

**Stigmatization, discrimination, violation of autonomy and compromised confidentiality:**

**Lived experiences of people living with HIV on the onset of their illness in Turkey**

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## **Abstract**

**Background:** It's known that people living with HIV (PLWH) are subjected to stigmatization and discrimination while accessing healthcare services. The purpose of this study is to understand the perceptions of PLWH in Turkey, about whom there are limited data on how their lives are affected by such experiences.

**Methods:** Semi-structured interviews were carried out with 20 people, and the obtained data were analyzed thematically.

**Results:** The results highlighted the following themes: problems with patients' autonomy, failure to protect patients' confidentiality and personal health data, spouse/partner notification issues, and stigmatizing and discriminatory attitudes intrinsic to healthcare professionals' approach. The attitudes of healthcare professionals and health institutions negatively influence the utilization of healthcare services by PLWH.

**Conclusions:** We have argued the necessity to raise the healthcare professionals' and the society's knowledge and awareness, and develop national policies that would contribute to structure partner notification services and prevent HIV-related discrimination and stigmata.

**Keywords:** HIV/AIDS; Confidentiality; Discrimination; Lived experience, Access to Health Care, Ethics

## **Background**

Since its first emergence in the early 1980s, Acquired Immune Deficiency Syndrome (AIDS) cases have spread across the world regardless of any age, sex and/or geographical boundaries. As a continuing community health problem (1), the disease has occasionally been a topic of discussion on the public agenda in terms of the problems faced by people living with Human Immunodeficiency Virus (HIV) while trying to access healthcare services and facing HIV-related discrimination and stigma. In time, such attempts have paved the way to restructure public health policies to a certain extent (2, 3). Nevertheless, the ethically unjustifiable cases that persevere to this day have caused the debates on attitudes towards people living with HIV (PLWH) to gain an ethical dimension.

The financial and emotional burden that HIV/AIDS lays upon a person differs from other transmissible and chronic illnesses (4). For instance, one can be fired from their job for being an HIV carrier or having AIDS, and this poses a big financial challenge to that person. In addition, being subjected to discrimination both in health institutions and social spheres imposes an emotional burden on the person, which might cause them to refuse treatment and thus put their physical and psychological health at risk. Moreover, the fact that this illness was mostly observed in men who have sex with men (MSM), sex workers, and intravenous substance abusers in its early years is the main cause of the prevailing biases towards PLWH (5, 6).

The studies and campaigns such as 90-90-90, Fast Track and Undetectable=Untransmittable have led to significant progress in terms of raising public awareness and prevention of the epidemic (7, 8). Turkey is one of the countries where the prevalence of HIV is low. However,

the recent data of the Ministry of Health (MoH) have shown that its prevalence is surging and people with HIV are getting more and more visible in society (9, 10).

In many countries, PLWH are subjected to HIV-related stigma and discrimination (11, 12, 13). Although Turkey has a similar trend (14, 15), there are few studies on PLWH's perception of their diagnosis and treatment, their relationship with healthcare workers and other professionals, and their experiences in healthcare environments. The present study aims to rectify that gap in knowledge; its design was based on the premise that an ethical discussion of such findings is necessary. The study has focused on the PLWH's lived experiences that will provide an insight on how their perspectives on their illness is influenced while receiving healthcare service, how their sense of self is influenced after being labeled as "ill", and how the relationship with their immediate circles, their thoughts about their social status, and their lives are influenced and after being diagnosed with HIV.

## **Methods**

### **Participant Recruitment**

A PLWH group constituted the research population. The ones aged over 18 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 the treatment during which patients face more problems. The rationale behind this preference is that we expected them to have reached a certain phase of the illness where they can look at their experiences from a distance without having to deal with the initial difficulties such as receiving bad news,

adapting oneself to an unexpected and/or shocking situation, and etc. In total, 20 people were interviewed (19 in person, and 1 via Skype) between 18<sup>th</sup> October 2017 and 29<sup>th</sup> April 2018.

First of all, the Human Resource Development Foundation<sup>4</sup>, Pozitif-iz Association<sup>5</sup>, and physicians specialized in clinical microbiology and infectious diseases, who are working on HIV/AIDS, were contacted to reach PLWH volunteering to participate were included in the study. In addition, the snowball sampling method was used to contact other PLWHs that met our criterion. Informed consent was obtained from all individuals who agreed to participate in the study.

#### Data Collection

The researcher conducting the interviews (GS) contacted the participants directly and performed the interviews face-to-face. Only one of the participants preferred to be interviewed via Skype. An interview guideline form was used for the interviews. The interview questions, which sought information about the participants' demographic data, knowledge, experiences, emotions, and actions, were as follows:

- Can you talk about yourself?
- Did you have any information about transmittable diseases before being diagnosed with HIV?
- How did you find out you were infected with HIV?

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<sup>4</sup> It 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 (16).

<sup>5</sup> It is a non-governmental organization that aims to strengthen PLWH and their families in physical, psychological and social aspects (17).

