immunization, we risk overlooking normalized modes of immunization that are instances of slow and silent violence.⁹⁶ How can we interpret the U.S. ban on the entrance of PLWH into the country that lasted until 2010 if not through the immunitarian paradigm? Hasn't anti-migration politics always been in one way or another linked to the fear of contagion? There is no need to go back in history to find examples of how the terror of viral transmission became the defining characteristic of human relationships, and often the bases of stigmatization, discrimination, and violence. The skyrocketing of racist and xenophobic attacks on Asian and Asian-American people since the beginning of the COVID-19 pandemic is a living proof of the immunitarian configuration of social and biological life. Immunization, nevertheless, should not be considered solely in terms of aggressive responses to external threats with the purpose of defending life. If we remain true to the meaning of the word, we will see that immunization also widely takes place by setting dividing lines between institutions and dominant groups in the society, on the one hand, and potentially contagious others, on the other. This particular invocation of immunization could provide the ground on which we can think of why care is denied for certain groups of people or why it involves harm for some. If at the origins of community there is care, but there is also immunity, then we can rightly assume that care is inherently crosscut by an immunitary impulse. Those who carry the potential risk of polluting the biological health and social order simply do not deserve care. After all, hasn't biopolitics been about *letting die* as much as it is about *making live* from the beginning? And, what qualifies as a

⁹⁵ Esposito, *Terms of the Political*, 60.

⁹⁶ Rob Nixon, *Slow Violence and the Environmentalism of the Poor* (Cambridge, Mass: Harvard University Press, 2011); Berlant, “Slow Death: Sovereignty, Obesity, Lateral Agency”; For the original conceptualization of ‘slow violence’ see Michael J. Watts, *Silent Violence: Food, Famine, and Peasantry in Northern Nigeria* (University of Georgia Press, 2013).

contemporary example of letting die if not the denial of genuine care necessary for biological and social survival?

Although social scientists have carefully documented how care operates through biopolitical and necropolitical logics of governmentality at once, the nature of this paradox—why and how the power of life is transformed into power over life—is left unexamined. Once we think care through immunitarian paradigm, we can see that care is inherently crosscut by a defensive impulse to prevent social and biological contagion. This invocation of immunization could provide the ground on which we can think of why care is denied for certain groups of people or why it involves harm for some. I find immunity especially productive to think through the discrimination that HIV+ people have been experiencing all over the world in accessing care, particularly healthcare, given that HIV gave way to a radical shift of paradigm that made humans face not only their mortality but also, and most critically, their vulnerability to pathogens impossible to cure. With widespread sensational depiction of suffering and death in the media, HIV and AIDS have come to signify the unavoidability and imminency of death caused by viral transmission. When “the virus has become the widespread metaphor for all of our nightmares,”⁹⁷ a *viral line*, so to speak, has been set by respected institutions and citizens between themselves and HIV+ people, who are treated as the virus itself and not just someone who has it. When a person is registered by others as a viral agent rather than a human, there is not enough protective gear one can use to protect themselves, but they can always adopt physical and social distancing as the safest strategy to make sure there is no risk of contamination. It is in this context that we might better interpret why HIV-positive people in Turkey are denied healthcare in the hospitals or clinics by doctors and nurses who refuse to talk to them let alone examine them, why none of the politicians of the ruling Ak Parti have made a single public statement regarding HIV or recognized the existence of people living with it, why HIV organizations turn their back on HIV-positive queer people under the pretense of being worried about being associated with LGBTI+, or why pharmaceutical companies do not care for the wellbeing of HIV+ people as long as they are on drugs.

⁹⁷ Esposito, *Terms of the Political*, 60.

Bana Bi’şey Olmaz: Building Strong National Immunity

The immunitarian line between the state, its institutions, and its citizens, on the one hand, and HIV, on the other, was drawn long before the Ak Parti came to power. The idea that HIV is not a Turkish problem was established as early as 1985 and it continued to shape the state’s and society’s approach to the virus and those living with it. Although this dissertation is primarily focusing on the period after AKP’s election in 2002, the nationalist refusal to recognize HIV as a Turkish problem and the conservative impulse to discipline, as well as contain, sex and sexuality before AKP are still crucial to understanding the present-day politics of HIV care. The current state of HIV treatment and prevention in Turkey cannot be reduced to the long-lasting political rule of Adalet ve Kalkınma Partisi, *Justice and Development Party* (Ak Parti or AKP). A brief historical overview is therefore necessary to contextualize better Turkey’s historical response to HIV and AIDS. I will start this section with a quote from Sevgi, the only visible and outspoken woman in the nongovernmental HIV sector, whom I will write more about in Chapter 3.

Unfortunately, there is no habit of getting tested in Turkey. There are reasons behind this: ‘HIV won’t affect me’. For many people, HIV is a very distant topic. Or they only read about it in the newspapers. There is the idea that it can only happen to others. For instance, during a street interview we asked women what they knew about HIV/AIDS. They think, “my husband would never cheat on me, he would never do that, I cannot get it”... Some of our counselees say every time they go abroad, they use protection. But, HIV is not something that can only find you in a foreign country, it can happen in Turkey as well. Unfortunately, there is the perception that there is no HIV in Turkey... The worst part of this is to think that HIV solely concerns people who live on the margins of society. In reality, everyone comes to our organization: a veiled woman, a trans woman, a 7-year-old kid, or an elder man. Imams, priests, teachers, cops, academics, people from every part of society come to us... (Sevgi, personal interview, 2018)

Sevgi has been part of the civil organization of HIV since 2005, when the first HIV association was founded. In the quote above, she makes a key historico-epidemiological argument about the causes of low HIV testing rates. In addition to the fear of being stigmatized and outed or not

having any information, Sevgi contends that testing rates have been historically low because the Turkish public assumes a moral and corporal boundary between itself and the virus. In 2014, a short story book about HIV was published with the title of “Bana Bi’şey Olmaz!”, *nothing can happen to me!* Later, when I interviewed one of the authors of the book and asked him about their intentions with the title, he responded that they couldn’t have thought anything more apt. “Nothing describes people’s attitude about HIV in Turkey better than that sentence,” said Vahe, about whom we will hear more in Chapter 3.

Physician and medical anthropologist Özen Demir interprets the tendency to associate HIV always with others in terms of a reflex of national-cultural immunization. Historically too, HIV has been associated with foreign, debauched lifestyles.⁹⁸ During the 1980s and 1990s, HIV and AIDS were represented by the media, doctors, and politicians as a threat introduced in Turkey by *nataşalar* (sex workers from the former USSR), homosexuals, and promiscuous tourist women. The hegemonic social discourse of HIV was built on the premise that *a sexually transmitted virus like HIV can only be a risk for societies unsuccessful at following social morality and engaging in casual, extramarital, or queer sex*. In 1985, following the first HIV diagnosis in the country, the then prime minister Turgut Özal claimed that *AIDS cannot come to Turkey because the traditional family structure provides a natural protection against it*. Again, in the 1980s, a doctor wrote on a popular newspaper that *the virtues and honor of Turkish women and religious condemnation of homosexuality would protect the country against all sorts of sexually transmitted infections*.⁹⁹ By means of xenophobic, homophobic, transphobic, and sexist rhetorics, Turkey has been portrayed as fundamentally immune to HIV and AIDS. I read the history of this immunitarian reaction at the intersection of sexual conservatism and xenophobia.

The first HIV diagnosis in Turkey was given to Murtaza Elgin, who was a vocalist to famous singers and was known as Murti in the popular media. Although he was married to a woman, there were rumors in the newspapers about his sexual orientation. His story dominated

⁹⁸ Ozen Demir, *Biyopolitika ve Queer: Aids Krizi, Bağışıklık ve Ötesi (Biopolitics and Queer: AIDS, Crisis, Immunity and Beyond)* (Ankara: Nika Yayınevi, 2019).

⁹⁹ Enver Tali Cetin, “AIDS and the Respectability of Turkish Women,” *Milliyet*, January 15, 1993.

the headlines for over a year and there were many panic-inducing news stories. One of the news articles published in *Hürriyet*, a mainstream newspaper, was one of the many with the title "The Panic of M."¹⁰⁰ In a futile attempt to keep him anonymous, Murti's eyes were censored with a black strip, but his pictures taken next to famous stars and producers left no room for doubt about his identity. While using Elgin's story for sensational purposes, the article did not blame him personally for acquiring the virus and called him "a victim of AIDS." Right after the dissemination of rumors about HIV's arrival in Turkey, not only the prime minister Özal but Elgin himself denied he had HIV. Following this initial period of denial, Elgin's doctor, Hüseyin Sipahioğlu, thought it was his professional responsibility to share the bad news with the country. By giving Murtaza's full name, he announced publicly that his patient is diagnosed with AIDS.

Because of his serostatus, Elgin was accused in the media of committing a crime against humanity, and his prosecution was demanded. After he came back from a trip to Germany where he was to get tested for HIV again, hoping to confirm his innocence by proving his seronegativity, Elgin gave fresh interviews to show off his good health. Right before he left for Germany, he openly refused to get tested further in Turkey because he "was being sentenced to death by people who are capable of infecting his blood with AIDS only to prove him sick." After his return, Murti posed for *Milliyet* exercising in what looks like his living room and said, "I feel like I am reborn again." Although he claimed he tested negative in Germany and was hiding from public authorities, short after his arrival in Turkey he was arrested by police officers from vice unit (*ahlak masası*) and detained in a small cell called "AIDS ward" where he was to be quarantined with no toilet or running water. After a while Murtaza was released and from that point on his story rapidly lost its news value, at least until 1992. In that year Elgin made it to the headlines anew, this time with the news of his passing away. One of the articles reporting his death was entitled "Astronaut Imam for AIDS Funeral," referring to the protective suit worn by an imam before he washes Murti's body according to Islamic principles.¹⁰¹

¹⁰⁰ "M. Paniği," *Hürriyet*, November 3, 1985.

¹⁰¹ "Astronaut Imam for AIDS Funeral," *Hürriyet*, June 17, 1992.

As someone who experienced demeaning stigma and discrimination during the final years of his life, Elgin's dead body was also subjected to humiliation. By 1992, the ways in which HIV can and cannot be transmitted were widely accepted knowledge. Regardless, Murtaza's body was washed with bleach, wrapped in plastic bags, buried in a zinc coffin placed in a hole dug deeper than usual, and kilos of quicklime was poured on his coffin, preventing the dissolution of his body into the nature as required by Islam. His funeral found coverage in one newspaper under the title of "We made Europe laugh at us while burying Murti."¹⁰² This form of post-humous, symbolic violence is an enactment of necropolitics as a disciplining technology of the living.¹⁰³ Accompaniment of the funeral by the press ensured the public that the contamination of the soil was prevented and warned them about the fate that awaits them if they have AIDS. By sharing the detail that there was not a single acquaintance of Murti during the funeral—preachers carried his coffin and people who happened to be there for another funeral prayed for him—the public was also assured that they would not only die, but they would die alone.¹⁰⁴

Other than being the first known HIV diagnosis, there were two reasons why the case of Murti attracted so much attention in the media and the public: first, he was good friends with, and worked for, popular arabesk singers of the period such as Ibrahim Tatlıses and Ferdi Tayfur. Second, Elgin's marriage was never fully accepted as a proof of his heterosexuality and both his HIV status and his frequent visits abroad casted him as potentially queer. Maintaining rumors about Murtaza's homosexuality was essential for the interpretation of his seropositivity because it was deemed impossible that a married heterosexual man could have AIDS. If Murtaza was not homosexual, the institution of family would prove ineffective for the purposes of HIV prevention, which would consequently lead the general public into a chaos. It was easier to accept Elgin's HIV status when he was assumed to bring the disease upon himself by not following traditions and engaging in risky practices while he was not in Turkey. His HIV status

¹⁰² "We Made Europe Laugh at Us While Burying Murti," *Hürriyet*, June 20, 1992.

¹⁰³ Yener Bayramoğlu, "Border Panic over the Pandemic: Mediated Anxieties about Migrant Sex Workers and Queers during the AIDS Crises in Turkey," *Ethnic and Racial Studies* 44, no. 9 (July 15, 2021): 1589–1606.

¹⁰⁴ Hasan Atasoy, "Lonely Goodbye to Murti," *Milliyet*, June 18, 1992.

was ascribed to his not being Turkish enough, hence just being an exception that does not represent the Turkish society.

In a similar way, when young model Burcu Barkut, who was selected Miss Turkey in 1989 and again in 1991, died from AIDS-related complications in 1996, the press shared the news with an emphasis on the fact that Burcu lived and studied in the US. It was repeatedly insinuated that she acquired HIV while she was not living in Turkey¹⁰⁵. In a similar case, the press headlined “AIDSli Nurten,” *Nurten with AIDS*, who was quoted saying “I have slept with hundreds of men.” For the media and the public, Nurten was not just a public health threat.¹⁰⁶ Her sexuality and serostatus also raised important questions about the codes of honor for women because “the virtuosity of Turkish women” was regarded as a natural protection of the nation against HIV and AIDS. A similar rhetorical strategy was in effect while reporting the story of Nurten. The newspapers highlighted that Nurten grew up abroad away from her family and she was never loved as a child. This way she was pathologized to render her serostatus and sexual agency legible, as well as to protect the honor of Turkish woman.

In *Patient Zero and The Making of the AIDS Epidemic*, Richard McKay asserts that patient-zero was a foundational idea in the making of the North American AIDS epidemic. He successfully showcases the multiple ways in which the almost mythical figure of patient-zero was constructed and sustained by four key trends: “a broad societal need to imagine and then seek a simple explanation and source for complex patterns of contagion; the unintended consequences of hypotheses and decisions made by scientific and medical researchers who investigated the epidemic; tense divisions within the affected gay communities, where one response to the intense blame from without was to assign blame within; and a sensation-seeking media culture.”¹⁰⁷ Although never referred as patient zero, the case of Murtaza and others have been used for a very similar purpose: to give fear, panic, and obscurity a flesh-and-blood image,

¹⁰⁵ “Last Victim,” *Milliyet*, April 4, 1996.

¹⁰⁶ Ozcan Ercan, “AIDSli Nurten: ‘I Have Been with Hundreds of Men.’,” *Milliyet*, December 9, 1987.

¹⁰⁷ Richard A. McKay, *Patient Zero and the Making of the AIDS Epidemic*, Unabridged edition (University Of Chicago Press, 2017), 39.

and then to bill the problem on a single person and that person's foreign, therefore, risky lifestyle. Through the dangerous and suspicious otherness of figures like Nurten, Barkut, and Murtaza, the media, doctors, and politicians fed into the misperception that Turkish nation was inherently protected from HIV. In this way a negative correlation was established between adopting Turkish values and traditions and acquiring HIV. It was also made possible to give HIV and AIDS a human face. Even though a virus cannot be identified with the naked eye due to its microscopic nature, it is a much effortless biopolitical strategy to control and, if necessary, contain, the incarnated, embodied subjects of the virus. This makes it easier to mistakenly assume that public health is protected through the isolation of the so-called risky individuals.

The ideological construction of the HIV epidemic as solely pertaining to foreign countries where lax social norms give way to sexual degeneracy and sexually transmitted infections did not only take place through the symbolic abjection of Murtaza and others from national boundaries. Tourist women and migrant sex workers too played a crucial role in the public portrayal of HIV and AIDS. Both groups of women are at the same time seen as the sources and the reservoirs of the virus due to their assumed sexual excess ascribed to their foreign origins and/or involvement in prostitution. An article from 1987, entitled “Martial Law Against AIDS,” reported the first Council of AIDS meeting under Minister of Health Kalemli.¹⁰⁸ The decisions made at the end of the meeting concerned tourists more so than Turkish citizens. According to the article, the Council encouraged people to be wary of tourists who travel alone and announced a new action plan to open test centers in touristic zones and to educate the tourism students. It was, of course, not all tourists who were suspected to be risky, but just the women. A specialist of sexually transmitted diseases likened tourist women to a “ring of murderers and an AIDS-spreading sex machine.”¹⁰⁹ She went on accusing them of strategically choosing Turkey and intentionally spreading the virus. Tourist women were expected to receive a clean bill of health, *temiz rapor*, if they wished to visit Turkey.¹¹⁰ In 1987, *Milliyet* reported the story of a 30-year-old German tourist woman, who was taken into custody and tested for HIV

¹⁰⁸ “Martial Law against AIDS,” *Milliyet*, February 14, 1987.

¹⁰⁹ “Danger of AIDS,” *Milliyet*, January 19, 1993.

¹¹⁰ “The New AIDS Victim,” *Milliyet*, February 24, 1987.

against her will. She claimed she was withheld in custody for two days and in quarantine for an entire week.¹¹¹ In addition to sexism intrinsic to the labeling of foreign women as literal *femme-fatales*, anti-black racism was coming to the surface of Turkish public health politics in the same period. Another appalling event of the same year was the deportation of African-American male model Sony Preston after he was held in quarantine, where the staff burned his belongings after he left.¹¹² Another man of color who had to face the same insulting treatment in Turkey was the Nigerian football player Aneke. What makes this case even worse is that it took place thirteen years after Preston was deported.¹¹³

During the 90s and early 2000s, the tourist panic gave place to something akin to a witch-hunt, which was going to be one of the most defining events in shaping the perception of HIV/AIDS for Turkish people. Growing up, I remember frequently seeing on TV news about female sex workers from the former USSR, commonly called *nataşa* (singular) and *nataşalar* (plural). The reason why these migrant women, many escaping poverty and without papers, caused such public unrest is that they were perceived as more than an epidemiological threat, almost a national security issue that also fueled a moral panic. In the press, the threat of AIDS that come with migrant sex workers was depicted as the biggest threat for the Black Sea region of the country after the Chernobyl disaster.¹¹⁴ This matter of national security was expectedly not handled by the Ministry of Health but the Ministry of Internal Affairs and the Vice Unit under the General Directorate of Security. In 1996, the Ministry of Internal Affairs asked the General Directorate of Security to make a photo album of migrant prostitutes and distribute it to border patrols. The identity of those who had AIDS or syphilis was to be revealed in all media organs.¹¹⁵

¹¹¹ "AIDS Test against Will," *Milliyet*, September 4, 1987.

¹¹² "Preston: 'I Haven't Slept with Any Turkish Woman,'" *Milliyet*, November 14, 1987.

¹¹³ "Aneke's Deportation," *Milliyet*, February 2, 2002.

¹¹⁴ "Solution for Nataşalar," *Milliyet*, January 1, 1993.

¹¹⁵ "Photo Album for Natasalar," *Meydan*, March 7, 1996.

The late 90s and the early 2000s witnessed a dramatic increase in the press coverage of undocumented prostitutes who had HIV/AIDS. Some of the news titles were "operation morality," "AIDS operation," "sex bombs", and "Turkey in the clamps of AIDS."¹¹⁶ The news also started to report the distribution of arrests by countries amongst which Ukraine, Romania, Moldova, and Russia came in the first place. Nataşa stories garnered so much public and governmental attention as they were situated at the intersection of several tensions. Not only did they symbolize the penetrability of Turkish borders but also the values and biosecurity of the Turkish family. They brought more than sexually transmitted diseases. More importantly, they brought moral corruption. It is very telling that most of the AIDS cases were addressed by the infamous vice unit, including that of Murti. Why would the governance of an epidemiological matter be under the authority of the vice unit—which later became *The Office of Fighting Sexual Crimes*—and not that of public health officials? What does designating the vice unit to address matters related to sexually transmitted diseases imply for the meanings and risks of sex and sexuality for the Turkish State?

Moral panics have been addressed by Jeffrey Weeks and Dennis Altman among many others in relation to AIDS and by Gayle Rubin in the context of broader politics of sexuality.¹¹⁷ In *Policing Desire*, Watney calls attention to the ephemeral nature of moral panics, which emerge suddenly and disappear equally fast, igniting public tensions almost as a result of happenstance. According to Watney, moral panic theory “is unable to develop full theory concerning the operations of ideology within all representational systems. Moral panics seem to appear and disappear, as if representation were not the site of *permanent* ideological struggle over the meaning of signs.”¹¹⁸ According to this fitting observation, the moral panics caused by Murtaza, tourist women, migrants, gays, and sex workers in Turkey unveil much more than the

¹¹⁶ “Morality Operation,” *Milliyet*, August 5, 1991; Elvan Ezber, “Turkey in the Clamps of AIDS,” *Milliyet*, October 10, 2002.

¹¹⁷ Dennis Altman, *AIDS and the New Puritanism* (London: Pluto Press, 1987); Jeffrey Weeks, *Sexuality and Its Discontents: Meaning, Myths, and Modern Sexualities* (New York: R.K.P, 1985); Gayle Rubin, “Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality,” in *Pleasure and Danger: Exploring Female Sexuality*, ed. Carol S. Vance (New York: R.K.P, 1984).

¹¹⁸ Simon Watney, *Policing Desire: Pornography, AIDS and the Media*, 2 edition (Minneapolis, MI.: Univ Of Minnesota Press, 1987), 40-1.

ways in which national immunity has been built in Turkey. Beyond the fear of infection, they disclose permanent ideological panics around sex, promiscuity, and the family, that are anything but temporary, and face an imminent threat of dissolution at the sight of HIV.

Viral (Auto)Ethnography

Sexually transmitted diseases are the most successful dissolvers of boundaries.
—Jeffrey Weeks, *Invented Moralities*, 1995

When I first visited Istanbul in the summer of 2018, I knew I wanted to investigate the growing HIV epidemic in Turkey but didn't quite know how. During my first attempt to do fieldwork, I was asked many times about my purposes for conducting this research. My initial respondents either assumed I was HIV-positive or did not take my intentions to pursue this topic seriously. That summer, when I was trying to catch HIV, I was caught by it. This turned out to be the only way through which I could claim to have caught it myself. As Favret-Saada wrote in a different context when she was working on magic in rural France, “those who cannot be caught cannot talk about it.”¹¹⁹ Neither will those who are caught will fully reveal themselves and their stories to those who are not due to the issues of trust and intimacy.

When I went back to Istanbul in the summer of 2019, my relationship with the “field” and its members changed drastically. I arranged meetings with everyone I met the previous summer and, before we even began to speak, I disclosed my status in an effort to find some comfort in their presence—I got my diagnosis in the U.S. and did not have any community support until I went back to Turkey—and to let them know that I was no longer merely a researcher. They reacted to the unexpected news in a bittersweet way. The response was mostly a mix of affirming me that I was not alone and questioning me on my presumed inability to use protection, whether in the form of condoms or PrEP. Over time, as the news of my diagnosis spread, my “respondents” no longer seemed to be participating in an interview, which slowly

¹¹⁹ Jeanne Favret-Saada, *Deadly Words: Witchcraft in the Bocage* (Cambridge University Press, 1980), 14.

gave its place to a more comradely and intimate interaction taking place not between a researcher and respondent, but two friends connected through an invisible but unbreakable link that resists romanticizing and fetishizing. Although I did not claim to be a true insider on the basis of a recently acquired HIV diagnosis, I was quickly embraced as a legitimate member of the community. My long-lasting collaborations with local HIV organizations and my commitment to queer HIV activism no doubt accelerated others' approval of me. I rapidly found a place among several HIV activist groups and found a community that became the center and, so to speak, *élan vital* of my life. At that point, my field stopped being a research field and became a field of activism and advocacy, where I didn't have to be physically present to participate. The research has become inseparable from activism and activism has become the only fuel of the research. At some point, I am not sure which point, I abandoned the idea of pursuing this project for academic purposes and embraced it as a way to pay my unpayable debt to queer HIV activism and activists.

Since I received an HIV diagnosis, I have built beautiful friendships and formed new families. I spent the last four years, online and offline, getting to know many people closely, most of whom quickly became dear friends and some of whom I avoid to this date. The simple fact about this research is that it would have not been possible, or not the same, if I wasn't diagnosed with HIV and became virally entangled with my field and its inhabitants. That is why I think of my research methods in terms of *viral ethnography*. The term viral is employed here to evoke four deeply interrelated meanings: viral as it relates to the ontological materiality of the virus itself; viral as it refers to the researcher's and the participants viral load; viral as in viral disease, caused by pathogenic viruses; and, viral as a mode of transmission, a way for things (including maybe ethnographers) to travel. Viral ethnography is not an ethnography of the virus as much as it is of *contact zones*, in the words of Haraway, where humans and viruses encounter one another, whose end result can be equally catastrophic as beneficial.¹²⁰ There is an undeniable autoethnographic component to doing research in viral contact zones where the ethnographer

¹²⁰ Donna J. Haraway, *When Species Meet* (U of Minnesota Press, 2013).

explores his own community and his own experiences.¹²¹ Autoethnography dissolves the boundaries between ‘the researcher, the self, and the expert,’ on the one hand, and ‘the researched, the other, the nonexpert,’ on the other, until these anthropologically imposed categories lose their currency. It also renders the ethnographer as close as possible to an insider who can provide a unique window into the field and its actors. Autoethnography is a powerful methodological tool not because it reveals something about the researcher but because it reveals something about the field through the researcher. It is not the “I” autoethnography is interested in but what the “I” unveils about the larger social dimensions of the field in which they are deeply embedded. Still, though, the autoethnographer should not be trusted as an unhesitating vessel of knowledge but accepted as a volatile mapper of the field.

What does ‘the field’ become, or what is left of it, when the ‘researcher’ is virally and erotically engaged with his interlocutors to whom he is accountable both within and outside the academy? In his introduction to the edited volume on the erotics of the field research, *Taboo*, Kulick wrote, “I have come to appreciate that erotic subjectivity in the field is a potentially useful source of insight. This is because erotic subjectivity *does* things. It performs, or, rather can be made to perform, work.”¹²² Erotic subjectivity opened many doors to me, both metaphorically and literally. Although I have not had sex with any of my interlocutors—at least, not to this date—the erotics of my fieldwork guaranteed that I was not confined to the category of an impersonal and distant researcher, with whom one can only share so much. As hooks says, eros should not be reduced to sex and sexuality, rather it should be understood as a moving force: a force that was not only moving freely in our long conversations over countless glasses of raki or short coffee dates, but also moving and energizing us to talk, share, reflect, discuss, laugh, cry, and be aroused.¹²³

¹²¹ Ellis, C., *The Ethnographic I: A Methodological Novel about Autoethnography* (Walnut Creek, CA: Alta Mira Press, 2004); Ulrika Dahl, “Femme on Femme: Reflections on Collaborative Methods and Queer Femme-Inist Ethnography,” in *Queer Methods and Methodologies: Intersecting Queer Theories and Social Science Research*, ed. Kath Browne and Catherine J. Nash (Farnham, Surrey, England ; Burlington, VT: Ashgate, 2010), 143–66.

¹²² Don Kulick and Margaret Willson, *Taboo: Sex, Identity and Erotic Subjectivity in Anthropological Fieldwork* (London: Routledge, 2003), 5.

¹²³ Bell Hooks, *Teaching To Transgress* (Routledge, 1994).

Categories such as lover, colleague, researcher, ethnographer, and respondent lost their relational valence in my field and, instead, gave way to *friendship as a way of life*, to quote the late Foucault.¹²⁴ Insofar as we recognized our shared vulnerability, we were intensely co-constituted and deeply entwined.¹²⁵ Our HIV status, however, was not the vulnerability that brought us closer, or not the only or the most important one for that matter. If anything, HIV gave us a chance to form a community where we could face together other vulnerabilities we experienced for being feminine, lower-class, disabled, and persecuted because of our gender identities and sexual orientations. One night while we were smoking weed and giving each other back rubs, someone in the group asked if I was showing any progress in my research, because, to him, it didn't seem like I was doing a lot of research but activism. To explain the inseparability of the two for me, I resorted to the concept of "deep hanging out" () and told them that smoking a joint with them can very well be considered fieldwork for me as I always learned a lot from them, especially during those intimate house gatherings. This time, someone else in the group commented, "I am happy to hear about that but I need to know how *deep* do we need to hang out for your dissertation to be successful?" cracking up everyone in the room.

When it comes to the question of how I have actually done this research, I believe "patchwork ethnography" is the most helpful conceptual tool to describe what I consider, how I collect, and how I produce "data". To begin with, instead of data, I would like to think of my research as working with *quilts* and *patches* to distance myself from the conventional role of the ethnographer as distant and privileged with a claim to objectivity. By patchwork ethnography, Günel, Varma, and Watanabe refer to "ethnographic processes and protocols designed around short-term field visits, using fragmentary yet rigorous data, and other innovations that resist the fixity, holism, and certainty demanded in the publication process."¹²⁶ Patchwork ethnography, however, should not be confused with "one-time, short, instrumental trips and relationships à la

¹²⁴ Tom Roach, *Friendship as a Way of Life: Foucault, AIDS, and the Politics of Shared Estrangement* (State University of New York Press, 2012).

¹²⁵ Richa Nagar, *Hungry Translations: Relearning the World through Radical Vulnerability* (University of Illinois Press, 2019).

¹²⁶ Gökçe Günel, Saiba Varma, and Chika Watanabe, "A Manifesto for Patchwork Ethnography," *Member Voices, Fieldsights* (blog), June 9, 2020, <https://culanth.org/fieldsights/a-manifesto-for-patchwork-ethnography>.

consultants” but understood as “research efforts that maintain the long-term commitments, language proficiency, contextual knowledge, and slow thinking that characterizes so-called traditional fieldwork, while fully attending to how changing living and working conditions are profoundly and irrevocably changing knowledge production.” The authors also warn that “patchwork ethnography is not an excuse to be more productive. Instead, it is an effective, but kinder and gentler way to do research because it expands what we consider acceptable materials, tools, and objects of our analyses.”

My fieldwork consists of three short summer visits that totaled seven months and an eleven-month-long embedded fieldwork. While in the field, I worked closely with local HIV NGOs, writing and implementing sexual health projects for them. I also regularly joined the meetings of several activist groups and attended formal and informal events organized by pharmaceutical companies and nongovernmental organizations. I conducted my first interview in June 2018 and the last one in June 2022. This allowed me to create a temporal map of the field while capturing its changing dynamics over the course of four years. I had the chance to interview some interlocutors several times and to observe how their opinions changed over time. In the words of Marcus, I had the chance “to engage ethnographically with history unfolding in the present, or to anticipate what is emerging.”¹²⁷ During the pandemic, my ethnography has become partly digital. I attended over twenty zoom conferences and workshops on HIV treatment and prevention. In online meetings, I had the chance to build rapport with a lot of key actors of HIV care such as the employees of the Ministry of Health and healthcare professionals from all over the country. This allowed me to expand the geographical scope of my research and connect with interlocutors I would not have met otherwise. During that time, my relationship with the HIV activists have certainly changed due to different time zones and distance, yet we discovered that we could be more available to each other when we are just a phone call away. I have participated in regular video calls where we would discuss the agenda of HIV activism or simply check in with each other to make sure we are doing okay. In one of the

¹²⁷ George E. Marcus, “THE END(S) OF ETHNOGRAPHY: Social/Cultural Anthropology’s Signature Form of Producing Knowledge in Transition,” *Cultural Anthropology* 23, no. 1 (February 2008): 3.

activist groups I was a part of, more than half of the members were living in different cities, some of them in different countries. The digitalization of HIV activism in that context was both inevitable and beneficial in facilitating organizing and access (Chapter 5).

In terms of “data”, my dissertation draws on public and private archives, medical records, newspaper articles, official government reports, and 45 in-depth interviews. I formally interviewed health providers, pharmaceutical industry employees, nongovernmental staff members, civil servants, and HIV activists. By interviewing a rich variety of actors involved in HIV care, often with contradicting and conflicting views, I was able to capture how “discourses fold into each other in contingent and messy ways.”¹²⁸ A fitting way to describe my methodological approach is “following the actors,” a phrase I borrow from Aizura and his work *Mobile Subjects*. “Following the actors could be read as archaeological labors of tracing, discovering footprints, or as an act of tuning in or listening.”¹²⁹ Given how closely I followed HIV across several discursive and ethnographic locations, like Aizura, I too draw from David Valentine who demonstrated that we need not be delimited by geographical or communal boundaries in our pursuit of tracing concepts, ideas, and discourses across multiple registers.¹³⁰ Valentine’s seminal work *Imagining Transgender* is one of the first ethnographies I’ve ever read and it deeply influenced my relationship with and approach to ethnography.

Organization of the Dissertation

The first and the longest chapter of this dissertation provides a historical and political analysis of the transformation of sexual health services, as well as the definition of sexual health, throughout the twenty-year long AKP governance. I chronicle the emergence of a new regime of public health through a series of developments that directly contributed to the conservatization and neoliberalization of healthcare in general, and sexual health, in particular. Drawing on the

¹²⁸ Aizura, *Mobile Subjects*, 15.

¹²⁹ *Ibid.*

¹³⁰ David Valentine, *Imagining Transgender: An Ethnography of a Category* (Duke University Press, 2007).

concepts of symbolic immunization and strategic ignorance, in this chapter I explore the governmental logics and strategies of HIV care. To do so, I focus on three instances that crystallize the politics of HIV care under neoliberal Islam. First, I analyze the only existing public health poster shared by the Ministry of Health to inform the public about HIV. Both by providing a textual and visual analysis of this poster and by sharing how it is received by other actors of HIV care, I discuss how monogamy is established as the only legitimate method of HIV prevention and how heterosexual married couples are discursively constructed and materially treated as the only deserving recipient of care. Second, I look at the Ministry of Health's Strategic Action Plans and the processes of collecting and distributing data on HIV transmission. Referred by many as *eylemsizlik planı*, inaction plan, the content of these ministerial documents and the chronic failure to implement them demonstrate the way in which HIV care becomes an empty gesture of care devoid of any genuine intention to stop HIV transmission in the country. Official HIV statistics, on the other hand, reveal a concrete way in which the state can immunize itself against contagious others. By provocatively asking whether HIV surveillance data have politics, I question the meanings and implications of missing and inaccurate numbers for the management of the epidemic and the protection of LGBTI+ community from HIV. Lastly, I turn toward the voluntary testing centers (GTDMs) where one can access free and anonymous HIV testing. There are only seven of these clinics in the entire country and they are all funded by local municipalities under the oppositional party. By discussing the technical, logistical, and political obstacles experienced by GTDMs, I provide an ethnographic picture of how HIV care is undermined and slowed down.

Chapter 2 is a product of the many professional and social relationships I established since 2018 with people who work for or volunteer at HIV organizations. I will introduce some of the key actors of nongovernmental HIV care who step in with the hopes of making a difference in the zones of abandonment created by state institutions. There are only HIV organizations in the entire country—*Positive Living Association*, *Pozitif-iz*, *Red Ribbon*—and they are all located in Istanbul. This chapter provides an ethnographic glimpse into the distance between the hopes, expectations, and realities of nongovernmental care. I document how all three organizations were

founded with the purpose of providing services for people living with HIV, yet some of them significantly struggled in accomplishing their objectives while others completely failed it. By focusing on how HIV organizations kept repeating the same mistakes they sought to avoid, including adopting conservative public health discourses for which they criticized the state, and increased their services for the HIV-negative population at the expense of PLWH, I discuss the implications of depoliticizing, de-gaying, and monetizing HIV for public health.

Chapter 3 is built on the experiences of HIV-positive people in the hospitals and clinics, where HIVfobi materializes in the form of harmful, sometimes life-threatening, refusal to provide medical care. Some of the key concepts this chapter explores are medical violence, *doktor şiddeti* (doctor violence), iatrogenesis, and *tanrı egosu* (God ego). Medical violence can be defined as any act aimed at exploiting, violating, or threatening a person's dignity, bodily integrity, and/or safety in the pursuit of health care. In Turkey, healthcare professionals are expected to have a moral obligation to treat all patients equally regardless of who they are or what they represent. Yet, legally, just like the patients have the right to choose their doctors, doctors have the right to choose their patients as well, and they can refuse treatment based on personal or occupational reasons. Hence, this chapter unveils how the intensified fear of contagion among healthcare providers both precludes them from examining, operating, or simply seeing patients who happen to be HIV-positive and encourages them to disclose the status of the patient to the rest of the personnel. In this chapter, I specifically focus on what medical care mean for HIV+ queer people, whose access to treatment and prevention is simultaneously impacted by *HIVfobi*, *homofobi*, and *transfobi*.

Lastly, the central purpose of Chapter 4 is to illustrate the processes of the pharmaceuticalization of HIV care and its implications for HIV prevention. This chapter delves into the story of Gilead Sciences, a multinational pharmaceutical giant, and how it has become a critical actor of HIV care. To be able to ethnographically describe the nature of pharmaceutical HIV care in Turkey, I focus on two case studies. First, I discuss the role of corporate social responsibility projects in enabling the company to extend its reach over the prescribers and

consumers in a context where direct-to-consumer advertising is strictly forbidden. Within this context, I also consider the implications of neoliberal, market-driven, and profit-oriented ethics of care for the quality of HIV prevention and treatment. Second, I examine the politics of PrEP, *pre-exposure prophylaxis*, and how it has become a risky technology in Turkey. Although the focus of the chapter is on Gilead Turkey's rationales and strategies for not introducing PrEP, the examination of PrEP's contentious politics brings together every actor of HIV care.

CHAPTER 1

The Protection of Family and Family as Protection: Sexual Health in the Times of Neoliberal Islam

“[T]he immunitary dispositif, which is to say, this need for exemption and protection that originally belonged to the medical and juridical fields, has spread to all sectors and languages of our lives, to the point that the immunitary dispositif has become the coagulating point, both real and symbolic, of contemporary existence.”

—Roberto Esposito, *Terms of the Political*, 2013

“The anxiety produced through the epidemic is displaced and condensed in the regulation of sexual reproduction and the promotion of the family as the supposedly exclusive site of safe sex.”

