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STIGMA AND DISCRIMINATION TOWARDS PEOPLE LIVING WITH HIV/AIDS: A QUALITATIVE STUDY, ISTANBUL/TURKEY

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ABSTRACT

Objective: The human immunodeficiency virus remains one of the most important public health problems across the world. It has an important influence on mental and physical health, and social life. Early detection, regular examination, follow-ups, and antiretroviral therapy are preventive in progressing the disease from HIV to AIDS. However, stigma and discrimination are major impediments to cope with HIV and HIV related complications. Thus, it is crucial to understand the perception of stigma and discrimination towards HIV-positive within families, health care settings, communities and workplaces.

Method: A grounded theory-based qualitative analysis was used for data analysis. Purposive and snowball sampling method was used with a semi-structured questionnaire for data collection. The principles of the Consolidated Criteria for Reporting Qualitative Research (COREQ) were applied to report the methods and results. MAXQDA21 qualitative program was used for data analysis.

Results: The study consisted of 20 male and 3 female participants aged between 23 and 66 years old. Majority of them were men who have sex with men (69.5%; n:16). All of them, except one, contracted HIV by sexual intercourse. Almost half of them were university graduates; just over 13%(n:3) of them had job security. Two themes and five categories emerged from the codes defined by the data analysis. These themes were as follows: stigma and discrimination; and outcomes including mental health problems.

Conclusions: Almost all participants in this study experienced stigma and discrimination at all levels of life. Their coping strategies and interpretations of HIV/AIDS varied. Mental health problems were main outcome. Providing public engagement and increasing awareness/knowledge through social media, schools, universities, and formal and private communication resources may help them tackle negative life experiences, such as stigma and discrimination. It can be suggested that HIV, which is an important chronic infectious disease in terms of public health, should be included in the education curriculum of health departments.

Keywords: HIV/AIDS, stigma, discrimination, antiretroviral therapy adherence, grounded theory, depression, suicide ideation, social prejudice

HİV/AİDS İLE YAŞAYAN KİŞİLERE YÖNELİK DAMGALAMA VE AYRIMCILIK: NİTEL BİR ARAŞTIRMA, İSTANBUL/TÜRKİYE

ÖZ

Amaç: İnsan immün yetmezlik virüsü, dünyadaki en önemli halk sağlığı sorunlarından biri olmaya devam etmektedir. Ruh ve beden sağlığı ile sosyal yaşam üzerinde önemli bir etkiye sahiptir. Hastalığın HİV'den AİDS'e ilerlemesinde erken tanı, düzenli muayene, takip ve antiretroviral tedavi önleyicidir. Bununla birlikte, damgalama ve ayrımcılık, HİV ve HİV ile ilgili komplikasyonlarla başa çıkmada başlıca engellerdir. Bu nedenle, ailelerde, sağlık bakım ortamlarında, topluluklarda ve işyerlerinde HİV pozitiflere yönelik damgalama ve ayrımcılık algısını anlamak çok önemlidir.

Yöntem: Veri analizi için kuram temelli nitel analiz kullanılmıştır. Verilerin toplanmasında yarı yapılandırılmış bir anket ile amaçlı ve kartopu örnekleme yöntemi kullanılmıştır. Yöntem ve sonuçları

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raporlamak için Niteliksel Araştırma Raporlama için Konsolide Kriterler (COREQ) ilkeleri formu kullanılmıştır. Veri analizi için MAXQDA21 nitel programı kullanılmıştır.

Bulgular: Araştırma, yaşları 23 ile 66 arasında değişen toplam 20 erkek ve 3 kadın katılımcıdan oluşmaktadır. Katılımcıların çoğunluğu homoseksüel erkeklerden oluşmaktadır (%69,5; n:16). Katılımcılardan biri hariç hepsinin cinsel ilişki yoluyla HIV'e yakalandığı görülmüştür. Katılımcıların neredeyse yarısı üniversite mezunudur; %13'ten biraz fazlası (n:3) iş güvencesine sahiptir. Veri analizi sonucunda damgalama ve ayrımcılık, ruhsal sağlık sorunlarını da kapsayan sonuçlar olmak üzere iki tema ve beş kategori ortaya çıkmıştır.

Sonuç: Bu çalışmaya katılanların neredeyse tamamının yaşamın her seviyesinde damgalanma ve ayrımcılığa maruz kaldığı görülmüştür. Başa çıkma stratejileri ve HIV/AIDS ile ilgili yorumları farklılık göstermektedir. Damgalama ve ayrımcılığa maruz kalmanın ruh sağlığı üzerinde önemli etkisi olduğu anlaşılmıştır. Damgalama ve ayrımcılıkla mücadele için halkın katılımını sağlamak, toplumsal farkındalık ve bilincin arttırılması önemli olabilir. Bunun için sosyal medya, okullar, üniversiteler ve resmi ve özel iletişim kaynakları ile işbirliği yapılabilir. Toplum sağlığı açısından önemli bir kronik enfeksiyon hastalığı olan HIV'in özellikle sağlık bölümlerinin eğitim müfredatına dahil edilmesi önerilebilir.

