Stigmatization, discrimination, violation of autonomy, and compromised confidentiality: A descriptive qualitative analysis of the lived experiences of people living with HIV in healthcare settings in Turkey

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Abstract

Background: Human immunodeficiency virus (HIV) infection rates have been gradually increasing in Istanbul, Turkey. Many people living with HIV (PLWH) in Turkey encounter difficulties such as adapting to a chronic disease and maintaining continuous access to healthcare services. In this study, we explored the challenges PLWH face in their daily lives and understand their perceptions of themselves, healthcare professionals, their social spheres, and healthcare services via their expressed lived experiences in the healthcare setting.

Method: Individual semi-structured in-depth interviews were conducted face-to-face with 20 people living with HIV in Istanbul. All the interviews were voice-recorded and transcribed verbatim except one, upon participant request, for which the interviewer took notes. These logs and the interviewer's filed notes were analyzed thematically using the inductive content analysis method. Thematic pattern tables showing the relations of relevant contexts, main themes, sub-themes, and codes were then formed.

Results: The results highlighted the following themes: problems with patients’ autonomy, failure to protect patients’ confidentiality and privacy of personal health data, spouse/partner notification issues, the negative effect of living with HIV on their perception of themselves, stigmatizing and discriminatory attitudes intrinsic in healthcare professionals’ approaches, and their struggle to deal with such approaches. Our participants’ experiences suggest that PLWH may face multi-dimensional challenges that directly and negatively affect their lives, identities, relationships, and social status in Turkey.

Conclusion: This study showed the complex and shifting nature of stigma experiences. Healthcare professionals’ discriminative or inappropriate attitudes and customs prevailing in healthcare institutions impair PLWH’s utilization of healthcare services. Additionally, structural factors such as social pressure, societal ignorance about HIV, limited access to HIV prevention, and present barriers to HIV care and support originating from current regulations contribute to these challenges. Based on these results, we argue that it is necessary to raise healthcare professionals’ and society’s knowledge and awareness concerning HIV, to train qualified community service personnel providing assistance, care, support, and education to patients, to establish a well-functioning referral system, and to develop national policies to establish appropriate partner notification services. We believe that such interventions should begin to address the social, economic, and structural factors that drive stigma.

Background

Turkey is among the regions of Eastern Europe and Central Asia in which cases of human immunodeficiency virus (HIV) significantly increased between 2005 and 2014 (1). Although it is one of the countries where the prevalence of HIV is low, recent data published by the Ministry of Health (MoH) show that it is surging, and people with HIV are becoming more and more visible the society (2). According to the MoH records, the incidence of HIV infection was first recorded in 1985, and the total number of people living with HIV (PLWH) was three. Twenty years later, the official number of PLWH in Turkey significantly increased to 168. Exponential growth has been observed over the last few decades in Turkey, and the MoH most recently reported the total number of PLWH to be 26,164 (3).
The first relevant legislative regulations were put in place in 1985 when the first HIV case was recorded. Notification of HIV cases to the MoH has been mandatory since then. Thus, HIV testing was made a mandatory prerequisite for health-related applications, such as for transfusion of blood and blood products in 1986 and for tissue/organ donation and registration of sex workers in 1987. In the following years, HIV testing was included in the mandatory pre-marital tests, in tests performed during pregnancy, and in the screening procedures before surgical operations (4). The implementation of the notification code for reporting HIV and acquired immunodeficiency syndrome (AIDS) has been adapted to protect patient privacy since 1994 (2). Free voluntary counseling and test centers for HIV were established in Ankara, Istanbul, Izmir, and other provinces in 2005 (5). The MoH published a comprehensive diagnosis and treatment guide in the same year. The corresponding legislative regulations have been continually published by the MoH and are mainly limited to prevention and protection measures. In other areas related to HIV, such as education, social support, and criminal liability, no specific regulations exist. In other words, HIV and AIDS-related issues are not mentioned in Turkish Law, except for in MoH circulars (4). As the recorded HIV incidence is relatively low in Turkey compared to hard-hit countries, both policymakers and the community do not seem to consider HIV as an emerging health issue (6).

The financial and emotional burden that HIV lays upon a person differs from other transmissible and chronic illnesses (7). Moreover, the prevailing biases toward PLWH seem to originate from the fact that the illness was mostly observed in men who have sex with men (MSM), sex workers, and intravenous substance abusers in its early years of occurrence (8), (9). PLWH may anticipate and experience stigma from different sources, such as friends and family, sexual partners, coworkers, strangers, healthcare professionals, and institutions. Healthcare professionals' discriminative attitudes toward PLWH may cause distrust between patient and physician and, ultimately, unfavorable results such as poor adherence to the treatment process and discontinuation of medication (10). Similarly, a growing body of literature suggests that being subjected to discrimination both in health institutions and in social spheres imposes an emotional burden on a person, which might lead them to refuse treatment and thus put their physical and psychological health at risk (11), (12). On the other hand, one can be fired from their job if they are accused of carrying HIV or having AIDS, and this poses a significant financial challenge for that person (13). For instance, in studies from China and the Netherlands, employers were found to be reluctant to hire people with HIV (14), (15).

PLWH have been exposed to stigmatization and discrimination since the occurrence of the HIV epidemic both in Turkey and throughout the world. This phenomenon negatively affects PLWH's access to healthcare services and impairs public health by causing inequality in terms of both the frequency and the quality of the services they receive (16). Research has shown that in places with low HIV prevalence, there is a more intense strain on PLWH due to fear of HIV (17). In their study on the causes of HIV-related stigma toward PLWH, Koseoglu et al. (2020) showed that more than half of physicians and nurses did not have any specific training on HIV-related issues including stigmatizing attitudes toward patients. Additionally, the majority of the participants believed that HIV can be transmitted by handshaking and/or via droplet spread (18). Similarly, in another study, healthcare professionals were found to be prejudiced regarding HIV-related issues and lack accurate and adequate knowledge about the disease, such as contagiousness, mode of transmission, and sociodemographic risk factors (19). In their study, Kose et al. (2012) showed that PLWH in the third largest city in Turkey, Izmir, experienced problems at work, in their social relationships, and regarding access to healthcare services (20). Furthermore, in Turkey, HIV-related non-governmental organizations (NGOs) have periodically published reports of human rights violations. For example, according to a report published by the Positive Living Association
(PLA) on the violations of rights among PLWH from 1985 to 2007, it is noted that PLWH are subject to discrimination in health services, in family/social surroundings, and at work (21). In another report by the Pozitif-iz Association[1] covering human rights violation incidents between 2018 and 2019, it is mentioned that PLWH have limited access to healthcare and experience violations of their privacy in healthcare settings (22). According to the latest report published by PLA, the most common way of being exposed to discrimination is through the confidentiality of their personal information being compromised (23).

Campaigns directed by The Joint United Nations Programme on HIV / AIDS (UNAIDS) such as 90-90-90[2], Fast Track[3] and Undetectable=Untransmittable[4] have led to significant progress in terms of raising public awareness and prevention of the epidemic (24), (25). However, in many countries, PLWH are still subjected to HIV-related stigma and discrimination (26), (27), (28). Although it has been well documented that Turkey has a similar trend (29), (30), (31), there are few studies on PLWH's perception of their diagnosis and treatment processes, their relationship with healthcare professionals, and their experiences in healthcare environments. This study focuses on PLWH's perspectives on their illness experience while receiving healthcare services and explores how their sense of self is influenced after being labeled as “ill” as well as how their relationships with healthcare professionals, their immediate circles, their thoughts about their social status, and their lives in general are influenced during and after being diagnosed with HIV.

[1] The Pozitif-iz Association is a non-governmental organization that aims to strengthen PLWH and their families in physical, psychological, and social regards (81).

[2] In 2016, the United Nations General Assembly’s Political Declaration on Ending AIDS submitted nations to the 90–90–90 targets, which plan to bring HIV testing and treatment to most individuals living with HIV before the end of 2020 (82).

[3] The Fast-Track approach implies utilizing advancement to grow administrations, to more readily address individuals' necessities and viewpoints, and to shine a spotlight on the areas and populaces with the most elevated HIV trouble (83).

[4] Undetectable = Untransmittable (U=U) is a movement that demonstrates how to stop the sexual transmission of HIV (84).

