

**TACKLING WITH TABOOS: THE CASE OF HIV ASSOCIATIONS  
IN TURKEY**

by  
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**TACKLING WITH TABOOS: THE CASE OF HIV ASSOCIATIONS  
IN TURKEY**

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## ABSTRACT

### TACKLING WITH TABOOS: THE CASE OF HIV ASSOCIATIONS IN TURKEY

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Keywords: HIV, AIDS, activism, social movements, ethnography

This thesis aims to analyze the openings, limitations, and different forms of HIV activism with a particular focus on the self-organizations of people living with HIV in Turkey, which are called "positive associations". It aims to demonstrate how HIV activists position themselves, frame their activism, and develop discourses within a context where stigmatization, marginalization, and discrimination towards people living with HIV are widespread. Between October 2021 and April 2022, I conducted 6 in-depth interviews with activists who play an active role in HIV associations and 7 interviews with people living with HIV who have had contact with these associations as counselees. I also conducted ethnographic fieldwork in conferences, meetings, and workshops regarding HIV activism within the scope of this M.A. thesis research. This thesis attempts to arrive at a more nuanced understanding of social movements through a close analysis of a growing activist field in Turkey, problematizing static and fixed conceptualizations of activism. Secondly, it provides an anthropological lens to a highly medicalized field, contributing to the social science literature on health advocacy struggles in particular and social movements in general. Finally, it aims to bridge academia and activism through making the voices of HIV activists and people living with HIV heard in their struggle to destigmatize HIV within and beyond academia.

## ÖZET

TABULARI YIKMAK: TÜRKİYE’DEKİ HIV DERNEKLERİ ÖRNEĞİ

BESTE İREM KÖSE

KÜLTÜREL ÇALIŞMALAR YÜKSEK LİSANS TEZİ, TEMMUZ 2022

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Anahtar Kelimeler: HIV, AIDS, aktivizm, toplumsal hareketler, etnografi

Bu tez, Türkiye’de “pozitif dernekler” olarak adlandırılan HIV ile yaşayanların öz örgütlenmelerine odaklanarak HIV aktivizminin imkânlılıkları, sınırlılıkları ve farklı formlarını analiz etmeyi amaçlamaktadır. HIV ile yaşayanlara karşı damgalamanın, ötekileştirmenin ve dışlamanın yaygın olduğu bir bağlamda HIV aktivistlerinin kendilerini nasıl konumladıklarını, aktivizmelerini nasıl çerçevelediklerini ve ne tür söylemler ürettiklerini göstermeyi amaçlamaktadır. Ekim 2021 ve Nisan 2022 tarihleri arasında HIV derneklerinde aktif rol oynayan aktivistlerle 6, bu derneklerle danışan rolünde temas kurmuş olan HIV ile yaşayan kişilerle 7 derinlemesine mülakat gerçekleştirildi. Ayrıca bu yüksek lisans tezi kapsamında HIV aktivizmi ile ilgili konferanslara, toplantılara ve atölye çalışmalarına katılarak etnografik saha çalışması gerçekleştirildi. Bu tez, Türkiye’de gittikçe büyüyen bir aktivist alanının yakından analizini yaparak toplumsal hareketlere dair daha incelikli bir kavramsallaştırma yapmayı deniyor. İkinci olarak, oldukça tıbbileştirilmiş bir alana antropolojik bir bakış açısı sağlayarak sağlık savunuculuğu mücadeleleri özelinde ve toplumsal hareketler genelinde sosyal bilimler literatürüne katkı sağlıyor. Son olarak da HIV aktivistlerinin ve HIV ile yaşayan kişilerin akademi içerisinde ve dışarısında HIV’e yönelik damgalama karşıtı mücadelelerinde seslerini duyurarak akademi ve aktivizm arasında bir köprü kurmayı amaçlıyor.

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*To activists  
for making this world a better place*

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## LIST OF ABBREVIATIONS

<b>ACT UP</b> AIDS Coalition to Unleash Power .....	xii
<b>AIDS</b> Acquired Immunodeficiency Syndrome .....	xii
<b>AKP</b> Justice and Development Party .....	xii
<b>ASD</b> Association for the Battle Against AIDS .....	xii
<b>CHP</b> Republican People’s Party .....	xii
<b>COVID-19</b> Coronavirus Disease 2019 .....	xii
<b>GDTM</b> Voluntary Counseling and Testing Centers .....	xii
<b>HIV</b> Human Immunodeficiency Virus .....	xii
<b>HTP</b> Health Transformation Program .....	xii
<b>ICPD</b> International Conference of Population and Development .....	xii
<b>LGBTI+</b> Lesbian, Gay, Bisexual, Trans, Intersex and Plus .....	xii
<b>MEDULA</b> Prescription Provision System .....	xii
<b>MHP</b> Nationalist Movement Party .....	xii
<b>NGO</b> Non-governmental Organization .....	xii
<b>PLWH</b> People Living with HIV .....	xii
<b>SRH</b> Sexual and Reproductive Health .....	xii
<b>SRHR</b> Sexual and Reproductive Health Rights .....	xii
<b>STI</b> Sexually Transmitted Infection .....	xii
<b>TAPV</b> Family Health and Planning Foundation .....	xii

<b>U Equals U</b> Undetectable=Untransmittable .....	xii
<b>UNAIDS</b> The Joint United Nations Programme on HIV/AIDS.....	xii

## 1. INTRODUCTION

During the ethnographic fieldwork that I conducted for this thesis, which aims to analyze the openings, limitations, and different forms of HIV activism with a particular focus on positive associations<sup>1</sup>, I had some encounters which made me reflect on the aim, significance, and possible reception of this endeavor. In our in-depth interview, Batuhan, who lives with human immunodeficiency virus (HIV) and also a former counselee of the association that I chose to name as Living with HIV Association, told me about his past relationship. He narrated how he shared his HIV status with him one night and covered his face immediately and involuntarily, fearing that his partner could hit him. To his surprise, his partner responded “If we ever break up one day, this won’t be the cause.” They stopped using condoms from that night onwards, as Batuhan was in “undetectable=untransmittable” (U=U) status, meaning that he could not transmit HIV to his partner whether he used condoms or not since his virus load was undetectable (UNAIDS 2018). At the end of two and a half years of sleeping together, his partner was blood-tested and he turned out to be HIV negative. “I did not transmit anything. Am I making myself clear?”, he said and went on emphasizing the significance of U=U multiple times. At one point, he stated the following:

“This story is an evidence. I don’t know how you will write this down in your thesis but please do. This is one hundred percent true. I slept with someone for two and a half years without protection, and there was no HIV transmission. Alright? Nothing was transmitted.”

This request of Batuhan was not unique to this interview as two of my other inter-

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<sup>1</sup>As a term I often encountered during the fieldwork, positive associations refer to three self-organizations of people living with HIV (PLWH). Not necessarily led by PLWH, these associations are focused on improving the lives of PLWH, who receive counseling from them. Unlike doctor-led HIV associations that work on the medical aspects of HIV, these associations focus more on the sociocultural aspects of living with HIV. Although the "HIV associations" part in the thesis title seems to involve doctor-led HIV associations, they are excluded from the scope of this thesis.

locutors also asked me if I was going to mention U=U in my thesis. Such remarks made me reflect on the reception of my thesis not only for the audience possibly engaging with it but for my interlocutors as well. As U=U is an outcome of a series of scientific studies publicized as a campaign starting in 2016 (The Lancet HIV 2017, 475), which is relatively recent, it is understandable that my interlocutors would like to see a thesis written on it. It can be also inferred that the thesis itself can be perceived as a site of activism, where my interlocutors consider me as a medium in circulating the recent scientific knowledge on HIV to the broader public. Given the stigmatization and discrimination that they stated to have lived and/or witnessed someone else has lived, it was no surprise that they wanted to fight such obstacles by referring to scientific literature, which can also be called *activist* literature as HIV activists have been contributing to the scientific knowledge production since the very onset of the epidemic (Epstein 1996). This kind of interrelations between medicine and activism was going to be the main focus of this thesis at the time that I decided to conduct research on HIV activism. However, as I proceeded with my fieldwork, I came to realize that there was no such thing as the activism in the first place. Indeed, there were numerous forms of activism enacted and numerous ways to approach them. Upon this realization, I shifted my focus from medicalization of HIV activism to the variety of HIV activism practices with a specific focus on positive associations.

The aim of this thesis is to analyze the openings, limitations, and different forms of HIV activism enacted by the positive associations and people living with HIV (PLWH) within the context of the recent intensification of conservative gender and sexuality politics as well as the exponential slide into authoritarianism following the 15 July 2016 coup (Mutluer 2019). In accord with that contextualization, which I elaborate in Chapter 2, I seek answers to the following questions in this thesis:

- What kinds of strategies do HIV activists employ to maintain their existence in Turkey, where people with non-normative sexual identities and practices face numerous forms of violence (Altay 2022) and oppositional social movements face various forms of repression (Yabancı 2019)?
- How do HIV activists position themselves, frame their activism, and circulate their discourses in Turkey, where stigmatization and discrimination towards people living with HIV are widespread (Gokengin, Calik, and Oktem 2017, 18)?
- What kinds of possibilities and limitations does an attempt to categorize HIV activism, such as aggressive, necessarily conformist, and everyday forms, may offer us? Would that categorization bring an artificial division among the

activisms as static, definite, and separate groups?

Before continuing with the significance of studying HIV activism, I would like to provide background information regarding HIV in Turkey. It is possible to define HIV as a hidden epidemic in Turkey (Ay and Karabey 2006) due to the low level of publicization in contrast to rising rates. According to the statement published by the Turkish Medical Association (TTB) on the World AIDS Day, 1 December 2020, the HIV cases in Turkey have increased by 465 percent in the last 10 years in contrast to the general decline of HIV cases in the world (Türk Tabipleri Birliği 2020). Based on the official data of the Ministry of Health, there are currently 29.284 people diagnosed with HIV and 2052 with acquired immunodeficiency syndrome (AIDS) in Turkey (T.C. Sağlık Bakanlığı 2021). Although the HIV prevalence in Turkey is considered as low, it is important to take into consideration that these cases do not necessarily reflect reality (Gokengin 2018, 5-6). For example, a 5-years long study including 33 centers monitoring HIV reports a significant mismatch between real-life cases and the Ministry of Health data, where the former is higher than the latter (Erdoğan, Dokuzoğuz, and Ünal 2016; Gokengin 2018, 6). According to Gökengin (2018), the underlying reason for this mismatch is the stigmatization, of “men having sex with men” in particular, given the rise of HIV cases in men in recent years (Santos et al. 2016; Takacs et al. 2012; Gokengin 2018, 6). Voluntary Counseling and Testing Centers (*Gönüllü Test ve Danışmanlık Merkezleri*, hereafter GDTM), providing anonymous, free and widespread HIV testing, thereby facilitating access to diagnosis and treatment can be among the reasons why there is a rise in registered HIV cases. On the other hand, such a rise can also be explained by the insufficiency of state-led preventive measures (Yılmaz 2020, 45), which I elaborate while discussing the state-imposed limitations in HIV treatment and activism in Chapter 3.

In terms of the significance of this thesis, I can firstly argue that it sheds light on the complexity of discourses and practices within a growing activist field under challenging conditions in Turkey. Closely analyzing the case of positive associations does not only contribute to the literature of health advocacy struggles but social movements literature in general as well. Through leading a discussion on the symbolic boundaries of activism as specified in Chapter 5, I attempt to contribute to the social movements literature by arguing that the activism categories that emerged out of my fieldwork, aggressive, necessarily conformist, and everyday activism, are intertwined, fluid, and complicated rather than static, definite, and firmly separable. In addition, they are reconstructed in different ways in each and every context and encounter. Thus, this thesis aims to arrive at a more nuanced understanding of social movements.

Secondly, this thesis provides an anthropological lens to a field that is highly medicalized. The insufficiency of medical care for AIDS from the very onset of the epidemic illustrates how “long before AIDS was a biomedical condition, it was a social one” (Moyer 2015, 262). Yet, the academic studies on HIV can often be found in journals of medicine, moreover, it is quite difficult to find a study solely dedicated to HIV activism in social sciences literature in Turkey. This thesis aims to shed light on an influential form of activism, mostly in the sense of negotiation with the state authorities and facilitating access to medical services. As centering a form of activism dedicated to publicizing an epidemic, the transmission route of which is predominantly sexual, in an authoritarian time and space, this thesis also aims to contribute to the bodies of literature on sexuality regimes and social movements in authoritarian settings at the same time.

A third aspect in which this thesis can make a contribution, this one is for both for academia and civil society, is to make room for the subjects who struggle in representing themselves. That is to say, based on my fieldwork, I can state that there was a shared concern about the lack of representation of HIV activists in Turkey. An M.A. thesis using the method of ethnographic fieldwork can facilitate raising the voice of the activists and PLWH. Indeed, the high motivation of my interlocutors in participating in this research and their requests from me to publicize the activist literature on HIV, as I mentioned at the beginning of this chapter, made me think that they could be viewing their participation in an academic study as part of their activism. As this thesis attempts to critically reflect on the activist practices of positive associations and their counselees, it can help to render their struggles to destigmatize HIV visible to some extent, which gains importance within the context of misinformation, hostility, and silence regarding HIV. Taking into consideration how mutually dependent academia and activism are since activist movements rely on knowledge production and vice versa (Baldwin 2021), this thesis, too, attempts to bridge academia and activism.

## **1.1 Theoretical Framework**

This section aims to introduce the bodies of literature that I engage with in this thesis. Although the three sub-sections below do not involve the entirety of the literature that influence this thesis, they illustrate the three groups that I draw on the most. The sub-section “Biopolitics, Biosociality and Biological Citizenship” tries to follow the academic studies that question the applicability of Foucault’s theoret-



ical framework in more contemporary settings. “Social Movements and Everyday Activism”, similarly, mostly consists of studies that build upon the approach that attempts to decentralize macro-scale movements within the social movements literature. Finally, the sub-section “HIV activisms” is more selective in terms of engaging with the literature that more or less directly influence this thesis, acknowledging the fact that there is a broader literature that focus on HIV activisms in different time periods and a variety of geographical settings.

### 1.1.1 Biopolitics, Biosociality, and Biological Citizenship

This thesis is influenced to a large extent by the theoretical framework regarding biopolitics put forth by Foucault and contributed by more contemporary scholars. According to Foucault, disciplinary power has emerged at the end of the seventeenth century and lasted until the second half of the eighteenth century (Foucault et al. 2003, 242). In this mode of power, the rights and deaths of the subjects depend on the will of the sovereign. In the seventeenth century, a vital transformation ha“take life and let live” has been replaced by the right to “make live and let die”. Instead of operating in an individualizing mode directed at man-as-body, power started to operate in a massifying mode directed at man-as-species (Foucault et al. 2003, 240-243). With *biopower*, vital processes of human existence have entered the domain of politics: reproduction and sexuality; marital, parental, and familial relations; health and disease; birth and death (Rose 2007, 53). Foucault introduces the two main poles of biopolitics as follows:

“One of these poles [...] centered on the body as machine; its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and docility, its integration into systems of efficient and economic controls, all this was ensured by the procedures of power that characterized the *disciplines*: the *anatamo-politics of the human body*. The second, formed somewhat later, focused on species body, the body imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that can cause these to vary.” (Foucault 1990, 139).

Rose discusses how these two poles have come together with technologies of power, among which sexuality can be counted (Rose 2007, 53). Laying at the intersection of body and population, sex became an important target of power in managing life (Foucault 1990, 147). Sexuality has become an object and a target at the

same time since power spoke *of* sexuality and *to* sexuality through the “themes of health, progeny, race, the future of the species, the vitality of the social body” (Foucault 1978, 147). As a corporeal mode of behavior, sexuality is controlled through disciplinary mechanisms such as family and education on one hand and considered as a concern not only about the bodies of individuals but an element of the population due to its procreative effects on the other (Foucault 1990, 251-252).

More recent literatures on biosociality and biological citizenship have widened the scope of Foucault’s concept of biopolitics by updating it for the 21st century. Although the scholarly contribution of Foucault is still influential, it is important to note that they were produced within a specific political and medico-scientific context in the late 20th century (Cascio 2017, 194). Drawing on Foucault and then the concept of biosociality of Rabinow and biological citizenship of Petryna, Rose illustrates a new biopolitical context, synthesizing these earlier works (Cascio 2017, 194). This “new biopolitical theory”, as Cascio puts it, Foucault’s version of biopolitics is adapted to the contemporary developments in life sciences, mostly in genetical and molecular changes in human bodies (Kay 1993; Simon 2008; Cascio 2017, 195).

In his ethnographic study on Human Genome Project, Rabinow illustrates the ways in which genetics are shaping society and life as they are embedded within the social fabric of biopolitical practices and discourses (Rabinow 1997; Macgregor 2012, 592). Rabinow terms such a vision of the intertwinement of nature and the social as *biosociality* (Rabinow 1997; Macgregor 2012, 592). Rabinow describes how new forms of biosociality come together around categories such as “corporeal vulnerability, somatic suffering, and genetic risk and susceptibility” (Novas and Rose 2005, 442). The medical activism of biosocial groupings, which refers to the collectivities coming together around a biological understanding of a shared identity, precedes the contemporary biomedical developments as there were others who also refused to be passive “patients” (Novas and Rose 2005, 442), as it can be exemplified by the early AIDS activism.

