A QUALITATIVE STUDY ON THE PERSPECTIVES OF HIV ACTIVISTS ON HIV DISCLOSURE IN TURKEY

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DECLARATION OF ORIGINALITY

I, Oğulcan Yediveren, certify that

- I am the sole author of this thesis and that I have fully acknowledged and documented in my thesis all sources of ideas and words, including digital resources, which have been produced or published by another person or institution;
- this thesis contains no material that has been submitted or accepted for a degree or diploma in any other educational institution;
- this is a true copy of the thesis approved by my advisor and thesis committee at Boğaziçi University, including final revisions required by them.

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ABSTRACT

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The literature suggests that public health measures, which are vital to preventing the HIV epidemic, and the right to privacy of people living with HIV often come into conflict. Public health measures follow a strategy to combat the epidemic that focuses on identifying the HIV status of people living with HIV and taking measures to stop transmission. However, this strategy raises privacy and confidentiality concerns for people living with HIV. The thesis seeks to understand how HIV activists manage the tension between public health measures and the rights of people living with HIV as they develop their perspectives on sharing HIV status. Within the scope of the research, one-on-one structured in-depth interviews were conducted with eight HIV activists. The findings of this thesis are based on a thematic analysis of the interviews. The findings of the thesis are presented under three headings: Experiences of people living with HIV while disclosing their HIV status, HIV activists' perspectives on disclosing their HIV status, and factors affecting the decisions of people living with HIV to disclose their HIV status. The main finding of the thesis is that the HIV activists interviewed embrace the idea that HIV disclosure is not an obligation. In justifying this idea, the participants pointed to the discrimination they were exposed to after disclosing their HIV status, the fatigue of disclosing their HIV status to everyone and informing the disclosed people about HIV, the right to privacy and the Undetectable=Untransmittable campaign.

ÖZET

Türkiye'de HIV Aktivistlerinin HIV Statüsünü Paylaşmaya Dair Perspektifleri Üzerine Niteliksel Bir Çalışma

Literatür HIV salgınının önlenmesinde hayati önem taşıyan halk sağlığı önlemleri ve HIV ile yaşayanların mahremiyet hakkı sıkça çatışmalara yol açmaktığını söylemektedir. Halk sağlığı önlemleri, salgınla mücadelede HIV ile yaşayanların HIV durumunu öğrenmeye ve bulaşmayı durdurmak için önlemler almaya odaklanan bir strateji izler. Ancak bu strateji, HIV ile yaşayanlar için mahremiyet ve gizlilik endişelerini artırmaktadır. Bu tez HIV aktivistlerinin HIV Statüsünü paylaşmaya dair perspektiflerini geliştirirken halk sağlığı önlemleri ve HIV ile yaşayanların hakları arasındaki gerilimi nasıl yönettiklerini anlamaya çalışmaktadır. Araştırma kapsamında sekiz HIV aktivistiyle birebir yapılandırılmış derinlemesine mülakat yapılmıştır. Bu tezin bulguları yapılan mülakatların tematik analizine dayanmaktadır. Tezin bulguları üç başlık halinde sunulmuştur: HIV ile yaşayanların HIV statülerini paylaşırkenki deneyimleri, HIV aktivistlerinin HIV statüsünü söylemeye dair perspektifleri ve HIV ile yaşayanların HIV statüsünü söylemeye dair kararlarına etki eden faktörler. Tezin temel bulgusu görüşülen HIV aktivistlerinin HIV statüsünü söylemenin bir zorunluluk olmadığı fikrini benimsiyor olmasıdır. Katılımcılar bu fikri temellendirirken HIV statülerini söyledikten sonra maruz kaldıkları ayrımcılıklara ve HIV statüsünü herkese söylemenin ve söylenen kişileri HIV hakkında bilgilendirmenin getirdiği yorgunluğa, mahremiyet hakkına ve Belirlenemeyen=Bulaşmayan kampanyasına işaret etmiştir.

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CHAPTER 1

INTRODUCTION

There is an ongoing HIV epidemic in the world. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS, n.d.), there are 38.4 million people globally living with HIV as of 2021 while 1.5 million of them became infected with HIV newly in 2021. Therefore, HIV remains a vital agenda for humanity. On the one hand, medical advances since the beginning of the HIV epidemic are very promising. For example, thanks to HIV treatment, people living with HIV today have the same life expectancy as everyone else, and HIV transmission does not occur as long as they continue to receive treatment (CDC). This means that HIV is no longer a deadly virus. On the other hand, UNAIDS (2017) reports that stigma and discrimination regarding HIV prevent people from accessing HIV-related health services such as HIV testing and HIV treatment. In addition, social and structural barriers such as homophobia, transphobia, racism, poverty and educational levels may complicate for some people to seek and receive HIV-related health services (CDC, 2022). Apart from that, people living with HIV (PLWHA) do not face discrimination and stigma only when accessing HIV-related health services. HIV-related stigma and discrimination is a common phenomenon that exists in different aspects of life. According to UNAIDS (2021a), more than 50 percent of people aged between 15-49 displayed discriminatory attitudes towards PLWHA in 25 countries with recent data. Moreover, there were more than 50 percent cases in which HIV-related discrimination caused or contributed to job loss in 7 of 11 countries with data. In

summary, despite medical advances, stigma and discrimination still makes PLWHA's life harder and undermines the effort to alleviate HIV epidemic.

Nevertheless, many governments around the world does not put a political will to end discrimination and stigma against people living with HIV and AIDS. On the contrary, the misconceptions and myths on HIV cause politicians and decision-makers to employ discriminatory and stigmatizing practices against those living with HIV with the intention of ending the HIV epidemic. For example, there are HIV-specific criminal laws in a total of 82 countries and 35 of those countries applied HIV-specific criminal laws (Symington et al., 2022). Many countries applied these criminal laws to PLWHA even in cases of non-disclosure of their HIV status, potential or perceived HIV exposure, or unintentional transmission. UNAIDS (2021b) states that criminalization of HIV threatens the endeavors to HIV prevention because the fear of prosecution discourages PLWHA to seek HIV testing and HIV treatment or disclosing their HIV status even to their health professionals. Moreover, these laws lead to the violation of rights of PLWHA such as right to health, right to work and right to privacy. However, the right to privacy is of particular importance to PLWHA, because disclosing PLWHA's HIV status without their consent establishes a ground for further violations, stigmatization and violence. UNAIDS (2008) advises to withdraw the law which obliges PLWHA to disclose their HIV status to sexual partners or health professionals because everyone has the right to privacy about their health status.

In 2019, the joint post of *Cinsel Şiddetle Mücadele Derneği* and *Sağlıkta Genç Yaklaşımlar Derneği* for World AIDS Day on December 1 triggered a public debate on social media over non-disclosure of HIV. The posted image read "I Don't Have to Share My HIV Status" (Cinsel Şiddetle Mücadele Derneği, 2019). Most of

the social media users including some health professionals and lawyers who participated in the discussion framed HIV non-disclosure as a crime, saying that if those living with HIV do not tell the HIV status to their partners or health professionals, it will mean intending to kill the other party[1]. Thereupon, the Association for Combating Sexual Violence and the Young Approaches in Health Association issued a joint press release (Cinsel Şiddetle Mücadele Derneği, 2019). This joint press release stated that the assumption that "those living with HIV will knowingly and willingly transmit HIV to others through concealment or coercion" stigmatizes PLWHA because this assumption deems PLWHA as inherent criminals.

During this public debate, I witnessed that while the scientifically informed and rights-based views of HIV activists attracted a small number of people, the posts of people speaking on behalf of "public health" and using the language of sensationalism were spread more rapidly. Moreover, I realized how widespread the stigma and prejudice against those living with HIV is, and how low the society's level of knowledge regarding HIV is. I personally have identified with those living with HIV because I, as a gay person, am also subject to exclusion because of my sexual life and desires and society considers me a threat to the national pedagogy because of my sexual identity (which I will elaborate on in the 3rd chapter). As a result, with the desire to make the voice of HIV activists more tangible, I decided to explore HIV activists' perspectives on disclosure more deeply.

When I read the literature on HIV disclosure, I noticed that the literature also defines a tension between preventive public health interventions at large and the

[1] Ekşi Sözlük, which is a forum-like website with one of the highest number of members in Turkey, also has a discussion thread on this subject. To get an idea of the progress of the debate on social media, see this thread: https://eksisozluk.com/hiv-statumu-paylasmak-zorunda-degilim--6266412

protection of rights of PLWHA. The method used by the public health approach to respond to epidemics is based on identifying people infected with the virus, isolating infection origin, and informing the public about potential health risks (Gostin & Wiley, 2016). Accordingly, the public health approach uses methods such as name-based reporting, partner notification, contract tracing, HIV testing and quarantine to prevent the HIV epidemic. However, HIV activists criticized this method for paving the way for stigmatization and the violation of the right to privacy (Ainslie, 1999).

It can be argued that the reason why the public health method is subject to more intense criticism when it comes to HIV is the high prevalence of HIV among socially disadvantaged groups such as gays, trans people, sex workers and intravenous drug users and the fact that HIV transmits via sexual contact. Indeed, Hoppe (2013) shows how the public health approach may become a tool of social control over certain segments of society. In the 1980s, LGBTI+ activists in the US, who predicted that the pressure on them would increase with the onset of the HIV epidemic, criticized the public health method for setting ground for the government to put LGBTI+ people on a register (Ainslie, 1999). In response, they created their own sexual ethics named as “safe sex ethics”. This sexual ethic advised everyone to use prevention methods such as condoms during sex. Therefore, no one would have to disclose their HIV status. Indeed, in the 1980s, the HIV-infected gay community embraced this sexual ethic and unlike other epidemics, public health methods were not used effectively to prevent the HIV epidemic until the 1990s. Bayer (1996) calls this as HIV exceptionalism.

In the light of the public debate on HIV disclosure in social media in Turkey and the literature on HIV disclosure, my research question is how HIV activists in Turkey manage the tension between preventive public health interventions at large

and the protection of rights of PLWHA while developing their perspectives on HIV disclosure?

Throughout the thesis, I refer to “disclosure” as someone living with HIV tells their HIV status to others (Okumu, 2020). In the thesis, I benefited from cultural studies, social policy, bioethics, sexual ethics, law, medicine and sociology of medicine. I critically reviewed the literature from the perspective of the rights of PLWHA.

1.1 Research method

I conducted eight in-depth semi-structured interviews with HIV rights advocates online. The main purpose of the interviews was to explore their perspectives on HIV disclosure and their experiences of disclosure (see Appendix A for interview questions and see Appendix B for interview questions in Turkish). There were two eligibility criteria for participation in the study. The first one was to identify themselves as HIV rights advocates. It was important for this study because my main motivation to conduct this research was to explore the human-rights perspective on HIV disclosure. The second one was to live with HIV. This is equally important for this study because I would be able to listen PLWHA's experience at first hand regarding the rights violations caused by discriminatory and stigmatizing attitudes towards them and whether this shaped the perspective of those living with HIV on disclosure.

I employed purposeful sampling and snowballing sampling methods to reach out to my participants. I contacted three HIV Organizations to send my call to participate in the research to their volunteers and members. However, only members of one organization responded to my call. Five of the participants were from this

organization. I reached the remaining three through personal contacts. Participants were from İstanbul, Ankara, İzmir, Bursa and Antalya. Four of the participants were providing peer counseling to people living with HIV especially when they were newly diagnosed. Thus, these participants had a comprehensive knowledge about the experiences of PLWHA from various backgrounds and identities.

I received the ethics committee approval (see Appendix C for ethics committee approval in Turkish) for the research in June 2022. I conducted the interviews between March 2022 and April 2022. All the participants signed the information and consent form before the interview (see Appendix D for an example of the participant and consent form in Turkish). The average time of the interviews was 58 minutes. The longest interview lasted 75 minutes while the shortest one was 45 minutes.

1.2 Outline of the chapters

Chapter 2 presents the literature review. It consists of two sections. The first section presents the critical studies of medicine and sexuality as a domain of power. The second section introduces the literature on sexual ethics and public health interventions from the perspective of the rights of PLWHA. In this section, I attempted to show how the discussion regarding sexual ethics and public health interventions evolved with the changes in the epidemiological course of the epidemic and medical developments. Chapter 3 aims to give a context to understand the landscape regarding HIV disclosure in Turkey. It also consists of two sections. In the first section, I present the legal framework of HIV in Turkey. In the second section, I introduced a brief history of HIV response of different actors in Turkey by dividing it into four phases. Chapter 4 introduces the findings of the semi-structured in-depth

interviews with 8 HIV rights activists. Chapter 5 summarizes main findings of the study and discusses them in relation to literature review and background.

CHAPTER 2

LITERATURE REVIEW

Erni (1994) argues that two fantasies in the popular imagination serve to conceive of AIDS. The first one is containment fantasy. It refers to the faith in medicine in the struggle with AIDS. Based on a hyper rationality paradigm, this fantasy attributes enormous importance to medicine's curing power. The second one is morbidity fantasy. It deems PLWHA as dead, or it secretly desires that PLWHA were dead. What is common in these two fantasies is the desire to eliminate any possibility of HIV transmission. After 27 years have passed since Erni made this evaluation, neither fantasy comes true. Neither the entire PLWHA population died, nor did medicine eradicated HIV. However, HIV has ceased to be a fatal disease due to advances in medicine and technology. What remains the same was HIV/AIDS phobia and the inexhaustible desire to eliminate HIV transmission.

Between 2010 and 2019, the number of people diagnosed with HIV fell from 2.1 million to 1.7 million, corresponding to a decrease of 23 percent (UNAIDS, 2020). However, there are still 38 million PLWHA globally in 2019 (UNAIDS, 2020). While this progress in HIV prevention is promising, PLWHA still struggles with discrimination and stigma in many parts of the world. According to UNAIDS (2019), in 73 countries, there are laws that criminalize HIV transmission, exposure, or non-disclosure. Additionally, criminal laws were applied to similar cases in 39 countries (UNAIDS, 2019).

Since the emergence of HIV in the US in the 1980s, there has been considerable debate over HIV disclosure. Preventive health interventions such as

HIV testing, partner notification, name-based reporting, and contact tracing aims to identify PLWHA and take necessary measures to stop HIV transmission. However, PLWHA often are unwilling to disclose their HIV status and may not even want to know their HIV status because of internalized HIV/AIDS phobia and the fear of stigmatization. They are reluctant to disclose their status because this leaves them vulnerable to discrimination and stigma. On the one hand, preventive health interventions are irreplaceable to diminish the negative health effects of the virus on the population and increase the life quality of PLWHA. On the other hand, efforts to eradicate HIV may lead to discrimination and stigma against PLWHA. Moreover, addressing HIV only as a medical issue may outweigh the protection of rights of PLWHA. Hence, this creates tension between preventive health interventions targeting the population at large and the protection of the rights of PLWHA. How does the existing literature on HIV disclosure written from the perspective of the rights of PLWHA tackle the tension between preventive health interventions targeting the population at large and the protection of the rights of PLWHA?

In this chapter, I will introduce critical studies of medicine and sexuality as a field of power first. Then I will present an overview of the evolution of the discussions on sexual ethics and public health interventions in the literature regarding the rights of PLWHA, with the changes in the epidemiological course of the epidemic and medical developments. I would like to emphasize that my literature review mostly relies on the texts written from the perspectives of the rights of PLWHA.

2.1 Sexuality and medicine as a field of power

Foucault (2003) states that political rights underwent a significant transformation in the 19th century. It was a transformation from the old rights of the sovereign power to the new rights of biopower. For him, the right to live and die is the most fundamental feature of sovereign power. The subject has the right to live and die only as a result of the sovereign's will over the subject. Nevertheless, Foucault (2003) emphasizes that the sovereign's power over death and life is asymmetrical because the sovereign does not have power over life as it does over death. The sovereign exercises their power over life only as long as they can kill. He (2003) argues that in the 19th century, the new rights of biopower did not replace the old ones, but complemented them, diffused them. These new rights are "the right to make live and to let die" (Foucault, 2003, p.241). With the emergence of biopower, the main problem of power is not death but life. In other words, the power has spread its effect not to the extent that it can kill but to the extent that it can keep the subject alive.

Which technologies, techniques, and mechanisms does biopower use to "make" live? Foucault (2003) introduces disciplinary power to explain the way biopower operates by comparing them with each other. According to him, the techniques of disciplinary power emerged in the 17th and 18th centuries. The techniques of this power deal with the individual body and distribute bodies in a spatial relationship. It increases the productivity of bodies by training them. It uses bodies in the most efficient way through surveillance and hierarchies. The factory is a relevant example to understand disciplinary power. Bodies are spatially distributed around production machines. Specialization is achieved through training bodies.

Inspectors ensure that bodies and their cooperation work in the most economical way. This is the way disciplinary power operates.

Foucault (2003) states that biopower did not replace disciplinary power but adapted it, redesigned it. This new power became embedded in the techniques of disciplinary power. However, it operates at a different scale and a different level. He (2003) suggests that biopower deals with the population while disciplinary power targets the body. This new power put into effect on men-as-living beings or man-as-species but not on man-as-body. Biopower aims to increase the population's productivity, which is affected by mortality, morbidity, and fertility but not of the bodies. It aims to keep an overall equilibrium of the population and optimize a state of life. It does not discipline bodies. It regularizes the population by neutralizing variations within the population. It uses techniques, technologies, and mechanisms such as statistics, forecasts, medicine, public hygiene, public health measures, and natalist policies to increase the population's overall productivity. Thus, the new power is not an anatomo-politics of the human body but biopolitics of the human race.

Foucault (2003) attributes strategic importance to sexuality in the 19th century. It is because sexuality is a domain that crosscuts the body and the population simultaneously. Firstly, it is "an eminently corporeal mode of behavior" (Foucault, 2003, p.251). Therefore, power may diffuse into bodies through sexuality and discipline them. Secondly, sexuality has a procreative element, and thereby it affects the broader biological process. Hence, it has a vital role in regularizing the population. Consequently, sexuality exists at the intersection of the body and the population.

In her famous book named “Fatal Advice: How Safe-Sex Education Went Wrong”, Cindy Patton (1996) argues that a national pedagogy was employed in order to form a new American identity in the US during the first decade of the AIDS epidemic. She (1996) argues that post-1960s America was in an identity crisis, and its capitalist, cosmopolitan culture endangered the idea of “nation”. The emergence of a deadly sexually transmitted virus has been an opportunity to compensate for the failing American identity. A certain type of lifestyle and sexuality was encouraged through this new American identity and the fear of HIV transmission.

Patton (1996) states that the American government remained silent about AIDS for a long time in the epidemic’s early years. Throughout this period, on the one hand, AIDS was frequently associated with the lifestyle of gays and gay identity in the media. This lifestyle included sex work, drug use, and polygamy. On the other hand, a sense of compassion for PLWHA was created through beloved national figures, also known that were infected with HIV, such as Rock Hudson, Ryan White, Ali Geertz, and Magic Johnson. America’s initial response to AIDS was to propose a new paradigm of citizenship. While this new paradigm teaches people to be compassionate towards those living with AIDS, it has made them believe that they will never be infected with HIV because the average American could not have a lifestyle that would bring them sickness.

According to her, the government took advantage of the initial response when the Surgeon General’s 1988 campaign was launched (Patton, 1996). There were two main objectives of the campaign. The first one was to teach the American people that HIV is not transmitted by casual and social contact. By doing so, the campaign aimed to calm the fear of being infected with HIV within the general public. The second one was to advise the general public not to discriminate against PLWHA by

reminding them that PLWHA were under the protection of laws forbidding discrimination against disabled people. The campaign aimed to teach American citizens to be compassionate towards PLWHA. Compassion was an essential part of this new identity. This compassion was based on the idea that there was a distance between them and those living with AIDS. This national pedagogy told people that as long as they distance themselves from a certain type of lifestyle and sexuality, they can be compassionate citizens who are free from the risk of HIV transmission.

According to her, the national pedagogy was based on two basic approaches to sexual education (Patton, 1996). The first approach of sexual education targeted the general public. For example, there was no content in the campaign teaching the general public how to use risk reduction methods during sex. Instead, citizens were encouraged to avoidance tactics. It was advised to avoid dating people who had multiple partners currently and those who used drugs before throughout the campaign. It was the individuals' responsibility to ask people about their sexual history and their experience with drugs before dating them. It was the individual's responsibility to learn whether their prospective sexual partners had any STD. The second approach of sexual education targeted risk groups, that is, the gay community. Public health organizations provided safe sex education by using risk group-focused strategies instead of population-based strategies. It was claimed that the reason for this was not spreading the fear of AIDS in the general public. The choice of this strategy reinforced both the image of sexually deviant gays with AIDS and the general public's belief that they will not be infected. Apart from that, HIV testing has become widespread since 1985, but the risk group-focused strategy continued. It was believed that knowledge of serostatus would cause behavioral changes such as practicing safe sex or disclosing their status. In short, based on these

two approaches, the national pedagogy thought PLWHA the idea that they deserve the compassion of American citizens only if they do not infect the rest of society, that is, testing and practicing safe sex (Patton, 1996).

I think Patton's concept of national pedagogy and Foucault's account of the relationship between power and sexuality can be considered together (Patton, 1996; Foucault, 2003). As Foucault (2003) stated, while the sovereign maintains his power through their ability to kill, biopower emerges with the power to make life. This shows us that power can be not only repressive but also productive. In Patton's story about the US, we can see how sexuality turns into the realm of such power (1996). On the one hand, national pedagogy identifies a certain lifestyle and certain sexuality with life and spreads this kind of lifestyle and sexuality to the general population. It produces monogamous and heterosexual sexuality and a lifestyle in which you do not buy or sell sexual services or drugs. On the other hand, it disciplines the bodies of PLWHA with the methods of public health. It expects PLWHA to use their bodies in certain ways through sexual education. It teaches that only in this way they can deserve compassion. If they do not use their bodies in ways that disciplinary power dictates, more repressive power techniques can come into play.

Bayer and Fairchild-Carrino (1993) report that 10 PLWHA were quarantined because of their alleged recalcitrant behavior between 1990 and 1992 in the US. Recalcitrant behavior means that PLWHA continues to have sex with others, knowing that they live with HIV. According to the research, people who engaged in these behaviors between these dates were seen as a "public health threat" and were subjected to quarantine measures in accordance with the public health laws of the period (Bayer & Fairchild-Carrino, 1993). They (1993) states that although these quarantine measures were legal in 25 states, they were not used widely. Yet, they

underline that these measures are devices of social control. mostly sex workers and gays were subjected to quarantine measures.

A more recent study shows how public health interventions may become a means of social control in Michigan (Hoppe, 2013). Hoppe (2013) states that according to Michigan's health-threat laws, it was a crime for PLWHA to have sex without disclosing their status at the time Hopes conducted his research. What's more, the Michigan law criminalized HIV non-disclosure regardless of the presence of malicious intent or risk-reducing measures. In addition, the same law allows the use of public health measures such as mandatory testing, counseling, and quarantine for people viewed as a public health threat. Hoppe (2013) interviewed 25 local officials from 14 health jurisdictions and found that public health threats cases were identified in two ways. With the insights gained from the medical social control literature, he (2013) conceptualizes these two ways as formal and informal social control techniques.

Hoppe (2013) states that health officials use public health technologies such as partner notification, HIV testing, and name-based reporting for legal surveillance in formal social control. Interviewers maintained that they ask clients newly diagnosed with HIV or another STD to give their previous sexual partners' names. They also ask if these partners have disclosed their HIV status before sex. After that, they check whether the reported names are in the state's database of PLWHA people. If health officials identify that any of the reported names are on the list, they assume that these persons had unprotected sex, knowing that they are infected with HIV. With this cross-check method, they aim to identify public health threats. Hoppe (2013) argues that this technique is based on a wrong assumption that HIV or any other STD transmits only with unprotected sex.

Hoppe (2013) reports that the informal social control technique was based on "third-party phone reports". Accordingly, residents accuse someone in their community of having sex without disclosing their status even though they know they are HIV-positive. Some health officials stated that they did not have the authority to take action on the reported names since the information from these calls did not provide sufficient evidence, but if these names were on the list, they visited these people under the pretext of routine control.

Research conducted by Bayer and Fairchild-Carrino (1993) and Hoppe (2013) revealed that public health interventions might become a site of social control against PLWHA. As Hoppe (2013) mentioned, another field of social control is medicine. Foucault (2003) also attributes strategic importance to medicine. It is because medicine is a science that can link the knowledge of organic (body) and biological (population) processes with each other. He (2003, p.252) defines medicine as a power-knowledge that is "a political intervention-technique with specific power-effects". Moreover, medicine and sexuality are very intertwined spheres. As Patton's story about the AIDS crisis in the US shows, STDs may become a valuable vehicle for power to have effects both at the population and the individual level, thanks to medicine (1996).

Conrad (1992) reveals how medicine can become the domain of power in his famous article named "Medicalization and Social Control". According to him, medicalization is "a process by which non-medical problems become defined and treated as medical problems, usually in terms of illnesses or disorders" (Conrad, 1992, p.209). Conrad (1992) argues that medicalization is not an inherently bad thing. However, medical interventions are concerned with their efficacy regardless of their social consequences. It also has a special power, coming from its authority to

define and categorize specific behaviors, emotions, and persons. Thus, it may become a device of social control easily. It is not a must that this control will always be applied by medical professionals. It is because the key point of medicalization is the emergence of medical definitions for a non-medical issue. For example, in the context of HIV, certain persons, and sexual behaviors are defined and categorized by medical terms such as risk groups and risk behaviors.

Conrad (1992) identifies three types of medical social control. These are medical ideology, collaboration, and technology. In medical ideology, social and ideological interests are the main motivation to impose a medical framework. In medical collaboration, physicians as gatekeepers, information providers, technicians, and institutional agents are the mediators of social control. In medical technology, technologies that medicine offers, such as any type of screening, surgery, and drugs, are the devices of social control. In addition to these three types, Conrad borrows the concept of medical surveillance from Foucault and adds the fourth type of medical social control. In this type of social control, specific behaviors and specific conditions become subject to “medical gaze”. Hence, the physician can have authority over the activities regarding the condition.

Sexuality is an area of medicalization to a certain extent. Medicine interferes with people’s bodies and sexuality, especially under the pretext of STDs. Sometimes this can happen without the consent of the individuals. Mandatory HIV testing is an example of this. WHO and UNAIDS (2017) stated that mandatory or compulsory testing of people was not supported on the grounds of public health and HIV testing must respect human rights and personal autonomy. It is because public health and human rights reinforce and complement each other. However, it is still a widespread practice in many parts of the world.

Sheikh and Porter (2009) conducted research to investigate the perspectives of the practitioners on mandatory testing of patients before surgery in India. They (2009) report that pre-surgical HIV testing without consent and denial of care based on the result of pre-surgical HIV testing is a common practice in India. In the study, respondents reported several reasons to impose mandatory testing on patients before surgery. The first theme was the notion of risk. Most respondents stated testing is important to avoid the risk of becoming infected. Researchers (2009) reported that although practitioners had the necessary equipment for universal precaution, they did not consider it sufficient and claimed that mandatory testing was a preventive method. Secondly, respondents argued that pre-surgical testing was a practice indicating professionalism and thoroughness to achieve hygiene and safety. The researchers (2009) highlighted that the practitioners were confusing the use of hygiene and safety measures with mandatory testing. Another reason suggested by the respondents was the primacy of the surgical act. They argued that performing the surgery successfully was the most important task, and therefore surgery had a critical and demanding nature. They cited mandatory HIV testing as one of the many practices to provide near-ideal working conditions and specific requirements of the surgery.