—Linga Singer, *Erotic Welfare*, 1993

Socio-epidemiological events like pandemics function as a magnifying glass held on societies. The conditions created by pandemics feed on the already-existing social dynamics and make these dynamics even more visible. During the early months of the Covid-19 pandemic, HIV entered the mainstream Turkish discourse in an unforeseen way. Rumors that antiretroviral medicine used to suppress the replication of HIV in humans might be effective against the novel coronavirus gave way to a situation where people previously uncomfortable with the idea of talking about HIV started to treat the virus as a source of hope. Only for a moment, HIV stopped being a signifier of death and destruction and became a potential for cure. Also, because people with chronic diseases have been central to the discussions of the pandemic, HIV has garnered unforeseen public attention. The inclusion of HIV+ people by health providers in the category of “at risk” was the closest their existence came to being publicly recognized on television, although misrecognized might be a more fitting term since they were only acknowledged as a vulnerable, potentially sick group of people. While the problems with lumping all HIV+ people in the same risk category regardless of their differences in viral load, CD4 numbers, and overall condition of health went unnoticed, the news came soon that ARVs were not the cure they were hoped to be. But this was not going to be the last time of the Turkish public becoming interested

in HIV. In February 2022, HIV was a trending topic on Twitter under the hashtag #SivilarlaHivSoykirimini, *HIV genocide through liquids*, by a group of people who were conspiring that the Covid-19 vaccines infected people with HIV. The Ministry of Health was attacked by Twitter users for its 2019-2024 HIV Action Plan and accused of preparing the document to increase HIV testing in the anticipation of an epidemic of HIV caused by the vaccines. Quite interestingly, as I will mention in the last section of this chapter, these Action Plans are also widely criticized by doctors, activists, and civil society organizations for their inefficacy to improve HIV treatment and prevention.

Even before the Twitter incident took place, HIV had unexpectedly made its way into the speech of a top-ranking state official. In the midst of an ongoing and ravaging pandemic that took the lives of more than one hundred thousand people in Turkey, on the first Friday sermon of the holy month Ramadan, Ali Erbaş, the president of the Directorate of Religious Affairs (Diyanet, for short), the highest religious authority in the country, gave a sermon addressing the entire nation:

People! Islam accepts adultery as one of the biggest sins. It curses the people of Lot and homosexuality. What does homosexuality do? It brings diseases and degenerates generations of people. Every year hundreds of thousands of people are exposed to HIV virus as a result of having extramarital and illegitimate relationships. These are examples of adultery and are a big sin. Come join me in fighting to protect people from this kind of evil.¹³¹

Erbaş had the chance to inform his large audience about ways to prevent Covid-19 infections and to invite people to be in solidarity with each other. Instead, he targeted LGBTI+ and HIV+ individuals for endangering morality and public health, while insinuating a connection between HIV and SARS-CoV-2. Just like other societies at other times responded to viral outbreaks by

¹³¹ Fundanur Ozturk, “Diyanet İşleri Başkanı neden eleştirildi, Cumhurbaşkanı Erdoğan Ali Erbaş’ı nasıl savundu?,” *BBC News Türkçe*, accessed April 24, 2023, <https://www.bbc.com/turkce/haberler-turkiye-52447722>.

producing scapegoats that are then made to assume the burden of the spread of pathologies, Erbaş defined who the real threats are to public health and public order. Although *Diyanet* is a long-standing member of the National AIDS Commission that was established in 1996 yet has not gathered since 2008—a public health practitioner described the commission as “an amateur theater of public health that has not put out a single show”—the statements of Erbaş were not made from the position of a representative of a public health initiative. Rather, he spoke as a rightful representative of the Turkish state and the protector of Islamic values and beliefs. Lest there were any doubts that his opinions reflected the political will, President Erdoğan came to his defense when Erbaş was criticized on Twitter and confirmed that he does not only represent but symbolically embodies the state. In his 2020 presidential address, Erdoğan proclaimed that “the attack on our President of Religious Affairs is an attack on the state.”¹³²

In this chapter, I focus on four themes to uncover the contradictions of governmental HIV care which arise from the incompatible needs of protecting public health, on the one hand, and heteronormative and Muslim public morality, on the other. First, by closely analyzing an HIV prevention brochure distributed by the Ministry of Health, I demonstrate that structural and ideological obstacles to care arise when the necessities of public health are at odds with the conservative mission of protecting “the values and traditions of the society” and when any reference to sex and sexuality is considered a threat for the family, children, and the youth. Monogamy, as I discuss below, appears as the only prevention option that can solve the dilemma between public health and moral health. Second, I turn my attention to the neoliberalization of preventive healthcare and public health under the long-lasting rule of AKP and its implications for sexual health. Together the first two themes help me build the case that the politics of sexual health in Turkey should not be reduced either to authoritarian Islam or to neoliberalism but understood as a product of a dynamic relationship between the two. The third theme is an exploration of *Gönüllü Danışmanlık ve Test Merkezleri* (GTDM), voluntary testing and counseling centers, and through ethnographic insight, it demonstrates how HIV prevention is frustrated on a daily basis as a result of political deadlocks and reactionary attacks. The fourth

¹³² Ibid.

and the last theme engages with two different but related cases: HIV Action Plans and HIV Statistics. Action plans prepared by the MoH yet never put into action provide a strong case to interpret governmental HIV care as a neoliberal gesture of care that identifies what needs to be done yet never takes the necessary actions to reach the desired goals. Finally, by raising the question of whether *state-istics* have politics, I examine the role of strategic ignorance and symbolic immunization as methods of conservative public health governance.

“The Only Solution is Monogamy”

Contrary to the unbreakable relationship suggested to exist between homosexuality and HIV, an article published in the official journal of *Diyanet* states that HIV does not concern only homosexuals. The same article invites everyone to be “aware of the ways of transmission of AIDS in order to prevent the spread of the disease.”¹³³ What is interesting here is not the mistaken assumption that AIDS is the same thing as HIV and that it can spread like a pathogen—a rather common mistake committed even by health professionals. What makes this article worthy of attention is the HIV prevention mechanisms it suggests. Accordingly, the principles of preventive medicine in Islam can provide a great deal of protection against AIDS. These principles are listed as “family loyalty, the prohibition of adultery, the prohibition of blood impurities, the prohibition of drugs and alcohol, and the prohibition of harming someone by deliberately infecting them.”¹³⁴

It is revealing that family loyalty and the prohibition of adultery are the first prevention methods mentioned on Diyanet’s list. Family as an epidemiological and social unit is at the center of the Turkish State’s public health response to HIV. The heterosexual family is not only regarded as the sole deserving recipient of preventive care. It is also popularized as a prophylactic institution with guaranteed protection from HIV and other STIs. The protection of

¹³³ Abdurrahman Akbas, “AIDS’in Önlenmesinde İslam Dini’nin Koruyucu Prensipleri (Protective Principles of Islam for Preventing AIDS),” accessed April 24, 2023, <https://dergi.diyamet.gov.tr/makaledetay.php?ID=11269>.

¹³⁴ Ibid.

family and family as protection are indispensable to Turkish governmental HIV care as strategies of public health governance. Rather than being informed by epidemiological realities, such methods are designed to support the efforts of conservative nation building. Under the pretense of protecting the health of the public, marriage and monogamy are offered as sensible methods of HIV prevention. The imposition of monogamy as a prevention measure, nonetheless, prioritizes the reproduction of conservative norms over the protection of public health. Given family functions “as an element internal to population, and as a fundamental instrument of its government,”¹³⁵ it should not come as a surprise that it is put in use as a “prophylactic social device”¹³⁶ to discipline sexualities, bodies, and desires in the name of promoting healthy publics.

According to Mitchel Foucault, modern states cannot find areas more suitable than sex and sexuality for the biopolitical control of the population and for the disciplinary control of individuals.¹³⁷ The efforts to create a normative citizen body, therefore, are primarily invested in governing sex/uality. Within the ideological frame of the Justice and Development Party’s pronatalist and neoconservative governance of sex/uality, “the heterosexual family with children is promoted as the basic unit to reinforce hegemonic moral values and norms.”¹³⁸ It is in this context we should interpret the interchangeable use of homosexuality and adultery in the above-mentioned quote by the President of Religious Affairs. Homosexuality is attacked as a sin not only because it is assumed to be against nature, as the representatives of JDP publicly expressed more than once. It is also against the sacred requirements of marriage, an insult to everything the family stands for, particularly its function in social and biological reproduction. Besides their attack on the future of the family, homosexuals also threaten to eliminate it by introducing a disease into the general public’s porous boundaries. As Jean Comaroff astutely noted AIDS has

¹³⁵ Michel Foucault, *“Society Must Be Defended”*: Lectures at the Collège de France, 1975-1976, trans. David Macey, First edition (New York: Picador, 1976), 17.

¹³⁶ Singer, *Erotic Welfare*.

¹³⁷ Foucault, *Society Must Be Defended*.

¹³⁸ Dilek Cindoglu and Didem Unal, “Gender and Sexuality in the Authoritarian Discursive Strategies of ‘New Turkey,’” *European Journal of Women’s Studies* 24, no. 1 (February 2017): 39.

become “an iconic social pathology” not because of its public health implications, but because of how it imperils heteronormative family values.¹³⁹

The successful protection of the family as an institution calls for the support of legal frameworks and the help of willing subjects to enact them. According to Turkish civil law, couples are obliged to obtain a clean bill of health to be married in Turkey. The medical certificate should specify whether any of the partners have syphilis, gonorrhea, leprosy, or tuberculosis. Nowhere in the law the requirement to get tested for HIV is stated, neither is there any clause prohibiting HIV+ persons from marrying. Nevertheless, health providers, mostly family physicians, strongly recommend couples to also get tested for HIV. Often couples are tested for HIV without being asked or informed about it. Nonconsensual or enforced HIV testing is not even the only problem. The Positive Living Association documented numerous cases of being denied the right to marry for being HIV+. Registrars, who have no authority or legal basis to do so, reject performing marriage ceremonies of HIV+ persons to protect the sacred institution of the family. Some of the specific cases are worth mentioning: in one instance, the registrar did not only refuse to marry an HIV+ person but also publicly humiliated and physically attacked him in front of his guests while yelling “you cannot get legally married”; in another instance, they talked the fiancé of a positive person out of marriage by saying that HIV infection is inevitable in a marriage, although the person already knew about the status of their partner; last but not least, another registrar refused to perform the ceremony and expressed that “marrying an HIV+ person would be a crime [against family?]” vocalizing the informal position of the state on the matter.

¹³⁹ Jean Comaroff, “Beyond Bare Life: AIDS, (Bio)Politics, and the Neoliberal Order,” *Public Culture* 19, no. 1 (January 1, 2007): 197–219.



Figure 8: The only HIV prevention brochure distributed by the Ministry of Health.

Above is a popular image distributed by the Ministry of Health on each December 1st, celebrated as World AIDS Day since 1988. Visually, the representation of HIV by dark clouds in the image and the protection of the family from the ruin of the clouds by entering the safety of domestic space represented by a shape of house built by a pair of hands send the signal that heterosexual marriage and monogamy is how one can protect themselves and their family. If someone is not benefiting from the prophylactic power of the monogamous family, then they are being reckless, *tedbirsiz*, therefore putting themselves and their families at risk. The central text of the image, “Tedbir Sizsiniz,” is a common, elementary level wordplay in Turkish. When the two words are written adjacently and form a compound word as in “tedbirsizsiniz,” it means “you are reckless,” without any precaution. When they are written separately, “tedbir sizsiniz” means “you are the precaution.” The surface level meaning of this is that to avoid HIV infection, one needs not look for help in other places, such as preventive technologies, because you are the only precaution.’ Even though this can be read as a quintessential sign of neoliberalism that places the

responsibility of prevention on the individual, this poster should be situated in the broader ecology of HIV prevention. Although monogamy was proposed as a way to prevent an epidemic by a Minister of Health as early as 1996, “Tek Çare Tek Eşlilik”, *the only solution is monogamy*, became the official motto of the Ministry only under the governance of Ak Parti. This slogan rapidly became popular among some healthcare and public health professionals, and one of the oldest HIV research centers in Ankara, HATAM, has been endorsing the message that monogamy is the only way to be protected by HIV. In 2018, when I interviewed the general secretary of HATAM, Aygen Güner, whom will be introduced in Chapter 3, and asked her about her and her director’s opinions on the matter, she told me that “monogamy is scientifically the best way to prevent transmission,” and added, “although we know this is not the case all the time.”

Over the last three decades, the Ministry of Health has mistakenly focused on treatment—albeit imperfectly—while turning a blind eye to prevention. According to Salomon and his colleagues, however, “Over the long term, it is effective prevention that will reduce the burden of illness due to [HIV] and the number of people in need of [antiretroviral therapy].”¹⁴⁰ Several critical studies have too demonstrated a negative correlation between HIV incidence rates and (a) public investment in prevention campaigns,¹⁴¹ (b) public promotion of condoms,¹⁴² and (c) sex education.¹⁴³ These studies show that the immediate consequence of the lack of preventive public health mechanisms is rising HIV transmission. Therefore, the ease with which

¹⁴⁰ Joshua A Salomon et al., “Integrating HIV Prevention and Treatment: From Slogans to Impact,” ed. Joep Lange, *PLoS Medicine* 2, no. 1 (January 11, 2005): 0055.

¹⁴¹ Diana Bernard, Susan Kippax, and Don Baxter, “Effective Partnership and Adequate Investment Underpin a Successful Response: Key Factors in Dealing with HIV Increases,” *Sexual Health* 5, no. 2 (June 2008): 193–201; David R. Holtgrave and Jennifer Kates, “HIV Incidence and CDC’s HIV Prevention Budget,” *American Journal of Preventive Medicine* 32, no. 1 (January 2007): 63–67; AIDS Alert, “Special Report: HIV Prevention at 25 Years: HIV Prevention over Past 25 Years Had Early Successes, Now Treads Water.” (AIDS Alert, 2006).

¹⁴² “WHO | AIDS Epidemic Update: December 2007,” WHO, 2007, <https://www.who.int/hiv/pub/epidemiology/epiupdate2007/en/>.

¹⁴³ Douglas Kirby, *Emerging Answers, 2007: Research Findings on Programs to Reduce Teen Pregnancy and Sexually Transmitted Diseases* (Washington, DC: National Campaign to Prevent Teen and Unplanned Pregnancy, 2007); Heather Weaver, Gary Smith, and Susan Kippax, “School-based Sex Education Policies and Indicators of Sexual Health among Young People: A Comparison of the Netherlands, France, Australia and the United States,” *Sex Education* 5, no. 2 (May 2005): 171–88.

the Ministry of Health, supported by political and scientific authority, recommends monogamy as a legitimate HIV prevention method poses a bigger peril for the public than does HIV. By attributing safe sex to the confines of family, such ‘fatal advices’¹⁴⁴ put the public at greater risk of transmission. Monogamy and abstinence can be efficacious ways to prevent HIV transmission and other STIs, yet they are widely proven to be ineffective as public health strategies for failing to protect the public from pathogens and for violating fundamental human rights to health and information.¹⁴⁵ Messages like these not only ignore the realities of human life regarding sex and sexuality, but more critically cause harm to public health and put the society at greater risk by withdrawing information about prevention mechanisms.

When I asked him about the above brochure, a former director of the oldest and largest HIV organization in the country, Harun, expressed his disappointment with ineffective public health strategies through these sentences:

The state is not doing anything to raise HIV awareness. All it does is to distribute a poster one day a year and, on that day, it merely tells people to be monogamous. This is not possible. When we look at the data we collect, we observe that the increase of HIV primarily takes place in the age group 20-27. These are young people, they are sexually active, and you cannot tell them to be monogamous or to abstain. Then, there is the large group of married women who get HIV from their husband. How is monogamy supposed to protect them? If the state is not going to support prevention, it should at least not frustrate our efforts. As an HIV organization we cannot even distribute condoms on the street because it is considered as facilitating prostitution. When we go to gay bars to distribute safe sex pamphlets, we cannot even give people condoms. This is all because of conservatism, the fear of sex, and the sanctity of marriage in Islam. When we attended the meetings of the AIDS commission, we suggested distributing condoms in prisons and teaching children about protection in the schools. Of course, they refused it. They said it would create the perception that men have sex with each other in prisons and that children are encouraged in the schools to be sexually active. (Harun, personal interview, 2018)

¹⁴⁴ Patton, *Fatal Advice*.

¹⁴⁵ Kristen Underhill et al., “Access to Healthcare, HIV/STI Testing, and Preferred Pre-Exposure Prophylaxis Providers among Men Who Have Sex with Men and Men Who Engage in Street-Based Sex Work in the US,” *PLoS One; San Francisco* 9, no. 11 (November 2014): e112425; Weaver, Smith, and Kippax, “School-based Sex Education Policies and Indicators of Sexual Health among Young People”; Kirby, *Emerging Answers*, 2007.

In addition to explaining why the proposition of monogamy puts people at higher risks of HIV, Harun's powerful comments point out a crucial aspect of governmental HIV care. The MoH holds prevention synonymous with promiscuity and sometimes with prostitution. In 2016, the Supreme Council of Radio and Television (RTUK), known for its pro-government ideology, censured condom ads on TV. The Council fined a popular television channel for showing a condom commercial and harming "children's moral, physical, and mental development." It also concluded that "the promotion of sexually explicit products arouses curiosity for children [...] and it is tempting for the youth."¹⁴⁶ According to this logic, any prevention method other than monogamy and abstinence are disapproved and access to preventive technologies is hampered as a requirement of morality. Mehmet a microbiologist working at an HIV testing clinic in Istanbul, told me in 2022 when I visited him at the new location of the clinic that "the Turkish state turns a blind eye to sexually transmitted infections in order to protect its vision of public morality and decency". As I will recount later in this chapter, Mehmet was concerned about the interruption of HIV testing kits provided by the Ministry of Health to HIV testing centers. He expressed his concerns by saying that "if HIV was approached as a public health issue instead of a political and religious one, we would not have an epidemic right now". In a similar vein, during an online gathering in 2021, public health professor Selma Karabey criticized Turkish public health on similar grounds. According to her, "without being able to talk openly and freely about sex, without changing the taboo nature of sex for public health, we cannot prevent HIV."

It is important to note that Harun, Mehmet, and Selma, like many others, blame conservatism as chiefly responsible for the puritanical transformation of sexual health services and STI prevention in Turkey. *This is all because of conservatism, the fear of sex, and the sanctity of marriage in Islam.* Yılmaz and Willis too observe that post-2010 there is a "conservative turn that undermines the autonomy of sexual health policy in Turkey."¹⁴⁷ In the 2000s, Turkey experienced a process of democratization partly due to the Ak Parti's initial

¹⁴⁶ "RTUK Fines Condom Commercial (RTÜK'ten Prezervatif Reklamına Ceza)," *Cumhuriyet*, 2016, http://www.cumhuriyet.com.tr/haber/turkiye/645596/RTUK_ten_prezervatif_reklamina_ceza.html.

¹⁴⁷ Volkan Yılmaz and Paul Willis, "Challenges to a Rights-Based Approach in Sexual Health Policy: A Comparative Study of Turkey and England," *Societies* 10, no. 2 (April 1, 2020): 1.

commitments to human rights and partly due to the EU accession process. In this period, sexual and reproductive health got a lot of attention from the state and a right-based approach started to become dominant.¹⁴⁸ From 2003 to 2007, Turkey's Reproductive Health Program was implemented with the collaboration of the European Commission and Turkish Ministry of Health. Under this program, sexual and reproductive health have become integral to the health care system. In 2007, the Ministry created service standards for sexual and reproductive healthcare which identified STI prevention and family planning as the building blocks of sexual and reproductive health. The Ministry of Health also released a National Strategic Action Plan for Sexual and Reproductive Health to cover the period from 2005 to 2015. In this action plan STIs and HIV are not only taken seriously but likened to "bombs ready to explode" in the country.

Unfortunately, these progressive policy changes were interrupted "by a policy shift that led to the marginalization of sexual and reproductive health policies" as the rights-based approach began to recede in health policy as a result of rising neoliberal conservatism.¹⁴⁹ In the 2014-2018 National Development Plan, the references to family planning and sexual and reproductive health were replaced with protecting the family and maintaining Turkey's young population demographics.¹⁵⁰ The conservative turn of public health regressively changed the course of national STI prevention as well. One of the worst developments took place when the Ministry of Health stopped the distribution of free condoms. In 2013, Pembe Hayat Derneği, *the Association of Pink Life*, Turkey's first trans rights association, petitioned the UN because sex workers were no longer provided free condoms by the Ministry. As a response, the Ministry told them that they could find condoms at Public Health Centers. However, Kemal Ördek, then director of Kırmızı Kurdele Derneği, *Red Umbrella Association*, a sexual health organization that works with trans sex workers, reported that they tried to reach out to the Public Health Centers three times yet were completely ignored. "What they say is that if we agree to talk to you or

¹⁴⁸ Yılmaz and Willis, "Challenges to a Rights-Based Approach in Sexual Health Policy."

¹⁴⁹ Yılmaz and Willis, "Challenges to a Rights-Based Approach in Sexual Health Policy," 6.

¹⁵⁰ Ibid.

distribute condoms, we would be legitimizing prostitution. This is letting sex workers die” said Ördek in an interview they gave to a newspaper.

In a context where the distribution of condoms in the public space can be considered a crime under the misdemeanor law or an incitement to prostitution, we are safe to argue that the strategy pursued by the governmental HIV care in Turkey under the name of 'preventing HIV transmission' is simultaneously preventing the spread of unbridled sexuality. To quote Linda Singer's "logic of contagion" once more, not only the passage of bodily fluids, but everything that comes to mind regarding sexuality is risky and potentially harmful to the individual and society during an epidemic of HIV. Under the conservative governance of sexuality, however, an epidemic of a sexually transmitted infection is not necessary to ascribe negative meanings to sex such as contagion, infectiousness, and degeneracy. For being assumed to promote free sexuality, preventive mechanisms such as condoms (or PrEP as noted in Chapter 5) can put governmental HIV care in a deadlock when the goals of preventing HIV transmission and preventing the spread of sexuality may come into conflict.

Yılmaz and Willis conclude that “Turkey’s current treatment-centred approach and the increasing pressure on sexual health promotion have failed to tackle the spread of STIs.”¹⁵¹ Nevertheless, one should resist the impulse to read the gradual weakening of preventive sexual health under AKP vis-à-vis conservatism only. According to Korkman, who interprets AKP’s pronatalist policies as a way of neoliberal accumulation of cheap labor, “the contemporary politics of intimacy in Turkey seeks to regulate the realms of sexuality and reproduction in line with the intersecting rationales of neoliberalism and neoconservatism.”¹⁵² In the same vein, Evren Savcı argues that sexual politics in Turkey should be interpreted within the framework of neoliberal Islam because “Islamic morality factors as the key mechanism through which

¹⁵¹ Yılmaz and Willis, “Challenges to a Rights-Based Approach in Sexual Health Policy,” 7.

¹⁵² Zeynep Kurtulus Korkman, “Blessing Neoliberalism: Economy, Family, and the Occult in Millennial Turkey,” *Journal of the Ottoman and Turkish Studies Association* 2, no. 2 (2015): 335; Zeynep Kurtuluş Korkman, “Politics of Intimacy in Turkey: A Distraction from ‘Real’ Politics?,” *Journal of Middle East Women’s Studies* 12, no. 1 (March 2016): 116.

neoliberalism is ‘domesticated’.”¹⁵³ For Savcı, neoliberal binaries such as deserving/undeserving and responsible/irresponsible are animated by an Islamic morality in Turkey. Below, I extend these arguments by showing that not only sexual and reproductive politics but the politics of sexual and preventive health should be analyzed at the intersection of political Islam and neoliberalism—dubbed “neoliberalism with a muslim face” by Coşar and Özman.¹⁵⁴ In what follows, I provide an overview of neoliberalization of healthcare in Turkey and its implications for preventive and sexual health.

Sexual Health in Neoliberal Turkey

In 2018, I had the chance to interview a doctor, Tugay, who worked at the Directorate of Public Health in Tuzla district of Istanbul. He worked there because he had no time or money to attend the courses to help him score good enough for psychiatry in the specialization exam. He said he cursed his job every single day because it was extremely grueling to be in public health in contemporary Turkey. Only after a year at his government job, he resigned and started to work as a medical manager for a global pharmaceutical company. The next time we met in 2020, he shared that he was criticized by his colleagues for “selling his soul” to a private company. For him, though, these criticisms were missing a crucial point: that state-sponsored health is also a private sector in Turkey.

They think I was doing a better job as a public health practitioner. If only they knew what that means in Turkey today. Public health should be about preventive medicine before anything else. Yet preventive medicine is rapidly weakening due to the privatization of health under AKP. By not investing enough in prevention, the government is actively creating a much-needed surplus of patients. Now, when we think of the unparalleled increase in the number of private hospitals, we can see why there is also an increasing need for patients to be treated at these places. Not to mention the fact that many representatives of AKP hold shares of the private hospitals. For instance, The Minister of Health, Fahrettin

¹⁵³ Evren Savcı, *Queer in Translation: Sexual Politics under Neoliberal Islam* (Durham, NC: Duke University Press, 2020), 22.

¹⁵⁴ Simten Coşar and Aylin Özman, “Centre-Right Politics in Turkey after the November 2002 General Election: Neo-Liberalism with a Muslim Face,” *Contemporary Politics* 10, no. 1 (March 1, 2004): 57–74.

Koca, himself is the owner of a private hospital, Medipol... (Tugay, personal interview, 2019)

Tugay's critique of healthcare's privatization under AKP and the consequent reduction of preventive medicine illuminates the immediate consequences of healthcare's neoliberalization in Turkey. In order to understand the transformation of HIV care under Ak Parti's governance, we must first answer what happens to care under neoliberalism. According to Joan Tronto, a political theorist who has studied care throughout her career, care is understood in three different ways under neoliberalism.¹⁵⁵ The first is that care becomes an individual responsibility and obligation. Here, neoliberalism aims to reduce the burden of the state and state institutions by making individuals responsible for their own care. According to this neoliberal logic, it is the duty of the individual to take and access the precaution, and if the action is not taken, failure and irresponsibility belong to the person, and the consequences should be suffered. Here, it is useful to remember Foucault's comment on neoliberalism. According to him, neoliberalism, which is an art of management, is not just about markets or the economy. The reason why neoliberalism can infiltrate virtually all areas of life is that it pushes everyone to think and act as if they were a market actor. And actors in the markets should be able to calculate risk, take the necessary precautions and be responsible for themselves.¹⁵⁶ This expectation is, of course, far from reality as it ignores how increasing economic pressures make it impossible for many, especially marginalized people who work in the informal sector, to access healthcare.

Neoliberalism's second approach to care is to push it into the narrow confines of the family. When someone cannot take care of themselves, that is, they cannot fulfill their homework, this time the responsibility falls on their family. In this way, the amount of assistance that can be demanded from the state for care is diminished. The family should face all difficulties and, if necessary, lose their homes and jobs to take care of their own members. No one knows better than people living with HIV and LGBTI+s that things don't actually work that way. Due to

¹⁵⁵ Joan Tronto, "There Is an Alternative: *Homines Curans* and the Limits of Neoliberalism," *International Journal of Care and Caring* 1, no. 1 (March 23, 2017): 27–43.

¹⁵⁶ Foucault, *Society Must Be Defended*.

their gender identities, serostatus, and sexual orientations, many of them do not get enough support from their biological families and sometimes are exposed to violence and discrimination at the hands of family members. It is true that they stand in solidarity with their chosen families that provide them with the care and attention they need. However, this example of solidarity still does not change the fact that the material and moral burden of care is taken from state institutions and imposed on individuals and chosen or biological families.

The final change that care undergoes under neoliberalism is its reduction to a market problem. For example, the fact that the number of private hospitals increased from 271 to 562 between 2002 and 2015 within the scope of the Health Transformation Program (HTP) in Turkey and the number of beds in private hospitals increased almost four times can be considered in this context. Although healthcare services have been gradually privatized, the neoliberalization of health in Turkey does not mean that the state has completely withdrawn from this field. For Ak Parti, the ideologies of welfarism and neoliberalism do not contradict yet strengthen each other.¹⁵⁷ In order to better explain what I mean by this, in the rest of this section, I will discuss the Health Transformation Program by focusing on its consequences for healthcare in general and sexual health in particular.

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The full consolidation of neoliberalism that began to dominate in Turkey in the 1980s, only took place after 2002 when Ak Parti came to power as a single-party majority government thanks to a populist discourse that targeted all marginalized segments of the society whether their marginalization was based on religion, class, ethnicity, or sexuality. Realizing the importance of the votes of those who were excluded from participation in social and economic life under previous administrations, Ak Parti focused most of its efforts in transforming the healthcare and social security system. The domain where AKP believed that it could make the biggest

¹⁵⁷ Oyman Başaran, "Neoliberalism, Welfare, and Mass Male Circumcisions in Turkey," *European Journal of Cultural and Political Sociology* 8, no. 1 (January 2, 2021): 35–58.

difference in the votes of the masses, and perhaps was right, has been healthcare. When the AKP came to power, more than 30% of the population could not access health services under the three existing social security options—Pension Fund for civil servants, Bağ-Kur for the self-employed, or Green Card for low-income earners. This divided social security system was frequently criticized by the AKP as costly and ineffective. Based on the blueprints of the Health Reform Project carried out in the 1990s, the Health Transformation Program (HTP) was designed as an embodiment of these criticisms and implemented in 2003 to reorganize the health services and social security system. The purpose of the Program was to provide “accessible, qualified and sustainable health care for all” and it heralded the prospect of universal health insurance for everyone. Three distinct components of the HTP have been instrumental in the neoliberalization of healthcare: (a) the transformation of the MoH into a supervisory, managerial institution, (b) transforming hospitals into autonomous health enterprises, (c) and developing primary health care services within the framework of family medicine.

In 2012, only nine years after the HTP was implemented, almost 98% of the population was insured in the scope of *Genel Sağlık Sigortası (GSS)*, general health insurance. As a result, the AKP has come to be known as a success story and even considered as the party that revolutionized healthcare in Turkey. These numbers, however, should be approached with caution. Under the pretext of universal access to health, the HTP has repaired certain inequalities while at the same time building new ones. And at the heart of these inequalities is that patients have suddenly become customers as health has become a commodity to be bought rather than a positive right to be freely enjoyed. Since the scope of poverty is defined too narrow, it is obligatory for everyone to pay the premium (12,5% of their monthly income, 5% of which is covered by the employer), except those earning less than one-third of the minimum wage, which is around 450 dollars. In a country where unemployment has become a chronic problem (), having to pay monthly premiums and a contribution fee for each service except primary health care violates the right to health instead of providing universally accessible and affordable care.

It is not quite possible to talk about the universality of GSS for those who cannot pay their insurance premiums. In December 2021, it was estimated that the number of people who won't be able to benefit from healthcare services starting January 2022 because of their debts to the Social Security Institution was ten (10) million. Although these debts were postponed during the Covid-19 pandemic, they will not be pardoned in the near future and millions of people including those with chronic problems such as HIV and cancer will lose their access to healthcare and treatment overnight. Similarly, it is very difficult to talk about the universality of healthcare for those who cannot go to private hospitals to enjoy higher quality services without waiting in the line for hours or waiting for months for a simple procedure or screening. The HTP is credited by Ak Parti and its electoral basis for enabling those benefiting from social security to benefit from private hospitals and clinics. The number of medical visits, which was estimated to be around 14 million in private health institutions in 2002 when the AKP came to power, increased to 101 million in 2013. However, private healthcare is an option only made accessible to those who can afford out-of-pocket costs up to 200% of the amount covered by the SSI, or to those who also benefit from private insurance in addition to GSS.

When we start to think of the impacts of the Health Transformation Program in terms of sexual health, a question rightly arises: what has sexual health become in the days of AKP? Under the rule of Ak Parti, sexual health in Turkey has become synonymous with maternal and reproductive health. The most obvious sign of this change lies in the creation of Family Health Centers. Within the scope of the HTP, community clinics, *sağlık ocakları*, are renamed and restructured as Family Health Centers with the purpose of providing easily accessible first step of preventive care and basic health services to the local population.¹⁵⁸ The replacement of community clinics that were scattered all over the country with family health centers, however, had two critical implications: first, it became epidemiologically more difficult to evaluate the public health or forecast perils of emerging epidemics as a result of losing the public institutions with central roles in monitoring communicable diseases. Second, inequalities in accessing

¹⁵⁸ Balacan Ayar, "A Closer Look at Family Medicine Implementation in Turkey in Regard to the Doctor-Patient Relationship" (Istanbul, Koç University, 2019).

sustainable healthcare became inevitable.¹⁵⁹ Although community clinics were opened based on the geographic need, family health centers follow the principles of supply and demand to maximize profit. This creates grave problems for communities with lower income and rural communities. A family physician, who worked in Ankara for several years before her contract was canceled because she did not maintain the minimum number of 1000 registered patients, made the following observation:

The family health system separated the health of the individual from the health of the public: providing preventive care for the former is under the responsibility of family health centers while the latter is to be monitored by community health centers, *toplum sađlıđı merkezi*. “The HTP is trying to achieve the impossible. The MoH acts as though the health of the individuals can be held separate from that of the community they belong to. Before, it was the community clinics’ job to attend to both, but, now, they say community health centers will deal with public health. But how? Before, there used to be more than ten or twenty community clinics in a single district where there is only one community health center now. Besides, family health centers are mostly located in urban areas, making it very difficult for the rural population to access primary healthcare. (Ayşegül, personal interview, 2021)

Unlike community clinics that adopted a holistic and multidisciplinary approach to the health of the community they were located in, family health centers are structured around an individualized conception of health and prevention rooted in neoliberal capitalism. As a result, services such as STI prevention are abandoned as integrated aspects of primary health care. Today, family health centers are semi-privatized establishments where contractual health personnel may lose their contract or receive a deducted salary if they fail to achieve their performance targets. The performance-based nature of the work eventually creates a situation where certain services such as immunization, antenatal visits, and follow up visits with registered babies are given more weight by family doctors because they bring higher performance points.¹⁶⁰ A family health physician, Dr. Yonca, who works in one of the most populous neighborhoods in

¹⁵⁹ Egemen CeVaheir, *Türkiye’de Sađlık Sisteminin Dönüşümü - Toplumsal Yansımaya Örnekleri* (Istanbul: Kibele, 2016).

¹⁶⁰ Balacan Fatıma Ayar, “Deciphering the Intimacy Politics of the AKP Government Through Its Restrictions on Sexuality Education in Turkey: Resistance of NGOs and Emergence of New Repertoire of Actions” (Budapest, Central European University, 2017).

Istanbul, also known as the area with the highest concentration of LGBTI+ habitants, openly shared with me as she was showing me excel files with the clinic's profit and loss statement, that she feels helpless when it comes to prevention of STIs and communicable diseases as she is expected to fill certain quotas. When we met a second time, because I had further questions for her that I wasn't able to ask the first time when we were interrupted by a patient who unexpectedly showed up, she complained about the privatization of primary healthcare and told,

The only thing that the Health Transformation Program transformed is our health system that has since become a treatment-oriented one. Community clinics used to focus on preventive services, but now the focus has become treatment-centered with family medicine. The government says, 'I treat the disease instead of preventing it', and it's not the government or the public that benefits from this approach, but the pharmaceutical companies. Also, as a family physician, I get a limited budget from the Ministry of Health. Then, I need to pay for the rent, personnel expenses, and necessary equipment. So, I always have to find a way to cut the expense because I start thinking about the clinic as my personal business. The primary concern of a family physician should be public health, not financial survival. (Yonca, personal interview, 2021)

The change from community to family health is not only nominal as it also reflects how Ak Parti approaches the public health as the health of the heterosexual family. The preventive care in Family Health Centers is mostly limited to immunization and STI prevention is rarely, if ever, mentioned. Before, community clinics had free condoms to offer, yet Family Health Centers no longer have that service. Although sexual health is redefined in terms of reproductive health in FHCs, emergency contraceptives are largely unavailable too,¹⁶¹ as the use of contraceptives runs counter to the pronatalist public health. Many health personnel in FHCs do not have the sufficient capacity to offer sexual health services either. Between 2003 and 2007, within the scope of Turkey's Reproductive Health Program that was implemented with EU support, health personnel all over the country received comprehensive sex education. Today, the Ministry of Health does not offer any education opportunities and nurses are let down when they demand sexual health education from the Ministry. The public health specialist I quoted at length earlier used to work in Tuzla, a conservative district of Istanbul. Every time we met, he would complain

¹⁶¹ Mary Lou O'Neil, Bahar Aldanmaz, and Deniz Altuntaş, "The Availability of Emergency Contraception from Family Health Centers in Turkey," *Health Policy* 126, no. 7 (July 2022): 715–21.

about how “sexual health became all about babies”. Once I asked him to be more specific about what he means, and he warned me not to open the Pandora’s box. Yet, he still answered my question: “Before we could freely talk to people about sexuality. We were able to mention different protection options, how to prevent STIs, and how to self-examine genitals. Now, let alone being sex-positive, we must be cautious about how we talk about sex, which words we choose. We cannot normalize sex, talk about STIs, or recommend birth control because they suggest unbounded sexuality. We should be able to order as many ELISA tests as we want but if we order so many the MoH will ask for an explanation.”

One of the most critical consequences of neoliberalization of health is that informing the public about prevention mechanisms and making these mechanisms accessible is no longer the responsibility of the state. With the transformation in health, the Ministry of Health has stepped out of its role as a provider and assumed the role of an implementer. This critical role change has had two direct consequences: first, the ministry now outsources preventive care to civil society. The nongovernmental organizations are expected to undertake HIV and STI prevention by informing the public and reaching out to key populations, such as trans sex workers with whom the Ministry does not want to engage as a respectable state institution. NGOs may seek the help of the ministry by using public health as an excuse, but what they end up with may be like cheap and easily torn condoms distributed for trans sex workers in the past. The irony here is that while the burden of prevention is put on the civil society, NGOs’ attempts to provide sex education is regularly thwarted by AKP’s “neoconservative politics of intimacy” by keeping distance from NGOs providing right-based education models on sexual and reproductive health, and indirect or direct interventions in the content of the education programs of the NGOs.¹⁶²

The second result of the Ministry's changing definition of responsibilities is the increasing financial dependence on external resources and the concomitant decrease in the sustainability of preventive services. The Ministry of Health no longer wants to put its hand in its

¹⁶² Ayar, “A Closer Look at Family Medicine Implementation in Turkey in Regard to the Doctor-Patient Relationship.”

pocket, especially when it comes to sexual health. Instead, it supervises million-dollar projects supported by the European Union and the Global Fund to Fight Against AIDS, Tuberculosis, and Malaria (Global Fund, for short). Within the scope of the HIV/AIDS Prevention and Support Program for Turkey that was launched in 2005 with the support of the Global Fund (4 million dollars), sixteen projects were implemented in total by thirteen different organizations, most of which were shut down when they were not able to find funding after the Global Fund. One of the most critical consequences of the Prevention and Support Program was the opening of fourteen Volunteer Testing and Counseling Centers (GTDM) in various provinces of Turkey in 2007. When the budget from the Global Fund drained, only one GTDM remained in Şişli, Istanbul, with the funds allocated by the local municipality under the governance of the main opposition party.