In this new mode of biosociality, people come together on the basis of interest in their health and make demands from political authorities through means such as campaigns, thereby becoming key actors in the political economy of health (Demir 2019, 466). Lemke identifies such activism enacted by groups such as self-help groups and patient organizations as *biopolitics from below* (Lemke 2011, 99). Indeed, biological notions of citizenship have been in close contact with projects “from below”, for which feminist campaigns for legalizing contraception are an example (Rose 2007, 24). Rose further discusses how the “hierarchical, top-down approach of biopolitics is negotiated and resisted by the lay people” aiming to contribute to politics regard-

ing health and illness on the basis of their own perspectives and experiences (Rose 2007; Terzioglu 2012, 15)

In 2002, Petryna used the concept of biological citizenship in her ethnographic study on the aftermath of the Chernobyl nuclear accident in Ukraine. The Chernobyl victims have developed a new political and social identity on the basis of their biological condition as exposed to radioactivity. They demanded discursive and practical changes from the state concerning raising awareness and making policy-level and financial compensations (Petryna 2013; Terzioglu 2012, 21). As Petryna puts it, “the very idea of citizenship is now charged with the superadded burden of survival” (Petryna 2013, 7). Biological citizenship has both individualizing and collectivizing aspects. It is individualizing in the sense that individuals construe their relations with themselves in terms of acknowledging their somatic individuality. In terms of collectivization, individuals come together around a biological understanding of a shared identity (Novas and Rose 2005, 441-442).

In 2007, Rose expanded the concept of biological citizenship in a way not only includes the Chernobyl victims but many contemporary grassroots patient organizations, among which HIV/AIDS activism can be considered (Rose 2007; Terzioglu 2012, 21). Indeed, HIV/AIDS activism has formed a new template for biological/biomedical activism as HIV/AIDS activists came together on the basis of living or potentially living with HIV/AIDS. They had several purposes: to inform the public about HIV/AIDS, to gain rights and struggle against the HIV-related stigma, to provide a support network for PLWH, to produce strategies for the everyday management of HIV/AIDS, to help the development of alternative forms of treatment, and to raise their own voices in the development of medical expertise. In terms of the latter point, it is important to note that these groups operated as biological citizens as well as health educators (Rose 2007, 144). In this thesis, drawing on the given theoretical framework, I explore the ways in which biopolitics, biosociality, and biological citizenship function interactively with respect to the case of NGO-led HIV activism in Turkey. In such a way, I question the applicability of such concepts in an authoritarian gender regime.

### **1.1.2 Social Movements and Everyday Activism**

Before the early 1970s, *collective behavior theory* was dominating the social movements literature. Collective behavior theorists consider collective action as an extra-institutional phenomenon characterized by “spontaneous, unorganized, and contagious emotional reactions” to unstructured collective frenzy (Snow and Oliver 1995;

Tarrow 1998; Aslanidis 2015, 2). Addressing why social movements were taking place rather than how and neglecting the role of agency, these theorists also consider social movements as spontaneous phenomena coming and going in automatic outbursts and rapid declines (Aslanidis 2015, 3-4).

With the new social movements of the late 1960s and early 1970s, which can be exemplified by the ecology movement, women's movement, and gay and lesbian movement (Epstein 1996, 20), associating mobilization with irrationality was no longer seen as applicable (Aslanidis 2015, 5). The newly formulated *resource mobilization theory* claimed that social movement actors were acting rationally according to their interests, movement "entrepreneurs" have a vital role in the mobilization and allocation of the resources on which action is organized (Della Porta and Diani 2006, 14) based on a strategic calculation of costs and benefits (Aslanidis 2015, 6).

*Political process theory* has emerged criticizing the shortages of the resource mobilization theory such as its failure in centering the contextual political factors impacting grievances, resources, and opportunities (McAdam 1982; Meyer 1999; Aslanidis 2015, 7). According to political process theorists, mobilization was another form/expression of politics and connected with institutional forms. Movements are not irrational, yet they are not only products of strategic calculation of resources either. Instead of being extra-political; they are, in fact, politics. One of the criticisms to this approach is that political opportunity is not necessarily a condition of mobilization when there are counter-examples, for example, religious or subcultural movements (Aslanidis 2015, 7-10).

According to Aslanidis, the problem with resource mobilization theory and political process theory is their determinism (Aslanidis 2015, 12). The former claims that if resources are there, mobilization will follow; the latter claims if opportunities are favorable, collective action will take place. As such, they do not leave room for choice agency, or failure. As opposed to the top-down approach of resource mobilization, the newly found *social constructionist theory* focuses on the end of the receiver and how the individual is mobilized into action (Aslanidis 2015, 12). Social constructionist theory can be divided into four sections: emotions, framing, collective identity, and culture (Oliver, Cadena-Roa, and Strawn 2003; Aslanidis 2015, 13). In the following part, I focus on framing and culture as they relate more to this thesis.

Frames are "principles of selection, emphasis, and presentation composed of little tacit theories about what exists, what happens, and what matters" (Goffman 1974, 10-11; Gitlin 2003, 6; Epstein 1996, 4). The negotiation of meaning occurs through the strategic articulation of certain frames (Aslanidis 2015, 14). Social movements,

as Epstein illustrates, frame relevant events or situations in such a way to mobilize possible allies and demobilize antagonists (Epstein 1996, 24-25). Culture, on the other hand, is often theorized with regard to the *cultural tool kit* framework of Swidler. According to Swidler, each society has its cultural tool kit from which the social movement entrepreneurs can choose what is necessary to build frames and collective identities (Swidler 1986; Aslanidis 2015, 14). “Strategies of action” (Swidler 1986, 276) depend on relevant cultural themes if they aim that their repertoire becomes successful in the public eye (Jenkins 1983; Oliver, Cadena-Roa, and Strawn 2003; Aslanidis 2015, 17). In this thesis, I draw particularly on this framework of Swidler by arguing that different modes of activism form a repertoire from which they can be selected and used strategically depending on the context.

There is a new line of literature criticizing the premises of the mainstream social movements literature. In particular, the tendency of the social movements literature to prioritize movements with overtly defined structure, goals, and targets over micro-political, individualized, and decentralized practices (Veron 2016, 760) is criticized. In a similar fashion, the tendency of this literature to consider a grandiose, iconic, goal-oriented kind of activism led by key figures/thinkers as the activism (Horton and Kraftl 2009, 14) is under scrutiny. Horton and Kraftl claim that small-scale, personal, and quotidian activism, which they term implicit activism is generally excluded from the mainstream understanding of activism (Horton and Kraftl 2009, 14). Accordingly, this new line of literature put everyday activism at the center of their research.

It is possible to trace the roots of everyday activism literature to the influential theoretical framework of James C. Scott. Scott argues that “everyday forms of resistance” such as foot-dragging and false compliance should be treated as *political* and capable of constituting collective action although they are often overlooked in the social sciences literature (Scott 1989, 33-34), given its overemphasis on open rebellion (Scott 1990; Lüküslü 2013, 84). Although Scott’s focus is rather on the colonized, slaves, serfs, and subjugated races (Lüküslü 2013, 84), his theoretical contribution provides a tool for the subsequent researchers to shed light on the overlooked minor political acts of everyday life. De Certeau’s conceptualization of *strategy*, “the calculation (or manipulation) of power relationships that becomes possible as soon as a subject with will and power can be isolated” (De Certeau 1984, 35-6) as well as *tactic*, which refers to “a calculated action determined by the absence of a proper locus” (De Certeau 1984, 36-7), are also referred to in this thesis as they facilitate understanding resistances on the everyday level.

Véron identifies three biases in the contemporary studies on activism, which are a)

temporal singularity bias; namely, the overemphasis on the extraordinary moments of mobilization b) spatial singularity bias; the consideration of extraordinary places such as protest camps as the spaces of activism while overlooking ordinary places of activism c) case singularity bias; relegating micro-political acts to the margins of social movements (Veron 2016, 759). She also criticizes the sharp distinction made between lifestyle movements such as veganism and environmentalism and formal movements in terms of individual versus collective action, private versus public engagement, ongoing versus episodic action, challenging cultural norms versus directly opposing the formal institutions, and being diffused versus centrally organized since these seemingly distinct forms of activism may be “mutually constitutive” (Veron 2016, 761). In line with this approach, I take a look into both “formal” venues of activism such as non-governmental organizations (NGOs) and everyday lives of PLWH. In this way, I shed light on how mutually constitutive these seemingly distinct activist practices are.

My thesis is also related to another important discussion in the social movement literature; the issue of social movement actors calling themselves activists. According to Bobel (2007), there is an assumption that a participant of a social movement does and should identify as an activist whereas one can “do activism” while not “being activist”, which requires a more complicated analysis of identity in the social movement literature (Bobel 2007, 148-157). Moreover, Bobel finds that the people who engage in menstrual activism, which aims to criticize the mainstream framing of menstruation as dirty and shameful, measure themselves according to a “perfect standard”, referring to the attribution of extraordinary humility and rigor to activists, and often do not find themselves worthy of such traits (Bobel 2007, 150-152). Accordingly, I did not regard self-identification as an activist as the first and foremost rule of doing activism in this thesis as my aim is to trace activist *practices*, not people, as explained in the Methodology section of this chapter.

Maynard makes a fruitful discussion on the temporality of activism. Claiming that activism should be treated as a temporal process, she explains that “activism is encountered and enacted in different spatiotemporal moments in the lifecourse” (Maynard 2017, 1-3). Especially relevant to this thesis, she categorizes activism into three modes: circumstantial activism, dormant activism, and embedded activism. Circumstantial activism refers to an “activism emerging from specific spatiotemporal circumstances”, dormant activism is a kind of activism that is waiting to re-emerge upon changing social and financial circumstances, and embedded activism means small-scale activism that can be conceived as bold and confrontational (Maynard 2017, 2-5). In a similar fashion, I argue that the same people can engage in different modes of activism, which I categorize as aggressive, necessarily conformist, and

everyday activism. Whereas Maynard focuses on how different forms of activism can be enacted during different time periods of one's life, I demonstrate how these activism modes can be strategically enacted at the same time as they are quite fluid and dependent on the sociopolitical context. In this way, I point at the impossibility of such a categorization at the same time.

### 1.1.3 HIV Activisms

The HIV activism literature that contributes to this thesis dates back to 1992, to Berridge's study on the policy shift regarding HIV/AIDS in the United Kingdom between 1981 and 1986. She argues that the policy at the time was rather formed in a bottom-up approach with a significant influence of gay activists, clinicians, and scientists. Although this has changed with a new awareness that the epidemic affected heterosexuals as well and resulted in political emergency, the initial alliances formed until 1986 were later adopted in the political level (Berridge 1995, 303-305). This thesis also draws inspiration from the seminal work *Impure Science: AIDS, Activism, and the Politics of Knowledge* by Epstein. *Impure Science* provides a useful framework for studying the relations between HIV/AIDS activism and medical science in the USA. Epstein illustrates how AIDS activists have intervened in the production of science, thereby shifting our conception of who is a "lay person" and who is an "expert" (Epstein 1996, 2). Over time, the activists gained credibility as the ones who can legitimately use the medical language (Epstein 1996, 8-9). In Chapter 5, I demonstrate the applicability of this concept to the case of Turkey, drawing on my fieldwork.

In her book *Moving Politics: Emotion and ACT UP's Fight Against AIDS*, Gould focuses on the role of emotion in the activism of the militant AIDS activist group named AIDS Coalition to Unleash Power (ACT UP)<sup>2</sup> in the US context. Gould examines the motivations behind the militant activism of ACT UP with the help of the concept emotional habitus, meaning "a social grouping's collective and only partly conscious emotional dispositions, that is, members' embodied, axiomatic inclinations toward certain feelings and ways of emoting" (Gould 2009, 32). According to Gould, the emotional habitus of the gay and lesbian communities has started to shift with the homophobic Hardwick decision<sup>3</sup> to anger directed at the government

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<sup>2</sup>ACT UP defined itself as "people united in anger and committed to the use of civil disobedience and direct action to fight the AIDS crisis" (Gould 2009, 131).

<sup>3</sup>Upon being arrested for engaging in sexual intercourse with another man and thus violating Georgia's antisodomy statute, Michael Hardwick filed a lawsuit and the case went to the U.S. Supreme Court. The Court upheld with a five-to-four majority a statute that denied homosexuals the right to engage in consensual sex in the privacy of their homes, leaving the antisodomy laws in twenty-four states intact

inaction and discrimination towards PLWH, facilitating the adoption of direct-action AIDS politics and the emergence of ACT UP (Gould 2009, 133-142). Huebenthal makes a comparison between ACT UP and contemporary HIV activism revolving around undetectability in the case of the USA. The former framed AIDS as a structural problem, whereas it is a personal problem for the latter. While ACT UP has conducted a loud and visible activism, *undetectability* activism depends on silence and invisibility (Huebenthal 2017, 5-16). In this thesis, too, the characteristics of the activism of ACT UP are tried to be analyzed in comparison with the activism of positive associations particularly in Chapter 5.

As the earliest signs of HIV/AIDS activism were seen in the USA, the US case is the center of the HIV/AIDS activism literature. However, there are significant endeavors in the other geographical contexts and this thesis is an attempt to be one. For instance, Fassin conducts ethnographic research on the HIV politics in South Africa, which is hit the hardest by the AIDS epidemic in the world (Fassin 2008, xvi). He illustrates how AIDS denialism works in South Africa in relation to institutionalized racism (Fassin 2008, 115-161). Seçkinelgin also problematizes the role of international governance and discourse of HIV/AIDS on the interventions in Sub-Saharan Africa (Seçkinelgin 2008). Biehl, on the other hand, brings together HIV/AIDS activism and biopolitics in the case of Brazil. While the successful pharmaceutical policy of the state controls the mortality of the general public, the poorest and marginal are “let die”. To be more specific, “drug addicts”, “prostitutes”, and “non-compliant” are made indivisible in the public health system and blamed for their own death (Biehl 2004, 120).

Before moving on to the case of Turkey, I would like to mention a significant endeavor in problematizing the neoliberal agenda of HIV support groups in Canada. Murray illustrates how these support groups emphasize the notions of self-care and self-improvement, overlooking the socio-cultural, political, and economic inequalities in HIV treatment (Murray 2020, 3). This work in particular gave me the idea to critically study the claims of inclusivity of the HIV associations in Turkey. I question the issue of inclusivity mostly within the context of tensions with the lesbian, gay, bisexual, trans, intersex and plus (LGBTI+) activists in Chapter 4 and while discussing necessarily conformist modes of HIV activism in Chapter 5.

I mentioned above the insufficiency in academic studies solely dedicated to HIV activism in Turkey. However, there are studies covering this issue, which are relevant to this thesis. To name a few, Öktem’s doctoral thesis touches on HIV activism in one chapter in relation to HIV-related stigma (Oktem 2013). Although we both

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(Gould 2009, 122).



employ the methods of participant observation and interviewing, my thesis differs from this one in centering activism instead of stigmatization. In another thesis covering HIV activism in Turkey, Turan discusses the possibilities of *artivism* through his curatorial project dedicated to HIV (Turan 2020). While this thesis makes a creative contribution to the field by bringing together art and activism, mine differs both methodologically and theoretically. Along with using the research-creation methodology (Turan 2020, 7), he dwells on the trauma literature, whereas I mostly draw on the literatures on biopolitics and social movements. Çetin conducts a comprehensive study on the past and present of the HIV/AIDS movement in Turkey along with the social policies directed at HIV/AIDS (Çetin 2017). Çetin makes a sound periodization of the history of HIV/AIDS in Turkey along with an elaborate contextualization. The starkest difference between this study and mine is the research field that we are in since Çetin looks at the issue from a social policy perspective. Although I resort to social policy studies in Chapter 3, this thesis attempts to give weight not only to institutions but also the activist practices of PLWH on the everyday level.

## 1.2 Methodology

In this section, after providing a descriptive account on my methodology, I reflect on the fieldwork process, discussing ethics, positionality, and ethnographic truth along the way. This thesis is based on ethnographic fieldwork. Along with participant observation conducted in a 3-days-long hybrid conference and 5 online meetings, I conducted semi-structured in-depth interviews with open-ended questions. This thesis consists of 13 in-depth interviews with two groups with the following breakdown: a) 6 interviews with HIV activists who are active members of positive associations (*People Living with HIV, HIV Positives, 1 December*) and recently found initiative *Positives United* b) 7 interviews with PLWH who have had contact with the given associations as counselees. The second group introduced themselves as PLWH although I did not ask the HIV status of any of my interlocutors. My interlocutors' ages varied between 21 and 67 at the time of the interviews. 2 of them were identified as women, 1 as non-binary, and the rest were identified as men. The education level of my interlocutors varied between primary school graduate to PhD candidate. All my interlocutors were living in Turkey and the half of them were living in Istanbul (for more information, see Appendix). I conducted 2 of the interviews face to face, one in the workplace of 1 December Association and the other in the private meeting room of a café. The rest were conducted via Zoom due to the impact of COVID-19

pandemic and conflicts in time management.