- Did you take HIV testing on your own will?
- 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?
- What were the treatment processes after your diagnosis?
- Was your partner with you at that time, were they notified of the test results?
- Did you want to tell it to your immediate circle, what was their reaction?
- What reaction do you get when you go to a hospital for a health problem?
- What do you expect from healthcare institutions?
- Do you want to add anything else?

## Data Analysis

First of all, the voice-recordings taken during the interviews were transcribed verbatim, and each participant was assigned a code. The transcriptions were rough-read, and then, the statements made in response to the key questions in the interview guideline form were extracted and clustered. The key concepts given as a response to a specific question were dealt with according to their corresponding themes, and this process was repeated back-and-forth for a couple of times. It was investigated whether the themes in the theme list were specified under the same or different questions and the concepts classified under those themes could be grouped as main themes; moreover, whether it was possible to make a new clustering for these themes. The research team discussed the themes, questioned/interpreted the semantic relations between each theme, and organized the themes into a table which comprises the context, main themes, sub-themes, and codes (Table 1).

**Table 1.** Data Analysis Steps (18)

<b>Stage</b>	<b>Step</b>	<b>Function</b>	<b>Aim</b>
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 Understanding	7	Interpretation	Reaching an understanding and insight

### 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 make sure that the participants did not feel nervous or did not have a feeling that they were being prejudiced.

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 had wanted to be interviewed together. It was observed that the male participants could not express their feelings openly in the presence of their spouses. Nevertheless, respecting their request, we conducted the interviews as they wished.

The research technique also posed a limitation to the study. One of the participants was disturbed by the use of voice recorder, and only after it was turned off did he share some valuable information. Hence, the participants' responses were noted after voice recording, as well.

## **Findings**

### Participants

Aged between 27 and 55, research participants have a variety of social status profiles. The majority of them are single and in contact with the NGOs working on HIV. 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 their biological sex was taken into account. The number of male participants was significantly higher than that of female ones. However, the distribution of our participants by gender was in line with the data on the distribution of PLWH in Turkey by gender<sup>6</sup>.

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 for HIV treatment since this type of

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<sup>6</sup> The rate of females and males living with HIV was found to be 20.1% and 79.9%, respectively (10).

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 (Table 2).

**Table 2.** Descriptive data on participant PLWH

<b>Participants</b>	<b>Age</b>	<b>Gender</b>	<b>Occupation</b>	<b>Education</b>	<b>Marital Status</b>	<b>Health Insurance</b>	<b>Time lived with HIV (year)</b>
P1	41	Male	Editor	Undergraduate	Single	GHI <sup>7</sup>	11
P2	34	Male	Private sector	Undergraduate	Married	PHI <sup>8</sup>	3
P3	53	Male	Unemployed	High school	Single	GHI	15
P4	38	Male	Waiter	Primary school	Married	GHI	4
P5	41	Male	Doctor	Doctorate	Single	PHI	2
P6	34	Male	Shopkeeper	High school	Single	GHI	7
P7	34	Female	Unemployed	High school	Married	None	8
P8	55	Male	Retired	High school	Single	GHI	1,5
P9	39	Male	NGO Employee	Undergraduate	Single	GHI	12

<sup>7</sup> General Health Insurance (GHI): It denotes the insurance that finances employees' healthcare expenses and used in state hospitals and health institutions. The unemployed may also have this insurance on the condition that they pay the insurance charges. It covers diagnosis and treatment of HIV (10).

<sup>8</sup> Private Health Insurance (PHI): It is the customized insurance type determined in accordance with certain limits and general requirements and used for healthcare expenses. It doesn't cover diagnosis and treatment of HIV (18).

P10	28	Male	Engineer	Undergraduate	Single	PHI	6
P11	39	Male	Bank employee	Undergraduate	Single	PHI	3
P12	35	Male	Jeweller	High school	Married	GHI	3
P13	48	Male	Unemployed	Primary school	Single	GHI	5
P14	27	Male	Coach	Undergraduate	Single	GHI	1,5
P15	53	Male	Driver	High school	Married	GHI	7
P16	47	Female	Unemployed	Primary school	Married	GHI	7
P17	42	Female	Pastry chef	High school	Single	GHI	2
P18	44	Female	Private sector	Undergraduate	Married	PHI	14
P19	40	Female	Unemployed	High school	Single	GHI	20
P20	28	Male	Actor	Undergraduate	Single	GHI	3,5

### Thematic Analysis

The thematic pattern developed upon analyzing the interview files were examined in seven contexts: (i) the process of breaking bad news, (ii) being diagnosed with HIV, (iii) impact of HIV diagnosis on patient's life, (iv) PLWH's relationship with their physician, (v) PLWH's relationship with their spouses/partners, (vi) PLWH's experiences in the healthcare setting, and (vii) PLWH's struggle with the disease. The contexts, main themes, sub-themes, codes and functions/results are shown in Table 3:

**Table 3.** Coding table for PLWH

<b>CONTEXT</b>	<b>MAIN THEME</b>	<b>SUB-THEME</b>	<b>CODE</b>	<b>FUNCTION/ RESULT</b>
The process of breaking bad news	Being informed about the diagnosis	Withholding information from the patient	Performing tests without informing the patient Withholding information from the patient as to the test results Misinforming the patient about test results	Suspect Fear Being stuck with ambiguity Feeling embarrassed Feeling overlooked
		Inappropriate approach	Telling the diagnosis on the phone Telling the patient about the problems he/she could face after diagnosis and could affect his/her psychology negatively	
		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
Being diagnosed with HIV	Patient's feelings	Self-reproach after the diagnosis	Deeming that HIV is a disease associated with certain groups  The common conception that HIV is a homosexual disease  The bad impression that media organs create on the disease	Feeling guilty  Denying
		Difficulty facing the disease	Feeling bad upon getting the diagnosis  Reluctance to acknowledge his/her condition after diagnosis	Shock  Denying
		Fear of not being able to receive treatment for other health problems	Arousal of fear that he/she wouldn't be admitted for an operation in the future	Fear

Impact of HIV on patient's life	Changes in patient's life after diagnosis	Changes in lifestyle	Ceasing sexual activity Disruption of life plans Changing life plans Estimating a certain lifetime for himself/herself	Ambiguity Shock Isolation
		Isolation/Being Isolated from social life	Concealing the medications used due to fear of social exclusion Avoiding people in their immediate environment Separating his/her belongings from the ones lived with	Isolation Embarrassment
	Changes in family dynamics	Family's positive attitude towards the patient	Supporting the patient Keeping in contact with the patient	Feeling trust Receiving social support
		Not notifying the family of HIV diagnosis	Not telling the family that he/she has been infected with HIV so as not to upset them	Being deprived of social support Isolation
		Family's negative attitude	Separating their personal belongings	Stigma Being accused

		towards the patient	from the patient's Cutting contact with the patient Condemning the patient's lifestyle	
	Changes in the friendship dynamics	Friends' positive attitude towards 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 of social exclusion	Being deprived of social support
		Friends' negative attitude towards the patient	Losing friends due to HIV Friends' refraining from physical contact with the patient	Isolation Stigma
PLWH's relationship with the physician	Physician's attitude towards the patient	Physician's negative attitudes toward the patient	Not informing the patient about the process Under-informing the patient about medication use Not starting medication	Ambiguity Distrust Stigma Hopelessness

			<p>immediately</p> <p>Telling the patient religious verses which imply that diseases are redemption for sins</p> <p>Estimating a certain lifetime for the patient</p>	
		<p>Physician's inflicting psychological violence on the patient</p>	<p>Hurling documents at the patient</p> <p>Moving away from the table</p>	<p>Being subjected to disrespectful behavior</p>
		<p>Physician's positive attitude toward the patient</p>	<p>Providing professional guidance to the patient on his/her future life</p> <p>Referring the patient to the related foundations for counselling</p> <p>Giving time to the patient for starting medication</p> <p>Showing empathy</p> <p>Encouraging the patient to maintain his/her social relationships</p>	<p>Feeling trust</p> <p>Professional support</p>

	Physicians' relationship with the patient	Patients' reaction to their physician	Inability to object to the physician	Anger Feeling overwhelmed
PLWH's relationship with their spouses/partners	Spouse/partner notification after HIV diagnosis	Notifying the spouse/partner properly	Patient's notifying the spouse/partner of the disease Physician's encouraging the patient to do the spouse/partner notification Physician's doing spouse/partner notification together with the patient	Responsibility for third persons Protection of patient autonomy
		Inability to notify the spouse/partner	Patient's being single Patient's having multiple partners Difficulty in notifying the spouse due to "cheating"	Third persons' vulnerability
		Notifying the spouse/partner in a controversial	Healthcare professional's doing spouse/partner notification without	Distrust Failure to protect confidentiality

		manner	patient's consent Notifying the spouse that he/she has a different disease other than HIV	Causing anxiety/fear in third persons
PLWH's experiences in healthcare settings	Failure to protect confidential ity	Failure to protect confidentiality in healthcare system	Third persons' obtaining patient's health data from hospital database Private health insurance companies' notifying the employer of the patient's HIV status Manifesting the patient's HIV status in healthcare system database Patient's fear that their names and contact information are revealed to the MoH	Distrust in healthcare system Feeling under surveillance Failure to protect patient confidentiality
		Healthcare professionals' failure to protect patient	Telling the diagnosis in the presence of patient's family Notifying the family	Distrust in healthcare professionals Failure to

		confidentiality	without patient's knowledge Healthcare professionals' sharing patient's personal health data with third parties Calling out the patient's name and medications for HIV in pharmacies	protect patient confidentiality
		Not being attentive to patient confidentiality in physician's room	Leaving patient's files open on the desk Physician's 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 their private life to satisfy their curiosity	Distrust in healthcare professionals
	Being subjected to discrimination	Healthcare professionals' attitudes towards PLWH	Refusing to perform surgery on PLWH The conception that healthcare professionals	Being deprived of healthcare services Being