Voluntary Testing and Counseling Centers, GTDMs

Incredible disgrace from Mersin Metropolitan Municipality! Promoting prostitution on campus: Mersin Metropolitan Municipality has committed a great disgrace. Condoms were distributed by the municipality on the Mersin University campus under the name of safe sex and young people were openly encouraged to prostitution... While prostitution and extra-marital relations were normalized by motivating the young generation to engage in immoral practices through the written and visual media, the CHP-led [the main opposition party] municipality also supported the global plan to disrupt the morality of society by distributing condoms to young people on the university campus. ¹⁶³

The above excerpt is from a 2019 news piece published in Yeni Akit, a newspaper known for its pro-government, neo-conservative propaganda. The background of this news story is worth recounting: With a population of nearly two million, Mersin is an important hub of Turkey's economy. Turkey's largest seaport is located in the city that is colloquially known as the "Pearl of the Mediterranean". In December 2019, 'Developing Cooperation and Counseling Support Workshop' was organized for Mersin Voluntary Counseling and Testing Center (Gönüllü

¹⁶³ "Mersin Büyükşehir Belediyesi'nden akılalmaz rezalet! Kampüste fuhşa teşvik (Incredible disgrace from Mersin Metropolitan Municipality! Promoting prostitution on campus)," 2019, <https://www.yeniakit.com.tr/haber/mersin-buyuksehir-belediyesinden-akilalmaz-rezalet-kampuste-fuhsa-tesvik-962916.html>.

Danışmanlık and Test Merkez, GDTM) by Mersin Metropolitan Municipality, Turkish Family Health and Planning Foundation (TAPV), United Nations Population Fund (UNFPA) and Mersin University. Experts in their fields attended the workshop held at the university campus on the occasion of World AIDS Day. Condoms were also distributed at the workshop where the methods of preventing HIV were discussed.

Later that month, during a general assembly at the municipality, council member Mehmet Emin Kurt, representing AKP, raised his concerns through what was seemingly intended to be a rhetorical question. "Our Health Department went to Mersin University and distributed condoms there. Is this appropriate for the customs and traditions of our society?" asked Kurt, who comes from the far-right, ultranationalist gray wolves movement, whose youth chapter at Mersin University tried to prevent the distribution of condoms but was held back by the security forces. The mayor defended the event by proclaiming that it took place as a result of a protocol signed with the Ministry of Health. In the face of the criticisms, he added that they will no longer sign a similar protocol with the Ministry and if the Ministry wants, it can organize the event on its own and face the criticisms itself. The head of the Health Department, Dr. Hülya Atila, on the other hand, sought to fend off the critiques by emphasizing that the Municipality did not buy the condoms itself, which were provided to them by a nongovernmental organization.

As I mentioned earlier in this chapter, 14 Volunteer Counseling and Testing Centers were opened in Ankara, Istanbul, Izmir and Trabzon within the scope of the "Turkey HIV/AIDS Prevention and Support Program." This program was implemented within the framework of the agreement signed by the Ministry of Health and the Global Fund. The most defining aspect of GDTMs is their commitment to free and anonymous HIV care. Getting tested for HIV or other STIs is severely stigmatized in Turkey and many believe police will come to their house or that their employers and families will be notified. Stigma around STIs is the biggest factor, along with lack of information, preventing people from seeking testing. Because of the opportunity of getting tested without providing authentication information, GTDMs are mostly used by refugees, migrants, and LGBTI+ individuals, who fear loss of rights and livelihoods in the case

of testing positive. In GTDMs, applicants can get free and anonymous information and counseling on HIV/AIDS. Anonymous HIV testing can also be applied quickly upon request. Condoms, when available, and informational materials such as brochures and booklets are provided at the center free of charge. Physicians, psychologists, social workers or nurses serve as consultants in the centers, where they offer information to individuals on HIV/AIDS-related issues and answer their questions. Within the scope of counseling services, information and guidance are provided for HIV/AIDS as well as other sexually transmitted infections. Counseling is done in two ways: Pre-test counseling provides information on the HIV test method, when it should be done, where it can be done, and the meaning of positive and negative test results. If the test result is positive, special counseling service is provided and referrals are made to treatment centers and support groups, taking into account the profound effect this result may have on the individual. After the funds from the Global Fund drained, only one GTDM remained open in Şişli, Istanbul, as a result of the local municipality's initiative. In 2018, to celebrate the gay pride, Şişli Municipality renamed the center after Boysan Yakar, an outspoken LGBTI+ activist and an employee of the municipality who passed away in 2015 in a tragic car accident along with two other activists. Today, there are seven test centers in the entire country, six of which are opened by CHP-led municipalities.

When the conservative media and politicians were attacking Mersin GTDM and its personnel, the Ministry of Health did not come to their support, although it was aware of and supported the workshop. Nor did it intervene when Mersin GTDM discontinued its services for two years due to the political pressures it suddenly found itself under. When Emel Hanım from the Ministry was indirectly confronted by Dr. Ersöz during an online conference in 2021, she contented herself with saying that she is sorry but sometimes unpleasant things happen. This attitude of “we will endorse but we won't take responsibility” reflects the Ministry's general approach towards voluntary testing and counseling centers. Mehmet, a microbiologist from Şişli GTDM, believes that the Ministry of Health avoid responsibility to protect its name from being associated with a sexually transmitted disease.

The GTDMs are opened in a very secretive way. Few people know about them at the Ministry of Health and if more people were aware of them, they would be shut down. The municipal council members from AKP are already trying to get rid of Şişli GTDM and relentlessly insist that the municipality should not be paying for HIV testing. During the pandemic, GTDMs were the first places to be closed and a lot of people lost access to HIV testing. It's as if they are called "voluntary" because they are opened on a voluntary basis and not because people go there voluntarily. The services they provide are far from being sustainable. Besiktas, Nilüfer, and Konak municipalities are not able to perform tests for months because the Ministry stopped providing rapid test kits. The only reason we are able to continue our services is because we have our own testing device. (Mehmet, personal interview, 2021)

The fact that the Ministry of Health does not allow GTDMs to use its logo or provide them with sufficient tests is another proof of the immunitarian line drawn between the Turkish state and HIV. However, although the ministry maintains its distance from GTDMs, it also played a crucial role in their opening. One of the first interviews I conducted for my dissertation was in 2018 with the former director of Positive Living Association, Harun, who took credit for the emergence of GTDMs and explained that it would not be possible without the Ministry's involvement:

Three years ago we implemented a testing project with Gilead's funding and made an agreement with a private lab. People don't get tested in Turkey because they don't want to share their names. Through this lab, we helped people get tested anonymously. This project continued for three years with the funding of different drug companies. 11 out of every 100 LGBTs were testing positive in these labs and we shared this information with the Ministry. Some of the bureaucrats are reasonable there. They say 'I cannot come close to LGBTs because I work for a conservative state institution'. They also can't work with queer organizations such as Kaos or Lambda. But they accepted to work with us because our focus is on HIV not LGBTs. So, some bureaucrats from the Ministry's infectious diseases bureau said 'we will give free test kits, but you take care of the rest'. Then, we reached out to several municipalities and explained to them the situation. Later, they signed a protocol with the Ministry to get rapid tests and training for the personnel. The Ministry does not really support anonymous testing but overlooks what happens in GTDMs because it knows it is crucial to reach out to high-risk groups. (Harun, personal interview, 2018)

Even though it would not have been possible to open GTDMs without its cooperation, the absent-presence of the Health Ministry when it comes to GTDMs gives way to several vital issues. Most importantly, in the recent years there have been regular interruptions in the ministry's provision of rapid test kits which resulted in test centers being unable to perform HIV testing sometimes for months. One of the GTDMs used expired tests for months as it was awaiting the delivery of new test kits from the ministry. The nurses used an expired rapid test on themselves everyday to see if the tests were still giving accurate results. In addition to immunitarian impulses, the reason behind why the ministry does not equip these centers with the required technology or provide them with adequate testing might have something to do with local electoral politics. All existing GTDMs are opened as a result of initiatives taken by CHP-led municipalities. All these municipalities are found in urban metropolises critical for the future of any political party. Gulden Ersöz, an infection doctor from Mersin who almost lost her job when she got implicated in Mersin GTDM scandal because she works for the University where the condoms were distributed. Ersöz believes that the problems Mersin GTDM experienced are purely political as the purpose was to wear down the municipality and the attacks on the GTDM were merely instrumental.

The disparate approaches towards sexual health by the central administration and the municipalities is interpreted as “a local manifestation of the political polarization over a rights-based approach to sexual health.”¹⁶⁴ As opposed to the Ministry of Health, local municipalities governed by CHP are considered more progressive when it comes to sexual health. To some extent, this holds true as is shown by the support they provide for GTDMs, yet they still are not completely free of sexual conservatism. With the financial support of a pharmaceutical company, Gilead, Red Umbrella implemented a project to increase the number of GTDMs all over the country. The organization visited multiple municipalities to explain to them why and how to open an HIV testing center. Melis, a long-time employee of Red Umbrella and the person involved in meeting municipal personnel explained her strategy to convince municipalities as something akin to “straight-washing”:

¹⁶⁴ Yılmaz and Willis, “Challenges to a Rights-Based Approach in Sexual Health Policy,” 6.

When I go to a municipality to encourage them to open a GTDM, I don't say LGBTIs and trans people will come here. I say this is necessary for public health. This is the only way to make them believe in the importance of having a test center. They won't provide a service for LGBTIs only, both because of their homophobia and because they fear negative reactions from the public, media, and politicians." Although she described this tactic as "unideal" and found it demeaning as a trans woman to have to push the queer community into the background, she still believed that what matters is to get the test centers opened. "What is really important is to have more centers. Once a GTDM is opened, we direct so many gay and trans people there. So, as long as more queer people have access to tests and counselling, it doesn't really matter what we say to make the municipalities take this issue seriously. (Melis, personal interview, 2022)

In the face of decreasing opportunities of care for marginalized communities during AKP's long-lasting rule, local municipalities have become crucial providers of social assistance and care. Following a legislative reform in 2004, local governments began to undertake some of the responsibilities of the central state, transforming them into key actors of social policy. Nonetheless, "while service provision capacity was increased by localization to an extent, the social care provision capacity that district municipalities developed is not sufficient to transform social care policies into one that conforms to the principle of universalism."¹⁶⁵ For instance, Şişli municipality is known as one of the most LGBTI-friendly local governments. Its continuous support for Boysan Yakar GTDM is shown as an exemplary practice that should be adopted widely at a local level. Nonetheless, being named after a gay activist does not make Şişli GTDM accessible or safe for everyone. Testing and counseling services are provided at the center between 5pm and 10pm during the weekdays. This has serious consequences in terms of who can access HIV care and at what cost. Because of the designated time frame, many queer people run into each other at the center or are observed while entering the center located on a crowded street. This gives way to a potential violation of privacy, despite the fact that anonymity is the main purpose of GTDMs. I have heard of several instances where gay men were accused of being HIV positive on dating applications because they were spotted at the test center. On the other hand, the limited time frame makes it difficult for many trans sex workers to benefit from

¹⁶⁵ Elifcan Celebi, "Rescaling Social Care Services: The Case of District Municipalities in Istanbul," *International Social Work*, March 5, 2020, 002087281990115.

free and anonymous services since they work at night and sleep during the day. Even when they can make it to the center in time, there is no guarantee that they will feel welcome there due to the transphobic attitudes of the health personnel.

Whereas anonymity is what makes the HIV care offered at GTDMs accessible and preferable, it comes with its own problems. As Lisa Stevenson demonstrated in her meticulous exploration of care in the Canadian Arctic, anonymous care does not allow for the development of individual bonds as it does not give any importance to who the care-receiver is, where they come from, and what they might need. Anonymous care is too professional and too impersonal, rendering the care-giver indifferent to the affective and relational aspects of care work. The anonymity of care in GTDMs not only stems from the clause of nondisclosure but also by the fact that these centers are not community-based spaces. People who work at GTDMs are not queer or HIV+, and they cannot provide peer-support. GTDMs can also be physically inaccessible to LGBTI+ communities because of their locations. One GTDM is located too close to a police station which makes it risky for trans people to go there. Boysan Yakar GTDM was originally in the heart of Şişli neighborhood, and it had its own two-story building that was easily accessible to queer community members. After the pandemic, the GTDM was reduced into a few rooms on the first floor of a municipal administration building, deterring a lot of queer people from going there to avoid being harassed or outed as HIV+.

Çankaya GTDM in Ankara is the only testing center that could be considered community-based. This is made possible thanks to the efforts of a single nurse who stands out from the rest of the clinic personnel with her green/blue hair dye and her friendly attitudes. Ayşe hemşire, nurse Ayşe, has befriended many young queer HIV activists to make the clinic a welcoming place for its target community. I never forget the first time I met her. When I entered the meeting room where she was waiting for me and for my friend Ali, the first thing I told her was how I feel sorry for taking her time with this interview. She responded with giggle and told me that I should not worry about it because they haven't been working much lately since the Ministry of Health stopped sending them HIV testing kits. Then, she lit a cigarette and offered

me one as if to tell me to begin the interview. We talked for more than three hours that afternoon and when we paused, we collected mulberries from the trees in the clinic's front yard and enjoyed them while sitting on the green grass.

(In)Action Plans and Politics of HIV Statistics

In 2021, I was attending a virtual meeting with the participation of more than forty public and private actors involved in HIV care. The event was organized as part of a workshop series to establish a standard and inclusive terminology of HIV & AIDS. The medical and everyday language of HIV and AIDS are stigmatizing and pathologizing in Turkey, leading nongovernmental organizations to create similar platforms to address the issue. I was excited for this event because it was going to be the first time I am meeting a government official from the Unit of Diseases Transmitted Sexually or Through Blood. The unit is located under the Infectious Diseases Bureau of the General Directorate of Public Health, which works under the Ministry of Health and is responsible for family practice and preventive medicine. It is often difficult to meet anyone from the Ministry unless you are working for one of the three HIV NGOs, and I was never successful at securing an appointment either. I was informed by my friends in civil society that Emel Hanım was going to attend the meeting. *Hanım* is how everyone addresses her instead of the more common option, *hocam*, widely used when addressing doctors. Although both terms show respect, *hanım* means “miss, lady” whereas *hocam* means “my teacher,” in this case indicating a show of respect based on occupational authority. Emel Hanım is also a medical doctor by training, but her position as a government official grants her a privileged position among others.

In civil society, Emel Hanım is considered as “the best person who has ever worked for the bureau of infectious diseases” and as the “key person” when it comes to getting anything done about HIV. Some civil society employees address Emel Hanım as Emel abla, *older sister*, to express how close they feel to her. Although Emel Hanım does not allow herself to make political comments or criticisms, during the virtual meeting she confessed, “The field where I

love working at and contributing to most is HIV. The more you do, the more you realize that you haven't done much yet, and I am fine with it. But, at the same time, it is a very political field. And sometimes what I can do is limited. As an employee of the Ministry, I cannot do everything as I want.” To her credit, during my fieldwork I heard several examples of Emel Hanım stretching regulations to help HIV+ people access treatment and avoid persecution.

The online event took place as a virtual roundtable. The participants were expected to discuss a pre-determined list of terms and reach a consensus on the appropriate uses when possible. After heated discussions about how to use language properly, the next term on the list was epidemic and the purpose was to discuss whether it is scientifically appropriate to call rising HIV diagnoses in Turkey an epidemic. As I was curious about the opinion of a Ministry official, I directly asked this question to Emel Hanım, which she replied, “Of course there is, did you not see the Health Ministry’s National HIV/AIDS Control Plan for 2019-2024?” as she was pointing a copy of the plan to the camera so that everyone, especially I, could see it. Two months later, during another online event organized by the same NGO to bring together a large group of public stakeholders, we were discussing how to prevent stigma and discrimination in the hospitals, clinics, and workplaces. Minutes before the meeting was over, I brought up a recent study circulating among the activists. My purpose was to provoke the participants, but especially Emel Hanım, whom I was not expecting to see that night among the attendees. According to the article there was a discrepancy with the numbers of AIDS-related deaths between 2009-2018. Although the MoH recorded 115 deaths during the given period, the number reported by the article was 721.¹⁶⁶ The new data also pointed out an alarming increase in mortality by more than double since 2009. I asked what the explanations could be and whether the rising numbers of mortality could be interpreted in terms of stigma and discrimination creating issues with access to test, prevention, and treatment. Although my question was not directed towards her, one of the hosts of the event asked Emel Hanım if she would like to offer her opinion. After a moment of silence, she opened her microphone (her camera was off the whole time) and instead of answering the

¹⁶⁶ See Teker, “AIDS-Related Deaths in Turkey between 2009 and 2018.”

question gave a short speech about the significance of the National HIV/AIDS Control Program and the action plan included in it.

The persistent emphasis of Emel Hanım on the importance of HIV/AIDS control programs during online meetings can be read as a sign of covering up the incompetency of the Ministry of Health in addressing the epidemic. Many participants in these events are public health practitioners critical of the Ministry's lack of commitment to controlling the epidemic. In fact, the Ministry is known by many to be an institution where only a few people, including Emel Hanım herself, are invested in doing something whereas the rest is conservative bureaucrats who won't even say the words HIV or AIDS. Gökengin, a well-known infection doctor, expressed her frustration with the Ministry's competence and capacity in these sentences:

A lot of people ask me how I interpret the increase in HIV diagnosis, but there is no need to be a doctor to interpret the obvious. If a government does not believe in the importance of prevention and does absolutely nothing to facilitate access to or popularize prevention methods, it is inevitable to end up with an uncontrollable epidemic. It is accepted by all global health authorities that marginalized and vulnerable groups are key to slow down STI epidemics, that's why they are called key groups. Yet, there has not been a single attempt on the part of the Ministry to reach out to key populations. I recently published a study on the mapping of female sex workers, transgender sex workers, and MSM in Istanbul and Ankara. I shared this study with the Ministry and explained the necessity to conduct a similar study encompassing the entire country. But nobody responded to my emails or returned my calls. The people at the Ministry do not even have the necessary background to understand this study. If you saw the bureaucrats working there, you would understand what I mean. There are a few smart, hardworking people at the Bureau of Infectious Diseases, but these are lower-level bureaucrats without any authority. Their supervisors, those who are responsible for public health, are not the kind of people that would listen to or understand me. (Gökengin, personal interview, 2022)

Given that Emel Hanım is not proud of the Ministry's conservative approach to sexual health and that she would have probably done things differently if she had the authority, it is understandable why she would be protective of the only material thing the Ministry ever produced in relation to HIV during her tenure at the institution. What makes her attachment to these documents intriguing for me is her negation of the fact that National HIV/AIDS Control Programs have not given way to a single material improvement in HIV treatment and prevention. To explain better

what National Control Programs are, where they come from, and what they do, or don't, I would like to share a lengthy quote from an interview with the bioethicist and activist Muhtar Çokar, one of the kindest medical doctors I have ever met:

In 1987, the High Advisory Board on AIDS was established as a top-down intervention mechanism in public health matters regarding reproduction and sexual health. Reproductive and sexual health rights have always been granted in a top-down fashion in Turkey. The Advisory Board consisted of scientists and the Ministry of Health personnel, but it was not able to put forward tangible interventions. Then, in the early 90s, UNAIDS was encouraging all countries to create an organizational structure that can produce national HIV/AIDS plans. In 1996, with the funds provided by the EU, the Ministry of Health and TAPV () founded the National AIDS Commission. Unlike the Advisory Board, civil society, other Ministries, and several organizations became members of the Commission, yet people living with HIV were not involved in the organization. The main task was to design national strategies to control the transmission of HIV, but the Commission did not have a sanction power and the suggestions it made never materialized. The meetings were also irregular, and the same person would not attend the meetings twice, the ministries would send different representatives each time. After 2008, the Commission stopped gathering altogether although it continued its existence on paper. The strategic plans are now called National Control Programs and they are prepared by the Ministry of Health. It is a positive development that the Ministry designs action plans and designates different institutions as responsible for their implementation. However, none of these institutions are involved in the making of these plans or asked whether they have the capacity to carry out the tasks they are given. A system of monitoring is not in place to see if these plans are effective either... (Çokar, personal interview, 2022)

One of the most important aspects of national control programs is the design of action plans whose main objectives are identified as (1) to reduce the number of new HIV/AIDS cases and deaths from infection; (2) to improve the capacity of health services for HIV/AIDS; and (3) to prevent discrimination and privacy violations against individuals living with HIV. Nonetheless, “to date, national plans for preventing the spread of HIV/AIDS and for effective surveillance have made no significant contribution to limiting the epidemic.”¹⁶⁷ In a sense, the control plans are neoliberal gestures of care: they identify what needs to be done yet never take the necessary actions to reach the desired goals. The perfunctory nature of these plans highlights the absent-

¹⁶⁷ Gokengin, Calik, and Oktem, “Analysis of HIV/AIDS-Related Stigma and Discrimination in Turkey.”

presence HIV care in the hands of the Turkish state. As an HIV activist put it, “the Ministry of Health pretends that it gives a shit about HIV but it is all empty words. Nothing really happens. Those documents should be named inaction (eylemsizlik) plans instead of action”. The Ministry of Health does not abandon the language of care and responsibilities. It acknowledges what is necessary to prevent HIV transmission and take care of people living with HIV yet fails at materializing these goals.

The failure to put the plans in action is not the only issue with the National HIV/AIDS Control Programs, which are not necessarily prepared in the light of up-to-date HIV science. In the Control Program, the ministry informs that “transmission of HIV infection can be prevented by completely avoiding sexual activity or simply maintaining a monogamous relationship with an uninfected partner.” What this statement does is to divide the public body as those who are infected and those who are not. By othering and pathologizing HIV+ people, it also teaches HIV negative individuals to protect themselves not from the virus but those living with it. Warning the public against “HIV-infected” people and not to have sex with them is the epitome of sexual health being surrendered to moral panics. In addition, in the same document, there is no reference to LGBTI+s. Only “men who have sex with men” and “transsexuals” are mentioned once under the category of “risky groups”, *riskli gruplar*, not risk groups, attributing risk to their identities rather than the conditions under which they live.

It is not solely the national control program that suffer from lack of scientific credibility. HIV statistics too appear to be considerably far from representing the reality of the epidemic. In the 2019 Health Statistics Yearbook of Turkey, the Ministry of Health shared the numbers of AIDS-related deaths in comparison to a list of other countries. Because AIDS-related deaths are still relatively low in Turkey, this comparison allows the Ministry to showcase its success in keeping mortality under control. However, no data is available in the yearbook on the HIV incidence, perhaps to avoid a potential comparison with other reference countries where HIV incidence is either decreasing or remaining stable. The gathering and distribution of data on HIV and AIDS by the Ministry of Health is often criticized by public health practitioners, NGOs, and

activists. These actors raise significant doubts about the scientific appropriateness of data collection and distribution, which they believe to be of foremost importance to respond to the epidemic. As Dr. Ayşe, a public health practitioner, highlighted,

Turkey is one of the few countries that do not share its HIV/AIDS surveillance data with UNAIDS in spite of the organization’s continuing pressure. The HIV surveillance data is either not collected properly or not distributed for the use of others. Even public health practitioners do not have access to sufficient data. The Ministry of Health does not share its data with us or the public: it merely shares the cumulative numbers and the numbers of incidence by age, sex, and transmission route. This is not enough to develop appropriate public health measures. (Ayşe, virtual meeting, 2022)

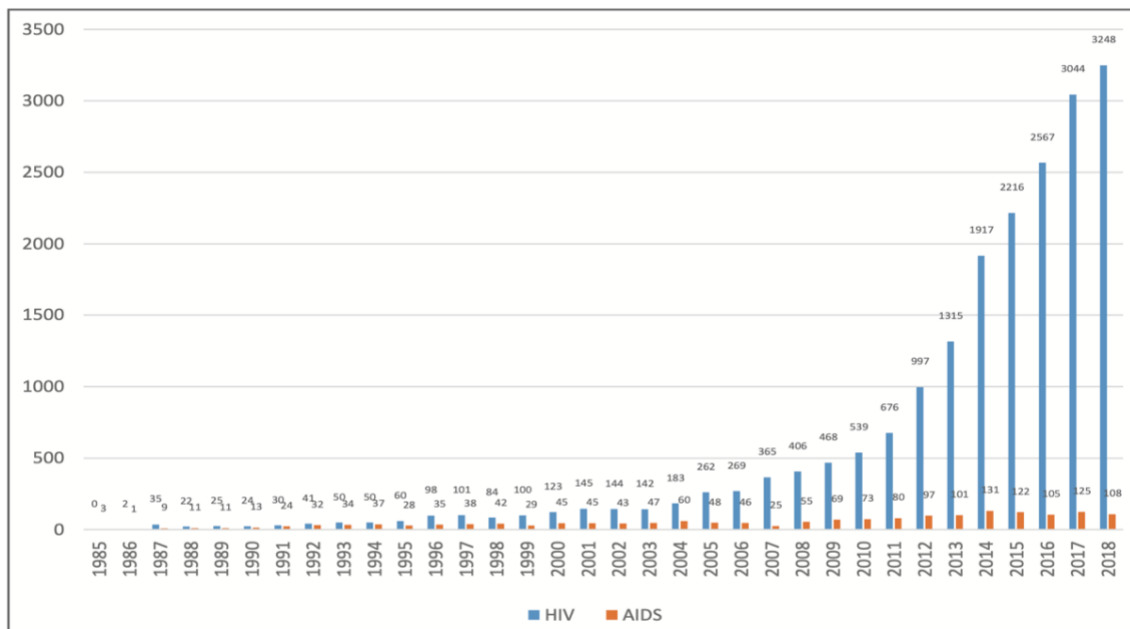


Figure 9: Distribution of HIV and AIDS cases between 1985-2018. Source: National HIV/AIDS Control Program 2019-2024.

The figure above shows how the epidemic of HIV unfolded in Turkey, at least based on the official numbers. This graph is considered by public health practitioners to be an underestimation resulting from a weak surveillance system and limited opportunities of HIV testing. Although official ministry numbers indicate nearly thirty thousand people diagnosed with HIV in the country since 1985, epidemiological estimates indicate considerably higher numbers and 2.5

million new diagnoses are expected by 2040.¹⁶⁸ Several arguments are made about the discrepancy between the official numbers and epidemiological estimations. First, even though millions of HIV tests are done yearly, the populations at higher risk of HIV are not getting tested. Since 1987, serologic tests have been compulsory for organ and blood donors, Turkish men who reside in foreign countries, but come to Turkey for their military services, and registered sex workers. HIV tests, nonetheless, are not targeted effectively as a result of which unregistered sex workers, LGBTI+ individuals, and intravenous drug users are left out from the reach of public health surveillance. Although there is no updated data on it, in 2004 the estimated number of sex workers in Turkey was 100.000, a mere 3% of which were registered. A year before, out of 2.5 million HIV tests, only 0.5% was performed on sex workers.¹⁶⁹ Furthermore, provided that only cis women or post-operation trans women can work as registered sex workers in Turkey, HIV testing efforts exclude trans sex workers.

Another argument concerns the predicament of HIV notification. Since 1985, notification of HIV is mandatory in Turkey. However, on the one hand, private hospitals and clinics are observed to be less strict with regulations. On the other hand, only infectious diseases specialists can notify local health authorities who then inform the General Directorate of Public Health (GDPH). It is, nonetheless, advised that other branches too, such as family doctors who work directly under the GDPH, should be able to notify new cases. The only problem with notification is not the failure to notify though, sometimes the same cases are notified several times or different cases are given the same anonymous code. An employee of an HIV NGO, who was afraid that low numbers of incidence shared by the Ministry will curtail foreign funding opportunities, once made a joke about how insignificant HIV statistics would look in Turkey if it was not for the duplicate cases. Since 1994, HIV and AIDS cases are reported anonymously. Although anonymity is vital to protect patient privacy, without a functioning registry and surveillance system in place, it makes it difficult to track individual cases. New HIV diagnoses

¹⁶⁸ Emine Yaylali et al., “Modelling the Future of HIV in Turkey: Disease Implications of Improving Prevention, Diagnosis and Treatment,” *JOURNAL OF THE INTERNATIONAL AIDS SOCIETY* 23 (2020); Murat Sayan et al., “Dynamics of HIV/AIDS in Turkey from 1985 to 2016,” *Quality & Quantity* 52, no. 1 (December 1, 2018): 711–23.

¹⁶⁹ Ay and Karabey, “Türkiye’de Gizli Seyreden Bir Hiv/Aids Salgini Mi Var?”

are notified by using a form called D86. Each case is given an anonymous code by using the first two initials of the patient’s name, their father’s name, and their last name, as well as the last two digits of the year they were born in. In this format, the code I am given would be TAMUAT91 (Tankut, Mustafa, Atuk, 1991). However, another person (Tarik, Murat, Atay, 1991) would be given the same code and there would be several different notifications with one code. In the opposite scenario, and this is what happens more frequently, because the notification process is not digitalized yet—the D86 form is filled and submitted by hand—the same diagnosis can be notified several times. For instance, if someone tests positive in one hospital but repeats the test in another one, or if they change their doctor for any reason, the HIV diagnosis is notified more than once. In the database there is no way to assure whether one case is notified multiple times or different cases are given the same code, so they are counted individually.

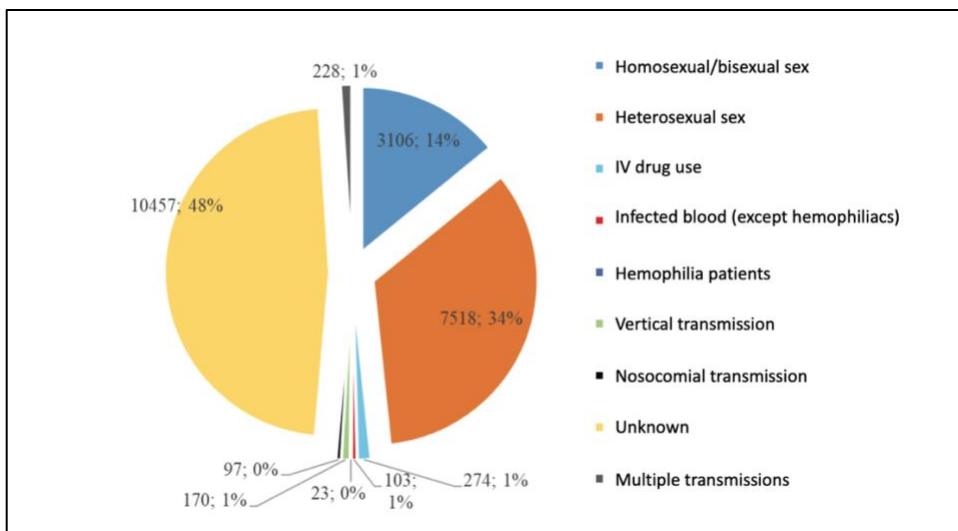


Figure 10: Distribution of HIV cases by routes of transmission. Source: National HIV/AIDS Control Program 2019-2024.

The last argument concerning the authenticity of official numbers is related to the process of data collection. The pie chart above demonstrates the distribution of HIV cases according to transmission routes from 1985 to 2018. The official numbers indicate heterosexual sex as the primary means of transmission (34%) which is followed by homosexual sex with a percentage of 14. Like other HIV statistics of the Ministry of Health, this one too should be approached with caution. Public health scholars and epidemiologists predict a significantly higher percentage of

“homosexual transmission” that is not reflected in the numbers.¹⁷⁰ This raises questions about the procedure according to which newly diagnosed patients are notified to the local health authorities. It is assumed that the “unknown cause” is the largest category of transmission with 48% of total cases because of individuals’ unwillingness to declare their sexual orientation. Dr. Gülden, an infectious diseases specialist whom I introduced in the previous section, explained the situation in the following sentences:

Right now, the statistics of the Ministry indicate heterosexuals as the group where the highest number of transmissions is observed. Yet, there is an error here because LGBTs are afraid of discrimination at healthcare facilities, therefore they do not share their sexual orientation. Understandably, they don’t want their sexual orientation to be indicated on a medical form that will be shared with state institutions. So, they mostly say they are heterosexual. I personally don’t ask anyone about their sexual orientation. I just choose the option ‘unknown cause’ because there is no medical justification for me to know how the transmission occurred. (Gülden, personal interview, 2021)

While it is commendable to avoid questions that can be invasive, without sufficient and accurate data it becomes more difficult to do advocacy work and to design appropriate public health interventions. Emre, one of the most vocal HIV activists I have known since 2018, believes that HIV statistics are “political” in the sense that they contribute to existing governmental and societal erasure of queer people:

HIV surveillance data specific to LGBTI+s is extremely necessary and important because it allows us to advocate for our rights and needs. Yet, we have no proof in our hands and this weakens HIV activism. Because the official numbers say HIV is more common among heterosexuals, public health interventions are not designed for LGBTI+s. This invisibilizes the various ways in which the rights of LGBTI+ people living with HIV are abused. Also, the way ‘homosexual transmission’ is used as an umbrella category makes it impossible to generate data specific to trans, bisexual, or intersex people. This is just a great way for the state to keep denying the existence of LGBTI+s in the country. (Emre, personal interview, 2018)

¹⁷⁰ Deniz Gokengin et al., “Programmatic Mapping and Size Estimation of Female Sex Workers, Transgender Sex Workers and Men Who Have Sex with Men in İstanbul and Ankara, Turkey,” *Sexually Transmitted Infections*, March 29, 2021, sextrans-2020-054894; Fatma Sargin and Safak Goktas, “HIV Prevalence among Men Who Have Sex with Men in İstanbul,” *International Journal of Infectious Diseases* 54 (January 2017): 58–61.

Emre's comments on the political nature of statistics and how they should be interpreted within the frame of Turkey's denialist politics must be taken seriously. Talin Suciyan, a scholar of Armenian genocide, invites us to judge Turkish politics as structured by a *habitus of denial* where denial becomes an ordinary event as well as a political strategy.¹⁷¹ Pinar Öktem, the first sociologist to work on HIV in Turkey, construes the issues with data collection and distribution as a reflection of how the Turkish government seeks to immunize itself towards HIV and HIV+ people.¹⁷² According to her, openly recognizing the existence of people living with HIV may oblige the state to provide them with required services. As Emre's words point out, the symbolic immunization becomes even more indispensable when there is a double threat of HIV coupled with queerness. "There are no LGBTs in Turkey" or "our society is not ready for them" are common statements adopted by the representatives of the ruling party. However, as the only official source that acknowledges the presence of homosexual sex in Turkey, HIV statistics pose a threat to the cogency of denialist governmental narratives. While coming to terms with a virus whose transmission takes place sexually at 98.6% of the times is already difficult for a conservative authority, recognizing the existence of an HIV epidemic among LGBTI+s would mean accepting the existence of an epidemic of deviancy in the country. Consequently, not knowing, hearing, or seeing becomes strategic political tools employed by the state and its institutions.

According to sociologist Linsey McGoey ignorance can be a willful strategy.¹⁷³ Denying the facts and having the least information possible can be an important governance method. It too can help individuals and institutions absolve themselves from taking responsibility in a situation of possible crisis. Eve Kosofsky Sedgwick too believed that the power does not lie in knowledge but in ignorance. In the *Epistemology of the Closet*, she writes that ignorance "can be harnessed, licensed, and regulated on a mass scale for striking enforcements – perhaps especially around

¹⁷¹ Talin Suciyan, *The Armenians in Modern Turkey: Post-Genocide Society, Politics and History* (Bloomsbury Publishing, 2016).

¹⁷² Pinar Oktem, "Patriarchal and Medical Discourses Shaping the Experience and Management of HIV" (University of East Anglia, 2013).

¹⁷³ Linsey McGoey, "Strategic Unknowns: Towards a Sociology of Ignorance," *Economy and Society* 41, no. 1 (February 1, 2012): 1–16.

sexuality, in modern Western culture the most meaning-intensive of human activities.”¹⁷⁴ In Sedgwick’s and McGoey’s formulation, then, Turkish state chooses to remain ‘closeted’ through a studied lack of information on matters that could jeopardize its authority and epistemic-moral boundaries.

¹⁷⁴ Eve Kosofsky Sedgwick, *Epistemology of the Closet* (University of California Press, 1990), 5.

CHAPTER 2

Caught Up Between Politics and Profit: Possibilities and Ruptures of Nongovernmental Care

“NGOs are caught up in relations with funding sources, governments, and neoliberal processes that create a double bind for NGOs, situated between the powerful forces dominating them and the disenfranchised communities they intend to serve.”
—Bernal and Grewal, *Theorizing NGOs*, 2014

What is at stake in the governance of HIV in Turkey is both micro- and macro-physics of power: while the latter pertains to the domain of the state whose biopolitical management of HIV takes place on a broader level through the regressive (and repressive) organization of sex and sexuality, the former is handled by NGOs concerned with the disciplinary regulation of individual bodies. In this chapter, I use the term ‘non-*governmental*’ to make a reference to *governmentality* defined by Foucault as the technology of power that does “not refer only to political structures or to the management of states,” yet designates “the way in which the conduct of individuals or of groups might be directed—the government of children, of souls, of communities, of the sick”¹⁷⁵ According to Foucault, then, “to govern, in this sense, is to control the possible field of action of others.”¹⁷⁶

HIV organizations have a unique relationship to the state in Turkey. On the one hand, they are not fully embraced or supported by the state as they work closely with HIV+ individuals. The Ministry of Health only cooperates with HIV organizations behind closed doors in order to protect the respectability of the institution. On the other hand, in its attempt at symbolically immunizing itself against HIV to avoid the perils of moral contagion, the Turkish state benefits from civil society organizations as a sterile barrier between HIV positive individuals and state institutions. Because the menace of social contagion precludes the state from attending to HIV and populations affected by it, the Ministry of Health employs HIV

¹⁷⁵ Michel Foucault, *Power: Volume 3: Essential Works of Foucault 1954-1984*, ed. J Faubion, trans. R Hurley (London: Penguin, 2002), 326.

¹⁷⁶ Foucault, *Power: Volume 3: Essential Works of Foucault 1954-1984*, 341.

organizations, so to speak, to do its “dirty job”, *kirli iş*, as an NGO worker put it once. In the face of the state withdrawal from and official indifference to HIV, local non-governmental organizations are transformed into indispensable quasi-governmental bodies providing essential services such as HIV awareness, testing, and counseling. The care they offer, however, is as ambiguous and paradoxical as the governmental HIV care. At times, nongovernmental care can function contrary to the requirements of HIV prevention or contribute to the further marginalization and debilitation of HIV+ people by not attending to their needs for different reasons.

