

AIDS Related Stigma in Social Relations: A Qualitative Study in Turkey

Aytul Kasapoglu, Elif Kuş Saillard, Nilay Kaya, and Feryal Turan
Ankara University, Ankara, Turkey

The actual number of HIV/AIDS cases in Turkey is higher than the number of cases reported, and People Living with HIV (PLWHIV) may refrain from acknowledging their sickness or seeking help because of the stigma associated with HIV and fear of discrimination from their close friends, workmates, and even their families. In this paper we aim to explore HIV-positive people's relationships with significant others such as family members, friends, sexual partners, employers and health professionals in order to present the patients' perceptions about stigma and attitudes that lead to pro-social or anti-social behavior towards them. We carried out a qualitative study based on in-depth interviews with 16 PLWHIV in order to understand the conditions of people living with HIV/AIDS in Turkey. Our results revealed that except for family relations, the fear of contagion is the main obstacle for HIV-positive people's relations with others. HIV-positive people are severely afflicted with discrimination due to the overlapping "instrumental" and "symbolic" stigmas that directly affect their relations. The attribute of responsibility is related to gender and socio-economic status of PLWHIV living in Turkey. Key Words: HIV/AIDS, Stigma, Social Relations, Attributions, Turkey, Grounded Theory.

The prevalence of HIV/AIDS in Turkey is considered to be low (Altan, 2008). Eastern European countries have one of the fastest-growing HIV epidemics in the world, and Central Asia also has a high incidence of HIV/AIDS. Turkey's position is between these two regions (Altan, 2008). In Eastern Europe, there were 250,000 new cases in 2001 (www.unaids.org). It can be said that HIV/AIDS is accepted as an emerging disease in Turkey.

According to the Country Report prepared by Altan (2008) for UNGASS, a total of 1,922 HIV cases were reported in Turkey from 1985 to 2004. It was also reported that 551 of the infected individuals had developed AIDS, of whom 63 had died in 2004. The total cases of HIV infection were 2,711 by the end of June 2007, whereas by the end of 2008, the number of HIV cases increased to 3,307. The most common mode of transmission was heterosexual contact; 75 percent of the transmissions were attributed to heterosexual practice, and approximately seven percent were infected through intravenous drug use (Altan, 2008).

The actual number of HIV/AIDS cases in Turkey is unknown, and certainly the actual number of HIV/AIDS cases is higher than the number of cases reported (Ay & Karabey, 2006). The main reason involves the recording system for illnesses in Turkey and a long asymptomatic period of HIV (Duyan & Yıldırım, 2003). The number of women contracting HIV has been rising due to the lack of education about AIDS and

infections. Most of the victims remain silent about their HIV status because of the fear of being exposed to stigmatization and discrimination (Greef et al., 2008).

Stigma

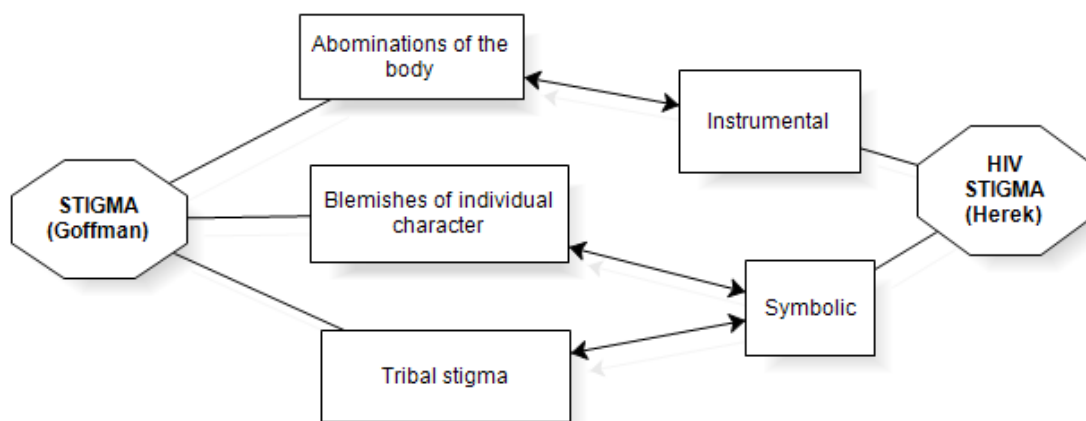
In his famous work on stigma, Goffman (1963), defines stigma as “an attribute that is deeply discrediting” (p. 3). According to Goffman, stigma is a process by which the reaction of others spoils normal identity. This is because an individual with an attribute that is highly discrediting in a society faces rejection. Therefore, to understand how stigma is constructed in a society, it is crucial to focus on attributions on a sociological level.

Goffman (1963) identified “three grossly different types of stigma: abominations of the body, blemishes of individual character, and tribal stigma” (p. 4). The first one includes the negative attributes attached to physical deformities; the second type includes the negative attributes attached to personal character. And the last type includes the negative attributes attached to a community with a specific nationality, religion, race, etc.

On the other hand, Herek (1999) based on his studies about HIV/AIDS, divided HIV-related stigma into two types: “instrumental” and “symbolic.” Instrumental stigma is a reflection of fear and apprehension that is likely to be associated with any deadly and transmissible illness, whereas symbolic stigma includes all kind of attitudes towards the social groups or lifestyles perceived to be associated with the disease. Thus, we can also divide attributions into two types: Those attached to a disease that is perceived as deadly and those attached to a person or social group who has this disease.

Although they used different labels, it is obvious that there are similarities between Goffman and Herek, and a combination or transformation of their conceptualizations is presented in Figure 1.