			do not see patients as people Pharmacists' feeling pity for PLWH Healthcare professionals' taking excessive precautions for PLWH Healthcare professionals' scaring PLWH	subjected to unfair treatment Being stigmatized Being subjected to psychological violence
		Attitudes of healthcare institutions towards PLWH	Lack of dialysis centers offering healthcare service to PLWH Lack of obstetric follow-up clinics offering healthcare service to PLWH Reluctance of health institutions/hospitals to provide care for PLWH The conception that private health institutions do not have adequate knowledge on	Being deprived of healthcare services Being subjected to injustice

			HIV	
PLWH's struggle with the disease	Patients' protecting themselves against adverse consequenc es of the disease	Seeking personal solutions	Not disclosing the test results Reluctance to share their HIV status with other medical branches Searching for a new physician Searching for a reliable pharmacy Patient's insistence to determine the physician and the hospital himself/herself Challenges in receiving healthcare services Getting information from related foundations	Fear of being hurt The need to trust Anxiety Awareness

## Results

### *The Process of Breaking Bad News*

It can be deduced from the participants' statements that they had negative impressions and feelings when healthcare professionals told them the bad news, which in their case, was being diagnosed with HIV.

**Being Informed about the Diagnosis:** 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 health reports required before marriage. Moreover, they asserted that they were not informed about preliminary test results when they were asked to give a blood sample for a verification test, and thus thought that healthcare professionals were withholding 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 this. 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. (P2, lines:37-40)<sup>9</sup>

In addition, notifying the patient on the phone, informing the patient immediately after diagnosis about the potential HIV-related problems, and discriminatory acts they might face was deemed as an *inappropriate approach*; breaking bad news in the presence of family members and not acting attentively while giving information were considered *inattentive approach*.

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<sup>9</sup> This code shows that this quotation was extracted from the interview made with Participant number 2 between the lines 37-40 of the relevant transcription.

Two young doctors came to my room and told the diagnosis when my mother was there. Now, I think that it's a very serious violation of rights. I may or might not want to share it with my mother. I don't think adequate attention is paid to patient confidentiality. (P20, lines:54-57)

[The doctor] told me that I should hide this from my family, shouldn't be so enthusiastic about finishing school, and due to this my work life could be affected. He even advised me to suspend school for some time till I pulled myself together. I was shocked, but still it occurred to me what he said was not so logical, but it is horrifying. (P10, lines:83-86)

On the other hand, physicians' preferring an isolated environment to notify the patient and to inform them about the test results was evaluated as an *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 a 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 service during the diagnosis process. (P20, lines:87-89)

### *Being Diagnosed with HIV*

Since the disease is prevalent among individuals subjected to discrimination in society, we assumed that this might have caused biases and anxieties in participants about HIV.

**Participants' Feelings:** It was seen that participants' main source of information about HIV was the news on television and newspapers. Some of the participants stated that they had never thought they would have AIDS since 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 the proper knowledge on HIV tended to blame themselves as they failed to protect themselves.

(...) 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 didn't happen to me. (P18, lines:52-56)

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. (P20, lines:69-71)

The participants did not want to acknowledge their condition for a long time after the diagnosis, some even refrained from getting treatment. Moreover, due to the discrimination instances they had known of in healthcare institutions, some participants developed a fear of rejection by the 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. This could happen to me too. (P5, lines:126-128, 132-133)

### *Impact of HIV on Patient's Life*

In this context, the main concerns of the participants were centered on whether to share their diagnosis with others or not, adherence to the treatment, decisions on sexual activity and issues about parenthood.

**Changes Occurring in Patient's Life after Diagnosis:** One important change in patients' lives after diagnosis is ceasing sexual activity. In addition, participants tended to isolate themselves from social interactions both considering the possibility of being exposed to discrimination and because they did not know the modes of transmission of the virus.

(...) I haven't had any [sexual intercourse with anyone] for 14 years. I don't want it. Anyway, I can't find anyone like me. It's difficult, especially in this country.  
(P3, line:104-105)

"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 would die], if the one who is supposed to support me treats me badly, how can I explain it to the public? 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; no one would know me. And, I left the city. (P9, lines:120-123)

**Changes in Family Dynamics:** The participants stated that their family relationship changed either positively or negatively after they shared their HIV status with family members. Some participants asserted that their families were supportive of this process.

How well they looked after me and how much attention they paid to me... Let alone being ill and I thought had to get better. I almost got crazy seeing them feeling sad 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... (P6, lines:149-152)

Four of the participants stated that their families ended their relationship with them and put the blame of 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 jumped too much, you've been on the loose; you deserved it." I'll never forget that. (P19, lines:48-49)

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

I didn't want to tell it. Well, it was because they don't have awareness on 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. (P5, lines:91-92)

**Changes in Friendship Dynamics:** It was seen 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, few of them stated that their friendships ended and their friends avoid 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. (P6, lines:169-172)

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. (P9, lines: 202-208)

The majority of the participants asserted that they had not had any problem with their friends and their illness had not affected their relationship.