The ways in which NGOs and other non-state actors anywhere take over what should be the state’s responsibility as a result of neoliberalization and concomitant diminishing of welfare programs have been addressed in different contexts.¹⁷⁷ What these accounts have in common is an emphasis on the withering away of the state as a central actor of care. In Turkey, however, HIV organizations and the care they provide is still under the surveillance and regulation of the Turkish state either directly or indirectly. Governance of populations is at once indispensable to biopolitics and too big of a project to be undertaken by a sovereign state. The figure of a central authority, therefore, is replaced by a state with multiple heads whose success in governance does not reside in archaic vertical domination but in a kind of (bio)power that is horizontal and nonproprietary.¹⁷⁸ For this reason, the seeming absence of the state in the realm of HIV care does not imply total abandonment. The state’s—or, *para-state’s*—presence is felt by NGOs on a daily basis who need its approval and to earn it they must embrace the conservative ethics of HIV care to a certain extent. In the last decade, the Ak Parti continuously increased its surveillance over civil society and has shut down a large number of organizations for carrying out risky or terrorist activities. Since October 21, 2021, the nongovernmental organizations are

¹⁷⁷ See Adams, *Markets of Sorrow, Labors of Faith*; Vinh-Kim Nguyen, “Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship,” in *Global Assemblages*, ed. Aihwa Ong and Stephen J. Collier (Oxford, UK: Blackwell Publishing Ltd, 2007), 124–44; Ramah McKay, *Medicine in the Meantime: The Work of Care in Mozambique* (Durham, NC: Duke University Press, 2017);

¹⁷⁸ Nikolas Rose, Pat O’Malley, and Mariana Valverde, “Governmentality,” *Annual Review of Law and Social Science* 2, no. 1 (December 2006): 83–104.

audited and classified in terms of their risk of terrorism.¹⁷⁹ As the definition of terrorism is gradually expanded by the Ak Parti to include different forms of dissidence, organizations providing services for HIV+ and/or LGBTI+ beneficiaries are more likely to be convicted of carrying out risky, terrorist activities.

In this chapter, I demonstrate how conservative political pressures and lack of financial support from the state render nongovernmental HIV care anti-political, exclusionary, and, at times, for profit. Yet, as I will demonstrate below, the care provided by local HIV organizations is not only undermined by a neoliberal and conservative state. The capacity of these organizations to provide HIV care is to a significant extent determined by pharmaceutical companies such as Gilead. As a result of not having financial support from the government, local NGOs have inadvertently become dependent on external donors like pharmaceutical companies. HIV organizations have to cater to the desires of the private donors in order to be deserving of the external funding (Chapter 4) and this requires designing interventions that will serve the interests of the companies more than that of public health. In return for funding, NGOs are expected to act as an intermediary between the target population and the third-party donors. In addition, in order to prove the money they receive is used properly, they are expected to enumerate all of their services and beneficiaries. This foresees that they are mostly providing services that can be counted instead of services that are needed. As Vincanne Adams writes, evidence-based public health interventions “change the notion of health that must be used to obtain funding and justify interventions, and they sometimes prevent good projects from being pursued at all.”¹⁸⁰

Sociologist Cindy Patton criticizes what she calls AIDS Service Organizations (ASOs) involved in the “business of solving bodily problems” for having an institutionalized relationship to the medical industry and government, for forgetting their activist past, and for medicalizing

¹⁷⁹ <https://www.resmigazete.gov.tr/eskiler/2021/10/20211021-3.htm>.

¹⁸⁰ Vincanne Adams, “Against Global Health? Arbitrating Science, Non-Science, and Nonsense through Health,” in *Against Health: How Health Became the New Morality*, ed. Jonathan M. Metzl and Anna Kirkland (New York: NYU Press, 2010), 52.

and de-gaying HIV.¹⁸¹ These critiques, although from a different time and location, directly speak to the issues with the local HIV NGOs in Turkey. In the rest of this chapter, I provide glimpses into how three different HIV organizations—Positive Living, Pozitifiz, Red Ribbon—approach the *business of solving bodily problems*. But, before that, a historical overview of the emergence of HIV organizations in Turkish civil society would be helpful to understand the genealogy of the contemporary HIV organizations.

A brief history of the nongovernmental HIV organizations in Turkey

The history of civil society's involvement in HIV care can be divided roughly into three periods. The first phase, 1985-1991, begins with the first HIV diagnosis in the country. The Turkish state's initial response to the virus was to open test centers and to create the "High Advisory Board on AIDS" (AIDS Yüksek Kurulu) in 1987. Civil engagement with HIV has been limited during this time. The politically restricted environment created by the 1980 coup repressed the emergence of political and social movements.¹⁸² In 1985 and in 1988, "Family Health and Planning Foundation" (Turkiye Aile Sağlığı ve Planlaması Vakfı, TAPV) and Human Resources Development Foundation (İnsan Kaynaklarını Geliştirme Vakfı) were founded and they provided the first response to what was conceived as an emerging public health threat. These Foundations were able to cooperate with the Ministry of Health and raise awareness about HIV and AIDS. Because they did not align themselves with marginalized groups, they were in a privileged position to collaborate with the state institutions and guide their sexual health policies. The foundation, as its name suggests, has been largely focused on reproductive health and family as a unit of intervention. It did not openly embrace sex-positive and inclusive approaches to sexual health. During the first phase of the civil organizing around HIV, the organizations were predominantly concerned with reproductive health and although they recognized HIV's inseparability from it, HIV was still not a priority on their agenda. Provision of services to HIV+

¹⁸¹ Cindy Patton, *Inventing AIDS*, 1 edition (New York: Routledge, 1990), 5.

¹⁸² Zulfikar Çetin, "Intertwined Movements, Interwoven Histories: HIV and AIDS in Turkey. Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health" (EUROPACH, 2017), <http://europach.phils.uj.edu.pl/project-outcomes/library/workingpapers/>.

people, cooperation with key populations, and fighting against discrimination were not addressed by these foundations.

The second phase started with the establishment of first organizations with a specific focus on HIV and AIDS. In 1991, the Association for Struggle Against AIDS (AIDS ile Mücadele Derneği) and in 1992, the Association for Fighting Against AIDS (AIDS Savaşım Derneği) were founded in Izmir and Istanbul, respectively. The founders of these associations were two respected doctors, Melahat Okuyan and Enver Tali Cetin, who had worked for the Ministry of Health and served on the High Advisory Board on AIDS. In the post-coup era, these associations came into being in a context where different political movements and ways of organizing were becoming more visible in civil society through, for instance, queer, feminist, environmental, anti-militarist, anti-capitalist, and Kurdish activism.¹⁸³ By taking advantage of the political opening of civil society and their close relationships with the Ministry of Health, Okuyan and Cetin were able to increase the visibility of HIV and AIDS in Turkey. Especially AIDS Savaşım Derneği has become a prestigious organization with more than 20 locations and 650 members over the country.

These first HIV/AIDS associations were under the patronage of doctors and there was limited to no participation by people living with HIV. The hegemony of doctors and the exclusion of HIV+ people from the decision-making processes rendered their approach to HIV predominantly medical and epidemiological. Tuğrul Erbaydar, a doctor who worked for AIDS Savaşım Derneği explained that although the association mostly consisted of microbiologists, they were still aware of the social dimensions of HIV transmission. He also mentioned that HIV+ people might have been invisible but they were not absent. A group of persons living with HIV formed an action group, Positive Action (Pozitif Eylem), under the association and was influential in facilitating HIV+ patients' access to free medicine and making it possible for them to choose their own treatment regimen. However, Erbaydar also recognized that the association

¹⁸³ Çetin, "Intertwined Movements, Interwoven Histories: HIV and AIDS in Turkey. Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health."

has experienced an organizational jam because of its failure to socially organize and collaborate with HIV+ and LGBTI+ community. “Some doctors, like myself, wanted to be closer to the communities, to the social side of HIV, but microbiologists and infectious diseases physicians resisted that. There were serious discussions about whether to allow trans sex workers on the board of management, and, at the end, they never were.” According to Erbaydar, though, it was not the association’s disconnection from the grassroots that caused its closure, but the increasing professionalization and projectification of civil society. He said,

We weren’t working based on projects but when people saw that the availability for HIV/AIDS funds were increasing, they became appetent for the funds. They started writing large projects that required significant funding. Because we didn’t want to become project-oriented, we were no longer able to do much compared to others. The projects create opportunities, but for whom? For the society, civil society, or for the funder? Professionalization can be something good but it wasn’t in the case of HIV. People began to say there are funds here, let’s start focusing on here. But, then, there is a service that is needed but no one is concerned with it because they aren’t able to find financial support. This is very dangerous. (Erbaydar, virtual meeting, 2022)

During the second phase, another critical development was the appearance of TAPV as one of the central actors of social policy regarding HIV. In 1996, with the support of the EU, the National AIDS Commission was established under the leadership of TAPV. The Commission played an important role in the early design and implementation of a uniform response to HIV. By means of an EU-funded project, “AIDS, intervention of top political and decision-making bodies”, with a budget of 55 million euros, the Foundation was able to mobilize politicians and bureaucrats, while sensitizing the media to appropriate forms of HIV/AIDS reporting. This project enabled TAPV to develop national strategies to prevent STI transmission, to educate society, and to motivate cooperation among different sectors that should be involved in the STI prevention efforts.

The third phase began in 2002 with the Ak Parti’s election and it was marked by two important events. One of them was the emergence of the first self-organized HIV organization, Pozitif Yaşam Derneği (PYD), *Positive Living Association*, founded by people living with HIV

in 2005. In the following years, two other organizations, Pozitif-iz and Red Ribbon Istanbul, came into life as a result of unresolved internal conflicts in PYD. These organizations are now named *özne dernekleri*, “subject organizations” instead of what they were used to called, “hasta dernekleri”, which is the direct translation of patient associations but, in Turkish, carries the meaning of “the associations of sick people”. *Özne dernekleri* were for the first time able to represent HIV+ people and advocate for their rights. Contrary to the medical approach adopted by the doctor-led organizations of the second era, they provided psycho-social, legal, and post-diagnosis counseling for people living with HIV and their families. Although their services have increasingly become targeted at HIV-negative people due to the global and local funding trends, they remain to be the key actors of nongovernmental HIV care. The second event that shaped the nongovernmental care was the increasing funding for HIV and AIDS prevention provided by the UNAIDS, European Union, and the Global Fund. These funds increased the visibility of HIV and allowed autonomous associations to reach out to larger publics while improving their services. At the same time, they led some of the associations to grow beyond their capacity and professionalize HIV care by reducing it to a technical and financial problem.

Muhtar Çokar, a doctor and a sexual health activist, describes the third phase as a period of desensitization, *duyarsızlaşma dönemi*. “It’s a period in which numbers [of HIV diagnosis] have risen a lot, yet no one seems to care about it” says Çokar to underline what he observes as a lack of uniform response given to the epidemic by the state and nongovernmental organizations. He also mentions that although some foundations were able to work with trans sex workers on the matters of sexual health during the second phase, this trend has visibly decreased in the 2000s as the international funding came to an end in 2008 and it has become politically riskier to work with key populations after AKP’s second electoral victory in 2007, when the party politics has taken a definitive conservative turn. As a result of decreasing funding and increasing political pressure, HIV has lost its priority on the Health Ministry’s agenda and NGOs have become less active, according to Çokar. As a positive development that took place in this period, Çokar notes the opening of LGBTI+ organizations to the topic of HIV. Already working under precarious conditions, many LGBTI+ organizations initially maintained a distance between

themselves and people living with HIV. Sometimes implicitly, other times explicitly, organizations justified their distant stance by saying “people already think we are sick, we cannot afford being perceived in relation to HIV on top of that”. This has changed, though, as politically organized activists began to disclose their HIV status and reshape their LGBTI+ activism. Organizations such as Kaos GL and SPoD (Sosyal Politika, Cinsiyet Kimliği ve Cinsel Yönelim Çalışmaları Derneği; *Social Policy, Gender Identity, and Sexual Orientation Studies Association*) became important locations for bringing LGBTI+ activism and HIV activism together. While queer organizations are getting more and more open to discuss HIV and to embrace HIV+ people, we cannot say the same thing for HIV organizations, as I recount below.

Positive Living Association: “We are not an LGBTI+ association”

On a December night in 2021, my close friend Oz visited me at my apartment in Istanbul. Right after he took his shoes off, he started to roll a joint. As he was sealing the joint, “I have to tell you something, I am very upset” he said. Then he started telling me the story of a young Syrian man he personally knew, whom I will call Azhar, meaning luminous in Arabic. A gay man diagnosed with AIDS, Azhar has been living in Istanbul for almost three years with a resident permit. He was not a refugee, and this meant that he was not under the status of “temporary protection” in place for Syrian refugees since 2011. The status of temporary protection provides refugees with legal recognition and access to essential services such as healthcare. This, however, was not the case for Azhar, because he is not a refugee, who had no health security when he was diagnosed with AIDS with critically low CD4 numbers and a handful of opportunistic infections, even an early-stage cancer. Before continuing with his story, Oz rolled a cigarette with his contraband tobacco and waited until he finished it. When he was ready to speak, he ironically asked, “Do you know where he went for help?” Without expecting an answer, he said, “He went to Poz Yaş (short for Pozitif Yaşam) and they didn’t do anything for him. First, he called Poz Yaş, left a message, yet no one called him back. Then, he called them for a second time and was invited to their office. He went to the office in his terrible health condition only to find out that he was called in to be at the office for an unrelated event. You

know how funders want to see a certain number of people when there is an event. So, they just made him come to be an extra there. He left the office without being able to talk to anyone.”

Azhar contacted Pozitif Yaşam because he thought it was the only place that could help him access the medical and pharmaceutical care he urgently needed. PYD is not only the oldest and largest HIV organization in Turkey, but, since January 2018, it has been directing a project called “Reducing Barriers to Access Protection Services for Key Refugee Groups in Turkey”, or Key Refugee Groups Project, for short. The project primarily aimed to provide protection services for four key groups—LGBTI+s, HIV+ folks, refugees, and sex workers—and to improve their access to healthcare. Even though the project is primarily framed as catering to the needs of refugees, because that’s what the funding was available for, an open-door policy is embraced when it comes to LGBTI+s, sex workers, and people living with HIV. Some of the primary objectives of the project are to increase the HIV awareness among gay refugees by encouraging them to get tested on gay dating applications, to facilitate access to healthcare, and to provide urgent ARV support. With the funds provided by the European Civil Protection and Humanitarian Aid Operations (ECHO), PYD and two other implementing partners opened seven refugee support centers in six different provinces. Because both Oz and I knew about this project, our first impulse was to think that PYD should somehow be able to help Azhar. So, I used my personal contacts to ask a manager at PYD if he could offer us guidance. As an answer we were told that we should contact United Nations High Commissioner for Refugees (UNHCR) because Azhar needs to be under temporary protection. This, however, was neither desirable nor easy for Azhar. Once under the temporary protection status, a refugee is sent to a satellite city in Turkey, and they cannot leave the city without official permission. These cities tend to be small, conservative places where homophobia is serious concern and health personnel do not want to treat HIV+ patients. In addition, when we contacted a UNHCR officer we personally knew in Ankara, we were told that acquiring temporary protection status might take a long time and it might never work for Azhar’s case. The UNHCR officer, who specifically attended to the cases of LGBTI+s, underlined that only PYD can be capable of providing Azhar with ARV medicine “because that’s what the key refugees project is for”. After our conversation with UNHCR, Oz and I called the PYD manager again and explained to him the situation. He asked us to share

Azhar's phone number with him and told us that he will take care of it. He also gave us the number of the refugee support desk for Azhar to directly contact. A few weeks later, when I called Oz to find out about Azhar's status, he said Azhar was doing much better, but he had to go to a private hospital because everyone, including Pozitif Yaşam, said there was nothing they could do for him.

At first, the difficulties Azhar experienced in finding medical help might be interpreted as a bureaucratic deadlock related to his legal status. This is partially true as it is likely to be more difficult for migrants to access medical care in Turkey than it is for refugees. However, on the other hand, Azhar's story points out a fundamental aspect of nongovernmental HIV care. When care is excessively professionalized and made dependent on external funding, that is when the potential care-receivers stop being individuals who deserve personal attention and start becoming an item to be enumerated while calculating the "monthly number of beneficiaries", those cases that cannot be counted towards the expected number of services provided end up getting little to no attention. The only time Azhar was of interest to Poz Yaş was when they needed his presence at the office to make a good impression on the donor. When it came to actually providing services for him, PYD chose to play the three monkeys. Ramtin, a queer activist from Iran, who lived in Turkey as a refugee for five years and worked in civil society, criticized PYD's refusal to help Azhar by asking, "how does an NGO buy an office in the center of Istanbul but is not able to pay for someone's medicine? Is it getting all this funding to invest in real estate?"

The key refugee groups project has been the target of many criticisms since the day it was implemented in 2018. Refugee support organizations, HIV associations, and HIV activists accused Positive Living of entering the refugee field with financial interests in mind. An infection doctor I interviewed in 2022 expressed her disapproval of PYD's involvement in refugee services through the following sentences:

I am one of the founding members of Pozitif Yaşam but I had to quit when I saw that it was going off track. I always told them that they should not forget their mission and stick to what they are good at. A civil society organization cannot do everything with limited

resources. You cannot support people living with HIV while, at the same time, working on prevention, education, and testing. Pozitif Yaşam was founded to support and empower HIV+ persons but it is a big question mark whether they are accomplishing it right now. You cannot start providing new services just because funding is available for them. I criticized them many times when they were rolling the sleeves to work with refugees. This is not their job but it's almost certain to get funded for humanitarian assistance. If they had enough capacity to successfully manage different projects, it would be okay. But, right now, getting involved in other fields means having less capacity to support HIV+ people. (Gökengin, personal interview, 2022)

Despite all the criticisms it received, one of the founders of PYD, Harun, was open about the financial motivations behind the project. When we met in 2019, he justified the implementation of the project based on foreign funding trends and an observed need for HIV care for refugees:

We experienced an increase in the number of Syrian clients at our office who were receiving HIV diagnosis. Our capacity was not enough to do something substantial so we wrote a project for UNFPA. With the funds we obtained, we hired a Syrian man and made an agreement with Hornet. Then, we started sending out Arabic messages on Hornet about HIV and testing. This project lasted a year and we received more than a thousand calls from people who saw our message and wanted to get tested. Then, with the help of UNFPA and two other organizations, we wrote a bigger project to screen for HIV among refugees in Turkey. The project is actually for LGBTI+s but we cannot say it in the name. On the other hand, we need funds and the state does not have any plans to fund us. Our donors are pharmaceutical companies, a few brands such as Mac cosmetics, Lewis, and H&M, and international organizations such as the EU and UN. In the last few years all the funds were being directed to the refugees and we experienced a concomitant decrease in our own funding. So, naturally we had to turn towards where the money is and we noticed that we need to write a project for refugees. (Harun, personal interview, 2018)

Pozitif Yaşam was founded in 2005 in Istanbul as the first self-organized HIV organization in Turkey. This found coverage in the mainstream media as “Turkey’s first association formed by the carriers of [sic] the AIDS virus”. The founders, who used to communicate through a Yahoo listserv titled “HIV Pozitif”, remained anonymous at first as they were worried about being ostracized in their social and laboral life. According to the organization’s self-description, Positive Life Association is a facility offering peer counseling, social services counseling, psychosocial support, psychological counseling, nutrition counseling, legal counseling, attorney

services, emergency medicine support and free HIV testing. The association was meant to be empowering not only for HIV+ people but their families too. Over the years, thanks to its organic connections to the HIV community, PYD has become the leading actor of HIV care in Turkey. Its indispensability for public health is also recognized by the Ministry of Health who made PYD a member of the National AIDS Commission. Today, in addition to its central location in Istanbul, PYD has four other support centers in Denizli, Yalova, Adana, and Izmir.

One of the founders of PYD, who was later among the founders of Pozitif-iz and whom I will call Sevgi for the purposes of anonymity, told the story of how they organized the first time I met her in 2020:

We were a group of people who were chatting and discussing online at Yahoo. During our online conversations, we all became aware that although our experiences with living with HIV and the difficulties we faced were sometimes very similar, they also differed significantly. Over time, because many of us were experiencing stigmatization and discrimination, especially in healthcare, we started talking almost exclusively about status-based discrimination. The discrimination we were facing was even lethal for some. I remember there was this kid, 12-years old, who seroconverted through a blood transfusion from his father during a critical surgery. After the surgery he had problems but he wasn't accepted to the intensive care unit because he was HIV+. That young child died because of medical discrimination. We witnessed several other traumatic events like this one and we were deeply bothered. We had to do something and we decided to create an organization. We didn't want to "fight or struggle against AIDS" [referring here to Association for Fighting Against AIDS and the Association for Struggle Against AIDS]—for us, it was an example of violent language. Hence, we wanted to focus on *living* and called ourselves Positive Living. Then, the financial support from the EU and Global Fund allowed us to get on our feet right after we obtained the official status of an association. We had capacity improvement trainings and we started to learn about our rights. We noticed that—and this is still the case—one of the reasons HIV+ people are discriminated against is because we don't know our rights. So, we began to become the subjects of HIV. We embraced GIPA and MIPA principles—the Greater Involvement of People living with HIV/AIDS and Meaningful Involvement of People Living with HIV/AIDS—and visited all the political parties in the government. Although today it is mostly bringing services to HIV-negative individuals, Poz Yaş was created to advocate for the rights of HIV+ people. *We wanted to break free from the doctor-led associations and decided to speak for ourselves.* (Sevgi, personal interview, 2018)

If one of the most important impetuses behind the foundation of PYD was to do something about the sweeping cases of discrimination, the other one was to end what nongovernmental employees in the field of HIV call *doktor himayesi*. This can be translated as the patronage of doctors and it seeks to underline how HIV associations founded and run by doctors did not welcome the participation of the HIV+ community and prevented HIV+ people from speaking for themselves. However, although challenging the medical authority was essential to initiate a grassroots HIV movement, HIV activists continuously express their concern over the ongoing hegemony of doctors in the nongovernmental sector. The volunteers and employees of HIV organizations are often blamed for being a sycophant, who will do whatever it takes to ingratiate itself to doctors. The fact that doctors are never called by their names in the civil society but always referred to as “hocam” (my teacher) to express respect is taken as a concrete proof of how medical hegemony does not belong in the past. Worried about the diminishing opportunities for the involvement of people living with HIV in the civil society, an activist, Emre, would often criticize HIV organizations for inviting doctors instead of people living with HIV as speakers to their events: “Okay, I understand that you will invite doctors for a panel on the medical management of HIV. But why would you invite them to be speakers for an event on HIV-related discrimination? There are visible activists who live with HIV and are as qualified as, if not more, those same few doctors who talk everywhere. Even on World AIDS Day, there will be only NGO employees and doctors on the stage sharing opinions about living with HIV.”

For another activist, Oğuz, the lack of representational space for HIV+ people in PYD is not only a result of the domination of social discourse by doctors. It is also a direct consequence of organizations losing its organic connection to the community from which it emerged.

According to him,

there is no culture of horizontal organizing in the field. They forgot that what made them strong was their organic connection to the subjects of the HIV movement. They forgot that one of their responsibilities is to create a space for the community where they can be visible and heard. Let alone providing a space for us, they sabotage our efforts to do activism. Sometimes, we cannot find the time and energy to deal with HIVfobi and discriminatory policies because we are always fighting with the HIV organizations.

They leave no room for us in the field because they are afraid, they won't be able to profit from HIV equally. They want to be the only ones, the new authority in the field after doctors. (Oğuz, personal interview, 2021)

When it comes to other organizations such Pozitif and Red Ribbon, they do not attack PYD for maintaining a close relationship with doctors because they do not consider that to be an issue. They, however, criticize the organization for becoming a new authority in the field. Once it acquired a legal personality, PYD drifted away from its roots in the pursuit of funds and acceptance by the state institutions and medical professionals. During one of our several meetings, Koray, a young gay man in his thirties, a long-time employee and the public face of PYD, expressed that no one in the nongovernmental field of HIV should be doing anything without consulting PYD first. “We have most of the resources, we have the connections, and we have the expertise. They shouldn't even write a project before talking to us.” Koray and I became good friends right after I started my field work. We shared many meals and had long conversations in *meyhanes*, traditional Turkish restaurants where the customers enjoy raki and a variety of small dishes, *meze*. However, as I became more vocal in the field and open about my critical views, Koray and I grew distant. We didn't necessarily lose touch with each other because of Koray's views on PYD being a leader, but because of his opinion on how close civil society and the state can be without compromising HIV care too much.

The biggest difference we had was that Koray argued in favor of maintaining a close relationship with the state at any cost, whereas I believed in the necessity of a healthy distance between the civil society and the state. Based on what I observed in Turkey I defended that the efforts of nongovernmental organizations to provide HIV care were thwarted by their compliance with the vision of governmental HIV care. One of the discussions I had with Koray was related to the question of how much freedom can an organization have from the state in Turkey. Whereas I believed the necessary cooperation with the Ministry could be maintained without compromising too much, Koray believed there was no room to oppose the politicians or bureaucrats. HIV activists, on the other hand, claim that the relationship between the PYD and the Ministry is not a healthy one since working with the Ministry requires the adoption of

conservative ethics of public health to a degree. As a result of an internally accepted yet unwritten rule, HIV and sexual health organizations do not mention LGBTI+ population in their projects should they seek the Ministry's support. To avoid mentioning the specific needs of the queer community in terms of prevention and treatment, organizations frame HIV as a threat to the general public. Oz, a gay HIV activist, commented on PYD's anti-LGBTI+ attitudes as a studied attempt to *heterosexualize* the organization:

by heterosexualizing (*heterolaştırmak*) HIV, PYD is also depoliticizing it. If it can sit on the same table with the Ministry of Health, then that means it has some leverage it can use. If the Ministry's own statistics show that there are homosexuals in this country, what is PYD afraid to recognize or admit? Instead, it chooses to pass as cis and straight institution. It doesn't want to do anything for gay or trans people because it thinks it must keep the Ministry of Health content. But, in this way, let alone improving it, Poz Yaş frustrates queer people's access to HIV care. (Oz, personal interaction, 2018)

In the face of similar criticisms about their cooperation with the Ministry of Health, Koray and other employees of PYD would often mention how they have no other chance if they wish to avoid being a target of the government. When I met Harun, the former director and one of the founders of the organization, in the summer of 2018, Istanbul was experiencing one of the hottest days of July in the recorded history of the city. So, Harun and I found comfort in the cool shade of a cafeteria at the French Consulate in Taksim Square and consumed more icy lemonades than either of us did before in a single day. Harun, who is an engineer by training, is a kind, amicable man in his fifties and that day he responded to all of my questions patiently in spite of the uncomfortable heat wave that forced him to put napkins under his t-shirt to soak up the excessive sweat. When I finally decided that he would not be bothered by my question, I asked him what he thinks of other HIV organizations' and activists' accusation about being a strange bedfellow with the Ministry of Health. Harun's answer was clear. "You must find a way for yourself in the system. You cannot do nongovernmental work in Turkey by attacking the state and being anarchist. You must work with the state. If Pozitif Yaşam has become a leader in the field, it's because we were able to work together with the MoH. We are the first HIV association who signed a partnership with the Ministry— we had to work three long years for that and don't want to lose, in fact, can't afford losing it now."

The erasure of the unique location of LGBTI+ people in relation to HIV is framed as a strategic necessity to be able to enjoy minimal support from the Health Ministry and to avoid reactionary reprisal both from the public and the state. PYD employees defend their organizational strategy by stating Pozitif Yaşam is not an LGBTI+ organization <<*biz LGBTI+ derneği değiliz*>> and they will not only lose their popularity amongst the positive population but also risk their relationship with the Health Ministry if they are perceived to be close to the queer community. As a gay man, Koray took the accusations about PYD being a homophobic organization personally. When we went out one night for dinner, Koray said, “People keep saying Poz Yaş is homophobic. What does it even mean? How can I be homophobic if I am gay? Our approach to the topic of LGBTI+s is completely strategic. We are officially registered as a health association. We don’t have the permit to function like an LGBTI+ association. We just don’t have the luxury to do whatever we want. If people think Poz Yaş is for LGBTI+s, we will lose a large majority of our clients. They won’t come to the office in the fear of being called gay.”

Koray’s concerns are valid. It may put all HIV organizations in danger if they are vocal about LGBTI+s or openly bring services to them. Nonetheless, the phrase <<*biz LGBTI+ derneği değiliz*>>. we are not an LGBTI+ association, has increasingly become a lazy excuse, readily mobilized when facing a critique. As Ali mentioned above, the Ministry of Health is aware that HIV does not only concern heterosexuals. Hence, Koray’s and others’ fears about being perceived as an LGBTI+ association might be at times inflated. Besides, there were instances where Koray continued to perform openly anti-LGBTI and sometimes pro-state politics in situations where he was expected to represent PYD. During the first meeting of the HIV commission formed under Şişli Municipality, known for its closeness to the LGBTI+ community, Koray had suggested that the commission should distance itself from the LGBTI+ movement to be successful. The other participants of the meeting, some of whom were queer activists, thought Koray’s statement was very uncalled for because the commission was already

formed as a part of the LGBTI+ assembly, therefore, they had no reason to worry about pleasing state institutions.

The efforts of Positive Living in setting quasi-immunitarian boundaries between itself and the LGBTQI+ community has direct implications for the HIV care it provides. Although it always has some queer representation in its staff, Positive Living is not a welcoming space for queer HIV+ individuals. Gay men and trans women commonly express feeling uncomfortable while visiting the office to get support. Some only reach out to the organization by phone should they need anything, instead of physically going in, because this is the safest and most comfortable they feel. One of the most popular services of the organization before the Covid-19 pandemic were support group meetings held at its Istanbul office. Queer people would either abstain from attending these gatherings, and if they do, they will silently sit in the back of the room. If any queer individual makes a public remark or asks a question, the other participants will show physical signs of distress, while the moderator reminds all participants that HIV is not a gay issue. The enormous difference between stating that “HIV is not a gay issue” or “HIV is not *only* a gay issue” is lost on the PYD personnel. For them, associating HIV with queerness is dangerous not because it stigmatizes LGBTQI+ people but because heterosexual people may no longer feel comfortable getting support from the association. Besides, there is the fear of Positive Living losing its privileged position and becoming vulnerable to political conservatism.

As I mentioned at the beginning of this chapter, Turkish HIV organizations often find themselves in need of pleasing both the state and the funding bodies. For PYD, this meant growing more distant not only from the LGBTQI+ people, as discussed above, but also from HIV+ community. Over the course of the years PYD has steadily increased its HIV-negative personnel and services for the HIV-negative population. Both developments were prompted by an expansion of external funding opportunities and the growing pressure of donors’ expectations.

A previous employee of PYD, Kezeb, who worked there for several years, chose the term “ngolaşma”, *ngoization*,¹⁸⁴ to describe the organizational change of the association:

When I started working there, there was one project manager and one project. Later, there were three projects and still one manager. They were having more projects than they could manage. So, they started to hire more and more people. They approached it professionally, rather than as a grassroots organization should, and ended up hiring a lot of negative employees. They not only employed negative people but began to target more HIV-negative individuals as recipients of services. The kind of project that brings in money is not the kind you do for already diagnosed people but for those who are not yet diagnosed. At the end, when I was leaving my position after three years, Poz Yaş had become a place run by and for the HIV-negative people. (Kezeb, personal interaction, 2022)

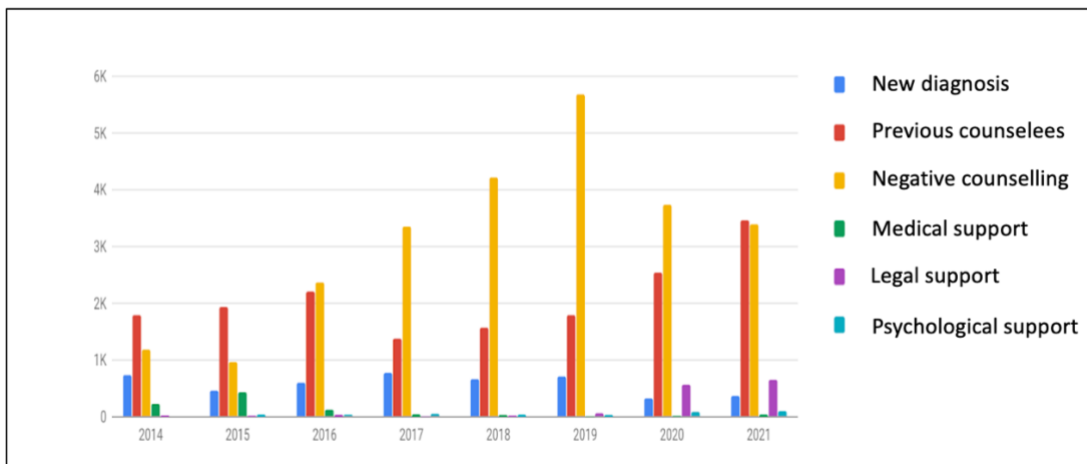


Figure 11: Distribution of services provided by the Positive Living Association

Kezeb’s comments on PYD becoming by/for HIV-people elucidates one of the contradictions of nongovernmental HIV care that emerged as by/for HIV+ people. As the figure above also mirrors, the changing demographics of beneficiaries who enjoyed counseling services from Positive Living. The bright orange color represents the HIV-negative individuals whose number steadily increased until the Covid-19 pandemic in 2020. The blue bar is for the recently diagnosed, whereas the dark orange is for those who have received counseling in the past and

¹⁸⁴ Aziz Choudry and D. Kapoor, eds., *NGOization: Complicity, Contradictions and Prospects*, New ed. edition (London; Palgrave: Zed Books, 2013).

sought the service again. What these numbers say is that prior to the pandemic, PYD offered more and more consultation services to people who do not live with HIV. These services include providing information about getting tested and answering questions about HIV transmission. Although we cannot know for sure whether this increase took place at the cost of people living with HIV, we do know that the social workers and case managers at PYD have to spend a lot of time explaining people that HIV is not airborne and you cannot get it for being in the same room with a positive person. Most social workers complain about spending time like this, but that's also where most of the funding comes from. The promise of directing HIV-negative clients with a suspicion of contagion to testing and potentially treatment is how PYD affords to hire several social workers. Yet, still, there are always more cases than there are people and those who need help the most might not always get support because of busy phone lines.

One night in 2019, Oz and I went out to have a cup of coffee near his apartment. That day, the main topic of our conversation was Oz's post diagnosis experiences, which he describes as traumatic. He had to wait for two months for the result of his confirmation test. To receive a definite HIV diagnosis, all blood samples should be sent to a lab for confirmation and since there are only a few of these labs in the entire country, the results are given considerably late. The long waiting periods generate a lot of anxiety for not knowing the HIV status, sometimes more anxiety than receiving a positive diagnosis. Once his diagnosis was confirmed, Oz went to see an infectious diseases physician near his apartment in Istanbul. He described his initial encounter with the doctor as unnerving because in the face of questions about his sexual orientation, sex work history, and drug use, he felt like he was being interrogated. Because he didn't want to disclose any of this information at a public hospital for safety reasons, Oz waved off the questions with "safe answers". After his unpleasant encounter at the doctor's clinic, Oz visited Pozitif Yaşam with the hopes of accessing HIV counseling. However, he was not happy with what he found there either. The aggressive and invasive approach of doctors towards the newly diagnosed persons were also reproduced within the spaces of nongovernmental care. After our second, or maybe third, cup of coffee, Oz made a joke which made me laugh more than it was

intended to. “If organizations could have an HIV status, Poz Yaş would be negative” he said and continued,

When it was a small association, Poz Yaş employed counselors who were HIV positive. Now, it’s mostly HIV-negative people who don’t know much about HIV let alone HIV counseling. If you go to Poz Yaş as an HIV+ person to get counseling, you will see no empathy. You will not feel comfortable by talking to a person who doesn’t understand you. When I first went, I was asked about my CD4 numbers, viral load, if I was gay, if I did drugs, if I did sex work... These are the same questions I was asked at the hospital. I didn’t feel safe there to answer them all correctly and I didn’t feel safe enough at Poz Yaş either because I felt interrogated again. The only difference was that they didn’t give me a physical examination... (Oz, personal interaction, 2019)

Pozitif-iz: “We are not doing politics”

Tankut: How did Pozitif-iz come to life?

Sevgi: In 2015, a group of friends left Pozitif Yaşam due to differences of opinion. When we left Poz Yaş we didn’t have any action plan. But we were still being contacted by many people to get HIV counseling. In a way, we left the field, but it didn’t leave us. When we saw the numbers of people coming to us in the hope of help, we decided to create our own association. Doctors and Pozitif Yaşam told us not to create a new organization, but we didn’t listen to them. In 2016, we started as an initiative, and we made a promise to each other and ourselves that we would not repeat the mistakes of Pozitif Yaşam. So, we decided not to have a hierarchical structure and not to employ anyone. We all work as volunteers at Pozitif-iz, nobody makes money here. This is essential to our principles as we know what happens when money is involved in civil society. Luckily, we had many volunteers since the first day and they helped us with everything. Also, to free ourselves from the chains of the money, we refused to write made-to-order projects to get funding. There were times we had to pay the rent of our office from our pockets and if it’s necessary we will do that again rather than chasing funds. One of our golden rules is not to chase money because we saw how the project business affects what we do. We don’t want to grow bigger either, we don’t need to be a large, professional organization that is out-of-reach of positive people. We don’t want to start writing projects about refugees to find money either.

T: What does Pozitif-iz focus on?

S: We focus on HIV+ people, not on public health. I mean, our priority is people living with HIV, and protecting public health is our second job. Our purpose is to provide support and counseling for the newly diagnosed and their relatives. We want to touch people’s lives in a good way, empower them, and help them love and respect themselves again. We care a great deal about the trauma people experience upon receiving an HIV diagnosis. At that stage, it is critical for people to access support mechanisms to be able to cope with the initial trauma. When we left Poz Yaş, we noticed what the field needed the most was counseling services and that’s what we

are best at. So, we said this is what we will do. I cannot emphasize enough how important peer counseling is when you receive an HIV diagnosis. We don't consider peer counseling separate from advocacy work and awareness-raising. Many of our counsees say they felt suicidal after their diagnosis and peer support was what kept them going. But, when you go to Poz Yaş, you won't talk to a peer, you will talk to someone who doesn't personally experience or understand living with HIV. Other than counseling, we offer capacity building trainings for HIV+ people to help them know about their rights and how to handle stigma and discrimination. We also really care for nonviolent language use. We try to change the perception that HIV is an enemy that is attacking us, waging a war on us, that our cells are soldiers. HIV is already an extremely negative thing for people and the language only makes it worse. We prefer to say HIV is just an uninvited guest that lives in our body.