Methods

This study is a descriptive qualitative analysis of the lived experiences of PLWH in healthcare settings in Istanbul, Turkey. We asked our participants to share their accounts regarding their experiences with physicians and other healthcare professionals as well as their families, friends, and colleagues and with healthcare institutions' bureaucratic bodies and insurance companies in the process of being informed about their diagnosis and the planning of their treatment. We examined their perceptions by thematically coding these in-depth interviews conducted by one of the researchers (GS).

Participant Recruitment
A group of PLWH constituted the research population. Those aged over 18 years and living with HIV for more than a year were included in the study. Living with HIV for more than a year was determined as a recruitment criterion because we expected our participants to have gone through the time-consuming processes of testing, diagnosis, and onset of treatment during which patients tend to face more problems. The rationale behind this preference is that we expected them to have reached a certain phase of the illness where they could view their experiences from a distance without having to deal with the initial difficulties, such as receiving bad news and adapting oneself to an unexpected and/or shocking situation.

In this study, we used the snowball sampling method. This method is considered applicable when “there is no accessible sampling frame for the population from which the sample is to be taken” and creating such a sampling frame poses complexity. Additionally, in this sampling method, “the researcher makes initial contact with a small group of people who are relevant to the research topic and then uses these to establish than are samples based on probability sampling” (32). Similarly, in our study, we could not define an easily accessible sample group, as our research necessitated reaching vulnerable people. Therefore, initially, we contacted NGOs such as the Human Resource Development Foundation[1], the Pozitif-iz Association, and physicians specializing in clinical microbiology and infectious diseases who work on HIV to reach PLWH who might be willing to participate in our study. After recruiting these first-order participants using the contact information they provided, we reached other PLWH who met our criteria (the second order). Informed consent was obtained from all individuals who agreed to participate in the study. We did not pay any financial compensation to the participants.

**Data Collection**

The researcher conducting the interviews (GS) was the chief researcher in this study, which she conducted within the scope of her master's thesis. She is especially interested in vulnerable groups such as the PLWH. Although she was a freshman, she interviewed participants attentively to minimize the risk of bias. Nevertheless, after the completion of the interviews, she reported that she might have been affected emotionally by some of the stories told by the interviewees. Additionally, some participants conveyed that they had not been sure if she really understood the cases they were telling. However, she does not think that she made any major mistakes that would lead to a significant decrease in the data quality while conducting the interviews.

GS contacted the participants directly and performed face-to-face interviews in various places such as clinics, cafes, and participants’ homes. Only one of the participants preferred to be interviewed via Skype. One person refused to participate in the study because she/he had an issue of distrust regarding the services she/he received at the institution with which the researcher was affiliated at that time. GS took field notes during and after the interviews about the surroundings, the participants’ modes, and unexpected interruptions.

The interviews lasted 25 to 80 minutes and 51 minutes on average. Repeat interviews were mostly unnecessary. In cases in which the researchers thought that it might be necessary, they preferred to avoid doing so if possible because it was too time- and energy-consuming to arrange a second interview with the same person.

An interview guideline form, developed through a literature review, was used for the interviews. Based on the results of three qualitative studies—(20), (34) (35)—we discussed interview questions with sociology specialists and modified them accordingly. The in-depth interview guideline was carefully designed to ensure a logical flow
and appropriate expression of questions so as to minimize any potential disturbance on the participants’ side. The key interview questions, which sought information about participants’ experiences, emotions, and actions, were as follows:

- How did you find out you were positive after the tests were verified?
- How were you notified?
- How did you feel after the physician notified you?
- Was your partner with you at that time, and were they notified of the test results?
- Did you want to tell your immediate circle about the diagnosis, and what was their reaction?
- What reaction do you encounter when you go to a hospital for a health problem?

Recruitment proceeded until 20 participants had been interviewed. After the analysis of the interview logs, it was seen that data saturation had already been achieved. In other words, it was seen that no new themes had emerged; thus, no further recruitment was necessary.

Data Analysis

The voice recordings taken during the interviews were transcribed verbatim into raw logs, and each participant was assigned a protocol number. The raw logs were analyzed thematically by using the inductive content analysis methodology (36) by two researchers (GS and MVK). The coding was carried out manually, that is, without the use of software. The analysis includes seven steps, which are presented in Table 1. First, a rough reading of the raw logs was conducted to gain a general understanding of the interviews (Step 1). Next, expressions regarded as relevant answers to the key questions were sorted and clustered (Step 2). These responses were reviewed and matched via suggested themes (Step 3). The researchers discussed and structured the themes by first cross-checking and then cross matching their findings to reach a consensus (Step 4). Themes, sub-themes, and codes were determined, and tables were created. Initially, it was questioned whether some concepts could be clustered together according to their meaning-closeness and, if so, whether these clusters could be classified under the main themes (Step 5). Afterward, the relationships between these elements were defined, and semantic homogeneity was constructed by attempting to reconstruct the data on macro and micro scales. On a macro scale, a contextual framework was attributed to every distinct semantic group. On a micro scale, the possible manifestations of those relevant experiences in the individuals’ lives were noted (Step 6). The findings were interpreted in comparison to the data obtained from prior relevant studies to gain a comprehensive understanding (Step 7).

[1] The Human Resource Development Foundation is a non-profit, non-governmental organization that contributes to the solution of health, education and employment problems which have a negative effect on the economic, social and cultural development of human resource (85).

Results

Twenty people were interviewed (19 in person and one via Skype) between 18 October, 2017, and 29 April, 2018. The participants were composed of five women and 15 men, representative of Istanbul, ranging in age from 27
to 55 years. Two married couples were interviewed as a couple upon their request. Research participants had varied social status profiles. They had been living with HIV for 1.5 to 20 years. The majority of them were single and associated with NGOs active in the field of HIV-related issues. Since the focus of the research was PLWH's experiences in their HIV diagnosis and treatment processes, the participants’ sexual orientation was not questioned, and only their biological sex was taken into account. The number of male participants was significantly higher than that of female participants. However, the distribution of our participants by gender was in line with the data on the distribution of PLWH in Turkey by gender[1]. A summary of the demographics of the study participants is given in Table 2.

a GHI: Denotes the insurance that finances employees’ healthcare expenses and is used in state hospitals and health institutions; the unemployed may also have this insurance on the condition that they pay the insurance charges; covers diagnosis and treatment of HIV (2).

b PHI: The customized insurance type determined in accordance with certain limits and general requirements and used for healthcare expenses; does not cover diagnosis and treatment of HIV (33).

The type of health insurance that our participants benefit from varies. All of the participants asserted that they do not use their private health insurance (PHI) for HIV treatment since this type of insurance does not cover HIV treatment and/or insurance companies can notify their employers of their HIV status. One of the participants was a foreigner and did not have any health insurance.

The results obtained from the thematic analysis were examined in seven contexts, which were attributed to the clusters of themes while mapping the thematic pattern (analysis step 6)[2]: (i) physician-patient communication around the diagnosis, (ii) being diagnosed with HIV, (iii) impact of HIV diagnosis on patient’s life, (iv) PLWH’s relationship with their physicians, (v) PLWH’s relationship with their spouses/partners, (vi) PLWH’s experiences in healthcare settings, and (vii) PLWH’s struggle with the disease. The contexts, main themes, sub-themes, codes, and functions/results are shown in Tables 3–9.

Physician-Patient Communication around the Diagnosis

Two main themes, which concern physicians’ reluctance to inform the patient fully and their different approaches while doing so, are classified under this context (Table 3).

Withholding Information from the Patient: The majority of the participants stated that they were tested for HIV without their knowledge when they went to the hospital for other health problems or to get an official health report required from every couple before marriage. Moreover, they asserted that they were not informed about preliminary test results when they were asked to give a blood sample for verification, and they thus felt that healthcare professionals withheld information from them.

“We need to redraw blood from you” And I asked why? They said they couldn’t tell it at that moment. It was exactly like that. I said “You have to tell me because you requested me to come again. You want to draw blood, it’s my right to know.” “No, we don’t want to turn your stomach by saying it now.” That’s exactly what they said. (Male, 34 years old, 3 years since HIV diagnosis)
**Informing the Patient about Diagnosis:** In addition, notifying the patient on the phone, informing the patient immediately after diagnosis about the potential HIV-related problems, and not giving whole and complete information or giving wrong information were deemed as *inappropriate approach* for two rationales. First, since such difficult conversations are a form of breaking bad news, the physician should take adequate time to talk to the patient and should do so in person unless there is an obstacle precluding this option. Second, for the same reason, the physician should not give all of the information to the patient at once but, rather, wait for her to digest the bad news before continuing with further details.