Figure 1. *HIV Stigma: Combination/Transformation of Goffman and Herek's Conceptualizations*



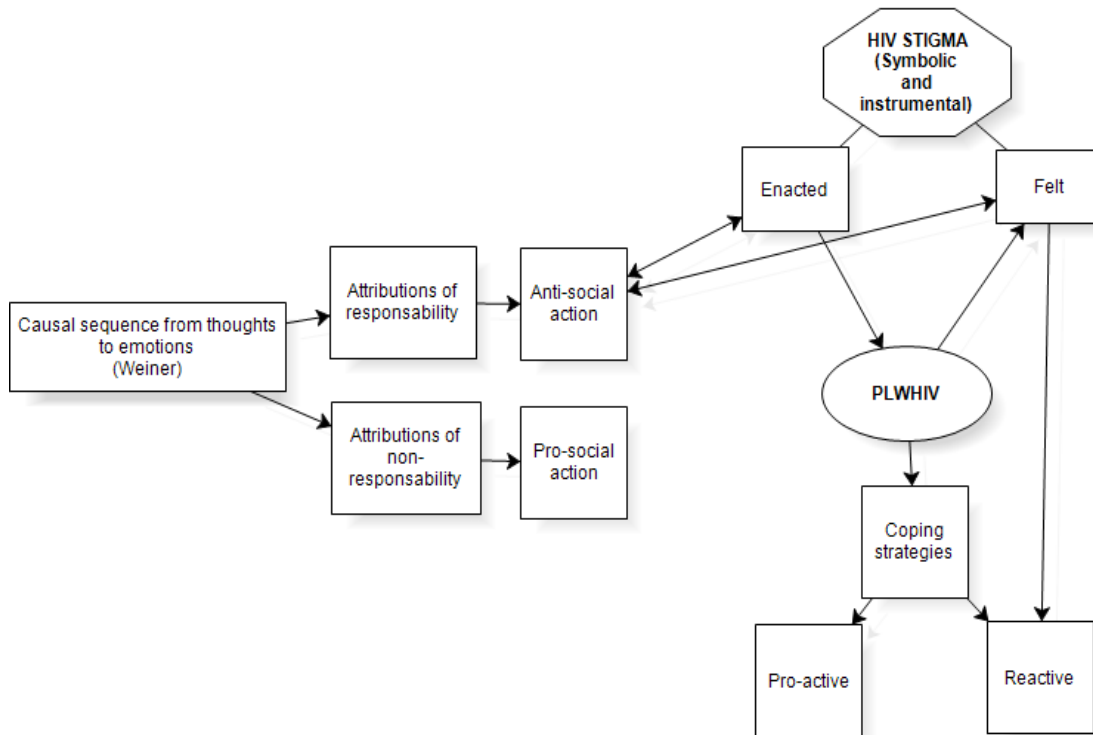
There is also another distinction that should be taken into consideration: “Enacted” and “felt” stigma (Scambler, 1998). Enacted stigma refers to actual discrimination or unacceptability whereas felt stigma refers to the fear of such

discrimination. This distinction lets us consider the stigmatized individuals' personal feelings. Stigma is a complex social phenomenon that involves interplay between social and economic factors and psychological issues of affected individuals. Enacted stigma is strongly associated with pre-stigmatizing conditions prior to HIV.

HIV and AIDS carry most of the characteristics associated with heavily stigmatized medical conditions. First of all, people living with HIV/AIDS are associated with socially improper forms of sex and intravenous drug use, socially censured behaviors that are assumed as the *responsibility* of the individual (Ogden & Nyblade, 2005). The instrumental stigma that refers to fear of contagion can be the dominant type across cultures, but the symbolic stigmatizing differs among cultures. Hence, the discrimination as a result of HIV-related stigma also varies according to cultural context.

According to Attribution Theory (Weiner, 1993; Rudolph, Roesch, Greitemeyer, & Weiner, 2004), "help-giving decision" is strongly associated with the "responsibility" of the person who needs help. Lack of controllability and non-responsibility for a negative outcome often elicits sympathy. But if the person who needs help is thought to be responsible for his/her conduct, anger replaces sympathy. In this situation, the person rejected is not given any help. In short order, an attributional explanation of helping and aggression proposes a casual sequence from thoughts to emotions to behavior (Rudolph et al., 2004). In addition, in Attribution Theory, if an aspect of self is perceived to be causing an event, the attribution is called *internal*; on the other hand if something or someone in the environment is perceived to be causing it, the attribution is called *external* (Schmitt & Branscombe, 2002). Thus, according to attribution theory, individuals are constantly drawing inferences regarding the cause of particular events or behaviors (Quist & Wiegand, 2002). Therefore, to understand how discrimination takes place in the case of HIV/AIDS, these causal thoughts and emotions that contribute to this discrimination are critical. Symbolic HIV/AIDS stigma that might result in discrimination could be associated with the rejection of help-giving basing on perceived *responsibility*.

It should be mentioned here that, in our view, similar to Symbolic Interactionist Perspective (Crittenden, 1983), these attributions are also socially constructed instead of being only intrapersonal, cognitive processes. Accordingly, it is important to ascertain social construction of attributes in a given social context and their effects on help-giving decisions. In Attribution Theory, these causal thoughts and emotions lead to two types of actions: "pro-social action" in which help-giving behavior takes place and "anti-social action" in which help-giving is denied and aggression takes place. Based on this distinction, it would not be wrong to say that pro-social actions are *admissive* or *inclusive* whereas anti-social actions are *discriminative* or *exclusive* in a given social context. Summary of mentioned definitions as a demonstrative model of our conceptual framework is given in Figure 2.

