

The Social and Health Problems of People Living with HIV/AIDS in Izmir, Turkey

HIV/AIDS Hastalarının Sosyal ve Sağlık Sorunları: İzmir, Türkiye

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Abstract

Objective: The aim of this study was to describe how AIDS, as well as the stigma associated with it, affects the lives of HIV positive patients and their family members.

Materials and Methods: Three large state hospitals in the metropolitan area of Izmir participated in the study. Six focus groups were conducted with people infected with HIV (n=32) and their family members (n=11). Participants were asked to fill out a questionnaire to assess their HIV/AIDS knowledge and to convey how the stigma had affected them.

Results: The most important problems identified were society and work-related social problems and access to health services. The patients and their family members stated that education was needed to correct misconceptions about HIV and to help them cope with related problems. We found that patients and their family members were sensitive about disclosure.

Conclusion: We determined the education, counseling and support needs of HIV-infected patients and their families. Additionally, we found that health personnel who monitor the patients should make more efforts on patients' education and counselling.

Key Words: AIDS/HIV, Discrimination, Patient, Prevention, Stigma

Özet

Amaç: HIV/AIDS hastalarının ve yakınlarının hastalığın yaşamlarını nasıl etkilediğinin ve damgalanma deneyimlerinin saptanmasıdır.

Gereç ve Yöntem: Çalışma İzmir'de yer alan üç devlet hastanesinin katılımı ile gerçekleştirilmiştir. Altı odak görüşmesi 32 HIV/AIDS hastası ve 11 yakınlarının katılımı ile gerçekleştirilmiştir. Ayrıca katılımcılar HIV/AIDS hastalığı ve damgalanma hakkında soruları içeren bir anket formunu tamamlamışlardır.

Bulgular: Odak grup görüşmelerinin sonuçlarına göre hasta ve yakınlarının belirttiği en önemli sorunlar, toplumla ilgili sosyal problemler, damgalanma ve sağlık hizmetlerine erişimdir. Hasta ve yakınlarının hastalık hakkında bilgilerinin de yetersiz, ayrımcılık konusunda duyarlı olduğu saptanmıştır.

Sonuç: HIV pozitif hasta ve yakınlarının desteklenmesi ve eğitilmesi gerektiği belirlenmiştir. Hastaları izleyen sağlık personelinin daha fazla çaba göstermesi gerekmektedir.

Anahtar Kelimeler: AIDS/HIV, Ayrımcılık, Hasta, Korunma, Damgalama

Introduction

Acquired immunodeficiency syndrome (AIDS) is one of the most significant health and social problems facing the world today. Over the last decade, due to the rise of 'mobile prostitution' with illegal workers from abroad, especially from Eastern European countries, infection with STDs has risen. Additionally, an increasing number of workers from Africa, one of the most infected continents in the world [1], are entering Turkey illegally.

Every new infection starts with someone who is already infected. New infections occur because infected persons do

not take the necessary precautions or because of poorly organized protective services. Patients are not being sufficiently educated on their responsibility to prevent the spread of HIV and are not being included in protective service studies [2]. Generally, an HIV diagnosis is a traumatic experience that significantly changes a person's life. Commonly, the patient does not reveal their diagnosis at all or only reveals it to a limited number of people. A strategic goal of HIV prevention studies is to understand how and why patients hide their diagnosis and to determine a solution [3-5]. AIDS is a disease that is feared because of misinformation about the transmission routes. A previous study determined that the most common

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reason patients hide their diagnosis is fear of stigma and exclusion [6]. Because of the stigma associated with HIV, the patient and their family may face psychosocial problems during diagnosis, treatment and progression. In previous studies, it has been shown that having a family member diagnosed with HIV can affect family members in different ways [7].

A study performed in Turkey found that in addition to problems with employment, health and education, the biggest problem in Turkey is stigma [8]. Studies carried out in different countries and in different cultures and religions have reported that patients and their families face the same problems as those in Turkey [9]. The first step in solving these problems is to educate the patients and their families. The best method to prevent the hopelessness experienced by the patient and their family is education and effective treatment [10].

The aim of this study was to determine the problems that HIV/AIDS patients experience, to measure the patients' knowledge regarding HIV/AIDS and to determine their opinion regarding health and social problems and stigma.