Anahtar kelimeler: HIV/AIDS, damgalama, ayrımcılık, antiretroviral tedavi uyumu, gömülü teori, depresyon, intihar düşüncesi, sosyal önyargı

1. INTRODUCTION

The human immunodeficiency virus (HIV) remains one of the most important public health problems across the world. In the last half-century, great efforts have been made globally to prevent HIV transmission and to provide efficient treatment (Ghiasvand et al., 2020; Ornek & Ardic, 2019; Wagener et al., 2015). Thus, the number of people who live with HIV (PLHIV) has been reduced in countries where basic human rights are protected, socioeconomic status is high, democracy culture is developed, preventive health is prioritised, and easy and free access to health services and antiretroviral therapy (ART) are provided (Carlander, Wagner, Yilmaz, Sparén, & Svedhem, 2021). However, the prevalence of PLHIVs in Turkey is on the rise. According to the latest national data in 2018 by the Ministry of Health in Turkey, the total number of diagnosed and registered PLHIVs was over 21,500, with the majority being 25–34 years old people. The majority of PLHIVs were men (79.9%), and over 15% of them were foreigners (Republic of Turkey Ministry of Health, 2019). In particular, Istanbul has over 42% of registered PLHIVs in Turkey, according to data from a cohort study that took place in only four PLHIV care centres between 2016 and 2017 (Mete et al., 2019). The main leading cause of transmission was heterosexual intercourse, but over 48% of PLHIVs did not report any possible transmission. Sex workers, injection drug users, men who had sex with men (MSM), and transsexuals were the main risk groups (Republic of Turkey Ministry of Health, 2019). In Turkey, it is compulsory to perform HIV tests before blood and organ donations, before surgery, in registered sex workers, and before getting married. However, it is also widely conducted before planned pregnancy and during pregnancy, and for job recruitment and health screenings (Gokengin, Calik, & Oktem, 2017; Ornek, Tabak, & Mete, 2020). A person who starts a new job in Turkey is also commonly required to undergo a general medical examination and clinical tests, including HIV testing, at regular intervals while working (Öktem, 2014). People in Turkey also need to be tested for HIV before enrolling in some leisure centres, such as swimming pools. Thus, some of these voluntary applications have become unofficially mandatory which may cause unnecessary stress on PLHIV’s life

Stigma and discrimination are major challenge among HIV-positive people. Many studies in related fields show that stigma and discrimination may have an important influence on managing HIV and comorbidities in the world, especially in Turkey (Abedinia, Rasoolinajad, Noorbala, & Badie, 2019; Haffejee, Maughan-Brown, Buthelezi, & Kharsany, 2018; Ornek et al., 2020; Yathiraj et al., 2018). Because, stigma and discrimination by professional health staff and at the workplace by colleagues and employers, or in social life, are the most common and main negative factors coping with HIV/AIDS (Andrewin & Chien, 2008; Öktem, 2014; Ornek et al., 2020). These cause many problems among PLHIVs, such as not seeking health care, giving up on ART, job search or job loss, mental, and physical health problems, social isolation, losing self-confidence, and social identity (Bader et al., 2006; Gesesew et al., 2017; Oran & Şenuzun, 2008; Ornek et al., 2020; Zhao et al., 2019). Society prejudice, insufficient or spurious knowledge, traditional cultural approach to gender roles, sexual life and coping profiles, and sociodemographic characteristics such as gender and sexual preference seem to be the main reasons for developing stigma and discrimination towards PLHIVs (Bezabhe et al., 2014; Eshun-wilson, Rohwer, Hendricks, Oliver, & Garner, 2019; Yathiraj et al., 2018). MSM and women are the most vulnerable compared to heterosexual men due to their traditional culture and beliefs in society of Turkey. In the case of HIV disclosure, these groups also have to deal with being homosexual, which is predominantly believed to be “sinful” in society. Some studies have reported that these kinds of approaches and thoughts towards PLHIVs in social life make them feel shame and guilty, prevent them from seeking health care behaviours, or decrease their level of ART adherence (Brion, Leary, & Drabkin, 2015; Monroe-wise et al., 2019). Thus, PLHIVs may strive very hard to overcome internal and external difficulties due to their HIV-positive status (Boucher et al., 2019; Brion et al., 2015; Naidoo & Premdutt, 2019).

As a result, it is crucial to understand the perception of HIV-related stigma and discrimination among PLHIVs, and their experience, reactions, and coping strategies in managing HIV-positive status. However, there is insufficient studies about perception of HIV-related stigma and discrimination towards HIV-positive people in Turkey. Thus, a grounded theory-based qualitative study was designed for an in-depth examination of PLHIV’s perception and experience of stigma and discrimination, including reactions, coping processes, outcomes, and underlying factors, which might also be a framework for a future quantitative study. To our knowledge, this is the first qualitative research study related to the perceptions and experiences stigma and discrimination towards PLHIVs in Turkey. We suppose that the data of this study will increase social awareness, sensitivity, and democratic awareness against HIV/AIDS disease in society, which may consequently improve the quality of individuals’ lives, prolonging the program in the future for a systemic solution.

2. METHOD

2.1.Study design

The study was based on grounded theory and had a qualitative explorative design (Glaser & Strauss, 1967). Purposive and snowball sampling method was used with a semi-structured questionnaire for data collection. The principles of the Consolidated Criteria for Reporting

Qualitative Research (COREQ) were applied to report the methods and results (Tong, Sainsbury, & Craig, 2007) (Supplementary form 1).

2.2.Study site

Istanbul is the most developed and crowded metropole city in Turkey, with over 15 billion registered residents. It is an attractive city for internal and international migrants owing to health care resources and a variety of work positions available. There is no specific data on number of PLHIV who lived in Istanbul, but we estimated that Istanbul has more than 40% of total registered PLHIV in Turkey when compared the national report regarding HIV prevalence in Turkey and a cohort study which took place in Istanbul (4,5). Interview times and places were organised with the PLHIV, and all the interviews took place in a separate room with only the researchers and interviewer.