From here onwards, I discuss my journey and the concepts I critically engaged with before, during, and after fieldwork. What sparked my interest in studying HIV activism in Turkey was the intense online debate on the “*HIV statümü paylaşmak zorunda değilim*” (“I do not have to share my HIV status”) tweet posted by Association for Struggle Against Sexual Violence on December 1, 2019, which marked the publicization of a new discourse putting PLWH at the center. As this debate mainly took place on Twitter, social media platforms became the first settings I resorted to for observation. Along with familiarizing myself with the medical literature on HIV and AIDS, I started conducting ethnographic fieldwork on social media, observing the accounts and hashtags dedicated to HIV activism and living with HIV in April 2021. My participation in the field at that time can be best described with the term “lurking”. Hine claims that lurking can be a significant part of the ethnographer’s repertoire as it sheds light on the ordinary practices of the group and enables the researcher to have a “smooth entry” into active participation (Hine 2008, 8). Accordingly, I got used to the terminology commonly used in the field through lurking, which enabled me to have a little command over the HIV/AIDS terminology. In my preliminary interviews that took place between May and June 2021, I benefited from this repertoire to some extent as I was able to grasp remarks such as “I was in the U=U status”, “My T-cells were on the rise at that time”, “PeP is not within the insurance coverage”. Such familiarity helped me more significantly while conducting participant observation and in-depth interviews between October 2021 and March 2022.

In October 2021, I participated to a conference on HIV activism in Turkey as the only physical attendee except for the members of positive associations who were there to organize the conference or give a speech. One of the activists, Eray was about to start hosting the conference. He recognized me in the audience since we had an online contact back in August, when he wanted to publish my semi-academic piece on the grassroots AIDS activist group ACT UP on the website of 1 December association. As he promised, we chatted after the live broadcast, where he jokingly asked “Everybody asks us this, now it’s your turn to answer: Why are you studying HIV activism?”. I explained that I started to be interested in the issue firstly through online debates and when I dug deeper, I was more and more impressed by achievements of HIV activism in Turkey such as their legal battles against the discrimination of PLWH. As such, I got curious about its sociocultural context, which eventually turned into an academic pursuit. In retrospect, my answer seems somewhat plausible yet incomplete since I did not critically reflect on my personal connection with the issue. In 2016, a close friend of mine was diagnosed with HIV,

which coincided with a turbulent time in our friendship. I was so overwhelmed by my own resentments and personal issues that I could not provide enough support for her. When we overcame our problems two years later, she told me she had all the support she could get from one of the positive associations, which is stuck with me. In our conversation with Eray, or the other times where I was asked to explain my interest in HIV activism, I did not think of sharing this story as it was so personal. However, my guilt about not having shown the solidarity that a group of strangers was able to show has been an underlying motivation for me to pursue this research, which makes this research partly a belated attempt to solidarity.

Two weeks after the conference, I made my first in-depth interview with Eray in the workplace of 1 December Association. He wanted to remain non-anonymous in the research, however, I chose to use pseudonyms for both his name and the positive association he was affiliated with after the interview, considering the harm due to possible breaches in external and internal confidentiality (Tolich 2004, 102). In terms of internal confidentiality, Tolich argues that connected people are particularly vulnerable to harm due to such breaches (Tolich 2004, 102). As I study a very small community of activists and counselees, who seem to know each other well, I tried to be extra careful in not disclosing personal information of my interlocutors to each other as well as the broader audience of this thesis. However, I resorted to snowball sampling to get into contact with 4 of my interlocutors, which might be deemed as a violation in this sense. On the other hand, through snowball sampling, I was able to get into touch with interlocutors with similar backgrounds, characteristics, and interests, which were directly related to my research interests (Biernacki and Waldorf 1981, 141). Yet, this may have also caused imbalances in representation such as the majority of my interlocutors identifying as men, although matching with my observation of a male dominance in the meetings I attended.

In terms of sampling, my initial aim was to conduct in-depth interviews with self-identified HIV activists engaged in positive associations. Yet, as I started to reflect more critically on the category of activism and its boundaries while I was introducing myself to the literature of everyday activism, I have decided to take into consideration the accounts of people living with HIV as well. Given practical limitations such as the timeframe of a M.A. thesis, I decided to limit the sample of people living with HIV to those who have had contact with a positive association. In this way, I would be able to reflect on the evaluations of the practices of HIV associations from a perspective not necessarily from within as well as reaching to possible interlocutors relatively easier. Yet, I believe that an ethnographic research with a broader sample including members of LGBTI+ associations, given the fact that some of which are quite engaged in HIV activism recently, as well as people liv-

ing with HIV without a necessary connection to positive associations would be more comprehensive in terms of introducing a wider perspective on a variety of forms of HIV activism and/or living with HIV. Since living with HIV itself can be a site of struggle, as I demonstrate in this thesis, I believe that an affinity with a positive association is not necessary, although feasible for the scope of this research.

Through this thesis research, I tried to meet three major “classic concerns” regarding ethics (Ryen 2016). Firstly, I took into consideration that my interlocutors were giving “informed consent”, meaning the right of research subjects to know that they are being researched, to be aware of what the research is about, and to be able to withdraw in any given moment (Ryen 2016, 60). Accordingly, I made my interlocutors sign a consent form specifying the given information. In terms of confidentiality, referring to our obligation not to disclose the identities of the participants (Ryen 2016, 61), I changed the names of all of my interlocutors as well as the positive associations, and any signifying characteristic of both. Thirdly, Ryen mentions another classic concern, namely, not spoiling the field in order not to discourage potential participants to be studied (Ryen 2016, 61). As I mentioned above, this was particularly a challenge for me to overcome as I was studying a very small community who were in close contact with each other, for which I tried to be careful about informed consent and confidentiality.

There is an ongoing debate on positionality in research both within and outside academia. It has been discussed whether the researcher should be from a specific community if they are going to conduct research on that community. Firstly, I aim to reflect on the academic discussion on insider/outsider ethnography, since it is closely related to that positionality debate, which I prefer to refer as the debate on being a subject (*özne olmak*) in research. O’Reily summarizes the insider/outsider ethnography debate as following:

“... Interestingly (and perhaps predictably), the debate goes both ways: being an insider is seen as both an advantage and a disadvantage. Some argue for the privileged perspective of the outsider and the objectivity that goes with that, while others argue that the insider view is far superior. There is an assumption that outsiders can more easily read a society’s unconscious grammar, while the insider is too familiar to achieve the required curiosity.” (O’Reily 2012, 98).

Yet, he goes on to problematize such dualism by stating that “all ethnographers are to some extent outsiders and to some extent insiders” since they all trying to “make the strange familiar, and the familiar strange” (O’Reily 2012, 98). In other words,

one cannot firmly demarcate being insider and outsider as such a boundary is bound to be blurry. Based on my fieldwork, I can say that I agree with this statement. In the beginning, in my first participant observation in particular, I felt as an outsider since I was not directly engaged in HIV activism and I recently got a HIV-negative test result, although I was diagnosed with another STI last year and the presence of HIV “somewhere out there” continues to shape my sexual encounters. Spending more time in the field, I realized that I have been eventually considered as an activist or someone who is engaged in activist practices by my interlocutors themselves. Indeed, I was surprised that an interlocutor from my preliminary interviews said “Activists like you achieve great things with regard to HIV”. As I proceeded to my fieldwork, my interlocutors continued to address me as such and comment on my positionality. Eray stated the following during our interview:

“What I am going to say is applicable to you as well. When you do something about HIV, which is a subject that is prone to be stigmatized, in Turkey, they immediately think that you are HIV positive, your boyfriend is HIV positive, or you are LGBTI+. They don’t even ask you whether you are one of these, they are just sure that you are one.”

Five months later, when I asked Eray if he could introduce me to Mert, who is from 1 December Association as well, he introduced me by saying “Beste is like our volunteer since she wrote an amazing piece for us and also came to the conference”. When I continued writing articles for the association, I realized that I was now being introduced as a volunteer on the website of the association. In a meeting on HIV activism, after he asked the audience whether they identified themselves as activists, he recognized me in the audience and said “I see Beste here, she is one of them”. Similarly, the chairperson of the People Living with HIV association said “We would like you to become our volunteer” at the end of the interview. All these encounters made me critically reflect on my positionality again and again. As I aim to challenge the boundaries of activism by arguing that everyday forms of activism, such as online advocacy, are not less significant than its more formal kinds, such as working for an NGO, these remarks of my interlocutors on my positionality match with my findings. That is to say, I cannot strictly deem myself as an outsider since writing a thesis on HIV activism in Turkey can be classified as an activist practice. Another pattern I observed in my interviews that my interlocutors asked me to “disseminate true knowledge about HIV”. Three of my interlocutors requested me the same thing with almost exact wording: “Please inform people about U=U in your thesis”. This goes to show how my thesis research is seen as an activist contribution. I would like to clarify that I am not arguing that I am an insider, yet,

my practices can be considered as activist practices and it is significant to mention since my main emphasis is on activist practices, rather than the people behind them, in this thesis. The final discussion that I would like to dwell on is the concept of “truth” in ethnographic research. The in-depth interviews, the ones with PLWH in particular, were topical life stories to an extent. I tried not to analyze such narratives provided by my interlocutors as self-evident realities since the narratives can only be versions of reality and it is important to consider the ‘narrative necessity’ that is shaping them (Bruner 1991, 4). Instead of a positivist approach, which deems reality “out there” and reachable, I tried to keep in mind that the narratives collect in the field are “contextually produced, designed for a particular audience, serve purposes locally produced and embedded in wider cultural contexts” (Ryen 2016, 63). This approach made me reflect on my role as a researcher as well. Holstein and Gubrium direct attention to the fact that researchers are expected to be passive, aiming to unearth and collect data, which is already there (Holstein and Gubrium 2016, 108). However, they claim that the researcher is an active subject engaged in narrative work together with the respondent and interviewing is unavoidably interactional and constructive (Holstein and Gubrium 2016, 109-11). Thus, I cannot disregard my own role in the production of the narratives I encountered and then analyzed.

### 1.3 Thesis Outline

The introductory section of this chapter attempted to briefly point out the significance of the endeavor to study HIV activism with a particular focus on positive associations in Turkey. The second section “Theoretical Framework” classified the bodies of literature that have influenced this thesis into three groups. In doing so, I discussed the ways in which these studies relate to my thesis. In the “Methodology” section, after a brief introduction to the methods I have used, I tried to critically reflect on my research process, questioning my positionality in particular. I organized the rest of this thesis into four chapters. While the second chapter aims to contextualize HIV activism in Turkey, the following three chapters are relatively more argumentative.

The second chapter “Contextualizing HIV activism in Turkey” attempts to present the historical background of HIV and its activism grouped in four eras: 1980s, 1990s, 2000s, and 2010s onwards. While discussing the sociopolitical context of the 1980s, I focus on the case of Murtaza Elgin, the first known person living with HIV in the mainstream media, arguing that the contemporary HIV-based stigmatiza-

tion has been constructed in this era under the heavy influence of institutionalized homophobia. The section on the 1990s illustrates the relation between the first doctor-led HIV associations and the trend of NGOization. The 2000s section traces the foundation of the first positive association within the context of conservative and authoritarian politics of the era. The section on the 2010s onwards, similarly, introduces the challenges to contemporary HIV activism under the influence of increasing conservatism and authoritarianism. Overall, this chapter tries to locate the HIV activism within the web of power relations surrounding it while introducing points of discussion for the later chapters.

The third chapter, “Encounters with the state”, demonstrates the complexity of an endeavor to carve out the relations between the state and positive associations since the positive associations face significant challenges in their attempt to maintain their activist stance while they are able to negotiate with the state regarding health-related policies at the same time. This chapter begins by contextualizing the social policy related to sexual health rights in Turkey. The section “Negotiations with the state” focuses on some contemporary HIV-related collaborative efforts between the state and positive associations, arguing that the positive associations are able to exert their power through making their health-related demands met in a highly challenging sociopolitical context. The final section “State-imposed limitations on HIV activism” describe the challenges ranging from the heterosexist health campaigns to limited financial and social support to the positive associations. This chapter overall attempts to indicate how a small community of activists can be able to resist structural challenges, which exemplifies the working of biosociality and biological citizenship in a non-Western conservative and authoritarian context.

“Key Populations”, the fourth chapter, tackles the issue of HIV-related vulnerability attributed to certain population segments with regard to the theoretical framework of intersectionality, especially in the first section. Drawing on the intersectionality literature and in-depth interviews with the LGBTI+ interlocutors living with HIV, the “Key populations through an intersectional lens” section tries to illustrate multiple layers of stigmatization experienced by them. While the second section “The tensions between positive association and LGBTI+ activists” attempts to reflect on the criticism directed by LGBTI+ activists to positive associations, the final section “What do they even do?: LGBTI+ activism dealing with HIV” attempts the opposite. In doing so, I tried to trace the similarities and differences in their lines of criticism, yet, the fact that I made limited in-depth interviews with LGBTI+ activists might cause this chapter to overemphasize the positive associations’ gaze on the LGBTI+ associations. While positive associations tend to criticize LGBTI+ activists for their belated attempt to engage in HIV activism to avoid further stigma-

tization, LGBTI+ activists criticize how positive associations frame themselves in a way to distance themselves from LGBTI+ to maintain their negotiations with the state and funding agencies. I develop the latter discussion in Chapter 5, particularly while introducing the mode of necessarily conformist activism.

Chapter 5, “Forms of HIV activism” attempts to make an analytical classification of HIV activism in Turkey, namely, aggressive, necessarily conformist, and everyday activism without limiting activism into these three groups or suggesting that these are static, fixed, and firmly separable categories. The first section “Aggressive activism” discusses the cases where HIV activists that I interviewed distance themselves from, idealize, and/or engage in aggressive modes of activism while emphasizing the limitations imposed by the sociopolitical context on this mode of activism. The second section “Necessarily conformist activism” addresses how the possibility of being closed down and the pressure to seek funding might lead HIV activists and positive associations to fashion themselves in a more compliant and professionalized manner regardless of their idealized modes of doing activism. Drawing on the recent social movements literature, the section “Everyday activism” reflects on more micro-scale individual practices of HIV activism in depoliticized settings, trying to contribute to the decentralization of macro-level “iconic” kinds of activism and to extend the scope of the activist practices covered in this thesis beyond NGOs. Finally, the last section “To a more complex understanding of activism” argues that the given categories of HIV activism are quite fluid and form a repertoire from which they can be strategically chosen depending on the context.



## 2. CONTEXTUALIZING HIV ACTIVISM IN TURKEY

This chapter aims to contextualize HIV activism in Turkey through a periodization starting from the first known HIV case until today, the second year of the COVID-19 pandemic. I grouped this historical background in four eras: 1980s, 1990s, 2000s, and 2010s onwards. Although I am aware of the fact some of the phenomena that I focus on such as conservatism and authoritarianism have no clear beginning and ending points and overlap between the given periods, therefore not firmly classifiable as such, I made this periodization in order to be able to focus on some major sociopolitical trends affecting HIV activism in detail. In the first section on 1980s, I argue that the non-existence of HIV associations is closely related to the oppressive political atmosphere following the military coup in 1980. The section on 1990s focuses on the formation of the first doctor-led HIV associations with regard to the trend of NGOization. In the section on 2000s, I illustrate how the EU accession process and digitalization relate to the foundation of the first positive association. In the final section, 2010s, I reflect on the foundation of the other two positive associations, specifying their distinctive characteristics, within the context of the authoritarian and conservative slide. Although I mention the changing healthcare policy especially in the last two sections, I engage in a broader discussion on it in Chapter 3, which concerns the encounters between the HIV associations and state within the context of regressing sexual and reproductive rights in Turkey.

### 2.1 1980s: The Case of Murtaza Elgin

In 1981, a report was published in the USA, stating “5 young men, all active homosexuals” had three infections at once. Soon, this mysterious disease named AIDS was referred to as “gay plague” regardless of the fact that it was seen among other groups (Chambre 2006, 1-2). The Reagan administration kept its “aggressive indifference” to the epidemic regardless of the AIDS-related death rate exceeding 20.000

until 1987 (Demir 2019, 67-68), when the president Reagan uttered the word AIDS for the very first time, in order to maintain the strategical affinity with the leaders of the homophobic right (Gould 2009, 354). In the meantime, Turkey's Minister of Health Mehmet Aydın explained that it was a disease of "homosexuals" and the Turkish society was immune to this disease thanks to its customs, traditions, religion, morality, and family values in 1985 (Cumhuriyet 1985; Turan 2020, 33). Here it can be seen how a symbolic border is drawn between the immoral West and moral us (Bayramoğlu 2021). The following remark of the Bedrettin Dalan, the mayor of Istanbul, in 1985 was reinforcing the association between AIDS and homosexuality: "AIDS is the wrath of God for homosexuals" (Turan 2020, 33).

The homophobic remarks of the state officials at the time requires a broader contextualization of institutionalized homophobia. Following the 1980 coup, the state has intervened in every aspect of life, criminalizing LGBTI+ along the way (Gursu and Cingöz 2013, 12). To exemplify, trans women were deported from Istanbul and LGBTI+ artists such as the "diva" singer and actress trans woman Bülent Ersoy were banned from performing on stages. Moreover, trans women have been facing systematic violence at the urban settings of Istanbul and Ankara on the pretext of prostitution since then (Gursu and Cingöz 2013, 12-18). As such, the very existence of LGBTI+ has been perceived as a threat to the survival of the state as the state was promoting Turkish-Islam synthesis as its official ideology (Alkan 2017, 19) and emphasizing "traditional family values" (Çoruk 2020, 113).