Materials and Methods

Study design and study setting

This descriptive study was performed between January and June 2007. Because Izmir has a high number of reported HIV cases, it is considered the second highest risk region. The infectious diseases department at the Regional Ministry of Health contributed to this study, and three large state hospitals in the metropolitan area of the city participated in the study. The participating hospitals are tertiary care centers and serve the Aegean area, which contains 14% of Turkey's population and has the second highest population density in the country.

Study group

HIV-infected people and their family members were the target population for this study. As seen in the literature, a significant issue in AIDS research revolves around ensuring confidentiality; thus, it is not possible to obtain a 'representative sample'. Therefore, a purposive sampling technique was used [11]. The authors (excluding those working at the university) invited patients that they were already following and that fit the criteria to join the study. The inclusion criteria for participation in the study were that participants were diagnosed as HIV positive, were aware of their HIV status, were mentally capable of providing voluntary informed consent, and were willing to participate in a half-day session. The patients were also asked to bring a family member of their choice to the meeting. All participants were 18 years of age or older.

The patients were given the times and locations of the meetings and informed that research was for academic purposes and to educate the patients and their family members. Additionally, they were informed that the study findings would be published anonymously. The study was performed with patients who came to the meeting of their choice. Meeting invitations were sent out one week prior to the meeting date. Those who did not attend were reminded of the next meeting date. In total, 32 HIV-infected patients that were receiving care at one of three infectious diseases clinics at the Ministry of Health hospitals in Izmir and 11 family members or partners participated this study. Participation was voluntary. Expenses related to travel and meals were covered. The focus group interviews were performed in a hotel conference room in Izmir. Furthermore, all participants were provided with standard HIV/AIDS information, a medical consultation, and complimentary observation by a psychiatrist.

Data collection

The study used qualitative and quantitative methods to collect data regarding the experiences, perceptions and knowledge about HIV from the participants. A pilot study was conducted to test the questionnaire and key points in the interviews with a few patients and their family members. These data were not included in the study. A brief semi-structured interview guide was used to facilitate the focus groups. Six focus groups were performed with patients and their family members. Each group consisted of six to ten participants. The second author transcribed all of the focus group interviews by hand. Because the patients were concerned about confidentiality, no recording devices were used. At the beginning of the sessions, the moderator (first author) explained the aim of the focus group discussions and encouraged the patients and family members to express their opinions. All of the authors participated in each session and asked open-ended questions to encourage the patients and their kin to engage in the discussion. During the focus groups, participants discussed living with HIV. At the end of the sessions, the participants completed a questionnaire on demographic characteristics, HIV/AIDS and stigma. The key points of the focus groups were as follows:

- Experiences/issues with the HIV diagnosis, treatment and medication;
- Challenges of living with HIV, e.g., health services and community life;
- Stigma and segregation of people living with HIV.

The focus group interviews, collection of the subsequent survey data, the education session, the consultation, and determination of additional needs were all completed in a half-day session.

The study received ethical approval and permission from the Ministry of Health. The purpose of the study was explained to each potential participant, and they were informed that the study was completely voluntary and that all data collected would remain confidential. Oral consent was obtained for participation in the study.

Data analysis

The qualitative data were analyzed manually using thematic content analysis. Then, the data were organized into meaningful segments. A code list was developed for the data and was used to rate each of the focus groups notes. The second author coded all of the transcripts, and all of the authors independently read this material and then discussed the final contents.

The quantitative data were analyzed using the software package SPSS, and general descriptive statistics were calculated. The mean knowledge and stigma scores prior to the seminar and independent variation comparisons were made using ANOVA and the two-sample *t*-test. The questionnaire consisted of 41 items (26 knowledge and 15 stigma related items) that were scored on a 3-point scale; higher scores indicated greater knowledge and a more negative feeling toward stigma. The internal consistency reliability for the Likert questionnaire was acceptable at 0.75 (Cronbach's alpha).

Results

Participant characteristics

The sociodemographic characteristics of the participants are shown in Table 1. While most of the participants were men, the majority of the kin were women. Approximately 25% of the patients had a primary school education level or below. Four patients were gay and one was bisexual.

Focus group interviews related to HIV and how the infection affected their lives

In the focus group interviews, the patients and their kin mostly complained about health services. We found that discrimination by health personnel had led to problems in treatment and health problems for all of the participants. Additionally, they agreed that dental health was also an important problem. However, they explained that having more information about their illness would help them to overcome health problems more easily.

The participants were experiencing severe physical side effects from the antiretroviral treatment. Additionally, the potential side effects of the medication had not been fully explained, and for various reasons, they were not taking their medications on time. Furthermore, they were sometimes unable to find the medications in pharmacies.

