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HIV-AIDS Stigma in the Workplace: A Qualitative Study in Türkiye

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ABSTRACT

HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome) epidemic is one of the most critical global health problems in history. Stigmatizing attitudes towards PLWHA (people living with HIV/AIDS) in the workplace lead to the loss of jobs or not being preferred for new recruitment. This study aims to shed light on the situations related to stigma and stigma fears that they have experienced in their work life. A phenomenological research design was used in the research while volunteer sampling and snowball sampling were used as sampling methods. The study was conducted through face-to-face interviews with 10 male participants living in Türkiye (formerly known as Turkey), who were infected with HIV, between March 10, 2022, and March 17, 2022. Open coding was used in the first stage of the research, and axial and selective coding was achieved after the selection of the core category. While homosexual individuals stated that they had learned about their first diagnosis during routine blood test controls, heterosexual individuals stated that they had learned about their first diagnosis incidentally. They stated that they had felt emotions such as denial, sadness, helplessness, and fear when they had learned it, however, their fears eased later on. While married individ-

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uals first shared their diagnoses with their spouses, single individuals shared their diagnoses with partners or close friends. Most participants hide their HIV infection from their colleagues or managers. All participants stated that being an HIV/AIDS patient would hurt recruitment and promotion. They stated that if they lost their jobs, they would seek their rights through legal means. They also stated that the first emotion they would feel when they lost a job would be anger, sadness, disappointment, and anxiety. They stated that in order not to be stigmatized, society should be enlightened, and social media should be used to create awareness. It has been found that stigma in the workplace is still significant in Türkiye and harms PLWHA. It was emphasized that it is crucial to inform society to eliminate the stigma.

Keywords: HIV, HIV-related Stigma, Strategies, Türkiye, Workplace

INTRODUCTION

Etymologically, stigma is an Ancient Greek word meaning “to sting, to pierce, to mark.” Stigma was also used in Ancient Greek to refer to the tattoo or branding of slaves (Frisk, 1970). According to American sociologist Goffman, who is the pioneer of the theory of stigma, “the behaviour of valuing the stigmatized individual less [is described as] that people who carry this label are less desirable and almost not perceived as human.” In other words, according to Goffman, stigma is a concept constructed by society based on differences or deviation and it contains negativity (Goldman, 1999). Stigmatization (labelling or stigmatization) is the behavior that leads society to take a stand against some patient groups and exclude them from society due to prejudices (Kocabaşoğlu and Aliustaoğlu, 2003). Discrimination caused by stigma and prejudice leads to the deprivation of certain rights and benefits of individuals or groups in society. Cancer, tuberculosis, leprosy, sexually transmitted diseases, epilepsy, psychiatric disorders, alcohol and drug addiction, and AIDS (Acquired Immune Deficiency Syndrome) are diseases associated with stigma (Van Brakel, 2006).

The most important factors contributing to the stigma associated with HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome) are the lethal dimensions of the disease and the fear of transmission. The main source of this fear is that many people have insufficient knowledge of the disease or misunderstand the issue of transmission. The main source of negative attitudes and unwarranted fears about the disease dates back to times when little was known about HIV/AIDS and its causes. However, despite the new knowledge acquired about the disease, the negative attitudes toward patients gained momentum (Oran and Şenuzun, 2008).

One of the most important complications of stigmatization is the internalization of this situation by stigmatized individuals and depression, feelings of loneliness, decrease in social support, and social, communal, and familial isolation caused by such internalized stigmatization (Öztürk et al., 2021).

Social stigma is a chronic source of stress for PLWHA (people living with HIV/AIDS). As a result of stigma, which can occur at any stage of the disease and negatively affects the coping and adjustment level of the person, an increase in the level of anxiety, depression, and interpersonal insecurity is observed (Oran and Şenuzun, 2008).

Stigmatizing and discriminatory attitudes and practices towards the PLWHA in the workplace may prevent that person from having a new income source as well as causing them to lose their existing source of income. Considering that working in a job is the essential condition for people with chronic diseases to maintain their income levels and living conditions, stigma and discrimination cases also make it difficult for PLWHA to have a job that will provide them with a regular income (Hong et al., 2004). However, the fact that PLWHA, who can work for many years without losing their productivity and do not pose a danger to others, are discriminated against when they need work the most, is one of the biggest obstructions to HIV/AIDS prevention efforts (T.C. Sağlık Bakanlığı, 2008).