Pozitif-iz has two meanings: without the hyphen, *pozitifiz* means we are positive, and with the hyphen, it means a positive mark, touch. The Pozitif-iz Association occupies a special role for this dissertation because it demonstrates that even while being part of a formal regime of HIV care, it is possible to put the wellbeing of HIV+ people before profit and prestige. This small organization is a proof that conservative politics and pharmaceutical interests do not always have to determine the capacity and nature of care offered by HIV NGOs. Pozitif-iz has no regular funding and must rely on small pharmaceutical grants to implement projects to raise HIV awareness and empower PLWH. As Sevgi underlines above, the purpose of the organization is “to touch people's lives in a good way” and there is no doubt Sevgi and other volunteers transformed and strengthened thousands of lives with the little resources they have. When Pozitif-iz was being formed, there were no funds to rent an office or buy the necessary equipment. The volunteers collected money among themselves for the rent and all furniture were donated by those who at some point in the past received peer-support and counselling either from Sevgi or other volunteers. Because of the financial burden of finding an office space that is both accessible and safe, Pozitif-iz was only able to rent an apartment looking over a cemetery in Istanbul, which became a worry for the volunteers who did not want recently diagnosed persons to face this view while receiving counselling.

Over the course of years, I have come to admire Sevgi, the only visible woman in the nongovernmental sector of HIV. Sevgi, meaning love, is her own chosen nickname that she uses to remain anonymous on social media. She says she owes her freedom to HIV because her

diagnosis gave her an agential capacity she did not know she had before. She became a motherly figure for many young HIV activists, including myself, and taught them how to organize better. After my diagnosis and during my field work, Sevgi always supported me and answered all of my questions with patience, no matter how big or small they were. With a warm and beautiful smile, she is one of those persons that easily make you feel like you are loved and accepted. When you meet her, you immediately know that you can trust her and that she won't let you down. I heard other activists describing her as a shoulder to cry on. I met Sevgi for the first time at a local coffee shop in 2019. When I was on my way to meeting her, I was going through the transcripts of a previous interview with Harun, one of the founders of Pozitif Yaşam. A part of the interview caught my attention where Harun was criticizing the separation of people from Poz Yaş to create new organizations. He was saying “I don't approve of Pozitif-iz and Pozitif Kurdele. The more organizations there are in the field, the harder it gets to find funding and the competition becomes inevitable. They should have just created new branches under the roof of Poz Yaş. But, people saw that there is money in this business and they wanted to have their share of the pie.”

Harun's sentences were echoing in my mind when I arrived at the coffee shop to meet Sevgi. After I ordered two iced coffees for us, I began telling her about my research. When she asked whom I had interviewed so far, I did not want to lie so I told her that I had interviewed Harun. She did not seem to be surprised or bothered by this answer. Instead, she started telling me about her past in Pozitif Yaşam, which led to the conversation excerpts I shared above. Although we were initially supposed to meet during her lunch break, Sevgi stayed with me that afternoon for more than two hours. We talked about a variety of topics as though she was trying to help me catch up with the history and contemporary politics of HIV in Turkey. I was eager to hear everything she had to say, and she was content with being able to share her side of the story. Almost each thread of conversation we began that day led Sevgi to the critique of *projecilik*, and, indirectly, of Pozitif Yasam. The “projectification”¹⁸⁵ of HIV care landscape, opines Sevgi, is the most pressing issue with the nongovernmental sector. She believes that care is imminently

¹⁸⁵ Susan Reynolds Whyte, *Second Chances: Surviving AIDS in Uganda* (Durham, NC: Duke University Press, 2014).

beneficial and the provision of services in the pursuit of profit goes against the nature of HIV care. “Every Lira that enters an organization should go to HIV-positive people. Not a single Lira should go to someone’s pocket,” according to Sevgi.

The next time I met Sevgi was during the pandemic and we were at the same zoom conference to organize an upcoming event to improve cooperation among nongovernmental organizations in the area of sexual health. My activist friend Oz was also participating in the meeting where I witnessed an interesting conversation between him and Sevgi. When Oz was finished talking about the importance of politicizing the nongovernmental sector to endow it with the skill of being transformative of the political system that frustrates the efforts to make sexual health available and accessible, Sevgi took the floor to say that politics is not their business. “People keep telling us that we should be politically active. I don’t agree with this. The purpose of Pozitif-iz is very clear and it is not to develop a policy. We only want to be able to support HIV+ folks and have no interest in becoming politicians. We will eat the grape but won’t beat the vintner, *biz üzümü yeriz, bağcıyı dövmeyiz.*” Sevgi was playing with the proverb *üzümünü ye bağını sorma*, meaning ‘eat the grape but don’t ask about the vineyard it comes from’. The proverb communicates the message that one should take advantage of certain things without questioning where they come from or how. What Sevgi meant is that they do not have the responsibility to criticize the state or the ministry of health, let alone transform the politics of sexual health.

Sevgi and other volunteers at Pozitif-iz do not claim to be activists. For them, care work does not necessarily require being politically active or critically engaged. They do not consider their efforts to raise HIV awareness or capacity building trainings as political either. The kind of HIV care they offer is expected “to touch people’s lives” and “make them love and respect themselves”, not to revolutionize HIV care. Nonetheless, I do not want to dismiss the possibility of an apolitical way of caring. Depending on how we define being political, we might, in spite of the insistence of the volunteers, see something quite political in the act of voluntarily helping

others achieve emotional and physical well-being in an *atmosphere of violence*.¹⁸⁶ However, there are issues with the depoliticization of HIV care and, particularly, with open declarations of apoliticism. Remaining willfully apolitical supports the state of inertia and maintains the immunitarian boundaries built around HIV. Depoliticization of HIV organizations ensures that they neither seek nor have the resources to tackle the root causes of socio-medical problems they claim to solve. Because the funding is contingent on having immediate results, social structures that are the driving forces of HIV pathogenicity are left untouched since their solutions require long term investments. Depoliticization additionally transforms inherently political questions into technical matters which, then, need not be politically discussed.¹⁸⁷ Given that once an issue is ideologically rendered irrelevant to politics, brought into the realm of private and professional management, it is extremely difficult to bring it back to the political agenda, for it requires a representational change of how the issue is framed.

I heard other critiques of Pozitif-iz “mixing religion with politics of HIV advocacy”. An HIV activist O., once established an interesting distinction between providing care as a human right or as a rightful share, *kul hakkı*. “Kul hakkı is the right bestowed on people by God, different from *insan hakkı*, a human right, as defined by national and international institutions. If you provide services based on kul hakkı, you will miss the political roots of the human rights’ violations.” What O. offers here is not a critique of being religious and doing care work because your faith requires you to. His contention is with the diminished capacity of addressing potential abuses of rights when HIV-related discrimination is not framed as a political matter. According to O., when a human right approach is abandoned, peer counseling will lose its unique ability to detect and prevent the cases of discrimination and violence. He even had an example to explain what he meant.

At a capacity building training I attended, I heard of a case in which someone was being thrown out of their apartment because the owner of the property somehow found out

¹⁸⁶ Eric A. Stanley, *Atmospheres of Violence: Structuring Antagonism and the Trans/Queer Ungovernable* (Duke University Press, 2021).

¹⁸⁷ Hans-Martin Jaeger, “‘Global Civil Society’ and the Political Depoliticization of Global Governance,” *International Political Sociology* 1, no. 3 (September 1, 2007): 257–77.

about their HIV status. The owner wanted to see the results of a negative test result if they wanted to stay in the apartment. This person reached out to Pozitif-iz and Sevgi told them to ask an HIV-negative friend to get an HIV test by using their national identity card. This advice can easily work and solve this person's immediate problem. But, there is a case of right violation here. It should be reported because no one can be denied housing based on their HIV status. If you pursue this case and initiate a legal process, you can win the case and it can set an example in the future when HIV+ people are denied safe housing. Not treating this as a violation of a human right is not only not being apolitical but being anti-political. (O., personal interaction, 2022)

Anti-political is indeed an apt choice of concept to understand nongovernmental HIV care. During my entire fieldwork, “elim(iz) kolum(uz) bađlı” was a common expression used by people who work for HIV organizations. The phrase literally means *my/our hands and arms are tied* and is often referred to when someone wants to express their inability to do something about a situation due to external constraints. I heard this phrase numerous times as it was a habitual way of excusing one from any political responsibility because of what many ambiguously referred to as the *current political atmosphere*. Particularly for NGO workers who are under constant government surveillance, it was uncommon to ever define what they meant by this atmosphere. Maybe, they thought it was obvious and there was no need to talk about it. Or, it was an internalized fear of vocalizing what is wrong with the system, what needs to be changed—the recognition of the problems' roots in the witnessing of others would make it more troubling to absolve one of personal responsibility. Miriam Ticktin uses anti-politics of care to describe a form of caring that is performed as a moral imperative as opposed to a political means of disrupting the established order that created ubiquitous precarity and an unmet need for care in the first place.¹⁸⁸ This explains why nongovernmental actors in Turkey situate their care work outside the domain of politics while refusing to take responsibility to address structural issues. Making the case that their job is not doing politics, as many have done so, allows these actors to remain apolitical while actually participating in politics by maintaining the status quo. This also enables the HIV activists to criticize them for willfully preserving the so-called political atmosphere because that's what makes them necessary and profitable.

¹⁸⁸ Ticktin, *Casualties of Care*.

The kind of care work that does not seek the dismantling of the social, political, and economic conditions of vulnerability and marginalization can also be considered as a band-aid care. Sangaramoorthy defines it “as a quick fix or temporary remedy” that “maintained and made life possible” for migrants.¹⁸⁹ While being aware of the temporal logic of this kind of care and how it fails to address broader longer-term needs of those deemed most vulnerable, the author focuses on the affirmative potentials of band-aid care as is practiced by immigrants and health providers in Maryland’s Eastern Shore. I believe a necessary distinction is in order here: when professional or community-based caregivers do not have any other option than quick fixes that will provide temporary relief, when band-aids are all they have and no one can get stitches, ephemeral acts of support and kindness can be extremely caring and needed for the survival in the meantime. Nevertheless, in the hands of actors who have the organizational capacity to intervene in the socio-political order of things and to negotiate with state institutions, band-aid care rather seems to be an open invitation to an infectious wound that will only spread further if not treated properly. Covering up the roots of infections with makeshift efforts is not treating them, nor can they potentially be beneficial for the individual or public health in the long term. The danger with ethical projects that prioritize providing help unlike political projects with a clear objective of ending the conditions that keep the harmful political and economic structures in place is that the former replaces the enemy with an invisible form of structural violence instead of assigning responsibility to specific actors or assuming self-responsibility.

Red Ribbon Istanbul: “We are not like other HIV organizations”

Tankut: What is the story of Kırmızı Kurdele (Red Ribbon)?

Vahe: When I decided to create Kırmızı Kurdele, it was a very personal thing. The idea just came to me in a moment, so it was a one-man project. After I worked at Pozitif Yaşam for fifteen months, I no longer wanted to continue there. I wanted Kırmızı Kurdele to be different from Pozitif Yaşam and Pozitif-iz in every possible way. I wanted to produce and share scientific knowledge on HIV. We strongly believe that the most effective tool to prevent the spread of HIV is scientifically-proven information supported by data. So, I was not interested in offering counseling or having a support center. As I said, I didn’t want to be another Pozitif Yaşam. I

¹⁸⁹ Thurka Sangaramoorthy, “Chronicity, Crisis, and the ‘End of AIDS,’” *Global Public Health* 13, no. 8 (August 2018): 982–96.

don't want to run a project for refugees because I want to be able to take my own decisions instead of becoming a puppet of the UN. Pozitif Yaşam has lost its identity because of this. And, Pozitif-iz is trying to be just like Pozitif Yaşam with their own projects lined up... I will say something that I had to say in the beginning: in countries like Turkey where the culture of democracy and participation is not fully developed, civil society remains weak as well. Here, the civil society is desperately in need of the persistence of the issues it claims to eradicate. To survive as an NGO, you need problems to be solved. But, nobody wants to solve them for good. So, the entire model is wrong.

Vahe takes HIV activism very seriously and to do activism, he believes that one has to maintain a healthy distance from the state and the private donors. He pretty regularly attacked Pozitif Yaşam and Pozitif-iz for forgetting their activist past and for compromising their principles to maintain rewarding relationships with the state and the pharmaceutical companies. Although Kırmızı Kurdele's website mentions the importance of establishing cooperation with state institutions and the private sector, during our conversation Vahe said, "My dream is to become sustainable without having any financial relationship with drug companies. I won't submit to big corporations. I won't grovel to the state either to make myself accepted." I first met Vahe through one of his short stories published in a book about living with HIV, *bana bi'şey olmaz*, nothing will happen to me. Then, I found out that he had a past as an actor and writer. When I learned that he was the founder of Kırmızı Kurdele, I decided I had to meet him in person and sent him an email. Vahe promptly got back to me, and he said he was happy to hear about someone writing a dissertation on such an understudied topic. He, himself, suggested that we meet when I am in Turkey, so we did. It was the summer of 2018 when Vahe and I met at a coffee shop in Istanbul, which turned out to be the longest interview I had to this date.

Vahe is a smart, charismatic man who loves to talk and has a lot of things to say. Because he processes his thoughts faster than he can speak, he doesn't necessarily follow a linear line as he talks, which makes it difficult to follow him as he smoothly jumps from one thought to the next. During those four hours I formally interviewed Vahe and he informally interviewed me, I learned a lot about him. He was, for example, very proud of himself for learning English after he founded Kırmızı Kurdele. He wanted his organization to be part of international networks and he taught himself English. Thanks to his charisma and hard-work, Vahe found himself a place in

international HIV/AIDS organizations and was quickly embraced by known activists. He also rebranded himself as an activist and described his activism as “knowledge-based”, *bilgi temelli*. For him, activism is about informing as many people as possible about how to prevent HIV transmission and how to live healthily as an HIV+ person. To this end, he and other volunteers of Kırmızı Kurdele translate research summaries and news articles into Turkish and share it on their virtual platform. Vahe has been a vocal advocate of the global U=U (undetectable=untransmittable) campaign; he even gave a speech at an event organized by the Prevention Access Campaign. It was very important to him that Kırmızı Kurdele was a pioneer in Turkey by publicly supporting the U=U campaign for the first time.

When I was doing fieldwork in 2021 and 2022, I noticed that Vahe grew more amiable since our interview. While he still refused to attend events organized by pharmaceutical companies, he began to develop closer relationships with Pozitif Yaşam, Pozitif-iz, and the Ministry of Health. Despite his growing cordiality, his feelings for queer HIV activists did not change since the last time we saw each other. When we met again in 2022 for an event, Vahe repeated his criticisms of the activists. He said, “I really don’t like the activists. Because they involve themselves in the field based on their diagnosis. I don’t understand why it is so important to be positive to do activism. If they say they are activists and act like gods like the doctors do, then they shouldn’t say ‘there is nothing I can do about it’ every time they face problems. If you cannot do anything, why do you pretend to be a hero? That’s why I don’t like the activists, they are all talk and no action”.

Vahe’s feelings are mutual as many HIV activists have had negative interactions with him. Defne Güzel, a talented journalist, HIV activist, and a great friend of mine, said,

HIV organizations act as though only they have the authority to do something or to say something about HIV. Sometimes they even gatekeep against each other. Needless to say, I do not agree with what Vahe says about queer activists not doing anything substantial... There is a historical and cultural relationship between LGBTI+ activists and HIV. LGBTI+ organizations have historically adopted HIV as one of their own struggles. These organizations have been creating HIV caucuses, yet we have not seen the same

when it came to HIV organizations. They have not taken a single step to include LGBTI+ people in their organizations. (Defne, personal communication, 2023)

Another activist from Ankara, Ali, whom I will write more about in the next chapter, shared with me that Vahe has been an obstacle in the face of their effort to create Pozitif Dayanışma, *positive solidarity*. “When we were first organizing, Sevgi helped us a lot. She was happy that a group of young HIV+ people were organizing in Ankara. She asked if we needed anything and how she could help us. Vahe is a completely different story. He doesn’t want us to get in his way. He wants to maintain the hegemony of three organizations in the field and he is afraid of queer activists raising their voice to stand against the heteronormativity of the field. He is worried that we will become an organization too and there will be more competition. Once we received an email from a sexual health platform regarding our participation in an event. It was sent to us, Pozitif Yaşam, Pozitif-iz, and Kırmızı Kurdele. Vahe replied all without removing us from the recipients and said something along the lines of ‘we don’t need Pozitif Dayanışma, the participation of the three big organizations should be enough’. We didn’t know what to make of this or how to address it.”

I was not surprised to hear that Vahe was giving activists a hard time. What surprised me were the claims about him actively sabotaging the efforts to create a grassroots organization. I knew that he had similar problems when he was in the process of founding Kırmızı Kurdele. He explained to me that doctors made fun of his ideas about a virtual association and told him to continue working with Pozitif Yaşam instead.

When I was laying the foundations of Kırmızı Kurdele, Pozitif Yaşam was the most well-known organization in the field. Including doctors, everybody recognized Pozitif Yaşam as the sole representative of HIV+ population. Doctors told me to improve Pozitif Yaşam instead of creating a new organization... One day I went to a well-known infection doctor and explained to her the model in my head. She said, ‘I don’t think this is necessary. You should upgrade the existing model instead’. (Vahe, personal interview, 2018)

For the past six years that I have been involved in the HIV activism, it seemed to me that Kırmızı Kurdele was unwillingly committing the mistakes they wanted to avoid repeating the most. In its attempt to “be different from Pozitif Yaşam and Pozitif-iz in every possible way”, Kırmızı Kurdele kept repeating some of the same old patterns. Although Vahe criticized Pozitif Yaşam for trying to be an authority in the field, he was doing the same when it came to younger organizations. Vahe has been called a gatekeeper not only for trying to block the entry of younger HIV initiatives into civil society, but also for trying to define what is HIV activism and who is considered an HIV activist. Vahe, who was questioned in the past if he could really be an HIV activist as a straight man, does not find the activism practiced by queer people convincing, desirable, or needed. He criticizes queer people for acting like heroes, although he is known to be, and agrees with being, considerably egotistical. Most of Vahe’s sentences start with I and involve at least one fact about his local and global achievements.

Gatekeeping is not the only way in which Kırmızı Kurdele reproduces the conventions of nongovernmental HIV care. Although Vahe positions himself and his organization as more progressive and liberal compared to Pozitif Yaşam and Pozitif-iz, his approach to sexual health shares some degree of conservatism as well. As I shared earlier, informing the public about HIV prevention methods constitutes the heart of Kırmızı Kurdele’s knowledge-based activism. It is true that the organization has been faster and more effective in disseminating information about PrEP and U=U. Nonetheless, despite its attention to promote up-to-date and scientific approaches to HIV prevention, Kırmızı Kurdele’s emphasis on the use of condoms for safe-sex purposes is described by activists as excessive, at best, and inherently discriminatory at worst. The insistence of Kırmızı Kurdele on the use of condoms is often teased about through mock safe-sex advices such as wearing three condoms on top of each other or through references made to an old, kitchy Turkish pop song named *kondom*. I heard someone making fun of Kırmızı Kurdele’s condom-related posts on social media by saying that “imagine someone tells you they don’t like oranges, and, yet, you keep asking them every day whether they would like an orange, instead of offering something that they might like.” These jokes aside, several people used the term “koru politikası”, *the politics of fear*, while talking about Kırmızı Kurdele’s condom policy. The

constant emphasis on the condom, according to them, makes it harder to represent HIV+ people outside the frame of infection and contagion. Defne Güzel, writes in her book *AIDSli İğne*, “needle with AIDS,” that HIV and AIDS have been historically used as tools of social engineering to keep the public in line. Condom-centered HIV prevention messages, according to her, are just extensions of the *society of control*¹⁹⁰ that remind the public that HIV+ people remain dangerous no matter how much the scientific developments disprove that.¹⁹¹



Figure 12: "They have found HIV's cure."

¹⁹⁰ Gilles Deleuze, "Postscript on the Societies of Control," *October* 59 (1992): 3–7.

¹⁹¹ Defne Güzel, *AIDSli İğne (Needle with AIDS)* (Ankara: KAOSGL, 2020), chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://kaosglidernegi.org/images/library/aidsl-ig-ne-web.pdf.



Figure 7: "A very beautiful gift demonstrating how much you love, care for, and protect each other. "

Where the public health institutions are not invested in popularizing prevention methods, Kırmızı Kurdele's insistence on condom use can be considered as a natural nongovernmental reflex. However, Brisson and his colleagues argue that as efficacious as condoms can be in preventing HIV transmission, they are still not effective due to their growing unpopularity.¹⁹² The authors conclude that it is counterproductive and unethical to insist on condom use where it is proven fruitless. According to local surveys, condom use remains extremely low in Turkey and many of my respondents mentioned that condoms are highly stigmatized.¹⁹³ I heard of strange encounters where suggesting to use condoms is taken as an indication of an underlying STI. In this context, it is rather counterintuitive that condoms emerge as the quintessential technology of self to be employed by individuals to avoid HIV transmission. Referred to as "the cure of HIV" and "a beautiful gift"¹⁹⁴ in Kırmızı Kurdele's social media posts, the representation of a condom as a

¹⁹² Julien Brisson, Vardit Ravitsky, and Bryn Williams-Jones, "Towards an Integration of PrEP into a Safe Sex Ethics Framework for Men Who Have Sex with Men," *Public Health Ethics* 12, no. 1 (April 1, 2019): 54–63; Julien Brisson, Vardit Ravitsky, and Bryn Williams-Jones, "Agency, Pleasure and Justice: A Public Health Ethics Perspective on the Use of PrEP by Gay and Other Homosexually-Active Men," in *Remaking HIV Prevention in the 21st Century*, ed. Sarah Bernays et al., vol. 5, Social Aspects of HIV (Cham: Springer International Publishing, 2021), 131–41.

¹⁹³ "Korunmayı öğrenemedik! (We couldn't learn protection)," *Hurriyet*, December 10, 2009, <https://www.hurriyet.com.tr/gundem/korunmayi-ogrenemedik-13162670>.

¹⁹⁴ One of Red Ribbon Turkey's mottos is "Bil, önemse, korun," meaning "Know, care, use protection." The problematic aspect of this message is the equation of caring for someone with using condoms.

life buoy in the above image and ascribing it the power of a cure is not inconsequential. Medical Anthropologist Sandra T. Hyde, who has worked on HIV in China for many years, states in her acclaimed book that the emphasis of civil society and state institutions on condoms has two consequences.¹⁹⁵ One of them is to create the perception that sex is possible only through penetration, and the other is to create the perception that sex is inherently dangerous.

The topic of risky sex has been central to the discourse of nongovernmental HIV care in general. Condemnation of “irresponsible sex” as harmful to the health of the individual and the public is a shared sentiment among the actors of civil society. HIV organizations carefully distinguish between the kind of sex that is okay to have, i.e. with condom, and the kind that should be avoided at all times, i.e. condomless. When the condom is portrayed as a cure for HIV, though, HIV transmission is reduced to a biomedical phenomenon and its socio-political and bodily dimensions are rendered invisible anew. Preventing HIV transmission is possible with social, political, cultural, and pleasure-oriented policies rather than biomedical interventions. Therefore, not only sexual rights and sexual health, but also sexual pleasure should be at the center of all prevention efforts. The 'public' of public health is not constituted by abstract statistics and numbers, but bodies and identities that desire and are desired.

To conclude, I'd like to repeat the importance of making sure that people get the prevention methods that will work for them and their lifestyles. As sociologist Hector Carrillo, who was among the first to study sexuality and HIV in Mexico, emphasized as early as the early 2000s that HIV prevention efforts should focus on factors such as sexual passion, spontaneity, and motivation. According to Carrillo, when it comes to HIV and other sexually acquired infections, the important thing is to discuss how prevention methods can become a part of everyday life without damaging romantic and sexual relationships. He wrote,

In other words, the knowledge and skills needed to carry out HIV prevention properly need to be contextualized within the reality of people's sexual loves, with all their wonderful moments and their complications. This means, for instance, that rather than

¹⁹⁵ Hyde, *Eating Spring Rice*.

attempting to convince everyone that condoms are the norm and are quite erotic, it might be more productive to recognize that they indeed frequently constitute a barrier to intimacy and pleasure and to emphasize that nonetheless they are a necessary measure to prevent potentially deadly diseases such as AIDS.¹⁹⁶

¹⁹⁶ Héctor Carrillo, *The Night Is Young: Sexuality in Mexico in the Time of AIDS* (University of Chicago Press, 2002), 281-2.

CHAPTER 3

At the Limits of Medical Care: “Doctor Violence” and “God Ego”

Istanbul, 2020. A man who wishes to remain anonymous and whom I will call Halil reaches out to the Pozitif-iz association to seek legal support. He needs legal assistance because a hospital brought a case against him for “taksirle yaralamak,” which translates as *injury by negligence*. Turkish Penal Code defines injury by negligence as harm caused by someone who acted on their free will and failed to see the foreseeable consequences of their actions. Although the injury is not caused intentionally, it could have been prevented if the person acted with caution or common sense. The sequence of events that resulted in an HIV+ patient being sued for causing injury begins with a young man requiring a minor surgery. Before the surgery he consults the infection doctor he has been seeing and queries whether he must share his HIV status with the surgeon. His doctor tells him that there is no need for that both because he is virally suppressed and because the operating room procedures for protection and sterilization are standard and not dependent on the patient’s serostatus. It is the physician’s responsibility to follow the necessary precautions to protect both their health and that of their patients. HIV+ patients in Turkey, however, are frequently denied surgical operation based on the premise that the operating room is not equipped with the necessary tools to handle someone who is positive. In many cases, a letter is required from an infectious diseases expert to convince a surgeon to operate HIV+ patients. In a lot of cases though the patient is denied surgical treatment and they need to find another provider, if they can.

Under normal circumstances a patient would not need to disclose their status to a surgeon because the standard procedure requires everyone to get a full panel blood test before a surgery and if someone is positive, it would come out in the process prior to operation. This is how numerous people get diagnosed in Turkey. But, in this case, the surgeon does not ask for a comprehensive blood test. Perhaps he forgets, perhaps he thinks of it unnecessary due to the minor nature of the surgery. A day after his surgery the young man receives a phone call from

his doctor and is asked to report to the hospital urgently. When he arrives at the clinic, he finds the doctor agitated. The doctor says, “during the operation I was exposed to your blood when it splashed into my eye. I got really panicked because of this and sent the blood we drew from you before the surgery for testing. I know that you are HIV+ and you had an obligation to share this information with me before the harm was done.” Upon finding out that he was called back to the hospital immediately because he was HIV+ positive and not because they detected cancer or something that is killing him, he calmly explains to the surgeon that he knows his status. He also reassures him that he is virally suppressed and does not pose any transmission risk. Still, he advises that it would be wise for him to use post-exposure prophylaxis, PeP. The surgeon seems unaware of what PeP is and consults the hospital’s infectious diseases unit. There another doctor tells him that this is a judicial case and that they need to inform the hospital police.

This is how an HIV+ patient is sued by a hospital on the grounds of inflicting harm although there is zero risk of contamination. As it is often the case with the criminalization of HIV, the target of the law is not the protection of public health (defined as the health of HIV-people) but the punishment of the HIV-positive individual.¹⁹⁷ In this case, the doctor from infectious diseases believes that a police report is necessary to be able to prescribe PeP. However, such a report would only be necessary when PeP prescription is required in the case of a sexual assault. Without the report, the cost of the medicine would have been on the survivor’s shoulders. Infectious diseases doctors are usually the ones most informed about PeP and we can only speculate regarding the purposes of that doctor in bringing the matter first to the police, then to the jurisdiction. He might have been confused about the procedure because the Ministry of Health never established transparent guidelines for the use and prescription of PeP. He might have also wanted to save his colleague from a medical expense because health providers need to pay for an urgent PeP treatment too if the hospital they work at does not have available medicine at its disposal. Regardless of the possible reasons, the end result is the same and it carries the only “risk factor” in this story. That is the risk of a person living with HIV being prosecuted for

¹⁹⁷ Trevor Hoppe, “From Sickness to Badness: The Criminalization of HIV in Michigan,” *Social Science & Medicine* 101 (January 2014): 139–47.

being positive and failing to disclose his status even though his viral load is too low to be detected or transmissible. Thanks to the legal support from Pozitif-iz that followed the case and prepared the defense, the young man was not found guilty. He could have sued the hospital to set an example and to demand financial reparation, yet he did not want to pursue the matter any further since he wished to remain anonymous.

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In December 2017, a pregnant woman in her thirties started experiencing labor pain in the city of Siirt located in southeast Turkey. I will call this woman Hevi, meaning dream and hope in Kurdish. Hevi and her husband had to drive three hours to go to the nearest university hospital found in Diyarbakir and named after the river of Dicle (Tigris). They couldn't just go to a local hospital because three years ago when Hevi gave birth to her first child she was not admitted to any of the nearby hospitals because of her HIV status. The couple also sought to minimize the risks of being outed in a small town as that would imply social isolation both for themselves and for their children although the kids are HIV-negative. A lot of HIV+ patients in Turkey follow the same path and travel to larger cities when they need treatment to avoid small town gossip and marketplace glare.

When Hevi arrives at the hospital, her travail is excruciating, and she needs to be taken into the operating room immediately for a c-section. To their surprise, the attending physicians scheduled to work at the gynecology clinic that day do not want to admit her either. However, this is the hospital where she gave birth to her other children and Hevi doesn't have time to get on the road again in search of another clinic. As a result, she is admitted but the specialist doctors are determined, and they refuse to perform the surgery. When three standing physicians reject delivering the baby, putting the lives of both the mother and the child at grave risk, the cesarean is performed by another specialist doctor and an assistant doctor who started working at the clinic only a few months ago. The operation goes trouble-free for the mother and the child, yet the assistant doctor has a needlestick injury and comes into contact with the patient's blood.

Even though Hevi has been under treatment for six years and virally suppressed, this incident creates a small-scale scandal in the media where the accident finds coverage as “HIV-infected woman infecting a doctor with AIDS”.

While Hevi is brought under suspicion for causing injury by negligence or even manslaughter, the hospital does not mention her untransmittable status or the use of post-exposure prophylaxis by the assistant. On the other hand, whereas everyone is concerned for the wellbeing of the injured doctor who was not at risk of HIV transmission, the struggles and harms Hevi had to endure in the process are lost on the public and healthcare professionals. In a newspaper interview, the president of the faculty of medicine, the head of the department of gynecology at the same time, offers the following explanation as to what went wrong, shedding light on the extent to which the rejection of healthcare services for HIV+ people has been normalized within the medical industry and the “problem” has come to be defined as being HIV+:

“These complications happen in all surgeries. I have been performing surgeries for over thirty years and I have seen countless similar cases. The problem here is that the patient is HIV-positive. Because of this reason some doctors did not want to enter her delivery and this can happen. We found others to perform the procedure so it’s not a big deal and we should stop acting as though it’s a huge deal.”

*

As the stories of Hevi and Halil unveil, HIV+ people in Turkey do not so much suffer due to being positive but due to discrimination they encounter on a daily basis. But not all discriminations are the same or have the same implications, and there are risks of treating discrimination as a stable and uniform category. While the discrimination experienced in the hands of state institutions and nongovernmental organizations wears HIV+ community down, according to PLWH none of the discrimination is as debilitating or detrimental as the one they face in healthcare. When discrimination becomes an obstacle in the way of accessing treatment and holistic wellbeing, its negative consequences are not limited to social exclusion as they may involve biological damage for each day passing without treatment. Hevi’s case is especially

helpful to consider the reverberations of the denial of urgent medical care to HIV+ people, which can lead to, and has led to, preventable deaths.

In reference to the roles played by doctors in the extermination of demographics considered as risk for the purity of the Arian bloodline, Esposito writes, “genocide was the result not of an absence, but of a presence, of medical ethics perverted into its opposite” (Esposito, :). He also wrote that, “if ultimate power wore the boots of the SS, *autocritas* wore the white coat of the doctor” (ibid.: 82). As Esposito reminds us, it was only the physician’s right to inject phenol into people’s hearts and to open the gas valve for the final “shower”. However extreme it may seem to share an example on Nazi doctors, my purpose here is not to draw a parallel between the atrocities of the Nazi regime and the experiences of medical neglect and abandonment in the hands of doctors. Rather, I seek to underline that in spite of their assumed incapacity of inflicting harm, doctors are not inherently incapable of wrongdoing. Just like any other profession or social demographic, they too are not immune to political ideologies and social stigmas that represent certain groups as contagious super spreaders. In fact, the violence and injury engendered by medical professionals is precisely targeted at immunizing them against so-called infectious others, or viral underclasses,¹⁹⁸ whether it is Jews, homosexuals, or HIV+ people.

The term ‘medical violence’ is not commonly used in Turkish. Instead, the preferred term is “doktor şiddeti”, *doctor violence*. This seemingly inconsequential substitution, in fact, directly speaks to how patients interpret the harms caused on them in medical settings not as issues pertaining to medicine as a practice but as the individual mistakes of medical doctors. In Greek, *ιατρός* (*iatros*) means healer and *γένεσις* (*genesis*) means origin. *Iatrogenesis* then is a term that implies originating from, brought forth by a healer. Although the term itself does not make a judgment about the quality of the healer’s actions, it has widely come to mean medical harm since its introduction into sociology in 1976 by Ivan Illich—an Austrian Roman Catholic priest and a social critic.¹⁹⁹ Illich argued that life is overmedicalized in industrialized societies and,

¹⁹⁸ Steven W. Thrasher, *The Viral Underclass: The Human Toll When Inequality and Disease Collide* (Celadon Books, 2022).

¹⁹⁹ Ivan Illich, *Medical Nemesis: The Expropriation of Health* (Pantheon Books, 1976).

ironically, the boundless subjection of people to the medical science and practitioners has adverse health impacts for populations. Since Illich revived the term, iatrogenesis has been widely used as a synonym for medical errors such as surgical malpractice, wrongful prescriptions, and inaccurate therapies. Medical error is one of the leading causes of death in the United States with roughly 250,000 dying every year²⁰⁰—this number exceeds 2 million globally.²⁰¹

When we consider the harms produced during or as a result of medical encounters, as well as the lives lost due to preventable reasons, medicine can no longer be framed as the origin of healing, as the harm is and has always been inherent to medicine. Some therapeutic interventions such as chemotherapy is known to have iatrogenic consequences that lowers the patients' life quality significantly to the extent that more and more cancer patients refuse the treatment. What makes such medical interventions still beneficial for some is that their benefits outweigh their harms. Yet what happens when this equation is broken and the benefits are no longer worth experiencing the side-effects? Because it reveals the liminality of medicine, i.e. the existence of extremely blurred lines between medical harm and benefit, Varley and Varma refer to iatrogenesis as the “medicine’s shadow site.”²⁰² Not surprisingly, the recent work on iatrogenesis uncovered that already marginalized populations such as women, LGBTQ+ individuals, and people of color are victims of medical harm and neglect in disproportionate numbers.²⁰³

In the rest of this chapter, I provide an ethnographic depiction of iatrogenic violence in HIV care. First, I discuss the implications of medical rejection and denial—in other words, *injury*

²⁰⁰ Martin A. Makary and Michael Daniel, “Medical Error—the Third Leading Cause of Death in the US,” *BMJ* 353 (May 3, 2016): i2139.

²⁰¹ “WHO Calls for Urgent Action to Reduce Patient Harm in Healthcare,” accessed April 24, 2023, <https://www.who.int/news/item/13-09-2019-who-calls-for-urgent-action-to-reduce-patient-harm-in-healthcare>.

²⁰² Emma Varley and Saiba Varma, “Introduction: Medicine’s Shadowside: Revisiting Clinical Iatrogenesis,” *Anthropology & Medicine* 28, no. 2 (April 3, 2021): 141–55.

²⁰³ Lauren Textor and William Schlesinger, “Treating Risk, Risking Treatment: Experiences of Iatrogenesis in the HIV/AIDS and Opioid Epidemics,” *Anthropology & Medicine* 28, no. 2 (April 3, 2021): 239–54; K. Eliza Williamson, “The Iatrogenesis of Obstetric Racism in Brazil: Beyond the Body, beyond the Clinic,” *Anthropology & Medicine* 28, no. 2 (April 3, 2021): 172–87.

by negligence—for HIV+ people’s quality of life. I specifically focus on the case of dental and plastic surgery clinics infamous for refusing services to PLWH. While examining different forms of medical harm, I pay special attention to the intersections of HIVfobi with homo- and transphobia that are rampant in Turkish hospitals and clinics. In the first half of the chapter, I also describe the temporally extending side-effects of iatrogenesis in cases where the privacy of HIV+ patients is violated and their HIV status is disclosed to the hospital personnel and their family and partners. Second, I turn my attention to what many of my interlocutors referred to as “god ego” while they were describing the attitudes of doctors toward HIV+ patients. In this section, I focus primarily on infection doctors and the way their paternalistic, patronizing, and sometimes aggressive manners can frustrate access to HIV care. I also reflect on the anti-political nature of medical care as observed in how healthcare providers refuse to acknowledge or engage with HIV+ people outside the category of *vulnerable patient*, which, in return, diminish the agency of people living with HIV. Yet, as I shall explain in further detail below, anti-politics of medical HIV care does not only stem from a refusal to recognize HIV+ people as more than patients, for it is also rooted in the inability of doctors to recognize their shared vulnerabilities with HIV+ and LGBTQI+ communities and the political potentials of organizing across differences.²⁰⁴

“We don’t provide services to HIV+ people”

When I first started preliminary fieldwork in the summer of 2018, I was aware of the countless stories of medical violence and discrimination against PLWH. Yet, this awareness did not stop me from being utterly stunned when I was shown a billboard ad for Istanbul Estetik Merkezi, *Istanbul Aesthetic Center*, about their plastic surgery services. When a friend showed me the picture of the billboard in his phone, at first I did not understand what I was looking at. Then, at the bottom right of the image, I noticed a white text on a dark blue background saying

²⁰⁴ Ernesto Laclau and Chantal Mouffe, *Hegemony and Socialist Strategy: Towards a Radical Democratic Politics* (Verso, 2001).