Figure 2. *Conceptual Framework*

AIDS stigma is a global phenomenon and people living with HIV are subjected to rejection, social ostracism, discrimination and violence. If we focus on how stigma affects face-to-face interactions, we can detect the attributions that cause *inclusive* or *exclusive* behaviors. In this context, the social categories should also be regarded. HIV/AIDS stigma has a *layered* construction (Deacon, 2006) that includes other stigmas already existing in a society. That is, other pre-existing stigmatizing conditions should also be considered. For example, gay and bisexual men living with HIV are more stigmatized than heterosexual women with the disease. In fact, this symbolic HIV/AIDS stigma in this example is just a vehicle for expressing hostility toward other groups that were already stigmatized before the epidemic began (Herek, 2002). Unfortunately, symbolic HIV related stigma derives its force from the association of HIV with disliked groups. Depending on the local epidemiology of HIV and preexisting prejudices, symbolic HIV stigma varies across cultures.

Symbolic HIV/AIDS stigma focuses on male homosexuality and Injecting Drug Use (IDU) in the most countries (Herek, 2002; Fife & Wright, 2000). But in Turkey, it is more related with sexual behaviors rather than IDU, as in the Caribbean and Jamaica – where transmission through IDU is rare (White & Carr, 2005). As mentioned earlier, to understand stigma and its affects, it is assumed that stigma is not a singular concept expressed and experienced in a common way (Fife & Wright, 2000). Rather, it is subjectively experienced in multiple ways depending on the nature of the stigmatizing condition and the social circumstances of the individual. While it is a well known fact that HIV/AIDS is associated with “a-blame-the-victim” ideology (Siegel & Krauss, 1991), it is also important to understand how this ideology, in other terms, causal beliefs

of responsibility and non-responsibility (Weiner, 1993), affect people living with HIV. More concisely, which causal attributions affect the perception of people living with HIV as being *innocent* or *guilty*?

To understand the stigma as a social construction, a stigma trajectory should include “the essential processes through which individuals personalize the illness, dilemmas encountered in interpersonal relations, strategies that are used to avoid or minimize HIV-related stigma, and sub-cultural networks and ideologies that are drawn upon to construct, avow, and adapt to an HIV identity” (Alonzo & Reynolds, 1995, p. 303). Therefore, in this study, we focus on HIV-positive people’s relationships with significant others in order to develop a deep understanding of the stigma-construction process.

This paper primarily focuses on social relations of PLWHIV in Turkey to find out instances of perceived stigma and the causal attributions affecting the perception of people living with HIV/AIDS.

Objectives

Although the main study is more comprehensive and detailed, the objectives of this paper are to explore the answers to the following questions based on the theoretical framework given in the introduction section:

- a) What are the instances of perceived stigma by PLWHIV in relation to family/friends, sexual partners, health personnel, and co-workers/employers?
- b) Which causal attributions affect the perception of people living with HIV as being *innocent* or *guilty*?
- c) What is the role of attributes in social relations of PLWHIV?

The authors were involved in this study of PLWHIV through a project called “Vulnerability Assessment of People Living with HIV in Turkey” in 2007 by United Nations Development Programme (UNDP) and the Sociological Association of Turkey. IRB approval had been obtained from executive committee of Sociological Association. The focus of this project was to explore problems occurring in three sectors: education, employment and health. During the data gathering process we met with HIV-positive people, their relatives and/or friends and they provided us rich and quite detailed accounts of their experiences as HIV-positive people. The empirical process of this research has led us to some sociological concepts such as stigma and gender, which in turn have been used for further analysis. As a research team, we traced the concepts rising from the data.

Method

We carried out in-depth interviews with PLWHIV in order to understand the problems of people living with HIV/AIDS in Turkey in accessing health, education and employment. As we mentioned above, this was mainly a UNDP project with qualitative design. Our prior experience with qualitative research helped us in all stages from conducting the interviews to analyzing and reporting. Based on our qualitative research

experience, we conducted our analysis by following the steps in Grounded Theory (Glaser & Strauss, 1967).

We carried out 20 interviews: 16 of them were with PLWHIV; three interviews with parents (one father and two mothers) and one with a wife of PLWHIV. It should also be noted that those relatives were not HIV positive. We carried out the individual interviews during the period of April to July, 2007.

Sampling

The researchers adopted purposive sampling that reflected an appropriate distribution for the PLWHA population in Turkey. Sixteen of them were recruited through “X” Non-Government Organization (NGO), three of them by a “Y” State University Treatment and Research Center and one through a “Z” State Hospital.

Design

The team carried out interviews in Ankara and Istanbul by conducting face-to-face and telephone interviews. Whenever possible, we tried to interview the PLWHIV in person. However, we conducted telephone interviews when the people refused personal interviews or preferred phone contact. In those instances, we received the phone numbers from Y (University Center) or X (NGO) to make the appointment for the interview.

Interviews were semi-structured and an interview schedule (topic guide) that was used to understand the respondents’ experiences, problems and access to education, employment and health care. The semi-structured questionnaire was prepared by UNDP to be used in five countries. As for Turkey, our team translated the questionnaire but did not make any changes. Interviews generally lasted between 40 and 60 minutes.

During the interviews, researchers first introduced themselves and explained the objective of the research. After establishing sincere social relations, the participants’ oral consent was requested. First of all, we clearly explained our research purpose and the institutions involved in this research. For those who agreed to participate, we guaranteed to protect their anonymity and we promised to keep the interview recordings and transcriptions confidential. Concerning the potential effects of our study on the participants, we informed them that this study was intended to reveal their problems occurring in education, employment and the healthcare sector, but we did not promise any positive change in their situation.