2.3.Selection of participants

Two main approaches were used to reach the participants. The first process was purposive sampling conducted through policlinics of infectious diseases at five hospitals in Istanbul. For this, permission was obtained from the provincial health directorate of the head of the hospitals. A formal and informal meeting was also held with the heads of the Department of Infection Diseases of the hospitals to clarify the data collection methods, including measurements and the confidentiality of possible participants. However, three of these hospitals allowed us to contact the patients. Afterwards, flyers that explained the aim of the study, how confidentiality will be provided, and data protection were left with secretaries and physicians. These flyers were passed to patients who visited the policlinic. The patients who voluntarily agreed to join the study contacted the researcher. The second was a snowballing method involving a meeting held between the researcher and leaders of the Positive-Iz Association and Positive Living Association in Istanbul, which were advocates of the rights of HIV-positive people. These organisations also offered free counselling. An announcement of the study was made through regular meetings of the associations by the persons in charge. Some participants were contacted through their friends. The participants in the study were selected based on the following criteria:

- HIV-positive person who voluntarily agreed to attend the study.
- HIV-positive person who was at least 18 years old.
- HIV-positive person who had a HIV-positive diagnosis for at least six months.
- HIV-positive person who lived in Istanbul.

Initially, 27 PLHIV showed interest to attend the study. However, two of them refused to participate in the study, having learned that the sessions would be recorded, and another two did not volunteer to join the study. Finally, the study consisted of 20 male and 3 female participants (Table 1).

2.4. Ethical statement

Research Ethics approval was sought and obtained from Istanbul Bilgi University Ethics Committee (Ref no: 40016-48). Voluntary informed consent was given by the individuals verbally and in written form. All methods were performed in accordance with the Declaration of Helsinki. Identification codes were used to protect confidentiality and anonymity.

2.5. Data collection

The authors of the current study met with the participants to explain the aim and method of the study. A voluntary informed consent was then given to potential participants verbally and in written form. This form explained all information regarding the present study, including confidentially and ethical approval from the Istanbul Bilgi University Ethics Committee. Identification codes were also used to protect confidentiality and anonymity. Data were collected by two authors (a female/post-doc researcher, registered nurse, assistant professor, and a male/Ph.D. student, psychological counsellor, research assistant) from a total of twenty-three PLHIV using face-to-face semi-structured interviews. The first author worked for more than three years in the Department of Infection Diseases and Services at a university hospital. A semi-structured question form was used for data collection. Initial version of this form was sent to three experts (two of them were physicians of infectious diseases, and one of them was a psychiatrist). The form was edited after peer debriefing from the experts. Then, a pilot study was conducted with three PLHIVs. However, the edited version of this form was found to be understandable, meaningful, and relevant. Interviews were conducted between March 2018 and February 2019 in Turkish at which point concepts and categories were analysed from the data. Each of the interviews lasted 45–60 minutes and were audio-recorded with participants' consent. Participants' non-verbal responses were noted during the interview by the interviewers, and later connected with the results. The saturation point was reached after the 23rd interview. The point of data saturation was discussed to meet consensus by both researchers. Following the initial meeting, none of the participants refused to take part or opted to withdraw from the study, but repeat interviews were not carried out, as there was no need. The audio records were transcribed verbatim by the researchers at the earliest time, immediately after the review. None of the participants preferred to check their transcriptions due to fear or concern of the risk of disclosure, except for three participants who were also activists in defending rights and worked in the associations.

2.6. Data analysis

The transcripts in the Turkish language were imported into the MAXQDA 21 software qualitative program for systematic grounded data analysis following Straus and Corbin (Corbin, Juliet M.; Strauss, 1990). Themes and categories were identified from the data as follows: (1) sentences and concepts that have the same meaning were identified through line by line coding scanning; (2) these sentences and concepts were labelled with emerging codes with summarising information regarding participant's experience of HIV-positive status in life as the coding tree of data analysis (table 2); (4) these codes were grouped into categories based on comparative method, and each category consisted of at least two conceptual codes (open coding). At this stage, a model of core category was developed; (5) other themes and categories were developed based on this model, which illustrated the relationship between the individual characteristics of the PLHIVs, their reactions to HIV positive status, and other experiences after being diagnosed, and the underlined factors which affect process of adaptation and acceptance process among participants, and outcomes (axis coding)(table 2); and (6) the model was simplified to theoretically explain relationship between themes and categories (selective coding)(figure 1). Data analysis was performed using MAXQDA 21 programmes and was conducted independently by two authors (OKO, ES). The results analysis by these two authors was constantly compared, and differences in coding were discussed until consensus was reached. In line with ethical principles, the identities of the participants were not revealed in the presentation of the findings; instead, codes were assigned to the participants (such as K1, K2, and K3).

The emerging concepts, categories, and themes were first translated from Turkish into English by a bilingual language expert and psychologist (Ph.D.). The last version of the data was developed after a consensus was reached between the translators. The data were then translated back into English by two translators (medical physician and psychological counsellor). The English, Turkish, and "back-translated" versions were discussed by an expert panel on HIV/AIDS and mental health (Table 2).