“HIV+’lere hizmet vermiyoruz”, *we don’t provide services for HIV+ people*. We both knew that status-based discrimination is especially rampant among plastic surgeons. PLWH are either refused services upfront or coerced into paying exorbitant prices to “cover up for the risks they pose on the health personnel”. Yet, neither of us have heard or seen such an unapologetically blatant example of medical HIVfobi.

Should we consider iatrogenesis merely in terms of medical errors, we risk missing the multifarious forms in which medical and social harm is brought upon patients. For some patients, medical care and healing is only achievable when unpleasant iatrogenic side-effects are accepted and health is further sacrificed in the process. For others however, harm is not the price to be paid in the hopes of cure, either because there is no treatment in the horizon, or because the existing treatment is denied. One prominent form of debilitating injury for HIV+ people in Turkey is the pervasive denial of medical services by health professionals, as well as the stigmatizing medical discourses that contribute to the precarization of HIV+ patients.²⁰⁵ The iatrogenic side-effects of HIV care are not limited to the denial of treatment, however, for an equally common way to inflict harm on patients takes place when providers disclose the HIV status of their patients to the hospital personnel and the patient’s family. In some cases, doctors ‘medically’ suggest to the partners of HIV+ patients that they need a divorce. When a patient’s status is revealed without their consent, this does not only interrupt their access to healthcare services in the same facility, but also causes them to be socially isolated and potentially unemployed.

When I was volunteering for the Positive Living Association, I wrote a project to assess the HIV stigma among healthcare professionals. This project was awarded a large sum of funding by GlaxoSmithKline and with a portion of the funds we collaborated with a research company. Between May 24-July 12, 2022, the company was able to conduct 408 face-to-face surveys designed in accordance with the Harvard Implicit Association test. 49% of the respondents were located in Istanbul, whereas 26% of them lived in Ankara and 25% of them in

²⁰⁵ Oktem, “Patriarchal and Medical Discourses Shaping the Experience and Management of HIV.”

Izmir at the time of the interview. The distribution of participants by branch is as the following: General Surgeon (25%), Dentist (20%), Family Practitioner (20%), Patient Rights Expert (19%), and Occupational Physician (15%). When these sample groups were asked whether doctors have the right to refuse an HIV+ patient, the percentage of those who answered yes is respectively 25%, 18%, 25%, 18%, and 15%. When they were asked if HIV+ patients should be isolated, those who answered positively in each subgroup were almost twice as high as those who defended the right to refuse treatment. Moreover, according to the survey results, 33% of dentists and 56% of family practitioners expressed that they would inform the other hospital/clinic personnel if they have an HIV+ patient. 81% of family practitioners said that an HIV test should be compulsory before marriage and partners should be informed without the need for their consent. In a similar vein, half of the occupational physicians reported that they would inform the employer if a prospective employee is HIV positive and two third of them disclosed that if there were two equal candidates for the same position, they would recommend the HIV-negative candidate.

The results of the research emphasized two factors determining the doctor's attitudes towards HIV+ patients: ignorance and fear. These two are intimately related to each other for the latter is a direct byproduct of the former. According to findings, only one third of the respondents knew HIV's transmission routes and the rest reported significantly higher levels of fear and anxiety. The urgent need to improve the national medical curriculum and its coverage of STIs is a remark made by every HIV specialist I interviewed in Turkey. For instance, doctor Ersöz shared some of the problems her patients face,

Unfortunately, we have serious issues with medical education. In most medical faculties HIV and AIDS are covered only superficially for a period of one or two hours, if it's covered at all. I hear that medical students are still advised to stay away from HIV+ patients because of the immense risk. So, a lot of students graduate from medical faculties not knowing anything about HIV except that it's an incurable, deadly disease. The lack of knowledge naturally gives way to panic and fear, which in turn give way to traumatic experiences for patients. Lately, my patients are experiencing a lot of problems at urology clinics. I had this pregnant patient nine months ago and the urologist she visited at a university hospital told her that she will die of AIDS and take her baby with

her to the grave. Because of issues like this, before my patients see a doctor, I give them a call beforehand to explain that there is no risk of infection. This is surely problematic because it violates patient privacy but it's the best we can do right now. I had this other patient recently. He went to see a general surgeon without consulting me and he was chucked out of the clinic by the surgeon who blamed this patient for trying to kill him by entering his clinic. (Ersöz, personal interview, 2021)

The ignorance of doctors when it comes to HIV is not an instrumental or a strategic one unlike the Turkish state. Doctors are not interested in avoiding responsibility by refusing to acknowledge HIV and HIV+ people. Their ignorance rather stems from the inadequacies of the education they received in medical schools. Yet, this does not mean that their ignorance causes less harm than that of the state. Apart from denial of medical services, the viral panic induced by ignorance is what motivates many health providers to unlawfully disclose the HIV status of their patients to allegedly protect innocent others from the risk of transmission.

Once I was visiting a local HIV organization in Istanbul and as usual I brought a box of sweets with me as it is customary. As we gathered around the large table in the kitchen and started tasting the variety of eclairs, Mehmetcan, a social worker, turned towards me and told me “I have a story for your dissertation” and continued to casually share the details of a case about a woman whose status was disclosed to the entire hospital against her consent. The patient was wishing to have a baby and shared her HIV status with her gynecologist. Already under treatment and virally suppressed, she posed no risk to anyone, including the baby. Yet, believing her status is “a grave risk for all the personnel and patients at the hospital who have the right to know about the risk they are under”, the gynecologist individually contacted every single department in the hospital to let them know about the imminent threat they face. After this, the young woman had to find another hospital and a new provider. What is even worse, she has lost her job because one of the nurses in the hospital was the sister of a colleague she worked with. Then, the entire family became aware of her HIV status, and she and her husband had to leave everything behind and move to a different city.

Many people in Turkey find out about their HIV status without knowing they were ever tested for it. Regulations require everyone to get tested before undergoing surgical interventions and before getting married. Usually no one is informed that they are getting tested for HIV during the process of medical check-up. Several problems occur when someone receives an unexpected HIV diagnosis. First, in the absence of pre- and post-test counseling, they experience serious trauma. Second, this trauma is intensified by the fact that they often receive the diagnosis in front of their families or prospective partners. Although it is private health information, surgeons and family physicians do not respect the privacy of such a delicate piece of information. Health providers clearly show they care less about the privacy or wellbeing of their HIV+ patients than about the safety of medical personnel and future families—both perceived as sacred—who are under no risk of HIV transmission. At times, the privacy of HIV+ patients is not respected not because of the direct discrimination they face but because of the nature of archaic bureaucratic and medical procedures that were not put in place to protect patient wellbeing or privacy. When I returned to Istanbul for long term fieldwork in 2021, it was the first time I needed to access HIV care in Turkey. After postponing it for three months—until I ran out of the medicine I brought with me—I finally scheduled a visit at the nearest hospital. Haydarpaşa Hospital was built in 1894 on the Asian side of Istanbul and although a lot of its buildings are under risk of collapse, it has one of the most ostentatious and historical medical premises in the country. I went there because I knew the head of the infectious diseases clinic whom I trusted as a physician and, more importantly, as a person.

In spite of the judgment-free environment of the clinic, my experience in the hospital was heavily different from what I was used to in the context of private healthcare in the state of Minnesota. Following my first visit to the clinic, I was issued an official document stating my HIV status. Then, I was handed over this document and asked to bring it to another unit in the hospital so that they could complete my registry at the national database. At that unit, my diagnosis was passed around and examined by five people until it reached the right person. At the end, I was told that the diagnosis I acquired abroad was not valid and that I need to visit the hospital laboratory to repeat blood tests. In the laboratory, you first have to get a number and

wait in the line. The initial line is not for blood draw but to give the patients the tubes they will need for the tests. Once you procure the tubes, you need to get in a second line. As I was waiting for my turn, I noticed that the tubes I was given had stickers on them saying serological test. When it was my turn around 3pm following an hour-long wait, I entered a large room with more than ten nurses drawing blood simultaneously. When the nurse held my tubes and glanced at them, she side-eyed me and remarked very loudly, “you have come for HIV tests, but you need to come back in the morning for those,” as though to make sure everyone in the room hears it.

Fear and ignorance, according to a family practitioner I interviewed in 2019, are not the only relevant factors in explaining the chronic interruptions of HIV care. Tugay highlighted that there are two registers of *doktor şiddeti*, or doctor violence: the violence caused on patients by the doctors and the violence caused on the doctors by the patients and their families. Both modes of violence have been increasing in frequency since the AKP came to power. AK Parti officials have been largely employing a public rhetoric that posits healthcare providers as the “servants” of the voters. During the neoliberal transformation of the national health system between 2003 and 2012, one of the strategies of the party to support its dubious promise of universal health coverage was to fabricate a public feeling that doctors were to be held responsible for all the misgivings of the healthcare system. Tugay expressed his and other doctors’ resentment in the system with following words:

Of course the lack of good education and the fear of the unknown are important factors, but we should also think about the hard feelings doctors have in this country. We all sacrifice a lot, work long hours, make little money, and for what? So that the state not only won’t protect me but also will incite further violence against me. Doctors are being harassed, beaten, and murdered by their patients or their families and these people walk around freely without any punitive sanction. When I was working as a family practitioner, I was insulted and yelled at daily, and I don’t know how many times I barely saved myself from being physically assaulted. This is only my second year in practice. The way AKP legitimizes and aggravates violence against doctors pushes many doctors to avoid procedures that they think will pose yet another risk to their safety. (Tugay, personal interview 2019)

The resentment of doctors in the system for financial and political reasons might shed some light on their attitudes in the face of perceived medical risk. After all, the way medical professionals and organizations are criminalized and disciplined by the Turkish state in an effort to depoliticize and weaken medical authority has already been documented.²⁰⁶ Yet, the politics of attrition cannot offer an explanation for the homophobia and transphobia profoundly radicated in Turkish healthcare. In 2022, several medical faculties, including the oldest medical faculty dating back to the 15th century, found social media coverage when they removed a sentence from the Hippocratic oath to prevent the graduating class from reciting it collectively. The sentence was “I will not discriminate based on gender identity or sexual orientation.”

In 2021, on a freezing evening in Ankara, I met Ali in-person for the very first time, although we have known each other for a while from online gatherings and workshops. I was expecting him at my hotel room to have a cup of warm fennel tea before we stepped out in the cold, yet the reception did not let him go upstairs potentially because he is a visibly queer man. So we had to meet outside instead and soon after we sat down on a park bench to share a cigarette, Ila began to complain about his dental procedure that was left half finished. Access to dental care is particularly troublesome for HIV+ folks as there are only a few dentists even in metropolises who will operate on a positive patient. Even in that case, due to the limited number of available dentists, prices go up and the waiting period can be months. The difficulty of finding a provider for proper dental care is a topic that came up frequently during my fieldwork. When I first met Hasan, one of my early connections and interlocutors in Istanbul, I remember feeling uneasy when he showed me the dark, empty spots in his mouth where he used to have teeth. I remember that almost because he sensed my discomfort, Hasan joked about the only characteristic shared by HIV+ people in Turkey being missing or decayed teeth.

²⁰⁶ Başak Can, “Human Rights, Humanitarianism, and State Violence: Medical Documentation of Torture in Turkey,” *Medical Anthropology Quarterly* 30, no. 3 (2016): 342–58; Salih Can Aciksoz, “Medical Humanitarianism Under Atmospheric Violence: Health Professionals in the 2013 Gezi Protests in Turkey,” *Culture, Medicine, and Psychiatry* 40, no. 2 (June 1, 2016): 198–222.

Ila is a queer guy from Azerbaijan who has been living in Turkey for nearly a decade now. When he first moved to Ankara to start his undergraduate education, he, like many other foreign students, was not aware of the legal requirement to enroll in the General Health Insurance within the first three months of college enrollment. Because of this bureaucratic obstacle, Ila had to finish his education without a valid health insurance, and he had to travel back to Azerbaijan every three months to get his medicine. As he was not able to afford a flight, he took the bus each time and was on the road for 24 hours. When he started a master's program in migration at a public university in Ankara, he was already experienced and made sure that he did not miss the window period to apply for the insurance. Nevertheless, soon after he was insured, he had to learn firsthand that medical coverage does not guarantee access to healthcare when you live with HIV, as the story below shall explain better.

One day, Ila went to a dental clinic of a public university for root canal treatment. At first, everything seems fine as he is able to schedule an appointment without having been asked about his HIV status. On the day of his appointment, the staff is initially very kind and attentive, until they start having some doubts about Ila's sexual orientation. Ila is the kind of queer person that cannot and won't pass as a cis straight man in the pursuit of social, and in this case, medical benefits. And, he believes that when the surgeon stopped the operation abruptly and asked him about his HIV status, this was because his mannerism left no room for doubt about his queerness. When Ila responds to the awkwardly timed, invasive question and says he does not know his HIV status, the dentist says you are in a "risky group" (sic) and leaves the surgery room to wear a face shield and protective suit. When Ila sees the excessive protection he is angry but still thinks that extra precautions are taken in order to finish the surgery. This is not what happens, however, and Ila is sent home with an open canal and told to come back in a few days with the results of a recent HIV test. This is the last straw for Ila and he demands to see the head physician as he is well aware that it is not legal to request an HIV test result for a dental procedure. The head physician comes down to the operation room only to confirm that the test is required in order to guarantee the safety of dentistry students.

When he returns to the clinic in three days without the demanded results and is waiting for his turn in the reception room, he sees his name on the nurse's list and notices the warning of "HIV RISK" typed in capital letters right next to his name on the patient intake form. As someone involved in HIV activism, Ila is familiar with such discriminatory violations of patient privacy in medical settings and for that day he chooses not to make a scene, partially because he is well-aware of the alternative scenario where he leaves the clinic still with a hole in his upper tooth. So, he continues into the operation room when his name is called by the technician. When he enters the room Ila is terrorized by the look of the operation chair covered in aluminum foil. The futuristic-horror tones of the clinic is only intensified when he throws a glance at the surgeons, both of them dressed head-to-toe in biohazard suits, reminding of Dustin Hoffmann in the 1995 movie *Outbreak* where he tries to stop the global spread of a fictional zoonotic and airborne virus, named after Motaba river in Democratic Republic of Congo. Under these extreme precautions, Ila's operation is completed, and a special team enters the room to collect all the operation tools and equipment.

Although his root canal treatment is completed for now, Ila believes that he needs comprehensive dental care to do something about his deteriorating dental health. Yet, he postpones it both because of financial concerns and because of the multiple forms of insults he might have to endure in the process. Delaying of medical services is alarmingly widespread among HIV+ people and one of the most poignant stories I heard on this subject was also shared by Ila about a close friend of his. The young man whom I will call E. here did not start on antiviral treatment for almost eight years following a distasteful encounter at his first infectious diseases visit in early 2010s. After experiencing severe flu-like symptoms for several weeks and unable to get better in spite of taking medicine, E. is sent to an infection clinic to get some tests done. After getting all the requested blood work, E. makes an appointment in the same hospital to show his results to an infection doctor. When he shows up for his appointment, the doctor began browsing his recent test results and finds out E. tested positive. He shares the bad news with E. only by saying that "you have HIV" and then, he leaves the examination room and tells E. to wait there. E. does what he is told because he needs guidance and medicine. Yet, the

waiting gets longer and heavily unbearable at some point. After waiting almost for an hour, which must have felt like infinity amid the shock of receiving what he believed to be a death sentence back then, E. goes out and asks the nurse when the doctor will be back. The nurse answers his question with a bewildered look in her eyes and informs him that the doctor left the clinic an hour ago.

The fact that both İla and E. experienced interruptions in access to healthcare long after their initial clinical encounters demonstrates that iatrogenesis is a phenomenon that temporally and spatially exceeds the clinic, and it can have continuous impacts on a patient's health and wellbeing. Often medical violence is used to refer to instances of physical or verbal aggression, yet it also has implications for patient's future experiences with the healthcare system. Traumatic experiences impact individuals' and communities' trust in healthcare and healthcare providers, deterring many from seeking help. The lack of trust becomes an issue especially for already marginalized communities whose members have been historically discriminated against at healthcare facilities.

In 2022, I visited a general surgeon at a city hospital in Istanbul. Şehir hastaneleri, *city hospitals*, are regional large medical complexes built under AKP administration and considered as one of the main ways the nation was impoverished for personal gains.²⁰⁷ The purpose of my visit was to get an examination for the hemorrhoids I began to suffer during the fieldwork. The doctor I was going to see had positive online reviews, and he seemed to be an experienced surgeon. When I entered his examination room, he told me to go to the back of the room and get ready. Few seconds later, he followed me into the room and told me to lay down on my side. As I was taking a fetal position, he was putting on his gloves and preparing the surgical lubricant. Everyone who has ever experienced a vaginal or anal examination knows that these are extremely invasive procedures and often create an unequal power dynamic between the doctor and the patient. My sense of discomfort significantly increased when he started asking me

²⁰⁷ "TTB: Bir kara delik gibi büyüyen şehir hastaneleri bütçeyi yutmaya devam ediyor," Evrensel.net, accessed April 24, 2023, <https://www.evrensel.net/haber/474458/ttb-bir-kara-delik-gibi-buyuyen-sehir-hastaneleri-butceyi-yutmaya-devam-ediyor>.

questions about my life as he was examining my rectum. He asked what I was doing, and I said a PhD in anthropology, skipping the part about gender and sexuality studies. As he continued twisting his index finger inside me, he asked, “since you are studying anthropology, what do you think of the people of lut?”

His question made my blood run cold. In Turkey, a lot of queer people know that if someone is asking you about *lut kavmi*, the people of lut, they are insinuating that you are one of the descendants of those people who got ravished by God's anger. As AKP intensified its attrition strategies against LGBTQI+ communities, the people of lut have become a central figure for the hateful public discourse that found supporters among ultra-religious groups and Ak Parti representatives (). The invocation of *lut kavmi* as an anti-LGBTQI+ symbol and its ideological association with diseases, however, precedes AKP. On August 29, 1985, the mayor of Istanbul gave a press conference where he made the following observation: “AIDS is a divine retribution for homosexuals. A similar incident happened a hundred years ago, and it is known as the story of the people of lut. In this calamity, many homosexuals died. I believe AIDS is the modern-day reflection of the punishment God brought upon the people of lut.”

I could have told him that he is homophobic and left the examination room that second. But being confrontational does not come in handy when you are in a fetal position and urgently need medication for the pain and inflammation you have been having for a week. So, instead, I took the question seriously and gave him a detailed explanation regarding the popular misinterpretations of *lut kavmi*. When the examination was over and I was getting dressed to leave the room at once, he asked from the other end of the room divider if I recently got tested for AIDS. On my way back from the hospital, I was thinking in the backseat of a taxi about what made him think that I was gay and HIV+. Was it my manners that are commonly read as being too “kind” for a straight man in Turkey or was it the fact that I had hemorrhoids, which made him think I was probably having anal sex, or was it a combination of both? I previously wrote about the construction of anal penetration as the antithesis of masculinity by medical practices

and discourses in Turkey.²⁰⁸ This incident at the hospital made me notice that anal health (i.e. not bearing the physical symptoms of penetration) is not only a medical marker of masculinity but also of heterosexuality, and potentially of HIV status.

Through diagnostic procedures that involve tactile contact and penetration, medical professionals practice a form of “violent intimacy”²⁰⁹ that does not respect bodily integrity. In the experiences of trans women, if the one side of the coin is the violent touch involved during the gender affirmation surgery,²¹⁰ the other side of it is the complete denial of the touch. On May 25, 2021, Pelin went to Taksim Eğitim ve Araştırma Hastanesi, *Taksim Training and Research Hospital*, located at the touristic center of Istanbul, Beyoğlu neighborhood, hosting a large number of LGBTQI+ inhabitants. Pelin’s appointment with the general surgeon Erol K. was initially positive as he was very attentive and kind. Things took an unexpected turn for Pelin when the doctor asked for her national identification number to be able to issue her a barcode. When he was staring at his desktop screen, the surgeon started yelling at Pelin, “Are you a travesti? I am not a travesti doctor. The ministry of health gives me the right to choose my patients and I refuse to be your doctor.” “But, you already examined me, touched my body, what is going on now?” asked Pelin. Before he forced her out of his room by pushing her shoulders, his answer was “if I knew you were a travesti, I wouldn’t have touched you. My hands got dirty now,”

Given that trans women’s access to healthcare is already frustrated because of their gender identity, it should not come as a surprise that HIV+ trans women are the most vulnerable group to medical discrimination and violence. Every year countless trans women reach out to HIV and sexual health organizations to seek medical help they are denied in healthcare facilities. The denial of medical services for HIV-positive trans women has been exceptionally prevalent in plastic surgery clinics. Aesthetic operations are sought in distinct contexts to support a person’s

²⁰⁸ Atuk, “Comrades-in-[Each Other’s]-Arms.”

²⁰⁹ Asli Zengin, “Violent Intimacies: Tactile State Power, Sex/Gender Transgression, and the Politics of Touch in Contemporary Turkey,” *Journal of Middle East Women’s Studies* 12, no. 2 (July 1, 2016): 225–45.

²¹⁰ Zengin, “Violent Intimacies.”

ability to live comfortably in their bodies, and gender affirmation is one of the many scenarios in which the denial of medical attention will have severe psychological and physiological implications. Refusing a trans person their right to self-determination is no less than an act of social murder. In May 2021, a trans woman, Arel, posted a question on the Facebook page of HIV support group hosted by Pozitif Yaşam Association:

“Hi everyone. I am a trans woman and there are some plastic surgeries I want to get. A nose job, chin prosthetics or implants, voice feminization surgery, breast implants etc. Unfortunately, I had problems at several clinics because I am positive. The ones who agreed to do it asked twice as much as the regular payment. Is there a plastic surgeon you can suggest? Thank you.”

This post found a large audience among other trans members of the group, as one of the most popular topics in the group is how to find discrimination-free healthcare, particularly plastic surgery, services. Several trans women provided the contact information of their surgeons, some of them gave hospital suggestions, and the rest got involved in the conversation because they were having the same problem and needed good advice. One of the members recommended avoiding private clinics and instead choosing private hospitals. Arel responded that she already reached out to Memorial and Acibadem hospitals and was let down by each. This came as a surprise to many others who were following the conversation, including myself, because those are two of the most well-known and expensive private hospitals in Istanbul. Another member chimed in by sharing a recent experience where she went to a private hospital for a nose surgery and ended up disclosing her status to the surgeon. The surgeon told her that he cannot proceed with the procedure because of her HIV status and that she needs to go to a public hospital. The news of private hospitals turning their back on HIV+ and trans patients sent out a wave of panic since public hospitals and clinics have never been welcoming spaces for trans people, HIV+ or not. The decreasing opportunities to access needed medical services for HIV+ trans women, in return, contribute to the precarization of an already debilitated community by paving the way for financial exploitation and unaccountable medical malpractice.

“Tanrı Egosu,” or *God Complex*

In July 2018, I conducted the first interview for my incipient project which turned out to be an unpleasant and uncomfortable experience that would nevertheless shape my research in significant ways. It was the summer when I made a decision to interrogate HIV care despite, or maybe because, I was told by my very first interlocutor that “there was nothing to study about HIV in Turkey.” When I left her small office in a crowded infectious diseases ward at an underfunded university hospital, I was covered in a nervous sweat on a blazing July afternoon in the capital city of Turkey, Ankara. As I was trying to find a way to center my thoughts to take notes, I was replaying in my mind the part where she eulogized the Turkish state and the Ministry of Health for successfully responding to the HIV epidemic by providing ARV treatment. When I finally gave up on writing because of the excessive heat that keeps getting more and more unbearable, I took a cab and called a close friend, an HIV activist, to share with him the conversation I just had with one of the most well-known and well-regarded HIV specialists in Turkey. Because I did not record the interview, I was afraid I would forget the details if I did not share them with someone else. But, to this day, I still remember everything she said:

I neither understand nor accept any criticism of the Ministry of Health. It provides free medicine, what else is there to be done? NGOs and activists are creating problems where they do not exist just to make profit. I am so tired of HIV organizations. We fight all the time because all they talk about is discrimination at the hospitals. There is nothing else they can talk about. People get their medicine, without even paying, what else? They also say trans women experience discrimination in health facilities. If they come to the hospital with the same clothes they wear when they are prostituting, what do they expect? They say the nurses are treating them poorly, but what can I do? I am just a doctor, it's not my job to educate people. (Dr. Aygen, personal interview, 2018)

It all started when I asked her opinion about the Ministry of Health's management of the HIV epidemic. She answered, “it's a great institution. The Ministry does everything it can,” to which I responded with a follow-up question, “what about prevention?” To my surprise, she said the Ministry was best at prevention. Knowing well that the same Ministry does not distribute free

condoms or provide access to pre- and post-exposure prophylaxis, I pushed her a little bit and asked whether the Ministry educates the public or reaches out to key populations. Her answer to this question was equally surprising as she claimed “it is not the Ministry’s responsibility. The NGOs should take care of that.” After having lost my ability to stand her indifference and condescending attitude while she was praising a dysfunctional state institution considered to be the only authority with the capacity to control the soaring HIV transmissions in the country, I directed her a final question. “What do you think about the Ministry’s slogan on monogamy being the only solution to HIV?” Her answer did not falter in being controversial. “I embrace the slogan,” she said, and offered an explanation: “If you are monogamous, you cannot catch the virus. We know this is not always the case, but there is still only one way to prevent this disease: monogamy, and it is the scientific truth.”

This interview was with the assistant manager of HATAM, an HIV/AIDS research center of a public university hospital in Ankara and one of the leading medical institutions in the field of HIV, working closely with the Ministry of Health. The person who uttered these sentences is found quite helpful and caring by many people living with HIV and known for pushing the institutional limits to help people access testing and medicine. But, for her, HIV care ends there, for there isn’t anything else biomedicine could offer. She does not consider the need and possibility of another form of HIV care other than drugs even though biomedical treatments will fall short of their potential when the socioeconomic factors that determine access to prevention and treatment are not addressed. Although her authority is challenged and her scientific credentials questioned because she is not an infectious diseases physician but a practitioner doctor, Dr. Aygen is one of the most influential actors of HIV care and a long-standing member of the National AIDS Commission, founded in 1996 to set the national parameters of HIV treatment and prevention before it became inoperative in the late 2000s.

Dr. Aygen is still respected by many of her patients despite her questionable ideas and manners since she treats HIV+ people not as moribund infectious threats but as patients whose life quality can be significantly improved through medicine. This sets her apart from the majority

of doctors in the country who will deny talking to HIV+ patients let alone examine or treat them. At the same time, she shares a fundamental similarity with the rest of the doctors in that she does not see beyond the category of patient. In her perception, someone living with HIV is a patient not a person. This implies a hierarchy of power because the category of patient requires to be devoid of agency and fully docile. Dr. Aygen's boss, Dr. Serhat Ünal, once publicly chastised an HIV+ Turkish activist during an international conference. He told the young activist, "we don't like patients like you," by which he meant patients doing activism and occupying a position that could defy medical authority. Before there was an HIV movement, it was infectious diseases doctors who worked towards popularizing, although not so much normalizing, HIV. Ünal is one of those people and, yet, like many of them, he too is accused of not opening space for positive people in the civil society to maintain his own status. "Koltuk sevdası," literally the love of chair, was a common expression used by my respondents to describe doctors' rejection of leaving prestigious, public-facing positions. Historically, doctors have been the only ones who could speak authoritatively about HIV, and patients becoming activists risks taking that privilege away.

Another central figure of HIV care in Turkey is Dr. Deniz Gökengin and she has been involved in HIV treatment and prevention since 1985 when she graduated medical school. Gökengin started seeing HIV+ patients as early as 1996, when her dissertation advisor transferred his patients unto her. When I interviewed her in summer 2022, in the hospital she works at in Izmir, where she double booked me, she told me that nobody wanted to work with HIV in those years because there were not a lot of patients or financial incentives. Now, she thinks, all infectious diseases doctors want to see patients with HIV because there is unforeseen support from the pharmaceutical industry. She also indicated to me that she never enjoyed being like the others and that's why instead of choosing an easy field like antibiotic treatment, she became an HIV expert. Gökengin has also been a well-known figure in the civil society, and she is known as an advocate among the older generation of HIV activists. In contrast, younger activists are more critical of her because of her paternalistic and high-sighted mannerism. She is particularly disliked among queer activists since she has published a paper in 2021 blaming LGBTQI+ population in Turkey for spreading the epidemic, even though the article suggested

strengthening HIV prevention services for key populations. Even before the paper, she was not exactly considered a queer ally for she was observed to be dismissive, to say the least, in her interactions with gay and trans patients.

Sevgi, the volunteer of the Pozitif-iz Association, described Deniz Gökengin to me as “the most activist doctor” in the country. She remarked that self-organization of PLWH officially began in 2005 and this was partly indebted to Dr. Gökengin. That year during the National HIV/AIDS Conference, HIV+ attendants, including Sevgi, were carefully avoiding sitting or hanging out together since they were afraid of being outed to other participants of the conference, majority of whom were doctors. Deniz Gökengin gave a speech that year on medical violence that was highly poignant as she mentioned cases of AIDS patients who died because they were refused treatment at health facilities. According to Sevgi, at the end of her speech, positive participants were so moved that they felt empowered to come together and organize in the days following the conference.

Sevgi’s story about Dr. Gökengin being a catalyst for the emergence of the HIV movement is critical in that it underlines the indispensable role some doctors played in HIV awareness-raising and advocacy. From 1985 until 2005, HIV organizations were run by infectious diseases, virology, and microbiology experts, who did not have a political agenda other than informing the public on HIV/AIDS and mobilizing the government agencies to take an active role in preventing a future epidemic. The lack of political consciousness among doctors prevented them from opening up space in the public arena for those living with HIV to speak for themselves. Even today, self-organized HIV associations are heavily criticized by activists for continuing their presence under the auspices of doctors. What attracts the most vehement form of criticism is the fact that in almost all public events organized by Pozitif Yaşam and Pozitif-iz, invited speakers are doctors rather than someone living with HIV. Although Deniz Gökengin played a part in the founding of Pozitif Yaşam, she no longer maintains her relationship with the organization because she disapproves of its uncontrolled growth and changing mission in quest of funding. She, on the other hand, provides full support to Pozitif-iz and appears as the guest of

honor in online and offline gatherings planned by the organization. This intimacy between HIV associations and doctors can be a dangerous one for it helps doctors conserve their authority and influence, even when it is not the most desired or beneficial outcome.

An encounter that took place between Dr. Gökengin and a volunteer of Positive Solidarity Association in 2022 crystallizes the problem with unchecked medical authority. The aforesaid volunteer is a woman who was pregnant at the time. She has been seeing Gökengin for many years and had her first birth under Gökengin's care. The first baby was born HIV-negative and remained that way in the following years, for which she was ever grateful for Gökengin's help. However, when she got pregnant with her second child, her experience changed drastically. When she shared the news of her pregnancy with Gökengin during one of her regular visits, expecting nothing but good wishes, Gökengin got very upset and began yelling at her so loud that people outside her office could hear her angry accusations. Gökengin gave the patient two options: either she was going to find herself a new infection doctor or she was going to terminate the pregnancy. When I first heard this story, I automatically assumed that the pregnancy was risky either for the mother or for the baby, or both. To my surprise, I found out that Gökengin's reaction was not based on a medical diagnosis but on her patient's inability to follow her advice, even though it was not of medical sort. The only reason Gökengin threatened her patient with ceasing her treatment was because she did not listen to her and divorce her treacherous husband after they had their first child.

I learned this story from Ali, whom I introduced in the beginning of the chapter, one of the founders of Positive Solidarity. Once he was done reporting the details of the case, he began telling me about a similar encounter he had with Dr. Gökengin. Soon after he was diagnosed with HIV and before he became an activist, İla attended a meeting organized by Pozitif-iz where Gökengin was the guest speaker again. As she was giving a presentation on the importance of drug adherence and regular doctor visits, İla asked permission to speak and shared his situation. Because at the time he did not have health insurance, he was acquiring his medicine from Azerbaijan but had no chance at all to see an infection doctor in Turkey, let alone making regular

visits. When Gökengin heard this, she became visibly angry and raised her voice yelling, “are you out of your mind? How can you even do this? I refuse seeing patients like you. If you don’t care for yourself, I cannot care for you either.” This kind of psychological violence exercised by doctors is no less hazardous than the more accustomed forms of medical violence, for in each case what is put in jeopardy is the patient’s access to treatment.

When I asked an infection doctor, whom I met during an online workshop and became very fond because of her unusually political approach to medicine, about the medical hegemony doctors practice upon their patients, she answered, “ultimately they think they are better than their patients for being HIV-negative.” While many doctors might consider themselves superior to their patients based on their medical knowledge, in the case of an HIV+ patient there is an additional layer of moral judgment about the inferiority of the patient. An HIV+ patient’s medical record indicates their viral load and CD4 count, but more critically reveals the information that the patient must have behaved irresponsibly and brought this infection upon themselves. The intensity of the medical blaming and shaming is folded when the patient is not only HIV+ but also queer. In the case of queer patients, when they test positive they are not diagnosed solely with HIV—they are also diagnosed with potentially lethal promiscuity. It is a common experience for gay and trans people to be scolded by their infectious diseases doctors for failing to use condoms and putting others at risk. Although there is no scientific evidence that would point to a more frequent use of condom among heterosexual people, it is commonly queer people who are expected to shoulder the responsibility of condomless sex. When heterosexual people get HIV, it’s due to a one-time, unfortunate mistake, yet when it’s a queer person, the infection is an inevitable result of an insatiable, murderous, and self-annihilating death drive.

A lot of my interlocutors living with HIV used the expression “tanrı egosu,” *god’s ego*, to describe the contemptuous and deprecating attitudes of doctors towards patients. The first few times I heard this phrase I let it escape my attention as I was not quite sure what it meant. Later, it came to my notice that it was used interchangeably with “doktor egosu,” *doctor ego*, a much more common way to address the holier than thou personality of medical doctors. “We usually

observe this with surgeons and infection doctors. They think if it wasn't for them, their patients would have been long dead. Because they help people stay alive, they feel like a god in the possession of a supernatural power," Can explained to me when we ran into each other at the same infection clinic in Istanbul and decided to have some tea and simit sold by a local vendor at the hospital courtyard. Other than providing a working definition of *tanrı egosu*, Can also made me realize the parallels between this expression and the superiority complex, a nonclinical term for narcissistic personality disorder, commonly defined as the conviction that one is infallible and more important than everyone else around them.

What is ironic about *doktor egosu* is that while it is built on the foundations of scientific authority, scientifically established facts can be challenged by doctors, or objectivity may be sacrificed when faced with critique. Feminist Science and Technology Studies as a field demonstrated over and over again the ideological nature of objectivity and the volatile nature of scientific truth.²¹¹ Truth is by essence vulnerable to manipulation and the claim to objectivity is what makes it look like a discovery rather than a product. However, that claim may sometimes be renounced when a piece of scientific information is considered harmful for the public. Every year, during the National HIV/AIDS conference, there are doctors who deny the scientific evidence behind U=U (undetectable=untransmittable) and PrEP. As I share in more detail in the next chapter, some infection doctors refuse to accept that HIV transmission can be effectively stopped or find it dangerous to share that information with the public because it will lead people to have riskier sexual behaviors.

Objectivity, though, is not only surrendered in the fear of increasing HIV transmission and debauchery. It is also abandoned in the pursuit of warding off criticisms. In October 2022, infection doctors, public health employees, and civil servants were gathered in Istanbul to

²¹¹ See Karen-Sue Taussig, "Science, Truth, and the American Way," *American Anthropologist* 121, no. 1 (2019): 196–200; Banu Subramaniam, "Moored Metamorphoses: A Retrospective Essay on Feminist Science Studies," *Signs: Journal of Women in Culture and Society* 34, no. 4 (June 2009): 951–80; Karen Barad, *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning* (Duke University Press, 2007); Donna Jeanne Haraway, "A Game of Cat's Cradle: Science Studies, Feminist Theory, Cultural Studies," *Configurations* 2, no. 1 (1994): 59–71; Donna J. Haraway, *When Species Meet* (U of Minnesota Press, 2013).

discuss the potential of increasing the number of voluntary testing centers across the country. Speakers gave presentations on both the benefits of such testing centers and how they can minimize the experiences of discrimination in health facilities. Some of the presentations were focused on various case studies to familiarize the attendees with the kinds of medical violence experienced by PLWH. At the end of the event, a participant, also an infection doctor, shared his disappointment at the face of the critiques targeted at doctors by resorting to urban legends about an HIV+ person willfully infecting hospital personnel with HIV through a contaminated needle. According to the details provided by the organizer of the workshop, he expressed his sentiment of betrayal in the following way:

“I am shocked right now and I cannot believe what I heard. You made it sound like doctors are the bad ones here, as though they are the monsters. Do you know what we have done for HIV-positive patients? We washed surgical gloves and boiled needles to be able to reuse them. Everyone talked about *doktor şiddeti*, then why don’t you talk about people with AIDS who come to the hospitals with an infected needle to make others sick just because they got sick? What about *hasta terörü* (patient terror)?

It is interesting to me that this doctor refers to the legend of patients with infected needles as *hasta terörü* to make the point that doctors are the victims here whereas the patients are the actual perpetrators of violence. A similar expression, *travesti terörü* (transvestite terror), has been widely mobilized against trans people by conservative media which framed trans women’s self-defense in the face of life-threatening aggression as an act of irrational violence. Even when we assume that there has been a case where an HIV+ patient attempted to infect others with a contaminated needle, it is rather illogical, if not deleterious, to make a sweeping statement in order to make a generalized point about HIV+ patients. The outcry of this doctor is reminiscent of the arguments commonly mobilized in the defense of criminalizing the non-disclosure of HIV.²¹² Just like in the case of non-disclosure laws and rationales behind them, and similar to the unjust and unfounded depiction of Gaetan Dugas, the so-called patient-zero, as a death-spreading murderer in the second half of the 80s, this doctor contributes to the popular image of HIV+

²¹² Hoppe, “From Sickness to Badness.”

people as monstrous and always-already criminal—both for being positive and for infecting others. What also attracts attention in the quote above is the suggestion that the doctor boiled used gloves and needles because of HIV+ patients. This statement not only reeks of a dramatic exaggeration, but it is also historically inaccurate since single use medical gloves and needles have existed long before 1984 when HIV was first identified as the causal agent of AIDS.