In October 1985, with the headline "Here is the Turk with AIDS", the newspaper *Hürriyet* introduced Murtaza Elgin to the public as the first "AIDS case" in Turkey upon the unethical disclosure of his medical information by Dr. Hüseyin Sipahioğlu (Hürriyet 1985c; Bayramoğlu 2021, 1594). Although his eyes were covered with thin black stripes in the picture on the news and his name was shortened into "M", the public soon found out who he was due to the excessive information the media shared about him. His profession as a celebrity agent, close relations with celebrities, and marriage to a 25-years-older woman were introduced along with commentary on his "abnormal" lifestyle (Turan 2020, 37-38). The newspapers at the time also implied his non-heterosexual identity and practices (Turan 2020, 38-39). The obsession of the media with his sexual life is quite direct in this commentary: "He must stop having sex" (Hürriyet 1985b; Turan 2020, 41).

Elgin did not only face violence on the discursive level but also on physical one as the police forcibly quarantined him when he tried to flee to Germany (Hürriyet 1985a; Bayramoğlu 2021, 1596). He eventually managed to visit Germany and returned clean blood test results, proving that he was HIV negative (Milliyet 1985;

Turan 2020, 42. Nevertheless, he died due to an HIV-related opportunistic infection in 1992 Turan 2020, 45. Just like his living body, his corpse became a site for necropolitical violence (Mbembe 2003; Bayramođlu 2021, 1596). At his funeral, which only a handful of people attended, his body was washed with bleach and buried in a galvanized coffin due to the fear of AIDS. Elgin’s body was perceived as bringing death to the population (Çetin 2017, 13), which exemplifies the operation of biopolitics. That is to say, even his dead body was medicalized and perceived as a threat to the living population, which is tried to be kept healthy and sterile (Foucault 1990). Additionally, symbolic and physical boundaries were set between living and dead people with the excuse of preventing infection.

It is important to note that the onset of the “AIDS crisis” in Turkey is in the aftermath of the military coup in 1980. Following the coup, association and union-based activities were repressed, all political parties were banned, and the freedoms of assembly, press and speech were restricted to a great extent. It is no surprise, then, why people living with HIV could not form a self-organization in this era (Çetin 2017, 13-15). When compared to the HIV/AIDS movements in other geographical contexts, the impact of the 1980 coup appears as a significant problem in Turkey. For instance, there was a grassroots HIV/AIDS movement named ACT UP in the USA, which started in 1987. ACT UP has intervened in every aspect of the AIDS epidemic with great influence through “raucous demonstrations, acts of civil disobedience, zaps and disruptions, die-ins and other forms of street theater, meetings with government and other officials, and eye-catching agitprop” (Gould 2009, 4). In Turkey, however, it was not possible to engage in this kind of activism, or activism of any kind, due to political repression in that period.

Muhtar Çokar, both a medical doctor and activist, defines the period between 1985 and 1991 as a period of tutelage, where the media and doctors were the key actors (Güzel 2020, 12), with the exception of the Family Health and Planning Foundation (*Türkiye Aile Sağlığı ve Planlaması Vakfı*, TAPV), founded in 1985, addressing AIDS (Çetin 2017, 15). As a self-reflection, he claims that the doctors at the time were interested in the scandalous aspect of the epidemic instead of trying to prevent it. It was the period that the Ministry of Health started to implement preventive measures such as testing of blood products for HIV and using single-injection in hospitals (Çetin 2017, 12-14). It was also the time when the junta regime was integrating the Turkish economy into the emergent neoliberal global economy, which was followed by the marketization of public healthcare services (Yılmaz 2017, 62-65). The high costs of the HIV treatment at the time can be considered in this light along with stigmatization since Muhtar Çokar argued that although HIV treatment could be included within the scope of social security, there was a resistance against it in the

governmental agencies (Güzel 2020, 12).

I would like to elaborate more on the role of media, which I introduced while discussing the case of Murtaza Elgin. My 50-year-old interlocutor Olcay, an activist from the HIV Positives Association, shared that the first thing he has ever heard about AIDS was the death of Rock Hudson due to AIDS. “I think the entire world learned about AIDS this way” he stated. The publicization of the death of Rock Hudson exemplifies how stigmatizing discourses regarding HIV/AIDS circulate from the USA to the rest of the world due to intensified globalization at the time. Stigma, according to Goffman, is a process of devaluation related to stereotyping and prejudice (Goffman 1963, 3). Certain characteristics of others are defined as “discreditable or unworthy, resulting in the person stigmatized becoming ‘discounted’ or ‘tainted’” (Thomas 2006, 3175; Liamputtong 2013, 2). HIV-related stigma, in particular, is closely related to already taboo topics such as sex and drug use (Epstein 1996, 11) as these are its main modes of transmission.

Consequently, the case of Murtaza Elgin cannot be considered as a singular and isolated event since 1980s is a period when the foundations of HIV-based stigmatization and discrimination was laid. HIV-based discrimination is closely linked with the institutionalized homophobia, which has been deeply inscribed in the sexuality regime. That is to say, sexuality has been tried to be confined within the frame of a reproductive heterosexual family, which will be discussed thoroughly in Chapter 3. Murtaza Elgin, then, is among many who faced the burden of embodying a virus that is considered to be a threat to the idealized mode of (hetero)sexuality of the nation (Bayramoğlu 2021; Turan 2020). Viewing 1980s in retrospect is critical as it demonstrates how residues of HIV-based stigmatization and discrimination of that period can also be observed today, affecting the strategies and tactics adopted by the contemporary HIV activists.

## **2.2 1990s: The Foundation of NGO-led HIV and AIDS Activism**

Muhtar Çokar defines the era starting in 1991 as the era of social response, referring to the fact that civil society organizations have become key actors in the field (Güzel 2020, 13). As the 1990s saw human rights violations and political repressions related but not limited to the Kurdish movement, the marginalized sections of the society started to engage in human rights activism. No longer strictly associating themselves with left or right, social movements of this period rather put human rights at their center and tried to implement them through activism. To name a few, women’s

movement, environmental activism, queer movement, Kurdish liberation struggle, student self-organizations, and antimilitarist struggles became more visible in this decade (Çetin 2017, 16-17).

The first organization solely dedicated to HIV/AIDS, Association for Combating AIDS (*AIDS ile Mücadele Derneği*), was founded in 1991 in İzmir. As a more influential organization, Association for the Battle against AIDS (*AIDS ile Savaşım Derneği*, ASD) was founded in 1992 in İstanbul. These organizations were led by doctors, lawyers, and intellectuals (Çetin 2017, 18). Çokar states that ASD was a prestigious association that many doctors were trying to be a member of (Güzel 2020, 13). Moreover, it worked closely with the Ministry of Health, receiving state subsidies (Çokar 2006; Çetin 2017, 18). ASD viewed HIV and AIDS dominantly from an epidemiological/medical perspective, which caused their social dimension to be disregarded, mostly in its first years (Çetin 2017, 18). In 2021, in a meeting organized by a sexual rights platform regarding the history of HIV activism in Turkey, a former member of ASD explained why ASD had a crisis, which led to its dissolution. According to him, the issue of working with key populations such as LGBTI+ and whether ASD was going to act like a social movement instead of an NGO became a matter of discussion. The participation of trans people in the board of ASD was a problem, which signaled an identity crisis within ASD. Such a “crisis” suggests that there was a deliberate effort within ASD to frame itself as a legitimate actor, given their close relations with the state. Chapter 4 dwells on this issue as it illustrates how the positive associations founded after ASD position themselves, frame their activism, and develop discourses regarding the issue of “key populations”.

In 1990s, there were successful initiatives in directing the attention of the state to HIV and AIDS. In 1994, TAPV initiated its first action plan against HIV and AIDS. Çetin interprets this action plan as the first attempt at lobbying within the HIV and AIDS movement (Çetin 2017, 21). Upon the approval of the prime minister, National AIDS Commission was founded in 1996, met on a regular basis until 2007, and met once again due to increasing cases in 2007. The major areas of focus were social education, social counseling and support academic work, and legislation (Çetin 2017, 21-23). I believe that it is important to realize how the HIV movement in 1990s was framed in a way to emphasize medical proficiency and consequently received state support since the contemporary positive associations and LGBTI+ associations often have difficulties in receiving aid due to institutionalized homophobia, which will be covered in Chapters 3 and 4.

These civil society developments in this era can also be read with regard to the

global trend of NGOization. In the 1980s and 1990s, the role given by the United Nations to the NGOs regarding the issues such as human rights, women's rights, and environment (Kamat 2004, 152) increased the importance of NGOs as agents in the democratization process (Edwards 2009; Kendir 2019). Social movement actors employed the NGO form as a "method of survival" during times of political repression (Alvarez 2009; Bernal and Grewal 2014, 6; Ismail and Kamat 2018, 571). The trend of NGOization is often criticized for depoliticization in the literature. Ismail and Kamat illustrate the ways in which NGOs can contribute to the demobilization of radical politics and suppress opposition to neoliberalism (Ismail and Kamat 2018, 573). Ribot, similarly, demonstrates that NGOs turn into company-like structures as a result of project-based works, seeking funds, and waging tasks, which signals a process of professionalization and depoliticization (Ribot 2004, 168; Bayraktar 2017; Kendir 2019). In this case, ASD's strategic distancing from LGBTI+ can be an example of depoliticization, considering how closely related the AIDS crisis was to LGBTI+ politics. In the case of positive associations, however, there appears a more complicated picture in regard to identity politics.

While the HIV movement started to take an NGO form and negotiate with the state, the media continued to fuel HIV-related anxieties feeding the stigmatization and discrimination toward PLWH. When I asked Sevgi, an activist from the HIV Positives Association, when she has first heard of AIDS, she responded:

"I heard it on a program of Uğur Dündar, in which a sex worker bargains with a truck driver. The woman says "I have AIDS". The terminology of that time was of course so ignorant. The driver says "Forget it, let's throw caution to the wind." It was associated with something very negative, you know, there was an impression that it would happen in the lives of sex workers, marginal people in quotation marks."

As I continued my fieldwork, I realized that this particular scene of Uğur Dündar's Arena program, which reappeared regularly, was emblazed in the minds of a generation. It is no surprise that Sevgi made an association between AIDS and the marginal(ized) as the initial public response to HIV and AIDS was marked by stigma and moral panic in Turkey (Çetin 2017, 14). Additionally, HIV and AIDS have been used as a means to stigmatize the already-stigmatized groups; firstly gay men and injecting drug users (Scambler 2003; Parker and Aggleton 2003) then sex workers (Lekas, Siegel, and Leider 2011; Liamputtong 2013). In the case of Arena, the writers sensationalize the issue by stigmatizing both HIV and sex workers at once, relying on the existing stigmas regarding sex work.

Sex work was stigmatized in another context during the 1990s, namely, the case of the arrival of migrant sex workers from former Soviet Union, particularly in the East Black Sea region after the collapse of the country in 1992 (Bayramoğlu 2021, 1598). According to Bayramoğlu, they were not only portrayed by the media as bringing HIV from the outside into the borders of Turkey but also as embodying a moral threat, representing non-Turkish sexualities that were as contagious as the virus itself (Bayramoğlu 2021, 1591-1602). Bayramoğlu conceptualizes the Turkish border not only as a physical barrier but also a discursive border between known Turkish values and alien practices (Bayramoğlu 2021, 1590-1591) such as non-heterosexual and non-marital sexuality.

All in all, it can be seen that the HIV activism in the 1990s tried to engage in formal ways of activism in line with the trend of human rights activism in the NGO form. While the media was continuing to fuel HIV-based stigmatization particularly for LGBTI+ and sex workers, the first doctor-led HIV associations focused more on the medical aspects of HIV, thereby framing themselves as legitimate actors suitable for negotiating with the state. In this mode of activism, successful negotiations were made with the state in terms of treatment. However, PLWH were out of sight and not able to collectively engage in politics for the stigmatization and discrimination that they face first-hand, which necessitated the emergence of positive associations in the 2000s.

### **2.3 2000s: The Foundation of the First Self-organizations**

The EU-accession process characterized the politics on civil society in Turkey in the 2000s. Following the candidacy of Turkey for the European Union in 1999, it was expected by the international agents that Turkey would improve the conditions for minorities and civil society in general. The EU-directed developments in Turkey contributed to the new social movements such as facilitating the foundation of new associations. Upon the reformation of the Turkish Associations Law as part of the negotiations with the EU in 2004, the first HIV self-organization was formed in 2005, which I choose the name as Living with HIV Association in this thesis for ethical concerns. The association was formed by people living with HIV, their families, activists, and medical experts, followed by the foundation of another positive association in 2006, which is not active anymore (Çetin 2017, 23-26).

Digitalization was a major component of the formation of the first HIV self-organization, the first one of the positive associations, in Turkey. In fact, the Living

with HIV Association has emerged out of a mailing group, as its former member Sevgi narrates below:

“I asked my doctor whether there was an association or organization that I could go to and meet people like me. He answered there was none, yet, there was a Yahoo mail group and there were people mailing there. He learned its address and I participated in the group the next time I went there. It was a Yahoo group called HIV Turkey... Then we started to write to each other there... There I read about the abuses people were going through. One is not being operated on, one is fired from their job, one is abandoned by their family and there were so dramatic cases. For example, a 12-year-old kid was infected by the blood donated by her dad and he was not accepted into the ICU due to being HIV positive. And he died. The stigmatization resulting in death was so widespread in those years. As we tried to figure out what to do, some of us started saying “Let’s form an association””

The relation between digitalization and HIV activism can be conceptualized with regard to the theoretical framework of bio-digital citizenship introduced by Petersen et al. Drawing on the literature on biosociality and biological citizenship, Petersen and his associates use the concept bio-digital citizenship to explain the transition from a right-based activism to a funding-based one within the context of increasing digitalization (Petersen, Schermuly, and Anderson 2018, 478). This kind of citizenship is marked by the intertwinement of biological identities and digital practices, enabled by citizens’ production and consumption of biological knowledge on the Internet, social media in particular. Both HIV/AIDS activists and breast cancer activists are identified as two key groups engaging in bio-digital citizenship (Petersen, Schermuly, and Anderson 2018, 481-485). In the case of the Living with HIV association, the Yahoo group HIV Turkey opens up the possibility of digitally coming together on the basis of a shared biological condition, thereby exemplifying the working of bio-digital citizenship.

The chairperson of Living with HIV association, Ali, explains the three major aims of the associations as follows: providing support to PLWH, rights advocacy, and raising awareness of the public on HIV. Currently, the association has a project directed at providing support to refugee PLWH, Syrian refugees in particular. Ali shares that they name the refugee LGBTI+ and sex workers as “key refugee group” when working with the government since they cannot openly use the name LGBTI+, which will be contextualized in the next section while discussing the recent attacks towards LGBTI+. In the 2000s, the LGBTI+ movement gained more visibility in Turkey. The first Pride march was organized in 2003 (Özlen 2016) and started



to take place annually. As opposed to the struggle to be accepted as “normal” in the 1990s, LGBTI+ activism started to embrace its own identity as it engaged more in identity politics (Atalay and Doan 2019, 112). LGBTI+ associations also started to collaborate with the positive associations. For instance, a new platform named HIV/AIDS Civil Society Platform was founded in 2007, including LGBTI+ associations as well as positive associations (Çetin 2017, 27).

One year after being elected to the office, the Justice and Development Party (AKP) government launched the Health Transformation Program (HTP) in 2003 with the aims such as facilitating access to health and increasing the quality of the health system (Çetin 2017, 9). However, HTP signals a paradigmatic shift from the concept of health care as a public good to a health care as a commodity to be marketed (Acar 2009, 3) with its other aims such as increased productivity, competitiveness, marketization, and deregulation (Gider and Top 2007; Acar 2010, 150). While there was a trend of privatization of healthcare since the 1980s, the introduction of the Green Card in 1992 marked an increase in public health coverage (Yılmaz 2017, 61-62). Until the year 2012, despite being criticized because it was a means-tested program, the Green Card provided access to health for the disadvantaged groups without insurance including PLWH (Çetin 2017, 11). On the other hand, the Mother-Child and Family Planning Directory that was providing reproductive health in primary care was replaced by family physicians system (Dayı 2019, 60-61), which illustrates a regression in sexual and reproductive health rights covered in detail in Chapter 3.

Although being intensified in the 2010s, the AKP’s approach to family and motherhood was signaling conservatism since the very beginning of their rule (Yeğenoğlu and Coşar 2012, 199; Güneş-Ayata and Doğangün 2017, 616). Women were often mentioned within the context of family and their role in raising new generations was overemphasized in the government programs (Güneş-Ayata and Doğangün 2017, 616). The anti-natalist approach of the 1960s has been visibly shifting towards a pro-natalist one in this period, which can be exemplified by the demand of the Prime Minister Erdoğan from women to have at least three children (Çilingir 2021, 30-33). Moreover, Erdoğan expressed his wish to recriminalize adultery in 2004, which was among the reasons for the suspension of the EU membership process (Güneş-Ayata and Doğangün 2017, 615). Such a stance against non-marital sexual practices signals how the AKP government would react to HIV, which is often associated with non-normative sexual practices.

The 2000s, then, staged the foundation of the first positive association within a context of increasing digitalization and a shifting political climate. That is to say, the

liberal outlook at the first years of AKP might have facilitated the foundation of the Living with HIV Association, yet, the increasing conservative policies it implemented towards the end of the decade started to put forward challenges for HIV activism as it denotes non-normative sexual identities and practices. Such challenges became more tangible in the 2020s onwards, as introduced in the section below.