3. RESULTS

3.1.Demographic characteristics

Finally, the study consisted of 20 male and 3 female participants aged between 23 and 66 years old. Majority of male participants (69.5%; n: 16) expressed their sexual orientation as homosexual. Over 69% of them were single. Almost half of them were university graduates; just over 13% of them had job security. All of them, except one, contracted HIV by sexual intercourse (Table 1).

FIGURE 1

We found that HIV status was required in many spheres of life, such as at an antenuptial (before getting married), before beginning to new work, and regular intervals at the workplace, especially before surgical operation without their consent at hospital, before registering at swimming pools at leisure centres in Turkey, when travelling to some countries, or getting resident permits in some countries. HIV-positive status of patients is clearly stated in the prescription when buying medicine, which makes them avoid getting their medication on time, or they may prefer to get medications from an unfamiliar part of the city to avoid their acquaintances getting know of their status by coincidence (Ornek et al., 2020). All of these requirements put patients at risk of HIV status disclosure without their will, which may also result in stigma and discrimination. As a result, two themes and five categories were emerged from the data analysis.

3.2.Theme 1: Stigma and discrimination

Enacted stigma and discrimination

More than two-thirds of the participants (N:15) experienced stigma and discrimination directly in formal and informal institutions due to their internal policies, practices and approaches, at workplace and health care settings. For example, a Turkish student studying at a university in Cyprus, who was not granted a residence permit because he was HIV-positive, and was expelled right after, expressed his grievances as follows; *"…it is a somewhat sad story for me. Because I had to be recorded … I was a university student too… I learned in the middle of the 2nd year". (K9).* Likewise, it is known that the majority of workplaces include HIV serology testing in routine employment tests. Therefore, there is a general concern that they will not be hired if their test positive for HIV. Some of the participants experienced this discrimination directly. It has been observed that there are such stigmatized and discriminatory approaches and practices even in institutions such as state airlines and hospitals. For instance, it was observed that the inpatient with advanced neurological health problems and who had almost reached the level of AIDS was discharged from the hospital without any cooperation and guidance with the infection service physicians. However, he continued to have problems due to HIV positive result when the patient wanted to be taken to his hometown due to the need for close family care, it was observed that this patient, who had neurological problems at a bed-ridden degree, had great difficulty in finding airlines and an ambulance. In his hometown, it was seen that many hospitals did not admit the patient to the hospital. The participant expresses this situation as follows: *"…anyway, I went there, I was taken directly to a hospital by ambulance (he paid for it). First, X state hospital did not want to accept me. They clearly said that don't bring it here. They said to me go to a private hospital". (K12).*

Some participants exposed to stigmatising and discriminative behaviours, attitudes, and negative atmosphere within families. Some of the participants stated that after sharing their HIV status, people in their inner circles became distant and no longer met with them. A young male participant explained his experience as follows: "*Because she sees it like that, she sees it from her perspective. One day she said something to me, "I don't even want to hug you." So it is very difficult for a mother to say that...*" (K12).

One of the most common concerns of the participants is to be unemployed one day in the coming future. Because, although it is not a legal requirement, some workplaces have consciously or unconsciously included HIV testing in their routine job entry tests. However, in this study, the HIV-positive status of 3 people was learned by their colleagues and managers at the workplace. When their colleagues at workplace become aware, which resulted in unbearable stigmatisation and discriminative behaviours by their employer and colleagues, or even in job loss as in the case of a young woman who stated:

"…I came the next day, after this speech, these bags that have been taken to the toilet, these bags are passed. The bag has been taken. Everyone got a glass, everyone did something like this. I went insane, you know, at that moment, I went insane… then the same day, no, my manager called me the next day, he said K8, everyone united, everyone would resign if you worked… but you know, like a cat, they threw me in front of the door". (K8).

In addition, the results of current study show that more than 56% of the participants experienced stigma and discrimination during the hospital services process. These experiences vary, but the most common are; failure to perform the surgery planned by the physician, refusing the treatment, early discharge from the hospital, refusing to touch the patient when the individual declares to be HIV-positive, scolding, physicians wearing gloves or interrupting the examination with washing their hands, or being scolded, blamed and judged by the other auxiliary personnel of the hospital... For example, a young man expressed his experience as follows;

"*I went to the plastic surgeon, ... I already told my status there, HIV testing is a mandatory thing before surgery, but I declared it without being tested. The plastic surgeon lady said, "Unfortunately, our hospital does not accept HIV-positive patients. Because hepatitis C from a patient to a doctor has been infected before, our chief physician does not want it*". (K10)

In addition, a 44-year-old single teacher and a 31-year-old male participant, who were exposed to discrimination and stigmatizing behavior, described their experiences as follows: "*There has already been enough discrimination in the treatment process. I couldn't get treatment, I was officially expelled from a hospital, I was discharged, a hospital didn't accept it, I couldn't get physical therapy*" (K12)

"*Here was a private hospital, the doctor said I can't operate on you...In the second time, an operating room attendant in the operating room said bad things, of course he said something like "Do you know how you got this disease, how you will live from now on, what patients I saw, everything will be very bad". Of course, he said these when I was about to sober up* (K1)

It was found that "AIDS" or "HIV" was written on the patient- ID wristband and file of some inpatients in a way that everyone can see, although the diagnosis of any patient who is in the hospital or during the operation is not written on the wristband and file. It was observed that this approach and attitude greatly affected the spirituality of the patients. In addition, although the general majority of the participants did not want to tell their closest relatives or friends that they were HIV-positive without their consent, it was observed that writing HIV/AIDS on their wrist or on the file made them uneasy and affected the continuity of the treatment. Participants expressed their experiences, reactions and feelings on this issue as follows;

"*In one of the two surgeries, they wrote HIV positive on the bandage*". (K1)

"*While I was being treated there, I said I am HIV-positive before I started the treatment, so I said take your precautions accordingly. He did the procedures directly at work, then there was a prescription about the teeth like a report card, they wrote AIDS on it. So what can you expect at this point? I say HIV-positive, the healthcare provider, the doctor writes AIDS there, they don't even know what these two concepts are. I mean, what kind of healthcare professionals are these people?"* (K6).