When I was in 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. (P18, lines: 152-153)

### *PLWH's Relationship with the Physician*

The physician-patient relationship was found to be a determinant factor in patients' perception of their illness process.

**Physicians' Attitude towards the Patient:** Participants stated that the physicians' positive or negative attitudes towards them influenced their treatment process and caused a change in their lives after the diagnosis. They deemed the physicians' misinforming them about the treatment process and medication use, estimating a survival time for them and not establishing open communication with them as negative attitudes.

They said the situation was new and my immune system was very strong, so there was no point 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 had started it right away. Afterwards I had lymph surgery. I might not have gone through it if I had started medication. (P14, lines:104-109)

[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 40<sup>th</sup> 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. (P6, lines:54-57)

In addition, the participants also stated that the physicians' certain behaviors caused them to feel bad and 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, smoke, had nightlife, had had a lot of partners for 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 closed a couple of times. (...) Then, I left the room and tore the test results into pieces. (P9; lines:103-111)

Most of the participants asserted that physicians and other healthcare professionals working at infectious diseases clinic treated them sympathetically, provided professional guidance to them on their future life, and referred them to related foundations.

“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 counselling service. You can find any information you need there.” Then I received information from them. (P2, lines:206-209)

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 talk to doctors about my worries. (P7, lines:251-253)

**Physicians' Relationship with the Patient:** In this context, few of the participants stated that instead of making a mutual decision, they follow the doctors' orders to avoid any problem from occurring. One of them, for example, said he could not object to his doctor's request to take his photo just because he was a doctor.

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 afterwards," he said. I asked if I was in a bad state at that time and why he put is as now, before and after. He told me that he wanted to follow-up 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. (P9, lines:63-67)

#### *PLWH's Relationship with Their Spouses/Partners*

Since HIV is a sexually transmitted virus, it arises problems between the patients and their spouses/partners, which emerged as one of the main contexts in our study.

**Spouse/Partner Notification After HIV Diagnosis:** As was stated by the participants, various methods were used for spouse/partner notification. Some of these methods were favored by them, while some influenced their relationship with their spouses/partners negatively.

The participants stated that they were pleased when physicians encouraged and supported them to notify their spouses/partners. They also appreciated when they informed their spouses/partners 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, 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. (P2, lines: 61-63)

One of the problems expressed by our participants was the inability to do partner notification. For example, single participants stated that they did not know exactly when they had been infected, and thus could not contact all their ex-partners. Moreover, the ones 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. Besides, in addition to the shock of being diagnosed with HIV, there was an "infidelity" aspect in the case of married people. Therefore, they feared a possible breakdown in their marriage/relationship, which deterred them from notifying their spouses/partners.

Well, I had 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. (P13, lines: 122-125)

On the other hand, the participants stated that their spouses/partners were notified by their physicians without their knowledge and this damaged their relationship. Moreover, one of the participants told his wife that he had another illness.

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 got over it. (P6, lines:116-127)

I went abroad for business and stayed there for three years. They told me I had HIV there. Then, I came back here. (...) To be honest, we told my wife that I had hepatitis. We had her and the kids tested for HIV as if they had the risk to have hepatitis. Thank God, their test results were negative. And that's it. But my conscience still bothers me. (P12, lines:110-114)

### *PLWH's Experiences in the Healthcare Setting*

The experiences of the participants on this theme were presented in two contexts, which were *confidentiality* and *discrimination*.

**Failure to Protect Confidentiality:** It was deduced from the statements of all the participants that their confidentiality was not protected in healthcare environments. One problem in this regard is the failure of the health system, health databases, and private health insurance companies to take the necessary precautions to protect the confidentiality of the personal data/information of people receiving service 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 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 to these data. (P20, lines:115-118)

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 GHI for this. (P2, lines:184-186)

In addition, participants stated that healthcare professionals did not pay enough attention to protect 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 internal diseases clinic. And he told it to my father (...) I think it's a very serious violation of human rights, right to privacy. (P18, line:69-71)

There were two other customers waiting next to me. I was sitting on a chair when the pharmacist asked the pharmaceutical technician to bring 3 boxes of Stribild by shouting out the names of the drugs. Then, speaking loudly again, he said "Your medication is ready, Mr. X." The one sitting beside me stood up, and I understood at that moment that he was living with HIV. (P20, lines:274-277)

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

test results visible. I see it very often. (...) People add me on Facebook, for example, saying that they had seen my file on doctor's desk. We get treatment from the same doctor, and they add me. (P10, lines:154-157)

Moreover, the participants thought that some health professionals ask questions such as "how did you get the virus?" out of curiosity, and this has nothing to do with a a professional attitude.