Mandatory testing is a violation of individuals' rights, such as the right to bodily integrity and the right to privacy in the name of public health and professionalism. Moreover, it may cause further violations, such as the denial of care of PLWHA. This practice can be seen as a type of medical social control. In the research (Sheikh & Porter, 2009), respondents mentioned the primacy of the surgery and professionalism in order to justify the practice of mandatory testing. Their

patients were subject to “medical gaze”. So that the physicians laid claim authority over activities and bodies of the patients.

In this section, I tried to analyze HIV policies by associating them with the concepts of sexuality and medicine. Moreover, I have attempted to show how sexuality and medicine can be seen as a field of power. It is obvious that public health interventions such as name-based reporting, HIV testing, and partner notification include a kind of disclosure of HIV status. Moreover, these public health measures have primary importance in order to be able to implement further public health measures such as quarantine. However, we saw in this section that these interventions could easily turn into tools of social control and power. Consequently, HIV and efforts to eradicate it cannot be perceived only as a medical issue. Furthermore, treating HIV as a purely medical issue can justify and reproduce the discrimination PLWHA has experienced.

2.2 An overview of the literature regarding sexual ethics and public health interventions

In this section, I will attempt to provide an overview of the debates on sexual ethics and public health interventions from the perspective of the rights of PLWHA, centering on the issue of disclosure in light of the insights provided by the previous section. Also, I want to show how the debates evolved with the changes in the epidemiological course of the epidemic and medical developments. By doing so, I hope to be able to identify factors shaping the perspectives on HIV disclosure. I argue that HIV is not just a medical issue. Nevertheless, we must recognize that medical and public health interventions are indispensable both for PLWHA and for the rest.

2.2.1 Sexual ethics and public health interventions in the early onset of HIV epidemic

The first HIV case was reported in the United States in 1980 ("History of HIV/AIDS", n.d.). In the early years, AIDS was called the 4H disease because it was thought to occur only in homosexuals, Haitians, heroin users and people with hemophilia. Although this nomenclature had no medical basis, it was a hint that HIV would become a tool to increase the pressure on already marginalized groups. Similarly, the virus was also named gay-related immune deficiency (GRID) because it was believed that the virus was spreading among people with a certain lifestyle that is also owned by gays ("People With AIDS", n.d.). In presenting the early years of the HIV epidemic, I will focus more on the experience of the gay community.

With the onset of the AIDS epidemic, homophobia became much more common in American society. There were several reasons for that. Firstly, during the early years of the epidemic, the transmission routes of the virus were unknown. (Epstein, 1996). Secondly, as Patton (1996) reports, the silence was the only policy the American government followed until the Surgeon General campaign in '88. Thirdly, the gay community was one of the groups most affected by the virus ("People With AIDS", n.d.). All these factors caused the homophobia that already existed in American society to intensify. For example,

In the first decade of the AIDS epidemic, the gay community has struggled to survive from a deadly virus in the face of homophobia of the American society and the silence of the government. Not surprisingly, they had a distrust of medicine and public health institutions during these years (Bayer, 1991; Epstein, 1996). Epstein (1996) claims that the gay community had already had distrust in medicine before the AIDS epidemic because it labeled them as "sick". However, with the onset of the

epidemic, this distrust became more acute. Bayer (1991) argues that this distrust has played a decisive role in public health responses because it has hindered the implementation of public health measures as in other epidemics. In parallel, Epstein (1996) argues that the attitude of the gay community was decisive in HIV policies. However, he points to another factor besides distrust. He states that the gay community struggled against medical institutions in the 1970s because these institutions categorized homosexuality as a disease. On the contrary, with the emergence of the virus, they changed strategy from demedicalization to the use of medical methods for their own interest. However, they were not simply co-opted with medical institutions. They struggled to influence knowledge production. Many gay HIV activists have become expert enough to be able to measure the credibility of AIDS trials. They even conducted their own clinical trials. He argues that this is why they had an impact on HIV policies.

I argue that as a result of distrust and adverse health effects of HIV, the gay community developed its own sexual ethics. By doing so, they have developed their own preventive interventions within the community. They also challenged public health principles with the knowledge they produced on sexual ethics. In the remainder of this part, first, I will explain the sexual ethics of the gay community and then the criticism of the gay community of public health interventions.

2.2.1.1 Sexual ethics

Drugs for antiretroviral therapy (ART) were first invented only in 1987, and the virus started to spread again after a while, as the drugs originally used could not suppress the immune system for a long time (“History of HIV/AIDS, n.d.). Effective modern antiretroviral therapy was invented in 1996, and this method is called highly active

antiretroviral therapy (HAART) (“Management of HIV/AIDS”, n.d.). Since there is no treatment opportunity and the epidemic has been ignored by the state, the groups affected by this epidemic have started to look for ways to fight it themselves. A group of gay-led activists set up peer support groups in San Francisco and New York (“Gay Men’s Health Crisis”, n.d.). Gay Men’s Health Crisis was established in 1982 and was one of the first organizations to work in this field (“Gay Men’s Health Crisis”, n.d.). In 1983, a group of HIV activists realized that the AIDS crisis was not even mentioned at the National Lesbian and Gay Health Conference and attended the conference and declared their so-called Denver Principles (“Gay Men’s Health Crisis”, n.d.). The Denver Principles became one of the founding texts of HIV activism.

This text advises people living with HIV to disclose to their partners with whom they had sexual intercourse and to have safe sex for people who were not infected. (Ainslie, 1999). However, when it was realized that the virus could survive in humans without showing symptoms for a very long time, the advice to disclose to partners was thrown into the secondary plan by the gay community because a policy based on the disclosure of people living with HIV was not enough to reduce the spread of the epidemic. Safe sex was the most effective method against the epidemic. Moreover, a policy based on disclosure gave an incentive not to test those who were not infected and to lie to those who were infected because individuals could fear discrimination and rejection by their partners. This set of principles put forward by the gay community is also called safer sex ethics (Ainslie, 1999).

However, in order to understand how these principles came about, the historical background described above, and the peculiarities of the gay community should also be kept in mind because these principles did not appear only for practical

purposes aimed at preventing the epidemic (Ainslie, 1999). There are two reasons to understand why this kind of ethics originated in the gay community. Firstly, gays consider sexuality as one of the main sources for defining their existence due to the exclusion they were exposed to because of their identity and created a subculture dominated by sex-positivity. Multi-partnership and casual sex are quite common in the community. This ethics prevents people from deciding whether their partners will have sex with them based on their HIV status because sex should be done safely under all circumstances. Secondly, as HIV is so prevalent among the gay community, the likelihood of any gay's close friends or herself becoming infected is very high, and inter-community solidarity has been achieved through a policy that does not force disclosure. With this kind of ethics, the responsibility for combating the epidemic is not only left on the shoulders of people living with HIV and AIDS (PLWHA) and is owned by the whole community. Thus, they are spared isolation and the possibility of lying about their status (Ainslie, 1999).

2.2.1.2 Public health interventions

The approach of the public health professionals were different from the safer sex ethics of the gay community. Public health systems have adopted methods to combat the epidemic by collecting people's health information and using that information for the well-being of the public (Gostin, 2000). This method made it easier for public health agencies to identify and respond to health risks and to inform the public about them and gave them the ability to influence funding decisions. These institutions used methods such as name-based HIV reporting and partner notification accordingly. These practices have been highly criticized by community organizations due to concerns such as violation of privacy and the emergence of discrimination.

Indeed, these concerns were not unfounded. For example, in the 1990s, a health official in Florida disclosed a list of people living with HIV to a dating site. Although there are examples where the methods of public health institutions violate the rights of people living with HIV, they are very effective tools in combating the epidemic. For example, the partner notification method allows contact tracing, and people at risk can take protective measures before getting infected (Gostin, 2000).

Bioethics is also important to understand the public health approach because its principles are of universal importance for public health professionals. It is a field of study that addresses ethical issues that arise in the provision of health services. It has four fundamental principles such as respect for autonomy, beneficence, non-maleficence, justice (Beauchamp & Childress, 2001). The principle of beneficence obligates to act in a way that will create the best possible outcome for the patients. The principle of maleficence describes an obligation to avoid deliberate harm or intentional omission that would cause possible harm. However, these two principles are not enough because what is beneficial to one person may be harmful to others or what is beneficial for the public may be harmful for individuals. The principle of justice requires to distribute the cost and benefits fairly and therefore complement other two principles. On the other hand, the principle of respect for autonomy addresses to the capacity of individuals to weigh costs and benefits and decide what is best for them without coercion.

In relation to the principles of bioethics, it is seen as a professional duty to warn people and protect their health when there is a predictable risk for public health workers (Gostin, 2000). There are even laws that define the “duty to warn”. Thus, this is not only a professional code of ethics but also a legal responsibility, and the method of partner notification was employed to fulfill this legal and professional

responsibility. There are two types of models of partner notification such as partner referral and provider referral. In partner referrals, infected people are asked to inform their contacts. In provider referral, public health personnel take the responsibility to inform partners at risk and provide counseling and treatment (Gostin, 2000).

Ainslie (1999) argues that this expert ethics takes the Tarasoff case as a reference point. According to this case, one of the clients of a psychiatrist says that he intends to kill a woman named Tarasoff, and later this psychiatrist is held responsible for the damage she suffered because the psychiatrist did not give the necessary warning. Although public health professionals take this case as their point of reference, they also consider conditions specific to the HIV epidemic. They take confidentiality precautions to prevent people from suffering from HIV stigma. They also care about building a relationship of trust with the community, as public health can be achieved through people's collaboration with experts. For example, they think that practices that comply with the privacy of private life will encourage people to take tests (Ainslie, 1999).

In addition to these, Ainslie (1999) argues that expert ethics must show two more parallels with the Tarasoff case. First, in the Tarasoff case, there was a clear intention to harm, and there was a fundamental moral violation. Second, Tarasoff's damage was predictable, and she was a potential victim. Thus, a warning was necessary. Based on this, he argues that expert ethics includes two assumptions. First of all, disclosure of PLWHA is an obligation. Second, this kind of ethics considers the person at risk to be infected with HIV as a victim.

Safe sex ethics does not deem disclosure as an obligation because it contends that it is the responsibility of all parties to have safe sex. It can be argued that safe sex ethics puts an emphasis on the principle of self-autonomy. On the other hand, it

can be argued that public health professionals' duty to warn (i.e., telling their patients' HIV status to third parties) is an implication of the principle of justice because public health professionals should distribute costs and benefits fairly. That is, there is a tension between the principle of respect for the autonomy and the principle of justice.

Ainslie (1999) states that bioethics mostly thought of the case of bisexual men cheating on his wife and hence considered disclosure as a moral imperative. Since the reference case was bisexual man cheating on his wife, it became inevitable favoring of public health in the expense of the rights of individuals while managing to tension between respect for autonomy and justice. He asks why didn't public health professionals and expert ethics see the experiences of the gay community at the heart of the epidemic? According to Ainslie, in a statement made by US Surgeon General Everett Koop in 1987, he wrote that PLWHA should avoid sex with seronegative people. Moreover, some US state legislatures even offered to criminalize the sexual activity of PLWHA. In short, they intended to establish a cordon sanitaire between PLWHA and others. Ainslie says that in such an atmosphere, bioethics neglecting to examine the experiences of the gay community can easily be seen as serophobia or homophobia. He suggests that transcending the dichotomy between the general public and the PLWHA can be overcome by including these experiences in the studies as a case.

2.2.2 What happens to sexual ethics when the population affected by the HIV epidemic changes?

Due to the silence of the American government and the distrust of the gay community in public health and medical institutions, the sexual ethical principles of

the gay community formed the basic paradigm in the fight against AIDS until the 90s. On the other hand, preventive public health interventions have not been implemented as effectively as in epidemics caused by other viruses. Public health agencies did not treat HIV the same as other STDs due to AIDS organizations' concerns for privacy and confidentiality. Bayer (1991) calls this situation HIV exceptionalism.

One of the important developments in the 1990s was the partial end of HIV exceptionalism. As a result of scientific studies since the beginning of the epidemic, more information about HIV has been gained, and the effectiveness of public health measures has been proven (Bayer, 1991). For example, in the first years of the introduction of HIV tests in 1985, the gay community still prioritized safe sex over HIV testing because the results of the tests were not valid for sexual contacts in the last six months. However, when it became clear that HIV could be asymptomatic, the gay community began calling for HIV testing in 1989 (Bayer, 1991). In addition, few states have used the name-based reporting system until 1991, although HIV has been reportable since 1983 (Bayer, 1991). This was due to the view that people might avoid being tested because of privacy concerns. With the spread of testing, name-based reporting began to be seen as a more effective prevention intervention. In 1990, the Centers for Disease Control and Prevention (the CDC) declared its support for name-based reporting (Bayer, 1991). Finally, with the widespread use of name-based reporting, partner notification may be an effective preventive intervention. Since 1990, nearly a dozen states have passed laws that allow physicians to warn partners of people diagnosed with HIV (Bayer, 1991).

Another important development in the 1990s was the changing course of epidemiology. Especially after the mid-1990s, the HIV epidemic began to affect

other vulnerable groups (Dixon-Mueller, 2007). For example, HIV began to spread among adolescent girls and married women because the gender inequality greatly weakened the bargaining power of these two groups vis-à-vis men regarding condom use. HIV also began to spread among racial and ethnic minorities, immigrants and refugees because they did not have access to information and materials on sexual health. Bayer (1991) claims that this change in the course of epidemiology is also one of the reasons for the end of HIV exceptionalism. He argues that public health measures have become widespread because ethnic minorities are not as organized as the gay community, and concerns about privacy are not widespread. Apart from this, the changing course of epidemiology has led to the need to question the effectiveness of the sexual ethics of the gay community. Bayer (1996) claims that the safer sex ethics, which is based on self-protection, does not work for women and young gays because they are vulnerable to get infected by men or older generations due to structural inequalities. For example, MacGregor and Mills (2011) state that there is a correlation between gender-based violence, poverty, and HIV infection among women. Thus, Bayer (1996) suggests rethinking sexual responsibility and disclosure to partners.

MacGregor and Mills (2011) interviews women living with HIV from South Africa in order to explore how these women negotiate their responsibilities, such as adherence to ARV and HIV disclosure and their sexual and reproductive rights. By analyzing what they gathered from the interviews, the researchers identify a few themes. The first theme was the response of these women to the HIV diagnosis. One of the women stated that although she thought she was infected by her husband, she could not tell for fear of being abandoned. Another respondent stated that she received a positive reaction when she revealed her status to her partner, but they

never met again afterward. The majority of respondents stated that they did not disclose their status due to fear of violence and abandonment. The second theme was the difficulties with negotiating disclosure in sexual relationships. One of the women stated that she has not had a partner since her HIV diagnosis and was looking for a husband who would understand her "situation". Others reported that they prefer to use condoms instead of disclosure. However, they stated that men often refuse to use condoms, and they cannot insist on using condoms.

Another study regarding perspectives of women living with HIV on disclosure was conducted with African American women living with HIV in the South-eastern United States, who were also primary caregivers of young children (Black & Miles, 2002). The study focused on the process and the patterns of disclosure of these women to their husbands, their families, and communities. Participants reported that their disclosure process was determined by calculating risks associated with disclosure and benefits of disclosure. Some women found disclosure to be risky because they had witnessed reputable people within their communities making stigmatizing speeches about AIDS or other women gossiping about women living with HIV. Moreover, some participants felt stigmatized by the healthcare professionals. On the other hand, the benefit of disclosure for these women was that they met their need for support. For these women, talking about HIV and receiving emotional support was an unmet need. In addition, it was an important need to get help in childcare for these women who had to go to the clinic at regular intervals. Disclosure could ensure that these needs were met. These women mostly carefully managed the information about their illness. They measured the risks and benefits repeatedly in the process. The disclosure, they reported, occurred at the "right moment" when they needed additional support.

These two studies (Black & Miles, 2002; MacGregor & Mills, 2011) show that women and gays have different priorities when negotiating the issue of disclosure. The gay community has developed a sex-positive culture against discrimination based on their sexual identity, and therefore sexual freedom is of vital importance to them. Also, gays do not experience gender inequality because they have sex with same-sex partners. Safe sex ethics based on the use of condoms rather than disclosure is suitable for the gay community. However, women experience gender inequality and as a result, being free from violence and coercion is a priority for them. Women's agency may be weak due to structural inequalities. This makes it difficult for women to practice safe sex ethics. As mentioned above, men can insist on not using condoms (MacGregor & Mills, 2011). Moreover, women can become infected with HIV as a result of the sexual violence they are exposed to (MacGregor & Mills, 2011). For all these reasons, women's views of the disclosure may differ from the gay community. Adam et al. (2015) reported that heterosexual women have the highest expectation rates of their sexual partners to disclose them, followed by heterosexual men, bisexual men, and gay men. In parallel with this, MacGregor and Mills (2011) reported that the respondent women had a sense that they were victims of their previous male partners who did not disclose their status on contrary to the critique of the gay community regarding being perceived as victims. Nevertheless, the respondents were tolerant of women who did not disclose their HIV status (MacGregor & Mills, 2011). In short, women's attitude to HIV disclosure reflected gender inequalities.

2.2.3 What lessons safe sex ethics can teach us today?

In the 2000s, important developments took place in the field of HIV treatment. Problems such as high drug prices, limited access, and insufficient clinical data on safety have begun to be overcome (Ford et al., 2017). Furthermore, according to UNAIDS (2018), three large studies conducted between 2007 and 2016 showed that virally suppressed people living with HIV did not infect their HIV-negative partners. Based on these studies, UNAIDS (2018) launched a campaign to give the message of "Undetectable=Untransmittable" (U=U)[2].

All these developments have led to radical changes in the public health approach to HIV because ARV therapy could now be used not only to treat PLWHA but also as a preventive public health intervention to end the epidemic. Accordingly, UNAIDS (2021c) set 90-90-90 targets to accelerate progress towards ending the AIDS epidemic as a public health threat. Accordingly, it is aimed that 90 percent of those living with HIV know their HIV status, 90 percent of those diagnosed with HIV will sustain antiretroviral therapy, and 90 percent of those who sustain therapy will be virally suppressed by 2020.

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[2] The new generation of HIV activists in Turkey translate the word "transmission" as "aktarım" (transference) instead of "bulaş" (contagion) because they claim that the negative connotations of "bulaş" contribute to the stigmatization of people living with HIV. However, activists translated the "Undetectable=Untransmittable" campaign as "Belirlenmeyen=Bulaşmayan" or "Belirlenmeyen=Bulaştırmayan" so as not to diminish the punch of the campaign's name. However, the choice between "bulaşmayan" and "bulaştırmayan" has been a matter of debate between the new generation of and the older generation of activists living with HIV. The new generation of activists preferred the word "bulaşmayan" because it has a more neutral connotation than "bulaştırmayan", they argued, and it frees us from the logic that makes people living with HIV "guilty" of HIV transmission. They also argue that this usage is more grammatically correct since both "belirlenmeyen" and "bulaşmayan" describe HIV. Older generation activists, on the other hand, defend their translation, arguing that U=U campaign launched for the first time in Turkish with the translation "bulaştırmayan", and that this is how it is used in the literature. Nevertheless, this debate on "gramatically correct translation" appears to be secondary because the underlying distinction is between the new generation of activists who see eliminating the negative cultural connotations attached to HIV as a way to avoid stigmatization and discrimination, and the older generation of activists who see the sense of "fear" created in reference to these negative connotations as a useful pedagogical tool to educate the public against the spread of HIV.

In parallel with this, WHO declared its vision for a public health approach in 2006 (Ford et al., 2017). Accordingly, the main aim of the new vision was to scale up ARV, especially in resource-poor settings. After it became clear that ARVs can prevent transmission, it has become a top public health strategy for those living with HIV to learn their own HIV status and start therapy in the early stages. In order to achieve this strategy, key principles of the approach were promoted as the standardization and the simplification of ARV regimens, task shifting, decentralization, and the integration of HIV treatment and care. After WHO set forth its vision of public health approach, the number of people who were receiving ARV therapy increased from 1.3 million to 19.5 million people in low-income and middle-income countries (Ford et al., 2017).

Advances in the medical field and the promises of the public health approach have raised the hopes of the end of the AIDS epidemic all over the world. Faith in preventive public health interventions is no longer as low as it was in the 1980s. However, disclosure is still a big problem for PLWHA due to stigma and discrimination against PLWHA. This situation still causes people to be wary of HIV testing or to be skeptical of public health methods such as partner notification and name-based reporting.

In 2014, a study was conducted with PLWHA to discover their characterization of responsibilities and expectations regarding HIV disclosure in their sexual life in Canada (Adam et al., 2015). In this study, data were collected through two survey questions added to two cohort studies conducted in Ontario and in-depth interviews with 122 participants in these studies. In the first survey question, the participants were asked about the expectations of their casual sex partners to disclose them and their practices of disclosure to these partners. In the second survey

question, the reasons determining whether they disclose their own status or not were asked to the participants. The survey found that almost 50 percent of the respondents do not have a casual sex partner. Additionally, almost 45 percent of respondents expected their HIV-positive partner to disclose their status to them. The expectation for disclosure of HIV-negative partners was in the range of 20-25 percent. This shows that the expectation for PLWHA to disclose their status is widespread. The survey also found that most participants either disclose to their sexual partners or don't have sex with partners whose HIV status is negative or unknown (Adam et al., 2015).

As part of the same study, data collected from in-depth interviews with PLWHA proved that there are multiple rationalities behind the decision to disclose. Some participants reported that the obligation to disclosure and the fear of rejection created a double bind, and therefore disclosure turned into an uneasy act. Others experienced the obligation to disclose as an act that breaks HIV taboo. Some assessed the feasibility of disclosure through certain assumptions and intuitions by reading the context. Several participants stated that they employed indirect or partial forms of disclosure. For example, they had a talk about HIV with their partners. In the gay community, the practice of reading the context has led to the assumption that someone who wants to have unprotected sex gives a sign that they were HIV-positive because the gay community was considered to have a high level of awareness of HIV, and protection is routine. However, for some other gays in the study, this tacit assumption resulted in misunderstanding or deception that caused exposure to HIV. As a result, disclosure is an emotionally complex act. Having misread cues or personal histories of individuals involved complicates the decision to disclose or how to disclose even more. As a strategy to avoid of emotional complexities of disclosure,

some participants reported that they have sexual and romantic relationships only with persons living with HIV (Adam et al., 2015).

Another study (Edelman et al., 2014) was conducted to examine the experiences and the perspectives of medical case managers (MCS), disease intervention specialists (DIS), and men who have sex with men (MSM) in the US. In collaboration with an AIDS service organization and the Connecticut State Health Department (Edelman et al., 2014), data was collected through a focus group of MCS and in-depth interviews with DIS and MSM. The study shows that there are differences between the perspectives of MSM and providers.

First, providers and clients have different perceptions of determinants of sexual risk behaviors. MSMs stated that stigma and discrimination lead to risky behaviors such as drug use and anonymous sex with multiple partners. On the other hand, providers claimed that the reason for the risky sexual behavior was internet use and the sex-loving nature of men. Second, there are different perceptions of factors influencing the disclosure of MSM among MCS, DIS, and MSM. There were those among both providers and MSMs who felt that disclosure would be limited for reasons such as fear of denial and stigma. On the other hand, there were those among both providers and MSMs who considered disclosure as a must. Although there are differences of opinion among them, the researchers suggest that there are indications in providers' responses that they do not understand much of the dynamics that cause stigma and fear of rejection.

The third theme that the respondents mentioned was the barriers to trusting relationships between MSM and providers. Both providers and MSM stated that it is important to understand the emotions of the clients and to withhold judgment in order to build a trusting relationship between them. However, some providers argued

that the health care system context within which they are working created some barriers. For example, a provider reported that it takes time to establish a trust relationship with a client, but the system punishes spending a long time with a single client (Edelman et al., 2014).

These two studies show that both the implementation of preventive interventions based on disclosure, such as partner reporting and disclosure to sexual partners, pose problems for PLWHA (Adam et al., 2015; Edelman et al., 2014). The findings of these two studies show that Ainslie's (1999) criticisms are still valid. Firstly, PLWHA prefer to have sex with HIV-positive people to avoid the emotional turmoil of disclosure (Adam et al., 2015). This brings to mind the criticism of the establishment of a cordon sanitaire between PLWHA and others that Ainslie (1999) mentioned. Secondly, public health specialists do not understand the dynamics that cause stigma and fear of rejection and the experiences of PLWHA properly (Edelman et al., 2014). As Ainslie (1999) suggested, the public health approach takes the experience of PLWHA into consideration in order to overcome the barriers between PLWHA and public health specialists.

Webber (2013) argues that public health implicitly or explicitly always codes sexually transmitted diseases as a risk and assumes that people will avoid risks because they are rational beings. This is the reason why there is a gap between the experiences of PLWHA and the expectations of the public health approach. For example, the public health approach assumes that people will always have safe sex if they know that they or their partners are HIV positive. Moreover, public health makes a distinction between the rational person and the irrational person and explicitly or implicitly codifies the rational person as heterosexual, monogamous, and the person who doesn't sell or buy drugs and sexual services (Weber, 2013).

Thus, it codifies not only the infection itself but also certain locations, forms of relationship and sexuality, and people as risks (Weber, 2013).

For example, collective sex environments are coded as inherently risky because it is highly possible that there will not be dyadic sex in there (Frank, 2019). Frank states that collective sex environments are not homogenous because sexual risk-taking behaviors are affected by structural factors (such as safety and privacy) and psychosocial factors (such as intimacy, trust, and a lack of love). For instance, environments such as bathhouses and saunas may support safer sex because condoms and educational materials are often available, and risk reduction practices such as using condoms and changing them between partners, withdrawing before ejaculation, and using sex toys instead of penetrative sex are very common in these environments. On the other hand, unprotected penetrative sex and not withdrawing before ejaculation is very common in dyadic sex or in private homes because people have a chance to experience intimacy and privacy in these environments (Frank, 2019). Frank (2019) argues that the codification of certain locations, forms of relationship and sexuality, and people as risks may not be misleading.

Additionally, the assumption that disclosure will lead to safer sex may not be correct. A review of 25 studies attempted to find an answer to whether disclosure leads to safer sex (Simoni & Pantalone, 2004). Only 15 of 25 studies provided data to explore the relationship between disclosure and safer sex. They found conflicting results and did not find a consistent relationship between the two, unlike those who said disclosure is essential for safe sex. The authors highlighted that people might prefer not to be protected even if their partner is disclosed to them. The authors highlighted that people might prefer not to be protected even if they are disclosed to their partners. This is called “informed exposure”. People may choose “informed

exposure" because they consider it as a sign of their commitment to the relationship, or they may be under the effect of a drug during sex. Moreover, some people may have a sexual fantasy for "barebacking" (unprotected anal sex), which often exists as a subculture practice of the gay community.

Webber (2013) explores the sexual ethics and sexual practices of the Montreal queer community in her study. She shows that Montreal queer community provides collective sex environments, and these environments have three principles: accessibility, consent, and safer space. Accessibility means that spaces and materials for safer sex should be available for everyone in terms of physical, linguistic, and economic accessibility. The principle of consent highlights the importance of communication and consent during sex. Safer space refers to respect for people's boundaries and limits. The availability of safer sex materials in non-intrusive ways is directly linked to the safer space principle because these materials are tools for people to set their boundaries (Weber, 2013).