In addition, demographic characteristics, occupation, economic situation, history of HIV-positive diagnosis, and related knowledge and individual perceptions of HIV, cultural values, and personality traits. It seemed that cultural values and personality traits had an important impact on seeking health care behaviours and adherence to ART. Traditional cultural norms seemed to be very strong barriers in a controversial and closed society, which shaped the roles of gender and expectations from a "normal" family. For example, we observed that the majority of the participants were MSMs, who most likely left the city where they used to live to protect their social identity, including the "honour" of their family, preventing possible discrimination and stigmatised behaviours against them. Thus, living in a big city seemed much safer and also appeared to be a reasonable life possibility for preventing stigma and discrimination towards them.

HIV is often directly associated with homosexuality and sexual relations with women sex workers, or especially with women from ex-Soviet Union countries in society. Thus, this common approach and belief of society in Turkey places a great burden on HIV-positive people, but especially on MSMs. They were scared of exposing to stigma and discrimination within communities. Therefore, some of them do not prefer to get health care until their clinical deterioration becomes very apparent to hide their sexual preferences, which may damage their professional and social relationships. "*After learning about my situation, I went through a period of unacceptance for three years. I did not share with anyone…some kind of process…. I got to an advanced stage in 2016, where I was in the AIDS stage. I was down to 40 kilos. I started treatment by being taken to the hospital" (K10).*

Women were also found to be much more vulnerable due to gender norms. Being an HIV-positive person is kind of being out of conformity by social norms, and thus they may be easily judged morally and ostracised, as HIV is generally associated with sexual relations, which is a big taboo for women according to cultural norms. A young woman who divorced from her husband and hid HIV-positive status from everyone except her mother expressed her desperation: "*I cannot share this with any of my friend. I do not share…because all of my friend have diverged from me when they learnt this…I got isolated myself. I seriously isolated myself. At the moment, there is just my mum, father, sister, and brother…that is all. My close acquaintances know me as having cancer. We told them this. Because, they kept coming and coming and going. I was in bad shape, I was not able to walk, and I was crawling. I have been through such a serious transitional period. We told them I have cancer, that way so…"(K5).*

However, we observed that PLHIVs who had positive perceptions about HIV, high education, reasonable income, high self-efficacy, social support, and correct information about HIV rather than spurious knowledge, and fortunate enough to have a physician who had high ethical norms and sufficient knowledge regarding HIV, were found to be more successful in fighting against to stigma and discrimination and to cope with HIV-positive status and adherence with ARTs.

Self-stigma, Felt stigma and discrimination

Almost half of the participants expressed felt-stigma and discrimination within communities, family, close friends and at health care settings. Thus, stigma and discrimination were observed as the main perceived negative feelings towards themselves since they became aware of their HIV-positive status. Some of them could not get over internalising negative attitudes and thoughts about HIV, which made them avoid establishing new relationships while socially withdrawing themselves.

In this study, the results show that 26% of the participants experienced felt stigmatization feelings as if they were "worthless", "ugly", "like nothing", "dirty", "infected", "germ". Due to these internal accusatory and judgmental attitudes, it was observed that he was worried that he would infect people when he touched office materials they shared in the workplace, kissed their relatives or shared the same environment with close individuals such as family. A young woman, a divorced accountant, a young single teacher and a worker, and the principal expressed their feelings as follows.

"*you feel like a very contaminated virus is something and this germ will never go away from you…*"(P12).

"*A very cheap person, not like a human being, how can I say, you can say that it is either a leftover of something or a human, not valuable. I am not such a worthless, complex person in life, but I see myself as such a worthless, cheap, simple, ugly and bad thing. So I'm bad.* (K5).

"*As I said, it comes to the same point, you are looked at as if you are a person with the plague, as if you are carrying something deadly and you are going to kill people*". (K6)

The reactions of the hospital staff when they learned that the patient was HIV-positive were quite hurtful.

"*…so even if I die at that moment, it would be better if I didn't see that look and that expression"* (K4)