I went to see a psychologist for the first time. Anyway, I was talking to her, telling about it. She asked me how I had got the virus. People are very curious about it.

What's it to you! (P17, lines:129-130)

**Being Subjected to Discrimination:** It can be deduced from the participants' statements that PLWH are subjected to conducts in healthcare environments that can be deemed as discriminative/segregative.

The main concerns of the participants in this regard are healthcare professionals' reluctance to operate on them, taking excessive precautions before any medical intervention, scaring the patients, and the feeling that healthcare professionals do not see them as people and that the pharmacists feel 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 couldn't get it. I felt that he was abstaining. But I didn't swallow it, say something else. (P10, line:251-255)

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 MoH came to the hospital, but then of course I understood she was talking about me. (P18, lines:164-168)

In addition, the majority of the participants expressed the need for necessary regulations so that just like other patients, PLWH could receive healthcare services from health institutions without being subjected to any segregative acts and that healthcare professionals should be more understanding of their condition.

I heard that only this hospital offers dialysis treatment to patients like us, which means patients with HIV virus are deprived of this service. In whole Istanbul, only this hospital and, as far as I know, another one in Maslak provides 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! (P8, lines:93-95)

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 have I gone? (...), then I didn't give blood sample no matter who requested it. I lived like this for three years. (P7, lines:180-184)

Some of the participants also stated that they think healthcare institutions do not want to provide service to them and the healthcare professionals working at private healthcare institutions are not knowledgeable enough on 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 they were too busy and referred me to another hospital. I went there (...) They said providing healthcare service to such kind of patients is not welcomed at their hospital. They told me "Go the hospital that you get treatment for it and have yourself operated there." (P1, lines:83-86).

### *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.

**Patients' Protecting Themselves against Adverse Consequences of the Disease:** It was derived from the participants' accounts that they tend to hide their HIV status in the healthcare setting and their social sphere so as not to encounter any negative reaction.

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 tell 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. (P14, lines:146-149)

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 the 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. (P1, lines:87-88)

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. (P2, lines:163-165)

## **Discussion**

In the present study, PLWH's perceptions of the healthcare services they receive was analyzed based on their lived experiences. In light of our findings, the discussion was centered upon the following themes: autonomy and getting informed consent, the impact of

HIV on personal and social life, the right to privacy and private life, responsibility for third parties, 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 regarding the PHWH 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. In Turkey, HIV tests are administered in healthcare institutions and at volunteer testing and counseling centers (10, 20). Nevertheless, the lack of general awareness and knowledge on its modes of transmission and preventative measures, and discriminating and stigmatizing attitudes and behaviors towards PLWH both in Turkey and other countries can be seen as the barriers to direct HIV testing and diagnosis disclosure (21, 22).

In this context, the process of notifying the test results to patients is particularly highlighted. Being diagnosed with HIV might have a shocking effect on individuals and lead to anger, sorrow, and fear in them even if they have already been suspecting it (23). Similarly, in our study it is inferred from the participants' statements that they experienced a sudden emotional trauma upon getting the bad news and thus could not make a rational evaluation of what physicians were telling them. They also said they did not get a satisfactory explanation or clear answers to their questions when they were asked to give blood samples for a verification test, which might have caused them to feel uncertain about their health condition and added to their fears and concerns. Some participants stated that they were notified of the diagnosis in the presence of their families or on the phone. However, any test result must be kept confidential between the patient and the physician, and delivered privately to the patient by

the responsible physician, especially in cases where patients are likely to be subjected to discrimination, like in the case of PLWH (24).

Our findings suggest that the participants experienced a shock at this stage since the test was performed without their knowledge and the results were delivered to them without any accompanying counseling service. For example, according to the results of a survey study carried out by Gokengin et al. 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 service in 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 (21). Besides, the report issued by the Positive Living Association (PLA) regarding the violation of rights revealed that PLWH's rights in terms of informed consent and autonomy, confidentiality of private life and medical records, the right to health, and prohibition of discrimination have been violated, which, as was also stated in the report, stemmed from the preconceptions associated with HIV (25). Furthermore, 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 might cause certain problems in informing and notifying the patient (19, 26).

The guidelines specified by the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) urge that HIV related services must adhere to 5Cs: consent, confidentiality, counseling, correct test results, and connection. In this respect, the confidentiality of the patients must be protected and they must be adequately informed

and notified of the process for HIV testing and counseling, their right to refuse testing and/or treatment, and that self-testing is medically not safe. Then, their consent must be obtained for medical procedures (27). Nevertheless, to make HIV testing more widespread, self-testing kits that can be bought online or from pharmacies are used and there are centers that offer counseling service and HIV testing in many countries (28). In Turkey, self-test kits are sold online, though they have not been approved by the MoH. Besides, due to the lack of knowledge in the society as to the diagnosis, treatment, and modes of transmission of HIV/AIDS (29) as well as a shortage of HIV testing and counseling centers, patients are likely to be left without support against the problems they will face upon being diagnosed with HIV such as being subjected to societal discrimination and coping with the feelings of intensive anxiety and fear of being excluded (30, 31). Some of our participants stated that their doctors referred them to the related foundations where they can receive counseling for such problems. However, these volunteer foundations cannot reach all the people in need of such services. Therefore, such services should be offered as part of public services at hospitals and other healthcare institutions so that they could be sufficient in number and service quality, and easily accessible for PLWH.