Montreal queer community's sexual ethics and practices challenge the mainstream public health approach in many ways (Weber, 2013). They do not reduce a satisfying sex life to staying away from diseases, and they introduce concepts like consent. Moreover, they use the concept of "safer sex" instead of "safe sex" because they argue that each practice protects at different levels from different diseases, and 100 percent safe sex is not possible. Additionally, they argue that people should decide for themselves how much "risk" they want to take, and they do not impose the use of "safe sex" materials as a necessity. The public health approach explicitly or implicitly suggests that the best way to avoid sexually transmitted diseases is to refrain from sex or to have a monogamous relationship or have penetrative sex with condoms. However, they show that kink sex practices such as fisting, bonding, using

sex toys are also a way of protection and that sex-negative suggestions are not the only way to avoid risk. Apart from that, they adopt the slogan “I do not have to tell my HIV status” by reminding that PLWHA using antiretroviral therapy do not infect others with HIV and thus criticize Canada’s laws that criminalize HIV non-disclosure. In short, they put the self-determination and sex-positivity values against the sex-negative and paternalistic methods of the public health approach (Weber, 2013).

2.3 Conclusion

In this chapter, I reviewed the literature on HIV disclosure from the perspective of the rights of PLWHA. The literature describes a tension between preventive health interventions targeting the population at large and the protection of the rights of PLWHA. I have tried to provide an overview of how the literature on HIV disclosure tackles the tension between preventive health interventions targeting the population at large and the protection of the rights of PLWHA from the perspective of PLWHA.

In the first section, I have tried to show that HIV is not just a matter of health at an individual level. We need to reveal the relationship between discourses and policies regarding HIV and power relations in order to understand why PLWHA suffer from discrimination and stigmatization since the beginning of the HIV epidemics. Foucault's conceptualization of power helps us understand this aspect of HIV. According to Foucault, power permeates by managing death and life through its technologies such as medicine, public health and population policies. Foucault's concept of power is useful in two ways for understanding the relationship of HIV to power. Firstly, HIV is intertwined with discourses about death and life since the first years of the epidemic. Secondly, HIV is an issue at the intersection of medicine,

public health, population policies, law and ethics. Therefore, HIV was both a useful instrument for power to operate with over life and death through its discourses and policies regarding HIV and a field for power to permeate into through its technologies. Once we establish the relationship of HIV with power, HIV is no longer just a health issue at the individual level. HIV can become an instrument of nation-building, as Patton (1996) suggests, or a social control over those living with HIV, as Hoppe (2013) shows. Accordingly, I also presented studies that critically address medicine and sexuality as a power domain. My purpose in addressing these studies was to show that treating the HIV epidemic as a purely medical issue can obscure the stigma and discrimination PLWHA has experienced.

In the second section, I tried to show how the view of sexual ethics and public health interventions has been shaped by changes in the course of epidemiology and medical developments. I argued that there is a conflict between PLWHA's experiences and the public health approach. Furthermore, in addressing this conflict, we must consider the diversity of PLWHAs' experiences and societal structures such as patriarchy and heteronormativity.

As a result of my literature review, I came across only one research conducted to explore the perspective of HIV activists regarding HIV disclosure[3]. I think that it would be a valuable contribution to the literature investigating how HIV activists negotiate the tension between preventive health interventions targeting the population at large and the protection of the rights of PLWHA while developing their perspective on HIV disclosure for a couple of reasons. First, learning from activists'

[3] The research has been published as an article under the following name: Hayley MacGregor & Elizabeth Mills, "Framing rights and responsibilities: accounts of women with a history of AIDS activism".

perspectives allows us to treat HIV as a public debate, not a mere medical issue. Second, it can contribute to bridging the gap caused by the public health approach's failure to take into account PLWHA's experience.

Apart from these, as a result of my literature review, I saw that all research was conducted either in underdeveloped African countries or in developed European and North American countries. Conducting research in Turkey as a developing country would be helpful to explore the unique problems and the advantages of developing countries in the struggle with the HIV epidemic.

CHAPTER 3

AN OVERVIEW OF THE HIV EPIDEMIC IN TURKEY

3.1 Legal framework of HIV in Turkey

The legal system discusses HIV non-disclosure, both as a right within the scope of the right to privacy and as a crime over the possibility of HIV transmission. For example, some countries have criminalized HIV non-disclosure to the extent of considering non-disclosure of PLWHA who take necessary precautions to prevent HIV transmission as a crime, and these laws undermine PLWHA's right to privacy. Furthermore, in countries where the criminalization of HIV non-disclosure is not that extensive, if they are not adequately informed about their rights, PLWHA may feel obliged to disclose even in cases where HIV non-disclosure would be considered as a right to privacy since they fear that they will be committing a crime. That is, although the cases in which HIV non-disclosure is a crime and the cases in which HIV non-disclosure is a right are not the same, ambiguity in the law about the difference between the two can in practice lead to overly criminalization of HIV non-disclosure and violations of the right to privacy. That's why it's crucial to discuss HIV criminalization and I will focus on that under this title.

According to UNAIDS (2021b), HIV non-disclosure, exposure or transmission was criminalized through HIV specific or general laws in 92 countries in 2020. As of December 31, 2018, the progress report regarding HIV criminalization published by HIV Justice Network states that there was a total of 75 countries which have laws specifically mentioning HIV (Cameron, 2019). However, countries without HIV specific laws still criminalize HIV through laws against endangerment, physical or sexual assault, or attempted murder. For example, half of

the HIV criminalization cases that occurred globally between 2015 and 2018 were through general criminal laws (Webb, 2020).

Expert consensus statement on the science of HIV in the context of criminal law (2018) argue that the fact that judges are so often informed by concepts produced at the onset of the HIV epidemic by public health professionals rather than current scientific knowledge prepares ground for the widespread criminalization of HIV non-disclosure currently. The public health approach produced simple definitions by comparing the possible risks of different acts in order to promote broad-based, effective public health education campaigns. Accordingly, public health terminology defines relative risk but not absolute risk. For example, it categorizes sexual acts as varying from "low risk" to "high risk". However, Barre-Sinoussi et al. (2018) maintain that up-to-date scientific knowledge shows that its generalized categories of riskiness may not reflect the actual risks at the individual level. For example, it is correct that sexual intercourse is a prevalent transmission route at the population level, however, at the individual level, the possibility of HIV transmission regarding a single sexual act ranges from no possibility to low possibility, while this possibility regarding oral sex, spitting and biting ranges from none to negligible.

Apart from that, these descriptions of public health originated in the early years of the HIV epidemic before the current scientific knowledge on HIV transmission developed. Despite the fact that risk categories of the early HIV epidemic were aimed at fortifying an influential public health education campaign to prevent HIV transmission, they create genuine handicaps for contemporary HIV health promotion based on up-to-date scientific knowledge (Barre-Sinoussi et al., 2018). For example, these risk categories fail at recognizing that HIV is not a fatal disease anymore and PLWHAs under treatment cannot transmit the virus thanks to

antiretroviral therapy. In the same manner, the courts often lack recent scientific evidence about HIV and use these challenged and population-level risk categories to justify their discriminatory decisions. For example, in many cases filed due to HIV transmission around the world, the court decided on the unscientific assumption that the party to be diagnosed with HIV first infects the other party (Webb, 2020). However, the expert consensus statement on the criminalization of HIV demonstrates that it is almost impossible to identify direction and timing of infection conclusively (Barre-Sinoussi et al., 2018). Consequently, the court and the judges need a different approach than the public health approach to discuss HIV criminalization because categories of population-level risks used by the public health approach may be misleading in the context of criminal justice (Barre-Sinoussi et al., 2018).

The lack of up-to-date scientific knowledge not only leads to discriminatory decisions by the courts, but also to vague and broadly written laws on HIV disclosure. Irrespective of whether HIV is criminalized through general criminal laws or HIV-specific laws, these broadly and vaguely written laws frequently lead to unrighteous prosecution of PLWHA (Webb, 2020). For example, even in cases where HIV transmission did not occur, the courts may punish PLWHAs because of perceived HIV exposure or HIV non-disclosure.

HIV exposure refers to any action that creates the possibility of passing HIV to the other person, regardless of the occurrence of HIV transmission. The reason why HIV exposure is criminalized is because courts assume that HIV exposure will always occur when a person engages in acts such as sexual contact, spitting, biting, or breastfeeding (Webb, 2020). However, as mentioned above, the possibility of HIV transmission through biting, spitting, or oral sex varies from none to negligible (Barre-Sinoussi et al., 2018). Additionally, the possibility of HIV transmission

through a single sexual act without condom ranges from no possibility to low possibility (Barre-Sinoussi et al., 2018). These are good examples of how the lack of current scientific knowledge leads to the criminalization of HIV disclosure through vaguely and broadly written laws.

In some countries, it is a legal obligation for PLWHA to disclose their status to their partners prior to any sexual intercourse (Webb, 2020). Moreover, some laws are written in such a way that if you have not been diagnosed yet, but you have a doubt about your HIV status, it is considered a crime to engage in sexual acts without sharing this suspicion (Webb, 2020). At this point, it is crucial to emphasize the difference between intentional act and recklessness. It is very clear that we cannot seek for intent when HIV transmission occurs from a person who does not know his or her HIV status to another. Apart from that, in some countries, courts have prosecuted PLWHAs even in cases where defendants used condoms or were under effective treatment, which could be evidence of no intent to harm. On the contrary, some courts still consider the fact that the defendant is under treatment as evidence of criminality instead of innocence (Symington et al., 2022). In parallel with that, Webb (2020) reports that many HIV criminalizing laws around the world impose heavy penalties on unintentional or "reckless" HIV exposure or transmission. UNAIDS (2008) states that extending criminal liability from intentional acts to recklessness can result in large numbers of people to be prosecuted without their being able to anticipate their liability for such a prosecution, and such miscarriage of justice should be avoided. Apart from that, an analysis shows that in almost 50 percent of cases, defendants were women, gay and bisexual men, immigrants, racial and ethnic minorities, sex workers or transgender people (Symington et al., 2022). Symington et al. (2022, p.9) state that "HIV criminalization is often used as a proxy

mechanism for increased state control, policing of marginalized groups, the enforcement of morality, and punishment of social vulnerability, thus exacerbating existing inequalities and power imbalances". Hence, many countries apply broadly and vaguely written criminal laws in a way inconsistent with recent medical knowledge. The application of criminal law in this manner exaggerates the power of HIV for damage to a person's health and wellbeing and the possibility of HIV transmission and therefore bolsters stigma against PLWHA (Barre-Sinoussi et al., 2018). Moreover, the criminalization of HIV leads to the violation of human rights, including the right to health, privacy, equality, and non-discrimination, and undermines efforts to prevent and treat HIV because the fear of prosecution based on HIV status discourages people to get HIV testing or to receive treatment (UNAIDS, 2021b). To prevent negative consequences of HIV criminalization, UNAIDS (2021b) suggests the following:

> The application of general criminal law should be limited to cases of intentional transmission, where a person knows his or her HIV status, acts with intention to transmit HIV, and does in fact transmit it. (….) Instead of criminalization, states should act to create enabling social and legal environments that support safe and voluntary disclosure of HIV, free of stigma and discrimination. They should ensure access to available, acceptable, affordable HIV prevention, testing and treatment and empower individuals to be able to negotiate safe sex.

Also, UNAIDS (2008) suggests governments refrain from enacting HIV-specific laws and instead "apply general criminal law to cases of intentional transmission" in accordance with international human rights obligations. In the light of this discussion by the international community of HIV advocates, which I have summarised here, I will examine the legal framework for the criminalization of HIV in Turkey.

There are some laws in the Turkish Constitution that are expected to provide constitutional assurance regarding areas where PLWHAs often experience violations of their rights. In the remainder of this section, I will first present the articles of the

Constitution that are supposed to provide legal protection for PLWHA, followed by a discussion on the quality of the constitutional protection provided by these articles. Finally, based on the implication of my discussion, I will explore the relationship between the laws that are supposed to protect PLWHA's right to privacy and non-discrimination in Turkey and the violations of rights and discrimination experienced by PLWHA.

The tenth article of the Constitution defines the principle of equality before the law as follows:

> Everyone is equal before the law without distinction as to language, race, colour, sex, political opinion, philosophical belief, religion and sect, or any such grounds. (The Turkish Constitution, 1982)

This article does not contain a provision that clearly prohibits discrimination, but it introduces constitutional equality which is a means of preventing discrimination (Güzel & Dikmen, 2020). For example, this article ensures that laws passed by parliament are such that they do not undermine the right of persons to be equal before the law.

Another vital constitutional protection for PLWHAs is contained in the provisions of Article 20. According to this article:

> Everyone has the right to demand respect for his/her private and family life. Privacy of private or family life shall not be violated (The Turkish Constitution, 1982).

Based on this article, PLWHAs have the right to confidentiality of their HIV status, as health information is considered a part of private life. Through this article, the private life of PLWHAs is protected from both the state and third parties at the constitutional level. However, in the same article, there is a provision regarding exceptional situations of this protection. Article twentieth states that:

> Unless there exists a decision duly given by a judge on one or several of the grounds of national security, public order, prevention of crime, protection of

> public health and public morals, or protection of the rights and freedoms of others, or unless there exists a written order of an agency authorised by law, in cases where delay is prejudicial, again on the above-mentioned grounds, neither the person, nor the private papers, nor belongings of an individual shall be searched nor shall they be seized (The Turkish Constitution, 1982).

One of the exceptions listed in the article is public health. In other words, according to this provision, the health information of PLWHAs can be used without their consent in order to protect the health of the broader public. In the continuation of the same article, there is a provision such as "Everyone has the right to request the protection of his/her personal data." (The Turkish Constitution, 1982). Thanks to this provision, the use of information that has become known to the state can also be restricted.

Article 56 and Article 60 are also very important in terms of providing constitutional protection for those living with HIV to access health services and treatment. According to the Article 56:

> Everyone has the right to live in a healthy and balanced environment. (…) The State shall regulate central planning and functioning of the health services to ensure that everyone leads a healthy life physically and mentally and provide cooperation by saving and increasing productivity in human and material resources (The Turkish Constitution, 1982).

Although the first paragraph of this article puts the environment at its centre instead of people, it imposes responsibility on the state to create a health policy with the provision that health services will be planned and regulated centrally (Güzel & Dikmen, 2020). In other words, the state is obliged to develop policies to protect the physical and mental health of those living with HIV and to increase their productivity due to this article. According to Article 60:

> Everyone has the right to social security. The State shall take the necessary measures and establish the organisation for the provision of social security (The Turkish Constitution, 1982).

This article clearly states that everyone has the right to social security. Access to treatment for those living with HIV is guaranteed by this article.

According to Güzel & Dikmen (2020), the Turkish Constitution does not describe "fundamental rights" in a clear and decisive way, especially in terms of discrimination. The phrases in the Constitution about how the exceptions will be realised are much longer than the explanations for the essence of the right. For example, Article 20 defines privacy as a right; however, it then introduces the exceptions to the right with a long explanation. This long explanation states that personal information can be processed without seeking the consent of individuals in cases stipulated in the law. It expresses predicted situations with rather vague terms such as "national security, public order, prevention of crime, protection of public health and public morals, or protection of the rights and freedoms of others". Therefore, the quality of constitutional assurances has been seriously undermined. Apart from this, the Article 10 enumerates certain forms of discrimination by name and puts a phrase such as "any such ground" at the end. However, there is no health status among the nominal forms of discrimination. The expression "any such ground" is expected to protect people living with HIV against discrimination. The tenth article limited the forms of discrimination by putting a bag provision at the end. In other words, it is left to the interpretation of the decision maker and the legislator to decide which features will form the basis for discrimination. Since a constitution is a fundamental text to describe rights, its contents are also written in a very general way. It does not include a detailed legal arrangement. It is expected to put general principles in order to be able to meet the needs of changing times effectively. They (2020) suggest that it is understandable that the tenth article puts a umbrella provision at the end instead of counting all forms of discrimination; however, the

constitution alone cannot guarantee human rights unless the rights whose general principles are determined in the constitution are supported by legal arrangements made in accordance with the spirit of those principles. Considering that there is no law prohibiting discrimination against PLWHAs in Turkey, the fact that the tenth article does not include health status among the forms of discrimination listed, erodes the constitutional guarantee provided by this article for PLWHAs.

Unfortunately, there is no quantitative data to show how widespread human rights violations against PLWHAs are in society. Moreover, despite several data published concerning discrimination against PLWHAs between 2009 and 2020, there is no data to present in which legislation areas PLWHAs experience human rights violations in an elaborate way until late 2019s (Demir, 2020). However, in parallel to the weaknesses of the constitutional guarantees in the article 10th and 20th, PLWHA continue to face frequent rights violations and discrimination. According to the report published by the Pozitif-iz Association, PLWHAs suffered from violations of rights based on the legislation on access to healthcare services, the legislation on the right to work, the legislation on military services, the legislation on criminal law and the legislation on family law in 2020 in Turkey (Demir & Salar, 2022). In this report, the rights violations experienced by 42 people who applied to the Association for legal advice were used as data. Of these 42 cases of violation of rights, 22 were experienced in accessing health services. Thus, the most frequent violation of rights occurred in access to health services. According to the violation of rights report of the Pozitif-iz Association published the following year, the category with the highest number of violations was access to health services, with 44 percent of the 140 violations reported (Tuğcu, 2022). It was followed by the right to work with 25 percent and the personal data protection law categories with 16 percent. In parallel,

the quarterly reports of the Positive Living Association from November 2019 to March 2021 show that people living with HIV are exposed to violations of their rights (The Positive Living Association, 2020; Topaloğlu & Erin, 2020; Erin, 2020a; Erin, 2020b; Yamaner & Erin, 2020; Yamaner, 2021). The first four reports published by the Positive Living Association have very similar results (The Positive Living Association, 2020; Topaloğlu & Erin, 2020; Erin, 2020a; Erin, 2020b). According to these reports, the area where PLWHA are most frequently exposed to rights violations is the right to privacy. PLWHA are exposed to questions about their gender identity and sexual orientation. Their status is shared with third parties by their relatives, public employees, or employers without their consent. The second area where their rights are violated the most is the right to work. PLWHAs are forced to take an HIV test and are exposed to questions about their lifestyles during the recruitment process and their working life. Also, their work conditions are discriminatively changed, their employment contracts are terminated, and their social rights are restricted because of their HIV status. The third area where PLWHAs are most frequently discriminated against is the right to access to health services. In accessing the right to health of PLWHAs; The physician refuses the treatment of the patient living with HIV, during the treatment, they are approached with prejudiced attitudes, this situation sometimes evolves into hate speech, the confidentiality of the status of them is violated, HIV testing is forcibly performed without their informed consent, and they are exposed to questions about their private lives by healthcare professionals.

Since constitutions are written to set the general principles of the legal framework and to give laws their spirit, the provisions in constitutions are often not written in detailed form. The Constitution's non-practical generalities may create a

void in terms of implementation and interpretation and laws are supposed to fill the void. However, despite all the constitutional guarantees I listed above, PLWHA continue to be subject to violations of their rights, especially the right to privacy and the right to non-discrimination. Moreover, PLWHA are exposed to these rights violations in public institutions, which we think should be implemented in the strictest way in these institutions. Based on this fact, I will argue that laws are unsuccessful to fill the void created by the Constitution and it lay groundwork for the violation of PLWHA' rights, especially the right to privacy and non-discrimination.

The law regulating the use of personal data such as health information in Turkey is the Personal Data Protection Law. According to the first article of this law:

> The purpose of this Law is to protect fundamental rights and freedoms of persons, particularly the right to privacy, with respect to processing of personal data and to set forth obligations, principles and procedures which shall be binding upon natural or legal persons who process personal data (Personal Data Protection Law, 2016).

This law defines personal data as "any information relating to an identified or identifiable natural person". The law also defines a special category of personal data. This category refers to "personal data relating to the race, ethnic origin, political opinion, philosophical belief, religion, religious sect or other belief, appearance, membership to associations, foundations or trade-unions, data concerning health, sexual life, criminal convictions and security measures, and the biometric and genetic data" as special category of personal data. With this provision, HIV status becomes more protected by law because it counts health data as a special category of personal data. Likewise, according to this law, a special category of personal information cannot be processed without the explicit consent of individuals. However, the law defines an exception regarding the processing of special categories of personal data:

> Personal data, except for data concerning health and sexual life, listed in the first paragraph may be processed without seeking explicit consent of the data

> subject, in the cases provided for by laws. Personal data concerning health and sexual life may only be processed, without seeking explicit consent of the data subject, by the persons subject to secrecy obligation or competent public institutions and organizations, for the purposes of protection of public health, operation of preventive medicine, medical diagnosis, treatment and nursing services, planning and management of health-care services as well as their financing (Personal Data Protection Law, 2016).

In other words, while the law protects health information within the scope of a special category, it also defines exceptions where this information can be processed without even seeking consent. Along with this provision, a very wide area of exception is created regarding the processing of data on HIV status, which we consider within the scope of health information, and sanctions against persons authorized to process this information without seeking consent and actions that may constitute a violation are not clearly revealed (Güzel & Dikmen, 2020). Both the Twentieth Article of the Constitution and the Personal Data Protection Law (PDPL) create uncertainty about what is within the scope of the right to privacy and what is a violation of this right because of the exceptions they define. The uncertainty created by these laws has also permeated the relevant laws and regulations. For example, both "Blood and Blood Products Law" and "Communicable Diseases Surveillance and Control Principles Regulation" have a similar problem (Güzel & Dikmen, 2020). The former obliges information about blood donors to be stored electronically for thirty years (Blood and Blood Products Law, 2018). This includes the health information of blood donors (i.e., data on HIV status). The latter classifies HIV both as a contagious and notifiable disease (Communicable Diseases Surveillance and Control Principles Regulation, 2007). Accordingly, all public institutions and organizations and real and legal persons are obliged to notify HIV to the Ministry of Health through their local health units. Both do not clearly state who will have the authority and of what period to access information and how it is going to be

processed. This legal vacuum puts the right to privacy of PLWHAs in a highly vulnerable position. The exceptions defined by Article 20 and PDPL not only infiltrate other laws, but also lay the groundwork for executive practices that may cause infringement.

An example of this is the rights violations experienced by PLWHAs due to MEDULA, which is an information system belonging to the Social Security Institution (SSI). This system stores all diagnoses and prescriptions of patients. The purpose of this system was that SSI could collect all billing information electronically and pay for services. Thanks to this system, all healthcare professionals who know the patient's identification number have access to all the diagnosis and prescription information of the patients. This was of concern to many PLWHAs, as thousands of healthcare professionals, including those who do not provide HIV-related healthcare services, could easily find out about people's HIV status. For instance, when you go to the pharmacy to buy flu medicine in your neighbourhood, the pharmacist can easily find out your HIV status, thanks to MEDULA. This has caused a concern that the HIV status of PLWHAs will be learned by third parties, especially for those living in less populated areas. Moreover, PLWHAs was concerned that health professionals or third parties who learned their HIV status, could violate their right to health or work. Before 2021, patients could apply to SSI Provincial or District Directorates with a petition in order to ensure that the information in the system is confidential. In addition, access to this information could be blocked by a court decision. Many PLWHAs have prevented access to their health information by petitioning due to privacy concerns and fear of discrimination. On 16 August 2021, SSI Presidency Service Delivery General Directorate published a circular on "Work and Transactions of the Service Delivery General Directorate".

This circular brought a regulation that the health information accessed through MEDULA can only be kept confidential by the request of the relevant administrative institution or judicial decisions, and the applications made by the persons themselves or by proxy will not be processed in any way, and the previous transactions will be eliminated. In other words, this meant that health information of PLWHAs was made available to all healthcare professionals and access to information could not be blocked by petition anymore. Access to health information could still be prevented by a court decision, but court processes take a lot of time. Until the access to information was blocked by a court decision, people either refrained from receiving health services due to privacy concerns or accessed health services at the expense of their privacy rights. Apart from that, many PLWHAs did not want to go to law as it is very tiring financially and morally. After the circular was published, Positive Life Association filed a lawsuit demanding the stay of execution and the annulment of the execution on the grounds that this circular is against the law of protection of personal data and privacy of private life. Positive Living Association Lawyer Altundağ (2022) stated that SSI shows public order and public health as a reason for the circular but does not explain how preventing health workers from accessing patients' health information through MEDULA will disrupt public health and public order. Altundağ (2022) explains that this circular is a violation of rights with the following words:

> In order to create a balance while the state is implementing an action to protect public health and order, it should not introduce regulations that would cause the people who are in a weak position to waive their rights or that would touch the essence of the rights.

In the example of MEDULA, we can see concretely the violations of rights caused by the exception created in Article 20 and the Law on the Protection of Personal Data. Besides these laws, there are regulations in secondary legislation that protect PLWHAs' right to privacy and non-discrimination in healthcare institutions. The

Medical Deontology Regulation (1960), which was prepared in order to include the values and ethical codes that the members of the medical profession are obliged to comply with, and the Patient Rights Regulation (1998), which regulates the rights of the patients, can be cited as examples. The second article of the Medical Deontology Regulation (1960) explicitly prohibits discrimination against the patient. The fourth article (1960) provides a basis for the right to privacy by prohibiting the disclosure of the patient's identity unless there is a legal necessity. On the other hand, the fifth article of the Patient Rights Regulation (1998) is as follows:

> In the provision of health services, the race, language, religion and sect, gender, political thought, philosophical belief, economic and social status and other differences of the patients cannot be taken into account. (....) The confidentiality of the patient's private and family life is inviolable, except in cases permitted by law and medical obligations.

Therefore, this article defines both the patient's right to privacy and the right not to be discriminated against. Güzel & Dikmen (2020) argue that although this regulation is protective at the theoretical level, it opens the door to the violation of privacy by referring to the law. In addition, they (2020) add that the fact that this article is content with a general reference to the law and does not provide examples are factors that reduce the assurance. In short, it can be argued that the ambiguities and exceptions in the Constitution penetrate into laws and regulations that are legally subordinate to them. The decision of the Ombudsman Institution on 19 April 2022 regarding the application of a person living with HIV was one of the most recent examples of violations of rights that may result from ambiguities in the law (Demir, 2022). According to the news published in Kaos GL, the doctor to whom a person living with HIV went to prescribe medication in 2021 disclosed his HIV status to his girlfriend next to the patient (Demir, 2022). Thereupon, the patient applied to the Ombudsman Institution on the grounds that her privacy and patient rights were

violated. In the decision that the institution rejected the application and found the doctor and the hospital justified, the following statements were included:

> In the case subject to the application, the disclosure of the applicant's HIV-positive status to his girlfriend, who was with him by the doctor who carried out the examination, should be evaluated in terms of personal benefit and social benefit. People who benefit from health services often want information about their private life not to be disclosed or known, and this information not to be accessed by others, and it is essential that physicians do not disclose their patients' medical information to third parties. However, in case of a contagious disease and the possibility of transmitting this disease to others, the physician who is aware of the situation may disclose the information regarding the diagnosis and treatment of the patient to third parties. For this reason, it has been concluded that there is no objection to the physician's disclosure of the patient's HIV status to third parties in line with the relevant articles of the Personal Data Protection Law, the Patient Rights Regulation, the Medical Professional Ethics Rules and other legislation. (Demir, 2022)

In this decision, the justification for the violation of the right to privacy of an ambiguous concept such as "social benefit" is given without making it concrete. Lawyer Enes Salar from the Social Policy, Gender Identity and Sexual Orientation Studies Association stated that there is no legal regulation that obliges the physician to disclose to third parties that his patient is living with HIV. On the contrary, disclosing the health information of individuals with third parties without their consent is considered a crime according to Article 134 of the Turkish Penal Code (2004), titled "Privacy of Private Life". However, since the obligations of the state to the privacy right of the citizen are not clearly defined in the Law on the Protection of Personal Data and the Law on Blood and Blood Products, the scope of application of Article 134 narrows considerably, as in this example (Güzel & Dikmen, 2020). Secondary legislation, on the other hand, does not mean that there is a policy on citizens' right to privacy in health-related services (Güzel & Dikmen, 2020). In short, there is a loophole in the law protecting PLWHAs against the government in terms of the right to privacy. In addition, the scope for imposing sanctions on government

agencies and officials when violating PLWHAs' right to privacy is narrow because of the exceptions defined in the law. Hence, the government fails to fulfil its positive obligations towards PLWHAs in terms of right to privacy.