As a result, social prejudice is the most influential factor that feeds HIV-related stigma and discrimination(Li et al., 2017). This include the cultural characteristics of society, the existence of sexual taboos, and the stereotype that sexually transmitted diseases are resulted in deviant and sinful acts against HIV. For example, a young heterosexual man expressed his thoughts as follows: "*First, there is a lot prejudice because there is no knowledge; it is not known at all. There is a lot of fear where there is no knowledge. In addition, you can afford to a certain level individually. After a while to explain to everyone, …you don't want to be alone with someone, feel tired, want to take care of your own life. You do not want to have to explain to everyone, or to face their prejudices and their possible or unlikely prejudices, that is, to experience the process" (K11).* The participants were highly affected by the negative perceptions created in society about HIV. We think that the judgmental and marginalising language used, together with the cachectic patient picture by the national media in the first periods of identifying the disease in the world, contributed to this. Thus, they interpreted being HIV-positive as the same as being in the last stage of AIDS, and equated it to death. Therefore, their reactions to HIV-positive diagnoses were generally very extreme. For example, *"Of course, the first question that comes to mind before you get acquainted with the illness is, Will I die? How much time do I have left? Of course, it was more frightening since I was younger at the time. I didn't know what's going on. Of course, after getting acquainted with them, people overcome their fears faster."* (K9). Another important reason for the reactions is the widespread belief within society that HIV is transmitted sexually, mainly from MSMs. Sexuality and different sexual preferences are big taboos and very open to moral judgement due to cultural norms. This common approach and beliefs among society may make PLHIVs feel guilty, shameful, angry, concerned, self-accusatory, and upset, especially in the first weeks of diagnosis, which might also prevent them from seeking health care behaviours and cause stigma and discrimination towards the PLHIVs.

For example, some participants were found to have suicidal thoughts due to fear of death and stigmatisation, thinking that their lives were ruined when they had learned about their HIV status. "*I even thought of suicide at some point. I was aware of the result.*" (K13). We observed that some of them could not get rid of this feeling for long time. They did not seek health care, gave up on life, ostracised themselves from society, and became depressed. They were taken hospital when they were almost unconscious due to their health conditions. For example, a young single man who was homosexual expressed his feeling as "*I did not accept this situation for 3 years. I did not go to any hospital, I did not share it with anyone, I quit my job, I was in dark despair, I went through that process" (K10).*

Being employed with permanent jobs for HIV-positive individuals to sustain their lives is another important underlying factor of adaptation to HIV. They stated that having a guaranteed financial income helped them cope better with this process. Coping strategies adopted by HIV-positive individuals in dealing with the stigma and discrimination, exclusion, and losses also have great significance in their adaptation to life with HIV. We found that the participants mostly used active coping strategies, such as focusing on something else, gathering more information about HIV, seeking social support, speaking to an expert, an optimistic approach, and turning negativity into positivity. Individuals' beliefs, values, and practices appear to be significantly influenced by their sociocultural context. We observed that some participants adopted religious and spiritual coping strategies at some point. For example, the individual may cope with the losses arising from HIV-related stigma through approaches such as seeing it as God's will, considering it as a test, saying, 'There is a good in everything' and focusing on the positive. "*Now I have nothing in mind about that. Like it never happened. I think of this situation like 'this is the will of God; If he says OK, let's go, there is nothing to do,"* the participant coded K14 explained.

3.3.Theme 2: Outcomes

This theme consisted of positive and negative outcomes, which were associated with other themes and categories, as Figure 1 illustrates. The most negative outcomes were in descending order: psychological health problems, including depression, anxiety, and stress; fear of job loss; suicide ideation; social isolation; loss of confidence; inconsistent health-seeking behaviour; physical health problems; and loss of education rights and resident permit. The prevalence of these results was high among women and MSMs compared to heterosexual men. It may be possible to observe the influence of all these factors in the example of a 38-year-old married woman who got infected through her husband, as she learned the diagnosis when she lost her first baby because of her HIV-positive status. She felt betrayed by her husband, and could not share with anyone who was close to her except her mother to prevent stigma and discrimination within family and society. Afterwards, she also lost her job because of HIV disclosure by the physician directly when her colleague was in the room. She stated, *"I felt myself very unvalued. Felt very bad…(cries). Psychologically was too much …(cries) …bad, I did not also get psychological help, but I needed it a lot at this time. I thought I could get over it myself. In every minute…I was thinking, ok, that is it. I got over, but after two minutes I began to cry (she cries)" (*K8). Some participants changed their work so often or move to different city to prevent disclosure. Thus, they could protect themselves from stigma and discrimination within society and at workplace. X stated that "…*That's why I changed jobs very often, which hurt me economically*.". (K14)

Some participants who had high income, good education, support from family, close friends, or the association, were examined and followed up by knowledgeable and respected physician, had high self-efficacy, or were activists were found to be in a better adaptive process and coping with stigma and discrimination. For example, a 37-year-old, single heterosexual man who had good support from his sister, physician, and friends and who also worked abroad independently and with a high level of income stated that "*I continue living a perfect life and actively participate in several things. I feel very energetic, well, singing songs, taking photos, no decline in energy, neither on my perspective nor mentally.*" (K2). However, we observed that religion (Muslimism) was quite supportive generally in the case of being heterosexual man. Thus, they interpret this health problem as a fate, as a 38-year-old man who recently lost his job because of being HIV-positive stated that "*I am a religious person, thank God, and at this point, I believe that everything happens for a reason. In other words, it is a part of God's plan. Of course, first, there is negligence, but some things are fated to be; you know, no matter how hard you try, at some point, it happens and I accepted it.*" (K8). It was found that traditional family ties were also found to be supportive even in cases of sexual interference with a sex worker, which was much more tolerated and acceptable culturally compared to MSMs. For instance, a fifty-year-old man expressed his feelings and experience as: "*Yes, I feel lucky, because my wife is an Anatolian woman. Anatolian women usually keep such things quiet and do not tell anyone outside, and she sees shame about it as I do. I mean, that is me, you know. If I were married to a woman with a career from a big city, maybe we would have separated.*" (K15).