The participants highlighted the significant effect of the physicians' attitudes on their lives and treatment process. 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 processes; moreover, exhibited avoidant behaviors such as moving away from the patient during face-to-face encounters. Similar to these findings, the studies conducted in other countries also demonstrated that the quality of the physician-patient relationship is a significant factor influencing a patient's desire to pursue treatment (32, 33). For example, a study carried out in Baltimore revealed

that strong communication between the physician and the patient plays an important role for engagement in treatment (34). An essential component of a healthy physician-patient relationship is the physician's ability to provide appropriate professional guidance to their patients. Therefore, it's imperative that the undergraduate and graduate medical education in Turkey cover subjects such as professional approach to vulnerable groups and communication skills to ensure that the physicians face their preconceptions on PLWH, improve their professional attitudes, and act for the good of the patient.

Living with HIV might pose a significant risk factor for a person's private life and psychological health (35). For instance, the conception that HIV is a disease of homosexuals and sex-workers have caused most of our participants to blame themselves and develop a fear of rejection and stigmatization, and thus to be reluctant to acknowledge their diagnosis. They stated that they had to make certain changes in their lifestyles, the most prevalent of which was ceasing all sexual activity. They also avoided close physical contact with people around them and separated their personal belongings from the ones living with them for fear of communicating the disease to them. Some participants did not share their HIV test results with the family or friends so as not to upset them and/or to prevent any possible discriminatory act. Struggling with this on their own might cause 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 face were being subjected to discrimination, sharing their HIV status with others, sexuality, and financial issues. For such problems they mostly used palliative coping strategies and developed anger (36). In another study conducted in Izmir, Turkey in 2018, in-depth interviews were performed with 27 PLWH, and the obtained results showed that the patients tended to keep their HIV status to themselves due to the

existing discriminative and stigmatizing incidents in the society (37). Our findings were found to be in line with the results of these two aforementioned studies.

The majority of the participants stated that healthcare professionals notified their employers, families, and friends of their HIV status without their prior knowledge and consent. Similar results reported in a survey conducted by Gokengin et al. in 2017. While 43.9% of the participants said they were sure that their HIV status was disclosed to third persons and institutions by healthcare providers without their consent, 30.6% of them had suspicions about it (21). The problem of not respecting the confidentiality of personal data is prevalently witnessed in other countries as well, especially in the case of PLWH (38, 39, 40, 41). In a study conducted in African countries, for example, the participants asserted that healthcare professionals shared their HIV test results with their families (42). Considering that physicians in Turkey have difficulty breaking the bad news to patients and thus prefer to notify their families (43) and that there is no regulatory framework on this issue, further large-scale studies both on the experiences of PLWH and healthcare professionals need to be conducted in Turkey to reach an absolute conclusion.

In addition, some participants stated that their health insurance companies shared their HIV test results with their employers. Some of them said they did not use their private health insurance for HIV treatment fearing that they might be fired them once these companies disclose their HIV status to 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 (44), and in that case, the workplace physician or the health insurance company have 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 (45). However, the

basic problem this causes to an employee living with HIV is the risk of being fired after their HIV status is disclosed. In a previous study where the problems PLWH face in the workplace was investigated, it was found that PLWH lose their jobs and are unable to find other jobs due to their HIV status (44). Most countries have various legislative regulations to prevent the discrimination PLWH experience in their workplaces (46, 47). Although there are no such regulations in Turkey, PLWH have the right to work just like other citizens (48). According to the code of practice specified by the International Labor Organization (ILO) on HIV/AIDS and the world of work, HIV-related personal information can not be required of job applicants, HIV infection can not be considered a cause for termination of employment, 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 (49).

Outside of the 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 protection of confidentiality and arouses questions as to with whom and to what degree such data be shared (50). As of 2003, with the implementation of the Health Transformation Programme, the private sector has played a bigger role in the delivery of health care services (19), and personal health data has been collected by the MoH, Social Security Institution, and private health insurance companies. As a result of this, the rate of the 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 third persons and paves the way for their disclosure at the national and international levels (51). Similar examples have been reported in the literature (52, 53). In a study carried out on people with chronic diseases in

South Ontario, for example, the participant PLWH group was found to be more concerned about privacy due to the fear of HIV-related stigma (54). It can be deduced from these findings and examples that the failure to protect confidentiality causes problems to PLWH in their access to healthcare services as well as in the workplace. To eliminate discrimination and related problems, legislative regulations can be introduced and campaigns aiming to raise awareness on the issue might be organized.