Also, the situation is not very encouraging for PLWHAs in terms of negative obligations. To demonstrate this, I propose to examine the Turkish Penal Code in detail. The reason why I propose this is that the power of criminal sanction is the most effective tool of the government in combating discrimination between individuals. Besides, the exercise of penal power has a mixed effect. Punishment of discrimination both leads the punished person to directly associate the punishment with the act defined as a crime and also reveals the consequences of doing this act for third parties (Güzel & Dikmen, 2020). According to Article 107, what the spouses do should be considered a crime.

First, I would like to focus on Article 107 of the Turkish Penal Code, which criminalizes blackmail. One of the most common violations of rights PLWHAs face is threats that their HIV status will be disclosed to third parties. PLWHAs are exposed to these threats by their spouses, especially during the divorce period. According to the report of the Pozitif-iz Association, the spouses of two people living with HIV who are in the process of divorce threatened the counselees with disclosing their HIV status to people they know and demanded that they transfer all their assets to their spouses in a consensual divorce (Demir & Salar, 2021). However, Article 107 does not define the crime of blackmail to be committed based on the identity or status of individuals. It is clear that the blackmail crime committed on the basis of the identities of individuals is more serious in terms of its consequences than individual blackmail acts (Güzel & Dikmen, 2020). However, making the HIV status

of PLWHAs known to third parties may lead to other rights violations. Thus, the law does not have an effective penalty policy against blackmail faced by PLWHAs.

There is a similar problem in Article 122 of the Turkish Penal Code, titled "Hate and Discrimination". According to this Article:

> Due to hatred arising from language, race, nationality, colour, gender, disability, political opinion, philosophical belief, religion or sectarian difference;
>
> a) Selling, transferring or renting a movable or immovable property offered to the public to a person,
>
> b) Benefiting from a certain service offered to the public by a person,
>
> c) Recruitment of a person,
>
> d) A person who prevents a person from performing an ordinary economic activity,
>
> shall be punished with imprisonment from one year to three years.

The forms of discrimination listed in this article are limited and health status is not among those. The fact that PLWHAs is a systematically discriminated group especially in areas such as right to work and right to health services has been proven by the reports of associations fighting for HIV rights. Unfortunately, the Turkish Penal Code does not provide protection against discrimination for PLWHAs.

In addition, the Turkish Penal Code does not define any special protection for PLWHAs, they do not have equal access to existing penal codes to be able to protect themselves from others' harmful actions. There are several reasons for this. First, they are not adequately informed about PLWHAs rights (Demir & Salar, 2021). Most physicians tell newly diagnosed people what they cannot do (not being able to join the military, etc.), but they do not tell what rights they have or do not direct them to the relevant institutions for information. Moreover, even PLWHAs who are aware of their rights may not want to seek their rights because they feel powerless and alone (Güzel & Dikmen, 2020). Second, PLWHAs do not want their HIV status to be

known to the court (Güzel & Dikmen, 2020). They do not trust the court to protect their privacy. This lack of trust isn't just about their privacy. PLWHAs are also afraid of being exposed to other forms of discrimination in the institutions they apply to seek their rights (Demir & Salar, 2021). Thirdly, the possibility that the proceedings take too long and support mechanisms disappear during this time also deters PLWHAs from seeking justice (Demir & Salar, 2021). It is also a deterrent that PLWHAs think that after all this long trial period, the perpetrators will not be punished, especially if they are public employees (Demir & Salar, 2021). In summary, PLWHAs are also at a disadvantage in accessing justice. This is not because PLWHAs are reluctant to access justice. For example; PLWHAs participating in Güzel & Dikmen's research (2020) stated that even if they do not seek their rights when faced with discrimination, they encourage other PLWHAs around them to seek their rights. Therefore, the disadvantages of PLWHAs in accessing justice are the result of a structural inequality.

Aside from the problems in punishing those who violate PLWHAs's right to privacy and ensuring equal access to justice by PLWHAs in Turkey, legal loopholes regarding human rights of PLWHAs are sometimes filled by the discriminatory practices of judges, and this leads to the criminalization of HIV (Demir & Salar, 2021). For example, there are judicial decisions in which the person does not share their HIV status with their sexual partner as a factor of provocation, and as a result, the perpetrators receive a reduced sentence (Güzel & Dikmen, 2020).

One of the most mentioned articles in the discussion of the criminalization of HIV in Turkey is Article 86 of the Turkish Penal Code. Begin with, it should be noted that there is no law in Turkey that directly prohibits non-disclosure, exposure, or transmission of HIV. Article 86, titled "Intentional Injury", does not contain

provisions directly related to HIV. However, in very rare cases, transmission of HIV may be criminalized under this article. In order for HIV transmission to be considered a crime, certain conditions must be met. Demir (2019) lists these conditions as follows:

> 1- The accused person should be knowing that they is HIV-positive (In cases where the person does not know, it can be said that the crime is committed by negligence. These are of course discussed in criminal law theories. However, in practice, during a trial, in such a case, questions such as which of the parties are infected first comes out.)
>
> 2- Having a viral load capable of transmitting HIV (see: U= U)
>
> 3- Refraining from protection despite being a carrier and capable of transferring
>
> 4- Despite all these, HIV transmission has occurred
>
> It is obvious that in the continuation, of course, it will be necessary to prove that the transition took place "with the relationship with the accused person".

Therefore, she argues that unless HIV transmission did not occur, "perceived" HIV exposure or non-disclosure of HIV cannot be considered as a crime. In addition, any act cannot be considered as "intentional injury" unless there is evidence of intentional transmission of HIV, such as not receiving treatment or not using a condom. Although the scope of application of this law is narrow, those living with HIV are often threatened with lawsuits based on this article, as they do not disclose their HIV status. The latest example of this is the hate campaign targeting PLWHAs on Twitter after the two associations jointly shared a poster saying "I Don't Have to Disclose My HIV Status" for World AIDS Day on 1 December 2019 (Salar & Akbay, 2020). Some lawyers have contributed to the criminalization of people living with HIV by discussing the issue around "Intentional Injury" on social media. During this hate campaign, those living with HIV who chose not to disclose their HIV status and demanded their right to privacy were declared as “criminal” by many based on Article 86. In a society where people living with HIV are not informed about their

rights and stigmatising ideas about HIV are widespread, such hate campaigns cause many people living with HIV to assume that it is a crime not to disclose their HIV status.

In summary, I argued that there are gaps in the legal framework regarding HIV in Turkey. Existing laws and their enforcement are far from protecting people living with HIV from discrimination and guaranteeing their rights. In fact, some laws lead to the criminalization of HIV. In addition, it becomes almost impossible for people living with HIV, a disadvantaged group, to access their existing rights while struggling with the discrimination they are exposed to by others or their internalized prejudices about HIV. A law that aims to protect people living with HIV from discrimination in Turkey would eliminate the obstacle in PLWHA' access to rights and justice.

3.2 A history of HIV response in Turkey

I will present the history of HIV response by dividing it into four periods from 1985 when the first case was reported until the present. The periodization I use depends on Çokar (Güzel, 2020) and Çetin's (2017) periodization, but I add one more period to the three periods that they presented.

There are various actors that responded to HIV such as the state, media, civil society, health professionals, PLWHA and the LGBTİ+ community. Thus, by the term "HIV response", I do not refer only to the state's HIV policy, but all responses given by different actors. I will attempt to show that there are (dis)continuities between the ways these different actors problematize HIV. In my periodization, the change that closes one phase and opens another is a new actor responding to HIV and problematizing it in a new way. The incidents that I claim to have ushered a new

phase have the power to show the differences between the previous phase and the new phase at a symbolic level.

3.2.1 First phase

In parallel with Çetin (2017), I describe the period between 1985 and 1992 as the first phase of HIV response. This phase coincides with the time interval from the reporting of the first HIV case in Turkey, known as the case of Murtaza Elgin, to his death. The case of Murtaza Elgin has a significant place in the history of HIV in Turkey because we can trace the approach of three actors (state, media, and health professionals) who played roles in the 1980s regarding HIV by investigating the life and death of Murtaza Elgin. Before introducing the life of Murtaza Elgin, I would like to give the political background briefly in the 1980s. Hence, we can contextualize the responses given by these actors.

In 1980, there was a military coup in Turkey. After the 1980 military coup, there was a political atmosphere where polyphony disappeared, and freedoms were restricted. For example, the military administration restricted the activities of various associations and unions, and banned political parties (Çetin, 2017, p. 13). The aim was to suppress the right-left conflict that had become most violent during the 1970s by narrowing the civil society and political space with the bans of the military administration. In addition to these bans, the military administration introduced Turkish-Islamic synthesis as a social glue to end the right-left conflict in the 1980s and began to strengthen the center-right against the radical fascist right and left (Savcı, 2021, p. 16-17). These bans were part of the targeted de-leftification and de-radicalization process with the use of Islam as a social glue. As a result, it has become almost impossible for an AIDS discourse and AIDS movement to emerge.

Activism and civil society did not properly take issue with the HIV epidemic and the state, taking full responsibility for public services, became the dominant actor in the HIV response (Çetin, 2017).

What was the response of the state, which was the dominant actor of the period, to the HIV epidemic? Çokar et al. (2008, p. 7) state that in the first ten years, the only state institution that made regulations on HIV was the Ministry of Health, and these regulations are limited to the circulars issued by the Ministry. These regulations mainly included prevention and protection interventions, and the state did not make any HIV-specific regulations in areas such as education, social support and criminal responsibility related to HIV/AIDS. For example, The Ministry added HIV and AIDS to the list of communicable infections and notifiable diseases in 1985 (Başer, 1998). In 1986, screening of all blood and blood products for HIV became routine practice. Moreover, the Ministry made HIV testing mandatory for those coming from abroad who will do their military service in 1988. The AIDS High Advisory Board is established in line with the recommendations of the World Health Organization. The committee consisted of representatives of the Ministry of Health and health professionals. It was a crucial development as the Board is the first institutional body established for the health professionals to respond to HIV and plays a role in the publication of many circulars. As a result of the circulars issued by the Ministry of Health in line with the recommendations of the Board, the health directorates attempted to implement measures such as routine screening of sex workers, use of disposable syringes and needles, disposal of these materials, distributing condoms in health centers, and not performing circumcision by unqualified persons (Başer, 1998, s. 277). Although the Ministry has published these circulars, we do not have any data on how determined it was in the implementation

of these preventive measures. For example, Çokar et al. (2008, p. 7) state that at this phase, the Ministry aimed to provide HIV testing to everyone who applied to hospitals, but due to infrastructural deficiencies, HIV testing has practically only been applied to people undergoing major surgery. Apart from this, Başer (1998, p. 277) reports that the AIDS High Advisory Board could only meet twice whereas other relevant ministries and more than one sector did not participate in these meetings. On the other hand, Turkey was taking into consideration the recommendations of the World Health Organization regarding HIV in these years. Most of the administrative regulations for prevention mentioned above were published within a few years after the first HIV case was reported in Turkey. For example, Turkey was one of the first countries to add HIV to the list of communicable infections (Çetin, 2017, s. 14). Government intervention in the early years was an advantage in preventing the spread of HIV. While these circulars are important in understanding the government's HIV response, our efforts will be incomplete if we do not investigate the rationality of the decision-makers who issued these circulars. For this reason, I propose to examine the discourses produced by state officials and experts about HIV and their reflections on the media.

In 1983, before the first case was reported, Turkey became acquainted with HIV through the *Cumhuriyet* newspaper's article titled "Homosexual Blood" (as cited in Soydan, 2018). The news reports that at the International Hemophilia Congress held in Stockholm, it was requested to ban homosexuals from donating blood. In the same year, the newspaper stated that AIDS was mostly detected in homosexuals and summarized the attitude of the American society towards HIV with the sentences "many people do not want to work in the same workplace with homosexuals"

(Soydan, 2018). Two years later, in January 1985, Minister of Health and Social Assistance Mehmet Aydın made the following statement to Yankı magazine:

> There are no patients diagnosed with AIDS in 1983 and 1984 in our country. However, our ministry has been warned against this disease. AIDS is a newly defined disease in the world. This disease is characterized by a weak immune system in humans. Although they said that it is most common in homosexuals, our customs, religion, morals and the strength of our family structure are our advantages against such a disease. (as cited in Soydan, 2018)

Following the news and the Minister's statement, in July 1985, discourses such as "trans people should be expelled from Izmir " began to circulate. İzmir Police Department, Public Security Branch Deputy Director declares that "There is no place in İzmir for these people, who are the source of all kinds of diseases." (Soydan, 2018). *Milliyet* newspaper was published on 14 August 1985 with the headline "AIDS is in Istanbul " (ceviizcom, 2018). The article includes the following statements:

> While the discussions on whether "there was AIDS in Turkey or not?", four days ago, a patient with AIDS escaped from the German Hospital in Istanbul. (ceviizcom, 2018)

In the news, it was alleged that a Turkish citizen living in Germany came to Istanbul while receiving AIDS treatment there and continued his treatment by applying to the German Hospital in Turkey, but fled first from the hospital and then from Turkey in the following days. Although HIV is not on the list of notifiable diseases, the hospital authorities reported the situation to the Provincial Health Directorate after he applied to the hospital (Soydan, 2018). Two days later, in the same newspaper, there was more detailed news about this young man, and this news claimed that the young man was a "drug addict". Moreover, the article included his name, the name of his family members, his hometown and where he lives in Germany. On August 17, *Milliyet* newspaper found this young man, this time in Germany (as cited in ceviizcom, 2018). According to the news, he stated that he did not escape; he returned to

Germany with the permission of his doctor. He also stated that he is gay, but on the advice of doctors, he has not had a homosexual relationship for months, and moreover, he told his family that he has skin cancer because there is little information about the disease. Unfortunately, the press had already talked to his family about the issue. After the sensational news for days underlining that this young man came from abroad and was gay, on September 10, 1985, HIV was included in the list of notifiable diseases by the Ministry.

After this case, the discussions about whether there is an HIV case in Turkey have flared up even more. The Prime Minister at the time, Turgut Özal, ignored these discussions and made the statement that "our state has taken all kinds of precautions regarding the issue" (as cited in ceviizcom, 2018). However, this statement did not end the panic-stricken and sensational debate about HIV. The statement by the Minister of Health and Social Assistance that Turks were advantageous against HIV must have found a response in the minds of the citizens, as *Milliyet* newspaper reported on November 23, 1985 that Turks avoided tourists for fear of AIDS (as cited in ceviizcom, 2018). In the news, a German tourist named Iris Maier stated, “Even my Turkish friend of five years, Mustafa, ran away from me. Then I caught him, asked why. He asked me, 'Do you have AIDS?' Of course, I was confused as to what to say. Turks cannot live with this fear”.

The first known death due to AIDS occurred in September 1985. Gülhane Military Medical Academy (GATA) Commander Major General Necati Kölan underlined in his statement that the 35-year-old person came to Turkey for paid military service and fell ill five months before coming to Turkey (ceviizcom, 2018). As in the case of the young Turkish man living in Germany, this case too was claimed to be of foreign origin and therefore the discourse "There is no AIDS in

Turkey " kept still valid. In the same year, against the denial of the state authorities, a doctor began to take his place alongside the media's language of sensation and disinformation. Prof. Dr Hüseyin Sipahioğlu, at the Gastroenterology Congress he attended in October 1985, claimed that the ministries and bureaucrats were trying to cover up this disease and that he had patients with AIDS. Thereupon, a polemic started between the ministry and Sipahioğlu, consisting of questions such as "whether there is an HIV case in Turkey, if so, who is this case and why it was not reported to the Ministry ". *Hürriyet* newspaper disclosed the person mentioned by Sipahioğlu with his name and photographs in its news titled "Here is a Turk with AIDS " on November 2, 1985 (as cited in Soydan, 2018). The person mentioned in the news was Murtaza Elgin, the first case reported in Turkey. Sipahioğlu is the person who gave this information to the *Hürriyet* newspaper, contrary to professional ethics. Sipahioğlu uses the following expressions in an interview he gave to the newspaper:

> Their close relations and their relatives are in a great danger circle. We need to convince this person who has the virus, we need to start treatment immediately, and we need to take it under control. In addition, it has become mandatory to examine the blood serum of people with whom he is closely related. The patient is homosexual.

After today, the media did not leave Murtaza Elgin's pelt, they scrutinized his life and carried every second of it to the headlines in a sensational way. Elgin claimed that he did not have AIDS, that this was Sipahioğlu's misdiagnosis. Although Elgin, who went to Germany for the verification test, stated that he was very healthy on his return from this trip, he was arrested by the vice unit at his home and was detained alone in a ward called the AIDS Ward, which did not even have a toilet (Atuk, 2021a). Murtaza Elgin was taken to Haydarpaşa Numune Hospital for quarantine by seven policemen. When Elgin died in 1992, an instruction signed by Haseki Training

and Research Hospital Chief Physician Ahmet Çetinsaya was published on how the body would be buried. (ceviizcom, 2018). Accordingly, Elgin's body was washed with bleach, wrapped in plastic bags, and after being buried in a grave dug deeper than usual, lime was poured over him. As Atuk (2021a) said, the importance of these details is not because they have the power to cause sensation or pity. These details are important because they allow us to confront the fact that the same attitude towards PLWHA still exists, albeit in different forms, from the past to the present. In order to understand the importance and meaning of the response of various actors to HIV today, it is necessary to have a comprehensive understanding of how HIV has been responded to in the past. In other words, it is necessary to consider not only the official documents such as the circulars, but also the political atmosphere and social history of the time period when those official documents were produced. These details are helpful to be able to answer why the measures taken in this phase were limited only to the circulars, how the decision was made on which subjects to issue circulars, and why no action was carried out in areas such as sexual education, social support, and the fight against discrimination. In short, I am trying to understand the rationality behind the HIV response of the actors of the period.

In the 1980s, the state used Islam as a social glue to integrate society. It aimed to create a Turkish-Islamic identity based on religious and nationalist values in order to ensure the integration of the society (Savcı, 2021). Therefore, the state's perception of the HIV epidemic was based on this conservative worldview. The state considered HIV as a danger posed by gays, trans people, sex workers, tourists and immigrants. Because of this point of view, for the state to accept that there is a spread of HIV in Turkey would mean recognizing the existence of these groups. This conservative point of view can explain the denial policy of the state. The state had no

interest in preventing the spread of HIV among the disadvantaged groups I mentioned above and protecting these groups from discrimination and violence. I argue that this is one of the reasons why the government's response to HIV was limited by circulars. As Atuk (2021b) maintained, the state was concerned with creating a Turkish identity based on national and religious values, symbolically immune to HIV and AIDS, through xenophobic, homophobic, transphobic and sexist discourses. In order for this symbolic immunity, that is, the ideal of purity of the Turkish identity, to be sustainable, HIV should not be spread among acceptable citizens who embrace this identity. In my opinion, despite the denial policy of the state, the government issued the circulars about the subjects on which a wave of panic and fear that HIV will spread among acceptable citizens cannot be concealed. For example, cannot we say that there is a relationship between the Turkish youth coming from Germany reported on the news and HIV being included in the list of notifiable diseases only a month later? Likewise, is not there a relationship between the reflection of the AIDS-related death of a citizen who came to Turkey from abroad for paid military service to the media and the circular on the compulsory testing of soldiers coming from abroad? In an atmosphere where ideas about the expulsion of trans people from Izmir are reflected in the media, is the circular issued for HIV screening of sex workers a coincidence? Although there seems to be a conflict between the sensational and panic-inducing language of the experts and the media and the denial policy of the state, I argue that the panic language of the experts and the media is the driving force of the limited amount of precautions taken during this phase. Moreover, I argue that the denial policy of the state and the panic language of the experts and the media does not conflict with each other necessarily, in fact, these two may feed each other because both originate from a very similar

point of view. The former denies HIV in order not to recognize LGBTI+s, sex workers and foreigners because it considers them as carriers of HIV, and the latter considers them dangerous for the same reason. The former believes that the Turkish race is immune to HIV because of the assumed moral superiority of the Turkish race, the latter suppose that the life of the Turkish race is more precious than the others because of the assumed moral superiority. What Murtaza Elgin went through from the beginning to the end is the summary of it, so to speak. First the state denied him and then Sipahioğlu and the media declared him gay, after that the state quarantined him, and finally based on an expert instruction, lime was thrown on his grave. Murtaza Elgin either did not exist or was dangerous and worthless. Elgin was also the common danger that brought the Turkish race together. The opposite of every feature of the Turkish race was symbolically embodied in his body. Murtaza Elgin's body establishes the Turkish race in a mediated way through every feature it carries. In the previous chapter, I summarized the argument of Patton (1996) on the construction of American identity based on a national pedagogy developed through the HIV epidemic. In parallel with the argument of Patton (1996), I propose to call the approach of state-expert-media triangle during the first phase as the national pedagogy of Turkishness.

3.2.2 Second phase

The second phase is the time period between Elgin's death in 1992 and 2005, when an association was founded by those living with HIV for the first time. During this phase, civil society developed a response to HIV. The response of civil society to HIV is the development that characterizes the second phase. In the 1990s, as a result of the developments in the field of medicine and the work of AIDS activists

especially in the USA, ignorance about HIV decreased somewhat. With the increase in scientific knowledge about HIV, it paved the way for the emergence of health professionals who approached the issue from the perspective of the right to health. These health professionals established associations in the 1990s aimed at combating AIDS. I consider this development as the discussion between the state and Sipahioğlu moving to a new ground. As I discussed in the first chapter, the relationship between medicine and society is somewhat ambivalent. While medical developments facilitate our access to the right to health, on the other hand, medicalization based on the benefits of these developments contributes to the formation of a new power area. The national pedagogy that I mentioned in the first phase and the medical view of HIV establish different discourse areas. Despite the fact that these two establish different fields of discourse there are also continuities. In the first phase, I argued that there was both a discontinuity and a continuity discursively between these two frameworks. Thanks to medical advances, the power of the medical framework on HIV expanded, and as a result, in the 1990s there was a discursive break with national pedagogy. The strengthening of the medical discourse against the national pedagogy led to a greater emphasis on the right to health. For example, Çokar (Güzel, 2020, p. 13) states that pioneering works on prevention first started at this stage. Yet, the emphasis of the medical perspective was on preventive policies centered on HIV negatives as it was in the previous phase. Steps have been taken to prevent, diagnose and treat, but have not been concerned with what challenges people living with HIV face in their lives after diagnosis. The interest of the associations was limited to providing health services to PLWHA so that they would not spread HIV. The hierarchy of values established by the national pedagogy over conservative morality was replaced by a hierarchy of values based on being

healthy in the medical discourse. Before explaining the establishment and history of health professional-led associations, I would like to briefly draw the political and social landscape in which they were established.

During these years, the war between Partiya Karkerên Kurdistanê (PKK) and the state intensified. In the 1990s, the main factor that shaped the political agenda was this war and its consequences such as socio-economic and political instability (Çetin, 2017). In addition to this war, the neoliberal policies that the ruling Motherland Party produced led to results such as rapid urbanization, industrialization, privatization, and the re-internationalization of the Turkish economy. In these years, there was rapid urbanization, increasing inflation, the impoverishment of big masses and growing unemployment. The ruling Motherland Party failed to address the human rights violations and political repression inflicted by the military regime. In fact, with the intensifying war, violations of rights and political pressure increased again, and the criminalization of leftist organizations continued. All these developments both paved the way for the emergence of social movements and had negative effects on them. These emerging social movements did not describe themselves as left or right, but as spokesmen for the rights of various social groups (Çetin, 2017).

In such a political and social context, two associations were established in the 1990s specifically to respond to AIDS. The first of these is the Association for Combating AIDS (*AIDS ile Mücadele Derneği*), which was established in Izmir in 1991 (Başer, 1998, p. 278). This association aims at informing the relevant groups by training of health personnel and organizing community education, panels, conferences, and seminars, and providing the necessary materials for HIV diagnosis and treatment at world standards. In the 1990s, the association organized certified

trainer training programs for target groups in many provinces and provided school training in cooperation with the Ministry of National Education. The name of the second association is the Association for the Battle against AIDS (*AIDS Savaşım Derneği*), which was established in İstanbul in 1992 (Başer, 1998, s. 278). This association aims to provide information about the AIDS epidemic to all segments of society and to stop the spread of the virus by empowering key groups and those living with HIV. Among the main areas of work are information campaigns with tools such as brochures, posters, advertisements, dissemination of self-help groups, defense of patient rights, counseling and organization of training programs for target groups. Although these two associations were not confederations, they opened branches in many other provinces in the following years (Çokar, 2006, p. 30). For example, the Association for the Battle against AIDS had a nationwide network with 22 branches. The founder of the Association for Combating AIDS was Prof. Dr. Melahat Okuyan and the founder of the Association for The Battle against AIDS was Prof. Dr. Enver Tali Çetin. Both leaders served on the scientific boards of the Ministry of Health. As a result, both associations had strong leaders, they could use high capacity with limited local financial resources, and they had political power.

Another common feature of these associations is the words "combating" and "battle" in their names. The fact that these associations have chosen these names for themselves is closely related to the fact that both of them were founded by doctors who aimed to spread preventive measures because of their ideal of protecting public health. Sontag (1990, p. 98) argues that the metaphors such as “battle” or "war", which considers disease as an invader, has historically been invoked by public health to refer to efforts to reduce the mortality caused by the disease. The military metaphor causes illness to be viewed as the alien 'other', and demonization of the

illness inevitably results in attributing it to the patient as their fault. This is the case even if patients are seen as "victims" because being a victim suggests innocence, and innocence suggests guilt. As result, Sontag (1990, p. 99) argues that this kind of metaphors play a role in the stigmatization of the disease and the ill.

Since 1994, NGOs working in the field of reproductive health have also started to be active in the field of HIV and AIDS (Çokar, 2006). According to him, the United Nations International Conference on Population and Development held in Cairo in 1994 showed associations working in the field of reproductive health that this field is more than reproduction. This conference did not result in a wholly new international human rights framework, but applied the existing framework of rights to reproductive and sexual health (UN, 1994). This conference is revolutionary in this respect because it was the first time that reproductive and sexual health were defined as fundamental human rights and as a result, this policy domain was granted with autonomy especially in the context of population and economic development policies and empowerment of individuals (Yılmaz & Willis, 2020, p. 3). Accordingly, everyone has the right to a satisfactory and safe sex life, to the capability to reproduce and to decide when and how often to reproduce (UN, 1994). In other words, this conference declared that sexual health is an integral part of reproductive health. Organizations such as the Family Planning Association of Turkey (TAPD) and the Human Resource Development Foundation (IKGV), which mainly work in the fields of women's and child health and family planning, started to focus on advocacy, prevention and key groups in the field of HIV and AIDS after this conference (Çokar, 2006, p. 30). These organizations had a relatively successful cooperation with the state in these years. There may be a couple of reasons for this. First of all, Turkey has been following antinatalist policies since the 1960s due to its

national developmentalist economic strategy, and it has developed a capacity for family planning services since then (Yılmaz & Willis, 2020, p. 5). In parallel with this, TAPD was established due to the increase in population in Turkey and even before the conference in 1994, it assumed some government duties while implementing the policies of the government on the basis of controlling and regulating population growth (Çetin, 2017, p. 19). Thus, these organizations both already had close relations with the state and were not directly seen as representatives of marginalized groups by the state, since their first field of study was reproductive health. Another reason is that the transition from the introverted authoritarian state of the 1980s to the re-internationalization process in the 1990s may have caused the international norms and values to find space for their implementation in Turkey. In summary, the response of civil society to HIV seems to be basically divided into services provided by reproductive health associations and anti-AIDS associations.