Once their informed consent was provided, all the interviews were tape recorded, with the exception of two cases. The recorded interviews were all transcribed carefully. Later, in order to support the evaluations, some of the referred parts of Turkish transcriptions were translated into English. All data are presented anonymously.

Sample Characteristics

People living with HIV/AIDS in Turkey were the study population. Although PLWHIV are representative of almost all urban areas, most of them are from metropolitan cities like Istanbul, Izmir, Ankara and Antalya. It is also possible to say that HIV/AIDS cases are identified in all provinces, but most of the PLWHIV are registered

in Istanbul, where more than 15 million people live. Recruiting participants in Turkey was particularly difficult despite concerted efforts by the research team and their collaborative organizations. The sample was heavily from Istanbul, where most of PLWHIV live. We were also able to access some PLWHIV residents in Ankara or other cities like Malatya, Konya and Iğdır.

The team tried to recruit equal numbers of participants from each target risk group identified by the UNDP: Commercial sex workers (SW), men who have sex with men (MSM) and PLWHIV, except Injecting Drug Use (IDU). The team really faced difficulties in finding and recruiting IDU participants due to the lack of information about them. Neither governmental (police institutions) nor the Positive Living Association as an NGO couldn't provide any data toward IDU people with HIV/AIDS. The majority of PLWHIV in the sample were heterosexual. The team interviewed with three MSM and two SW.

Of these, seven were female and nine were male. The age of participants varied from 24 to 42 years of age. Of these, one was illiterate, five were primary school educated, two were secondary school educated and the other had a university degree.

Data Analysis

During the analysis, the verbatim transcriptions of all interviews were transferred to the software NVivo7 (QSR International, 2006). Our analysis process evolved by following the steps offered in Grounded Theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998). At the first step, categories based on each questions were created. Then, the texts (transcribed documents of interviews) were coded case by case into these categories. This classification technique helped the researchers to see all the replies of interviewees separately into one category. At the second step, the sub-categories were created by browsing through the answers of interviewees. So, these sub-categories were the first-level categories which reflect the "own words or phrases" of participants in all its richness (*open coding*- *invivo* codes in Grounded Theory). At the third step of the analysis, researchers created new categories (axial coding) in order to reclassify the codes according to the present study aims. These new categories were "relations with family," "relations with friends," "relations with employers," "relations with sexual partners," and "relations with health professionals" (*selective coding*; core category "relations").

The data were analyzed by using NVivo7 (QSR International, 2006) software program for qualitative data analysis and the key findings are presented in the final report based on brief interpretations. Using software enabled to do analysis in a circular (back and forth) way (Dey, 1993). All the original data were in our hands and available to check the compatibility of our categories (concepts).

Results

The results of our study are presented below. We describe five different social relations in order to draw a complete picture regarding PLWHIV/AIDS in Turkey.

Stigma and Family Members

In our sample only two of the participants were living alone, the rest were living with their families. Four of them stated that they began to live with their families after the diagnosis. Most of our participants stated that they feel themselves stronger because their family members gave them moral support. The majority of the participants stated that they didn't confront any bad treatment in the family that might be construed as stigmatization. While some of them preferred disclosing their HIV status to their family members, some others stated that their family members had learned the diagnosis from medical personnel. Except for one negative case, all of them were satisfied with the awareness of family members. Just one of our participants experienced a dramatic change in her life and in her family relations due to being disclosed:

I didn't disclose. The assistant physician, who had done my tests, left my report on the desk uncovered and my mother learned by reading it. The carelessness of the assistant could cause any other one to learn my diagnosis. If my father had learned, he might have killed me immediately. You know the families are different from each other; I wouldn't be able to make it acceptable for my father. (P11, female, 26)

Experience of this case is an important example displaying the layered character of stigmatization. In traditional gender roles, young women have to be virgins until marriage. Her HIV status evoked the discrediting attributions judging her behavior to be immoral. Thus, it came to a point where she felt forced to leave the city in which she lived:

I felt myself responsible to save my family. I was tired of the derogatory gossips and discriminations of those unconscious people in that small city. So I left my family and moved to another city. (P11, female, 26)

Interestingly, some participants had not disclosed to their parents mainly because they thought their parents are old and ill:

My parents are too old. My father is 70 and my mother is 60 years old. They have many chronic illnesses. Heart disease, diabetes etc... Thus, they would have worried about me more even if I would have a small illness. Not because I am HIV positive, instead I don't want to burden them. (P3, female, 31)

Everyone knows in my family except my father... we don't tell him because he is ill and not used to these issues. You know, the old authoritarian persons have some perceptions and attitudes. (P4, male, 26)

And the other reason was that it is difficult to make a change in old persons' prejudgments:

It is difficult to tell the family. There are old people and it is hard to break down their prejudices. (P14, male, 30)

One of the participants stated that he stopped hiding from his parents because he needs their support:

I told my parents two days ago. I had decided to tell because you need to be relaxed. You share at least some responsibilities... our nutrition problem is very important. Your family can cook minding your diet. Besides, their support is very important. Your motivation has to be high to maintain sustain stability of immune system... moreover, one day you might encounter some health problems and you might need to be taken to hospital in case of emergency. So, it is useful of course. (P15, male, 30)

Those who prefer to disclose to their parents stated that their parents are conscious enough to understand their situation:

My mother is a nurse. At the beginning she had been worried about my health... but now she isn't sad because my cell counts are OK and I don't need pills for the present. (P18, male, 28)