#### **2.4 2010s Onwards: HIV Associations in a More Authoritarian and Conservative era**

In 2013, over 100.000 people participated in the Pride march and thereby marking the most crowded march in LGBTI+ history in Turkey, which coincided with the Gezi Protests<sup>1</sup> (BBC 2013), becoming a symbol of freedom (Mutluer 2019, 106). According to Mutluer, Gezi Protest was a turning point for the AKP to start becoming openly homophobic (Mutluer 2019, 105). In 2015, the Pride march was banned by the Istanbul Governorship on the pretext that it coincided with the holy month of Ramadan. The march was still organized and faced violent attacks by the police (Mutluer 2019, 105-106), which has been experienced in each Pride since then. In this case, we can see conservatism and authoritarianism go hand in hand, which indeed marks the period from the 2010s onwards.

The increasing conservatism of the AKP was also visible in the case of the roles attributed to the women. In 2011, the AKP changed the name of the Ministry of Women and the Family to the Ministry of Family and Social Policies. According to Öztan, erasing the word woman from the name of the ministry reflected how the AKP saw women as second-class citizens with the main responsibility of reproduction for the provision of a cheap labor force (Öztan 2014; Mutluer 2019). In 2012, Erdoğan introduced a legislation for partially banning abortion, which was backfired by the women's organizations and eventually withdrawn. However, there still is a de facto ban on abortion since many public hospitals do not perform abortions (Mor Çatı 2014; Mutluer 2019, 109). Mutluer argues that such gender and sexuality-related politics are not an attempt to hijack the public agenda as it is often assumed but “a medium to regulate the neoliberal redistribution of the conservative values adopted by family, community, and market in their new functions and roles” (Mutluer 2019, 101).

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<sup>1</sup>Gezi Protests refer to the protests erupted in opposition to the removal of the Gezi Park, which is one of the remaining green places in the city center, for a modernization project proposed by the AKP. The police violence against the protestors as well as the political repression going on at the time led the protests spread across Turkey (Taştan 2013).

The failed coup attempt in 2016 resulted in severe repression of civil society through formal and informal means. During the two-year-long state of emergency following the coup attempt, the government shut down 1600 civil society organizations in total (IHOP 2017; Yabancı 2019, 291). Within this context of an exponential slide into authoritarianism (Mutluer 2019, 112), two new positive associations emerged. 1 December Association, as the second one of positive associations, was founded in 2016 as the first digital NGO working for HIV awareness as well as empowering PLWH. Eray, a 40-year-old HIV activist, narrates his motivation for founding the association as follows:

I joined international HIV organizations and umbrella organizations and started to join their meetings often. This way, I had the chance to see what other people were doing about HIV in other parts of the world. I was already a member of the board of management for the Living with HIV association between 2013 and 2015. I was asking them whether we should change the structure and shift to the information provider model since there were great things happening in the world: they were working with doctors and PLWH were becoming part of the research. Could NGOs do something like this? Living with HIV association was insistently and rightfully saying “No, it is not what is needed at the moment because the community has needs”. Then I decided to found another association within the field I wanted to specialize, Living with HIV would continue as it was, these structures would support each other. But this was not a smooth process, there were lots of arguing. It took some time that we started working together [as two separate associations].

As it can be seen in the quote above, the main disagreement between the Living with HIV Association and 1 December Association was whom to address. 1 December Association differs from the other positive associations by adopting another model, i.e., evidence-based activism, as Eray explains. Evidence-based activism refers to a “collective inquiry associating patients/activists and specialists/professionals in the conjoint fabrics of scientific statements and political claims” (Rabeharisoa, Moreira, and Akrich 2014). “We wanted to talk to the whole society”, Eray said, explaining that the majority of the HIV activism models in Turkey and the rest of the world focus on the process after diagnosis, trying to help traumatized PLWH. 1 December Association, on the other hand, is aimed at addressing HIV-negative people as well by providing them updated information about HIV. Indeed, 85 percent of the audience of the association consists of HIV negatives based on the clicks to the content addressing HIV negatives. Accessing the broader population appears as the primary motivation of this kind of evidence-based activism, serving an ultimate ideal of ending HIV in Turkey.

As opposed to the aim of the 1 December Association to address the whole society, the HIV Positives association, officially founded in 2018 by the members who left the Living with HIV association, actually preferred to remain as a small-scale association according to its co-founder Sevgi. That is to say, as the last one of the positive associations, they did not have the intention of growing this much due to their limited number at the beginning. Their primary aim in the foundation process was to provide peer consultation, which means bringing together a PLWH who is trained by the association with a newly diagnosed one. In this way, a support network is found among PLWH, facilitated by the association. Although the Living with HIV association questioned whether there was a necessity for another association at first, the three positive associations “perform a common stance” such as issuing a statement together when there is a problem regarding HIV. As an initiative found in 2019, Positives United separates itself from these positive associations to some extent as it “is more intersectional, focuses more on LGBTI+” as its activist member Vagif stated.

In March 2020, the “severe acute respiratory syndrome coronavirus 2” (SARS-Cov-2) causing COVID-19 was defined as a global pandemic by WHO (2020). The COVID-19 pandemic coincided with the “shift towards total authoritarianism in the marriage between political Islam and ultra-nationalism” (Altay 2022, 6), referring to the coalition of the AKP and ultra-nationalist Nationalist Movement Party (MHP) in Turkey since 2018. It also coincided with the unprecedented economic crisis in Turkey, which had the biggest effect on the disadvantaged and marginalized (Altay 2022, 2). Within this context, Ali Erbaş, the President of the Directorate of the Religious Affairs made the following remark in his sermon addressing COVID-19 on 24 April 2020:

“O people! Islam accepts adultery as one of the greatest harams. It condemns the people of Lut tribe because of their homosexuality. What is the wisdom in this? It is the wisdom in this that it brings diseases and extinction along with it. Hundreds of thousands of persons each year are exposed to the HIV virus caused by this great haram, the name is which is adultery in the Islamic literature of illegitimate and unmarried life. Let’s fight together to protect people from this kind of evil.” (Güzel and Dikmen 2017, 53).

When I asked my interlocutors living with HIV what they thought of this statement, Bahadır defined it as “ignorance and pure evilness” and criticized it for “inducing hate”. Batuhan used the word “horrific” to describe it, and Nilay found it “illogical” as it does not represent the truth. According to Altay, this statement marked a

strategic transition to “political homophobia”, which refers to “a purposeful practice of scapegoating sexual minorities and expressions of sexuality as a tactic for state building and retrenchment” (Bosia and Weiss 2013; Altay 2022, 2). This statement targets gays and PLWH at the same time and strengthening the association between them in doing so. Sevgi, an activist from the HIV Positive Association, states that they issued a notice on the same day of the statement, which was found “soft” by the LGBTI+ activists. I provide a more detailed discussion on this tension in Chapter 4 and while discussing the “aggressive” and “necessarily conformist” modes of activism in Chapter 5.

In parallel with the global trend of the suspension of sexual and reproductive health rights during the COVID-19 pandemic (Hall et al. 2020; Michielsen et al. 2020; Riley et al. 2020), COVID-19 had practical limitations for PLWH in Turkey as well: the activities of GDTMs were suspended and some PLWH had difficulty in continuing treatment due to reasons such as the transformation of some hospitals into pandemic hospitals (Yilmaz 2020, 65-68). However, the government also took some measures to compensate for the COVID-19-related withdrawals. For instance, the Ministry of Health allowed prolonged reports and prescriptions, through which PLWH could access the medicine (Yilmaz 2020, 66). Due to misinformation especially at the beginning of the COVID-19 regarding both HIV and COVID-19, positive associations tried to provide information regarding the relation between them. In the in-depth interviews, the members of positive associations also stated that they tried to inform the public with the most updated and scientifically valid information. Indeed, Yilmaz accounts that healthcare workers were satisfied by the information provided by the NGOs to PLWH (Yilmaz 2020, 64).

All in all, the period lasting from 2010 to today staged the emergence of two new positive associations and a new initiative, each specialized on a different aspect of HIV, thus improving the field of HIV activism in Turkey. Their endeavor is particularly significant within a period of intensified authoritarian gender regime and repression on civil society. On top of that, the shadow of another global pandemic, COVID-19, has had practical limitations on HIV activism. As the next chapter will discuss, despite the challenges including but not limited to the ones stated above, positive associations in Turkey have a significant potential to lead an effective activism.

### **3. ENCOUNTERS WITH THE STATE**

In this chapter, I focus on the complexity of the encounters between the HIV associations and the state within the context of the regressing sexual and reproductive health rights (SRHR) in Turkey. In the first section, I present an overview of sexual and reproductive health (SRH) in Turkey, emphasizing the historical turning points since the foundation of the Turkish Republic in 1923 until 2022. The second section focuses on the negotiations between the positive associations and the state, drawing examples from collaborative projects such as HIV/AIDS Control Program. In the final section, I discuss how state-imposed limitations are experienced by HIV activists. Although this chapter puts in its center the role of Ministry of Health, it will also point out how the other actors, such as the media and medical institutions, also play a vital role in shaping the encounters between the state and positive associations. Overall, I argue that the positive associations have the potential to effectively challenge the state policies regardless of the structural limitations they are facing.

#### **3.1 An Overview of the Sexual and Reproductive Health Rights in Turkey**

Until 1965, The Republic of Turkey implemented pro-natalist policies such as prohibiting abortion, decreasing the legal age of marriage, and encouraging families to have more than five children (Akin 2007, 86) in order to increase the population to compensate the population loss experienced 1911 and 1923 due to the World War I, the War of Independence, and epidemics (Akin and Sevenscan 2006). Due to the adverse consequences of these policies such as rising maternal and infant death rates (Karaca Bozkurt 2011, 68) the first Five-Year Development Plan implemented in 1963 took an anti-natalist turn by emphasizing that a high population growth rate was an obstacle to achieve a higher level of social welfare (Seckinelgin 2008, 29-30).

Such a turn was partly made possible by the efforts of medical experts, academics, and associations such as the Turkish Gynecological Association to remove the ban on birth control methods (Dayı 2019, 58).

The new anti-natalist policies were focused on increasing the female employment rate and decreasing the maternal death rate rather than the empowerment and rights of women. Moreover, there was no mention of legalizing abortion, and the maternal death rate did not decrease as expected (Çilingir 2021, 30-31). Following the long-lasting advocacy of the Turkish Medical Association, Turkish Family Planning Association (TAPV), and Turkish Gynecological Association as well as the public health reports demonstrating the connection between unsafe abortions and maternal death, in 1983, abortion on demand was legalized through a revision of the 1965 Law on Population Planning (Dayı 2019, 59). As medical doctor Akin (2007) reports, the legalization of safe abortion resulted in a significant decrease in maternal and infant death rates (Çilingir 2021, 31).

In the 1990s, a right-based approach to SRH started to be more dominant globally. Accordingly, the Turkish government adopted a women's health-focused approach instead of a maternal-health-focused one by signing the International Conference of Population and Development (ICPD) Action Plan in 1994 (Çilingir 2021, 31). Indeed, struggles over women's health was "virtually synonymous with the emergence of second-wave feminism (Annandale and Clark 1996; Tong 2019, 329). After 1994, there have been collaborative projects taking place by the Turkish government and international organizations such as UNAIDS (The Joint United Nations Programme on HIV/AIDS), a global effort to end AIDS, regarding SRH (Çilingir 2021, 32). However, such a right-based approach was gradually abandoned following the election of the AKP in 2002, given its conservative agenda reducing the role of women to motherhood as discussed in the former chapter. Instead of citizens in their own right, the AKP portrayed women only within the framework of their familial roles (Acar and Altunok 2013, 14-23; Dayı 2019, 59). To exemplify, Mother-Child and Family Planning (AÇSAP) Directory was closed and replaced by family physicians system (Dayı 2019, 60-61), limiting sexual health with reproduction.

Promoting a pro-natalist policy, as outlined in Chapter 2, the AKP reignited the abortion debate starting as early as 2003. In 2003, the government tried to redraft the therapeutic abortions, which met objections by the women's organizations, medical associations, and media, resulting in the removal of the draft. In 2012, Erdoğan made an analogy between abortion and mass murder, referring to the killing of 24 Kurdish citizens in Uludere for which the AKP was criticized as the perpetrator, in an ICPD conference (Dayı 2019, 59). He also denounced cesarean birth as a

“conspiracy to end the population”, while the Minister of Health stated that cesarean birth was an obstacle to having a young population since it was “decreasing subsequent births” (Frank and Çelik 2017, 202-2015). Such remarks of the AKP government, particularly its attempt for a partial ban on abortion, were met with a strong opposition from the feminist movement (Dayı 2019, 59), who put into circulation the slogan “My body, my choice”, spanning even in the government-controlled mainstream media. The government took a step back and did not change the abortion law (Dayı 2019, 59), however, it is not possible to have an abortion in the majority of public hospitals at the moment, which suggests that there is a de facto ban on abortion (Mor Çatı 2014; Mutluer 2019, 109). Such instances illustrate how sexuality is tried to be confined within the frame of reproduction, which puts HIV activism in a challenging position since it is associated with non-normative sexual practices.

Against this background, however, there were still efforts on the part of the AKP government to support rights-based sexual health policies in the 2000s, which can be exemplified by the reproductive health program implemented by the Turkish Ministry of Health and European Commission lasting from 2003 to 2007 as well as the issuance of a national strategic action plan for SRH from 2005 to 2015 (Köse 2010; Yılmaz and Willis 2020, 6). Although such efforts were abandoned starting in the early 2010s due to the policy shift mentioned above, interestingly, free STI (including HIV) testing and treatment have continued to be covered by the universal social insurance benefits package (Yılmaz and Willis 2020, 6). While confidential and anonymous STI testing is not available in hospitals, a small number of district municipalities implement it in the centers called GDTMs since 2014, following the demands from the LGBTI+ rights organizations (Eralp 2015; Yılmaz and Willis 2020, 6).

I would like to end this section with a recent turning point for HIV activism in Turkey. In 2019, Mersin Metropolitan Municipality led by Republican People’s Party (CHP), an opposition party, was under attack by the ultra-conservative media and local conservative politicians due to distributing condoms within the scope of a sexual health promotion campaign they initiated in a public university (Aydm 2019; Yılmaz and Willis 2020, 7). Indeed, the campaign was a collaborative project between the municipality and the Ministry of Health, yet, the latter withdrew its support from the campaign (Yılmaz and Willis 2020, 7). I argue that this incident captures the extremity of the recent conservative and authoritarian politics in Turkey, thereby posing a challenge to HIV activism. That is to say, HIV activists have to devise new strategies to maintain their existence and influence in a context where they cannot even distribute condoms.



Ali, the co-founder and current chairperson of Living with HIV Association, describes the latest HIV policies in Turkey as follows:

Since HIV is not a priority of the state, it does not see the number of PLWH as a threat. The state does not prioritize HIV and it does not want to do so. Since the current government is a conservative one, it presents monogamy as a prevention method. I mean, we cannot even organize events on the streets. For example, it is now forbidden for us to distribute condoms. Because the police see the condom as an incentive for prostitution. They do not even see it as a prevention method in the first place.

Ali's remarks outline how condoms, that were once were a vital part of the pro-natalist policies, are now turned into elements of crime to some extent. It is not possible to analyze such criminalization separately from the recent attacks directed toward LGBTI+ and women. As non-normative sexual identities and practices are increasingly marginalized by the state, the positive associations find themselves in a more vulnerable position and devise strategies accordingly. For example, as Ali mentions above, street events such as the annual marches that formerly took place in the Istiklal Street on the World AIDS Day to fight against HIV-based stigmatization and discrimination are nowhere to be found today. However, as the next section illustrates, this does not mean that the positive associations do not have the potential to lead an effective activism.

### **3.2 Negotiations with the State**

In Chapter 2, I touched upon some negotiations between the HIV activist organizations and state such as the foundation of the National AIDS Commission as a result of the collaborative effort of TAPV and the Ministry of Health, including members from civil society, ministries, media and professionals (Çetin 2017, 21). In this section, I focus more on the recent collaborations between the positive associations and state, problematizing how such efforts are made possible given the above-mentioned repressive political atmosphere regarding SRHR.

In the HIV/AIDS Control Program issued by the Ministry of Health in 2019, to be detailed below, it is stated that GDTMs have been found in Ankara, Istanbul, Izmir, and Trabzon since 2005 with the help of global funding efforts in order to provide free counseling and testing for the society, "high-risk communities", referring

to “sex workers, men having sex with men, transsexuals, drug users” in particular (T.C. Sağlık Bakanlığı Halk Sağlığı Genel Müdürlüğü 2019, 8). More recently, new GDTMs were found in Ankara, Istanbul, Bursa, Izmir, and Mersin. The document also states that there are efforts on behalf of the ministry to open new GDTMs, especially where the tourism sector is active, and where international round-trip and population mobility are high. This document presents a view as if the efficiency of GDTMs is plausible, although their number can be increased, along with portraying the ministry as the sole agent of these endeavors. However, the social policy literature and my fieldwork suggest otherwise. To illustrate, Yılmaz and Willis indicate that currently active GDTMs are opened due to the efforts of advocacy groups such as positive associations, which led some municipalities of one of the opposition parties, CHP to assume responsibility to open them (Yılmaz and Willis 2020). Yet, the approval of the Ministry of Health for the GDTMs did not protect these centers from becoming targets of far-right groups (Habertürk 2019*a*; Yılmaz 2021, 12).