One of the most important works carried out by TAPD regarding AIDS was the "AIDS and Initiative of Top Political and Decision-making Bodies" project. It was carried out between 1994-1997 with the financial support of the EU and targeted especially members of parliament, senior bureaucrats and members of the media (Başer, 1998). One of the outputs of this project was the establishment of the National AIDS Commission (UAK) in 1996. The Commission was working under the coordination of the Prime Ministry, under the chairmanship of the Ministry of Health and in the secretariat of TAPD. It has objectives such as determining national policies to prevent the spread of HIV, making recommendations for the preparation of a national action plan in this direction, and ensuring inter-sectoral cooperation and coordination. In its early work, the National AIDS Commission determined its goals

and strategy in the areas of prevention, diagnosis, treatment and social support, legislation and research. Until 2000, the Commission aimed at educating the society about the ways of transmission and prevention with priority on groups at risk, 100 percent safety of blood and blood products, reaching the sufficient number of validation and testing centers, standardizing the diagnosis and treatment, the dissemination of AIDS and Sexually Transmitted Diseases Consultation and Protection Centers, making necessary ethical, social and legal regulations that protect individual rights and freedoms, and providing reliable information about the dimensions of the AIDS epidemic. NGOs carrying out AIDS prevention activities have produced projects to receive funding from international financial resources in order to realize some of the actions included in the national action plan (Başer, 1998).

Until the end of the 1990s, some progress was made in HIV policies as a result of the efforts of these associations. For example, D-86 forms began to be used in 1993 to collect the transmission route and demographic information of reported HIV cases (Tümer, 2018). In 1994, in order to ensure the privacy of individuals, the notifications of the diagnosed cases were started to be recorded in a coded manner without specifying their names (T.C. Sağlık Bakanlığı, 2019). In 1995, the program on "the battle against prostitution and preventing venereal diseases" were clarified in terms of HIV/AIDS-related work and procedures, and how routine examinations would be arranged. For example, when 183 women who were sex workers in state-run brothels were screened for HIV, it was found that all of them had negative results. (Kıyan et al., 1996). Researchers (1996) attributed this result to the fact that women had regular follow-up examinations and used sexual protection methods. In addition, the Green Card application has been initiated for citizens who cannot afford

to pay (T.C. Sağlık Bakanlığı, 2019). In 1996, antiretroviral therapy (ART) reimbursement began. Also, a prevention program targeting key groups was implemented by IKGV for the first time at this phase. Çokar (Güzel, 2020, p. 15) states that with this program, which they started two years after the 1994 Cairo Conference, they aimed for sex workers to gain safer sexual behavior. To achieve this, IKGV trained a group of sex workers and had them train their friends (Başer, 1998). Çokar (Güzel, 2020, p.15), who was working at IKGV at that time, conveys this experience as follows:

> At that time, we were always reaching out to women as part of family planning projects. We thought that sex workers would easily support our work since HIV is an important problem, but we hit a wall at the first stage. For sex workers, their health was not an issue at the top of their agenda. Sex workers, most of whom worked in unsafe conditions, were not in a position to bargain for condoms. Stigma, exclusion and discrimination were at an extreme. They were not in a position to care about our education. Then we somehow communicated and met. The social life of sex workers should have been supported first. That's why we set up a community center. In addition to health-related services, we provided services that support sex workers on how to access legal support and deal with violence. We named the center we established as the Women's Gate. We moved a lot. We even made the Women's Gate mobile for a while, and we bought a minibus and delivered the Women's Gate to the sex workers working on the street.

Sex workers who participated in the training program of IKGV shared their experiences at a congress they attended as speakers. One of the speakers named Demet said:

> IKGV started working with sex workers (training, condom distribution, etc.). Within the scope of this training, 10 sex workers were informed and trained. Thus, the fight against AIDS was brought to the bottom. (Kaos GL, 2002)

And she added:

> We, two friends on Ülker Street, started to use condoms and have our friends use them as well. What this took away from us was that customers resisted not using it and then ran away. And thanks to our suggestions, condom use started to increase. (Kaos GL, 2002)

As in the case of the Women's Gate, we witness the first contacts of key groups and PLWHA with associations working in this field. In my opinion, these first contacts are very important in two respects. First, these contacts can help us understand how the experience of key groups regarding HIV has been shaped at a time when post-diagnosis services are lacking, and HIV-related services are limited by preventive measures. For example, from an article written by a gay person to Kaos GL, we learn about his first fearful test taking experience in 1996 (Ege, 1999). He finds out that his partner, whom he has been with for a while and has had unprotected penetrative sex, has been tested for HIV. As soon as he learned of this, he panicked at the possibility of being infected with HIV and describes his feelings about his partner getting tested as following:

> When we meet in the evening, I said that ‘fool, what if you have AIDS? is there any benefit to know whether you have AIDS or not, even worse, you are going to live the last five years of your life in agony’

In a situation where policies on HIV are only about protection from HIV, discriminatory rhetoric is reproduced everywhere from government agencies to the media, and there are no services and legislation to protect PLWHA, it is not surprising that he avoids testing. In the continuation of the article, he describes taking the test as "an act of courage". Despite this fear, his partner persuades him to take the test. Afterwards, he went to the Association for the Battle against AIDS, and he asked a doctor what the use is of learning the test result there. The doctor gives a speech to him in which the doctor strongly emphasizes that he should be protected so that he does not infect others. As we have seen in this experience, the relationship between service recipients and associations is both an inevitable need and a threatening one. Although these associations seem intimidating due to the preventive-oriented services they provide, a contact between key groups and

associations is possible due to necessity. Another importance of these first contacts, which started in the second phase, is that they created a ground where PLWHA could find each other and organize. Erbaydar (2021), who worked in the Association for the Battle against AIDS at that time, conveys his own experiences as follows:

> A working group called the Positive Action Group, in which HIV+ people participated, started its activities in the association in 95-96. They communicated directly with the Ministry of Health, participated in congresses, and took the initiative in changing some practices. For example, at that time, for green card holders, HIV drugs were covered by reimbursement only for inpatients, but as a result of the meetings of this group with the Ministry of Health through our association, HIV drugs were also included in the scope of reimbursement for outpatients. By creating files containing the treatment protocols, we suggested PLWHA to ask their doctors to prescribe the treatment according to these protocols when they go to the outpatient clinics. Thus, it was a process that accelerated the transition from "one drug" treatment to "cocktail treatments".

Therefore, although these associations have a medical approach that does not center PLWHA, it paved the way for the next phase in terms of bringing PLWHA together. At this phase, we also witnessed that anti-AIDS associations have started to contact the gay movement that started to organize in these years. For example, Lambda Istanbul was involved in the project titled "Examination of Health and Social Rights of Young People in the Vulnerable Groups in Turkey" jointly carried out by the Association for the Battle against AIDS and the Dutch Consulate in Istanbul (Kaos GL, 2002). This project aimed to reduce the spread of HIV and other sexually transmitted infections among vulnerable young groups. However, Kaos GL (2004) criticized anti-AIDS associations for not conducting enough works on the gay community at that time. Moreover, this article criticizes anti-AIDS associations for marginalizing gays by using the concept of "risk group". It emphasizes that it is "what we do" rather than "who we are" that determines the transmission of HIV and suggests using the term risky behavior rather than risk group. Çokar (Güzel, 2020, p. 14) also mentions that in these early projects with key groups, they used the term

"risk group" and later switched to "risky behavior" instead. While the article of Kaos GL (2004) criticizes the term risk group, it maintains that this term causes homophobia against gays to increase by bringing them and HIV together and adds that being homosexual does not necessarily require to get infected with HIV. Although this argument is factually correct, an effort to save homosexuals from being identified with HIV catches the eye. In fact, it means that the authors of this article have no qualms with the stigma directed at those living with HIV. Another striking point is that only the experience of gays are in the center of the article and there is no mention of trans people. This attitude quite overlaps with what Şevval (Cingöz & Gürsu, 2013), one of the trans sex workers who attended the trainings of IKGV, told:

> There was Murti or something, then a trans woman Onion Head Banu appeared in the newspapers as "Banu with AIDS". These are the years when she first appeared in the newspapers. Pride Week meetings are held, one trans woman attends the meetings, and gay friends are asked not to attend the meetings again, saying that "you are a sex worker, you are transvestite, you are transgender, you are degrading our prestige".

It is observable that the widespread stigmatizing view of the media and the state regarding HIV and trans people was also reflected in the gay movement of that period. The language of fear and panic about HIV did not remain in the 1980s and continued into the 1990s. For example, Health Minister Yıldırım Aktuna said in a statement in 1996 that the only cure for HIV is monogamy (Atuk, 2021c). It is clear that monogamy is not the only way to prevent HIV. The way to stop the spread of HIV is not to push people to change their behavior, but to facilitate them to make those behaviors safer. In a society where sexual health education is not widely given, a Minister of Health making a statement as "monogamy is the only solution" is a conservative approach that moralizes the issue and places the responsibility on non-monogamous people. In the same years, the Ministry of Health used the slogan

"some relationships can sweep you off your feet" in a poster it published and had to remove the poster due to the opposition (Kaos GL, 2002). Here again, the Ministry portrays sexuality as something dangerous and magnifies fear of being infected with HIV. The Ministry's attitude towards total de-sexuality or the removal of certain forms of sexuality shows that the national pedagogy of the 1980s continued. The situation is no different in the media. For example, sex worker women who immigrated to Turkey from Soviet Russia in the 1990s were named 'Natasha' in the discriminatory language of the media and portrayed them as a national security problem (Atuk, 2021c). A sex worker who participated in the training of Women's Gate reports that customers refused to use condoms and said, "We are Turks, nothing will happen to us." (Kaos GL, 2002). In the same speech, she also states that the media frequently make news such as "homosexuals cause death". In other words, in the 1990s, the national pedagogy still found a response both at the institutional and societal level. In addition, the fear of "Is there a case of HIV in Turkey?"in the first phase was replaced by the fear of "The number of HIV cases will enormously increase" in the second phase (Çokar, 2020, p. 14; Kaos GL, 2000). It can be argued that the national pedagogy of the state and the prevention-oriented policies of the associations have exacerbated fears in the society that the number of HIV cases will increase.

3.2.3 Third phase

The third phase can be dated from the establishment of the Positive Living Association in 2005 in İstanbul. The Positive Living Association was founded by people living with HIV. With the establishment of this association, for the first time since the HIV epidemic began in Turkey in the 1980s, those living with HIV directly

represented themselves through an official organization. This development characterizes and initiates the third phase. This phase lasted until 2015 when new actors responded to HIV. Before describing the HIV response at this phase in more detail, I will give the political background that prepared this phase.

After the short-interrupted coalition governments of the 1990s and the political instability it created, the newly formed party *Adalet ve Kalkınma Partisi* (AKP) came to power alone in 2002. Despite its Islamist roots, the AKP was a centre-right party that introduced itself as a conservative democrat in the first years of its establishment (Çetin, 2017). In addition, the AKP declared its commitment to meet the Copenhagen criteria to complete the EU candidacy process, which became official at the 1999 EU Summit in Helsinki. AKP announced that they would make radical reforms in the constitution in order to guarantee the rights of all segments of society, regardless of their differences. Consistent with this, the AKP made a series of legislative changes under the name of "harmony packages". These reforms led to positive developments in civil rights areas such as freedom of assembly, freedom of expression, freedom of association, prevention of torture, and the right to privacy. In addition, as a result of the EU negotiations in 2004, the government reformed the Turkish Association Law. In the Constitution enacted by the military administration in 1983, establishing an association required a lot of bureaucratic effort and the associations were subject to strict control. Moreover, this Constitution prohibited associations from lobbying, claiming representation of any segment of society, and engaging in politics. Thanks to the reform, a significant part of these restrictions and difficulties in establishing associations and organizing through these associations have been removed. As a result, the social movements that started in the 1990s

quickly became institutionalized and became more visible in the public sphere (Çetin, 2017).

AKP took many important steps in the early 2000s to integrate into international political norms and economic institutions. The developments I mentioned above are examples of this. This effort also had reflections on Turkey's HIV policies. For example, the Ministry of Health published the country progress report covering the 2003-2005 period, showing how close it is to the Millennium Development Goals for reversing the HIV epidemic, according to the indicators determined by UNAIDS (Altan, UNGASS Indicators Country Report, 2006). The publication of a report showing Turkey's situation in the HIV epidemic according to the indicators determined by the United Nations was also an indication of Turkey's will to comply with international norms regarding HIV. In parallel, the Reproductive Health Program in Turkey, designed to improve the quality of service delivery and strengthen institutional capacity in the field of SRH, covering the 2003-2007 period, was launched in partnership with the European Commission and the Ministry of Health (TC Sağlık Bakanlığı, 2004). Reproductive Health Program in Turkey is one of the highest budgeted programs implemented in the field of reproductive health in the world with a budget of 55 million euros and approximately 10 million euros of this budget was spent on sexually transmitted diseases (Çokar, 2006). In the program, 48 NGOs carried out activities in the field of STI/HIV/AIDS for young people and the general public. All these developments in the early 2000s were the harbinger of the beginning of the new phase.

In 2005, the Positive Living Association was established (The Positive Living Association). For the first time, PLWHA had an organization in which they directly represented themselves in Turkey. A few individuals living with HIV, who came

together through personal connections in 2003, held the first meeting of the association. In October 2003, the HIV POSITIVE email group was established, enabling continuous communication via the internet. This mailing list made it possible for PLWHA to build solidarity with each other and share their experiences. This solidarity and sharing of experience was of great importance for them to deal with the discrimination and stigma they are exposed to. This email list was a breathing space especially for PLWHA, who is not in Istanbul and has internet access. Some people on the list took face-to-face meetings and started an initiative to establish an official organization. The association states on its website that the purpose of its establishment is to defend the fundamental rights of PLWHA, to ensure their empowerment and solidarity by organizing, to increase their level of knowledge, to fight prejudices and to raise awareness of HIV (The Positive Living Association). For this purpose, Positive Living Association provides services such as peer counseling, legal counseling, psychosocial support, free and quality treatment and access to medicines and nutritional counseling for those living with HIV, which focuses more on the post-diagnosis process. Çiğdem Şimşek (2021), one of the founding members of the association, conveys the motivations of those who founded the association as follows:

> The Positive Living Association is the first PLWHA-led association. If you notice, there is always an expression of violence such as the battle against AIDS or combating AIDS, even if the intention is good. In other words, it created a perception that there is a monster like AIDS and there are people fighting with it. For this reason, while establishing the Positive Living Association, the process was designed by looking at its positive aspects such as "living" and "people living with it".

In the same year, a protocol signed between the Global Fund and the government and the HIV/AIDS Prevention and Support Program with a budget of 4 million dollars was initiated (Çokar, 2006). The Ministry of Health was the executive of this

program and a total of 16 projects were implemented with the participation of 14 NGOs. Within the scope of this program, preventive interventions were made for key groups such as sex workers, men who have sex with men, injecting drug users and prisoners. In addition, voluntary testing and consultancy centers were opened for the first time in Turkey. A research study was also conducted in which the behavior of key groups was evaluated. Staff who worked with key groups under this program were trained on HIV/AIDS and human rights. Finally, protective materials such as lubricants and condoms were distributed to key groups. This program ended in 2008. Another important study at this phase was *Türkiye'de Cinsel Yolla Bulaşan Önemli Enfeksiyonlar ve HIV ile İlgili Hizmet Araştırması*, conducted within the scope of the Reproductive Health Program in 2007. This study is the first attempt to develop second generation observer surveillance for STIs in Turkey. It aimed to establish an infrastructure for the development of an active surveillance mechanism. These programs set a good example in that they involve multiple sectors, including civil society and government, and are carried out at a national level, and that they include prevention as well as anti-discrimination work (Çetin, 2017).

The large budget provided by the HIV/AIDS Prevention and Support Program has led to the establishment of four new associations working in the field of HIV/AIDS (Çokar, 2006). Positive Living Association is one of these four associations. Şimşek (2021) describes that process as follows:

> In the process that accelerated the establishment of the association in 2005, the Global Fund was handed over to the Ministry of Health in Turkey and many people applied and were accepted with projects tailored to their needs. The Positive Life Support Center was the first project applied and accepted by the Positive Living Association. Simultaneously, UNAIDS Turkey Office took ownership of the issue and started to support this self-organization.

In other words, Turkey's good relations with international organizations and the EU at that time and the budget allocated to Turkey by these organizations encouraged the

establishment of new associations. Positive Living Association received funding under this program in 2006, one year after its establishment. The second of these associations was the Association of Positive (Çetin, 2017). This association also works for PLWHA and aims to give them access to treatment and empower them in their daily life. The association did not claim to be an activist association or representative of PLWHA. The association explains its purpose as supporting PLWHAs in their daily lives through services such as care and counseling. It does not operate today and more detailed information about the association is not available anywhere. According to Arda Karapınar (2021), among the associations established owing to this fund, only the Positive Living Association continues its activities recently.

This phase started quite productively due to good relations with the EU and AKP's claim to democratize Turkey. However, especially after 2008, a period of silence and indifference began in the field of HIV. This period of silence and indifference coincides with 2008, when the harmonization process with the EU slowed down and the economic stagnation began. For example, the National AIDS Commission met on a relatively regular basis from the day it was founded until 2007 but did not hold any meetings after 2007 until 2015 (Çetin, 2017, p. 23). The Association for the Battle against AIDS ended its activities in 2010 (Erbaydar, 2021). In 2010, disagreements and financial problems started to emerge within the Positive Living Association (Karapınar, 2021). In 2013, the board of directors of the association changed due to disagreements. This year was also the year when the financial resources of the association were completely dried up.

Çokar (2006a) explains the reasons why the National AIDS Commission has become dysfunctional over time and the inability of NGOs to influence decision-

making processes in his article. These reasons can also be seen as the reasons for the period of silence and indifference that started after the program of the Global Fund ended. Firstly, HIV prevention and support work in Turkey is still not a priority. This restricts associations working in this field. Second, the National AIDS Commission has no legal identity. Although there is a wide participation of NGOs in the commission, its impact on the determination and implementation of national policies is limited since it has no sanction power. This prevents NGOs from influencing the decision-making processes. Third, an "HIV/AIDS Monitoring and Evaluation System" has not yet been established in Turkey. Thus, it is unrealizable to determine the extent of the epidemic and the appropriate requirements. In other words, it is not possible for associations to create policies accordingly. Fourth, the lack of political commitment and monitoring and evaluation system prevents the effective use of existing financial resources and limits the support provided by international resources to Turkey. In addition, Karapınar (2021) and Erbaydar (2021) discuss the process that started with the withdrawal of the Global Fund from Turkey by drawing attention to dependency on external funds and its negative returns. Karapınar (2021) argued that due to the attraction created by the funds from the EU, amateur people applied for the funds and managed projects, and this was one of the reasons why the Positive Living Association entered a financial crisis. He cites as an example the survival of only one of the four associations established with the program initiated by the Global Fund in Turkey. Erbaydar (2021), on the other hand, stated that with the entry of fund-oriented NGOs into the field, the Association for the Battle against AIDS had to withdraw from the relationships it had created by digging a well with a needle. He (2021) stated that the Association for the Battle against AIDS received only two small amounts of funds from international organizations, received a lot of

support from the Ministry of Health through the relationships it established in 1990s, and that he worked for the Association for three years as a permanent employee of the Ministry of Health. In summary, Erbaydar maintains that when NGOs receiving funding from international sources entered the field and started to work with the state, the Association had to withdraw from this network of relations. This process that Erbaydar mentions reminds of Atuk's critique of neoliberalization in Turkey. Atuk (2021d) states that the neoliberalization process that has been going on in Turkey since the 1980s has been consolidated with the populist government established by the AKP, and accordingly, the Ministry of Health has taken the role of implementer/planner out of its provider role as a result of the Healthcare Reform. He (2021d) argues that one of the consequences of this new role that the Ministry of Health has acquired in accordance with neoliberal policies is that:

> The second result is an increase in dependence on external resources. The Ministry of Health no longer wants to put its hand in his pocket, especially when it comes to sexual health. Instead, it chooses to manage the multi-million dollar budgets it receives from the EU or the Global Fund. For example, in 2003, Volunteer Testing and Counseling Centers were opened in more than ten provinces of Turkey within the scope of the HIV/AIDS Prevention fund provided by the Global Fund and worth 4 million dollars. However, the increase in economic dependence on foreign countries hinders the sustainability of the programs implemented. Because when the budget from the Global Fund ends, only one GTDM remains, and this is possible as a result of the local government's own initiative. Likewise, the most comprehensive information and empowerment activities for sex workers, LGBTI+s, people in prison and people who inject drugs were realized thanks to the Global Fund and have not been possible again.

When we look at the past from today, we see that the developments in the field of HIV under the AKP government in the early 2000s did not come to a sudden halt after 2008 because the AKP's interest in sexual health policies was limited to the EU harmonization process even before 2008. For example, no legislation regarding discrimination against PLWHA was made under the AKP government. In addition, in the country progress report evaluating the years 2005-2007, when the HIV/AIDS

Prevention and Support program was carried out, we see that the national pedagogy developed by the state in response to HIV in the 1980s and 1990s still exists in the 2000s. In the report, after claiming that the major driver of the epidemic is sex workers, more specifically women who come from former Soviet countries to Turkey and do sex work - Natashas, in the discriminatory language of the media – the report explains the low HIV prevalence in Turkey with the following words:

> The overall low HIV prevalence is thought to be the result of the traditional lifestyle to which most Turkish citizens adhere and the nature of the sexual networks which are threatened by the mobility of the populations in and out of the countries.

These statements do not overlap with the fact that in the data shared in the same report, the population with the highest prevalence of HIV is heterosexual men (Altan, 2006), and as we learned from sex workers, male customers refuse to use condoms by saying "We are Turkish, nothing will happen to us." (Kaos GL, 2002). Apart from that, another incident occurred which created confusion about the government's stance on HIV in 2006. In the United Nations Special Session on HIV/AIDS held in 2006, the Organization of Islamic Cooperation (OIC) decided to act jointly and rejects the proposals for measures to be taken urgently on HIV/AIDS on the grounds that it is against Islam. Turkey is one of the member countries of the OIC. Adana Deputy Gaye Erbatur asked the following questions about the rejection of the proposals in 2006 and the Minister of Foreign Affairs left unanswered:

> 4. Why did Turkey act together with the OIC instead of acting together with the Western countries in this conference, despite the road it has taken, and all the concessions made for EU membership?
>
> 5. Expressions such as "one of the most important methods to prevent HIV/AIDS is to provide widespread sexual education urgently in all countries. There is a need for education for groups at risk. There is a need for programs for girls and women in the 15-24 age group." were rejected by Islamic countries, so they could not be accepted in the declaration. What was Turkey's stance at this conference? (Erbatur, 2006)

Why would state officials choose to remain silent on an issue that points to a fundamental difference of opinion on the right to sexual and reproductive health? Why wouldn't a government that is committed to ensuring that its citizens can fully enjoy their sexual and reproductive health rights allay these concerns? Considering all this, I argue that the contribution of the AKP government in sexual health services in the early 2000s is the product of a populist policy aimed at benefiting from the political legitimacy of the EU harmonization process. The government's sexual and reproductive health policy in the next phase can also be seen as a proof of this.

3.2.4 Fourth phase

The feature that characterized the fourth phase that began in 2015 was the divergence of approach within subject-focused HIV activism. In this phase, new PLWHA-led organizations emerged. There has also been a serious shift in the government's sexual health policies. There are several reasons why 2015 represents the beginning of a new phase. First, the discursive shift of the government, not only in sexual health policies, but on a broader scale, became clear when the AKP won the 2015 general election. Secondly, in 2015, two people who would later establish two different HIV associations left the Positive Living Association due to disagreements within the association. Finally, this is the first time that the İstanbul Pride March, which has been held incessantly since 2003, was banned by the governorship of İstanbul. I will explain in more detail how all these incidents are interrelated and hence their convergence requires the introduction of a new phase.

Yılmaz (2017) states that after 2013, the AKP experienced an ideological shift from conservative democratic discourse to Turkish-Islamic discourse. According to him, the Turkish-Islamic identity established itself based on the

narrative that they are the real owner of Anatolia and victims of the modernization process carried out by Kemalist elites with the cooperation of Western countries in a top down process. After 2013, the AKP embraced the Turkish-Islamic identity strongly but it added a new layer to this narrative of victimization and authenticity. The AKP established a reactionary mood around this identity. For example, party leaders expressed their desire for regime change (transition from a parliamentary system to a presidential system) and as a result of the rising war in the Kurdish region of the country, the peace process ended. Yılmaz (2017) gives these incidents as an example of the reactionary mood and considers it as the beginning of the ideological shift that will take place after 2013. In 2013, Gezi prostests revealed the weaknesses, failures, and limitations of the project of AKP that brought together neoliberalism, democratization and Islam based on conservative democratic discourse. After the Gezi protests, the AKP clung more tightly to the Turkish-Islamic ideology in order to suppress the rising social opposition against it and to mobilize the electorate. After 2013, Islamic motifs became more visible in the speeches of AKP officials, Erdogan's calls to "raise a religious generation", and Islamic themes in the foreign policy discourse became more prevalent. Party leaders used the phrase "local and national" in their speeches more often and established an anti-Western discourse as it is in the discourse of the Turkish-Islamic ideology. Parallel to this discursive shift, there was a fundamental shift in the AKP's economic and population policies.

From the 1960s to the early 2010s, Turkey implemented anti-natalist population policies as part of its national developmentalist economic strategy (Yılmaz & Willis, 2020). After the 1994 Cairo Conference, a rights-based approach to sexual and reproductive health gained visibility, especially in the 2000s in Turkey.

That is, sexuality and reproduction were discussed as a human right issue in addition to being the subject of population policies. In the early years of the 2010s, the AKP's discourse on reproduction and sexuality underwent a dramatic change. For example, Erdoğan in an 2012 speech said that "every abortion is a Uludere" likening abortion to a massacre in which Turkish Armed Forces killed 34 smuggler on the excuse that they were terrorists in Şırnak (Erdoğan, 2012). After that, the provision of abortion services in public hospitals was de facto banned (Yılmaz, 2018). In the 2014-2018 national development plan, the emphasis on family planning and sexual and reproductive health in previous years was replaced by "protection of the family and the young population". In other words, AKP abandoned anti natalist population policies and started to implement pronatalist population policies. Also, the government marginalized sexual and reproductive health policies. Sexual and reproductive health policy became subjected to anti-natalist population policy of the government and a rights-based approach vanished from the official documents. While these changes were taking place, between 2014 and 2017, three district municipalities under the power of the CHP started to offer free and anonymous STI testing and counseling services. Yılmaz & Willis (2020) argue that that this is a local reflection of the global polarization over a rights-based approach to sexual and reproductive health. Accordingly, ultra-conservative media outlets and local politicians targeted the sexual health campaign launched by the CHP Mersin Metropolitan Municipality at a public university and politicised the condom distribution. Although the Ministry of Health was one of the partners in this campaign, the Ministry remained silent after the media and local politicians targeted the campaign. Yılmaz & Willis (2020) cite this incident as one of the examples of the conservative turn in government discourse and the polarization of sexual and

reproductive health policies. In 2015, the AKP won the elections again and consolidated its power. As a result, this shift in sexual and reproductive health policies gained legitimacy, and marginalization of sexual and reproductive health policies have become permanent. For these reasons, 2015 elections represent a shift and contribute to the factors that initiate a fourth phase.