On the other hand, PLWH's wish not to disclose their personal data and thus keeping their spouses/partners or persons they have sexual interaction with uninformed about the risk that they pose on them causes an ethical dilemma (55). This is also important for the physician who understands the potential harm that it would cause to the patient and their partner spouse/partner (56, 57). Although partner notification (PN) can be a life-saver for 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 (48). 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 provide them psychiatric support in this process and their partners will get a medical notification unless they respond to the form (58). Likewise, as was stated by the participants in our study, PN is performed in various ways. Some participants stated that they had been encouraged by their doctors to notify their spouses/partners, others said they had done partner notification either by themselves or together with their doctors. Single patients or patients with multiple partners said they had difficulty doing the PN, and some of them said their doctor had notified their

spouses/partners directly without their consent. 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 (59). 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 (60). In some countries, under certain circumstances HIV transmission is considered a criminal offense. In the United States of America for example, due to the conducts that cause intentional transmission of HIV infection or another sexually-transmitted disease, a person can be charged with attempted murder, though there is no such law specific to HIV (61). In Turkey, people are prosecuted under general legal provisions in such cases (62). However, rather than trying to prevent HIV transmission by prosecuting PLWH for transmission of the virus, governments should prioritize developing programs that are proved to be effective in reducing HIV transmission and allocating resources for this matter. In this way, not only the dilemmas that PLWH face would be solved but also 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 (63). It was reported that people who are aware that they've had 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 (64, 65). 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.

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 as a form of discrimination. Likewise, it was reported in a study conducted in South China that almost half of the PLWH participating in the study were subjected to discrimination in healthcare environments and thus refused to benefit from healthcare services (66). In a study carried out in Kazakhstan, it was found that PLWH experience denial of services by healthcare professionals and tend to avoid healthcare professionals due to such perceived negative attitudes (67). Another study conducted in the Netherlands revealed that PLWH have negative experiences in their interactions with healthcare professionals such as being exposed to irrelevant questions, impolite behavior, blaming, excessive or irrelevant precautions, care refusal, unnecessary referrals, delayed treatment, and violation of confidentiality (68). There are also studies in Turkey which demonstrated the stigma and discrimination in the healthcare setting both on institutional and individual levels against PLWH (15, 21, 69). The report issued by the PLA regarding the violation of rights revealed that PLWH are subjected to discrimination mostly in healthcare environments, the necessary medical care is not given to them, and their right to health is impeded (25). In a study, where healthcare professionals' attitudes were examined, it was found that preconceptions and the lack of knowledge on the modes of transmission and prevention was high among all participants, and 50% of the participants stated that they did not want to follow-up PLWH (70).

In the 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 so that they cover the content of professional approach towards PLWH to prevent discrimination in healthcare environments against them. Especially HIV-related stigma and discrimination in

the healthcare setting cause challenges to PLWH in their access to healthcare services and thus pose risks to their health status. To prevent possible miscellaneous harms from occurring, the current regulations on patient rights must be put into effect. As was deduced from our findings, people benefiting from counseling services tend to take action to pursue their rights when faced with a problem. As a response to their pursuit, campaigns on raising PLWH's and their families' awareness must be held and centers that would provide country-wide professional counseling services should be established.

### **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 the participants' thoughts on issues such as not getting informed consent of PLWH before HIV testing, breaches on the protection of confidentiality and privacy, problems in spouse/partner notification, and PLWH's being subjected to discrimination and stigma from healthcare professionals and institutions. Moreover, the magnitude of such problems and their prevalence in Turkey remain tentative. The poignancy of the obtained results emphasizes the need for further studies representing the whole universe 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 and to increase people's knowledge of the issue. Besides, to encourage individuals to take volunteer testing, pre- and post-testing counseling services designed in line with the 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 to be taken to

protect PLWH's personal health data against their improper accessibility by the 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 widespread the institutions providing clinical ethics support for the ethical conflicts that healthcare professionals and patients' families experience regarding this issue might contribute to the protection of the professional values of physicians and ensure the patient's beneficence.

### **List of abbreviations**

AIDS: Acquired Immune Deficiency Syndrome

GHI: General Health Insurance

HIV: Human Immunodeficiency Virus

ILO: International Labor Organization

MOH: Ministry of Health

MSM: Men who have sex with men

PHI: Private Health Insurance

PLA: Positive Living Association

PLWH: People living with HIV

PN: Partner notification

UNAIDS: Joint United Nations Programme on HIV/AIDS

WHO: World Health Organization

## **Declarations**

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### Ethics Statement

Approval for the present work was obtained from Acibadem Mehmet Ali Aydinlar University, Ethical Committee for Scientific Research and Evaluation with the decision dated 03.08.2017 and numbered 2017-13/35.

### Conflict of Interest

The authors declare that they have no conflict of interest.

### Authors' contributions

Gamze Senyurek devised the study, the main conceptual ideas and proof outline, conducted the interviews.

Mustafa Volkan Kavas contributed to the analysis, reporting and interpretation of the results and to the writing of the manuscript.

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

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