In one of my in-depth interviews, Olcay, who has been engaged in HIV activism since the 1990s and who is now the chairperson of the HIV Positives Association, made the following comment regarding GDTMs upon my question on the challenges HIV activism faces in Turkey:

One of the weaknesses of HIV activism, for which activists are not responsible, concerns how bureaucratic obstacles and a certain social perspective prevent HIV from being talked about and becoming a mainstream issue. For example, there is a very low number of GDTMs in few cities. These are test centers provided and supported by local governments. But the municipalities, which are ideologically and politically different, do not pave the way for something like this. They even try to cancel the existing centers. Thus, HIV is something that is silenced given the existing political, bureaucratic, and social perspectives.

Olcay’s remarks pose a challenge to how GDTMs are portrayed in the HIV/AIDS Control Program by suggesting that the operation and even the existence of such centers are made difficult in a repressive setting. Indeed, the effectiveness of the HIV/AIDS Control Program itself is severely criticized by three of my interlocutors. The preface of the document written by Fahrettin Koca, the Minister of Health, states the following:

“Although our country is among the countries where the disease is seen less frequently in terms of HIV/AIDS, an increase in the number of cases has been observed in recent years. For this reason, although successful

steps have been taken in our country and studies with increasing impact and scope have been carried out, there are many activities that need to be done for the prevention and control of HIV/AIDS.

In this context; to combat risk factors for the spread of HIV/AIDS, in line with the global targets set by UNAIDS, by observing human rights, and to create a roadmap for HIV/AIDS studies in our country under the mission of protecting and improving the health of the society by providing equal access to diagnosis, treatment, care and support for every individual. “Turkey HIV/AIDS Control Program, 2019 - 2024” has been prepared.” (HIV/AIDS Kontrol Programı 2019, V)

Then, the document provides information regarding HIV/AIDS and introduces the targets for combatting it, including advice on how to prevent discrimination and privacy violations against PLWH. Living with HIV Association is among the stakeholders of the program. When I asked Ali, an activist from the Living with HIV Association, what he thought about the efforts of the Ministry of Health on HIV such as the HIV/AIDS Control Program, he laughed and asked “What efforts?” and then told me that he does not find the program either effective or sincere:

"We are a part of the HIV/AIDS Control Program of the Ministry of Health. We are a member of it. We also join its meetings. But they do this kind of stuff just for the sake of formality. I mean, it is just a matter of bureaucracy. It is only on paper. They [the policies] are not implemented. I mean, if you ask them, “Did you do such a study?”, they will say “Of course we did”. But it is not effective at all in reality.”

Mert, an activist from the 1 December Association, also questioned the efficiency of the program, as can be seen in this exchange between us:

Beste: What can you say about the HIV/AIDS Control Program that has started to be implemented by the Ministry of Health in 2019?

Mert: “Started to be implemented?” That’s funny. What about it?

Beste: What are your views about it?

Mert: Let me tell you about the process behind it. We went there, the plan was made and signed. It was August 2019. In March 2020, the pandemic erupted and that plan was put to rest. In the second year of the pandemic, the department head was retired. Three people were appointed for her position. Two of them were retired and one of them dropped the task (Laughs). Now, there is no department head in the infectious diseases department. The officers there are trying to do

something. That plan is discarded. It was planned until the end of 2023 anyway. There is only 1 and a half years left. They will probably revise it. I mean, they will write a directive explaining the invalidity of that plan. I guess they are planning to do something like that.

The bureaucratic obstacles experienced in the implementation of the program should be viewed with regard to the stigmatization of HIV and PLWH. I argue that such indefinite postponement of the program and prioritization of COVID-19 reflects how the ministry marginalizes HIV as a concern of “high-risk groups”, whereas COVID-19 was relatively deemed as everyone’s problem, at least at the beginning of the pandemic. Indeed, the following remarks of Vagif, who is an activist member of the initiative Positives United, suggest how the marginalization of PLWH is imprinted in the program itself:

“When we look at the program, we see many awful problems. While it promises to increase the number of GDTMs, on the contrary, we see them closed or at the risk of being closed. Plus, it talks about ensuring everyone’s access to treatment but not everyone can access treatment. With a moralistic discourse, the prevention methods are reduced to monogamy. We talk about how migrants and immigrants cannot access treatment but there is no information about this in the HIV/AIDS Control Program. I mean, there is one sentence in which the word “migrant” is used, which concerns the migrant pregnant women’s access to treatment. We don’t know whether it has been implemented, we don’t know anything.”

Indeed, as Vagif mentioned, “having more than one partner” is listed among the risky behaviors for HIV/AIDS, while it is not among the risk factors in the guidelines of contemporary health organizations (World Health Organization 2021). Moreover, there is no mention of PrEP, the short for pre-exposure prophylaxis, in the whole document. PrEP refers to a highly effective medicine people can take to prevent themselves from being infected with HIV resulting from having sex or injecting drugs (Centers for Disease Control and Prevention 2022). At a conference on HIV activism in Turkey that I attended, an activist from the Living with HIV Association announced for the first time that PrEP is currently on sale in Turkey, yet, it is very expensive. Although PrEP is now imported to Turkey, it is not possible to prescribe it and it is not covered by the healthcare system, therefore it is only accessible through pocket money. Mert, an activist from the 1 December Association, defined the commercial efforts that have brought PrEP to Turkey as “bold” and suggested that they can lower the price with the activism they will engage in. The fact that the HIV/AIDS Control Program overlooked these major developments illustrates how

the Ministry does not find HIV/AIDS significant enough to update its HIV-related knowledge and implement effective policies. However, despite these shortcomings, it is worth emphasizing that HIV activists from the positive associations are included in the preparation of the HIV/AIDS Control Program. Within an authoritarian political climate where participatory policy-making is highly limited, it is significant how HIV activists insert themselves into decision-making processes.

I would also like to mention a recent example of petition-making to further discuss the complexity of negotiations between HIV associations and the state. On May 28, 2021, 1 December Association wrote a petition to the Ministry of Health demanding PLWH to be included in the priority group for COVID-19 vaccination. Signed by the other two positive associations as well, the letter has a very polite tone and begins as follows:

“As representatives/members of the Turkish HIV community, we have been following carefully and proudly your achievements in the management of the coronavirus pandemic in Turkey, and the valuable work you have carried out since the first day of the coronavirus pandemic, with a superhuman performance and perseverance.”

In a matter of a week, the Ministry of Health accepted the petition and included PLWH in the priority groups list. 1 December Association shared the news with the caption “Well done to us!”. I find this exchange between the positive associations and the ministry significant as it happens in the middle of an unprecedented health crisis, COVID-19. The fact that the ministry swiftly responds to a demand from a stigmatized community also suggests the relative autonomy of the Ministry of Health. That is to say, we witness a democratic effort from a public actor that is a patient organization and a consequent negotiation with the state (Yılmaz 2021), illustrating not only a relatively autonomous exchange against the repressive political context but also the working of biological citizenship. To be more specific, through coming together around a biological understanding of a shared identity (Novas and Rose 2005, 442), HIV activists make a successful demand from the state.

### **3.3 State-imposed Limitations on HIV Activism**

I explained above how Mersin municipality faced attacks due to distributing condoms, which resulted in the Ministry of Health withdrawing its support from the sex-

ual health promotion campaign. I also discussed how the support given to GDTMs is not sufficient and some of them are on the verge of being closed down. Along with these recent instances of backlash to HIV activism, the insufficiency or, indeed, absence of a comprehensive national sexual education was a common concern of my interlocutors. Nilay, in particular, said she cannot stress the importance of sexual education for HIV activism enough and returned to this topic multiple times during our in-depth interview. As an academic, PLWH, and counselee of the HIV Positives association, she stated the following:

"We must incorporate HIV and the sexually transmitted infections into our curriculum because everyone experiences sex whether they are conservative, atheist, or experiencing any other lifestyle. When they don't know anything [about HIV], they have to receive lifelong treatment - actually, you can of course be healthy while living with HIV but there are other STIs that can lead to cancer, you know. That's why we need to break the taboos related to these topics. We need to make young people aware of it before they start to have sex. I remember when the topic of sexual health was somewhat addressed in the public health week or something, everyone in the class would be so embarrassed. These are the organs of our bodies, right? If I don't get embarrassed when I talk about my arm, then I shouldn't be embarrassed about these topics as well. It doesn't mean that we should talk about these topics non-stop in the public, which would be weird, but this information should be known. We need to raise awareness, that's for sure."

According to Nilay, sexual health education is a vital responsibility of the state, which is not adequately performed. In the instances that there are such efforts such as the public health week that she mentions above, the existing taboos among the society hinder their effectiveness. However, she draws another boundary when stating that it would be weird to be too vocal about sexual health in the public. Vagif, an activist from the Positives United Initiative, agrees with Nilay on the necessity of a comprehensive sexual education. Indeed, they have a specific ideal in mind:

"Firstly, sexual health education should be incorporated in the curriculum but this should be based on updated data, it should not have moralistic undertones such as "Monogamy protects you". I mean it should be comprehensive and inclusive."

Elsewhere in our in-depth interview, Vagif refers to the poster below of the Min-

istry of Health when criticizing HIV/AIDS Control Program for not being inclusive enough. There is a word-play on the top of the poster below, saying “You are the precaution/You are not precautions”. While warning the audience for not taking precaution regarding HIV and AIDS, it also emphasizes that there can be no precaution found without having monogamous sexual relations within a family. This kind of an understanding of health as the responsibility of the individual has its roots in neoliberalism, which promotes self-care and self-sufficiency (Murray 2020). In such a way, I argue, the state is able to evade its own responsibility on ensuring the health of the population.

Figure 3.1 World AIDS Day Campaign of the Ministry of Health



Vagif: “You know, the Ministry made a poster depicting a happy family put under a roof, displaying to us a heterosexist family structure. [The ministry] does not even talk about HIV. When it does, you see, it talks from a moralistic, pronatalist standpoint and criminalizes HIV once again.”

When I asked Sevgi, an activist, what she thought about the future of HIV activism in Turkey, she referred to this poster like Vagif:

“The way things are going, we will need to do activism for a long time since the government does not address the problem or the idea of “This is everyone’s problem” is not embedded in the public. We have a long way to go, you know. I mean, it was 2019 or 2018, the Ministry of Health made a poster depicting a family with two children. They were standing in the grass and there is a hand protecting them from the black smoke beyond. I mean, it says “If you are a heterosexual couple, if you are monogamous, you live in a bed of roses. All the darkness take place outside your house, if you go there, your life will be a mess”. It does not include LGBTIs, it does not include anything. It just imposes a heterosexual viewpoint.”

It can be seen from these remarks that this poster stands out so emblematic for these activists in the sense that it reflects the insufficiency and exclusiveness of the state-led sexual health politics. For Sevgi, such a marginalization of HIV adds to the timeframe one would engage in HIV activism. When I discussed the weakness of HIV activism in Turkey with her, she gave me another instance of a contemporary mispolicy of the Ministry of Health, that is, the recent opening of the prescription provision system (MEDULA) for a broader range of health professionals. The MEDULA system refers to a digital program made by the Ministry of Health, displaying the diagnosis of the patients to hospitals, doctors, pharmacies, and opticians (Habertürk 2019b). With the new revisions to the system, the data of PLWH are made accessible, mobilizing the positive associations to file a lawsuit. 1 December Association wrote the following sentence in their statement on the post they update the public on the case that is still open today:

"We would like to remind you that our capacity to forge public opinion regarding this issue is limited due to how the HIV issue is addressed in Turkey and the majority of our counselees -rightfully- tend to remain invisible."

In this statement, it is possible to see that the 1 December Association refers to the repressive political atmosphere discussed above. Reflecting on the limited capacity of the HIV community to change public opinion, they seem to put forward a somewhat realistic picture of HIV activism in Turkey. However, based on the discussion in this chapter, I argue that HIV associations hold a significant activist capital as they manage to negotiate with the state and achieve successful outcomes for PLWH as well as raising awareness. These achievements are also significant in the sense that they are enacted during a conservative and authoritarian shift, which not only overlooks SRHR but also tries to take back the achievements in this area. Therefore,



positive associations act as agents that put pressure on the state with regard to the SRH politics in Turkey despite their low number of members, insufficient financial support received from the national funding agencies, and lack of visible support from PLWH due to stigmatization.

## 4. "KEY POPULATIONS"

This chapter discusses the controversial issue of “key populations”, which refers to the “population groups that are particularly vulnerable to HIV and frequently lack adequate access to services” (UNAIDS 2022), with regard to HIV activism. The first section introduces key populations and approaches the issue through an intersectional lens. The second section analyzes the tensions between positive associations and LGBTI+ activists in Turkey, drawing heavily on my fieldnotes. The final section reflects on the commentary made by the positive associations on the shortcomings of LGBTI+ activism in dealing with HIV. However, given the limited scope of this M.A. thesis, this chapter draws on the in-depth interviews with only members of positive associations, not LGBTI+ activists except for Vagif, which may lead this chapter to rather reflect the gaze of the positive associations on LGBTI+ activists. Based on the ethnographic data, this chapter points out that the HIV activists and LGBTI+ activists criticize one another for a deliberate effort not to associate HIV and LGBTI+, which is the main source of tension between them. I demonstrate how the positive associations criticize LGBTI+ activists for starting their HIV activism too late whereas LGBTI+ activists criticize positive associations for framing their activism in a way to be perceived as legitimate in the public eye, for which they put the issue of key populations to the background.

### 4.1 Key Populations through an Intersectional Lens

In 2016, the World Health Organization (WHO) issued a guideline on HIV prevention, diagnosis, treatment, and care for “key populations”. The document lists 5 key population groups “which in almost all settings are disproportionately affected by HIV”:

- men who have sex with men

- people in prisons and other closed settings
- people who inject drugs
- sex workers
- transgender people (World Health Organization 2016)

UNAIDS, another influential global effort aiming to end HIV, identifies the same groups as key populations with the addition of gay men (UNAIDS 2022). According to WHO (2016), such a classification indicates the common behaviors among the given key populations and certain legal and social barriers that put them in a more vulnerable position (2). I believe that it is important to take into consideration that each of these given groups faces multiple layers of stigmatization and discrimination, which requires them to be analyzed through a lens of the theoretical framework of intersectionality. Although Romero states that the intersectionality theory has arisen from social activism by the efforts of scholar-activists to conceptualize class, caste, and status, Crenshaw is often credited for coining the term (Romero 2018; Crenshaw 1989). Crenshaw analyzed how black women were experiencing discrimination on the basis of race and sex simultaneously (Crenshaw 1989). Drawing on the theoretical foundation of Crenshaw, Davis defines intersectionality as follows:

“‘Intersectionality’ refers to the interaction between gender, race, and other categories of difference in individual lives, social practices, institutional arrangements, and cultural ideologies and the outcomes of these interactions in terms of power” (Davis 2008, 68).

Closely linked with contentious issues such as sex and drugs, HIV “intersects with long-standing social hierarchies that seemingly render some groups more expendable than others” (Watkins-Hayes 2014, 433), which also suggests the working of biopolitics. Foucault argues that the right to kill can be exercised not only through direct murder but also through indirect murder such as increasing the risk of death for some people (Foucault et al. 2003, 254-256). As mentioned in Chapter 2, AIDS was conceived as a “wrath of God” on homosexuals in its initial stage, which resulted in government inaction and consequent increase in death rates. In this case, sexuality and HIV status together mark certain segments of the population as more expendable.

Watkins-Hayes describes HIV as an epidemic of intersectional inequality triggered by racial, gender, class, and sexual inequities (Watkins-Hayes 2014). The above-listed key populations, in particular, face intersectional inequalities. For instance, “men

who have sex with men” bear HIV-related stigma along with facing homophobia. To further complicate the picture, in the United States, black MSM experience the highest rate of HIV infection due to a variety of reasons, one of them being undetected or late HIV diagnoses (Watkins-Hayes 2014, 433-437). This case illustrates how intersecting categories of difference affect the lives of PLWH, particularly those who are within a web of intersecting identities. This point can be further illustrated with my encounters within the field. Batuhan, who is both LGBTI+ and living with HIV, stated that it was already difficult living as a gay man from childhood onwards. To be diagnosed with HIV, on top of that, made his experience “uniquely” different. Vagif, who is also both LGBTI+ and living with HIV, shared their experience of living with these multiple identities as follows:

“When I was diagnosed, I found this experience similar to being gay. I identified myself as gay at that time. [HIV] was very similar to the processes when I knew that I was gay but I did not accept myself, I hid it from the other people, and I acted like I was not gay. On the other hand, I overcame these about being gay but I thought HIV would not be like this, ever. I questioned whether it was due to the fact that I had one of these identities since birth but I acquired the other later.”

This experience of Vagif exemplifies how intersecting identities can feel similar but have different dynamics at the same time. It is also important to acknowledge that these seemingly distinct categories mutually shape each other. Indeed, many PLWH face intersectional stigma, meaning that they are marginalized due to their HIV status and other disadvantaged statuses (Berger 2006; Watkins-Hayes 2014). The next section illustrates how the intersection of LGBTI+ and HIV is handled in activist spheres.