Table 1. Demographic characteristics of the participants

	Patients (n=32)	Kin (n=11)
Gender		
Male	75.0	30.0
Female	25.0	70.0
Age groups		
15-24	3.8	25.0
25-34	34.6	37.5
35-44	38.5	25.0
45-54	3.8	12.5
55+	19.2	-
Marital status		
Single		
Married	31.3	30.0
Divorced	56.3	60.0
Have children	12.5	10.0
Yes	81.5	66.7
Educational level		
Illiterate	6.3	-
Primary school	21.9	50.0
Secondary school	21.9	20.0
High school	40.6	30.0
University	9.3	-
Working status		
Yes	31.3	18.8
Social security		
Currently Receiving	96.9	90.0
Substance use	-	-
Smoking	17.0	6.0
Alcohol use	37.5	22.2

The patients stated that HIV had a negative effect on their lives. They also stated that when they first found out they were HIV positive most of them experienced psychological trauma. The period of shock, while temporary, lasted a very long time for some. During this time, they stated that they did not have psychological support and that health services were inadequate in this area or that they had not been referred to the proper resources.

They explained that living in smaller communities was problematic and that it was easier to access health services and to live anonymously in big cities. Family support was very important to the HIV-infected patients, and they emphasized that it was easier for people with family support than

for those without. One participant discussed the benefits of being a member of a non-governmental organization (NGO). This patient was able to learn more about HIV at an earlier stage, and their problems were addressed earlier. Furthermore, the NGO provided an important social support system outside of the family.

The patients discussed stigma and expressed that they thought people did not have enough education about HIV. Furthermore, they felt that people were afraid of the disease, and that the media was careless and uninformed about HIV. One female patient felt that women were in a worse situation than men in Turkey.

Patients also expressed that they had financial problems and that financial problems were preventing them from accessing health services and getting medication.

In the survey, we found that only 50% of the patients had shared their status with their spouse. Three people had hidden their status from everyone. The others had told relatives, friends or their spouse. Eight of the patients stated that they had not heard of "safe sex". Four others thought that "safe sex" meant monogamy, and the other 21 thought it was condom use. Apart from 6 of the patients, all stated that they used condoms. Of those who do not use condoms, 3 said it was unnecessary, and three said that they were not sexually active and did not use condoms.

Quantitative data results

The mean knowledge score for the patients prior to the study was 45.5 ± 5.9 (32-55). The mean knowledge score of their kin was 43.2 ± 3.1 (37-47). There was no significant difference between the patients' and the kins' scores. A one-way ANOVA test or t-test was conducted to determine whether there were differences between the knowledge scores for each demographic variable. No relationship was found between the knowledge score and the age, gender or occupation of the responders. However, there was a significant difference between education level and the participants' knowledge score; Less-educated persons had lower scores ($F=3.92$, $p=0.014$). In addition, five patients reported that they their HIV test was associated with pre-test counseling. These patients had significantly higher knowledge scores than the other patients ($t=4.19$, $p=0.03$).

The answers given by the patients and their next of kin regarding HIV and its transmission are listed in Table 2. Most of the kin knew that AIDS was the progression of the HIV infection. The kin knew more about HIV transmission than the patients. Even though the number was small, there were both patients and next of kin that thought HIV was transmitted through mosquitoes, using common objects such as towels, shaking hands, common bathroom-toilet usage, and using an HIV-positive person's private things. A small, but not insignificant

number thought there was a possibility of hereditary transmission. Twenty percent of the patients believed that lesbians could not be infected with HIV. Furthermore, most of the patients and their next of kin believed that people at risk for acquiring HIV and health personnel should be tested regularly. Approximately, twenty percent of each group thought there was a vaccination for HIV.

The responses regarding prevention of stigma are shown in Table 3. The participants indicated that they knew an HIV-positive person who did not have access to health services (43%), had been exposed to violence (60%) or had been excluded from society (65%). In total, 41.4% of the participants thought that HIV-positive health personnel should not care for patients and 36.7% thought that HIV-positive people should not have sexual intercourse. Sixty percent of the participants believed that if an HIV-infected person's status was known they could lose their job, and most of them believed that the community was disturbed by HIV-positive individuals.