Another important incident in 2015 was the separations in the Positive Living Association. One of the names who left at that time was Çiğdem Şimşek, one of the founding members of the association, and the other was the association employee Arda Karapınar. One year after these separations, *the Pozitif-iz Association* was founded by a group of people, including Çiğdem Şimşek, and Red Ribbon Istanbul was founded under the leadership of Arda Karapınar. The reason for these separations was the disagreements on two main issues. Karapınar (2021) summarizes these two issues as follows:

> There is an important problem underlined by our teacher Tuğrul, which causes the identity crisis and confusion experienced by developing countries in the world: Trying to take action by turning towards projects or money. In countries where there is no funds for urgent needs, projects carried out emerge within the areas and boundaries determined by large donors. After Positive Life, we can say that the issues that led to the birth of both Red Ribbon Istanbul and Pozitif-iz are both the enlargement attempt because of the funds received, and the identity crisis that followed.

In other words, the first of the two main issues that caused the difference of opinion was the quality of the association's relationship with the funds, and the other was the differences in approach to the HIV issue. Karapınar (2021) summarizes this difference in approach as follows:

> At that time, I was one of the addressees of the identity crisis. With encouragement, I started to work more in Europe, I went back and forth. In fact, I saw that there are many other things being done in the world. When we look at HIV specifically, we can talk about two basic approaches. There are models, one of which focuses on the stages of diagnosis and enables those living with HIV to get out of the society's pressure and lead an equal life. Another model in America addresses the entire society, producing

> information and advocacy based on evidence for the entire society, not just HIV+ and those affected. (…) That was the 2015 debate. I advocated the use of energy for addressing the entire society and for prevention, but at that time they rightly argued that Positive Living was established for a need. They underlined the importance of working focused on post-diagnosis, and there was a separation.

Parallel to these ideas, there are the following statements in the section where Red Ribbon Istanbul explains why they were established on its website:

> We see that the works carried out by both the public and non-governmental organizations on HIV and AIDS have concentrated on the stages after individuals are diagnosed with HIV. However, when we look at the good examples in different countries, we see that even the limited resources allocated to prevention and awareness works are more effective than just getting interested with the treatment phase in terms of both the efforts of NGOs and the use of public resources. From this point of view, it is clear that there is a serious need for awareness and prevention activities, as well as supporting and strengthening patient groups, which is one of the main arguments of HIV activism. (Kırmızı Kurdele İstanbul)

When we consider the statements of Karapınar (2021) and the statements on the Red Ribbon Istanbul website together, we see that the difference in approach is between a post-diagnosis focused service delivery and a preventive focused service delivery. In addition, Karapınar (2021) argues that project writing for funds makes the approach he has adopted impossible to exist. Another association that was established as a result of these disagreements is *the Pozitif-iz Association*. Unlike Red Ribbon Istanbul, this association focuses on post-diagnosis service. In other words, the disagreement that led to the establishment of *Pozitif-iz* is not due to the difference in approach. On *the Pozitif-iz Association* website, there are the following statements under the heading "Corporate Experience":

> The founders are mostly people living with HIV and have taken roles in the management and inspection committees, participated in many activities, coordinated lots of projects and carried out the peer counseling and case management for many years in Positive Living Association which is in the same kind of charity. After leaving Positive Living Association due to the disagreements experienced in the association lately, the changes and poor-quality services given to the people living with HIV and the metal fatigue among the board members and managers, the founding members and the

> team have gathered and united their knowledge in a new association, which is Pozitif-iz. (Pozitif-iz Derneği, n.d.)

Çiğdem Şimşek (2021), one of the founders of *the Pozitif-iz Association*, explains the vision of their association at an event where differences of opinion in 2015 were discussed:

> We also avoid the situation of writing projects for the funds mentioned by our teacher Tuğrul. We know that HIV+ people need this and we insist on projects for it. We don't want to get too big. Getting too big means getting bulky, leaving the phone unanswered. We want to stay boutique, get a small fund and work towards our goal with that fund.

Above, I quoted Karapınar's statements (2021) that one of the two disagreements that caused the separation was the enlargement attempt of the Positive Living Association in 2010. In my opinion, Şimşek's critical stance (2021) on writing projects for funds and the decline in quality that comes with growth explains his reason for leaving the Positive Living Association. The expression "the changes and poor-quality services" used on *Pozitif-iz*'s website is another proof of this. With all these separations and the process of establishing new associations, we see that the HIV movement made self-criticism in this period and that there was a diversity of approaches within itself.

After 2015, we witnessed that LGBTI+s living with HIV started to organize and engage in HIV activism intensely. For example, in 2015, Kaos GL started providing counseling for people living with HIV (Kaos GL, 2015). *Hêvî LGBTI+ Association* and *17 Mayıs Association* established respectively in 2015 and in 2019 determined HIV as one of their main fields of work (17 Mayıs Derneği, n.d.; Hêvî LGBTİ+ Derneği, n.d.). *Hêvî LGBTI+* published a book called “HIV Stories in Turkey” consisting of interviews with PLWHA in 2018 (Araç, & Aydın, 2018) and organized a panel entitled “Where Does HIV Stand in LGBTI+ Activism?” in 2020 (Kaos GL, 2020). *Kaos GL* and *17 Mayıs Associations* published the "Human Rights Report of LGBTI+s Living with HIV" in 2020 (Güzel & Dikmen, 2020). It is the

first report presenting the discrimination faced by LGBTI+ people living with HIV. In 2021, this report was presented as part of Istanbul Pride Week (Kaos GL, 2021). In addition, between 2019 and 2021, in the scope of İstanbul LGBTİ+ Pride Week, LGBTİ+s living with HIV organized panels such as "Queer Criticism of HIV Policies", "Current Approaches to HIV" and "Who Has a Voice in HIV Activism?" (Tar, 2019; Tar, 2020; Kaya, 2021). Also, SPoD established the HIV Studies Unit due to the increase in questions about sexual health to the SPoD LGBTI+ Hotline (SPoD, 2021). A year later, *17 Mayıs Association* and *Kaos GL* established a joint HIV studies unit named the "Positive Field" (Kaos GL, 2021). This unit explained its mission as making visible PLWHA in areas such as academic, art and media in the text it published to announce its establishment. These are only a brief list of activities by LGBTİ+ living with HIV. I think there are two reasons for the increasing interest of LGBTI+ people living with HIV in HIV activism. The first concerns the conservative turn in the government's discourse in the 2010s. As a result of this shift in discourse, the government has begun to promote reproduction-centered sexuality while marginalizing any form of sexualities other than it. In accordance with it, it marginalized LGBTİ+ identities because it equalizes these identities with sexualities that do not result in reproduction. For example, the Istanbul LGBTİ+ Pride Parade, which has been taking place uninterruptedly every year since 2003, was banned in 2015 and it has been banned since this date. Following this ban, every year, another Pride Parade in other cities were banned and these bans spread all over the country (Eşit Haklar İçin İzleme Derneği, 2019; Yıldırım, 2022). As a result, the right of LGBTI+s to express their political demands in public was criminalized. Another example of the marginalization of non-reproductive sexualities was the following statements used by the President of Religious Affairs Ali Erbaş (2020) in his sermon:

> O people! Islam considers adultery as one of the greatest harams. It condemns Lutism, Homosexuality. What's the wisdom of it? The wisdom is that it brings diseases and rots the generation. Hundreds of thousands of people are exposed to the HIV virus every year, which is caused by illicit and unmarried intercourse, by this great haram, whose name in Islamic literature is adultery. Let's fight together to protect people from such evil.

Erbaş equates homosexuality with "illicit and unmarried intercourse" and claims that these kind of intercouses will cause the extinction of the generation by spreading HIV. In other words, Erbaş alleges that homosexuality leads to the transmission of HIV. The fear of extinction and the emphasis on marriage in Erbaş's speech are reminiscent of the government's family-oriented population-increasing policies since the 2010s. In addition to that, Erbaş implies that reproductive-oriented, marital sex, that is, a "traditional lifestyle" will protect people from being infected with HIV as stated in the country progress reports published by the government in the 2000s (Altan, 2006; Altan, 2008; TC Sağlık Bakanlığı, 2010). This shift in the government's discourse and policies regarding sexuality has had many consequences. One of them ise that LGBTI+s living with HIV have become more vulnerable to multidimensional discrimination and violence (Engindeniz, 2020; Güzel & Dikmen, 2020). Likewise, the government's marginalization of LGBTI+ identities and sexual and reproductive health services has made LGBTI+s more vulnerable to being infected with HIV. For example, according to the data of the Ministry of Health, which categorizes HIV cases according to possible transmission routes, the share of "homosexual/bisexual sexual intercourse" in total cases was determined as 9.9 percent in 2013, 13.1 percent in 2016 and 14.46 in 2021 (T.C. Sağlık Bakanlığı Halk Sağlığı Genel Müdürlüğü, 2013; T.C. Sağlık Bakanlığı Halk Sağlığı Genel Müdürlüğü, 2016; T.C. Sağlık Bakanlığı Halk Sağlığı Genel Müdürlüğü, 2021). The reliability of the data of the Ministry of Health is open to discussion. Therefore, it is difficult to know how much this increase reflects reality. However, it is a fact that

while the number of diagnosed homosexual/bisexual persons was 670 in 2013, this figure increased to 4531 in 2021 (T.C. Sağlık Bakanlığı Halk Sağlığı Genel Müdürlüğü, 2013; T.C. Sağlık Bakanlığı Halk Sağlığı Genel Müdürlüğü, 2021). In other words, the number of homosexual/bisexual people diagnosed with HIV in Turkey has increased tremendously in this time period. I can be argued that the shift in the government's discourse on sexuality and the increase in the number of gay/bisexual cases are closely related to the increasing interest of LGBTI+ people living with HIV to organize and advocate for the rights of PLWHA. In this process, many newly diagnosed LGBTI+ activists started to raise their voice in the field of HIV. The fact that these activists are already organized and visible within LGBTİ+ rights movement has enabled them to organize easily and make their voices heard in HIV activism. In addition, sexual and reproductive health has inevitably become an area where they speak up for LGBTI+s who already oppose the government's conservative sexuality policies. Atuk (2021b), an LGBTI+ who currently conducts research on HIV care in Turkey and is an HIV activist, reads the organic link between LGBTI+s and the risk category, especially the "HIV risk", through the idea of "the positivity of queerness, the queerness of positivity". Referring to Aliye Kavaf's statement in 2010 that she stated homosexuality is a disease (“ Ęşcinsellik hastalık,” 2010), Atuk draws attention to the fact that not being heterosexual is seen as a contagious disease that needs to be treated, and that the conservative view sees being queer as a viral/microbial national security issue, whether it is related to HIV or not. This is the positivity of queerness. On the other hand, Atuk emphasizes the idea of the conservative epidemic logic claiming extramarital, anal, polygamous, or non-reproductive sexualities, which are mostly equated with LGBTI+ identities, will cause HIV transmission. For him, as a result of this idea, these sexualities are seen as

ambiguous, which endanger both public health and social order, and which need to be controlled. This is the queerness of positivity. This reading of Atuk explains how HIV and LGBTI+ issues inevitably intersect especially after the conservative turn in the 2010s. At this phase, LGBTI+ activists living with HIV formed an integrated political stance on HIV and criticized the state, HIV associations and the LGBTI+ movement from their own perspectives. For example, Positive Solidarity activist Kaya (2020) criticizes the Ministry of Health's post on social media on 1 December. In this post, the Ministry (2019) stated:

> The fact that HIV-positive individuals do not have regular health checks is one of the most important factors in the spread of the disease.

Kaya maintains that many people avoid getting tested, or even if they get tested, they may refrain from treatment because of discrimination and stigma. Kaya reminds that the Ministry of Health does not take measures to overcome this problem such as providing post-diagnosis trauma services and anonymous testing. Thus, Kaya argues that this statement only contributes to the stigmatization of those living with HIV by blaming them for being responsible for the HIV epidemic. In the same article, he (2020) criticizes the Ministry of Health for using the categories of "heterosexual intercourse" and "homosexual/bisexual intercourse" instead of the categories of anal, vaginal, and oral intercourse under the heading "potential transmission routes" while collecting data through the HIV surveillance system. Kaya argues that this categorization reduces sexual orientations into sexual intercourses. Moreover, he states that even if a person is gay, this person choose not to declare their HIV transmission route or to choose the category of "heterosexual intercourse" because of homophobia. For this reason, he argues that the data collected by the Ministry through this categorization is not reliable. He also maintains that the Ministry does not do any work for LGBTI+s and therefore the only function of this categorization

is to stigmatize LGBTI+s. Another LGBTI+ HIV activist, Demir (2019) criticizes HIV associations that produce HIV policies based on the data collected by the Ministry's unreliable surveillance system. According to these data, the share of heterosexuals among those diagnosed with HIV is higher than that of LGBTI+s (T.C. Sağlık Bakanlığı Halk Sağlığı Genel Müdürlüğü, 2021). Demir reports that HIV associations repeats the argument that "HIV is not a LGBTI+ disease" based on the data of the Ministry and argues that, of course, HIV is not an LGBTI+ disease, but this argument prevents these associations demanding sexual health policies to meet the unique needs of LGBTI+s and renders the discrimination that LGBTI+s living with HIV face invisible. They also criticizes those who use this argument to fight against homophobia within LGBTİ+ community for accepting negative judgments about HIV and trying to push this "label" out of the LGBTI+ community. According to Demir, HIV associations and LGBTI+s who use the argument "HIV is not a LGBTI+ disease" produce both HIVphobia and LGBTI+phobia. This criticism of Demir is in contrast with Kaos GL's statement in 2004 that "HIV is not a homosexual disease". Kaos GL's statement in 2004 was criticizing anti-AIDS associations for labeling homosexuals by using the term "risk group" (Kaos GL, 2004). From that year to now, we can see how LGBTI+ movement's approach to HIV has transformed on the issue of HIV. In addition to these criticisms, Demir (2018), in their article titled "Awareness not against HIV/AIDS, but for those living with HIV", stated that the researches on HIV/AIDS are mostly focused on HIV transmission/death rates or the attitudes/knowledge of people who are not/are assumed to be not living with HIV. Demir identifies the lack of reporting and field studies on the discrimination experienced by those living with HIV. Demir draws attention to the fact that the Positive Solidarity Association did not published a report on discrimination for the

last eight years, and underlines an independent struggle in which the agenda of the fight against HIV is determined not by funds, but by those living with HIV. Similarly, Atuk (2022a) criticizes that dependency on funds results in the subordination of the needs of those living with HIV. Atuk states that pharmaceutical companies distribute funds under the name of social responsibility in countries such as Turkey where the advertising of prescription drugs is prohibited, and gives an example of the funds distributed in Turkey by Gilead, which sells HIV drugs. He claims that Gilead allocates most of its funds to free test projects that will enable it to sell more drugs thanks to the increase in the number of diagnoses, and HIV associations that cannot receive the necessary support from the state have to turn to these funds due to financial needs. Atuk states that in countries like Turkey where there is no post-diagnosis counseling and support services, the diagnoses given as a result of the aggressive testing policies lead people away from treatment. Atuk also criticizes the conservative preventive policies of the state. He (2021c) points out the HIV Control Program's recommendation to abstain from sex or to have monogamic relationships with HIV-negative people in order to avoid being infected with HIV, and describes it as conservatism when the state gives a highly stigmatizing and sex-negative recommendation, ignoring the fact that PLWHA receiving HIV treatment cannot transfer the virus. Atuk (2022b) also finds the condom-oriented prevention policies of the associations conservative. He reports that the HIV associations does not mention methods such as PReP, PeP or non-penetrative sex as a protection method. He argues that the HIV associations put safety before pleasure and the safety concerns underlying the condom-oriented prevention policies of the associations create fear among people. Similarly, Nuh, coordinator of SPoD HIV Studies, underlines the importance of healthcare professionals telling clients about other

protection methods besides condoms and allowing them to choose the most appropriate method for themselves (Tar, 2019). In short, LGBTI+ activists living with HIV produced many criticisms at this phase on principles such as inclusion, intersectionality, sex positivity and autonomy. They also emphasized the importance of a struggle that puts those living with HIV at its center and is not dependent on funds.

3.3 Conclusion

In this section, I overviewed the history of HIV response given by various actors over four periods. Each actor's response to HIV differed according to the way they problematized HIV. To understand how actors are problematizing HIV, I have not examined solely at what policies they have suggested to respond to the HIV epidemic, but I also examined the discourses produced by these actors about HIV. Moreover, I took into account the social and political conditions that enable a variety of HIV responses in order to contextualize these responses. During the period between 1985 and present, main actors responding to HIV were state, health professionals, media, civil society, PLWHA and LGBTI+ community.

I contended that the state-expert-media triangle jointly established a national pedagogy in the first phase. Xenophobic, homophobic and sexist discourses produced by these actors about HIV marked sex workers, trans women, gays, foreigners, and immigrants as carriers of HIV. At the same time, through discourses about HIV, these actors re-established a Turkish identity based on national and religious values as the opposite of sex workers, trans women, gays, foreigners, and immigrants, and symbolically immune to HIV. As a result, a national pedagogy teached people who identify themselves with Turkish identity to stay away from

people who are assumed to be carriers of HIV instead of teaching to use protection such as condoms and get informed about HIV. Although these three actors embraced the national pedagogy, their strategies in responding to HIV differed. A conflict arose between experts-the media and the state over whether there are HIV cases in Turkey. The state followed a policy of denial regarding HIV because it bases its legitimacy on the purity of the Turkish identity. However, the experts and the media, which consider itself as the spokesperson of the Turkish people, used the language of fear and panic. The tension between these two strategies was the driving force of the state's HIV-related actions in the first phase. At this phase, the state's actions on HIV were limited to those that would alleviate the panic and fear of the Turkish people and strengthen the symbolic immunity of the Turkish nation against HIV.

In the second phase, the xenophobic and homophobic language of health professionals stemming from the desire to "protection of the Turkish nation from HIV" in the first phase replaced by the language of “rights”. For instance, some health professionals established non-governmental organizations aiming to fight against AIDS with the emphasis on the right to health in this phase. There were some developments that facilitated this change in the approach of health professionals. Firstly, access to HIV-related health services have become more vital than before because of the improvements in HIV treatment and HIV testing. Secondly, with the Cairo Conference in 1994, a rights-based view of sexual health became more common. Thirdly, public opposition began to organize within civil society as a response to the criminalization of leftist organizations started in the 1980s. With the establishment of these health professionals-led associations, the xenophobic and homophobic elements in the approach of health professionals did not disappear at once. However, it paved the way to discuss HIV with a rights-based framework. It

marks a fundamental break from the previous discourse of health professionals in the 1980s. In addition to change in the language of health professionals, the establishment of health professional-led associations also meant that civil society responded to HIV for the first time in Turkey. Although there has been a change in the response of health professionals to HIV in these respects, the language of panic and fear of the 1980s remained to some extent in the 1990s. These associations took an approach that put HIV negatives at the center and aimed at their access to preventive health services against sexually transmitted infections. This approach to protecting HIV-negatives from HIV also used language that fueled fear and panic about HIV. In other words, although the response of health professionals to HIV in the second phase adopted a rights-based approach, it was limited to the right to health of HIV-negatives. Nevertheless, people living with HIV had the opportunity to come together under the roof of these associations and establish solidarity groups. One of the most important factors that made the transition to the third phase possible was these solidarity groups.

With the *AKP*'s coming to power in 2002, the EU harmonization process accelerated. Thanks to the EU harmonization process, legal obstacles in front of the democratization process in Turkey began to be lifted one by one in these years. The institutionalization process of civil society that started in the 1990s thus accelerated in the 2000s. Funds provided by the EU to non-governmental organizations in Turkey in many areas, including sexual health, also contributed to this process. These funds enabled the establishment of four PLWHA-led associations in 2005. These associations took an approach centering the rights of PLWHA and focused on post-diagnostic services rather than preventive services. Moreover, these associations gave the opportunity to PLWHA to demand their own rights directly for the first time

since the HIV epidemic started in Turkey. However, in line with the stagnation of the EU harmonization process in 2008, HIV associations began to experience financial difficulties. In addition, there has been a silence regarding HIV by the state since 2008.

The Gezi Protests exposed the weaknesses, failures, and limitations of the *AKP*'s project that brings together neoliberalism, democracy, and Islam based on a democratic conservative identity. The winning of elections by *AKP* in 2015 was a turning point for AKP and it desist from its conservative democratic discourse into Turkish-Islam discourse. This ideological shift also represents the beginning of the fourth phase. It is because this turning point was reflected in *AKP*'s sexual and reproductive health policies. Population-reducing policies that had existed since the 1960s were replaced by population-increasing policies in the 2010s. Parallel to this, the *AKP* began to criminalize demands for the right to sexual health and sexualities that do not result in reproduction. For example, the *AKP* has increasingly embraced anti-LGBTI+ discourse and policies since 2015. In these years, we witnessed an increase in the number of HIV cases among LGBTI+s. As well, LGBTI+ living with HIV have begun to advocate for their own rights publicly. LGBTI+ activists living with HIV developed a perspective that criticizes fund-based rights advocacy and focuses on those living with HIV, and advocated a sexual ethic that centers on consent and self-autonomy. Along with these criticisms, there has been diversity in terms of approach within the community of people living with HIV in this phase, which started to organize in the previous phase. However, it was not only LGBTI+s living with HIV who were criticized within the community. In this phase, two associations were established by advocates living with HIV named Red Ribbon İstanbul and *the Pozitif-iz Association*. Founders of both associations addressed their

criticism of fund-based HIV activism because they argued that fund-based HIV activism both creates financial fragility due to external dependency and prevents people living with HIV from setting their agenda. Despite these criticisms, there was no radical refusal to receive funding. In addition, Red Ribbon İstanbul did not adopt the post-diagnosis approach of other HIV associations and chose to carry out informative and awareness-raising activities for the whole society. This diversification in the approach of advocates living with HIV was another crucial development that characterized the fourth phase.

CHAPTER 4

FINDINGS

In this chapter, I will present an analysis of my interviews with HIV rights activists. I will present the findings under three themes: how do people living with HIV experience HIV disclosure, perspectives of HIV rights advocates on HIV disclosure, and the factors determining PLWHAs' decision on disclosure.

The process of reaching the respondents may give some clues for us to understand what it is like to be a person living with HIV in Turkey. Hence, I will begin with explaining the process. I contacted three associations working for HIV rights in order to reach the participants. One of these associations refused to share my research participation call with the members of the association due to the fatigue caused by the frequently requested similar calls. Thus, I spread my call through two HIV associations. Members of one of the two associations did not respond to my call. The person I was in contact with from this association said to me that the members of the association did not want to participate in my research because they had privacy concerns, despite the fact that I had explained that I would use the answers given by the participants by anonymizing them in my thesis. Only members and volunteers from one HIV association responded to my call. I reached five participants through this association. I reached the remaining three participants through personal contacts. The process of reaching out to participants itself shows that those living with HIV are a hard-to-reach group, due to privacy concerns and the wearisomeness of talking about their experiences over and over again, which are often fraught with discrimination and rights violations.

It is important to take the participants' background into account in order to understand their responses. Seven of the eight participants defined themselves under the umbrella of LGBTI+. Five of them identified themselves as LGBTI+ rights activists as well as HIV rights activists. One person did not want to give information about their gender identity and sexual orientation.

The ages of the participants are as follows, respectively: 26, 36, 27, 42, 23, 21, 24, 27. That is, the average age of the participants was around 28 The young age of the participants may be a factor that makes it easier for these people to engage in HIV rights activism. For example, one participant stated that:

> Maybe the new generation can live with a little more awareness. In my age group, five years below or five years above, the perception of HIV is much different. The sources we feed ourselves are different. I was a child in the eighties. Maybe if you researched HIV in the eighties, you've seen it in documentaries etc. It was known to be a pretty terrible disease, and it was something not to be touched or approached. (Participant 4)

Five of the participants are university graduates and were employed at the time when I interviewed them. The remaining three were continuing their university education. The economic independence of the majority of the participants may have made it easier for them to be more vocal about HIV rights. Likewise, the educational status of the participants may have led to self-acceptance and awareness of rights.
Finally, three of the participants reside in Ankara and two in Istanbul. One person each from Bursa, Antalya and İzmir participated in the research. All of the participants live in big cities. The fact that it is easier to remain anonymous in big cities than in places with a low population may have reduced participant's privacy concerns. This may have facilitated their participation in the research.

4.1 How do people living with HIV experience HIV disclosure?

When I asked the participants if they feel any pressure to disclose their HIV status to their partners and healthcare professionals, they gave a variety of answers. Some participants stated that they do not feel any pressure to disclose, while others stated the opposite. There were also participants who had contradictory answers during the interview. Regardless of whether this expectation puts any pressure on them or not, all of the participants claimed that society expects them to disclose their HIV status to their partners and healthcare professionals even in cases where there is no possibility of HIV transmission. Moreover, some participants stated that society considers non-disclosure as a crime or PLWHAs as criminals:

> There are those people who consider PLWHAs as a murderer and a criminal and think that PLWHAs have to disclose their HIV status otherwise they intend to kill the others, while not knowing anything about HIV and U=U. On the one hand, they are not aware of current developments, on the other hand, your demands do not matter because you are a second class person, you are now a dirty person, you are unhealthy. As if living with HIV is a bad thing… On the one hand, there is pressure on us, on the other hand, an unwarranted, legally baseless, so-called legal discourse is produced in a very stupid way based on Turkish Penal Code Article 86 and Article 89 which are about intentional injury but, in the end, there is also human rights law that we need to think about. (Participant 3)

One participant underlined the importance of a rights-based perspective, pointing out that criminalization of HIV non-disclosure opens the door to further violations of privacy:

> It is something that will cause the workplace to say that you have to disclose it to me, the next day, your family to say you have to disclose it to me, and your friends to say that you have to disclose it to me or it will cause people to say "you have to disclose that you have HIV while crossing the street because you are crossing the street with me". Therefore, such concessions from human rights cannot be granted. If it is given, there is already a going back (in terms of rights) there. Therefore, it is necessary to underline the confidentiality of private life, the right to privacy, and that this (HIV status) is health data in particular. It -how can I put it- may seem in vain when it is said

> as a concept, but it is really not in vain. Eventually, a crack on one of them (human rights) could put the life of PLWHAs at risk. (Participant 3)

The criminalization of HIV disclosure shapes participants' experiences of disclosure and non-disclosure. For example, this may cause them to experience HIV non-disclosure as concealment or lying instead of as a right. One participant articulated it as following:

> I always think that we are a society that confuses privacy with concealment. What is hidden is always a crime or a sin, like you have to conceal it all the time. As if it might not be my choice to keep it private or you might not be forcing me to do it too, I mean the society. The issue is never perceived from here. (Participant 2)

Participant 2 emphasizes the importance of self-autonomy against the criminalization of HIV non-disclosure. Nevertheless, the answer of another participant shows that it is not always easy to overcome the feeling of lying, especially in close relationships:

> When we look at the relationship part, I give an example, we are talking about military service, and you have to explain why you did not do the military service. Apart from that, there is an issue related to HIV, maybe he shares his own HIV status. Maybe we're talking about anyone, about people, about HIV positivity. I have to pretend it doesn't exist, but it does. You're lying. This is lying. Saying "no, it doesn't exist" or, for example, making up an excuse to say "I didn't serve in the military". There is a specific reason for this. Privacy until here but lies from here. (Participant 8)

Not surprisingly, as living with HIV was portrayed as a crime or immorality, participants experienced HIV disclosure as a "confession". In order to overcome this feeling of "confession", some participants sought to make disclosure a part of everyday life:

> I don't disclose it saying, "I have to tell you something, I am living with HIV". I disclose it in a casual mood while having a daily conversation. I make disclosure as part of my daily practices. (Participant 1)

Additionally, as participants are HIV advocates, some of them are already publicly out about their HIV status. There are consequences of being publicly open.