[The doctor] told me that I should hide this from my family, I shouldn’t be so enthusiastic about finishing school, and because of this, my work life could be affected. He even advised me to suspend school for some time until I pulled myself together. I was shocked but still had the impression that what he said was not so logical, but horrifying. (Male, 28 years old, 6 years since HIV diagnosis)

Moreover, informing the patient in the presence of family members and not acting attentively while giving information in the eyes of the participants were categorized as *inattentive approach*.

Two young doctors came to my room and told me the diagnosis when my mother was there. Now, I think that it's a very serious violation of rights. I may or may not want to share it with my mother. I don’t think adequate attention is paid to the patient’s confidentiality. (Male, 28 years old, 3.5 years since HIV diagnosis)

On the other hand, physicians preferring an isolated environment to notify the patient and to inform them about the test results were evaluated as *attentive approach*.

(...) [the doctor] was so friendly and answered my questions one by one by building such a healthy relationship and informed me in such an appropriate manner that I realized guidance like this relieved me a lot. I mean, I saw how precious it is to have a good relationship with the doctor and to get counseling services during the diagnosis. (Male, 28 years old, 3.5 years since HIV diagnosis)

**Being Diagnosed with HIV**

Participants’ experiences related to blaming oneself after the diagnosis, experiencing hardship in confronting the disease, and fear of not being taken care of due to being diagnosed as HIV+ were the main themes we examined in this context (Table 4).

**Participants’ Feelings:** It was seen that the participants’ main source of information about HIV was the news on television and in newspapers. Some of the participants stated that they had never thought they would have AIDS since, according to their view, it is a disease that homosexuals and sex workers have. On the other hand, the participants who did not share this opinion and those who had proper knowledge of HIV tended to blame themselves as they failed to protect themselves from the virus.

(...) over the years so many pieces of information accumulate in your head, in your mind. Out of the blue, I pictured a scene: a famous journalist is bargaining with a blonde female sex worker, she says she has AIDS. (...) I told myself that I was neither blonde nor a sex worker; this couldn’t be possible; such a thing wouldn’t happen to me. (Female, 44 years old, 14 years since HIV diagnosis)
You experience a huge intrinsic stigma. “How can it be possible when I have so much knowledge about it?” You keep asking yourself. You get mad at yourself and blame yourself. (Male, 28 years old, 3.5 years since HIV diagnosis)

The participants did not want to acknowledge their condition for a long time after the diagnosis; some even refrained from seeking treatment. Moreover, due to the discrimination instances they had known of in healthcare institutions, some participants developed fear of being rejected by hospitals when they needed to undergo an operation.

I don't know what to do if I need to undergo an urgent operation. I have concerns. (...) Since I'm also a physician, I'm aware of some things. I know there are persons who have not been operated on. This could happen to me, too. (Male, 41 years old, 2 years since HIV diagnosis)

Impact of HIV on Patient's Life

In this context, changes occurring in the participants’ lives and in their relationship with their family members and friends constitute the main themes (Table 5). Their concerns center on whether to share their diagnosis with others, adherence to treatment, decisions regarding sexual activity, and issues surrounding parenthood.

Changes Occurring in Patient's Life after Diagnosis: One important change in participants’ lives after their diagnosis was ceasing their sexual activity. In addition, participants tended to isolate themselves from social interactions considering the possibility of being exposed to discrimination and fearing transmitting the virus to other people because they did not know the modes of its transmission.

(...) I haven't had any [sexual intercourse] for 14 years. I don't want it. Anyway, I can't find anyone like me. It's difficult, especially in this country. (Male, 53 years old, 15 years since HIV diagnosis)

"Why bother? I'll die in any case, so I should die without disgracing myself,” I said to myself. If the doctor also has this projection [that I will die], if the one who is supposed to support me treats me badly, how can I explain it publicly? I don't have to explain it, though. If my life is bound to end, it will. Then, I didn't leave home for several days. I thought I could change the city I lived in; then no one would know me. And I left the city. (Male, 39 years old, 3 years since HIV diagnosis)

Changes in Family Dynamics: The participants stated that their family relationships were affected either positively or negatively after they shared their HIV status with family members. Some participants expressed that their families were supportive in this process.

How well they looked after me and how much attention they paid to me... (...) I thought had to get better. I almost went crazy seeing them feeling sorry for me. It's the same now; they call me every minute. They tell me not to worry no matter what happens. Thanks to them... (Male, 34 years old, 6 years since HIV diagnosis)

Four of the participants stated that their families ended their relationship with them and put the blame for contracting the disease on the lifestyles they pursued.

I came back to Turkey so that my family wouldn’t find out. They found out later, of course. They told me “You’ve been changing lovers all the time; you’ve been on the loose; you deserved it.” I'll never forget that. (Female, 40
years old, 20 years since HIV diagnosis)

Some participants, on the other hand, decided not to share their diagnosis with their families.

I didn't want to share it. Well, it was because they don't have awareness of this disease and haven't encountered it before, and they aren't healthcare workers. I mean, everything is under control; what needs to be done is being done at the moment. I didn't want to upset them. (Male, 41 years old, 2 years since HIV diagnosis)

**Changes in Friendship Dynamics:** It was observed that the participants’ decision to disclose their HIV status was influenced by social dynamics. Although most of the participants said they were supported by their friends after diagnosis, several stated that their friendships ended and their friends avoided close contact with them.

People around me don't know it either. I don't want it to be known. I don't want it because (...) someone who has no idea about the disease would say “Look, he has AIDS!” In the society we live in, even that happens; they do not want to shake hands with us. So, I think no one needs to know it. (Male, 34 years old, 7 years since HIV diagnosis)

I lost only one of my friends. He was a really close friend that I really liked. He said, “Dear, I'm so sorry too, see you later.” But he never called again. How long? It's been about ten years since we last met. There wasn't any problem between us. (...) He should have called to see if I died or not. I got really upset, but, of course, there was nothing to do. (Male, 39 years old, 12 years since HIV diagnosis)

The majority of the participants asserted that they had not had any problems with their friends, and their illness had not affected their relationships.

When I was in the hospital, I had lots of visitors and phone calls. It seems that I had lots of people who loved me. I always had flowers in my room, lots of calls and messages on my phone. (Female, 44 years old, 14 years since HIV diagnosis)

**PLWH's Relationship with the Physician**

The physician-patient relationship was found to be a determinant factor in patients’ perception of their illness process. The relevant themes are presented in Table 6.

**Physicians’ Attitudes toward the Patient:** Participants stated that the physicians’ positive or negative attitudes toward them influenced their treatment processes and led to changes in their lives after the diagnosis. They deemed the physicians’ misinforming them about the treatment process and medication use, estimating their survival time, and not establishing open communication with them as indicative of negative attitudes.

They said the situation was new and my immune system was very strong, so there was no point in starting medication then, and they suggested waiting for a while. After some time, I saw on the Internet that medication should be started immediately after the diagnosis. I went to see another doctor, and he said that delaying medication was pointless. I wish they started it right away. Afterward, I underwent a lymph node surgery. I might not have gone through that if I had started medication. (Male, 27 years old, 1.5 years since HIV diagnosis)
[The doctor] said he could keep me alive for another 15 years. “What do you mean?” I asked. I was 22 then; add 15, it makes 37. I imagined not being able to see my 40th birthday. I felt so bad. I thought of my mother. I left the room immediately. I was baffled and didn't know what to do. I felt very upset. (Male, 34 years old, 7 years since HIV diagnosis)

In addition, the participants also stated that certain behaviors on the part of physicians caused them to feel humiliated.