My parents are experienced, they are conscious people. I told them in a cool manner. They said "there is nothing to do; it is a wish of god". (P17, transsexual, 31)

My mother was so cool... my family had never changed their behaviors towards me because they are so conscious. (P10, female, 30)

It is interesting that a mother of one of the participants stated that while her older daughter was a physician, she was also lacking knowledge:

Tough my daughter is a medical doctor; she asks me "what are we doing at home". I told her that "how absurd question it is, you are a physician". Even physicians don't know. This is the problem. (P9, mother)

This example enables us to think about another dimension that might produce stigmatization towards HIV-positive people by labeling the infected one as the one who carries the risk of transmission through social relations. In other words, this fear of contagion and disease reveals the "instrumental stigmatization" (Herek, 1999) that can be seen even among doctors.

The same mother notably stated that they were keeping everything in their daily routine or as "normal" because:

We live very normally at home. She doesn't have separate plate, glass... all of our laundry and dishes are washed together. We live normal because

we know the way of transmission... we don't have fear about transmission. (P9, mother)

Also, one participant stated that even among family members, the attitudes towards him varied:

My brother hesitates even we are shaking our hands. But my mother never avoids. We were so closed with my mother and the infection didn't transmit to her. After her tests had shown that she is negative, everyone got rid of their worries in my family. It is very difficult to break down the prejudgments. I gave a ring everyone to say that she is negative. (P4, male, 26)

Stigma and Friends

The HIV-positive people need social support to cope more positively with this infection. So, they prefer to disclose to some friends. Most of the participants preferred to disclose to the friends who were most close to them. Besides, some stated that they had not been exposed to any bad treatment because they were very selective about the ones who they thought were more conscious:

I disclosed to conscious people around me. I know the ones to whom I can disclose. I know the person to whom I shouldn't disclose; they would behave differently toward me if I had disclosed. I know the questions they could ask and my answers to them. So I decided not to tell them. I have shared just with conscious people. And they are a small number of people. (P15, male, 30)

I have never faced with those who treat differently. Because, at the beginning I had chosen the people to whom I will tell. I had shared with the ones who understand. (P5, male, 36)

A participant who has been dealing with this infection for 11 years stated her disclosure reason as such:

At the beginning I was telling various illnesses. Lies bring other lies after them. I felt that one day I would fail... I had told some people that I have a cancer and the others anything different. People began to worry about me. They wanted to be with me at hospital or to help me. I was at the infection clinic and I was isolated. Thus, I understood there is no alternative. I had waited for the right time and I told them at different times. (P3, female, 31)

This participant also stated that the entire circle of close friends, whom she had told, had never treated her badly, except one:

Just one of my friends didn't want me to touch her domestic pet. I broke off my relations with her. Even she knew that it doesn't transmit by touching she hesitated. The rest of my friends on the contrary share my cigarette, my water. There isn't any problem. (P3, female, 31)

One participant stated that he had difficulties disclosing to his friends because he was also gay:

I have some worries, I couldn't share with everyone. In the first months I didn't meet with my friends. I am gay and all of my friends are heterosexual, they have children and they live in a routine and normal way. If I have had some marginal friends, I might be disclosing more easily. But, telling them that I am a gay makes me feel guilty towards them. So, I couldn't have talked to anyone and stayed at home for a long time. (P4, male, 26)

Here again, we see that it is not the HIV status but the state of being gay that has the potential to evoke discrediting attributes. Symbolic stigmatization or "blemishes of individual character" strongly related with the cultural context in which discrediting attributes took place.

A woman, whose case was disclosed, stated that some of her neighbors had treated her badly while some had not:

Some neighbors say "that's a wish of god". But, others didn't take the apples I offered them. They refused. (P6, female, 24)

Quotations from participants P17 and P6 revealed an interesting assessment of others which can be interpreted as a positive attitude towards HIV-positive people. The phrase *God's wish* exemplifies a fatalistic view which refers to anti-stigmatizing attitude. It is anti-stigmatizing because it has the meaning that *everyone* might encounter this infection. In doing so, the *responsibility* of the person disappears. Case P6 was infected through her husband so, it is not surprising that she was not blamed or judged to be responsible but in case P17, though he was a gay, the belief that it was a wish of God protected him from being blamed or held responsible for his HIV status.

A transsexual participant stated that she had lost all of her friends soon after they learned the diagnosis. She also said that for this reason she had moved to her mother's house in a different town:

I lost all of my friends after the diagnosis. They excluded me. They think as if it can transmit through sitting side by side. They didn't drink water from my glass; they didn't ask for dinner. (P7, transsexual, 26)

This quotation shows the strength of the fear about disease and contagions as well as its negative impact on the social relations of an HIV-positive person. It is interesting that here we see the power of instrumental stigmatization.