Sometimes this can lead to stigmatization and discrimination. However, there can be some positive benefits. For example, if you are living with HIV and people know your HIV status, only people who are not HIV-phobic will form close relationships such as lovers, sexual partners and friends. So, there will be self-selection among the people with whom you form intimate relationships. Also, the fact that the other person knows your HIV status can mean that you can eliminate the stress of disclosure. That is, participants' experience with HIV disclosure may differ from the general.

> Then one day later we are in bed and chatting together. He said how beautiful your photo with the cat in your lap is. I had a thought process for a second or two there. In order for him to see the photo with the cat in my lap, he has to type my name and surname on google because it is a photo I put on a cat adoption page, and when he writes my name and surname on google, my HIV disclosure story in Kaos GL appears on the first page. Then I stopped and looked, I laughed, then I said you read the story, didn't you? He said: "And you say you won't share". “I was guessing that was it,” he said. It's one of the scenes that really left a mark in my life because I felt so relieved all of a sudden. I was relieved, I didn't want to go through that disclosure process. I didn't want to experience that tension. It relaxed me a lot. I was so happy. (Participant 5)

Apart from that, half of the participants reported that the pressure they felt to disclose decreased as they suffer from discrimination and gain a rights-based perspective and proper medical knowledge about HIV from the day they were diagnosed until today.

> I have been living with HIV for a long time and I am not the person at the beginning currently. Things have changed in the process. At first, I thought that I had to disclose it to my partners. Later on, I was like “OK! I don’t have to disclose but it is better to talk about it”. Then, it evolved into “Nevermind! It is none of their business”. It is actually what it is. It is a turbulent process. (Participant 1)
>
> It's not a question where I can say yes or no. I feel it (the pressure to disclose) from time to time. Sometimes I don't feel at all. I don't even care about it. However, when I consider the time until now linearly after the diagnosis, I remember feeling this more intensely in the first days. You have to share this (HIV status) because what if something happens to someone and you cause it? Of course, when I became aware of my rights and realized that if the

> health workers took the necessary precautions, there would be no need to share, I stopped feeling the need to share it. (Participant 5)

To summarize, high level of criminalization and stigmatization of HIV shapes the participants' experience of HIV disclosure. Participants mostly experienced HIV disclosure as confession and HIV non-disclosure as a concealment or lying. However, a rights-based approach helped them to avoid the feeling of hiding or lying. Moreover, increased medical knowledge about HIV empowered participants and positively changed their experiences of disclosure. Apart from that, participants developed strategies such as being publicly open or making disclosure a part of daily routine to avoid the stress of disclosure.

4.2 Perspectives of HIV rights advocates on HIV disclosure

As I showed in the previous chapter, HIV is still criminalized all over the world. HIV advocates have been fighting globally to prevent the criminalization of HIV. The international organizations such as UNAIDS, HIV Justice Network and The Center for HIV Law and Policy work to create a public debate on HIV criminalization and gain social and political support to influence decision-making.

We also have witnessed the emergence of a public debate on HIV disclosure in Turkey recently. In 2019, the social media post of the Youth Approach in Health Association and the Association for Combating Sexual Violence for World AIDS Day on December 1started a public debate on HIV disclosure on social media. This social media campaign aimed at bringing the relationship between sexual health and sexual violence on the agenda. As part of this campaign, the Association for Combating Sexual Violence shared an image that reads "I Don't Have to Share My HIV Status". The association used this slogan to empower people living with HIV who are often forced by their sexual partners to disclose their HIV status to them.

They argued that forcing people living with HIV to disclose is sexual violence. However, this public debate resulted in a backlash, with many social media users blaming those living with HIV who did not share their HIV status.

During the interviews, all of the participants embraced this slogan, despite the fact that I did not ask anything about the discussion on social media. Participants expressed their perspectives on HIV disclosure as a public debate in addition to their personal experiences of HIV disclosure. The participants stated that they do not claim that it would be better for people living with HIV to disclose or not disclose. Participants emphasized that there would be no one-size-fits-all advice on disclosure. However, they all agreed that HIV disclosure is not an obligation.

> I'm not saying you shouldn't disclose. What I mean, you do not have to disclose. I'm trying to highlight this (participant 1)
> This is actually something I say about my own situation. I prefer to disclose there but if you discuss it technically you have no obligation to disclose (participant 4)

There were some common arguments that the participants used when explaining why they should not be obliged to disclose their HIV status. First, most respondents cited the Undetectable=Untransmittable (U=U) campaign. These participants maintain that those living with HIV start to receive regular treatment immediately after diagnosis and so that there was no possibility of transmitting the virus to others, as the virus decreased to undetectable levels in the blood thanks to the treatment. They underlined that their HIV status does not concern others, as there is no possibility to transmit the virus to others. For example, one respondent stated that:

> Participant 1: This is one of the reasons: there is no difference between disclosing and not disclosing in terms of prevention, because people want to learn about it (HIV status) with the mindset of "Let me know it so I can protect myself" or because they (PLWHAs) may believe that they have to disclose it to others with this mindset. Basically, there is no such health issue. At least there is no such risky situation. Also, these people do not have the (safe) space to disclose as I mentioned. If this (conversation) had happened

> earlier, if we weren't talking about U=U, we could have discussed it in different ways
>
> Researcher: I guess you're actually making this evaluation based on U=U, right?
>
> Participant 1: Yes while emphasizing why it (disclosure) is not mandatory. If the reason why people argue that it has to be disclosed is to prevent (HIV transmission), or to protect themselves, if it is said that it has to be disclosed with this mindset, there is no such obligation. (Participant 1)

Secondly, another reason why the participants did not consider HIV disclosure as an obligation was the society's low level of knowledge about HIV. The literature about the knowledge level of the society about HIV in Turkey also supports the participants' claim. According to a survey conducted with university students from the USA, Nigeria and Turkey, Turkey is the country with the lowest level of knowledge about HIV and AIDS (Abiona et al., 2014). According to the same research, the main source of information for students about HIV and AIDS is the media (Abiona et al., 2014). Most of the participants expressed that it was exhausting for them to have to repeatedly educate each person they disclosed to about HIV:

> They are testing me: how do you know that this is so, you say U=U but where did you read it, where did you see it, show it. I know it will be very difficult for me to be asked for such a proof. Making an effort for them, trying to explain oneself... that's where it finally came to. Trying to explain myself will tire me a lot. I don't want that. (Participant 5)
>
> Researcher: What is the reason when you choose to hide it (HIV status)?
>
> Participant 8: When I choose to hide my information?
>
> Researcher: Yes.
>
> Participant 8: I prefer to hide because of the uninformed society. Let them know (about my HIV status) as long as I allow. I disclose it when I consider it necessary, when I feel comfortable. “Yes, this is my password, you can check it, the information is over there, I have such a disease and I live with it” and so on... But for the rest of time, frankly, not everyone is informed in this country. Most people are not informed. So it's okay if they don't know my HIV status (Participant 8)

Apart from that, a large majority of the participants reported incidents of discrimination and violence they were exposed to by healthcare professionals or sexual or romantic partners, to whom they disclosed their HIV status. While explaining that HIV disclosure should not be perceived as an obligation, they drew attention to the possible discrimination and violence they will be subjected to after disclosing their HIV status.

> Is there an obligation to disclose? No. I can't think of a case where it would be an obligation, but we also need a suitable environment for sharing (our HIV status with others). It's not just about sharing it. Who will you share it with, what will you share it with. I will share, but what will I be exposed to, what will I face? There are a lot of possible scenarios, but will all of these scenarios be true or worse? There are many questions like this. There are both experienced traumas and known incidents heard from around. They (PLWHAs) can't share it because of the fear that these scenarios will come true. This is the main reason for not sharing. Scientifically, there are studies that say that there is no need to be shared. What more is required? There is no suitable environment for sharing, I think it (HIV disclosure) is absolutely not necessary since there is no environment where the people I have shared with will say "oh okay" and move on with their lives. (Participant 1)
> These thoughts, these impositions (about disclosure) have no reality. This so-called obligation has no value in society. The reason it has no value is because the risk of violence to those living with HIV is more real and more vital than this "they have to disclose" bullshit (Participant 3)

In parallel with these statements, reports published by HIV Rights Associations show that people living with HIV experience rights violations regarding right to work, right to access to health services and right to privacy (Altundağ, 2022; Tuğcu, 2022). For instance, people living with HIV are exposed to a violation of their right to work by being unlawfully requested to have an HIV test while applying for a job or while they are still working, or by being dismissed or being suspended from the job after the employer learns about their HIV status (Tuğcu, 2022). While one of the participants explained why he does not consider HIV disclosure as an obligation, he mentioned about the fear of unemployment:

> As far as I can see, people, who have a problem about this (about being known their HIV status), experience anxiety about whether this will come their way in their work environment or when they want to apply for a job. I honestly don't have that kind of anxiety. Even though people learnt about my HIV status, this is not something that will prevent me from working, but those who want to work in the public sector or are currently students, those who are studying a health-related department or a food-related department, prefer not to be known about their status when they apply for a job, otherwise they will sincerely have a hard time to find a job. (Participant 4)

As stated by the participant, in some sectors, PLWHAs are more likely to be exposed to violations of their right to work. For example, according to the report of the Pozitif-iz Association, most of the sixteen private sector employees who applied for the unlawful termination of the employment relationship were healthcare professionals (Tuğcu, 2022).

While the participants argued that it should not be an obligation to disclose their HIV status, one of the most common forms of discrimination they pointed to was a violation of their right to privacy. One participant stated that their partner, who knew their HIV status, shared it with third parties:

> Participant 1: in a long-term relationship... it turns out everyone knows (about my HIV status). I didn't think anyone knew. Everyone knows, and the way he presented it to people during our relationship is as follows: "I loved him even though he was like that. He was in a mentality that is so dramatic like in the film named “İncir Reçeli”. "He loved you even though you are like that, how ungrateful are you?"
>
> Researcher: What does "even though you are like that" mean?
>
> Participant 1: This phrase means that “even though I am living with HIV”. It's like I was a needy person to be loved, but they deem me worthy of love and I became an ungrateful person because I could not properly respond to his love. it was actually a horrible process that my partner, my ex-partner built. When you share it with people, such things can happen, or you can hear something about your status from someone who has nothing to do with you.

In parallel, the report of the Pozitif-iz Association states that PLWHAs’ sexual or romantic partners violated their right to privacy in eleven reported cases in 2021(Tuğcu, 2022). According to this, the partner of a person living with HIV

obtained the information about these persons' HIV status and shared it with others without their consent, and threatened and blackmailed them by saying that they would share it with others (Tuğcu, 2022).

Also, those living with HIV are exposed to violations of their right to privacy in healthcare institutions. According to a study of Positive Living Association (2022), 15 percent of the surgeons who participated in the survey reported that when they learn that their patient is HIV-positive, they will inform the patient's family and relatives. Again, 24 percent of the family physicians who participated in the same survey reported that if they learned that one of the couples who came to them to get a medical report before marriage was HIV-positive, they would inform the other partner (Positive Living Association, 2022). While one participant stated that they did not have to share their HIV status, they specifically pointed to violations of right to privacy by healthcare professionals:

> As long as people (healthcare professionals) carry out their duties correctly and well, we should not experience any difficulties. I think at the end of the day, if everyone was aware that this is confidential information and healthcare professionals treated people living with HIV accordingly, no one would have to worry about disclosing or not. (Participant 2)

Finally, the majority of respondents stated that they do not have to disclose their HIV status because it is a fundamental human right to decide when to disclose and when not to. The respondents' emphasis on addressing the issue from a rights-based perspective independently of the responsibility of those living with HIV towards others or the discrimination they are exposed to was remarkable.

> As I said, it's not an issue that concerns anyone, it's an issue that concerns only me. I don't have to make a press release. I do not need to announce this matter to the public or to my own small circle. Leave the violations of rights, stigma, this and that aside. I am a person who has gave a battle in my own private at least either in the marxist circle or in the queer circle. Being stigmatized can't affect me that much from now on. It affects but not that

> much. However, no one has such a right. I am using my own right. I want the privacy of my private life. (Participant 7)
> Of course, there is no such thing as I will disclose to all the health professionals at every doctor examination and every time I go to the hospital. I don't believe it, it's not right because my HIV status is confidential health information for me. I can disclose to anyone I like and that's just my right, even if the other person is a healthcare professional. (Participant 2)
>
> This ultimately means that the will of the person living with HIV is usurped, and that the decision mechanisms and the right to choose are taken away, and it means that it is not thought that someone living with HIV can make smart, logical, healthy decisions like an individual but this is not true after all. Finally, I am a 27-year-old person. I have a job, I have friends, I have partners, I do not live a life that is very different from the life that everyone else lives. Of course, there are some basic rights that come with being a human being and being born as a human. These cannot be taken from me, just as these cannot be taken away from someone else. (Participant 3)

Participants agreed that HIV disclosure was not an obligation. In justifying this argument, participants pointed to the possible discrimination they might experience after disclosure and the fatigue of informing people about HIV every time. Moreover, referring to the U=U campaign, they said that antiretroviral treatment made it impossible for them to transmit HIV to others. While all participants agreed on these three points, there was some disagreement when participants linked their argument saying “HIV disclosure is not an obligation” with the right to privacy. Some participants considered non-disclosure as a right to privacy even if they could transmit the virus to others or would not experience discrimination. Others emphasized that without the U=U campaign, they would not consider it a right to privacy in all cases.

4.3 The factors determining PLWHAs’ decision on disclosure

In the previous section, I presented the perspective of HIV activists participating in the research on disclosure. For them, disclosure is not obligatory, but this does not mean that they do not disclose their HIV status to anyone under any circumstances.

Participants' decision about disclosure depends on who they were disclosing to. The answer to the question to whom they disclosed also determined the factors affecting their decision to disclose.

4.3.1 Disclosing to healthcare professionals

The main factor influencing the participants' decision to disclose to healthcare professionals was how this decision would have an impact on their health status. Accordingly, the participants stated that some diseases may be caused by HIV. In such a case, participants prefer to disclose:

> I can disclose to a health professional in the favor of my health, when there is a situation directly related to HIV or I suspect it might be related. Again, the person who will make this decision is me. Then of course I can disclose it to the health professional or physician I like. (Participant 2)
> If I think my (health) problem is HIV related, a question comes to my mind: should I share it? but I usually don't share it if it's just a medical examination, if I'm only going to go to see a doctor. I don't say anything until the medicine is prescribed. (Participant 7)

The most common example given by the participants was that when they needed to take medication for a non-HIV-related disease, it might interact with HIV drugs. Participants reported that they disclosed their HIV status to physicians when they thought a drug interaction could adversely affect their health:

> I mean these cases. The purpose... You can disclose if it is for your own good, if you are going to use drugs, you don't know the interaction, you need to be able to talk about it. In these cases it can be disclosed. However, it still depends on one's preference. (Participant 1)

> Regarding health issues, there is not any condition that creates an obligation to disclose. Physicians can ask patients' HIV status only when the drugs might interact with each other. Not all drugs interact with HIV drugs, and your doctor needs to know that too. So, healthcare professionals prescribing medicine need to have this knowledge. Therefore, when the question arises whether the drug doctors will prescribe will interact with the HIV drug, I think this is a question they can ask the patient. (Participant 3)

In parallel, some participants stated that they disclose their HIV status to physicians before the surgery, because of the complications that may occur due to the surgery:

> They interfere with your body when surgery is performed, and this may increase the risk of infection, lower your body's resistance, and there may be a requirement for an additional intervention. At the end of the day, we are living with a virus, and it is in my body and in my blood. At the same time, of course, they (physicians) go into these surgeries with protection under any circumstances, but I might be at a disadvantage because I didn't disclose it (HIV status). So I must disclose. I better disclose it. (Participant 8)

When I asked if the participants think they have a responsibility to inform healthcare professionals about their HIV status to protect them from the possibility of HIV transmission, most of the respondents answered no. One answer given by a respondent stated it in a very clear way:

> It still depends on the person's preference, but other than that, I don't plan to disclose it (HIV status) for the doctor to take precaution, for the purpose of informing the doctor - I'm saying it between the quotes- against possible threats. If you disclose it for your own benefit, in my opinion, it is fine to disclose it. At least that's what I do. (Participant 1)

When I asked the participants why they did not have the responsibility to protect health professionals, the majority of the participants maintained that health professionals are responsible to protect themselves.

> I prefer to disclose it (HIV status) but technically you don't have to disclose it. If a doctor is going to do that surgery, they have to take precautions anyway. They are the ones who must take precautions. Technically this is what it is. If you don't want to share it, it's your natural right not to share it. (Participant 4)

> For example, when it comes to sterilization, it (HIV disclosure) is not necessary at all because general sterilization, what is called, sterilization applied in medical procedures is a common procedure and procedure that should be applied with everyone and after each person. There is no other procedure to be applied to those living with HIV. There is no need for any other procedure. Therefore, the healthcare professional should pay attention anyway. I mean in this sense, the person may be undiagnosed and a person living with HIV who has not yet been diagnosed cannot be responsible for any accident that may happen to a healthcare professional. A person

> diagnosed with HIV is already in U=U status and there is no risk of HIV transmission. (Participant 3)

Participant 3 could not remember the correct term but she tries to refer to "universal precautions" with "general sterilization". After the HIV pandemic started in the 1980s in the US, The Centers for Disease Control and Prevention (CDC) introduced universal precautions between 1985 and 1988 (CDC, 1985; CDC 1988). It is a practice that aims to control infections such as HIV, HBV and others by using personal protective equipment such as masks and gloves and keeping medical apparatus hygienic. CDC recommends following universal precautions for all patients in all healthcare settings because you cannot always know whether the patient is infected or not.

Apart from this, a study (Rintamaki et al., 2007) revealed that complying with universal precautions or taking extreme measures only for those living with HIV is perceived as a discriminatory practice by those living with HIV. Another study (Treloar et al., 2004) argued that by applying universal precautions only for infected people, healthcare professionals make judgments based on people's health status. Moreover, they assert that these judgements stem mainly from misconceptions and fears about transmission. In parallel, one of the participants drew attention to the discriminatory aspect of taking additional precautions of health professionals against those living with HIV:

> The reason for this is that you have to take precautions already by law. Whatever measures you take for everyone, you will take the same precautions for me. I don't think there is any obligation or requirement for me to declare my status. so I prefer not to share and I believe it would be better not to share because it does not require doing anything extra. There is the dentist story that Çiğdem always tells: applications such as wearing two gloves on top of each other, extra sterilization of instruments. Seeing this - when everything is terrible enough - is a situation that can make the situation worse and make the person feel even worse. So, I guess I wouldn't dare do something like that. (Participant 4)

4.3.2 Disclosing to sexual or romantic partners

The main factor determining the participants' decision to disclose to their partner was the level of emotional investment they made in their relationship. Majority of the participants made a distinction between one-night stands and long-term romantic relationships when talking about disclosure to partners. Some of the participants stated that while they prefer not to disclose in one-night stands, they disclose to partners whom they are planning to establish a meaningful relationship with in the long term.

> For example, if you are going to have sex with a partner for an hour, why should you make a drama out of it? I don't care! I don't want to disclose for the sake of a relationship that I don't know how long it will last and what I will do with it. At the same time, I don't want him to share everything about himself with me but if he shares, I will cherish it. (Participant 1)
> Participant 4: To be honest, It depends on the partner. If a relationship is on the way to becoming an emotional one, of course, you should share it.
>
> Researcher: What motivates you to share it when there is an emotional bond?
>
> Participant 4: Being transparent. One of us has such a condition, and as a result, it is something concerning the other party, and he should know it.

Apart from this, one participant stated that it is practically almost impossible for those living with HIV in close relationships not to disclose their HIV status:

> I had begun an emotional relationship at that time. I had to disclose it because he constantly had an expectation of me in terms of sexuality. I am not an asexual person and I was able to stall it up to a point. After that point, he asked me what the problem was. I had to disclose. (Participant 7)

In parallel, another participant also pointed out the difficulty of not disclosing in close relationships, but he added that not disclosing in a close relationship can mean lying because you would have to hide it:

> Let me put it this way, If both parties use protection in one-night stands, there will be no problem with this (not disclosing to partner) but in a long-term relationship, even if you use protection, it can be counted as a lie in terms of morals. If there is someone that I seriously consider to be in a relationship

> with, I disclose it before too much time passes because I don’t want to be in such a position. (Participant 8)

Two of the participants did not make a sharp distinction between a one-night stand and a long-term romantic relationship. These two participants stated that they can establish relationships that include both sexuality and intimacy, but that do not require long-term commitment. They expressed that disclosing to their partners when they feel safe can be a means of establishing intimacy. For them, the factor determining their decision to disclose was that their partners were people they trusted and wanted to get intimate with.

> It's actually a nice feeling when they (a sexual partner) give me the feeling that I can talk to them about it (HIV status). As this also means that we can talk about a lot of things, a safe space is created. It is a space where I can express myself and also where I can open up. (Participant 1)

> Somehow we had to end the communication for various reasons and as we walked together on the road, I said that I wanted to share something. "I want to share something with you and it's important to me". These were times when I was more emotional about it (HIV) and when I approached it more emotionally. I guess I'm not that emotional right now. "I have to share something and I believe that when I share it, we will become closer. I believe it will create a bond between us." (Participant 5)

In addition to the level of emotional investment, another factor affecting participants' decision to disclose to their sexual partners was the use of condoms during sex. Participants reported that they may have to make a choice between disclosing to their partners or stopping to have sex in cases where their partner insists on not using condoms. For example, two of the participants consider condom use as a pre-condition for having sex with someone, even if they were in the U=U status:

> You don't get a chance to talk about it (HIV status) in one-night stands anyway. Even if you have the opportunity, it's okay if you don't talk about it because if you're using protection and you're not transmitting it, you don’t have to care about it. (Participant 7)

> If there is going to occur an unprotected sexual intercourse, I'm just giving an example, if the other party didn't ask me (to use protection), I would never get

> involved or I will press him to use protection. If I realize that there is no way, then I will get up and go. (Participant 6)

On the contrary, two participants stated that they would not disclose in cases where their partner do not want to use condoms because they were in the U=U status:

> I don't feel the need to share either in a relationship without a condom or in any other situation because there never was a spike (in the viral load), but for example, if he drinks my blood, I can share it in such a case. (Participant 5)
> Participant 4: Frankly, I had sex without using a condom and did not disclose to my partner, relying on treatment. Frankly, if I express my own opinion, this is how I got this virus. I don't know whether the other party knew that he was living with HIV. I sometimes say to myself that I wish I had used a condom too. This is something concerning me. Perhaps the other party should also consider this. If he has such a concern, maybe he should demand it (using condoms) from me. I also rely on treatment.
>
> Researcher: Would your perspective have changed if you had not been receiving the treatment?
>
> Participant 4: It would change then of course.
>
> Researcher: So, you take care of the other party after all?
>
> Participant 4: Of course.

Participant 4 mentioned his U=U status to explain the reason why he would have sex without condoms and did not disclose but he also drew attention to the responsibility of the other party for the use of condoms. Another two participants also drew attention to the other party's responsibility for the use of condoms. While these participants expressed that each party had an equal responsibility to use condoms, the concept of consent was at the center of their argument. Participants defined safe sex not only as protection from sexually transmitted infections but also with consent.

> For example, the issue of not using protection is a good example of this. "We do not use condoms in our sexual intercourse, they have to disclose it". People can have ideas like that. No. Everyone can use or not use condoms. It is a decision made by both parties. Neither party can force the other not to use it. If there is such a coercion, it is not just a matter of HIV. It becomes a matter of coerced consent. Therefore it is everyone's own responsibility to apply prevention methods and everyone should know this information. People living with HIV do not have to have a motivation to teach this information to anyone, to educate people. (Participant 3)

> Of course, I assume it does not happen because I don't do it (having sex without condoms and not disclosing), but people maybe don't get treatment or they don't know their status and they don’t use protection. All of these pose risks. Therefore, you should be able to say to the other party, but unfortunately, no one says: "I don't know my status" or "I have unprotected intercourses and I didn’t get tested". After saying that, if you are not going to use protection and the other party gives a consent for it, it is OK, it's a mutual decision, but it takes a lot of nerve to say this. (Participant 8)

The relationship that both participants established between consent and disclosure differed from each other. The former considered using condoms during sex as a decision that should be made individually, based on the assumption that the parties should be aware that they can become infected as a result of sexual intercourse. She defined taking a consent-based decision on condom use as the party who wants to use condoms not being forced to do the opposite. In short, being free from coercion was the pre-condition to having sex without using condoms but disclosure wasn't. The latter argued that the decision on condom use should be made jointly by the parties through mutual information on each other's sexual history. For him, consent regarding the use of condom required an informed decision. However, he did not reduce the scope of mutual information to HIV status of the person living with HIV only. By doing so, he does not overburden people living with HIV with the responsibility of informing the other party.

4.4 Conclusion

I can summarize the findings of the research under three themes. These are experiences of people living with HIV regarding HIV disclosure, the perspectives of HIV rights advocates on HIV disclosure and the factor determining the decision to disclose.

First, participants described their experiences of disclosure around dichotomies such as crime and right, everyday practice and confession. They

contended that the society expects them to disclose even though there is no possibility of HIV transmission, and it leads to the criminalization of HIV. These shape their experiences of disclosure and non-disclosure. For example, people living with HIV may perceive their decision not to disclose as concealment or lying. Participants underlined the importance of a rights-based approach on disclosure to be able to overcome this feeling of lying. Additionally, people living with HIV may experience disclosure as a "confession" due to the criminalization of living with HIV. Some participants suggested to disclose in a casual mood as a part of everyday practices in order to eliminate this feeling of confession. Being publicly out about their HIV status was another way of experiencing disclosure by HIV rights advocates. This enabled them to eliminate the stress of the disclosure process because the other party already had known their HIV status. Finally, the participants stated that they became aware of their rights due to the discrimination they were exposed to, and their level of knowledge about the medical aspect of HIV increased after they were diagnosed. This resulted in less and less pressure they felt on the participants to disclose.

Second, participants discussed HIV disclosure as a public debate and shared their perspectives on the issue. All of the participants stated that it is not an obligation to disclose their HIV status to anyone. Participants explained these arguments by addressing 4 points. First of all, they stated that thanks to the developments in HIV treatment, people who receive treatment do not transmit HIV and therefore they have no responsibility to disclose it to anyone. Secondly, they stated that the public's knowledge of HIV is very insufficient and therefore they had to educate everyone they disclosed about HIV. Participants maintained that doing this over and over is very tiring for them. Thirdly, the participants stated that they

were exposed to discrimination and violence after they disclosed in the past, so they may prefer not to disclose in order to avoid of discrimination and violence. Finally, the participants stated that since HIV status is a health information, it is considered within the scope of private information in the law and not disclosing their HIV status is to exercise their right to privacy.