In the "Young People and HIV/AIDS" report prepared by WHO with the contributions of UNAIDS (The Joint United Nations Program on HIV/AIDS), it is reported that most young people in the world do not have any idea about how HIV/AIDS is transmitted or how they can be protected from it. It has been reported that they do not have any ideas. In addition, what countries should do as part of their efforts to prevent the disease was summarized by the report in 10 steps. The first step was determined as "Ending Silence, Exclusion and Embarrassment" and the second as "Providing Information and Counselling to Young People" (İnce et al., 2006). The organization of awareness campaigns, especially among young people at high risk of contracting the disease, and the attitude of this generation will determine the future direction of the AIDS epidemic and the approach to HIV/AIDS patients (Oran and Şenuzun, 2008).

In Türkiye, there are hardly any field studies on the stigmatization of PLWHA by society and their environment. It can be argued that the main reason for the limited number of studies in this area is that the PLWHA constituted a relatively small group in the past, and it was difficult to reach these individuals. In addition, it is thought that PLWHA did not participate in studies due to fear of their identities being revealed. This study, it aims to illuminate the stigma and fear of stigma experienced at the workplace by individuals living with HIV who are in the dark.

METHODOLOGY

The main axis of the research is the question 'What are the fears of PLWHA about their illnesses and stigmatization in their work life and what are the ways to deal with these fears?' The phenomenological research design was used as the research group is a small and specific group to reveal the common experiences of the participants in the research. Open coding was used in the first stages of the research. Furthermore, axial coding and selective coding were achieved after the selection of the core category.

In the preliminary study, the main studies on PLWHA conducted worldwide and in Türkiye were reviewed. Semi-structured in-depth interviews were conducted during the research process, and a research diary was maintained. The list of questions prepared before the research was changed in parallel with the discourses of the participants during the research process. The sampling methods used are voluntary sampling and snowball sampling. The population of the study consists of individuals living in Türkiye and carrying HIV. Although the findings of the research do not claim to be generalizable to HIV/AIDS patients in Türkiye due to the qualitative nature of the research, the fact that the research participants are in Istanbul, the largest city in Türkiye in terms of population and heavy internal and external migration and that participants living outside of Istanbul are also included in the research allows the study to make meaningful inferences about the panorama of Türkiye. The hospital where the study was conducted provides services to PLWHA and systematically follows up on HIV/AIDS patients. Preliminary information about the study was conveyed to the PLWHA by the study coordinators, and patients who volunteered to participate in the study were included. Patient consent was obtained for in-depth interviews, and all interviews were recorded using a digital voice recorder. During the interviews, the pseudonyms preferred by the participants were not their real names. All interviews were held at the venues requested by the participants, paying attention to confidentiality criteria. A total of 10 face-to-face interviews were held with 10 male participants between March 10, 2022, and March 17, 2022. The total recording time was 8 h 41 min 13 s. The study was terminated when data saturation was reached. The demographic characteristics of the participants are shown in the table. All participants invited to the study participated in the study.

All data obtained were analysed using the MAXQDA software program. Although the data obtained in the initial stages of the research were coded using the open coding technique, the coding process turned into selective coding in the later stages of the research. The coding was changed or transformed comparatively with the new data. The diversity of the items and sub-items constituting the model was provided with new data, and the study was terminated when data saturation was reached.

The study was evaluated and approved by the Üsküdar University Non-Interventional Research Ethics Board (25.02.2022-61351342), and a signed voluntary consent form was obtained from all individuals participating in the study.

RESULTS

General Information

When participants were asked about their experiences of learning about their first diagnosis, it was observed that homosexual individuals were more knowledgeable about HIV and routinely had blood test controls. It was found that heterosexual participants incidentally learned about their diagnosis.

“I used to have regular tests as I have already had an active sex life and I am aware of the risks, even though I am constantly protected, you know there is no guarantee. I learned that I was positive in the tests I had had at certain periods for the reason I previously mentioned. It has been for approximately seven years. It should have been in the years 2014-2015. It’s been 6-7 years.” (K1, gay individual)

“When I went to nephrology for kidneys in 2015, they were going to operate, they did a blood test, I learned then.” (K9, heterosexual)

It was stated that the first feelings of individuals who had just been diagnosed with HIV were denial, sadness, helplessness, and fear. Afterwards, it was stated that these fears lessened as more information became available about HIV/AIDS. As the education level and cultural qualification of the person increase, the knowledge about the disease and the desire to research increase, and thus, the coping ability becomes easier. It is observed that younger, single, and highly educated individuals can continue their lives as if they have no disease as time passes.