Stigma and Sexual Partners

All of the participants who have a partner stated that their partner is HIV-positive and the only change after the diagnosis is their behavior regarding condom use:

I started to use condom, that's the only change. (P12, female, 33)

But the others, who do not have a partner, stated the difficulty to start a relationship with someone:

When we meet with a new partner, we can't tell this easily to her/him. It is difficult to tell. (P14, male, 30)

One day you can meet with a pleasant person but catching the suitable time to share with her is a problem. I don't know; maybe one day I will find a solution if I meet with a right person. And, at a time during the flow of relationship, if I share with her, I may see how strong her feelings are. (P18, male, 28)

One of the transsexual participants, who was a sex worker, stated that even after she explained her disease, some partners did not believe her and refused to use a condom:

They think as if a person with AIDS should be very thin like a skeleton... when I tell that I am AIDS, they don't believe me. They say "you look healthy; you can't be AIDS." For example, I have relation with a partner for 10 years. I told him and I used condom when I have sex with him. But one day, he refused to use condom saying that "what ever you have carry I am ready to have it." He didn't believe me. Unfortunately, I had to make sex with him without condom. After, I wanted him to be tested and his test results were negative. Now, it is very hard to convince him believe me. (P7, transsexual, 26)

This quotation reveals the importance of physical appearance for stigmatization. Using Goffman's (1963) terms, it is a kind of "abomination of the body". This example proves that this kind of stigmatizing is quite strong among people in Turkey. The majority of people think there should be a repulsive appearance to people living with HIV.

Notably, two participants stated that they got married to an HIV-person after the diagnosis. These two cases have different stories. One of them is a woman who had faced a serious stigmatization and moved to another city alone after the diagnosis. She got married there:

I left my own family and I moved to another city. I was lucky that I met with him there and we got married. (P11, female, 26)

And the other is a man who embarked upon his second marriage after the diagnosis. He has been infected for 14 years and his first wife died after he learned the diagnosis. He has an interesting marriage story:

After the diagnosis my wife died. I have participated in TV programs and my current wife had watched me. She is also from my town. She called me. We met when I was in Istanbul. We decided to marry. I told her everything and I took her to my doctors. They approved our marriage. Later on my wife got married with me voluntarily. (P16, male, 39)

But there was also a participant who divorced after the diagnosis. He was 33 years old. He learned of his situation during another, unrelated, medical treatment. After his wife learned that she was also HIV-positive, she divorced him.

Stigma and Co-workers/Employers

Most of the participants (eight) were working full-time, three of them were working part-time and the rest (five) were not working. It is a common problem for all of them to disclose their situations at the work place because they have fears about losing their jobs. Only one of the participants stated that she disclosed her situation to everybody at the work place:

All the people at work know my situation. I told them myself. I got bored by their jokes like “why don’t you use the same glass, are you AIDS.” I realized that they don’t know anything about this infection. One day, I said “yes, I am AIDS.” They didn’t believe me. They thought that I was joking. But I told about my situation and the ways of transmission. After a while they believed me. I am too lucky that now, all of them take care of me. They say “you know everything, do the right thing for your treatment.” (P11, female, 26)

Some of the participants disclosed to some people at work but not to everyone. One participant, who has a company of his own, stated that he disclosed to his work partner because he thought that he would die:

I told him soon after I have learned. Actually it was the second day. I thought as if I would die. That’s why I disclosed to him. I wanted to transfer all my work to him. (P14, male, 30)

The same participant also stated that he was withholding his status from other co-workers because he did not want to cause their departures from their jobs:

The main difficulty is to hide. I have a huge amount of test reports in a file and I couldn’t have brought it neither my home nor my office for one year. In the office we are 12 persons. There is possibility that this file can be read by one of them. So I started to keep them in the baggage of my car.

Even if I disclose at work and tell them about the ways of transmission, I'm sure that at least three of them will leave their job. (P14, male, 30)

While those who were working at an NGO related to HIV stated that they don't have the problem to be disclosed, they also stated that they would be afraid to have their HIV status disclosed if they were positive and had been working at a different place. The rest of the participants did fear disclosure of their HIV status:

If it is heard I am sure that they dismiss me. There are many people working there and they first consider health of others. It is a private company. (P17, transsexual, 31)

Stigma and Health Professionals

All of the participants stated that they had experiences of being treated differently by health professionals. While most of the problems reported happened in non-HIV related clinics, there were also problems in HIV-related clinics.

I returned to the doctor and told her that something was missing in the papers. I came close to her to give her the paper. She stopped me and said "get away from me, you will splash something." Meanwhile I had to wait for her instead of finishing my other paper work with the hospital administrators. When she came back half an hour later, I couldn't complain about her behavior. However her specialization was infectious diseases. (P3, female, 31)

They all complained about the hesitation of medical personnel during medical treatments:

When I injured my leg five months ago I had an open sore and therefore I was referred to the dermatologist. He/she gave some medication without examining but just looking at to my leg. He just looked at my leg and told me that I can put on my pants. (P14, male, 30)

I didn't experience any negative response from nurses until my disease have been diagnosed. The day I was diagnosed the nurses refused to help me. Even though my arm had swollen they didn't want to take the injector off. (P12, female, 33)

A transsexual participant stated that medical personnel had treated her as if she had the plague, so she had faced discrimination and isolation:

For example during my treatment at X hospital, they used to visit me with their gloves and bonnets. For example they didn't want to serve my food. I had to take my foods using my own plates. I was staying in a single room and they used to behave as if I am carrying any fatal and contagious disease like pestilence. Psychologically I was disturbed and I was almost

feeling that I had to go to the asylum. I was talking to blankets. I started to see illusions. Finally I myself left the hospital even though doctors wanted me to stay. (P7, transsexual, 26)

This quotation reveals the prevalence of stigmatization among some medical personnel. But also, it might be the result of the patient's status as both a transsexual and HIV-positive at the same time. That is, the situation of this participant might be due to a "layered stigma" in terms of double or triple oppression cited in the women-rights field (Link & Phelan, 2001; Deacon, 2006).