## **4.2 The Tensions Between Positive Associations and LGBTI+ Activists**

In October 2021, the 1 December Association organized a conference on HIV activism in Turkey, bringing together the other positive associations, medical doctors, academics, and activists from related fields such as sexual health and LGBTI+. Out of 12 sections, however, LGBTI+ activists were given a platform in only one of them, which was named “Key Populations in the Struggle against HIV”. Indeed, the lack of representation of LGBTI+ activists was raised as an objection by a LGBTI+ activist during the conference. In the prior session regarding HIV treatment, a social

scientist stated “The spread of HIV is not caused by the key populations”. When it was his turn to speak, an activist from the Living with HIV association addressed this by saying “It is a risky discourse because those populations do increase the spread”.

The tensions further arose in the session on the key populations. An LGBTI+ activist stated that there were meetings organized that do not include LGBTI+ and each conference that do not have LGBTI+ as speakers contribute to the discrimination against them, probably referring to the fact that it was the only session with LGBTI+ speakers. They also accused the conference of not being intersectional enough. According to them, HIV activism should not have just the role of a “service provider” but also a site of struggle, which must be intersectional. They also criticized the positive associations for reducing HIV activism to explain the prevention methods and distribute condoms. In fact, I observed that this argument itself was reductive since many other efforts of positive associations were introduced at the same conference such as facilitating access to other prevention mechanisms such as PrEP and fighting stigmatization.

Another LGBTI+ activist criticized both the concept of key populations itself and the relations between positive associations and so-called key populations. In terms of the concept of key populations, they pointed out that the label “men having sex with men” was problematic, for example, since it included those who do not identify as men. Regarding the latter, he defined the relationship between HIV activists and LGBTI+ activists as a relationship between “a husband and his mistress”. That is to say, it is an intimate relationship in the private sphere but it is not shown in the public. As I argue in Chapter 5, this mode of activism attributed to the positive associations can be labeled as necessarily conformist activism, meaning that the close relations with the LGBTI+ can be strategically rendered invisible for the sake of negotiating with the state.

Positives United, an initiative found in Turkey in 2019, can be both classified as a future positive association and an LGBTI+ organization as it puts LGBTI+ PLWH at its center. In our in-depth interview, Vagif, an activist from the Positives United, asserted that they also lead LGBTI+ activism and they think that the intersection between HIV and LGBTI+ is significant, which they do not see in positive associations. They are engaged in LGBTI+ activism in a variety of ways such as attending the Pride week organizations and distributing an HIV-phobia award at an ironic award show organize to award those who commit homophobia. Comparing their efforts in this kind with those of the positive associations, Vagif made the following criticism:

The positive associations stay within a certain frame to maintain their relations with the Ministry of Health and funding agencies. I get that but the responsibility of civil society should be different. That's why I don't legitimize their behavior. Because of this context, they don't really mention LGBTI+ but we do that at least, we try to do something for LGBTI+.

The strategic concealment of close relations with LGBTI+ attributed to the positive associations can be conceptualized as exemplifying necessarily conformist activism, which must be considered within the framework of the conservative and authoritarian policies and trends in Turkey. As discussed by Lüküslü, the term “necessary conformism” refers to a tactical adherence of young people to the rules of institutions such as family and society. Engaging in tactics such as using a wig while entering the university under the headscarf ban enables them to mask the strong discontent that they have for the rules (Lüküslü 2013). Vagif's comment above can be conceptualized with regard to this theoretical framework as the positive associations are regarded as strategically framing their activism in a way not the direct the institutional gaze onto themselves taking into consideration the consequences they might face, regardless of their discontent towards the governmental impositions on HIV activism as shown in Chapter 3. That is to say, the long-lasting institutionalized homophobia might have set the positive associations back from providing visible support to LGBTI+ although they are willing to support them. Additionally, out of necessity, positive associations may choose to prioritize other aspects of HIV activism such as the medical expertise and access to treatment. Their command over medical expertise enables them to gain credibility (Epstein 1996) in the eyes of the state, framing HIV activism as more “legitimate”. More visible relations with LGBTI+ could automatically risk such legitimization given the increasing attacks on LGBTI+. Indeed, this kind of legitimization of the positive associations is what enables them making successful negotiations with the state to improve the lives of people living with HIV.

### **4.3 “What Do They Even Do?”: LGBTI+ Activism Dealing with HIV**

The former section analyzed the criticisms made by LGBTI+ activists on the type of activism conducted by the positive associations, whereas this section attempts to reflect on vice versa. The most common criticism of the activists from the positive associations was that the LGBTI+ organizations strategically pulled themselves

away from HIV activism to avoid further stigmatization until very recently. Olcay, the chairperson of the HIV Positives Association, commented on this:

LGBTI+ organizations should give more emphasis to HIV. Actually, they are right too. LGBTI+ have too many adversities to overcome and HIV is only one of them. We always have close relations [with LGBTI+]. If the community reminds its members of HIV a little bit more, it would be better. But it is not enough. This is also a part of the stigmatization. Let's not forget, in Turkey, HIV is considered as an infection that belongs to LGBTI+. That's why I tried to avoid such sexist or homophobic discourses regarding HIV because HIV is an issue for everyone who engages in sex without protection.

Olcay tends to frame HIV as everyone's problem to avoid further stigmatization of LGBTI+, however, such an approach is conceived as "not doing enough" for LGBTI+ as stated by the LGBTI+ activist Vagif above. Ali, the chairperson of the Living with HIV Association and Eray, the founder of the 1 December Association both point out that the HIV cases increased in the LGBTI+ key population, for which LGBTI+ organizations did not take responsibility soon enough. Ali, who is engaged in HIV activism since 2005, states:

LGBTI+ organizations are too late. We held meetings on this topic 10 years ago. Although we say that this is not an LGBTI+ disease, the spread is more widespread within this group. Now, they access sex easier due to mobile dating apps. This group is at higher risk. 10 years ago, we told the LGBTI+ organizations "80 percent of our counselees are LGBTI+. You need to do something about this." Yet, they were hesitant. Maybe they were right too since they did not want to associate LGBTI+ with HIV. There was stigmatization that if someone is LGBTI+, they eventually get HIV. That's why they were hesitant but they left behind this hesitancy in the last 2-3 years. Now, they get counseling from us and they started counseling others too. I find these developments very positive.

In a similar fashion, Eray argued that the LGBTI+ movement did not want to build upon the existing association with HIV and LGBTI+. According to him, in the last two years, LGBTI+ associations started to take responsibility following the example of the HIV community. He explains their lateness by saying "We are living in Turkey anyway", referring to the repressive political atmosphere. Mert, an activist from the 1 December Association, was quite critical of how LGBTI+ activists deal with HIV for different reasons than the others. His main argument

was that LGBTI+ activists were not respectful to positive associations and did not act strategic enough in their encounters with the state. In our in-depth interview, we had the following exchange:

Beste: What do you think about the efforts made by LGBTI+ associations on HIV in the last 2-3 years in particular?

Mert: Are there any?

Beste: [Names a few LGBTI+ associations]

Mert: Are there any?

Beste: [Names a recent platform founded by an LGBTI+ association ]

Mert: I am asking something else. Are there any? You remember the conference, right?

Beste: Yes.

Mert: Remember, they attacked us at the conference. What do they even do? When I do something, I announce it anywhere. I was an LGBTI+ activist myself by the way. The LGBTI+ culture has this characteristic: “I did something, why don’t they see?” Baby, it doesn’t work like that. There is an LGBTI+ activist who started to work on HIV at an LGBTI+ organization [names them in the original quote]. That’s great. But do you know what I would do? I would call me and say “I found this working group. How should we lead each other?” See, this would empower the field. But what did they do? “We are providing this service, how come you don’t know?” No, I don’t know. I don’t know how you frame your counseling, I don’t trust it. . . An LGBTI+ organization had an issue with the Ministry of Health. The Ministry of Health removed them from a national committee. Because Görkem [pseudonym] said bullshit like “I swear to God that I will take my clothes off so you come to your senses” to the Islamist dudes there. I don’t want to be associated with you because I don’t act that way. OK, I respect it but what you do marks all of us as civil society. Plus, I don’t only address LGBTI+ like you do. . . We address Islamist families, veiled women, etc. This is what I mean when I say “broader population”.”

Firstly, Mert posits positive associations as the leading figures within the field of HIV activism by arguing that the LGBTI+ activists should inform them if they engage in HIV activism. Secondly, he argues that one has to act strategically when negotiating with the state. Considering that the positive associations have found themselves in negotiation with the state for a longer time compared to LGBTI+ activists, they might have a know-how, which yields successful results as it can be seen in Chapter 3. Indeed, this strategically framed distance to key populations can



explain how the positive associations manage to make their demands met unlike other activist endeavors within the highly authoritarian political climate of Turkey.

## 5. FORMS OF HIV ACTIVISM

In this chapter, I make an analytical classification of HIV activism in Turkey based on my ethnographic fieldwork: aggressive activism, necessarily conformist activism, and everyday activism. This classification aims to illustrate how HIV activists switch back and forth between different forms of activism, revealing the dynamism of the field of HIV activism. After describing each category supported by ethnographic data, I will provide a more nuanced approach to such a classification in the last section. I argue that such categories are not static and fixed but rather fluid in accord with my fieldwork outcomes. Aggressive, necessarily conformist, and everyday forms of activism indeed intertwine and constitute complex forms in each context and encounter. Together, they form a repertoire from which they can be strategically chosen and used by individuals in different occasions.

### 5.1 Aggressive Activism

In my fieldwork, “aggressive activism” was a term used by my interlocutors, which often denoted the activism of others such as LGBTI+ activists and ACT UP. I define aggressive activism as taking a direct, and often militant, stance on the institutions and actors who pose a challenge to HIV activism such as the state and drug firms. With the exception of Mert who individually engages in aggressive activism, the members of the positive associations generally tend to put a distance between themselves and aggressive forms of activism.

Sevgi, an activist from the HIV Positives Association explained how they issued a statement to condemn Diyanet’s hate speech regarding HIV and LGBTI+, introduced in Chapter II, and their tone was perceived as “too soft” by the LGBTI+ activists, who expected a more radical stance against the government. She said:

“But this is our style. We don’t speak up like that, we don’t utter so radical discourses. Not only LGBTI+ but other groups as well can prefer doing more aggressive activism.”

She went on describing aggressive activism through the case of ACT UP, an international grassroots group that is not present in Turkey, which is known for its militancy:

“There is a group called ACT UP, I am sure that you know them. Our stands were facing each other at one congress. On the second or third day, we saw that their stands were closed. We asked “What happened to them?” It turns out that they were arrested (Laughs). They went to the congress area early in the morning. In the congresses, there is one area with the stands of NGOs and another area with the stands of drug firms. They had broken all the computers of those drug firms. This is an activism too. They are saying “You make money out of us”. We, for example, don’t prefer this kind of an activism. You know, Greenpeace climbs to hills, roofs, or whatever. I mean our methods are different.

Indeed, it is understandable why ACT UP antagonizes drug firms. As Atuk argues, drug firms claim that they develop technologies to cure pathologies. Yet, they reinforce the existing pathologies or even create new ones by limiting the access of their treatment to few people. Consequently, they end up contributing to the pathologies through their expensive pricing and control over generics (Atuk 2020). Eray, an activist from the 1 December Association, also immediately thought of ACT UP when he discussed aggressive activism:

“We still can’t talk about an activism in a real sense, maybe we can’t talk about an aggressive and fearless activism like ACT UP in Turkey. It’s still lobbying, still a sweet talk, and so on. So, I would very much like, for example, I would very much like to have an ACT UP Istanbul in Turkey.”

He later expanded his discussion on the aggressive activism abroad, comparing them with the political context of Turkey to emphasize the impossibility to apply those methods here:

For example, I know that there is an NGO in New York, they went and raided the office of the mayor. So you’re not doing things about this

HIV program", you know, they raided the office. The mayor's office. And then the mayor agreed, "Yes, we have to do this". Now, if we go through such examples, I probably wouldn't be able to approach the mayor's office here anyway (Laughs). Even if we raid it, they will close this association the next day. So, imagine you are a fish, how you behave is related to the aquarium you are in."

These remarks of Eray should be regarded within the context of the increasing authoritarianism in Turkey discussed in Chapter 2. Since so many civil society organizations were shut down following the coup attempt in 2016, Eray's anxiety makes more sense. His remarks also suggest that the 1 December Association strategically chooses to distance itself from militancy taking into consideration the adverse consequences, although Eray wishes that an ACT UP would be formed in Turkey, which engages in a more idealized version of activism. However, regardless of working for the same association, Mert shared with me how he individually engaged in aggressive activism:

I came back [from an international HIV conference] wearing a U=U t-shirt. Of course, I am going to terrorize that ministry. Do you know what the Ministry had told me and Eray? We had written a letter to the Netherlands Embassy and said, "We will do something like this and that but we don't have money, so we can't go [to conferences]." They made some donations, we went there and came back. I also went to the ministry. We told Zeynep [pseudonym], who is now retired, about U=U. She said "There is no need for it. What would change if we wrote U=U on a document about treatment?" What would change, huh? See, you included U=U in the treatment guideline in 2019. Because that's what we do. Why? I came back wearing a U=U t-shirt, went to the ministry, Public Health Directory, made a fuss everywhere. You had to see how I insulted them in those meetings... That's the period when I was forbidden to enter Ankara (Laughs). Because I left there, I did the same thing to the drug administration, etc... That's the kind of activism I've had done. This kind of a fuss enabled U=U to be included in the treatment guideline document in 2019.

Mert's encounter with the ministry officers exemplifies direct action. According to Shaw, direct action not only takes place through marches and protests but also through immediately confronting certain individuals and corporations with specific demands (Shaw 2013, 268). Direct action was proved to be successful in the case of ACT UP (Shaw 2013, 275), resulting in achievements such as lowering the AIDS drug prices and including PLWH in decision-making mechanisms (Epstein 1996,

217). Mert, too, claims that his direct action was successful as it resulted in the inclusion of U=U in the treatment guideline although he faced the consequence of being banned from entering Ankara by the police. Both for Eray and Mert, aggressive activism is posited as an idealized mode of activism that one can switch to as long as the sociopolitical context allows. The annual marches organized by the Living with HIV Association on 1 December, the World AIDS Day, to raise awareness on HIV until 2012 exemplifies how a positive association can resort to direct action as long as the sociopolitical context allows. In 2012, the municipality of Istanbul refused the demand of the association to organize a march without giving a reason. The increasing conservatism and authoritarianism in this period rendering HIV activism a “marginal” issue is likely to be the cause. This cannot be isolated from the other social movements that are getting criminalized in Turkey such as the LGBTI+ movement and feminist movement. For example, the marches of these groups are also banned, which demonstrates that different kinds of activism are increasingly rendered “aggressive” by the government. Consequently, the resources of positive associations are becoming more and more limited to be able to engage in more aggressive forms of activism on one hand; previously acceptable forms of HIV activism are viewed as “aggressive” on the other.

## 5.2 Necessarily Conformist Activism

Amid the conservative backlash and authoritarian impositions on HIV activism discussed in Chapter 3, HIV activists sometimes resort to a kind of activism that prioritizes docility and professionalism to pursue their political objectives. This kind of activism can also facilitate receiving funding and prevent being targeted by the state. Additionally, they can strategically frame themselves more moderate compared to LGBTI+ activists to be able to negotiate with the state, as discussed in Chapter 4. I term the totality of such practices as necessarily conformist activism, drawing on the concept “necessary conformism” introduced by Lüküslü (Lüküslü 2013). The following remarks of Sevgi, an activist, exemplify the characteristics of this mode of activism:

[LGBTI+ activists] may have adopted a different style of activism. For example, let me tell you at least for my own organization, the attitude of the other two positive associations is also like that. Our aim is to play the ball, not the man. Because we have seen over the years that if you cooperate by understanding the other person and trying to explain

yourself, there are more positive results, but when you talk by shaking your finger at somebody, you cannot solve anything. Let me give you an example, you went to a doctor's examination. The doctor can be so evil, so annoying. When you do something like "You have to take care of me" (shakes her finger), they get even angrier. But when you say "May it be easy, you see so many sick people every day, your job is so busy, may it be easy", when you make him feel that you understand him, even the feeling that he is understood relaxes him and he starts to listen to you from a more positive place.

The doctor-patient analogy that Sevgi made can be interpreted as the relationship formed between the positive associations and LGBTI+ associations with the government. The "evil" doctor may be a reference to the government that is quite indifferent toward the rapidly increasing HIV cases in Turkey. LGBTI+ associations, depicted as the aggressive patient, cannot make their demands met if they continue their aggression. The positive associations, on the other hand, make some concessions to negotiate with the government and are able to get what they want as a result. As mentioned in the section above, Eray also argued how the members of positive associations were rather using the methods of "sweet talk" and "lobbying". Such methods seem to be useful in a conservative and authoritarian setting like Turkey, where making grassroots sexuality-related demands from the state is difficult.