Further, soldiering is another important issue among male participants as it is compulsory in Turkey, and is a crucial criterion for being defined as a "man" according to traditional cultural values. Soldiering is a routine question that generally comes up in curriculum vitae, as employers ask whether or not a person has served as a soldier. However, HIV-positive persons and/or MSM are not eligible to serve in the military according to the law in Turkey. Thus, we found that this situation put some participants under great stress due to fear of HIV disclosure and risk of unemployment, exposure to stigma and discrimination or made them feel devalued psychologically. By contrast, some participants interpreted not being able to serve as a positive outcome.

4. DISCUSSION

This study was conducted to examine PLHIV's perception and experience of stigma and discrimination, including reactions, coping processes, outcomes, and underlying factors, which might also be a framework for a future quantitative study. The continuous analysis of the data resulted in the identification of two main themes: stigma and discrimination, and the negative and positive outcomes. The network between the themes and its categories was picturised as a model of *stigma and discrimination towards HIV/AIDS positive people.*

The present study's results show that stigma and discrimination were crucial barriers to successful adaptation to HIV-positive status and adherence to ART among the participants of this study. Almost all participants were exposed to stigma and discrimination at the workplace, at the clinic, at social life, or at a combination of these locations. Thus, this caused a variety of problems, including mental health problems, delaying ART, social isolation, job loss, retardation in seeking health care behaviours and prevented patients' regular use of ART. Similarly, the results of a variety of studies in different societies, such as in Istanbul (Ornek et al., 2020), Ethiopia (Care, Tesemma, Abate, Abebo, & Madebo, 2019), Greece (Kontomanolis, Michalopoulos, Gkasdaris, & Fasoulakis, 2017), and Iran (Abedinia et al., 2019), Pakistan (Ali, Zakar, Junaid, Khan, & Fischer, 2021) among Arab-Palestinian women in Israel (Soffer, 2020), were supportive of these results. However, we observed that MSMs and women were much more vulnerable in cases of stigma and discrimination exposure compared to heterosexual men due to traditional, cultural, and gender norms. It seemed that strong traditional family ties, religious (Muslim) motives in society, and spurious knowledge about HIV transmission placed an extra burden on women and MSMs in particular (Gh.Barkish, Jalali, & Jalali, 2019; Soffer, 2020; Wong, 2013), which caused fear of being judged for a second time and exposed to social exclusion because of their 'different' sexual orientation. Thus, this may explain why most MSMs do not disclose their HIV-positive status to their social circles.

Working life appeared to be an important issue in this study, and the fear of job loss was one of the major concern counter to PLHIVs in Sweden(Carlander et al., 2021). Therefore, none of the participants shared their HIV-positive results with their colleagues at the workplace or occupational health staff except three of them, who were exposed to stigma and discrimination, unfair dismissal, or forced to resign due to HIV disclosure without their permission. A study in Turkey and in other countries also showed that HIV patients were exposed to many impediments during employment due to side effects of the disease, problems of getting sick days, permission to go to a doctor, stigma, discrimination, and prejudices (Oliva, 2010; Özdemir, Tosun, Özdemir, & Korkmaz, 2020; Wagener et al., 2015). Moreover, some physicians disclosed the HIV status of the patients at the workplace to their employers and did not approve their medical reports to continue or begin work. This approach seems common among health staff who have insufficient or incorrect information about HIV transmission (Ornek et al., 2020; Platten, Pham, & Nguyen, 2014; Wong, 2013), even though health staff have to protect patients' clinical results against anyone, including employers, which is compulsory by law in Turkey. This behaviour of the health staff is also against medical ethics and human-based rights. Thus, PLHIVs generally felt alone and preferred to resign or not legally struggle for their rights when they were dismissed from employment because of being HIV positive. The main reason is feeling guilty and ashamed due to their own HIV status. They also tend to protect themselves from community-based stigma and discrimination by preventing HIV disclosure, which might occur and spread over during the legal right process. However, it is important to highlight that some of them adapted well with HIV-positive status, were successfully adherent to ART, even interpreted it as an opportunity to improve their relationship with members of their family, and also interpreted being ineligible with serving in the military as a positive outcome, which is normally compulsory in Turkey.

The current study's results show the initial reactions of HIV-positive status were mainly three types. Some PLHIVs interpreted HIV as a chronic disease, others considered the disease as God's test-fate, and those who could not accept the disease interpreted it as a "shame" and equate it with death. PLHIVs who interpreted HIV as "shame" blamed themselves for being in a "sinner" position, and felt very desperate and shocked. We observed that this group had a suicide ideation. Those who interpreted as God's test and fate were mainly heterosexual, and were mainly dependent on traditions and customs. Spurious knowledge related to HIV transmission, and treatment, defining HIV as a "disease of homosexuals," society prejudice, and traditional cultural norms were found to be the main underlying factors in this study.

4.1.Strengths and limitations of the study

This study is the first qualitative study in the related field in Turkey that may provide valuable data to understand the stigma and discrimination, challenges, outcomes, and underlying factors that PLHIVs experience. However, the study mostly included single male participants, with a majority being MSMs. The low number of female participants can be considered a limitation of the research, as women's experiences with HIV can be more traumatic than men's due to cultural values and unfortunate social gender roles in some societies. The results of the study are limited to the sample, and the data were based on self-reporting. As such, the results would be partially generalised to PLHIVs in Istanbul.