To better understand the nature of *doktor egosu* and the dynamics of hierarchical power relations between doctors and patients, we should give an ear to the sociologist and anthropologist Cindy Patton, one of the greatest academic contributors to the study of HIV. Patton compares two ontologically distinct ways of knowing, understanding, and relating to HIV, with the intent of establishing a critical difference between the meaning of living with HIV (*witnessing illness*), on the one hand, and treating HIV (*witnessing disease*), on the other.²¹³ According to this distinction, the latter implies an objective, scientific, and detached view of HIV, making sense of the epidemic through abstract statistics. The former, in contrast, makes reference to the role of lived experience in the understanding of HIV and its treatment. In Patton's own words,

Witnessing illness requires the ongoing presence of the persons who are ill, as in the claims to dignity by the early persons with AIDS. Witnessing disease is the observation of the epidemic from the point of view of those who imagine themselves not subject to the disease, a disembodied meta-vision characteristic both of epidemiologists and research scientists who “see” the epidemic through statistical means, and also of the public officials who deploy that science as policy by speaking from the point of view of ‘the public’. (2011: 255)

Tanrı egosu does not only come with a feeling of being better than others but, maybe more importantly, knowing more than everyone else, at least more than patients. In the words of Haraway, some doctors play the “god’s trick” when they attempt to understand and judge

²¹³ Cindy Patton, “Rights Language and HIV Treatment: Universal Care or Population Control?,” *Rhetoric Society Quarterly* 41, no. 3 (May 2011): 250–66.

everything about patients' bodies and symptoms better than the patients themselves.²¹⁴ Should a patient reject their doctor's all-knowing faculty and demonstrate a desire to be taken as an equal in determining a suitable treatment plan for them, they are considered unmannerly, ungovernable, and unworthy of medical care. Because doctors speak from the position of unmistakable scientific authority, patients' thoughts and needs are not taken as worthy of consideration. The infantilization of patients by doctors plays a significant role too in how they are treated as subordinate and inferior. Consequently, "attempting to speak within science's genre of falsification, those who witness illness seem partial and subjective; what they say is not considered evidence and may not even be audible as testimony at all."²¹⁵ Although their lived experience is a valuable form of knowledge, patients' opinions are not only discarded as an unreliable source but also considered disrespectful for attempting to challenge the medical authority.

In other words, PLWH are confined in the category of "patient/hasta/sick" who can only become legible when they seek help and experience suffering. Outside of that category, patients not only violate socio-medical conventions but also ontologically threaten the status of doctors as superior and worthier. This is the reason why Dr. Serhat Ünal told an HIV activist that he doesn't approve of patients like him, and it's also the reason why that activist got a degree in health sciences, as he believed that was the only way to be heard by the doctors. French philosopher Rancière has famously written that politics is only possible when those previously excluded from participation break the chains that cast them into submissive and subaltern positions.²¹⁶ So, anti-politics of care is not only about a nongovernmental refusal to be involved in politics, as I raised in the previous chapter, but also about a medical rejection of the patients' agency and capacity. Many doctors are invested in maintaining the hierarchical order that structures doctor-patient relationships in Turkey. They place themselves on a higher level of the social hierarchy because

²¹⁴ Donna Haraway, "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective," *Feminist Studies* 14, no. 3 (1988): 575–99.

²¹⁵ Patton, "Rights Language and HIV Treatment," 263.

²¹⁶ Jacques Rancière, *Dissensus: On Politics and Aesthetics*, trans. Steven Corcoran, Reprint edition (London New York Oxford New Delhi Sydney: Bloomsbury Academic, 2015).

they presume to know more and be worthier for not being sick, especially not with sexually transmitted infections. Patients are often not considered as equals to medical doctors, and respecting their agency would disrupt the socio-medical order and the power arrangements that sustain it. In the words of Ranciere, *dissensus*, i.e. the disruption of the hierarchical status quo, is avoided by the doctors for the sake of medical hegemony believed to be necessary for the patients' own good since they are coded as incapable of knowing what is good for their health and wellbeing.²¹⁷ The refusal of doctors to see patients as equals, in return, gives way to another instance of anti-politics of care as evinced in doctors' inability to recognize their shared political vulnerability with other marginalized groups such as LGBTQI+ and HIV+ communities. Instead of acknowledging the parallels between the othering of marginalized communities and the precarization of healthcare personnel under the rule of AKP, doctors join forces with conservative politicians in pushing vulnerable groups to the margins of margins.

To conclude, it is appropriate to say that HIV patients are coded as simultaneously risky and vulnerable within the context of medical HIV care. Their assumed threat of infection and expected fragility are used by doctors as legitimate justifications to deny them treatment or to treat them as insignificant and subordinate. As I recounted throughout the chapter, experiences of medical violence and rejection abound when it comes to medical HIV care. One of the reasons why HIV is still mistakenly treated as a biomedical phenomenon in Turkey that can be solved with ARV medicine is that those living with the virus are not listened to carefully. Understanding and ending HIV can only be possible under the leadership of people with invaluable insights and observations stemming from lived experience. Treatment is important and necessary, but its intervention is microscopic and limited to the biomolecular level. What those living with HIV need are more systemic and macroscopic perspectives, policies, and services.

²¹⁷ Rancière, *Dissensus*.

CHAPTER 4

Pharmaceutical Frontiers of Care: Politics of Prophylaxis and Corporate Responsibility

As with other disease entities, pharmaceutical companies have operated astutely within legal and regulatory windows of opportunity in the case of AIDS, redirecting activist and political gains to their own advantage—be it as public relations gains through corporate philanthropy, as financial profits from global treatment projects, or as market expansion via developing states that have made AIDS ‘the country’s disease’ (as it is with Brazil, now a captive purchaser of ARVs).

—Biehl, *Will to Live*, 2007

Istanbul, November, 2021. On November 29, 2021, I witnessed one of the worst storms in Istanbul although I lived there for nearly a decade. The heavy rain and wind paralyzed life in the city for an entire afternoon and evening. Public transportation became inoperative, the traffic stopped, and motorcycles were almost thrown off the Bosphorus bridge if the bus drivers did not come to their help to block off the wind. I was at home at the time and was debating whether I am going to attend the event scheduled for that night. The said event was organized by Gilead Biosciences’, a California-based pharmaceutical biotechnology company known for its innovative HIV and hepatitis medicine, to celebrate ahead of time the World AIDS Day, which internationally takes place on December 1st.

I made a few quick calls to find out if the event was expectedly canceled and whether any of my friends were still planning to attend if it was not. Although to my surprise the event was going to take place as scheduled, none of my activist friends were going to make it since most of them were stuck at workplaces or apartments, unable to step outside. I still decided to go as Gilead’s World AIDS Day events are very popular both because there is free and unlimited alcohol and snack bars all night and because the company does not shy away from spending money on historical, famous, and expensive event venues. Activists always joke that if they were given the money the company spends on these organizations, they could have helped everyone living with HIV in the country. That year the event was taking place at a newly opened and

highly praised venue converted by a historical shipyard in the Golden Horn. It took me almost two hours to get there and I lost to wind both the umbrella I left my home with and the one I bought at a corner store outside of the train station. When I arrived at the location, my socks soaking wet, my hair messed up, I saw doctors and NGO staff leaving their ultra-luxury cars that were provided to each one of them by Gilead.

I was the only person that night attending the event as an independent HIV activist as I did not represent any of the three big HIV organizations—Positive Living Association, Pozitif-iz, and Red Ribbon. Yet I still knew a lot of faces from years of collaboration with NGOs. Soon after I entered the venue, some acquaintances waved at me, and I joined their table as they were in the middle of a heated discussion about the meaning of this year’s event theme. Last year the theme was “Birlikte HIV’den Güçlüyüz”, Together We Are Stronger Than HIV, also the name of Gilead’s corporate social responsibility platform. This year Gilead came up with an oblique slogan “Cesurum Hayata”, literally translated as *I am brave against life*. As we were discussing the possible meanings of this awkwardly phrased slogan, the public faces of this year’s campaign, well-known doctors, and NGO members, began to take pictures next to their real-life size posters. As I was studying the posters, the guy next to me on the table—Ali, whom I met that night but became good friends with eventually because of his charming cynicism and candor—whispered, half-joking half-serious, in my ear that the night is organized so that Gilead, doctors, and NGO staff could suck up to each other.

As part of its social responsibility, Gilead sought to encourage the Turkish public to get tested, just like the previous year and the year before that. Cesurum Hayata was intended to communicate the message that one should not be afraid of taking an HIV test and the invited attendees of the event were asked to share their stories of bravery. The NGO staff and doctors talked about how they overcame obstacles in their lives and encouraged everyone to be brave about testing for HIV. As I watched them relate their individual hardships to a positive HIV diagnosis, I wondered why Gilead Turkey did not invite one of the activists who have publicly come out about their HIV status and could actually talk about what a positive HIV test meant and

why people should or should not be afraid of it. Founded in 1988 as the first ever global health day, World AIDS Day is dedicated to commemorating those who have passed away from AIDS, empowering those who live with HIV, and raising awareness to prevent new HIV transmissions. However, Gilead celebrates this day as the perfect opportunity to increase nationwide HIV testing. While there is no attempt to remember the lost lives or to support lives that are affected by HIV, the heavy emphasis on testing is aimed at educating the public.

On the night of November 29, it was not only the exclusion of people openly living with HIV from the event that garnered negative attention but also the way they were referred to. During a panel on the importance of testing to prevent HIV, the speakers—two doctors, two NGO members, all men—were asked by the moderator, a famous TV host, “how to protect HIV+ people?” as though they were endangered species. The paternalistic and patronizing tone of this question is integral to the pharmaceutical discourses of HIV that register PLWH as an inherently vulnerable population in need of special help instead of acknowledging them as capable individuals who don’t need saving but to be empowered so that they are able to protect themselves. That night the same tone also dominated the welcome speech of Gilead Turkey’s general director, Şebnem Girgin, who referred to PLWH as “those infected with the HIV virus (sic)” and *Hivliler*, although activists and NGOs have been warning against using these expressions. “Hivli” or “Aidsli” are the most common ways of referring to PLWH in Turkey and they are accepted for being widely conducive to status-based stigma and discrimination. The suffix *-li* makes a noun into an adjective and it can imply belonging to a place. For instance, *İzmirli* means from the city of Izmir whereas *renkli* would mean colorful, derived from the word *renk*, color. When it is used together with HIV, the suffix *-li* functions to reduce the identity of people living with HIV into their HIV status. HIV becomes the essence of those living with it, not just something they have. In Turkish, calling someone *Hivli* has a similar tone and performative effect of calling someone leprous, *cüzzamli*, as both are meant to suggest caution against the embodied subjects of atemporal infection and contagion.

After addressing “Hivliler” and reminding how much Gilead does for their sake, Girgin went on to explain why they founded the initiative *Together We Are Stronger Than HIV* in 2018. For the purposes of this chapter, it is worth quoting her own words to understand how Gilead positions itself in the scene of HIV care:

In 2017, we took part in a public opinion study together with Hacettepe University and Başkent University. It was one of the largest-scale studies conducted in our country and we realized that three out of every four people did not have any knowledge about HIV. In fact, 80 percent of the respondents did not know that *Hivli* (sic) people could continue their lives normally when they are on treatment. We thought that this would give us the responsibility to run a long-term awareness campaign. And within this framework, we established the 'Together We Are Stronger Than HIV' platform three years ago. It is not possible for the private sector to move forward alone. However, we thought that we can make a difference if we work together with our physicians, physician associations, valuable representatives of civil society, activists, the media, the public, and the state.

Following the panels and the welcome speech, the night was concluded with a surprise appearance of Tankurt Manas, a newly famous rap singer. He collaborated with Gilead for the 2020 World AIDS Day campaign and was commissioned to write a song for Together platform.

I know you have worries, we can get out of this darkness
Fears gnawing at your head (HIV) also have a cure
It's in your hands, in your hands (Test, diagnosis, treatment)
In your hands

Together we are stronger than HIV
Say "it can't beat me"
Together we are stronger than HIV
Take your test now

Ya, it doesn't matter if you're positive, it's up to you (get your test)

Don't be afraid, don't think there is no cure
Time is running short, believe me, we'll win, we'll eradicate HIV altogether
Have your heart in life, come with me

Correct your mistakes today, look tomorrow will be late
Take a part in life, go get your test
The diagnosis doesn't matter, say "I'm in for the treatment"
This is the best part, hug your loved one and
Tell them, tell them, tell them
Tell them, tell them, tell them

Together we are stronger than HIV
Say "it can't beat me"
Together we are stronger than HIV
Take your test now

The lines above belong to *Test*, perhaps the most unanticipated song in Turkish rap history that rapidly became a joke among my friends who would sing the chorus in gay bars and imitate the choreography from the video clip. With the support of *Birlikte HIV'den Güçlüyüz* platform, this production "aimed to increase public awareness about regular HIV testing on World AIDS Day 2020," according to Toros Şahin, the company's market access and corporate affairs manager. Given that regular sexual health screenings are not carried out in Turkey because of the Ministry of Health's incompetence and widespread stigma, raising social awareness about getting an HIV test and trying to break the fear around HIV diagnosis are very admirable goals. However, when we look more closely, we see that with this and similar test-centered messages, HIV is framed as a pharmaceutical problem, reduced into a matter of testing and treatment.

Instead of treating 'Test' as a trivial rap song that does not deserve any attention, I take it as a rare cultural product of the "pharmaceutical nexus" that requires close reading. And there

are three points I want to raise. The first is the suggestion that the solution to HIV is hidden in testing. HIV testing is not a solution to anything on its own. As important as getting a diagnosis is the environment where the diagnosis is obtained. Positive diagnoses without adequate counseling and access to inclusive health care can prevent people from accessing treatment. In *Risky Rhetoric: AIDS and the Cultural Practices of HIV Testing*, Scott identifies the problem with the treatment of HIV testing as a magic bullet solution in controlling epidemics.²¹⁸ For him, HIV testing was originally a disciplinary diagnostic whose purpose was to protect the healthy public by detecting, containing, and managing risky individuals. The power of testing is exaggerated and privileged over other interventions, at the expense of testees who, upon receiving a positive diagnosis, are abandoned by families, friends, partners, and institutions. In a more recent essay, Cindy Patton shares the undesirable outcomes of public health strategies that adopt an aggressive approach toward testing as many people as possible such as “Seek and Treat” and “Test and Linkage to Care” initiatives.²¹⁹ The elimination of pre-test counseling, the elimination of confidentiality laws, pressure to override patients’ wishes regarding when to go on treatment, and the criminalization of HIV-positive persons who refuse or put off taking medications are some of the problems Patton observes in regard to mass HIV testing.

Second, I would like to question the assumption that it is the individual’s responsibility to get tested for HIV. While there are countless economic and socio-political obstacles in accessing health services, while free anonymous test centers are only available in seven (7) cities across the country, and while a positive HIV status means psychological, emotional, and physical violence, to say that it is the individual's responsibility to get tested is a reverberation of the neoliberalization and concomitant depoliticization of health. The neoliberalization of health(care) is harmful to millions not only because of the increased privatization of and reduced spending in public services.²²⁰ It is also because it diverts our attention away from the underlying causes of the problems that need to be tackled upstream, and toward magic-bullet solutions creating the

²¹⁸ Scott, *Risky Rhetoric*.

²¹⁹ Patton, “Rights Language and HIV Treatment.”

²²⁰ Vicente Navarro, *Neoliberalism, Globalization, and Inequalities: Consequences for Health and Quality of Life* (Baywood Pub., 2007).

illusion of healthcare at the expense of culturally and contextually sensitive public health interventions.

Third, I would like to take a moment to reflect on the meaning of *being stronger than HIV*. What does it mean for a pharmaceutical company to claim to stand together with others and stronger than a virus? Although not put in these exact words, a similar version of this question is voiced by many HIV activists I have met to this day. Activists are critical of the artificial necessity to be stronger than HIV as they refuse to treat the virus as an opponent or an enemy to be conquered. We need to stand against status-based discrimination and violence, not the virus, as activists remind us repeatedly. We must also not take the claim of *togetherness* at its face value as standing in solidarity with others and supporting them takes much more than paying lip service and hush money to activists and HIV organizations. It, above all, requires the recognition of key populations and their specific needs in regard to HIV prevention and treatment. It also requires improving the holistic wellbeing of people living with HIV, to whom Gilead owes its multi-billion-dollar fortune, through multilayered and multi-sector interventions that are not solely biomedical or pharmaceutical.

The question that I will attempt to answer in the rest of this chapter is whether it is possible for a multinational pharmaceutical company to stand together with local actors and institutions while globally being responsible for millions of people not having access to HIV care. In other words, is profit-oriented neoliberal capitalism compatible with care? Or, whether ‘caring corporation’ is an oxymoron? To answer these and other questions, I closely analyze two attempts of Gilead in becoming an actor of public health and providing HIV care. First, I look at the case of *Ideas that Have Come to Life*, a local fellowship program Gilead Turkey implemented in 2013 to support HIV organizations and infection doctors. The fellowship is a quintessential product of Corporate Social Responsibility and mirrors its tendencies to give precedence to public health interventions that promise profit rather than social and health benefits. Through the case of the fellowship program, I show how CSR is ultimately a tool of manufacturing readiness to consume. In the first section, I also discuss the implications of CSR

in mobilizing HIV testing as an aggressive public health technology and as a magic-bullet solution to the epidemic.

In the second section, I follow PrEP as a transnational technology that exceeds national and cultural boundaries. I use PrEP as a key to understand pharmaceutical HIV care which discards PrEP as a potentially empowering STI prevention for queer and trans communities because it is not financially profitable. I also rely on PrEP to expose the parallels between Gilead's global strategies and its local operations in Turkey in that in each instance rather than a genuine care, we are faced with a series of facile attempts at "ending HIV" and "supporting PLWH". Ultimately, PrEP helps me establish that a certain amount of harm is inherent to pharmaceutical care, almost to make justice to the original meaning of *pharmakon* as both poison and cure. Finally, I show that not only pharmaceutical but also governmental, nongovernmental, and medical ethics of public health foreclose the possibilities of framing PrEP as a prevention mechanism, a sexual health right, or simply a technology of enhanced sexual pleasure. I end the chapter by reflecting on the meanings of pharmaceutical frontiers and *potentiality*²²¹ in relation to the extraction of biovalue out of HIV+ bodies ethically.

Corporate Social Responsibility as Carewashing

The limited responsibility of corporatized philanthropy sits comfortably with an idea of Responsibility Ltd. It is a form of responsibility that is completely appropriable and appropriated by the interests and instruments of global capital.
—Kaushik Sunder Rajan, *Pharmocracy*, 2017

When I first started fieldwork in the summer of 2018, I was not imagining Gilead becoming a central figure of my investigation. It was not until I began seeing Gilead everywhere I turn that I noticed its magnitude for the questions I was raising and answers I was seeking: Gilead was on every NGO's webpage as a donor; it had several social media accounts and websites directed towards humanizing HIV by giving it a face; the big events gathering various stakeholders were

²²¹ Karen-Sue Taussig, Klaus Hoeyer, and Stefan Helmreich, "The Anthropology of Potentiality in Biomedicine: An Introduction to Supplement 7," *Current Anthropology* 54, no. S7 (October 2013): S3–14.

always organized by Gilead; it was virtually impossible to see an Instagram post about HIV without Gilead being tagged on it; NGO workers were proudly showcasing on social media the awards they received from Gilead; and, it funded the first series of public service ads entitled “my biggest disease,” seeking to portray HIV+ individuals as healthy and happy people. It was both revealing and humorous when during an interview I spotted a Gilead beverage coaster in one of the most influential HIV experts’ clinic in Istanbul, which became an unlikely key to my access to Gilead. It was after I pointed to the coaster and asked Fehmi Bey about Gilead’s operations in Turkey, he told me that he could help me interview Gilead’s medical team.

Gilead Sciences, Inc., is a research-based biopharmaceutical company founded in 1987 in Foster City, CA, operating in over 38 countries with more than 14,000 employees across six continents today. The company is invested in the discovery, development, and commercialization of innovative drugs for life-threatening conditions, and it is the leading company in the production and sales of antiretroviral (ARV) medicine globally. Acquiring its name from “balm of Gilead”, a potent medicine mentioned in the Bible, Gilead secures its position in the Fortune 500 list thanks to its state-of-art HIV and Hepatitis drugs. Gilead Turkey opened its Istanbul branch in 2007 and has been shaping the contours of HIV care in the country since then. It is expected to hold more than 80% of the antiretroviral market share in Turkey and since 2013 it has been widely supporting medical researchers and local NGOs working in the field of HIV. Through a fellowship program called *Hayat Bulan Fikirler*, “ideas that come to life,” Gilead has become the chief entity in Turkey funding medical studies and local HIV organizations. Besides HIV, the fellowship supports medical studies on hepatitis B and C as well as oncological investigations.

Each year, the fellowship program allocates between \$27k and \$38k and roughly 60% of it is used to fund medical studies while the rest is distributed among social intervention projects. To date, *Hayat Bulan Fikirler* has funded 45 scientific and 19 social projects and the sum of funds awarded amounts to almost \$860k, which is an insignificant portion of its global annual revenue of \$26b, with a net income of \$6b. By means of what the company designates as

“corporate giving” in its webpage, it aims “to improve healthcare access, eliminate the barriers to healthcare encountered by underserved populations and advance education among healthcare professionals, patients and community members”. Financial aid provided by Gilead is highly valued especially among health providers, primarily infectious diseases doctors, who praise the company to the skies for funding HIV research, which doesn’t get any support from the Turkish state. Local HIV and sexual health organizations, however, are more critical of Gilead’s involvement in HIV care and its underlying interests in establishing monetary relationships with NGOs and doctors, while, at the same time, recognizing the indispensability of the financial aid provided by the company.

The critiques voiced by the nongovernmental sector shed doubt on Gilead’s genuine interest in “eliminating the barriers to healthcare encountered by underserved populations”. The most common critique of *Ideas That Come to Life* is that not all ideas, not even the ones deemed urgently necessary for HIV care in the country, are approved to come to life. The social projects more likely to be supported through the fellowship program are the ones promoting HIV testing and drug adherence. Psycho-social support, comprehensive and inclusive sexual health education, as well as capacity building needed for people living with or under the risk of HIV, particularly for LGBTQI+ communities, are unlikely to be funded by Gilead. Sevgi, from Pozitif-iz, who has written several projects that were supported by Gilead, including one on peer-support and advocacy, expressed that she was very surprised when the peer-support project was selected to receive support.

We thought they didn’t accept social projects that are not exclusively focused on facilitating access to testing. One of the members on the selection committee is Dr. Aygen and she doesn’t believe in peer-support or anything like that. When we applied with a project to educate LGBTI+ organizations on HIV so that they could educate their own members, which is extremely necessary if we are to protect LGBT people from the risk of HIV, we were denied funding. The only reason we got funding this time is probably because we included steps to increase testing through peer-support. (Sevgi, personal interview, 2018)

In 2019, the return of biomedical reductionism promoted by major actors of global health such as WHO and Gates Foundation and the revitalization of pharmaceutically-driven magic-bullet solutions encouraged an esteemed group of global health scholars to question the limited conception of ‘social’ in global health.²²² Aside from explaining what ‘social’ stands for in corporate social responsibility projects and what is excluded from the conceptualization of social support, Sevgi’s words are instrumental in understanding the accelerating level of donor dependency when HIV care is restructured in accordance with the expectations of private donors. The degree of dependency is more serious when it comes to local NGOs that, unlike medical researchers, depend on external financial support. Not only do NGOs that cooperate with Gilead become dependent on financial aid, but also do they lose their organizational independence as they begin developing projects that will secure funding instead of projects that are needed. It is now widely documented that for-profit charity is likely to give precedence to interventions that promise profit rather than those that may bring social and health benefits without fiscal returns.²²³

In 2018, when I interviewed the then director of Red Umbrella, a sexual health organization working with sex workers, I learned from Sinan that the degree of dependency was positively correlated with the amount of money received from a donor:

The first time we received funding from Hayat Bulan Fikirler was in 2016 for a project to improve the sexual health of trans sex workers. In those early days, it was easier. Yet, over time, we were told that we shouldn’t be too specific about target populations, so we started applying with projects focusing on sex workers in general and their access to HIV testing. Of course, we value the ability to implement sexual health projects but the amount of money we get from Gilead is extremely limited, maybe enough to cover our rent for one year. We always need to look for additional funding. But, this has its own advantages. When the donation amount is so small, Gilead does not expect much from us as long as we carry out projects that help people. In return, we just use its corporate logo

²²² Vincanne Adams et al., “Re-Imagining Global Health through Social Medicine,” *Global Public Health* 14, no. 10 (October 3, 2019): 1383–1400; also see Peter Aggleton and Richard Parker, “Moving Beyond Biomedicalization in the HIV Response: Implications for Community Involvement and Community Leadership Among Men Who Have Sex with Men and Transgender People,” *American Journal of Public Health* 105, no. 8 (August 2015): 1552–58.

²²³ Ann H. Kelly and Linsey McGoey, “Facts, Power and Global Evidence: A New Empire of Truth,” *Economy and Society* 47, no. 1 (January 2, 2018): 1–26.

on our digital and print material to please the company. This situation drastically changes when we are talking about larger funds coming directly from Gilead's headquarters. We wanted to cooperate with the company to implement a large-scale project and the company's social outreach team was willing to find us a substantial grant. During our initial meetings, however, we noticed that when that much money was involved, we were no longer free to carry out the projects we envisioned. We found ourselves in a position where we had to implement projects that did not have much to do with sex workers and projects that would not be beneficial for our target population. We didn't want to be their puppets, so we only applied for small grants after that. (Sinan, personal interview, 2018)

The risks of financial and organizational dependency is not the only critique offered by the HIV organizations when it comes to Gilead's investments in social responsibility. The company is also judged based on its instrumental motives in providing funding to doctors and NGOs. In my conversations with Nadir and Koray, from Pozitif-iz and Pozitif Yaşam respectively, I was always surprised by how vocal and critical they were while mentioning Gilead's fellowship program. I was, though, not taken by surprise to see that they did not see corporate motives and ethical action as irreconcilable. As Susan Craddock wrote in *Compound Solutions*, "financial motivation is not necessarily incommensurate with doing good... Pharmaceutical companies are, after all, not charitable organizations."²²⁴ And, as Nadir explained to me,

Gilead is not doing this for the sake of good (*hayırna yapmak*). When we look at what kind of projects it funds, we can see that the hidden—or not so hidden—motive is to increase HIV testing. The more people are diagnosed, the more medicine Gilead sells—and, don't forget this is a life-long treatment. But, if you ask me, this is not all too bad. We do need more testing services to be able to stop giving late diagnosis, so it's fine if Gilead makes money while contributing to the control of HIV transmission. (Nadir, personal interview, 2019)

As someone who has spent almost half of his life volunteering for HIV organizations and living with HIV, Nadir knew very well that with pharmaceutical companies "profit ultimately boils down to prescription maximization."²²⁵ Although considerably younger, Koray is

²²⁴ Susan Craddock, *Compound Solutions: Pharmaceutical Alternatives for Global Health* (U of Minnesota Press, 2017), 23.

²²⁵ Joseph Dumit, *Drugs for Life: How Pharmaceutical Companies Define Our Health* (Durham: Duke University Press, 2012), 56.

experienced enough in the nongovernmental sector to recognize the instrumentality of corporate responsibility, while also emphasizing its indispensability:

Through the fellowship program, the first thing Gilead aims to achieve is to increase testing. But a positive diagnosis is not enough, it must also foresee that when someone tests positive, they will be given medicine sold by Gilead. And this requires, more than anything else, two things: first, establishing good relationships with doctors. Now, how can a company reach out to doctors if not through advertisement? Of course, by giving money to support their research. Second, pharma companies know how influential HIV organizations are in patients' decisions to choose one ARV treatment over another, even when they are pretty much the same. So, they use us in lieu of advertisement, but so be it. We don't have support from anywhere else, certainly not from the state, so we need this funding to survive. (Koray, personal interaction, 2019)

In the context of Turkey, where direct-to-consumer advertising of prescription drugs is prohibited, corporate responsibility comes to the rescue of Gilead in gaining the trust of health professionals, consumers, and civil society organizations. Pharmaceutical companies are not allowed to advertise prescription drugs in Turkey. Not only is it legally forbidden to show pharmaceutical commercials on TV but also is the distribution of any print material for the use of health providers and advocates strictly banned. According to Koray, this leaves but one way to approach health professionals and NGOs within legal limits. Kalman Applbaum, an anthropologist working largely on the question of pharmaceutical marketing, too underlines that what is to be extracted from developing countries today is not raw materials or labor, but *the readiness to consume*.²²⁶ He points out two ways in which the readiness to consume is harvested: either pharmaceutical companies intervene in the exchange environments, e.g. reimbursement policies and treatment guidelines, *and/or they invest in doctor and consumer awareness campaigns, referred to as 'education', to stimulate demand directly*. In this framework then, CSR is nothing but a tool of manufacturing the readiness to consume while creating new markets or monopolizing the existing ones.

²²⁶ Kalman Applbaum, "Pharmaceutical Marketing, Capitalism, and Medicine: A Primer (Part I/III) | Somatosphere," *Somatosphere* (blog), 2009, <http://somatosphere.net/2009/02/pharmaceutical-marketing-capitalism-and.html>.

Covering the systemic problems created by neoliberal capitalism with ostensible but hollow gestures, CSR is the quintessential example of *carewashing*, defined as commercial branding strategies which commodify care and attempt to increase corporate profit.²²⁷ In fact, not all HIV organizations agree that there is an ethical dimension to the patterns of corporate donations, nor that it is ethically acceptable to take money from pharmaceutical companies. Vahe, the director of Red Ribbon Istanbul, known for his confrontational and stubborn demeanor, not only refuses to accept money from Gilead, but also has made a promise to never attend a single Gilead event. He even shared that he had sent an email to Gilead's corporate headquarters asking for the cancellation of the fellowship program. Vahe's objection to the fellowship program derives from what the money is spent on, and which applications are favored:

The way they spend money is ineffective and ridiculous. Gilead throws money away on PR projects. They organize events at fancy and expensive venues to create a good image of the company, but how is this helpful for anyone? This is not even the only reason why this entire thing is unethical. They will say that the applications are selected anonymously but that's far from being true. This is such a small field that everyone knows what everyone else works on. So, when the jury receives applications, they easily discern which belongs to whom. The year my application was declined, I know that one other doctor's application was also declined. But then she called Gilead and threatened them with not prescribing their medicine. Then, they said 'oh, sorry, there must have been a mistake,' and funded her project. (Vahe, personal interview, 2018)

In *Markets of Sorrow*, Vincanne Adams writes about the aftermath of Hurricane Katrina in New Orleans and exposes the workings of disaster capitalism and its scavenging for profit amidst suffering and destitution.²²⁸ What is crucial in her account of the privatization of disaster relief is the "subtle replacement of an ethics of public care with an ethics of private profit" (2013: 8). We can observe such market-driven, neoliberal ethics of care and an equally subtle, yet much more pervasive, substitution of (health)care with corporate interests in the case of Corporate Social Responsibility. In the words of Adams, the operational logic of CSR is based on a simple

²²⁷ Andreas Chatzidakis et al., "From Carewashing to Radical Care: The Discursive Explosions of Care during Covid-19," *Feminist Media Studies* 20, no. 6 (August 17, 2020): 889–95.

²²⁸ Adams, *Markets of Sorrow, Labors of Faith*.

calculation of “how much profit can be made by doing good.”²²⁹ Elsewhere I raised the question of whether CSR “is not a brake in free-wheeling capitalism, but rather a strategy of extending and accelerating it by new means” as provocatively suggested by Ecks (2008, 178) or whether “the seemingly contradictory goals of ethical action and profit incentive are not mutually exclusive” as incisively pointed out by Craddock (2017: 57) as well as my interlocutors.²³⁰ Few years later, I came to acknowledge that these positions are not contradicting but supporting each other: CSR is indeed a strategy of capital accumulation, yet this does not mean that ethical action cannot be part of profit maximization especially when the value to be extracted is of “ethical” nature (a theme I will come back to at the end of this chapter). Nonetheless, as I will show in the following section, CSR is but one of pharmaceutical care’s many faces and not all strategies of corporate care bring along social or health benefits, at least not for everyone.

“There is Always a Goodness”

Hep bir iyilik var, or “there is always a goodness”, is how Pharmactive İlaç, a local pharmaceutical company, played with the acronym of HIV during the launch of PrEP. On the night of the launch party in Istanbul, I danced uninterrupted for nearly three hours with my beloved friend Leyla, whom I originally got to know through a collaboration when she was working for an HIV organization. One could have thought our happiness had something to do with the announcement that after nine years after its introduction, PrEP was finally going to be available in Turkey. As much as we welcomed the fact that a local pharmaceutical company was able to obtain the drug license for PrEP, with the generic name Truvent, we were not naive enough to take this as a success for HIV activism given that PrEP was to be entirely paid through out-of-pocket costs. Leyla and I were having a blast that night for two simple reasons. The performer who was invited to entertain the guests was an extremely talented non-binary artist, who has recently gained a large audience among LGBTQI+ communities. As they sang the

²²⁹ Adams, *Markets of Sorrow, Labors of Faith*, 169.

²³⁰ Stefan Ecks, “Global Pharmaceutical Markets and Corporate Citizenship: The Case of Novartis’ Anti-Cancer Drug Glivec,” *BioSocieties* 3, no. 2 (June 2008): 178; Craddock, *Compound Solutions*, 57.

colorful covers of 60s, 70s, and 80s Turkish pop songs—which, in my humble gay opinion, are the best eras of Turkish pop music—not dancing was not an option. This was also facilitated by the fact that we were being served alcohol at the concert venue even though the posters clearly indicated that this was going to be a non-alcoholic event.

PrEP, pre-exposure prophylaxis, refers to the preventive use of ARV medicine to minimize the chance of HIV infection by 99%.²³¹ Truvada is the first ARV drug approved for prophylactic use and it was approved by the FDA back in 2012. It consists of not one but two medications: tenofovir and emtricitabine disoproxil fumarate. What these complex molecules do is to prevent HIV from copying itself ad infinitum. HIV is a single-stranded RNA virus, which makes it by nature a volatile organism. Viruses need DNAs to replicate but this does not stop HIV from making its copies—it might have a volatile structure but makes up for it by being infectiously cunning. HIV has an enzyme called *reverse-transcriptase enzyme* allowing the virus to convert its single-stranded RNA into a double-stranded DNA, all that is necessary to insert itself into the host cell's DNA with the help of other enzymes. Tenofovir and emtricitabine are classified as nucleoside reverse transcriptase inhibitors (NRTIs) because they bind themselves to reverse-transcriptase enzyme and block HIV's ability to copy itself.

There wasn't supposed to be any alcohol consumption on the night of PrEP's launch since Pharmactive is owned by the Sancak family, a conservative family known for their support of the governing party. This is also said to be the reason why Pharmactive was able to obtain the license for PrEP from the Ministry of Health. Two other local pharmaceutical companies, İlko İlaç and Santapharma İlaç, had previously made attempts to acquire the license yet have been unsuccessful. Gilead, on the other hand, never applied to get the required license for PrEP in Turkey although it is the original patent holder. This might seem perplexing to a foreign eye that a conservative alliance between the government and the industry can open the way of making a

²³¹ Jared M. Baeten et al., "Antiretroviral Prophylaxis for HIV Prevention in Heterosexual Men and Women," *New England Journal of Medicine* 367, no. 5 (August 2, 2012): 399–410; Robert M. Grant et al., "Preexposure Chemoprophylaxis for HIV Prevention in Men Who Have Sex with Men," *New England Journal of Medicine* 363, no. 27 (December 30, 2010): 2587–99.

sexual prevention medicine available— although available does not mean accessible—in a politico-religious conjuncture where even access to condoms is thwarted. This is, nevertheless, how neoliberal conservatism functions in Turkey: when there are financial and/or social interests at stake, the religious boundaries can be stretched to an extent that it does not become evidently blasphemous. In this case, the boundaries were only extended to tolerate 4 tablets of PrEP in each bottle instead of the regular 30 pill option. People at the event commented that this was probably the only way Pharmactive convinced the Ministry of Health: an entire bottle would be an incentive to have sex whereas 4 tablets would deter its continuous use.

Although a year after its launch PrEP was still not available in pharmacies, Pharmactive announced its new product in December 2021 under the slogan of “4/4’luk Hareket”. “Dört dörtlük, 4/4” is an expression used in Turkish to say excellent or flawless. Pharmactive’s campaign is based on the suggestion that having four pills in each bottle is an ideal decision, literally a perfect move. This is, however, an enormous misbelief with significant risks for public health. PrEP’s on-demand use recommends taking two pills 2-24 hours before the sex, one pill 24 hours after the first dose, and a last pill 24 hours after the second dose. Also known as “intermittent, non-daily, event-driven, or off-label” PrEP, on-demand use is proven effective and recommended as a viable alternative to traditional daily use. Yet, the event-based use is only tested among gay men and is not recommended for heterosexual women and men, people who inject drugs, and transgender people. Even though the decision to sell four tablets at once can be considered as a necessary concession, it is anything but a perfect step for the interests of public health.

The question begging for an answer here is not why there is a long delay in releasing PrEP—it is rumored that the company had an internal disagreement about Truvent’s use for preventive purposes—but why it took almost a decade for HIV pre-exposure prophylaxis to be approved as a prevention method in Turkey. The answer to this question is not simply hidden in the pharmaceutical industry and its corporate strategies, as it also concerns an assemblage of

governmental, non-governmental, and medical politics of PrEP and sexual health more broadly. It is, though, still appropriate to start recounting the story of a pill with its manufacturer.

Berna and Özlem, two young, smart, friendly women, were my first contacts at Gilead. Both of them were opposite of what I expected from someone who works at a multinational pharmaceutical giant. The day we met at Gilead's ultra-luxury office in Levent, Istanbul, as though they sensed my prejudices, they repeatedly emphasized that they are doctors and they do not work for the marketing team, neither are they concerned with profits or how many drugs they sell. Rather, they are truly dedicated to providing more resources, especially for patients and (N)GOs, so much so that they try to increase the available funds through their personal efforts. Years after our initial encounter, I am still in touch with both of them even though they no longer work in the same position. When we met, Berna was just beginning a PhD in neuroscience and I was enrolled in my PhD program for about eight months. While working a full-time job, she completed her PhD before I did. Özlem became one of my favorite doctors and renewed my trust in the profession. She and I have been friends on social media since and diligently reply to each other's social media activity.