In their study on the everyday lives of grassroots, non-party political activists in the UK, Chatterton and Pickerill demonstrate how they transcend the binary between an activist and non-activist through rejecting the idealized militant struggle against oppression and rather engaging in a pragmatic goal orientation and professionalism (Chatterton and Pickerill 2010, 478-469). They find that individuals can intentionally adopt a professionalized activist persona, instead of a militant one by deliberately avoiding confrontational and aggressive encounters, to appeal to a broader public (Chatterton and Pickerill 2010, 480). In my fieldwork, after defining himself as an "NGO professional", Eray shared with me that he saw that the field of HIV activism in Turkey had a "potential" in which professionalization was possible. Eray deliberately adopts this NGO professional persona although he idealizes the aggressive activism of ACT UP. As the 1 December Association aims to address the whole society as mentioned in Chapter 2, Eray might be aiming to appeal to masses across the political spectrum in this way. Additionally, professionalism can make negotiations with the state easier, which can be seen in the case of successful petition-making in Chapter 3. That is to say, signing petitions as long-established NGOs instead of unprofessional individuals can make the former more legitimate

actors with valid demands in the eyes of the state. However, this case is exceptional within a context where some other advocacy struggles are condemned just for signing petitions, i.e., Academics for Peace being sentenced to prison for criticizing state violence against Kurds (BBC 2016), while those sentences were often deferred.

Professionalism is also useful in attracting funding. In their study on HIV activists and breast cancer activists, Schermuly et al. argue that their activism has shifted from a rights-based struggle to a professional and business-like endeavor, which requires activists to use their expertise to attract funding from corporations (Petersen, Schermuly, and Anderson 2018, 490). In the case of the positive associations in Turkey, however, there is still a strong emphasis on rights as it can be seen in the recent petitions in Chapter 3. Yet, they have to appeal to the sponsors, mostly foreign sponsors, for which they need a professional persona. In terms of the challenges in funding, Ali from the Living with HIV Association states the following:

In the first years, we had lots of financial struggles because we couldn't get funding within Turkey. So we've got funded completely from abroad, the United Nations, and drug firms. We still are. We are completely funded from abroad.

Mert, an activist from the 1 December Association, specified the difficulty of the associations in getting funded as follows:

The newly founded associations have this challenge in Turkey: You can't say "Let's make projects now and let the money come in". You just can't do that. OK, you may have been doing activism for years now but you're a civil society organization in the eyes of the state. That's why no money can come and go. In case that money goes in, it has to quickly go out in the due form.

These remarks of Ali and Mert suggest that it is difficult for civil society organizations to get funding without looking suspicious in the eyes of the state and HIV associations are particularly vulnerable in that sense as they have a more "marginal" agenda as Olcay states. According to Olcay, an activist from the HIV Positives Association, there is a certain kind of honor, morality, and lifestyle imposed on the society, in which individuals have no sexual liberties, rendering HIV a marginal issue. International organizations, on the other hand, may not marginalize HIV activism and may willingly provide support to the HIV associations in Turkey instead, which can be exemplified by the funding given by the international AIDS organizations

such as UNAIDS to the positive associations. These external sources of support, thus, become the means of survival for the positive associations.

In accord with the theoretical framework of “necessary conformism” put forth by Lüküslü, my interlocutors showed a clear discontent with the governmental and societal discourses and practices regarding HIV in Turkey (Lüküslü 2013). Yet, they can strategically frame their activism more moderate in their encounters with the state, such as adopting a polite tone in meetings with the government agencies and resorting to bureaucratic channels such as petition-making while making demands, as discussed in Chapter 3. Taking into consideration how the other activist groups often face violent attacks by the state for engaging in other activism forms such as street protests, this approach of the positive associations suggest that they opt for necessary conformism, which has so far yielded successful results. Thus, in the current sociopolitical context, which renders engaging in HIV activism itself as an aggressive act, necessary conformism proves to be an effective mode of activism enabling the very survival of the positive associations.

### 5.3 Everyday Activism

As illustrated in the Introduction chapter, there is a new approach in the social movements literature that draws attention to small-scale, personal, and quotidian forms of activism instead of its overemphasized macro-level and iconic kinds (Horton and Kraftl 2009, 14-16). Everyday activism, which can take place through ordinary and individual practices, might be indeed central to social movements by creating alternative politicized spaces (Veron 2016). In my fieldwork, accordingly, I tried to trace activist practices beyond the frames of NGOs. Hospitals, academia, and social media emerged as three examples in which everyday activism might take place. I classify the micro-scale individual practices such as raising awareness on HIV and building solidarity networks in seemingly depoliticized settings as everyday activism.

According to a report published by the Living with HIV Association in 2021, violation of rights of PLWH is quite widespread within the healthcare sector, which often results from the lack of information regarding HIV. Each one of Oğuz, Sevgi, and Mert faced HIV-based discrimination by a healthcare worker and they showed a reaction that I classify as activist. Oğuz, a 21-year-old student and a counselee of HIV Positives Association, shared with me the following instance with a nurse:



The people diagnosed with HIV face discrimination mostly by the health-care workers. They face stigmatization and bad words. I can give you an example that I went through. I was in another city and went to a new hospital since I had to give blood to be tested. The woman whom I gave my ID and tags started to mark the tubes as “+” after attaching the tags to the tubes. She tries to mark the tube since I was HIV positive, takes measures, you know, and stigmatizes me in doing so. I asked her what she was doing. She told me that they are doing this for all the infection patients, which doesn’t make any sense. I think she thought that I was someone who doesn’t know anything about rights or laws. When I told her what she was doing was a form of stigmatization, there was no need for this kind of behavior, and she was committing a crime for doing such a thing, her mouth was wide open. Then, she started to erase all the “+” signs on the tubes.

Sevgi shared two similar instances with the dentists that she went to. In one instance, the dentist dressed himself like an astronaut once he learned that Sevgi was HIV positive. Sevgi asked him “Now you feel safer, huh?” and then lectured him about how HIV cannot be transmitted when he takes the standardized precautions. Then the doctor responded, “Oh, I did not know that”. In another instance, Sevgi heard her dentist’s conversation with a colleague. He showed Sevgi to his colleague as “the one with AIDS”, and his colleague peeked at her. Sevgi recalls the rest as follows:

He must have wondered what I looked like. Now, looking from there, I felt the need to turn my head the other way involuntarily. Because you feel very naked, it is such a very unpleasant feeling. It’s a very bad feeling. Then I said, "Wait a minute, why am I turning my head?" I mean, I didn’t do anything bad, I didn’t do anything to be ashamed of. I just got infected with an ordinary infection, you know, it has such a simple explanation. Then I turned my head, looked him directly in the eye, you know, if someone needs to be ashamed, he should be. He is the one who disrespected my privacy. If there were no dental tools in my mouth, I would have said "You can touch me, come, come close" or something.

In this case, “looking directly in the doctor’s eye” can be classified as an activist endeavor as it is a refusal of being ashamed, a stance taken against stigmatization. Mert’s experience is similar to the ones of Oğuz and Sevgi:

"One day, I went to the hospital to give blood. There was a cute nurse who was only 19 years old. Once she saw the diagnosis, she started shaking. I was trying not to laugh. She approached me shakily. I mean,

she was about to shoot me in the head. I said “Stop. What’s happening to you?” She said, “I learned that you’re living with HIV.” “What are you living with?” I asked her. “With fear?” She stopped. “Don’t do this” I said, “Don’t take my blood now. Call the nurse who is the responsible person here”. She said, “Please don’t do this”. I said, “Don’t fear”. “I will do something beautiful.” The other nurse came. I said “Nowadays, not everyone can have on-the-job training properly but I know you for a long time. Now, shall we show this nurse how to take blood from an infected patient while protecting herself? Give me this chance. I would like to use myself as an experimental subject.” She started to lecture the [young] nurse, the other nurses came around us. The [experienced] nurse asks me “For how long you have been infected?” I say it. “For how long you have been taking your medicine?” I say it. “Then you don’t transmit anything due to [viral] suppression.” “Yes, I don’t.” The next time that I went to give blood, the young nurse caught me and confidently asked, “Can I take your blood?””

In all these experiences, my interlocutors engage in everyday activism as a spontaneous response to the context around them. Following the event, they do not issue a press statement or organize a march. In other words, these acts do not necessarily transform into an institutionalized response. As Horton and Kraftl argue, there is no linear, intentional, and inevitable progression from everyday lives to conventional forms of activism (Horton and Kraftl 2009, 16). Moreover, in each of these experiences, my interlocutors act as lay experts (Epstein 1996), meaning that they demonstrate medical expertise without officially being trained in medicine. Their expertise is to an extent that they are even able to challenge the medical authorities.

In my in-depth interviews with Batuhan, Bahadır and Olcay, they requested from me to educate the readers about HIV. As I wrote at the very beginning of the Introduction chapter, Batuhan, a PLWH, wanted me to share his personal story with his ex-partner, where there was no HIV transmission without using protection, as evidence of U=U. Bahadır, too, as a PLWH, asked me whether I would mention the importance of being diagnosed, that HIV is a treatable infection and that PLWH have no health issues. Olcay, an activist from the HIV Positives Association, wanted me to emphasize that there should be no prejudices about HIV, stating that PLWH are better choices for partners compared to those of whom we do not know the health status as the former routinely undergo health examinations. These remarks made me think that these thesis interviews themselves can be a site of everyday activism since my interlocutors use the platform of academia to raise awareness on HIV.

Social media appears as a third platform where everyday activism takes place. For

my preliminary interviews with PLWH, I accessed my sample through the social media platform Instagram. Each of my interlocutors had anonymous accounts dedicated to HIV. On these accounts, they were mostly trying to fight against misinformation and prejudices regarding HIV. Some of them also made posts about their feelings about living with HIV, drawing support from other PLWH. In our interviews, they told me that they found other PLWH through social media and helping each other since then, which suggests that these accounts are providing them with a solidarity network. It also exemplifies the operation of biosociality as these individuals come together and form a community on the basis of a shared biological condition, developing techniques for the everyday management of the condition (Novas and Rose 2005).

Positive associations also frequently resort to social media for doing activism. Whereas the Living with HIV Association and HIV Positives Association mostly tend to inform PLWH on HIV-based developments such as treatment updates, the 1 December Association often shares posts against HIV-based stigmatization since it aims to address the “whole society”, as stated by its founder Eray in Chapter 2. Positive associations also use these platforms to provide emotional support for PLWH, the newly diagnosed ones in particular. For example, one user comments under a post of the HIV Positives Association warning the audience about the deformed medication “When will we ever be happy?”. Other PLWH and the HIV Positives Association soothe this user together, mentioning their own experiences with HIV. In another instance, Bahadır shared with me how the HIV Positives Association took care of him when he was newly diagnosed:

When you're diagnosed, you try to reach other PLWH because, you know, only they can understand you. I wrote to the HIV Positives Association, Living with HIV Association, and the other one. HIV Positives Association responded more quickly. They took care of me more quickly. Even at the times when I didn't write to them, they asked “How are you? Did you get your report? Did you take your medication?”. That's how our connection became stronger. That's why I became their volunteer.

Such cases exemplify how the positive associations engage in care work, which might be regarded as a sub-form of everyday activism. Showing affection to the newly diagnosed PLWH might not seem as a “politicized” act with regard to the conventional social movements, yet, it is highly politicized when one takes into consideration the lack of institutionalized psychological support given to PLWH, except for few CHP-led municipalities in big cities, and the stigmatization they face in the society. In such an environment, positive associations take the responsibility of providing the

support which is not given to PLWH. Hines, in her study on transgender self-help groups, finds that the members of these communities “give something back” to the communities which they had received support from, thereby moving between the receivers and providers of care (Hines 2007). As the founders of the HIV Positives Association was a member of a Yahoo group founded by and for PLWH in 2005, as stated in Chapter 2, the motivation underlying her association’s care work can be understood as “giving back”.

#### 5.4 To a More Complex Understanding of Activism

Concluding this chapter, I aim to expand the classification that I made, i.e., aggressive, necessarily conformist, and everyday activism. Such a classification does not mean that these categories are fixed, static, and firmly separable from each other. They rather form a repertoire, which brings me to the theoretical framework of Swidler. Swidler argues that culture can be regarded as a tool kit or a repertoire, from which actors can select different pieces for constructing strategies of action, which refers to “persistent ways of ordering action through time” (Swidler 1986). In line with this framework, I argue that aggressive, necessarily conformist, and everyday activism are parts of an activism repertoire from which they can be chosen and strategically used depending on the context.

Mert, for instance, engages in aggressive activism when he makes a fuss in the Ministry of Health, wearing a U=U t-shirt. Yet, as an executive of a positive association, he tends to fashion the association’s projects in a way to seek funding from the corporations but not direct the negative attention from the state at the same time, which exemplifies necessarily conformist activism. In a hospital setting with a nurse, he changes the attitude of the inexperienced nurse towards HIV by making the experienced nurse explain to her how U=U works. In this case, he engages in everyday activism through this micro-scale attempt to politicize a seemingly de-politicized setting. Through the case of Mert, it is possible to see that the same actors can engage in these different modes of activism in response to the context around them.

In this chapter, it was exemplified how the positive associations can engage in each of these modes of activism. They organize street marches when the sociopolitical context allows, yet, they tend to engage in “sweet talk” and lobbying when there is pressure to attract funding and not being closed down. On social media, they perform everyday activism by taking care of the newly diagnosed PLWH, who feel

left alone given the lack of psychological care that they receive by the state and the stigmatization they face. This fluidity between these forms of activism suggests that such forms intertwine and constitute complex forms depending on the specific encounters and contexts. Therefore, while it might be analytically convenient to categorize modes of action, the complexity that this endeavor entails should also be regarded.

## 6. CONCLUSION

In this thesis, I explore the openings, limitations, and different forms of HIV activism with a particular focus on the positive associations in contemporary Turkey. I argue that the positive associations hold a significant activist capital enabling them to making their demands met through successful negotiations with the state against the conservative and authoritarian political climate that challenges HIV activism. Along with exemplifying biological citizenship, such an unexpected success is made possible through the efforts of HIV activists switching back and forth between aggressive, necessarily conformist, and everyday forms of activism. These forms of activism constitute a repertoire from which they can be strategically chosen and used depending on the context. Out of these three forms, necessarily conformist activism suits the current sociopolitical context the best. Opting for necessary conformism (Lüküslü 2013), the positive associations strategically adopt a more moderate stance towards the state regardless of their resentments resulting from the regression in sexual health rights in Turkey. This enables them to participate in decision-making mechanisms where many oppositional social movements struggle to survive, let alone making their demands met.

This thesis provides a more nuanced understanding of social movements through a close analysis of a growing activist field in Turkey, adopts an ethnographic lens to a highly medicalized field, and bridges academia and activism through making the voices of HIV activists and PLWH heard. However, in terms of sampling, this study does not sufficiently represent all actors involved in HIV activism in Turkey such as LGBTI+ organizations, sexual health associations, and doctor-led HIV associations. An ethnographic study that consists of fieldwork and in-depth interviews with these groups would better grasp the complexity of discourses and practices within the field of HIV activism. Additionally, as living with HIV can be a site of everyday activism as I tried to illustrate in Chapter 5, an ethnographic analysis of the daily experiences of PLWH regardless of their contact with NGOs would enrich the literature. As the majority of the fieldwork and in-depth interviews were conducted digitally due to

the COVID-19 pandemic, a future study based on a physical engagement with the activists, PLWH, and the settings where their activism and everyday struggles take place would provide a significant spatial analysis, thus conceptualize HIV activism more comprehensively.

Drawing on the bodies of literature on biological citizenship and social movements, this thesis aims to locate HIV activism within the contemporary health advocacy struggles and social movements in a broader sense and contribute to these bodies of literature. Nevertheless, since this research was conducted as an M.A. thesis with limited time and financial resources, the other health advocacy struggles and social movements have not been covered in depth. Further studies that focus on the interrelations between HIV activism and other patient activisms, women's and LGBTI+ movements would better demonstrate the particularities of HIV activism along with tracing its parallels with other social movements. The solidarity attempts between these targeted groups is also significant to analyze within the given sociopolitical context of Turkey, as they constitute new forms of activism. Additionally, a more thorough geographical focus is needed for future research, locating HIV activism in Turkey within the context of the social movements in the Middle East and the rest of the world. Despite the given theoretical and methodological shortcomings, this M.A. thesis is part of a solidarity attempt with HIV activists and PLWH with an aim of contributing to a compelling rights struggle within academia and beyond. The unexpected success of HIV activism in Turkey despite its limited financial and social resources within an authoritarian gender and sexuality regime reveals the potential for the other advocacy struggles to make a change.

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## APPENDIX A

Figure A.1 Participant information

<b>Name</b>	<b>Age</b>	<b>Education</b>	<b>Occupation</b>	<b>City</b>	<b>Affiliation with the Associations</b>
Eray	38	bachelor's degree	advertiser	İstanbul, Berlin	activist in the Living with HIV Association, 1 December Association
Batuhan	44	bachelor's degree	tourist guide	Antalya	counselee of the Living with HIV Association
Sevgi	40	high school graduate	healthcare worker	İstanbul	activist in the Living with HIV Association, HIV Positives Association
Oğuz	21	undergraduate student	translator	Ankara	counselee of the HIV Positives Association
Nilay	34	PhD candidate	academic	İstanbul	counselee of the HIV Positives Association
Olca	50	bachelor's degree	artist	İstanbul	activist in the Living with HIV Association, HIV Positives Association
Mert	38	master's degree	programmer	İstanbul	activist in the 1 December Association
Bahadır	22	undergraduate student	sales manager	Bursa	counselee of the HIV Positives Association
Ali	67	bachelor's degree	engineer	İstanbul	activist in the Living with HIV Association
Süleyman	45	primary school graduate	plumber	Antalya	counselee of the Living with HIV Association, HIV Positives Association
Vagif	26	master's student	NGO professional	Ankara	activist in the Positives United Initiative