"After those first few days, I went back to my normal life, I didn't mind it at all, there was no problem after that." (K2)

The first relatives with whom they shared their HIV diagnosis were their spouses of married individuals, while singles shared it with their partners or close friends after learning. In the next period, it is observed that married individuals living with HIV do not share it with anyone other than their families, but single individuals share it with their families and close circles. Single individuals shared their diagnoses more easily with other people.

"Most of my close friends know. It's a very special issue of mine, but with some people, when you're not telling the truth, you feel like you're lying when you don't say something without having to be asked. I told my close friends because I absurdly thought my close friends should know about it. My circle of friends, which I call close friends, is not a very narrow. Many of my friends know about this. Many people know about it because of me." (K1, single)

"I have not shared it with anyone, only my wife knows." (K2, married)

When asked about the first reactions of the people around them, they expressed sadness, crying, and bewilderment. After getting over the initial bewilderment, they said that they received positive reactions such as hugging and saying words of compassion. Single individuals living with HIV express their feelings about these reactions as happiness and confidence. On the other hand, married people stated that they felt inferior and shamed despite receiving positive reactions.

"There were those who were upset at first. Some participants tried to understand the subject. What is exactly what is not? They were upset at first, but after I descriptively explained the subject, what kind of process and treatment it was, and after that, like the quality of life, they got used to it in a very short time, just as I got used to it. Of course, when I talk to my friends that I haven't talked to for a long time, a few examples come to my mind, and they ask, 'How are you; is your health okay; there's nothing wrong, right?' They wondered about this issue. However, after making sure that I was fine, we never even talked about it. Because we know that there is no situation to be discussed with them, there is no problem with this situation." (K1, single)

"In the current reactions, I feel the same thing I felt that day even today: inferiority, inferiority, inferiority. Brief and clear." (K8, married)

As perceived by the participants, the positive effects of being infected with HIV are an increase in the level of knowledge of both them and their environment about the subject, strengthening family and friendship bonds, early diagnosis of other health problems due to regular check-ups and laboratory tests, and starting to pay more attention to personal health and care such as nutrition, sports, regular sleep.

"After HIV, I started to feel very strong. I have been playing sports for a long time, and I pay attention to what I eat. However, I did not attribute this to that. It helped me raise awareness. I also have a long-term relationship. I should have told this to the person I was in a relationship with. When I told him that, I said I don't want you to treat me good or badly because of this. When I told him that I was HIV positive, he was very scared. But the first time I told her/him, s/he said I love you so much, it's not that important to me. I have seen her love. There were times when I felt very strong because of it." (K3)

Workplace Stigmatization Experiences and Fears

When the participants were asked whether their colleagues and/or managers knew about their disease, it was observed that the majority of them had hidden their disease. It has been determined that voluntary sharing is only with close friends at work, while other shares are involuntary sharing. It has been stated that involuntary sharing occurs when they frequently ask for permission to go to the hospital during medical check-ups or at the initial diagnosis stage. However, it is observed that many participants hid their HIV infection from their colleagues or managers.

"There are some of my colleagues who have been informed before, but these friends are also my friends outside the work, so that's why they know about it. It's not because of work. However, because we are currently working in the same job, I can say yes to this answer. But their number is very limited. Even if you add up, my friends will not exceed 5 people in the company. These are the people I talk to most often. I also shared it with my managers. I shared it before because I had to take a lot of permission to go to the hospital. I was always using my days off." (K1)

"I worked for 3 years like that, no one knew. However, because of this pandemic, our ID numbers were entered into the system to ask what kind of medicine we were using, and then they took us on free leave. However, there is only me in this diagnosis, everyone at work started work, but they did not let me. When the managers asked the occupational physician about who is in the risk group and who is using drugs, s/he said that s/he told a few people such as human resources and managers." (K2)

When asked why they did not share with their colleagues and managers, they said they thought that they would not be understood, and that people would distance themselves because of the lack of information. As the level of education increased, the belief that there was no need to share also increased.