Furthermore, secrecy is the main source of pressure which provides a negative impact directly on patients' psychological well-being and indirectly on their social relations. Secrecy results in stress on them and influences their social life negatively:

When we are talking with my friend about other things rather than AIDS, if subject comes to AIDS and they start to say and discuss wrong things, although I know more based on my personal experiences, certainly I avoid or stop myself from intervening to correct them and this situation hurts me very much. They are all free to talk everything but I am not. Therefore I want to leave this town in order to go far a way. (P18, male, 28)

One participant stated that he feels guilty:

Although it is not very severe like locking myself at home, I feel sorry and regret about the thing that happened to me in my life and this psychological feelings are still continuing. I would feel better as if this disease contaminated to me with serum injector rather than sexual intercourse. At the beginning I blamed my self very much. (P4, male, 26)

It seems to me HIV positive person is a socio-phobic, because I also had experienced. I felt myself guilty about the subject that I am absolutely right. Because you hide something from others and you know very well that if you tell the truth to them you will be faced to their reactions or insults. (P3, female, 31)

One participant explained the reason for hiding their diagnosis as though:

People think as if the person deserved it. Because, they think that the person should have a marginal life. That's why we hide. We don't want to be regarded as we are living in abnormal way. (P5, male, 36)

So, the HIV-positive participants hide their status to protect themselves, especially from "symbolic stigmatization" (Herek, 1999). And this situation negatively affects their psychological well-being.

Discussion

According to the findings, the majority of the participants were supported by their families. This finding is consistent with the fact that “the family is the main source of care and support for PLWHIV in most developing countries” (Warwick et al., 1998; Parker, Easton, & Klein, 2000; D’Cruz, 2004).

The exception was one negative case, in which the participant left her family. She left her town because she didn’t want her status to be disclosed to her father. This young woman’s experience is strongly connected to a deviance from societal norms. It is a well-known fact that HIV/AIDS-related stigma is reinforced by pre-existing sexual stigma (Gagnon & Simon, 1973; Parker et al., 2000; Paxton et al., 2005). In this context, it is so meaningful that her status couldn’t have been disclosed to her father and her brother.

Except for this case, all of the participants shared their situations with their family members. However, there is also the significant point that some of them are still hiding their diagnoses from their parents because the parents are old and have some health problems, in addition to the difficulty in overcoming the parents’ prejudgments and ground rules.

It is also interesting that the participants did not report any kind of segregation or banishment. According to the findings, their families provided full support to them. Most of them live with their families. It is also observed that, in relation to HIV-positive participants’ family relations, there is a “reconstruction” through “signification” process, as Giddens (1984) pointed out. That is, family members together with the HIV-positive person, produce new meanings through the semantic codes given them by doctors. Those semantic codes are: Preferring the term HIV-positive instead of AIDS and defining it as a chronic illness. These semantic codes pave the way for production of new meanings. Thus, the infection sheds its label “being deadly” and it is transformed to an illness manageable by drugs. Thus, the semantic shift takes HIV from *incurable* to *curable*.

It can be said that this reconstruction of meanings is the only key for deconstruction of present stigmas (early AIDS metaphors like *death*, *horror*, *guilt*, *shame*, *otherness*, etc.) in society. As in the family, there is a need to create new “signification” procedures to cope with HIV-related stigmas and to reduce risks in society.

In their relations with friends, most of the participants prefer to disclose their situation to the ones whom they believe more conscious. In this way, participants stated that they didn’t risk any bad treatment. Even so, one participant, who is a transsexual, stated that she lost all of her friends because they were hesitant to be with her. These two different situations also show that the socio-economic status of the participants also plays a role in their social relations. The ones who reported they prefer to disclose to some conscious and sensitive friends were also the ones who were highly-educated and had occupations. There was one participant who stated that because he is gay, he couldn’t have disclosed his status to his heterosexual friends. This participant also stated that he sometimes feels himself guilty in his social milieu. The situation of this participant exemplifies the “internalized stigmatization” and also the fear to face “symbolic stigmatization” (Herek, 1999). It is a well-known fact that most heterosexuals associate AIDS primarily with homosexuality or bisexuality, and this association has strong correlation with higher levels of sexual prejudice or antigay attitudes (Herek & Capitanio,

1999). In general, all the participants shared their situation with a limited number of friends in order to avoid any kind of stigmatization. But, if the one who is exposed is like the participants P6 (female, 24) or P11 (female, 26), he or she will probably be confronted with stigmas in his/her social environment.