5. CONCLUSION

Almost all participants in this study experienced stigma and discrimination at all levels of life. Their coping strategies and interpretations of HIV/AIDS varied. The adaptation process of patients to life with HIV/AIDS is influenced by corporate policies, legal rights, the health system, the disclosure of HIV status information, social support, psychological support, coping strategies, perceived levels of stigma and discrimination, and HIV-related social prejudices. In addition, individuals' socio-demographic characteristics, cultural characteristics, self-efficacy, and life philosophy seem to play a role in successfully tackling this problem. Furthermore, providing public engagement and increasing awareness/knowledge through social media, schools, universities, and formal and private communication resources may help them tackle negative life experiences, such as stigma and discrimination. It is also vitally important to increase awareness and knowledge about HIV/AIDS and improve the medical ethics principles of health staff. Such efforts may cause decrease in the prevalence of stigma and discrimination at hospitals. Further, criminal sanctions should be imposed on those who lay off or put pressure on PLHIVs at workplace. Free attorney support should be provided to patients who are subjected to discriminatory approaches and/or who are dismissed and resigned due to their health status. Consequently, the results of this study, which was based on grounded theory, are considered to be effective in determining human-based policies for the solution of HIV-related issues as well as contributing to the relevant literature. Additionally, the data may be used to develop a program to impede social side effects of HIV-positive status. It is also thought that the research data can be used in interventional and cross-sectional research in the future to improve the quality of life of people living with HIV. The published version the current study will be also disseminated to public, HIV-related organisations and ministry of health in Turkey through meeting, and conferences. We recommend that researchers conduct long-term prospective studies that evaluate the multiple effects of being HIV-positive on humans in the future.

Abbreviations

HIV: Human Immunodeficiency Virus

PLHIV: People who live with HIV

ART: Antiretroviral therapy

COREQ: The Consolidated Criteria for Reporting Qualitative Research

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Author's Contributions: The first author (OKO) wrote project, and defined all steps of the study. The data was collected and interpreted together with second author(ES). Both authors took responsibility on writing this manuscript, and approved the version to be published. All authors read and approved the final manuscript.

FIGURE AND TABLE LEGENS

Table 1: The Coding Tree
Table 2: The Participants' Characteristics
Figure 1: Model of stigma and discrimination towards HIV positive people

Table 1: The Participants' Characteristics

No	Age	Gender	Education	Marital status	Occupation	Sexual Orientation	Time since HIV diagnosis	Reason for Acquiring HIV
K1	31	Male	University	Single	Cook	Homosexual	4 years	Sexual
K2	37	Male	High School	Single	Firefighter	Homosexual	7 month	Sexual
K3	23	Male	High School	Single	Unemployed	Homosexual	1 year	Sexual
K4	33	Male	High School	Single	Manager	Homosexual	14 years	Sexual
K5	32	Female	High School	Divorced	Accountant	Heterosexual	1 years	Sexual
K8	38	Female	High School	Married	Accountant	Heterosexual	8 year	Sexual
K6	29	Male	University	Single	Textile sector	Homosexual	1.5 year	Sexual
K7	33	Female	High School	Married	Unemployed	Heterosexual	8 years	Sexual
K9	34	Male	University	Single	Advertiser	Homosexual	10 years	Sexual
K10	42	Male	University	Single	Activist	Homosexual	13 years	Sexual
K11	30	Male	University	Single	Teacher	Homosexual	5 years	Sexual
K13	23	Male	Undergraduate	Single	Student	Homosexual	8.5 month	Sexual
K14	39	Male	High School	Single	Graphics Designer	Heterosexual	10 years	Sexual
K15	50	Male	Secondary School	Married	Driver	Heterosexual	4 years	Sexual
K12	44	Male	University	Single	Teacher	Homosexual	3 years	Sexual

K16	37	Male	High School	Single	Security Officer	Heterosexual	1.5 years	Sexual
K17	24	Male	Undergraduate	Single	Student	Homosexual	2.5 years	Sexual
K18	47	Male	High School	Married	Driver	Heterosexual	3 years	Sexual
K19	60	Male	University	Divorced	Retired	Homosexual	5 years	Sexual
K20	66	Male	Illiterate	Married	Porter	Heterosexual	2 years	Sexual
K21	40	Male	University	Single	Interior Architect	Homosexual	8 month	Unknown
K22	38	Male	High School	Single	Sales Officer	Homosexual	5 years	Sexual
K23	26	Male	Undergraduate	Single	Graphics Designer	Homosexual	7 month	Sexual

Table 2: The Coding Tree

Initial Codes	Axial Coding	Selecting Coding
Impact on future plans Challenges of living with the disease Impact on emotional and sexual lives Impact on social life Impact on business life Deprivation of rights Negative attitudes of health personnel Discrimination in the workplace Positive attitude (family, friends, etc.) Negative attitude (family, etc.)	Enacted stigma and discrimination - Structural - Within families and friends - At workplace - Health care settings Internal stigma and discrimination - Self-stigma - Perceived stigma and discrimination	Stigma and discrimination
Psychological health problems including depression, stress, anxiety, suicide ideation Physical health problems such as high blood pressure, gonorrhea, genital yeast infection, swollen lymph nodes, hair loss, and vaginal wounds Concerns about the future Inconsistent health seeking behavior Loss of confidence Social isolation	Negative outcomes	Outcomes
Acceptance and adaptation Fighting prejudice-activism Slightly positive outcomes of the disease Continuing the routine Perceiving the continuity of life	Positive outcomes	

Figure 1: Model of stigma and discrimination towards HIV positive people