“You sit down there,” she said to me. She opened the windows and the door, moved away from the desk, and took a piece of paper. It was only 15 minutes since I got the diagnosis. “How old are you? Are you homosexual?” she asked me directly. Then, she asked if I drank alcohol, smoked, had a nightlife, had had a lot of partners in the past six months... Well, at first, I had a humming noise in my head, but then it faded, and it turned to curiosity; I wondered what this woman's intention was. (...) I remember her reopening the window when it got closed a couple of times. (...) Then, I left the room and tore the test results into pieces. (Male, 39 years old, 12 years since HIV diagnosis)

In this context, several participants stated that instead of making a mutual decision, they followed the physicians’ orders to avoid any problem from occurring. One of them, for example, said he could not object to his physician's request to take his photo just because he was a physician.

He asked if he could take my photo, and I asked why. “As part of the follow-up; to keep record of your initial state, the treatment process, and afterward,” he said. I asked if I was in a bad state at that time and why he put it as now, before and after. He told me that he wanted to follow up on his patients visually. (...) He took a photo of me, which made me crazy, but I thought I shouldn't oppose; after all, he was a doctor. (Male, 39 years old, 3 years since HIV diagnosis)

Most of the participants asserted that physicians and other healthcare professionals working at infectious disease clinics treated them sympathetically, provided professional guidance to them regarding their future life, and referred them to NGOs active in the field.

“Look,” he said, “we are here with you whenever you have a medical problem.” He handed me a piece of paper in which there was information about the foundation. He said, “You can contact them; they have a good counseling service. You can find any information you need there.” Then I received relevant information from them. (Male, 34 years old, 3 years since HIV diagnosis)

Both the nurses and doctors were very friendly. “Don’t worry, I hope you’ll get better, take good care of your children, look after yourself.” (...) I feel so depressed and confused, but I can talk to doctors about my worries. (Female, 34, 8 years since HIV diagnosis)

**PLWH’s Relationships with Their Spouses/Partners**

According to the accounts of our participants, problems regarding how PLWH’s spouses/partners are notified of their diagnoses emerged as a prominent issue. As seen in Table 7, this is done in a variety of ways, some of which could be quite controversial.
Spouse/Partner Notification After HIV Diagnosis: As stated by the participants, various methods were used for spouse/partner notification. They favored some of these methods, while they thought that others negatively influenced their relationship with their spouse/partner. For example, they were pleased when physicians encouraged and supported them to notify their spouse/partner. They also appreciated when physicians informed their spouse/partner together with them.

I said [to the doctor] that I wanted to break up with my fiancée since I couldn’t tell her I had such a disease. He said, “just bring her over, let’s talk, then maybe she accepts.” I did so, and he talked to her. If he hadn’t talked to her, perhaps we would not have been able to get married. Now, my wife is the only one that I lean on. (Male, 34 years old, 3 years since HIV diagnosis)

One of the problems expressed by our participants was the inability to notify their partners. For example, single participants stated that they did not know exactly when they had been infected and, thus, could not contact all of their ex-partners. Moreover, those with multiple partners said they did not know the people they had had sexual intercourse with very well, so it was difficult to contact them. In addition to the shock of being diagnosed with HIV, there was an “infidelity” aspect in the case of married participants. Therefore, they feared the possible breakup of their marriage/relationship, which deterred them from notifying their spouse/partner.

Well, I had sex with another woman. I got this from her. Had I known, would I have done it? I didn’t tell my wife. I have two daughters. I didn’t tell her so as not to break up my family. After many years, she found out, but she wasn’t infected. After all, she divorced me anyway. (Male, 48 years old, 5 years since HIV diagnosis)

On the other hand, some participants stated that their spouse/partner was notified by their physician without their knowledge, which damaged their relationship. Moreover, one participant told his wife that he had had another illness to hide the actual diagnosis.

No, I didn’t know. (…) I mean I wasn’t hiding it, but I should have told her myself. [The doctor] told it to my girlfriend. (…) I’d rather have told her myself, instead of the doctor, and then we talked what was what anyway. (…) She got scared. We had a small crisis, but we got over it. (Male, 34 years old, 7 years since HIV diagnosis)

I went abroad for business and stayed there for three years. They told me I contracted HIV there. Then, I came back here. (…) To be honest, we [I and my doctor] told my wife that I had hepatitis. We had her and the kids tested for HIV as if they were at risk of developing hepatitis. Thank God, the test results were negative. And that’s it. But my prick conscience still aches. (Male, 35 years old, 3 years since HIV diagnosis)

PLWH’s Experiences in Healthcare Settings

The experiences of the participants in this context are presented via two main themes: confidentiality and discrimination (Table 8).

Failure to Protect Confidentiality: It was deduced from the statements of all the participants that their confidentiality was not fully protected in healthcare environments. One problem in this regard is the failure of the healthcare system, health databases, and PHI companies to take the necessary precautions to protect the confidentiality of the personal data/information of people receiving services from them.
Before I shared it with my friend, he had already shared it with another friend of mine because he could learn about my health situation by logging in to the hospital database system no matter which unit of that hospital he was working at. (...) Well, this means if you have any acquaintances working there, they can access those data. (Male, 28 years old, 3.5 years since HIV diagnosis)

I have private health insurance as well, but I didn’t use it for this illness because they immediately notify the institution where I work [about my HIV status], so I use my general health insurance for this. (Male, 34 years old, 3 years since HIV diagnosis)

In addition, participants stated that healthcare professionals did not pay enough attention to protecting patient confidentiality and that they frequently faced this problem, especially in physicians’ clinics and pharmacies.

Naturally, a friend of my father found out [my HIV status] as he was the head of the internal diseases clinic, and he told it to my father (…) I think it’s a very serious violation of human rights, right to privacy. (Female, 44 years old, 14 years since HIV diagnosis)

There were two other customers waiting next to me. I was sitting on a chair when the pharmacist asked the pharmaceutical technician to bring three boxes of X by shouting out the names of the drugs. Then, speaking loudly again, he said “Your medication is ready, Mr. Y.” The one sitting beside me stood up, and I understood at that moment that he was living with HIV. (Male, 28 years old, 3.5 years since HIV diagnosis)

It’s like this… For example, when you go in the doctor’s room, you see lots of files on his desk, files that are left open and with the patients’ names, CD4s, and visible test results. I see it very often. (...) People add me on Facebook, for example, saying that they had seen my file on the doctor’s desk. We get treatment from the same doctor, and they add me. (Male, 28 years old, 6 years since HIV diagnosis)

Moreover, the participants expressed that some health professionals ask questions such as “how did you get the virus?” out of curiosity, and they felt this reflected an unprofessional attitude.

I went to see a psychologist for the first time. Anyway, I was talking to her, telling her about it. She asked me how I got the virus. People are very curious about it. What’s it to you! (Female, 42 years old, 2 years since HIV diagnosis)

**Being SubJECTED to Discrimination**

The main concerns of the participants in this regard are healthcare professionals’ reluctance to operate on PLWH, taking excessive precautions before any medical intervention, scaring the patients, not seeing them as people, and feeling pity for them.

I went there for a dermoid cyst problem. (...) but I said I was HIV positive. He said, “I don't operate on HIV positives.” “Why not?” I asked him, “Do I have a different chromosome structure?” He said they wouldn’t be able to provide the necessary environment to prevent infections. I didn’t get it. I sensed that he was abstaining. But I didn’t buy it—tell another lie! (Male, 28 years old, 6 years since HIV diagnosis)

But when they came into my room that morning for routine controls after my diagnosis was explained, none of them looked me in the face. “From now on, I'll never ever touch anyone without gloves,” one of them said and
pulled up her gloves. At that moment, I thought inspectors from the Ministry of Health had come to the hospital, but then of course, I understood that she was talking about me. (Female, 44 years old, 14 years since HIV diagnosis)

In addition, most participants that expressed relevant regulations should be developed so that PLWH could receive healthcare services from health institutions just like other patients without being subjected to any discriminatory acts and that healthcare professionals should be more attentive to behaving in a manner showing understanding of their condition.

I heard that only this hospital offers dialysis treatment to patients like us, which means that patients with HIV virus are deprived of this service. In the whole city of Istanbul, only this hospital and, as far as I know, another one in Maslak provide dialysis treatment to us. Can you imagine? A person living in Tuzla or Kadikoy, for example, has to come all the way to this hospital or to the one in Maslak. How strange! (Male, 55 years old, 1.5 years since HIV diagnosis)

As I said before, I went to a hospital, a private one, after I came back. There, a doctor said, “Don’t tell anyone about your illness, don’t go to state hospitals, and don’t give blood sample because they would fire you once they found out.” I felt horrified. Where should I have gone? (...), then I didn’t give a blood sample no matter who requested it. I lived like this for three years. (Female, 34 years old, 8 years since HIV diagnosis)

Some of the participants also stated that they think healthcare institutions do not want to provide service to them and that healthcare professionals working at private healthcare institutions are not sufficiently knowledgeable about HIV.