Thirty-one percent of the patients indicated that they were ashamed of being HIV positive; 16.7% indicated that they were not invited to social events; 56.8% indicated that they had been discriminated against; and 39.3% indicated that they had been excluded. Nearly half of the patients felt guilty for being HIV positive. Approximately two-thirds of both the patients and their next of kin believed that people close to the HIV-positive person needed to be informed of the HIV positive person's status.

Discussion

In this study, we first determined the aspects of HIV education that the participants were misinformed about or did not know at all. After this, education was given emphasizing the areas that the participants were not fully informed about. Valuable data, especially in the qualitative section, were obtained in this study. Beusterien et al. reported that focus groups were a valuable qualitative method for studying issues in socially marginalized groups [12].

The results from the focus groups indicate that HIV-infected patients have several problems. The six focus groups had a limited number of patients with accompanying kin, despite receiving personal invitations from the authors. As the participants stated, all of the patients were very concerned about confidentiality, and we concluded that the patients who did not attend or were afraid that their confidentiality would be jeopardized. The fundamental problem for patients and next of kin was stigma. They stated that knowing their HIV status has created barriers in many areas, such as in their social lives and at work, and that they were excluded. The participants thought that the female patients felt more pressure

Table 2. Participants' knowledge level about HIV/AIDS and transmission routes

HIV/AIDS knowledge	% Agreed	% Agreed
	Patients	Kin
An HIV positive person may appear healthy	73.3	80.0
HIV destroys the immune system	82.8	90.0
A person with a negative HIV test definitely does not have the virus	22.2	40.0
AIDS is form of late stage HIV	57.1	81.8
AIDS does not have a cure	63.0	80.0
There is a vaccination against HIV to protect the public	17.2	20.0
Those at risk for HIV infection should have regular tests.	83.3	90.9
All health personnel should have HIV tests	76.7	90.9
HIV can be transmitted when more than one person uses the same needle	80.0	100.0
HIV can be transmitted from a pregnant woman to the baby	86.7	100.0
HIV can be transmitted during dental treatment	86.7	100.0
HIV can be transmitted from procedures such as manicures and shaving	83.3	100.0
HIV can be transmitted to a baby from breast milk	67.7	100.0
HIV can be transmitted through an innocent kiss	27.6	-
HIV can be transmitted through sexual intercourse	93.3	100.0
HIV can be transmitted through common plate/cutlery use	10.0	0.0
HIV can be transmitted through a mosquito bite	13.8	11.1
HIV can be transmitted through a common tattoo needle	80.0	80.0
HIV can be transmitted when shaking hands or hugging	7.1	10.0
HIV can be transmitted through receipt of blood or blood products	86.7	90.9
HIV can be transmitted genetically	32.1	30.0
HIV can be transmitted through organ or tissue transfer	73.3	90.9
HIV can be transmitted through anal sex	61.5	70.0
HIV can be transmitted through common bathroom-toilet use	27.6	10.0
HIV can be transmitted by washing an HIV-positive person's plate/clothes	17.2	10.0
Lesbians cannot be infected with HIV	20.7	10.0

in some social situations and were more excluded. In previous studies, it was also reported that women were more at risk for developing HIV infection during unprotected sex. It has also been reported that HIV-positive women have less access to social and health services [13, 14]. As stressed in other studies, HIV and its related problems, which include stigma, disclosure, the future and family, were some of the patients' common problems [15]. Those living in a metropolitan area, who are better educated and are of a higher socioeconomic status stated that they had fewer problems [16]. Furthermore,

those living in smaller cities or towns have more social and health problems with treatment and exclusion. The patients expressed that they encountered health, morale, social and financial problems. Discrimination in the workplace was also an important problem. As job opportunities become limited and incomes decrease, the problems with treatment increase. Stigma hinders HIV prevention, disclosure and care seeking, which leads to delays in getting tested and treated [9, 15]. Another one of the most important problems was access to health establishments and services. The participants also