During my interview with Berna and Özlem in August 2018, I waited until the end of our conversation to ask about PrEP as I wanted to establish some sort of a mutual trust before we discussed what to me was the elephant in the room. First, we talked for a long time about Turkey's failure in preventing and responding to the HIV epidemic. Later, when I finally asked them why Gilead, the company that treats PrEP as one of its most valuable investments in the global arena, did not take any steps so far to make the drug available in Turkey, they expressed with one voice that they are hesitant about a potential societal and political backlash. Özlem said, "people don't talk about sex here. Sex is a taboo, something you should be ashamed of even within the context of a nuclear family. So, how are we supposed to tell people that they can take a pill and be protected from a sexually transmitted virus?" Berna, on the other hand, was more strategic in her thinking and responded as follows:

If we try to introduce PrEP, they will be like ‘oh, people are having sex and you are facilitating.’ We cannot take the first step, the state must take it. We can only intervene if the state and society demands it. Talking about prevention is difficult here, you cannot even talk about sex. The government is horribly conservative and the people at the Ministry cannot take that risk even if they wanted to. We are ready to launch PrEP, but the Ministry and the NGOs should create the right conditions first. (Berna, personal interview, 2018)

Although the fear of conservative reaction might sound like a lazy excuse for a global firm, I believe that Özlem and Berna were completely sincere in their response. Nonetheless, three years later, when I interviewed two other doctors who took over Berna and Özlem’s positions, I found out that there was more to the story of Gilead’s strategic plan for PrEP. One of the interviewees, Ahmet, came to the meeting after reading my essay on Gilead published in a local queer magazine.. As a result, he was in a defensive state from the beginning of the interview and wanted to make sure that I had a better impression of Gilead as being logical and strategic with its decisions rather than profit-oriented. When I repeated the same question I asked three years ago about PrEP, Ahmet gave an answer which I was not expecting at all. He said,

When we look at the HIV landscape and its basic needs in Turkey, for example, for the next 5 years, we find it appropriate to use our resources in increasing HIV testing. We see that the epidemic is rising parabolically in Turkey, and PrEP is not the only solution—it is just one of the solutions, but when we look at the public health necessities, our most basic priority is to ensure that individuals who have not been diagnosed receive diagnosis.” (Ahmet, personal interview, 2022)

In simpler words, what Ahmet told me is that launching PrEP is not a necessary or even logical public health action in Turkey. It is true that in the age of TasP, or *treatment-as-prevention*, the possibilities of HIV transmission is reduced when someone knows their status and is on treatment. It is also true that the area in which Turkish public health fails most alarmingly is testing and diagnosis. Hence, Gilead’s decision to invest in increasing testing opportunities is not a wrong decision from the perspective of public health. However, Ahmet’s reasoning, embedded in the neoliberal logic of fabricated scarcity, suggests that there are not enough resources to invest both in testing and PrEP. Instead, the former is prioritized although it has been well

established for nearly three decades that we cannot ‘eradicate’ HIV while pitting prevention against testing and treatment.²³²

Besides Ahmet’s, and by extension Gilead’s, understanding of public health is limited and does not include all communities threatened by HIV equally. Today, PrEP could be most helpful for trans sex workers, who often find themselves doing extremely unsafe, street-based sex work because they are denied ‘respectable’ employment anywhere else. Trans community is under direct threat of HIV not only because they are systemically and systematically worn down and rendered immuno-compromised, but also because worsening financial precarity puts them in difficult situations where they have to agree on performing sexual services without condoms, lest they risk losing their customers due to increasing competition. By giving their sexual agency back to them, PrEP can help trans women protect themselves from HIV without financial consequences. When Gilead makes the decision that PrEP is not necessary, it does not take into consideration what is actually necessary for queer and trans communities.

In 2020, I wrote how Gilead promised to prevent pathology through PrEP, while reproducing social and biological pathologies by exposing already precarious communities to higher risks of infection. I argued that the fact that white gay men constitute the largest constituency of PrEP users while the risks of HIV transmission are disproportionately higher for QTBIPOC epitomizes the operating logic of the pharmaceutical industry: that life is protected only insofar as it offers surplus economic and social value. I used *pathopolitics* as a conceptual tool to account for how Gilead contributes to the pathogenicity of HIV by setting exorbitant prices, blocking generics, and relocating suffering from the ‘Global North’ to the ‘Global South’, while, at the same time, charitably offering co-pay assistance programs and donating medicine. In *Capitalizing a Cure*, Victor Roy writes about another example, this time a sofosbuvir-based antiviral medicine for hepatitis C, sold under the brand name Sovaldi.²³³ In this important book, Roy meticulously investigates how the drug’s unaffordable price (\$90k) was determined

²³² Salomon et al., “Integrating HIV Prevention and Treatment.”

²³³ Victor Roy, *Capitalizing a Cure: How Finance Controls the Price and Value of Medicines* (Univ of California Press, 2023).

according to logics of financial markets instead of concerns of public/global health. Drugs like Truvada and Sovaldi are investment tools for Gilead before they are medicine, and as every investment in technology, they are too expected to generate returns way above the costs associated with their discovery and production.

As I was transcribing the interview with Ahmet, I immediately regretted that I did not ask him what post facto seemed to me an obvious question: why does Gilead act against its own financial interests and opts for withholding PrEP in Turkey? Luckily, this question was answered in the summer of 2022 when I traveled to Izmir to meet one of the most well-known HIV physicians in the country, Deniz Gökengin, whom you can recognize from the previous chapter. Gökengin has been collaborating with Gilead since the company opened a branch in Turkey and many of her studies on social and epidemiological aspects of the epidemic have been funded by Gilead. Despite her close relationship with the company, she is also someone known for her straight bluntness and she does not shy away from voicing her contentious opinions, which, needless to say, I do not always agree with. Reminding of Stephan Ecks' observation that some medicines are never meant to be affordable in some places,²³⁴ Gökengin explained to me that PrEP could never be a lucrative product for Gilead when it comes to Turkey for at least three reasons: first, it would never be covered by the state-provided General Health Insurance or the private ones; second, the price cap Turkey imposes on pharmaceutical products would not allow Gilead to charge what it wants for the medicine— brand-name Truvada and its generic Hivent cost almost the same; and, lastly, according to Gökengin, because Truvada's patent as PrEP was going to expire in 2020, the company did not want to enter new markets with a product soon to be replaced by its generics. In fact, Truvada's first generic for HIV treatment—not for prophylactic use—was approved in Turkey in 2014 under the name of Hivent.

The absence of PrEP in Turkey, however, should not be blamed solely on Gilead since all actors of HIV care are implicated. The Ministry of Health, doctors, and NGOs all treat PrEP not as a barrier to contagion but as a contagious object that everyone avoids touching. In the words

²³⁴ Ecks, "Global Pharmaceutical Markets and Corporate Citizenship."

of Kane race, PrEP appears as a *reluctant object* nobody wants to talk or do something about because of its putative associations as enabling (risky) sexuality.²³⁵ This gives way to an interesting situation, described by one of my interlocutors as “throwing responsibility around like a ball,” because nobody is willing to take action. When it cannot be decided who should protect the public health, it becomes no one’s responsibility and is pushed outside the political agenda. You will remember Emel Hanım, from the Ministry of Health, who was introduced in the first chapter. During an online sexual health workshop that took place on Zoom in 2021, when she was challenged by one of the physician participants for not including any information on PrEP in Diagnostic and Treatment Manuals, Emel Hanım very calmly explained that there is nothing the Ministry can do about it. “The Health Ministry is not what is blocking PrEP in Turkey. All drugs have licenses and if its license does not say ‘for preventive use’, you cannot prescribe it for that purpose. So the company in charge should make a formal application to change drug indications.”

Emel Hanım’s response, of course, came as a big shock for many attendees who were aware of the failed attempts of local companies to obtain PrEP’s license. Some expressed their opinion that without the Ministry’s cooperation, it would not even be possible to get approval for—after all, the institution in charge of granting drug licenses in Turkey is the Ministry of Health. Towards the end of her speech, Emel Hanım summarized the situation by sharing that the fight for PrEP should be fought in two distinct fronts: one to get the approval for it—she said this was on Gilead and HIV organizations—and the other one to have it covered by the public insurance, which was a task to be performed by the Social Security Institution, a government agency that to this date considers HIV-infection a deadly disease instead of a chronic one. Nowhere in her speech did Emel Hanım recognize the obligations of the Ministry to provide prevention for HIV. The most striking part of her speech for me was the subtle neoliberal rhetoric she adopted to frame PrEP as a problem and duty of HIV organizations. I was struck by the feasibility of this proposal because I knew that local NGOs not only already had more than

²³⁵ Kane Race, “Reluctant Objects: Sexual Pleasure as a Problem for HIV Biomedical Prevention,” *GLQ: A Journal of Lesbian and Gay Studies* 22, no. 1 (2016): 1–31.

they can cope with on their plates, but also, they did not necessarily believe PrEP would benefit public health. Although there is a growing acceptance of PrEP among the civil society actors, what I captured in my initial interviews with HIV organizations was a genuine panic regarding the potential harms PrEP would bring to Turkish people and efforts of HIV prevention.

“Everything we have done in Turkey in the name of HIV awareness and prevention would lose its importance. Numbers of STI transmission would immediately skyrocket. It’s too dangerous.” This is not an observation made on the possible consequences of the criminalization of HIV non-disclosure. It’s rather an excerpt from an interview I conducted in 2018 with Harun, the director of Pozitif Yaşam, where I asked him about his opinions on PrEP, expecting a strong response about its importance. The last thing I expected to hear from the director of the leading HIV organization in Turkey was the outright dismissal of an HIV prevention mechanism alternative to condoms, highly unpopular, in addition to being inaccessible, in the country. Nadir from Pozitif-iz, on the other hand, believes that in comparison to PrEP, condoms make more financial and epidemiological sense. “PrEP it’s not 100% protective, condoms provide more protection to be honest. Both from an economic perspective and from the perspective of infectious diseases prevention, condom makes more sense. PrEP is not a miracle and we see that those who take it stop using condoms altogether.” What is interesting is that a year after our initial meeting, when I met Nadir next summer in a coffee shop in Istanbul and shared my newly acquired HIV diagnosis with him, the first thing he asked me was not why I did not use condoms, but why I was not taking PrEP. Nadir is a hundred percent right that PrEP is no miracle, for it is but an extension of the *pharmacopower*²³⁶ encapsulated in the form of a digestible magic-bullet. He is also right that PrEP does not protect against other STIs. But most other STIs, unlike HIV, are more easily manageable and treatable, for which they often don’t have the same impacts on people’s sexual health and sexual lives. Both Harun and Nadir echo the initial reactionary responses given to PrEP by long-time HIV activists such as Michael Weinstein and Larry Kramer. These influential figures found using antiretroviral medicine while being HIV-negative as cowardly and unethical. They also joined the conservative outcry that

²³⁶ Preciado, *Testo Junkie*.

PrEP would plant the seeds of uncontrollable STI epidemics such as antibiotic-resistant gonorrhea, which in recent years substituted HIV in disciplining people's sexual practices through fear.

At first, the stance of HIV organizations on PrEP might seem counterintuitive and be taken as an isolated opinion, yet some of their worries are shared among infectious diseases specialists who, in some cases, have even stronger reactions to PrEP and its allegedly risky nature. There are three dominant medical views on PrEP: a large group of doctors do not believe in the science behind PrEP—just as they deny the scientific legitimacy of undetectable=untransmittable (U=U) status—and claim that it is unfounded. They do not accept that HIV transmission can be effectively controlled by taking ARV medicine and that HIV+ people can achieve a noninfectious status. For these doctors, there is almost something psychoanalytic about their refusal to accept HIV as something manageable. They don't want HIV+ people to be noninfectious both because they don't want to see them mingling among the general public and because they have historically constructed their superior, healthy existence based on the ontological sickness ascribed to HIV+ people.

Another group of physicians do recognize the authenticity of the science behind PrEP and U=U but believe that the public should not be informed about these medical developments because they would only lead people to have riskier sexual habits. For these doctors, the idea of HIV becoming a manageable condition is unacceptable because if people don't fear HIV, they will end up getting it. The third group consists of the leading doctors in the field of HIV who consider PrEP as a critical public health tool that needs to be made available in Turkey. However, as a result of the conservative crackdown on HIV prevention, some physicians fear punitive consequences should they prescribe PrEP or inform their patients about it. Gülden Ersöz, introduced in the previous chapter, who almost lost her job for being involved in the distribution of condoms on a university campus, once said “I don't know if I could prescribe PrEP even if it was available in Turkey. I went through an investigation and nearly lost my job

solely for distributing condoms to college students, so I'm afraid I would be charged with facilitating prostitution.”

It is worth noting that PrEP is not the only medicine Gulden Ersoz was concerned about during our interview. Another medicine caught in the web of neoliberal conservatism in a similar way is PeP, HIV *post-exposure prophylaxis*. Until 2019, PeP was not offered to anyone free of charge. In 2019, a change of regulations allowed health personnel to access PeP when there is an emergency and a risk of seroconversion. Even under these circumstances, not all health facilities possess ARV medicine to be used as post-exposure prophylaxis. The new regulations also laid the way open for accessing PeP in the cases of sexual harassment. Yet, this failed to protect chronically marginalized populations. A lot of LGBTI+ people reported being denied a PeP prescription because their sexual encounter was consensual. It is important to note that due to the coverage system, even when PeP is prescribed, it must be paid out-of-pocket. Gulden Ersöz explained the obstacle in the way of PeP while also shedding light on the barriers standing between PrEP and making it truly accessible:

Because we cannot demonstrate a chronic problem in the case of PeP, people must pay for it. Even when we prescribe it, the Social Security Institution has the condition that only people with chronic conditions will be covered for ARV medicine. Even the health providers can't get it for free, so the hospitals provide them with medicine if they have any extra. So, this is where we are stuck at. Without a diagnosis of a chronic disease, PeP is not free no matter what the regulations say. At this point, I cannot even imagine a way in which PrEP would ever be covered by general insurance. There will be the same issue. Since we must prescribe these drugs precisely to prevent a chronic disease from happening, it is illogical to search for a chronic diagnosis. (Dr. Ersöz, personal interview, 2021)

In lieu of conclusion: Pharmaceutical Frontiers

“The activity of frontier is to make human subjects as well as natural objects”
—Tsing, *Friction*, 2005

In 2019, Gilead signed an agreement with a local pharmaceutical production facility in my hometown of Tekirdağ, to produce one of its hepatitis drugs and a state-of-art ARV medicine under patent protection until 2033. With this agreement, Turkey will become the third country in the world after Canada and Ireland, producing patented Gilead drugs, and Gilead Sciences Turkey will be able to produce more than 70% of its total turnover locally. The company that will manufacture Gilead's drugs is none other than Pharmactive. This agreement is partly indebted to Gilead's future goals of becoming a pharmaceutical leader in the region as HIV rates are alarmingly rising in Central Asia, Russia, and the Middle East. The general manager of Gilead Turkey, Şebnem Girgin, announced, in the long run, the facility will provide drugs not only for Turkey but the entire region. The adamant strategy of the AKP to nationalize medicine rendered this agreement a necessity and not just a strategic choice.

While thinking through the ethnography of global connection and capitalism, Anna Tsing offers the concept “frontier” by which she does not mean “a place or even a process” yet “an imaginative project capable of molding both places and processes.”²³⁷ Frontier is a resource making project that is not bound by national boundaries or natural limits: it is about producing resources by transforming nature and humans into resourceful objects—sometimes in the name of protection and preservation—from which profit can be extracted. Frontier is a highly divergent and heterogenous project: based on the availability of resources and industrial interests, how it looks, feels, and tastes can vary widely. Before subjects and objects of the frontier are made and value is extracted, though, it has to be speculatively created. “In speculative enterprises, profit must be imagined before it can be extracted.”²³⁸ When Ian Hacking wrote about “making up people,” he referred to the ways in which sciences give rise to new classifications of people who are then treated like new species with incommensurable differences.²³⁹ I believe a similar parallel can be drawn between sciences making up people and big pharma conjuring up epidemiological subjects as potential consumers. In my formal

²³⁷ Anna Lowenhaupt Tsing, *Friction: An Ethnography of Global Connection* (Princeton University Press, 2005), 24.

²³⁸ Tsing, *Friction*, 57.

²³⁹ Ian Hacking, “Making Up People,” in *Reconstructing Individualism: Autonomy, Individuality, and the Self in Western Thought*, ed. Heller, Sosna, and Wellberry (Stanford, CA: Stanford University Press, 1986), 222–36.

interviews and informal interactions with Gilead employees, I couldn't help but observe a quasi-epidemiological category which they commonly referred to as the "undiagnosed people in Anatolia". This reference became so prominent that I began asking people what they mean by it. The answers I received varied in degrees, but they all emphasized the importance of diagnosing and treating Anatolian population until no one is left undiagnosed. A Gilead staff joked that just like it is done during demographic censuses, what we need to do is to establish a curfew and test everyone in their homes.

In addition to strengthening public health response to HIV, Gilead's investment in increasing HIV testing and solidifying the rhetorical tool of undiagnosed Anatolian population serve the purpose of making formerly unidentified subjects-to-be, who escapes the state's and the industry's notice, into an easily diagnosable/identifiable therefore exploitable subject. What Gilead seeks to extract through investments in increasing HIV testing and diagnosing those who escape medical gaze is a virtual biovalue which is taken to be immanent to HIV+ bodies and freely available to be extracted. The concept of biovalue allows us to grasp the "potentiality"²⁴⁰ a pharmaceutical company conjures and harvests by extending the reach of medical surveillance, diagnosing HIV+ persons, and by putting them on drugs for the rest of their lives. What is so peculiar about the kind of biovalue I refer to is that it is extracted not as a result of oppression, exploitation, or violence, but by means of practices that are highly valued and respected in the context of public and global health such as testing and medicating. It is a kind of surplus-value that is produced by "doing good deeds," an ethical value, so to speak. Just as the exchange value of commodities in Marxist terminology invisibilize the labor conditions, such an "ethical" value that comes with the ability to disguise business as usual under social responsibility obscures the bleak reality behind its extraction. Ethical biovalue, in this particular instance, cloaks nothing but the profit-oriented nature of speculative capitalist enterprises.

²⁴⁰ Taussig, Hoeyer, and Helmreich, "The Anthropology of Potentiality in Biomedicine."

Conclusion

Minneapolis, April, 2023. As I am finishing this dissertation, Turkey is about to have historic elections. The question many are asking is whether the AKP, the party which came into power following the 1999 Marmara earthquake, would lose the election after more than two decades as a result of yet another earthquake. On February 6, 2023, southeast Turkey and northern Syria experienced two devastating earthquakes of 7.8 and 7.5 magnitude. In Turkey alone, more than 50.000 thousand people died, 835.000 buildings got severely damaged, and 105.000 buildings collapsed. While the social and psychological devastation of the earthquakes can never be captured in numbers, their economic damage is calculated to be around 100 billion dollars. The AKP government and President Erdogan refuses to take any responsibility for what happened and instead blame it all on the magnitude of the earthquakes. They also attack anyone who calls attention to the implications of the government's corrupt relationship with the construction sector by accusing them of “politicizing the earthquake”.

Turkey is geographically located in a tectonically active area where three tectonic plates—the Arabia, Africa and Anatolia plates—interact with each other, which is why it is known as a “deprem ülkesi”, *earthquake country*. Hence, we can confidently say that there is absolutely nothing political about when and where an earthquake hits. Yet, it is a purely political action driven by economic interests to permit unlicensed buildings to be constructed in cities built on top of fault lines. It is also strictly political to ban the use of Twitter—the most commonly used app in the hours and days following the earthquakes by people trapped in the wreckage to share their location and ask for help in the absence of cell towers—because people were spreading “misinformation”—i.e. criticizing the government both for paving the way for the disaster and for failing to immediately send help to the region populated by ethnic and religious minorities. Finally, it is a sad political decision to put profit over human lives, trapped under the debris for days because the apartment they bought after years of hard work was not constructed according to the safety guidelines. It is not a secret in Turkey that the AKP’s long-lasting rule is partly indebted to its lucrative relationship with the construction industry.

Although the party came to power right after the 1999 Marmara earthquake and promised the nation to dress its wounds (and to do that collected 38,4 billion US dollars in taxes through what is colloquially known as “deprem vergisi”, *earthquake tax*) this did not stop the government from issuing nine construction amnesties (*imar affi*) that granted official permits for buildings constructed illicitly and haphazardly without obtaining a license or following the regulations.

The political and economic factors that rendered Turkey vulnerable to earthquakes could be subject to another dissertation and I will not attempt to summarize it. Instead, in the last pages of this dissertation I want to turn my attention to another human made disaster, the Covid-19 pandemic. Just like what killed tens of thousands of people and demolished hundreds of thousands of buildings was not a tectonic plate movement, almost 7 million people died globally not as a result of underlying conditions, or a pathogen named SARS-CoV-2. They died because the destruction of forests brought wildlife and humans dangerously closer, they died because chronic conditions of poverty forced people to work and shop at unhygienic meat markets, they died because neoliberal economies do not allow any investment in public health for lack of immediate profitable returns, and they died because racism, homophobia, transphobia, xenophobia and ableism render people immunocompromised, hence, vulnerable to an airborne virus that infects the respiratory epithelial and alveolar cells. My purpose here is not to discuss how the conditions for SARS-CoV-2 to flourish were created long before it had a chance to mutate and jump on to humans. Rather, I want to focus on the Turkish public health response to the COVID-19 pandemic in order to provide a comparison that will help me explain better what I meant by pathogenicity in this dissertation.

As someone who studies the (bio)political governance of HIV in Turkey within the scope of his doctoral study, how the Ministry of Health responded to the novel coronavirus has been a very interesting point for me since the first days of the pandemic. To be frank, I was almost impressed at first by the performance I witnessed. The instant posts made by the Minister of Health, Fahrettin Koca, on Twitter to keep the public informed and protected were an unprecedented success for me. The Ministry of Health, which was afraid to take responsibility

when it came to HIV and did not take any preventive measures, was following a different strategy against coronavirus. The response to SARS-CoV-2 showed that the Ministry could take preventive measures very actively if it wanted to. Of course, one reason for the difference in strategies was that Covid-19 is a global pandemic whose reality can neither be questioned nor denied. The other reason is that HIV transmission takes place in Turkey through sexual means, unlike airborne Sars-Cov-2. Turkey, which embraces total denial, silence, and neglect about HIV, appeared to follow a different path when it came to coronavirus as it was never possible to deny a global pandemic to begin with.

As I followed the Twitter posts of Koca, however, my surprise was increasing day by day since I was not able to comprehend how, despite all the attention paid to the pandemic, its spread was not under control and the numbers of diagnoses were soaring. While, at first, I thought the answer might lie in public carelessness, it didn't take long for me to realize that the main problem was the insufficiency and delay of the measures taken. I noticed that what Turkey put forward was not a successful public health response to Covid-19 pandemic but a *pandemic theater* creating the illusion of an exemplary public health response by following an effective (social) media strategy. My initial mistake was to compare the measures taken against coronavirus with the measures taken against HIV. As a matter of fact, it was hard not to be almost impressed by the inadequate performance of the ministry. However, that doesn't mean we can't learn anything by comparing Turkey's HIV and Covid-19 policies. There is still much we can learn from this comparison such as the fact that *if not conservative and neoliberal ideologies, economic and political stakes will always outweigh the interests of public health.*

In relation to the pandemic, Turkey painted an extremely proud picture in three main areas: the high number of the tests performed, the low number of Covid diagnoses and deaths, and the excessive capacity of the measures taken. In fact, Minister Koca argued on Twitter on April 14 that Turkey's two biggest powers are treatment and precaution. However, the facts do not support these statements. Although Minister Koca announced nearly 15 thousand daily Covid-19 tests, according to Emrah Altındaş, a Turkish faculty member at Harvard Medical

School, the testing efforts were not implemented in a timely manner and by April, it was already too late to control the spread of the epidemic. Altındış also argued that not only was Turkey very late in taking action against the pandemic, but also it was hiding the actual numbers of Covid-19 mortality and morbidity. He claimed that the state, which is aware of how serious economic and political problems a pandemic can create, is playing with the numbers to show the situation under control.²⁴¹ Other doctors and public health experts joined Altındış in challenging the official account of the pandemic and uncovering the actual numbers, estimated to be at least three times higher than the official calculations. In response, the Ministry of Health opened an investigation against medical specialist Çınar for contesting Covid diagnostic numbers on Twitter. Çınar was forced to write an apology by Ankara University where they teach, and the letter of apology was also shared on Twitter.²⁴² On similar grounds, the co-president of Mardin Chamber of Doctors, Osman Sağlam, was filed charges against by the provincial directorate of health for “provoking fear and panic among the public.”²⁴³ Moreover, while doctors did not have sufficient protective gear but were afraid to make public statements because of the political pressure they felt under, another group of doctors gathered in front of a hospital in Ankara to make a joint public statement but were prevented by the intervention of police forces.²⁴⁴

Türk Tabipler Birliği (TTB), Turkish Medical Association, whose president was arrested and detained in 2022 following her statements of the use of chemical weapons by the Turkish army against Kurdish guerillas, criticized the Ministry of Health not only for strategically hiding the actual numbers of death and infection but also for withholding information vital to prevent further transmissions. Keeping the cities where the cases are seen secret and not sharing the demographic data of the infected people were among the biggest concerns of the TTB during the

²⁴¹ Hamdi Firat Buyuk, “Turkey’s Coronavirus Crisis Risks Rivalling Italy, Experts Warn,” *Balkan Insight*, March 24, 2020, <https://balkaninsight.com/2020/03/24/turkeys-coronavirus-crisis-risks-rivalling-italy-experts-warn/>.

²⁴² “Ankara Üniversitesi’nden sosyal medyadaki ‘koronavirüs videosu’ hakkında açıklama,” *BirGün*, March 19, 2020, <https://www.birgun.net/haber/ankara-universitesi-nden-sosyal-medyadaki-koronavirus-videosu-hakkinda-aciklama-292332>.

²⁴³ “Mardin Tabip Odası Eşbaşkanı’nın korona açıklamalarına soruşturma,” *Gazete Duvar*, March 28, 2020, <https://www.gazeteduvar.com.tr/gundem/2020/03/28/mardin-tabip-odasi-esbaskanina-korona-sorusturmasi>.

²⁴⁴ “Açıklama yapmak isteyen sağlıkçılara gözaltı,” *Text*, *Gazete Duvar*, March 31, 2020, <https://www.gazeteduvar.com.tr/gundem/2020/03/31/aciklama-yapmak-isteyen-saglikcilara-gozalti>;

early months of the pandemic.²⁴⁵ In a letter addressed to minister Koca, members of TTB expressed their concern over the fact that even physicians cannot reach the test results of their patients quickly (sometimes not at all), putting many physicians, patients, and their family members in danger.²⁴⁶ In the meantime, as though to dictate which deaths we should mourn and which ones we must worry less about, Minister Koca's social media posts kept underlying that the vast majority of those who died were elderly and had chronic illnesses.

Contrary to the statements of minister Koca, the scope of the measures taken were also far from being adequate and, sometimes, also being scientific. The Ministry of health adopted the public health message, “the most effective way to protect yourself from coronavirus is not catching the virus,” that offered no help or information necessary to protect the health of the public. This tautological statement resembles another prevention message the MoH offers in response to HIV—“the best way to avoid the virus is to be protected from it”—which has proven to be equally unsuccessful in curbing transmissions in a context where access to HIV prevention is undermined by state institutions. When it comes to preventive measures, one of the biggest failures of Turkey has been to delay quarantines until March 30. As President Erdogan did not hesitate to state clearly on live broadcast, Turkey should continue to produce under all circumstances and the wheels of the economy should keep turning (*ekonominin çarkları dönmeye devam etmeli*). The political decision to impose quarantines only for the young and the elderly but not for those who contribute to the economy should be interpreted as a purely strategic decision to guarantee the uninterrupted spin of the wheels. As anthropologist Povinelli observed, in neoliberal economies, today's suffering is justified for the sake of future market prosperity.²⁴⁷ What is worse is that for neoliberalism it does not matter if the wheels are spinning as a result of the weight of dead bodies as long as they are spinning. Besides, what neoliberal capitalism makes possible is that disasters spin those wheels even faster. In fact, AKP administration too must have realized that disaster capitalism is the fastest way to gain more in

²⁴⁵ “TTB Merkez Konseyi’nden Sağlık Bakanı’na Açık Mektup,” Türk Tabipler Birliği, 2020, http://www.ttb.org.tr/kollar/_COVID19/haber_goster.php?Guid=100a205c-703f-11ea-a219-c213173be5c8.

²⁴⁶ Ibid.

²⁴⁷ Elizabeth A. Povinelli, *Geontologies: A Requiem to Late Liberalism* (Durham: Duke University Press, 2016).

the shortest amount of time, because while people were still suffering an ongoing pandemic, the works in the construction, mining, and energy sectors accelerated, and a significant amount of protected green space were zoned for construction.²⁴⁸

In addition to the insufficiency of preventive measures, financial measures offered by the state too fell short of protecting the vulnerable constituencies of the public. Not unlike the U.S., the economic aid package was designed specially to help the private sector and banks, while making it impossible for workers, farmers, tradesmen, artisans and many other professions that do not have financial security to stay home, although Minister Koca gave everyone the order to establish their own state of emergency. If the Turkish state really wanted to control the epidemic, it would forbid layoffs, expand paid leave, delay loans and bills, and pass private health care facilities to public administration. Even though Minister Koca, the owner of a chain of private hospitals, tried to spread messages like “stay home” or “there is life at home” on his individual Twitter account with the help of celebrities, the Turkish state did not provide any assistance or protection for those who stayed home.²⁴⁹ What is more, as though there was already enough financial aid, the AKP administration blocked the distribution of help by opposition-led municipalities based on political interests. Despite blatantly jeopardizing community health and social solidarity, the bank accounts of Istanbul and Ankara Municipalities were frozen to prevent them from collecting and distributing financial aid.

The level of destruction and loss that followed the recent earthquakes and the Covid-19 pandemic is a clear indication that these were not natural disasters. Or, to put it differently, these disasters were natural solely in the sense that they are the expected consequences of putting political and economic interests before lives and livelihoods. Following the 1999 Marmara earthquake, a Turkish geologist and earthquake scientist, Ahmet Mete Işıkara, popularized the phrase *deprem değil bina öldürür*, “buildings kill people not the earthquakes,” thereby introducing the public to the material and social consequences of unlicensed constructions.

²⁴⁸ “CHP: Doğa talanını ‘corona’ bile durduramadı, krizi fırsata çevirdiler,” Diken, April 8, 2020, <https://www.diken.com.tr/chp-doga-talanini-corona-bile-durduramadi-krizi-firsata-cevirdiler/>.

²⁴⁹ Atuk and Craddock, “Social Pathologies and Urban Pathogenicity.”

Today, a similar phrase—*HIV değil HIVfobi öldürür*—is widely used by HIV activists to stress that what puts their life at risk is not necessarily or primarily HIV but the stigma and discrimination they experience in the hands of the so-called caring institutions, organizations, corporations, and professions. More than two decades apart, what these phrases have in common is their emphasis on the human factor in the emergence of disasters.

As I showed in the previous chapters of this dissertation, human-made factors such as denying the need for comprehensive sexuality education, refusing to protect and empower key populations, imposing monogamy as an HIV prevention method, undermining science, and impeding access to prevention evince that the HIV epidemic in Turkey is not a natural disaster but an essentially preventable political crisis created by conservative and neoliberal ethics of public health. This dissertation, then, is an examination of the social, economic, and political factors that enhance the virulence of a pathogen. It demonstrates that the Turkish HIV epidemic is not an inevitable result of dissident/terrorist sexualities, foreign lifestyles, or the human immunodeficiency virus per se, but an evitable product of governmental, nongovernmental, medical, and corporate ethics of public health. The central argument of this dissertation is that public health mechanisms, institutions, and actors in place to provide HIV treatment and prevention have become unexpected vectors of transmission under neoliberal Islam. This dissertation joins a growing body of literature contending that abandonment and harm are not only the results of absence but, sometimes, the presence of care mechanisms. As demonstrated in the previous chapters, empty of gestures of care—that is pretending to care for/about without taking concrete actions or taking actions that would jeopardize the well-being of care-recipients—contribute to the virulence, or pathogenicity, of HIV by rendering people defenseless and vulnerable against the virus, hence facilitating its spread.

The second argument of this dissertation is that the fear of medical and social contagion, as well as the consequent impulse to immunize life against infectious and risky others, lies at the center of the Turkish HIV epidemic. If Esposito is right and the contemporary social and political relations are overdetermined by the immunitarian paradigm, then, we can neither fully

understand nor successfully respond to the HIV epidemic without grasping how preventing contagion, symbolic and biological, becomes key to the preservation of life under contemporary biopolitics. If immunization is the “most intimate essence” of modern civilizations and if the “the virus has become the widespread metaphor for all of our nightmares,”²⁵⁰ then we can interpret the denial to provide HIV prevention and treatment in terms of a *viral line* set between those who deserve protection and those who are HIV+ or at risk. This means that for an effective public health intervention against the epidemic there is a great need both for a representational change of HIV+ and/or at-risk persons as always-already infectious and a structural change in how public health institutions approach contagion. We must make sure that immunization is not taken over a threshold at the expense of both those who are protected and those who are sacrificed. This is especially true in the age of zoonotic viruses such as Sars-Cov-2 and Mpox, which intensified the panics and tensions around viruses and viral transmissions. For more appropriate interventions, we need *porous* public health institutions and actors capable of embracing contagion (from Latin *con-tangere*, to touch together) as the basis of building stronger and healthier publics. After all, nothing strengthens a collective immune system better than an exposure to what at first sight might look like an external outsider.

In other words, this dissertation research unveiled how Turkish HIV care is shaped by a perfunctory investment in ending the HIV epidemic without recognizing the needs of those living with the virus and those who might need protection from it. As a friend asked once, “Then what? We have the medicine but how do we live, how do we have sex, how do we work and where do we go when we are denied dental care and jobs?” Insignificant as it may sound, ‘then what’ is a heavily loaded question with considerable implications for the quality of life of PLWH. Testing and medication should be the first steps of HIV care, not the final ones. Only through substantial improvements in what comes after these biomedical steps can HIV+ people’s wellbeing be sought. When the care providers are blind to what matters for people they are expected to care for, when they are deaf to their complaints, and when they are indifferent to their requests, it becomes painfully clear how those in whose name care is provided are the ones

²⁵⁰ Esposito, *Terms of the Political*, 60.

deprived of the healing outcomes of care. When the political and economic interests of care-givers are prioritized over social and medical needs of care-receivers, what we observe is the extent to which the vulnerability of the so-called “vulnerable groups” is produced by care-less gestures. In place of mechanisms of care created under the influence of immunitarian logics, what is needed in Turkey is a model of HIV care that listens to and opens up space for HIV+ people as well as key populations living under the risk of HIV. Only through the inclusion of HIV+ people and at-risk communities in public health decision making processes can there be an actual chance to control the epidemic.

When it comes to embracing contagion, or even desiring it, there is a lot we can learn from queer HIV activists and their non-prophylactic ethics of care. The care HIV activists provide for HIV+ people is not determined by an aggressive immunitarian impulse like the formal regimes of HIV care. They not only normalize being HIV+ and/or queer, but also affirm it as a basis for building stronger communities. For HIV activists many of whom live with HIV, the virus is not something evil or lethal. Instead, they see it as something that gives them a political capacity and agency to do activism. The activists don’t fight against HIV, nor do they have any interest in “ending HIV.” They do not even seek to discuss prevention because they don’t want to spend their limited time and energy on the HIV-negative population. What they care about/for is the well-being of HIV+ people who are neglected by formal actors of HIV care. In response to neoliberal and conservative public health politics, queer people adopt activist strategies such as (1) amplifying the voices and centering the narratives of those who live with HIV by engaging in what they call ‘subject activism’, (2) by disclosing their status publicly to raise HIV awareness, (3) by providing peer support.

Understanding activist care in its own terms requires taking the creativity and agency of the margins more seriously instead of easily dismissing them as insignificant acts of defiance. As Das and Poole always remind us, margins are not inert places—if anything, their marginalization is what grants them the creative power and energy to imagine and embrace alternative, political

ethics of care.²⁵¹ One shortcoming of this dissertation is that it reduces HIV care into treatment and prevention, whereas a broader conceptualization of care shows us that it includes “everything that we do to maintain, continue and repair ‘our world’ so that we can live in it as well as possible.”²⁵² This dissertation, however, is not a final product but a first attempt at an incomplete project that I will dedicate many years to come. In its future iterations, among many other things, I will reflect on (a) why queer HIV+ activists cannot mobilize based on ‘biological’, ‘genetic’, ‘therapeutic’ or ‘biosexual citizenship’²⁵³; and (b) how queer HIV+ activists find creative and political ways to perform HIV care in the ruins of authoritarian neoliberal Islam by organizing digitally and offering each other “tiny acts of love”²⁵⁴ which is as necessary as antiretroviral medicine to stay healthy.

²⁵¹ Veena Das and Deborah Poole, *Anthropology in the Margins of the State* (Santa Fe, CA: School of American Research Press, 2004).

²⁵² Tronto, *Moral Boundaries*, 13.

²⁵³ See Nikolas Rose and Carlos Novas, “Biological Citizenship,” in *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, ed. Aihwa Ong and Stephen J. Collier (John Wiley & Sons, 2008), 439–63; Adriana Petryna, *Life Exposed: Biological Citizens after Chernobyl* (Princeton University Press, 2013); Deborah Heath, Rayna Rapp, and Karen-Sue Taussig, “Genetic Citizenship,” in *A Companion to the Anthropology of Politics*, ed. David Nugent and Joan Vincent (John Wiley & Sons, 2008), 152–67; Vinh-Kim Nguyen, “Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship,” in *Global Assemblages*, ed. Aihwa Ong and Stephen J. Collier (Oxford, UK: Blackwell Publishing Ltd, 2007), 124–44; Steven Epstein, “Governing Sexual Health: Bridging Biocitizenship and Sexual Citizenship,” in *Biocitizenship: The Politics of Bodies, Governance, and Power*, ed. Kelly E. Happe, Jenell Johnson, and Marina Levina (NYU Press, 2018).

²⁵⁴ Marty Fink, *Forget Burial: HIV Kinship, Disability, and Queer/Trans Narratives of Care*, 1st edition (Rutgers University Press, 2020).

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