I had an epidermal cyst, and in order to have it removed, I went to the surgery clinic of the hospital where I get HIV treatment. They told me that they were too busy and referred me to another hospital. I went there (...) They said that providing healthcare services to such patients is not welcomed at their hospital. They told me “Go the hospital where you get treatment for it and have yourself operated on there.” (Male, 41 years old, 11 years since HIV diagnosis).

**PLWH’s Struggle with the Disease**

The participants used a variety of coping strategies for the problems they faced in their diagnosis and treatment processes (Table 9).

**Patients’ Protecting Themselves against Adverse Consequences of the Disease:** It was derived from the participants’ accounts that they tended to hide their HIV status in healthcare settings and in their social sphere so as to avoid negative reactions from both healthcare professionals and other people.

Of course, when I go to a dentist, I don’t tell him, “For your information, I have this.” So, I don’t experience such things. I don’t explain that I underwent this when I go to an ear, nose, and throat clinic for a cold or flu, etc. I don’t have to! I just explain the complaint for which I go there, and they do what they need to do. (Male, 27 years old, 1.5 years since HIV diagnosis)

Some of the participants stated that they attempted to find a new healthcare professional when they faced a problem, strived to stand up for their rights, and received help from foundations providing support to PLWH.
(... only after some struggle, after going to the chief physician and telling him that I had been rejected, and with his intervention, was I able to have the surgery performed. (Male, 41 years old, 11 years since HIV diagnosis)

One evening, I had a problem with my medication. There was no one at the hospital that we could reach at that moment. It was a state hospital; whom could I call? I wasn't getting treatment from a private hospital, so I didn't have any contacts there either. What do we do in such cases? We call the foundation. (Male, 34 years old, 3 years since HIV diagnosis)

[1] The rate of females and males living with HIV was found to be 20.1% and 79.9%, respectively (3).

[2] Please note that these contexts are not pre-determined. In inductive content analysis, the emerging themes are not classified according to the existing assumptions or evidence.

**Discussion**

In the present study, PLWH's perceptions of their relationships with healthcare professionals, family members, and friends as well as their accounts of the changes in their lives were analyzed based on their lived experiences at the onset of their illness. In light of our findings, the discussion was centered on the following themes: autonomy and obtaining informed consent; the impact of HIV on personal and social life; the right to privacy and private life; responsibility for third person and spouse/partner notification; and discrimination and stigmatization in the healthcare setting. The context of this argument is societal determinants, including the healthcare environment and the general perception of PLWH in Turkey.

The majority of our participants found out that they had HIV when they went to the hospital for other health problems or to get medical reports required before marriage. Our findings suggest that the participants experienced a shock at this stage because the test was performed without their knowledge and the results were delivered to them without any accompanying counseling services. According to the results of a survey study carried out by Gokengin et al. (2017) on PLWH in the cities of Istanbul, Ankara, and Antalya, it was demonstrated that 52% of the participants were tested for HIV without their prior knowledge and consent. Moreover, it was found in the same study that 77% of the participants were not offered any counseling services during the testing process, while 21% of them received it after diagnosis and 2% of them were offered such a service both before and after diagnosis (34). In another study, the epidemiologic and clinical features of patients with HIV infection and AIDS were investigated over 3.5 years. Sixty patients (44%) had clinical signs and symptoms of HIV and AIDS were investigated over 3.5 years. Sixty patients (44%) had clinical signs and symptoms of HIV and AIDS, while 76 (56%) were found to be HIV-positive during screening tests. The authors conclude that individuals having voluntary HIV tests is crucially important for both the patient and the community (37). However, there are obstacles to fulfilling this objective. The shortcomings in the healthcare system in Turkey, such as the restricted time allocated to patients, heavy workload of physicians, lack of professional experience in breaking the bad news to the patient, and lack of competence in communication and interpersonal skills may create certain problems in informing and notifying the patient (33), (38). The lack of general awareness and knowledge and the stigmatization of PLWH in both Turkey and other countries can be considered other barriers to HIV testing.
and diagnosis (34), (39), (40), (41). Regardless of the reason, being exposed to behavior such as that discussed in this paper may result in people refraining from having themselves tested.

Moreover, due to the lack of knowledge in society regarding the diagnosis, treatment, and modes of transmission of HIV (42) and the shortage of HIV testing and counseling centers, patients are likely to be left without support as they face problems such as societal discrimination, anxiety, and marginalization (6), (20). Some of our participants stated that their physicians referred them to the related foundations where they could receive consultancy for such problems. However, NGOs may not be able to reach all such people at the same time. Therefore, such services should be offered as part of public services at hospitals and other healthcare institutions.

Since the disease is prevalent among individuals subjected to discrimination in society, such as lesbian, gay, bisexual, transgender, queer + (LGBTQ+) people, sex workers, and drug users, we assumed that this may have led to biases and anxieties in participants regarding HIV. In this context, the process of notifying patients of the test results is particularly highlighted. Being diagnosed with HIV may lead to confusion, anger, sorrow, and fear in individuals, even if they have already been suspecting that they have it (43). Similarly, in our study, it is inferred from the participants’ statements that they experienced a sudden emotional trauma upon receiving the bad news and thus could not rationally evaluate what physicians were telling them. They also said they did not receive a satisfactory explanation or clear answers to their questions, which may have caused them to feel uncertain about their health condition.

The participants highlighted the significant effect of the physicians’ attitudes on their lives and treatment processes. Their statements suggest that most of them had a good relationship with their physicians. Some participants, on the other hand, stated that their doctors did not inform them properly about their diagnosis and treatment plans; moreover, they exhibited avoidant behaviors. It was demonstrated that the quality of the physician-patient relationship is a significant factor influencing a patient’s desire to pursue treatment (44), (45). For example, a study carried out in Baltimore revealed that intense physician-patient communication supports patient engagement in treatment (46). An essential component of a healthy physician-patient relationship is the physician’s ability to provide appropriate professional guidance to their patients. PLWH suffer from being subjected to intersectional stigma, “a concept that has emerged to characterize the convergence of multiple stigmatized identities within a person or group, and to address their joint effects on health and wellbeing” (47), p:1). In the case of PLWH, physicians should be aware of this phenomenon and approach patients accordingly. For improved communication between the physician and the patient, it is imperative that undergraduate and graduate medical education in Turkey covers subjects such as a professional approach to vulnerable groups and communication skills to ensure that the physicians confront their preconceptions of PLWH (47). This is important not only to facilitate physicians’ awareness of their attitudes contributing to or reinforcing the intersectional stigma but also to facilitate their ability to help their patients tackle being diagnosed and living with HIV in a supportive and protective manner.

Living with HIV may pose a significant risk factor for a person’s private life and psychological health (48). For instance, the conception that HIV is a disease of homosexuals and sex workers has caused most of our participants to blame themselves and to develop a fear of rejection and stigmatization, making them reluctant to acknowledge their diagnosis. Struggling with the lifestyle changes caused by the disease, such as ceasing all sexual activity, avoiding close contact with people, and not being able to talk about their HIV status with their
families or friends on their own, may put serious pressure on the patients. According to the findings of a mixed method study carried out on PLWH in Turkey in 2002, the biggest challenges PLWH faced were being subjected to discrimination, difficulty in sharing their HIV status with others, impaired sexuality, and financial issues. In the face of such problems, they mostly used palliative coping strategies and developed anger (35). In another in-depth interview study conducted with 27 PLWH in İzmir, Turkey in 2018, it was shown that the patients tended to keep their HIV status to themselves due to the existing discriminative and stigmatizing incidents in society (49). Our findings are in line with the results of these two studies.