Table 3. Opinions of the participants related to stigma

Stigma items	% Agreed	% Agreed
	Patients	Kin
I have heard of an HIV positive person being refused health treatment	43.3	30.0
I have heard of an HIV positive person being excluded from society for being HIV positive	65.5	70.0
I have heard of an HIV positive person exposed to violence for being HIV positive	60.0	70.0
I am worried about transmitting the virus to others	83.3	-
HIV positive health personnel should not care for patients	41.4	30.0
An HIV positive person should not have sexual intercourse	36.7	30.0
I have support for my disease from those close to me	76.7	-
I am not invited to social events (weddings, birthdays etc.) because I am HIV positive	16.7	-
If an HIV positive person has their status revealed they will lose their job	60.0	44.4
I feel guilty for being HIV positive	48.3	-
I have never been ashamed for being HIV positive	51.7	-
Many people feel uncomfortable around an HIV positive person	86.7	77.8
I believe I have been discriminated against	58.6	57.1
Some people stopped seeing me once they found out I was HIV positive	39.3	-
A doctor should provide information to those close to a person diagnosed with HIV	75.9	80.0

stated that in addition to specific treatment for HIV, other health problems had emerged such as health personnel who were not willing to treat them or who made unkind comments. This situation results in problems with treatment. The patients also stated that they were pleased with their infectious diseases doctors' approach and that they trusted them. A study by Hogan et al. found that patients preferred to learn about the disease from doctors they trusted [17]. In the interviews, it was expressed that those infected through tainted blood or unsafe medical practices were seen as more innocent and that this influenced society's behavior towards them. Additionally, in other cultures, people infected through sexual transmission experienced more negative treatment than those infected through tainted blood [18].

We found that only half of the patients had shared their HIV status with their spouse. However, the survey found that one-third of the respondents believed that this information should be shared with those close to the patient. A study by Kleven et al. found that HIV heterosexual people are aware that their sexual partner is at risk and that only 24% had told their partners [19]. In another study conducted by Ramchandani et al., 40% of patients had disclosed their HIV

status to their partner [9]. Disclosure can lead to positive or negative results. Our patients reported concerns regarding how much support would be given or what kind of reaction they would receive discouraged them from sharing their status with their partner. The most important reason for hiding their status is stigma [4, 6, 19]. In total, 25% of the patients expressed that they were unaware of "safe sex", which indicates that they are not being careful about transmission. However, only 3 patients were aware of the need for condom use. It has been reported that minimizing risk-taking behavior by HIV positive patients is an important protection method [10].

In the focus groups discussions, the patients and their kin emphasized the need for more HIV/AIDS education. According to quantitative results, most of the patients and their kin had insufficient knowledge about HIV/AIDS. Hicks et al. determined that HIV positive patients with a low education level believed that anti-HIV treatments prevent the transmission of the disease and that this was their reason they preferred unsafe sex [20]. Correcting misinformation regarding HIV/AIDS will lead to a decrease in risk-taking behavior [20]. Additionally, it was highlighted that the family members also needed to

be informed about the disease [21]. In our study, only five patients had received pre-test counseling. The counseling before an HIV test is important because taking the HIV test can be a traumatic experience. Pre-test counseling educates the patient about HIV/AIDS.

In this study, we found that participants were misinformed about infection routes. The level of knowledge that a patient has about transmission is important in regards to secondary risk and transmission to other individuals. Other studies have found that HIV positive patients have a low level of knowledge about HIV transmission routes [9, 10].

HIV/AIDS is a family disease, and when one member of the family has HIV/AIDS, the impact can be felt throughout the entire family. The family is the most important factor that determines the effect that the disease has on the patient. Family support included financial advice, support in the disclosure process, assistance with daily routine activities, medical assistance, or psychological support [9].

There were some limitations to the study. The results from the study participants are not representative of other HIV-positive individuals, and no *video* or *audio* was recorded. However, these six focus group interviews provide perspective on how much the disease has affected the lives of patients and their next of kin. Moreover, our study found that education was important for both patients and their next of kin. Patient education is important to encourage the patients to use self-help strategies. Additional education is needed to help the patient understand that AIDS requires long-term treatment and observation and that they can help control the disease with positive health-promoting behavior. Changes in attitude and behavior can be achieved through patient education [5, 22]. This study emphasizes that preventative studies such as counseling, testing and education are necessary. It has been reported that counseling services that emphasize basic protective precautions and help the patients share their HIV status with a partner should be available for all patients [9]. Poku et al. reported that stigma related to HIV/AIDS needs to be explored further from a cultural standpoint to foster the development of educational programs and interventions that are culturally appropriate [23].

In conclusion, the findings from the focus groups and questionnaire indicated that there were important misconceptions about HIV/AIDS, especially regarding modes of transmission. Additionally, both patients and their families fear discrimination and stigma. This study has provided important information about the education, counseling and support needs of HIV patients and their families. The data were obtained using qualitative methods that were supported by quantitative data. Moreover, the physicians following these patients are responsible for their care.

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