"I don't think everyone has this awareness. I do not like when people pity me. I told my friends too. I never want them to feel pity or humiliation." (K3)

"I think if they knew, maybe they would discriminate because they didn't know about it. For example, they do not share the same toilet and do not share the same computer and desk. They may think that they will pass by just touching or kissing. I do not want them to know because they do not have information about it. However, if there were people who could understand it, I would explain them." (K10)

When the participants were asked how HIV/AIDS would affect their recruitment or promotion, almost all of them stated that it would negatively affect them. It was stated by the participants that such problems would not be experienced in more global and LGBT-friendly companies, but individuals living with HIV would not be preferred in recruitment and promotions in smaller-scale and local companies.

"I was recommended to higher positions in my current company and my manager who recommended me was aware of my situation and there were no problems. I have never encountered such discrimination." (K1, working in an

LGBT-friendly company)

"I think I will create in Türkiye. It may not be a lot in every company, in every sector, or corporate companies, but it can be in many places." (K10)

"I think they probably won't give a promotion. If that person tells or finds out, they will fire him/her just like it happened to my friend before. Many people do not accept this yet, and they are not very few. I think they won't accept it; I see it as a direct reason for dismissal." (K4)

When the participants were asked what they would do if they were stigmatized in the workplace, the common answer was to seek their rights through legal means.

"The conditions of that time, the situation there, it may vary greatly by them, but I would not be silent; I would try to explain the issue. I could try for the biased one, of course, if it's worth it. However, if there was a situation such as an insult, I would plan it by learning the necessary steps, since it is a situation that leads to discrimination. If I were faced with such a situation, I would research what I could do legally. I would not hesitate to convey this to human resources." (K1)

They stated that the first emotions they would feel if they lost a job because they were individuals living with HIV would be anger, sadness, disappointment, and anxiety. They stated that if they lost their jobs due to this situation, they would seek legal rights.

"It would affect very badly. My salary is my only livelihood that takes care of my mother and house. Thus, being stigmatized and fired in such a situation can be devastating. This was not the end of the world. I can find a different job in many places, but of course, it would be very sad if that were the case." (K10)

"Anger, disappointment. However, if I were fired for this reason, I would initiate a legal process for discrimination. I don't know what the end will be tough. At least I would seek my legal right. Of course, I would be angry. People go to space. I am fired because of my health conditions and sexual preferences. I would not want to work there anyway. It would not be someone who deserved to work with me anyway. It's not a place that values me. I wouldn't want to be with people who have that perspective. However, legally, I would seek my rights. I would file a lawsuit. I will start looking for another job suitable for me. Of course, this situation bothered me, but I would never have been crushed under it. I say this because I have not experienced this situation, and I am sure I would have felt much worse if I had experienced something like it. Maybe it was a job that I loved very much, and I spent effort there to realize myself. Of course, such things would disappoint people, but as a result, I would seek my right and move on." (K1)

The first suggestion of the participants on what should be done to prevent individuals living with HIV from being stigmatized by society was to educate society. They think that this education should start from childhood with the idea that if children are educated, society will also be educated. They also stated that to reduce stigma in the workplace, employees should also be educated about the ways of HIV transmission. They state that using social media for education and awareness is a good way to reach a larger audience.

"Certainly, even if it does not take place every year, on December 1, a presentation about awareness can be presented in companies every few years. Health professionals can be brought in, and employees can be informed about what the disease is, what it is not, and what kind of process it is. Awareness is very important; this is created by telling people. This comes to my mind because it is not something to learn by living. The experiences of the people who have been discriminated against can be explained within the scope of that event. These are the first things to come to mind. Such information is provided on social media channels; however, on December 1, awareness-raising posts can be shared. However, in general, even a 1-hour presentation in the company by an expert from health institutions or one of the officials from associations on this subject may be important for raising awareness about the disease and the need to not discriminate." (K1)

"People need to be aware. I think they should be taught in school. I studied at the university; frankly, I did not see such an event properly. Therefore, education must be provided. There should even be a textbook on this topic. The more education is provided, the more conscious people will become. And here's something. I am talking about the articles I read. First, the child learns something, then teaches it to the mother, and finally the mother teaches it to the father. This is how the ranking proceeds. First, it is necessary to teach the child that this is a normal thing and that it can happen to anyone. I think that children can teach future generations and their elders." (K4)

“It may take many years, but if we can at least enlighten our environment, then we may enlighten other people’s own environments, but I think the biggest way can be achieved through social media, and people who give people certain inspiration can get into this issue and there may be a social media campaign explaining that this disease is not so deadly.” (K5)