The majority of the participants stated that healthcare professionals notified their employers, families, and friends of their HIV status without their prior knowledge or consent. Similar results were reported in a survey conducted by Gokengin et al. (2017). While 43.9% of the participants said they were sure that their HIV status was disclosed to third person and institutions by healthcare providers without their consent, another 30.6% of them had suspicions in this regard (34). Not protecting the confidentiality of personal data is frequently observed in other counties as well, especially in the case of PLWH (50), (51), (52), (53). In a study conducted in African counties, for example, the participants asserted that healthcare professionals shared their HIV test results with their families (54). Physicians in Turkey have difficulty breaking bad news to patients and thus prefer to notify their families (54). Informing the patient’s family about the diagnosis without the patient’s consent is against the principles of respect for patients’ autonomy and protection of their privacy. However, there is no legislation regulating how family members should be informed in such cases (55). According to a study examining PLWH’s experiences with their family members, the severity of the stigma exerted by family members is lower than expected (56). Furthermore, it is known that PLWH are mostly willing to share their HIV status with their partners to gain emotional support from them in addition to taking precautions against transmission. Subsequently, the family members with whom PLWH prefer to share their diagnosis come (35). Considering that PLWH should be able to decide when and how their close circle should be informed of their diagnosis and that they might actually need the support provided by their family members and friends, the experiences of PLWH and healthcare professionals regarding conversation about the diagnosis should be studied. A deeper understanding of the conditions and needs of both parties might inform efforts to produce guidelines and/or regulations on notifying patients’ social spheres.

In addition, some participants stated that their health insurance companies shared their HIV test results with their employers. Although it is not a legal obligation, most employers in Turkey require HIV testing from their applicants as a pre-requisite for recruitment (13), and in that case, the workplace physician or the health insurance company has the authority to notify the employer with the applicant’s consent. Such a procedure aims to allow the employer to take the necessary precautions in the workplace (57). However, in this case, the employee runs the risk of being fired after their HIV status is disclosed. In a previous study investigating workplace problems that PLWH face, it was found that once PLWH lost their jobs, they were largely unable to find new jobs due to their HIV status (13). Most counties have various legislative regulations to prevent the discrimination of PLWH in their workplaces (58), (59). However, there are no specific regulations to protect PLWH’s work rights in Turkey. It is known that PLWH feel threatened at work, are harassed in the workplace, and even get fired after diagnosis. In addition, practices such as asking for an HIV test before starting work, not employing PLWH, harassing them at the workplace, and forcing them to resign burden them with economic problems and social dilemmas. Moreover, there are cases where PLWH quit their jobs due to negative social reactions, stigmatization, discrimination, and guilt (60). It was demonstrated that the employability of PLWH
was significantly linked to age, time since diagnosis, illegal drug use record, and cluster of differentiation 4 (CD4) counts. Younger PLWH are more likely to be involved in the workforce. PLWH's employability was not substantially linked to education level (61). According to the code of practice specified by the International Labour Organization, there should be no discrimination against PLWH in the workplace, and employees with HIV should be able to work as long as they are medically fit (62).

Outside of healthcare institutions, the use of personal health data by employers, payment providers, and health insurance companies is acceptable as long as they serve a useful purpose such as meeting the needs of the patients, improving the healthcare system, and protecting public health. However, for sensitive groups, it brings about problems in terms of the protection of confidentiality and arouses questions as to with whom and to what degree such data should be shared (63). As of 2003, with the implementation of the Health Transformation Program, the private sector has played a bigger role in the delivery of healthcare services (33), and personal health data have been collected by the MoH, the Social Security Institution, and PHI companies. As a result, the rate of healthcare services provided by private companies has increased, which poses the risk of usage of health data for commercial purposes. This makes personal health data accessible to a third person and paves the way for their disclosure at the national and international levels (64). Similar examples have been reported in the literature (65), (66), (67). It can be deduced from these findings and examples that the failure to protect confidentiality causes problems with PLWH in terms of their access to healthcare services as well as in the workplace. To eliminate discrimination and related problems, legislative regulations, including regulations specific to PLWH, can be introduced, and campaigns aiming to raise awareness on the issue can be organized. Healthcare professionals should be trained HIV reporting and privacy policies. Professionals working in the field of HIV infection should inform policymakers on the issue. Patients should be informed of what information is recorded and what protection is available to prevent disclosure of this information. Physicians, who are liable to an employer or insurance company, should not share the information of their patients/workers with other persons unless there is a legal obligation or the patient consents.

Since HIV is a sexually transmitted virus, problems arise between the patients and their spouses/partners, which emerged as one of the main contexts in our study. PLWH's desire not to disclose their personal data and thus keep their spouses/partners or persons they have sexual interaction with uninformed about the risk that they pose to them causes an ethical dilemma (68). This is also important for the physician, who understands the potential harm to both the patient and their partner spouse/partner (69), (70). Although partner notification (PN) can save the lives of people facing the risk of being infected with HIV, it constitutes certain obstacles for the physicians and their patients that hinder its practice. For example, the lack of any legal framework on this issue might compel physicians to make personal decisions by acting at their own discretion (4). In a state hospital in Turkey, PLWH are given an informed consent form for PN. First, they are verbally informed that they need to notify their partners. If the PLWH do not inform the physician that their partners have taken an HIV test, they are given a written warning reminding them of the need to notify their partners and stating that they can be provided with psychiatric support in this process and that their partners will receive a medical notification if they do not respond to the form (55). According to the study, participants experienced the most problems with emotional distancing after sharing their HIV diagnosis with their partners (35). In a study conducted in Africa, it was reported that PN is performed via in-person meetings, home visits, phone calls, e-mail, text messages, and love letters (71). The legal regulations applied to this issue vary across regions in Europe. Some countries have legal obligations that enforce PN, while others have regulations making it an optional procedure, and some do not
have such regulations on this issue (72). In Turkey, people are prosecuted under general legal provisions in such cases (73). However, rather than trying to prevent HIV transmission by prosecuting PLWH for transmission of the virus, governments should prioritize developing programs that are proven to be effective in reducing HIV transmission and allocating resources for this matter. In this way, not only would the dilemmas that PLWH face would be solved, but additionally, the HIV-negatives’ health would be protected.

International guidelines recommend that healthcare professionals should give PLWH preliminary information about PN and make relevant suggestions. If the person refuses to notify their spouse/partner despite all efforts, within their knowledge, the person’s spouse/partner(s) must be anonymously notified of their potential exposure to HIV infection (74). It has been reported that people who are aware that they have HIV tend to use various methods of protection in their sexual life and notify their partners of their HIV status to prevent transmission of the virus to others (75), (76). In Turkey, further studies should be conducted on larger sample groups to fully comprehend the current situation. This might contribute to the development of practical undertakings that would help people alleviate their concerns and learn what to do.

It can be deduced from the participants’ statements that PLWH are subjected to conduct in healthcare environments that can be deemed discriminative/segregative. The participants stated that they faced rejection or met with excessive precautions when they went to a hospital for another health problem. They deemed such behaviors a form of discrimination. Likewise, it has been reported in studies conducted in several different countries that PLWH participating in the study were subjected to discrimination in healthcare environments and thus refused to seek healthcare services (77), (78), (79). There are also studies in Turkey that demonstrated the stigma and discrimination in healthcare settings at both institutional and individual levels against PLWH (30), (34). The report issued by the PLA regarding the violation of rights revealed that PLWH are subjected to discrimination primarily in healthcare environments, they are not given the necessary medical care, and their right to health is impeded (80). In a study in which healthcare professionals’ attitudes were examined, it was found that preconceptions and a lack of knowledge of the modes of transmission and prevention were high among all participants, and 50% of the participants stated that they did not want to follow up with PLWH (19).

In light of these findings and considering the increasing number of HIV cases in Turkey, it can be said that it is crucial to develop curricula for medical and other health faculties to ensure that they cover the content of a professional approach toward PLWH to prevent discrimination against them in healthcare environments. In particular, HIV-related stigma and discrimination in the healthcare setting cause challenges for PLWH in regard to their access to healthcare services and thus pose a risk to their health status. To prevent possible miscellaneous harm from occurring, the current regulations on patient rights must be put into effect. As deduced from our findings, people benefiting from counseling services tend to take action to pursue their rights when faced with a problem. In response to their pursuit, campaigns to raise PLWH’s and their families’ awareness must be conducted, and centers that would provide country-wide professional counseling services should be established.