Lastly, although the participants suggest that disclosure was not obligatory, there were instances in their personal lives where they preferred to disclose. The factors determining their decision to disclose varied according to whom they would disclose. While making the decision to disclose to healthcare professionals, the participants paid attention to whether the healthcare service they would receive from the healthcare professional was related to HIV. When they went to the hospital for a non-HIV-related illness, they chose not to disclose their HIV status. In addition, they disclosed to healthcare professionals in cases such as drug interactions and surgical intervention so that they can get better healthcare. Moreover, they stated that there is no need to disclose in order to protect the healthcare professional from HIV transmission because healthcare professionals have to take universal precautions. The main factor determining the participants' decision to disclose to their sexual or romantic partners was the level of emotional investment they made. Most respondents distinguished between one-night stands and long-term relationships. Accordingly, the participants expressed that it would be costly for them to disclose it to someone they will only see once. They chose to disclose to their long-term romantic partners because of the transparency required by such relationships. Some participants did not consider their partners in these two categories. They had partners that didn't require long-term commitment but got intimate with each other. These participants chose to disclose to their trusted partners as a means of intimacy.

Another factor determining the decision to disclose to partners was condom use. Some participants stated that they do not prefer to have sex with their partners without using a condom or they disclose their HIV status to these partners. On the other hand, some participants stated that they do not prefer to disclose to their partners that they have sex without using condoms. Participants gave two reasons for this. First, the participants cannot transmit HIV thanks to the treatment. Secondly, they argued that each party have equal responsibility to use condoms during sex. Therefore, they do not think that they should feel more responsibility than the other party who insists on not using condoms.

CHAPTER 5

CONCLUSION

A public debate (Cinsel Şiddetle Mücadele Derneği, 2019) took place on social media regarding HIV disclosure motivated me to conduct this research. Throughout this debate, many social media users equalized HIV non-disclosure to intentionally transmitting HIV to others and portrayed HIV non-disclosure as a public health threat. During this debate, I realized that the experiences and perspectives of HIV rights advocates did not have a platform to be heard by the public. This is why I decided to write my thesis on HIV disclosure from the perspective of the rights of PLWHA. Accordingly, the literature defines a tension between preventive public health interventions and the protection of the rights of PLWHA. Based on the literature on HIV disclosure and the public debate I mentioned above, the main focus of the thesis was to examine how HIV rights advocates manage the tension between preventive public health interventions and the protection of the rights of PLWHA while developing their perspective on HIV disclosure.

To my knowledge, there is only one research exploring the perspectives of HIV advocates in Turkey. It is a master thesis examining the openings, limitations, and different forms of HIV activism through interviewing HIV rights advocates and ethnographic field research (Köse, 2022). Apart from that, I found only one research examining HIV disclosure in Turkey. This study explores strategies and motives of PLWHA for disclosure by interviewing twenty four people in Turkey (Öktem, 2014). As a result of my literature review, I found out that the literature in Turkey mostly consists of epidemiological studies investigating prevalence and incidence of HIV,

studies on risky behaviors, and studies investigating HIV knowledge levels and attitudes of HIV-negatives or discrimination and rights violations PLWHA experience, and psychology studies evaluating the level of depression and anxiety of PLWHA. In these regards, my study contributes to the literature regarding HIV in Turkey.

I presented my findings under three themes: how PLWHA experience disclosure, HIV rights advocates' perspectives on HIV disclosure as a public debate and factors determining the decision to disclose. 7 of the 8 participants identified themselves under the umbrella of LGBTI+. My intention was not only to interview LGBTI+ people living with HIV at the beginning of my research. Based on an experience of an LGBTI+ participant, Köse (2022) states that being a person living with HIV and being LGBTI+ at the same time can cause these two categories to shape each other. Accordingly, she found out that there is a tension between HIV associations and LGBTI+ living with HIV because of their differing approaches to HIV activism. Her thesis study does not have any findings about whether there is a difference of opinion regarding HIV disclosure between LGBTI+ living with HIV and non-LGBTI+ living with HIV. Nevertheless, It is important to evaluate the findings of my study from this intersectional perspective. The findings of my study may not align with answers that non-LGBT HIV activists would give.

For example, while the participants talked about the use of condoms, they also discussed the issue of consent as well as safety. In a study examining the sexual practices of the Montreal queer community, Weber (2013) reports that this community does not reduce satisfying sexuality to staying away from STIs. The community introduces concepts such as consent in addition to safe sex and defines "safety" as respecting people's boundaries and limits during sex. Similar to the

participants in this thesis, the Montreal queer community embraces the slogan “I do not have to disclose my HIV status”. Also, both the participants of my research and the community values self-determination against the criminalization of HIV non-disclosure. Apart from that, the participants emphasized the equal responsibility of parties engaging in sex instead of suggesting an obligation to disclose. In parallel, Ainslie presents the concept of “safe sex” suggested by the gay community in the US. This concept argues that if everyone has equal responsibility to protect themselves from HIV, there would be no need for HIV disclosure. To summarize, there are several parallelities in the approach of the activism of LGBTI+s living with HIV and the approach of the participants. The reason for this may be that the majority of the participants identify themselves as LGBTI+ activists as well as HIV activists.

In addition to that, I suggested adding a fourth phase into the periodization of Çetin (2017) and Çokar (2020) in the third chapter. I summarized the developments that characterizes this additional phase as the diversification in the approaches of HIV activism and the shift in the AKP's policies and discourse regarding sexuality. In the 2010s, *AKP* abandoned its anti-natalist population policy and started to follow a natalist population policy (Yılmaz, 2018). In parallel, as I mentioned in the third chapter, state officials made statements criminalizing sexuality that does not result in childbirth and therefore certain segments of society such as PLWHA and LGBTI+s (Ali Erbaş, 2020; Erdoğan, 2012). Moreover, the government marginalized sexual and reproductive health services and the protection of family and youth became a priority over sexual and reproductive health rights (Yılmaz, 2018).

Foucault's concept of biopower (2003) can help us establish a correlation between the criminalization of PLWHA and LGBTI+s, and the shift in *AKP*'s

policies and discourse regarding sexuality. Foucault (2003) states that biopower is not an oppressive power, but a productive power that governs life. It spreads by "making live" or "letting die". It operates at the population level and aims to optimize the productivity of the population. This change in policy and discourse led the *AKP* to deem certain segments “useless" such as PLWHA and LGBTI+ because PLWHA and LGBTI+ are associated with unproductive sexualities. The criminalization of LGBTI+ and PLWHA and the marginalization of sexual health services caused LGBTI+s to be more vulnerable to get infected with HIV. Accordingly, HIV cases among LGBTI+ people increased constantly from 2013 to 2021(T.C. Sağlık Bakanlığı Halk Sağlığı Genel Müdürlüğü, 2013; T.C. Sağlık Bakanlığı Halk Sağlığı Genel Müdürlüğü, 2016; T.C. Sağlık Bakanlığı Halk Sağlığı Genel Müdürlüğü, 2021). In summary, it can be argued that although the political atmosphere and social and economic policies have changed since the 1980s, the national pedagogy of excluding LGBTI+ persons and PLWHA from society is still in place.

The fourth period was also when LGBTI+ living with HIV begin to engage with HIV activism intensely. It can be argued that this is due to the need for LGBTI+ people to respond to the intensifying attacks of national pedagogy and the increase in the number of LGBTI+ people with HIV. In the third chapter, I argued that LGBTI+ activists living with HIV developed their approach to HIV based on self-autonomy. The participants also demanded self-autonomy against the criminalization of HIV. As Köse (2022) stated, intersectional identities shape each other mutually. The bodily autonomy is a crucial principle for LGBTI+ movement against criminalization and conservative sexuality policies. Thus, based on the findings, It can be argued that LGBTI+ activism has an influence on the participants' perspective on HIV disclosure, considering the majority of them are LGBTI+ activists. However, It

requires further research comparing the approach of non-LGBTI HIV activists and LGBTI+ HIV activists regarding HIV disclosure.

I established a relationship between the participants' answers and the perspective of LGBTI+ activists. In addition to the identity of participants, considering that the perspective of LGBTI+ persons on HIV emerged after 2015 and that the participants are young in age, the possibility of the perspective of LGBTI+ activists having an impact on the participants becomes even stronger. In the third chapter of the thesis, I mentioned that the perspective of LGBTI+ activists on HIV is in tension with the national pedagogy that emerged in the first stage and the medical perspective that emerged in the second stage. In summary, reading my participants' answers in tension with national pedagogy and medical perspective can help us better understand the position of the participants.

In chapter two, I argued that there is a conflict between the safe sex ethics of the gay community and the public health approach. This conflict also manifests itself between bioethics' principles of respect for autonomy and justice. On the one hand, the safe sex ethics' emphasis on the principle of respect for autonomy leads it not to deem HIV disclosure as an obligation for the gay community. On the other hand, in parallel to the principle of justice that requires fair distribution of costs and benefits, public health workers emphasize the duty to warn those outside PLWHA of the virus. In the third chapter, I introduced how different actor such as medical doctors, PLWHA and LGBTI+s responded HIV and it can also be argued that a similar conflict exists between medical doctors who aim to protect the public through "the war on AIDS" discourse and HIV activists who prioritize protecting the rights of people living with HIV. However, participants' emphasis on the U=U campaign suggests that this conflict has technically been overcome. Today, there are ways in

which we do not have to give up PLWHA's right to privacy in order to protect public health thanks to antiretroviral therapy.

In her thesis, Köse (2022) frames HIV activists' emphasis on the U=U campaign as a process of medicalization and argues that this is interestingly in contrast to the historical position of HIV activists. However, HIV activists' use of medical knowledge as a tool for rights claims is not a new phenomenon. Epstein (1996) states that HIV activists developed their medical knowledge in the 1980s and influenced the science of HIV and AIDS in favor of the rights of PLWHA. This does not simply mean that HIV activists have contributed to the medicalization process because these activists have not co-opted with medical institutions. On the contrary, HIV activists have historically pursued a strategy of instrumentalizing their medical knowledge to escape the medical gaze (Conrad, 1992) and demand their rights. With the U=U campaign, this strategy has become much stronger.

Nevertheless, the U=U campaign has not led to a complete end to the medical gaze, paternalistic attitudes, and discriminatory practices among physicians in Turkey. Based on the findings of her research, Şenyürek, Kavas & Ulman (2021) categorizes the approach of physicians who inform about the diagnosis into three. The first is the inappropriate approach, which provides inaccurate or incomplete information to patients at the time of diagnosis. For example, one physician said to the patient that he would not live very long because of HIV. The second is the inattentive approach that informs patients about the diagnosis in a way that violates their right to privacy. For example, one physician informed the patient about his HIV status in the presence of his family member. The third is the attentive approach that provides accurate information about HIV to patients and respects their privacy. In

sum, although the rights-based perspective of people living with HIV emphasizing autonomy has technically eliminated the conflict between the medical perspective and the rights of people living with HIV following the U=U campaign, approaches among physicians are still fragmented.

The fact that the participants were HIV rights advocates may also have had an impact on their experiences and perspectives on HIV disclosure. For example, Öktem (2014) reports that participants experienced a dilemma between disclosure and concealment. Moreover, she reports that participants who are in close contact with HIV organizations overcame this dilemma by defining concealment as a right. In my research, participants also stated that they describe not telling as a right against the dilemma between disclosure and concealment. Both studies have similar findings in this regard. However, they preferred the word "privacy" instead of concealment because the latter evokes lying.

Apart from that, in Öktem's study (2014), participants preferred to disclose to health professionals because they deem it necessary to protect health professionals. In my study, participants did not consider disclosing to health professionals necessary due to health professionals' responsibility to take universal precautions. As I mentioned above, HIV activists uses medical knowledge to avoid medical gaze. It can be argued that in my research, although participants could not name the correct term for "universal precautions", they have a basic knowledge of this medical practice. They used this medical knowledge avoid medical gaze and demand their right to privacy.

Additionally, Öktem (2014) reports that participants preferred to disclose to people they are intimate with because of the value given to intimacy. In my research, the level of emotional investment was also a factor determining their decision to

disclose. Again, Öktem (2014) reports that the fear of discrimination was one of the factors discouraging them to disclose. In my research too, participants mentioned the fear of discrimination as a reason why they do not deem disclosure as an obligation. Therefore, the need for intimacy and the fear of discrimination may be determining factors about the decision to disclose irrelevant whether they are HIV rights activists or not.

To conclude, I would like to mention the limitations of this study. Firstly, these findings cannot be generalized for all HIV rights activists in Turkey. It can be a difference of approach among HIV rights activists in Turkey. There is a research gap in the literature regarding the approach of HIV activists. Secondly, this study explores the perspective of HIV rights activists on HIV disclosure but I could not find any research exploring the perspectives of healthcare professionals. Thus, comparing their perspectives on HIV disclosure may emerge further findings.

APPENDIX A

SEMI-STRUCTURED INTERVIEW QUESTIONS

1. Can you tell me a little bit about yourself? How would you define yourself?
2. How do you find the health services for people living with HIV in Turkey? What do you think are the strengths and weaknesses of these services?
3. What is the routine process of initial diagnosis and treatment for people living with HIV in Turkey?
4. How do you think the relationship between people living with HIV and healthcare professionals is during the HIV diagnosis and treatment process in Turkey? Could you share with me your positive or negative evaluations of this relationship?
5. Are you encouraged by healthcare professionals providing HIV-related services to share your HIV status with other healthcare professionals? If yes, what kind of encouragement is given?
6. Are you encouraged by health workers providing HIV-related services to share your HIV status with your partner or partners? If yes, what kind of encouragement is given?
7. Do you feel pressure to disclose your HIV status to health workers providing non-HIV-related services? If so, can you describe this pressure to me? Do you think a person living with HIV should share his/her HIV status with health workers providing non-HIV-related health services? Do you think there are situations where a person should share their status, and if so, what are these situations? If no, why do you think there is no need to share?
8. Do you feel pressure to share your HIV status with your partner or partners in your private life? If so, can you describe this pressure to me? Do you think a person living with HIV should share their HIV status with their partner or partners? Do you think

there are situations where a person should share their status, and if so, what are they? If no, why do you think there is no need to share?

9. Do you know what kind of legal regulations exist in Turkey regarding the confidentiality of health information of people living with HIV? If so, what do you think?
10. How do you think the confidentiality of health information of people living with HIV should be regulated? In your opinion, who or who should have access to this information and under what circumstances?

APPENDIX B

SEMI-STRUCTURED INTERVIEW QUESTIONS (TÜRKÇE)

1. Bana biraz kendinizden bahseder misiniz? Kendinizi nasıl tanımlarsınız?
2. Türkiye'nin HIV ile yaşayanlara yönelik sunulan sağlık hizmetlerini nasıl buluyorsunuz? Sizce bu hizmetlerin güçlü ve zayıf yanları nelerdir?
3. Türkiye'de HIV ile yaşayanlar için ilk tanı ve sonrasında rutin olarak nasıl bir süreç işliyor?
4. Türkiye'de HIV tanı ve tedavi sürecinde HIV'le yaşayanlar ve sağlık çalışanları arasındaki ilişki sizce nasıldır? Bu ilişkiye dair olumlu veya olumsuz değerlendirmelerinizi benimle paylaşır mısınız?
5. Size HIV'le ilişkili hizmet sunan sağlık çalışanları tarafından HIV statünüzü diğer sağlık çalışanlarıyla paylaşmanıza yönelik bir telkinde bulunuluyor mu? Evetse, nasıl bir telkinde bulunuluyor?
6. Size HIV'le ilişkili hizmet sunan sağlık çalışanları tarafından HIV statünüzü partner veya partnerlerinizle paylaşmanıza yönelik bir telkinde bulunuluyor mu? Evetse, nasıl bir telkinde bulunuluyor?
7. HIV statünüzü HIV'e ilişkin olmayan hizmetler sunan sağlık çalışanlarıyla paylaşmanız yönünde üzerinizde bir baskı hissediyor musunuz? Hissediyorsanız bu baskıyı bana tarif eder misiniz? Sizce HIV'le yaşayan bir kişi HİV statüsünü HIV'le ilişkili olmayan sağlık hizmeti sunan sağlık çalışanlarıyla paylaşmalı mıdır? Kişinin statüsünü paylaşması gereken durumlar olduğunu düşünüyor musunuz? Düşünüyorsanız bunlar nelerdir? Hayırsa sizce neden paylaşmasına ihtiyaç yoktur?
8. Özel yaşamınızda partner veya partnerlerinizle HIV statünüzü paylaşmanız yönünde bir baskı hissediyor musunuz? Hissediyorsanız bu baskıyı bana tarif eder misiniz? Sizce HIV'le yaşayan bir kişi HIV statüsünü partner veya partnerleriyle paylaşmalı

mıdır? Kişinin statüsünü paylaşması gereken durumlar olduğunu düşünüyor musunuz? Düşünüyorsanız bunlar nelerdir? Hayırsa sizce neden paylaşmasına ihtiyaç yoktur?

9. Türkiye'de HIV ile yaşayanların sağlık bilgilerinin gizliliği ile ilgili nasıl bir yasal düzenleme olduğunu biliyor musunuz? Biliyorsanız ne düşünüyorsunuz?
10. Sizce HIV ile yaşayanların sağlık bilgilerinin gizliliği nasıl düzenlenmelidir? Sizce bu bilgiye kim veya kimlerin hangi durumlarda erişimi olmalıdır?

APPENDIX C

ETHICS COMMITTEE APPROVAL

Evrak Tarih ve Sayısı: 17.06.2021-17982

T.C.
BOĞAZİÇİ ÜNİVERSİTESİ
SOSYAL VE BEŞERİ BİLİMLER YÜKSEK LİSANS VE DOKTORA TEZLERİ ETİK İNCELEME KOMİSYONU
TOPLANTI TUTANAĞI

Toplantı Sayısı	:	18
Toplantı Tarihi	:	17.06.2021
Toplantı Saati	:	13:00
Toplantı Yeri	:	Zoom Sanal Toplantı
Bulunanlar	:	Dr. Öğr. Üyesi Yasemin Sohtorik İlkmen, Prof. Dr. Ebru Kaya, Prof. Dr. Fatma Nevra Seggie
Bulunmayanlar	:	

Oğulcan Yediveren

Sosyal Politika

Sayın Araştırmacı,

"A Qualitative Study on the Perspectives of HIV Activists on HIV Disclosure in Turkey (Türkiye'de HIV Aktivistlerinin HIV Statüsünü Paylaşmaya İlişkin Yaklaşımları Üzerine Niteliksel Bir Çalışma)" başlıklı projeniz ile ilgili olarak yaptığınız SBB-EAK 2021/42 sayılı başvuru komisyonumuz tarafından 17 Haziran 2021 tarihli toplantıda incelenmiş ve uygun bulunmuştur.

Bu karar tüm üyelerin toplantıya çevrimiçi olarak katılımı ve oybirliği ile alınmıştır. COVID-19 önlemleri kapsamında kurul üyelerinden ıslak imza alınamadığı için bu onay mektubu üye ve raportör olarak Ebru Kaya tarafından bütün üyeler adına e-imzalanmıştır.

Saygılarımızla, bilgilerinizi rica ederiz.

Prof. Dr. Ebru KAYA
ÜYE

e-imzalıdır
Prof. Dr.Ebru KAYA
Raportör

SOBETİK 18 17.06.2021
1/2

Bu belge 5070 sayılı Elektronik İmza Kanununun 5. Maddesi gereğince güvenli elektronik imza ile imzalanmıştır.

APPENDIX D

PARTICIPANT INFORMATION AND CONSENT FORM

KATILIMCI BİLGİ ve ONAM FORMU

Araştırmayı destekleyen kurum: Boğaziçi Üniversitesi

Araştırmanın adı: Türkiye'de HIV Aktivistlerinin HIV Statüsünü Paylaşmaya İlişkin Yaklaşımları Üzerine Niteliksel Bir Çalışma (A Qualitative Study on the Perspectives of HIV Activists on HIV Disclosure in Turkey)

Proje Yürütücüsü: Prof. Dr. Biray Kolluoğlu

E-mail adresi:

Telefonu:

Araştırmacının adı: Oğulcan Yediveren

E-mail adresi:

Telefonu:

Sayın katılımcı,

Proje konusu: Boğaziçi Üniversitesi Sosyal Politika Anabilim Dalı öğretim üyesi Prof. Dr. Biray Kolluoğlu ve Sosyal Politika Anabilim Dalı Yüksek Lisans öğrencisi Oğulcan Yediveren tarafından "Türkiye'de HIV Aktivistlerinin HIV Statüsünü Paylaşmaya İlişkin Yaklaşımları Üzerine Niteliksel Bir Çalışma" adlı bilimsel bir araştırma projesi yürütülmektedir.

HIV salgınının başlangıcından bu yana tıpta ve halk sağlığında birçok olumlu gelişme yaşandı. Örneğin, antiretroviral tedavi sayesinde HIV ile yaşayanlar yaşam sürelerini ve yaşam kalitelerini düşürmeden yaşamlarına devam edebilmekte ve tedavi devam ettikçe virüs bulaşıcılığını yitirmektedir. Tüm bu olumlu gelişmelere rağmen UNAIDS'e göre 2019 yılında dünya genelinde 38 milyon HIV pozitif vardı. Ayrıca HIV ile yaşayan kişilere yönelik ayrımcılık ve damgalama halen yaygındır.

Bilimsel literatürde HIV salgınının önlenmesinde hayati önem taşıyan halk sağlığı önlemleri ve HIV ile yaşayanların mahremiyet hakkı arasında bir gerilim

bulunduğuna işaret edilmektedir. Halk sağlığı yaklaşımı salgınla mücadelede HIV ile yaşayanların HIV statülerinin farklı paydaşlarca bilinmesine ve bulaşı durdurmak için bu bilgiye dayalı önlemler almaya odaklanan bir strateji izlemektedir. Başka bir deyişle, temaslı takibi, halk sağlığı önlemlerinin çok önemli bir bileşenidir. Bunu yapmak için isme dayalı raporlama ve partner bildirimi gibi yöntemler kullanılmaktadır. İsim bazlı raporlama, sağlık kurumları tarafından HIV teşhisi konan kişilerin bilgilerinin saklanmasını ve sağlık çalışanları arasında bu bilginin paylaşılmasını mümkün kılar. Partner bildirimi, yeni HIV teşhisi konan kişilerin önceki cinsel partnerlerinin HIV bulaşma ihtimaline karşı uyarıldığı sistemin adıdır. Ancak bu yöntemler, HIV ile yaşayanlar için mahremiyet ve gizlilik endişelerini artırmaktadır. Bu endişeler, kadınlar ve geyler gibi ezilen grupların test yapmaktan veya halk sağlığı kurumlarıyla iş birliği yapmaktan kaçınmasına neden olmakta ve bu önleyici halk sağlığı çabalarının etkinliğini baltalamaktadır.

Bu araştırmada Türkiye'de HIV alanında savunu faaliyetlerinde bulunan aktivistlerle görüşülecek ve bu görüşmelerde önleyici sağlık müdahaleleri ile HIV ile yaşayanların haklarının korunması arasındaki gerilimin HIV aktivistleri tarafından HIV statüsünü paylaşma konusundaki bakış açılarını oluştururken nasıl müzakere edildiğine ilişkin niteliksel bilgi toplanacaktır.

Onam: Bu araştırma kapsamında sizi yaklaşık 1 saat sürecek olan bir mülakat gerçekleştirmeye davet ediyoruz. Kararınızdan önce araştırma hakkında sizi bilgilendirmek istiyoruz. Araştırmaya katılmayı kabul ettiğiniz takdirde sizinle 12 soruluk bir mülakat gerçekleştireceğiz.

Mülakat sırasında bizimle paylaşacağınız tüm kişisel bilgiler, isminiz ve iletişim bilgileriniz kimseyle paylaşılmayacak, araştırmada sırasında ve araştırmanın çıktısında isminize atfedilebilecek ya da sizi doğrudan işaret edecek bir bilgiye hiçbir

şekilde yer verilmeyecektir. İsminiz ve bu bilgiler tamamen gizli tutulacaktır. Aktarımlarınız doğrudan size atfedilmeyecektir.

Bu araştırmaya katılmak tamamen isteğe bağlıdır ve çalışmaya katılımınız karşılığında size herhangi bir ücret veya ödül verilmeyecektir. Bu çalışmaya katılmaya onay verdiğiniz takdirde çalışmanın herhangi bir aşamasında herhangi bir sebep göstermeden çalışmadan çekilme hakkına sahipsiniz. İstediğiniz zaman çalışmaya katılmaktan vazgeçebilirsiniz. Cevap vermek istemediğiniz soruları cevaplamak zorunda değilsiniz. Görüşme sonrasında, fikrinizi değiştirir ve araştırmadan çekilmek isterseniz lütfen bizimle bağlantıya geçin.

Aktardığınız deneyimlerin ve görüşlerin doğru yansıtılması için mülakatların ses kaydına alınmasına ihtiyaç duyulmaktadır. Ses kayıtları gizliliğin korunması açısından isimler ve kişisel bilgiler anonim hale getirilerek yazıya aktarılacaktır. Ses kayıt dosyaları ve ses kayıtlarının yazıya dökülmüş halleri çalışma tamamlandıktan sonra imha edilecektir.

Araştırmanın ileride HIV salgınının etkin bir biçimde kontrol altına alınmasına ve HIV'le yaşayan kişilerin hak ve özgürlüklerinin garanti altına alındığı bir sağlık hizmetleri yaklaşımının yerleşmesine yarar sağlaması beklenmektedir. Gerçekleştirmek istediğimiz araştırmanın sizin için bir risk oluşturması beklenmemektedir. Ancak mülakatın duyguları tetikleyebilecek bazı sorular içerdiği dikkate alındığında, ücretsiz psikolojik destek sağlayan kurumların iletişim bilgilerinin sizinle paylaşılması uygun görülmüştür. Hizmetlerle alakalı daha detaylı bilgi edinmek için Sağlık Bakanlığı İletişim Merkezi (SABİM) Danışma hattını (Alo 184) kullanabilirsiniz.

• Sağlık Bakanlığı bünyesindeki İstanbul İl Sağlık Müdürlüğü'ne bağlı Toplum Ruh Sağlığı Merkezleri istanbulism.saglik.gov.tr
• Sağlık Bakanlığı bünyesindeki Halk Sağlığı Genel Müdürlüğü'ne bağlı Sağlıklı Yaşam Merkezleri shm.saglik.gov.tr

Bu formu imzalamadan önce, çalışmayla ilgili sorularınız varsa lütfen sorun. Daha sonra sorunuz olursa, proje yürütücüsüne (Prof. Dr. Biray Kolluoğlu, Ofis Telefonu:) sorabilirsiniz. Araştırmayla ilgili haklarınız konusunda Boğaziçi Üniversitesi Sosyal ve Beşeri Bilimler Yüksek Lisans ve Doktora Tezleri Etik İnceleme Komisyonu'na (SOBETİK) (...) danışabilirsiniz. Adres ve telefon numaranız değişirse, bize haber vermenizi rica ederiz.

☐ Ses kaydı alınmasını kabul ediyorum.

Bana anlatılanları ve yukarıda yazılanları anladım. Bu formun bir örneğini aldım / almak istemiyorum (bu durumda araştırmacı bu kopyayı saklar). Çalışmaya katılmayı kabul ediyorum.

Katılımcı Adı-Soyadı:……..
İmzası: ……
Tarih (gün/ay/yıl):...../...../.....

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