DISCUSSIONS AND CONCLUSIONS

In the historical process, HIV/AIDS ranks first among the diseases that cause stigma due to some factors such as lack of information about the disease itself and its transmission routes, misinformation, and fear of the disease. One of the main reasons for this is the fear it creates in societies owing to the lack of information about the ways of transmission and the fact that it is considered a lethal disease. Despite the new information acquisition, the negative attitudes towards the disease and the infected people are gradually increasing because there is no definitive treatment for the disease, and it is mostly sexually transmitted. HIV-infected men are considered to be homosexual, bisexual, or a person having sex with sex workers, and women with HIV/AIDS are seen as sex workers. This leads to the exclusion of individuals living with HIV by society (Oran and Şenuzun, 2008).

When we look at the effects of the stigma experienced by individuals living with HIV, it is seen that people are excluded from their social environment, they face undesirable behaviours while receiving health services, their rights to education are restricted and they are exposed to mobbing in their working life (Kaya et al., 2020).

As a result of the field research carried out, it can be stated that individuals living with HIV share their illness with a close circle who will not harm them, who should be included in the control process due to their sexual contact, and who can empathize with the individual. According to Gökengin et al. (2017), whether a person is discriminated or not depends on whether they disclose their HIV status to others. It is observed that the participants tend to explain their HIV status more easily to other individuals living with HIV, their spouses/partners, adult family members and healthcare providers compared to their co-workers and colleagues (Gökengin et al., 2017).

While the first feelings of those with whom they voluntarily share this information are usually sorry for the individual, their first reaction is trying to console, hug, and cry. On the other hand, for married individuals, after sharing the situation with their spouses, while their spouses' first feeling was anger, their first reaction was to cry and shout. In the next period, it is one of the positive aspects of the disease that individuals living with HIV are accepted by the people with whom they share their health status voluntarily and that they can see how much they are loved. Another positive aspect is that individuals are diagnosed early if they have another disease due to frequent check-ups and paying attention to healthy living behaviours (health responsibility, physical activity, nutrition, spiritual development, interpersonal relations, and stress management).

It has been observed and determined that patients living with HIV do not prefer to be visible to avoid exposure to stigma by their colleagues and/or managers from their workplaces. Visibility is shared in workplaces, often voluntarily or involuntarily, with the expectation that it will bring about benefits. It has been stated that individuals working in lesbian, gay, bisexual, and transgender (LGBT) friendly companies report their diagnosis more easily and they do not encounter any negativity in the next process, even in the case of promotion. In the field study, individuals hide their diagnoses from their colleagues and/or managers due to the socio-cultural background and low educational level of employees of non-corporate companies. Individuals who hide their HIV status believe that their illness will negatively affect them during promotions. They hide their diagnoses because of fear of being fired, fear of losing their dignity, and fear of ridicule and exclusion. According to Ulasi et al. (2009), the stigmatization of HIV/AIDS can range from simple gossip to outright discrimination that results in job loss, evictions, rejection, isolation, and even the killing of the infected person (Ulasi et al., 2009). The reaction they will give when they lose a job due to their disease varies depending on their educational level and whether they are married. Married individuals and individuals with lower education levels prefer informing their managers about themselves and their disease first, whereas individuals who are single and have a high level of education prefer taking legal action first.

The relatively small number of participants and the fact that all participants are male is among the limitations of this study. Therefore, our study does not reflect the feelings of women living with HIV.

In conclusion, the negativities experienced by PLWHA regarding stigmatization in their work life are presented in detail in this study. When asked how these problems could be eliminated, all participants stated that the most important measure was to educate society. It is necessary to provide education on the ways of HIV transmission to the whole society and in schools through social media, TV, and print media, as well as to carry out studies in workplaces to raise awareness on 1 December World AIDS Day.

Ethical Approval: The study was evaluated and approved by the Üsküdar University Non-Interventional Research Ethics Board (10.01.2022-1005), and a signed voluntary consent form was obtained from all individuals participating in the study. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Authors' Contributions: All authors contributed to the study's concept and design. Organization of the sample and material preparation was performed by Servet ÖZTÜRK. Material preparation was performed by Haydar SUR. Data collection and analysis were performed by Nevin KORKMAZ. The first draft of the manuscript was written by Nevin KORKMAZ, and all authors commented on previous versions of the manuscript. All authors read and approved the first as final manuscript.

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