**Research Limitations**

One of the difficulties we faced in this study was to reach PLWH. This stemmed from their wish not to disclose or share their HIV status. Therefore, we gave utmost attention to ensuring that the participants did not feel nervous and did not feel prejudice directed at them. Overall, we do not think that they experienced such feelings
because the participants who were not related to an NGO conveyed as feedback that they had felt relieved to talk about such issues with the interviewer, as they usually hesitated to do so with others. Furthermore, some participants whom we had contacted via an NGO expressed that the interviewer could call them later if any more information was needed. The interviewer also checked with every participant by asking them whether they were disturbed by any of her questions or behaviors immediately after the interviews.

In addition, we observed several differences in the expressed attitudes of the participants who were associated with an NGO and those who were not. The former groups seemed more aware of their rights and were more eager to protect them than the latter. Moreover, they were more at ease with receiving support and consultancy from the NGOs with which they are associated regarding the problems they encountered. However, many participants in the latter group independently told the interviewer that they had previously shared their situation very few people. In addition, the experiences of PLWH in Istanbul and those of PLWH in other Turkish cities may differ significantly. Istanbul is known to be a modern cosmopolitan city where most people can express their identities explicitly, whereas in many other relatively small cities, this may not be the case. PLWH may encounter more severe stigmatizing and discriminative attitudes, which may originate from the predominant conservatism in smaller provinces.

Another limitation of the study was that the data obtained from the two married couples participating in our study might have been affected since they wanted to be interviewed together. It was observed that male participants could not express their feelings openly in the presence of their spouses. These two couples were together during all diagnosis and treatment processes, and they reminded each other of incidents they thought would be good to mention during the interview. For this reason, we chose to include the participants in order not to lose them.

We considered people might be hesitant to talk about sexual preferences in Turkey. We chose not to ask questions related to this issue so that the communication between the interviewer and the participant did not encounter any additional difficulties and was carried out in a salubrious way. This situation may have affected the data obtained to some extent.

Conclusions and suggestions

In light of the findings obtained in this study, the perceptions of PLWH regarding their lived experiences during and after HIV diagnosis were investigated. Our results demonstrated that the magnitude of HIV-related problems and their prevalence in Turkey remain tentative. The poignancy of the obtained results emphasizes the need for further studies representing the entire global population to be carried out on a larger scale.

Within the scope of our findings, we suggest developing and implementing informative and/or educational campaigns to raise public awareness, to foster public engagement, and to increase people's knowledge of the issue even though these endeavors might not be sufficient to reduce HIV-related stigma in most settings globally. In addition, to encourage individuals to be tested voluntarily, pre- and post-testing counseling services designed in line with international guidelines should be easily accessible for individuals, and the number and quality of such services in hospitals and other healthcare institutions should be increased. It is essential that precautions are taken to protect PLWHs personal health data against improper accessibility by third parties. The development and enforcement of a legal regulatory framework for PN would ease the burden of responsibility
that both physicians and patients experience. In the fight against discriminatory and stigmatizing attitudes in healthcare environments—a problem frequently expressed by our participants—all healthcare professionals should be given professional training, and in case of any negligence, the necessary efforts to make up for such acts should be made per the legal regulations and procedures. Making the institutions providing clinical ethics support for the ethical conflicts that healthcare professionals and patients’ families experience regarding this issue more widespread may contribute to the protection of the professional values of physicians and ensure the benefit of the patient.

In conclusion, combating the stigmatization of PLWH requires multidimensional, multifarious efforts in a society. These include the improvement of patient–physician interactions, consolidated with respecting patient confidentiality and privacy, the improvement of healthcare provision by institutionalizing partner notification in order to balance patient autonomy, the physician's responsibility regarding the partners' beneficence for a well-functioning healthcare system that entails social policies fostering professional contributions, public awareness, and public engagement to produce a purposeful legal framework based on ethical values.

List Of Abbreviations

**AIDS:** Acquired Immunodeficiency Syndrome  
**CD4:** Cluster of Differentiation 4  
**GHI:** General Health Insurance  
**HIV:** Human Immunodeficiency Virus  
**LGBTQ+:** Lesbian, Gay, Bisexual, Transgender, Queer +  
**MoH:** Ministry of Health  
**MSM:** Men who Sex with Men  
**NGOs:** Non-Governmental Organizations  
**PHI:** Private Health Insurance  
**PLA:** Positive Living Association  
**PLWH:** People Living With HIV

Declarations

**Ethics approval and consent to participate**

Approval for the present work was obtained from the Acibadem Mehmet Ali Aydinlar University Ethical Committee for Scientific Research and Evaluation with the decision dated 03.08.2017 and numbered 2017-13/35. All participants read a study information sheet gave signed consent to participate in this research.
Consent for publication

Not applicable.

Availability of data and material

The qualitative datasets generated and analysed during this study are not publicly available as they run the risk of identifying individual participants.

Competing interests

The authors declare that they have no conflict interest.

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Authors’ contributions

All authors have read and approved the manuscript.

GS developed the main conceptual and the design of the study. She vastly contributed to data collection process, the data analyses, and discussing the results. She took part in the writing of the manuscript majorly.

MVK contributed to the analysis, reporting and interpretation of the results and to the writing of the manuscript.

YIU contributed to the idea, planning and drafting of the study, and was in charge of overall supervision process.

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Table 1. Data Analysis Steps

| Stage                | Step | Function                              | Aim                                           |
|----------------------|------|---------------------------------------|-----------------------------------------------|
| Naive Understanding  | 1    | Rough reading                        | Familiarization                               |
| Structural Analysis  | 2    | De-construction of the raw data       | Extracting the main themes                    |
|                      | 3    | Cross-checking of the identified themes | Identification of a thematic framework         |
|                      | 4    | Indexing                              | Discussing and determining the themes         |
|                      | 5    | Charting                              | Creating tables for context, main theme, sub-themes, codes, and function/result |
|                      | 6    | Mapping                               | Reconstruction of the data: defining the pattern of relations between context, main theme, and sub-themes and codes |
| Comprehensive        | 7    | Interpretation                        | Reaching an understanding and insight         |

Table 2. Demographic information of the participants
| Gender       | Female (n=5) | Male (n=15) |
|--------------|--------------|-------------|
| Age          | Average: 41,5| Average: 34,5|
|              | Min: 34      | Min: 27     |
|              | Max: 47      | Max: 55     |
| Occupation   | Employed: 3  | Employed: 13|
|              | Unemployed: 2| Unemployed: 2|
| Education    | Primary school: 1 | Primary school: 2 |
|              | High school: 3 | High school: 5 |
|              | University graduate: 1 | University graduate: 7 |
| Marital status | Single: 2  | Single: 12 |
|              | Married: 3   | Married: 3  |
| Health insurance | General Health Insurance (GHI)\(^a\): 3 | GHI: 11 |
|              | Private Health Insurance (PHI)\(^b\): 1 | PHI: 4 |
|              | None: 1      |             |
| Time lived with HIV | Average: 10 years 2 months | Average: 5 years 7 months |
|              | Min: 2 years | Min: 1,5 years |
|              | Max: 20 years | Max: 14 years |

**Table 3.** Themes concerning the physician-patient communication surrounding the diagnosis
| MAIN THEME                        | SUB-THEME          | CODE                                                                 | FUNCTION/RESULT                        |
|----------------------------------|--------------------|----------------------------------------------------------------------|----------------------------------------|
| Withholding information from the patient | -                  | Performing tests without informing the patient                      | Suspect                                |
|                                   |                    | Withholding information from the patient as to the test results     | Fear                                   |
|                                   |                    |                                                                      | Being stuck with ambiguity             |
|                                   |                    |                                                                      | Feeling                                |
|                                   |                    |                                                                      | embarrassed                            |
|                                   |                    |                                                                      | Feeling overlooked                     |
| Informing the patient about diagnosis | Inappropriate approach | Telling the diagnosis over the phone                                 |                                        |
|                                   |                    | Telling the patient about the problems that he/she could face after diagnosis and that could affect his/her psychology negatively |                                        |
|                                   |                    | Misinforming the patient about test results                        |                                        |
|                                   | Inattentive approach | Telling the diagnosis in the presence of the family                 |                                        |
|                                   |                    | Giving information about the diagnosis irrespective of the patient’s psychology |                                        |
|                                   | Attentive approach  | Telling the diagnosis in an isolated environment                    | Feeling trust                           |

**Table 4.** Themes concerning being diagnosed with HIV
| MAIN THEME          | SUB-THEME                                      | CODE                                                                 | FUNCTION/RESULT      |
|---------------------|-----------------------------------------------|----------------------------------------------------------------------|----------------------|
| Patient’s feelings  | Self-reproach after the diagnosis             | Deeming that HIV is a disease associated with certain groups         | Feeling guilty       |
|                     |                                               | The bad impression that media outlets create regarding the disease   | Denying              |
| Difficulty facing the disease | Feeling bad upon getting the diagnosis        |                                                                      | Shock                |
|                     | Reluctance to acknowledge his/her condition after diagnosis |                                                                      | Denying              |
| Fear of not being able to receive treatment for other health problems | Arousal of fear that he/she would not be admitted for an operation in the future |                                                                      | Fear                 |

**Table 5.** Themes concerning the impact of HIV on the patient’s life
| MAIN THEME                        | SUB-THEME                        | CODE                                                                 | FUNCTION/RESULT               |
|----------------------------------|----------------------------------|----------------------------------------------------------------------|-------------------------------|
| Changes in patient’s life after  | Changes in lifestyle             | Ceasing sexual activity                                             | Ambiguity                     |
| diagnosis                         |                                  | Disruption of long-term life plans                                 | Shock                         |
|                                  |                                  | Estimating a certain lifetime for himself/herself                   | Isolation                     |
|                                  | Isolation/Being isolated from    | Concealing the medications used due to fear of social exclusion      | Isolation                     |
|                                  | social life                      | Avoiding people in their immediate environment                      | Embarrassment                 |
|                                  |                                  | Separating his/her belongings from those of the people he/she lives |                               |
|                                  | Changes in family dynamics        | Family’s positive attitude toward the patient                        | Feeling trust                 |
|                                  |                                  | Supporting the patient                                              | Receiving social support      |
|                                  |                                  | Keeping in contact with the patient                                 |                               |
|                                  | Not notifying the family of HIV   | Not telling the family that he/she has been infected with HIV so as  | Being deprived of social      |
|                                  | diagnosis                        | to avoid upsetting them                                              | support                       |
|                                  |                                  | Family’s negative attitude toward the patient                        | Isolation                     |
|                                  |                                  | Separating their personal belongings from the patient’s             | Stigma                        |
|                                  |                                  | Cutting contact with the patient                                     | Being accused                  |
|                                  |                                  | Condemning the patient’s lifestyle                                   |                               |
|                                  | Changes in friendship dynamics    | Friends’ positive attitude toward the patient                        |                               |
|                                  |                                  | Supporting the patient                                              | Receiving social support      |
|                                  |                                  | Not sharing HIV status with friends                                 |                               |
|                                  |                                  | Not telling friends that he/she has been infected with HIV for fear | Being deprived of social      |
|                                  |                                  | of social exclusion                                                  | support                       |
|                                  |                                  | Friends’ negative attitude toward                                   |                               |
|                                  |                                  | Losing friends due to his/her HIV status                             | Isolation                     |
|                                  |                                  | Stigma                                                              |                               |
Table 6. Themes concerning PLWH’s relationship with the physician

| the patient | Friends’ refraining from physical contact with the patient |
|-------------|----------------------------------------------------------|


| MAIN THEME                              | SUB THEME                              | CODE                                                                 | FUNCTION/RESULT                |
|----------------------------------------|----------------------------------------|----------------------------------------------------------------------|--------------------------------|
| Physician’s attitudes toward the patient | Physician’s negative attitudes toward the patient | Not informing the patient about the process
Under-informing the patient about medication use
Implying that HIV is a redemption for sins
Estimating a certain lifetime for the patient | Ambiguity
Distrust
Stigma Hopelessness |
| Physician inflicting psychological violence on the patient | Hurling documents at the patient
Literally moving away from the patient
Exercising paternalism over the patient | Being subjected to disrespectful behavior
Anger |
| Physician’s positive attitude toward the patient | Providing professional guidance to the patient on his/her future life
Referring the patient to an HIV-related foundation for counselling
Giving time to the patient before starting medication
Establishing empathy with the patient
Encouraging the patient to maintain his/her social relationships | Feeling trust
Professional support |

**Table 7.** Themes concerning PLWH’s relationships with their spouses/partners
| MAIN THEME                               | SUB-THEME                                      | CODE                                                                 | FUNCTION/RESULT                                                                 |
|-----------------------------------------|-----------------------------------------------|----------------------------------------------------------------------|---------------------------------------------------------------------------------|
| Spouse/partner notification after HIV   | Notifying the spouse/partner properly         | Patient notifying the spouse/partner of the disease                  | Responsibility for third person                                                  |
| diagnosis                                |                                               | Physician encouraging the patient to do the spouse/partner notification| Protection of patient autonomy                                                  |
|                                         |                                               | Physician doing spouse/partner notification together with the patient|                                                                                 |
| Inability to notify the spouse/partner  | Patient being single                          | Third person’s vulnerability                                         |
|                                         | Patient having multiple partners              |                                                                     |
|                                         | Difficulty in notifying the spouse due to “cheating on them” |                                                                     |
| Notifying the spouse/partner in a       | Healthcare professional doing spouse/partner notification without the patient’s consent | Distrust                                                               |
| controversial manner                     | Notifying the spouse that he/she has a different disease other than HIV | Failure to protect confidentiality | Causing anxiety/fear in third person                                            |

Table 8. PLWH’s experiences in healthcare settings
| MAIN THEME                        | SUB-THEME                                           | CODE                                                                                                                                                                                                 | FUNCTION/RESULT                                                                                                                                 |
|----------------------------------|-----------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------|
| Failure to protect confidentiality | Failure to protect confidentiality in the healthcare system | A third person obtaining the patient’s health data from the hospital database  
PHI companies notifying the employer of the patient’s HIV status  
Manifesting the patient’s HIV status in the healthcare system database  
Patient’s fear that their name and contact information are revealed to the MoH | Distrust in the healthcare system  
Feeling under surveillance  
Failure to protect patient confidentiality |
| Healthcare professionals’ failure to protect patient confidentiality | Telling the diagnosis in the presence of the patient’s family  
Notifying the family without the patient’s knowledge  
Healthcare professionals sharing the patient’s personal health data with third person  
Calling out the patient’s name and medications for HIV loudly in pharmacies | Distrust in healthcare professionals  
Failure to protect patient confidentiality |
| Not being attentive to patient confidentiality in the physician’s room | Leaving a patient’s files open on the desk  
Physician talking about the disease in the room in the presence of others | Distrust in physicians  
Failure to protect patient confidentiality |
| Not respecting personal space    | Healthcare professionals asking patients questions about | Distrust in healthcare professionals |
| Being subjected to discrimination | Healthcare professionals’ attitudes toward PLWH | Refusing to perform surgery on PLWH  
The concept that healthcare professionals do not see patients as people  
Pharmacists’ feeling pity for PLWH  
Healthcare professionals taking excessive precautions when working with PLWH | Being deprived of healthcare services  
Being subjected to unfair treatment  
Being stigmatized  
Being subjected to psychological violence |
|-----------------------|---------------------------------|-------------------------------------------------|---------------------------------------------------------------------|
| Healthcare institutions’ policies regarding PLWH | Lack of dialysis centers offering healthcare service to PLWH  
Lack of obstetric follow-up clinics offering healthcare services to PLWH  
Reluctance to provide care for PLWH | Being deprived of healthcare services  
Being subjected to injustice |

**Table 9.** Themes concerning PLWH’s struggle with the disease
| MAIN THEME                               | SUB-THEME                         | CODE                                                                 | FUNCTION/RESULT          |
|-----------------------------------------|-----------------------------------|----------------------------------------------------------------------|--------------------------|
| Patients protecting themselves against adverse consequences of the disease | Seeking personal solutions        | Not disclosing the test results                                     | Fear of being hurt       |
|                                         |                                   | Reluctance to share their HIV status with a professional from another medical branch | The need to trust        |
|                                         |                                   | Searching for a new physician                                         | Anxiety                  |
|                                         |                                   | Searching for a reliable pharmacy                                     |                          |
|                                         |                                   | Getting information from HIV-related foundations                      | Awareness                |