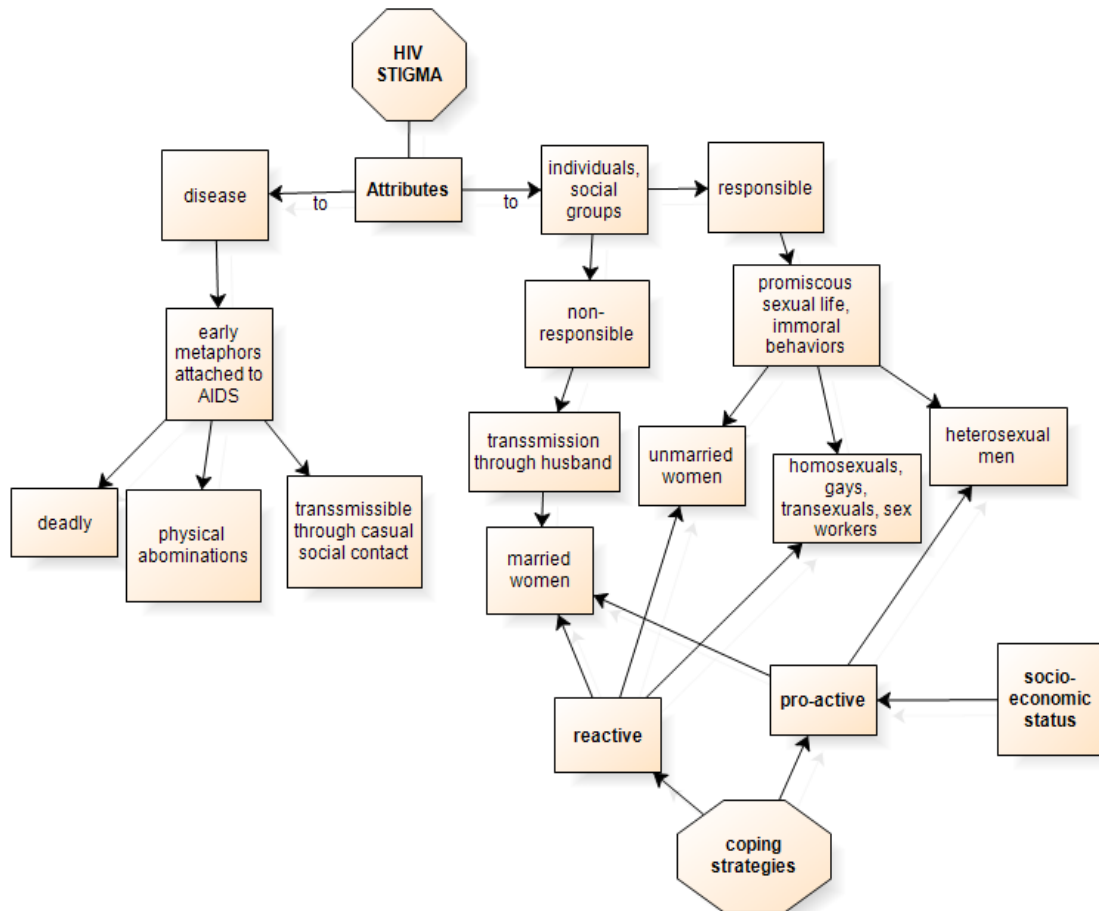
In their relations at work, the most prominent fact is their fear of being exposed at work. Most of the participants gave examples from other HIV-positive people who had lost their jobs after their status was disclosed. Therefore, they are hiding their HIV status at work. In addition, they pointed out the difficulty of finding a job. The findings of this research demonstrate that relations at the work place have commonalities with other studies (Varas-Diaz, Serrano-Garcia, & Toro-Alfonso, 2005).

In their relations with health professionals, their main problem was the hesitation in treatment arising from fear of contagion, even among doctors. This sometimes leads to refusal of treatment and care. And some of them emphasized the problem of breaches of confidentiality. This problem sometimes causes their status to be disclosed. Participants stated that these problems appear because of the lack of knowledge, even among doctors and also some accompanying stigmatizations. Our findings have supported the existence of stigmas, even among health professionals (Varas-Diaz et al., 2005). As Varas-Diaz and his colleagues (2005) have found, some stigmatizations among health professionals are overt and explicit while some are more subtle. That is, our findings also demonstrate the avoidance of interaction among health professionals.

Finally, the fear of contagion is the main obstacle for HIV-positive people in all their relations (except family). HIV-positive people are faced with discrimination due to the overlapping stigmas of both “instrumental” and “symbolic” (Herek, 1999) which directly affect their relations. While some cultural differences were seen with regard to their relations with family, friends and sexual partners, it was interesting that the relations with employers, coworkers and health professionals were more likely to be the same as in other countries (Deacon & Boule, 2006). As our findings demonstrated, the expression *God's wish* is an example of a culturally anti-stigmatizing attitude. This attitude paves the way for the support in their social relations in which a non-discriminative, *pro-social* behavior takes place (Kasapoglu & Kuş, 2008, p. 366).

The Attribution Model of HIV Stigma in Turkey (Figure 3) is a model which was constructed to show more clearly our theoretical concepts in relation to the findings that fit with these concepts. We used qualitative data analysis software Nvivo7 (QSR International, 2006) to draw this model. It is important to state here that this model was not drawn automatically by the software; on the contrary, this model construction process was done by the authors based on the attributes of the HIV-positive participants and our categories.

Figure 3. Attribution Model of HIV Stigma in Turkey



Limitations

There are limitations to our study. PLWHIV do not constitute a homogenous category. They are from different classes or socio-economic status, different sexual orientation, rural or urban environments, etc. While the participants in our research were representing different categories in terms of gender and socio-economic status, the total number of participants living with HIV was 16. Thus, concerning the theoretical sampling in Grounded Theory (Glaser & Strauss, 1967), qualitative interviews with more PLWHIV may give more empirical data to saturate the categories that we have developed in this study. Besides, to build a theory of attribution for PLWHIV in Turkey needs more empirical grounds in which friends and family members are included.

References

Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science and Medicine*, 41(3), 303-315.

- Altan, P. (2008) UNGASS Indicators Country Report: Reporting Period 2007- 2008. Ankara: MOH.
- Ay, P., & Karabey, S. (2006). Is there a “hidden HIV/AIDS epidemic” in Turkey?: The gap between the numbers and the facts. *Marmara Medical Journal*, 19(2), 90-97.
- Crittenden, K. S. (1983). Sociological aspects of attribution. *Annual Review of Sociology*, 9, 425-446.
- D’Cruz, P. (2004). The family context of care in HIV/AIDS: A study from Mumbai, India. *The Qualitative Report*, 9 (3), 413-434. Retrieved from <http://www.nova.edu/ssss/QR/QR9-3/dcruz.pdf>
- Deacon, H. (2006). Towards a sustainable theory of health-related stigma: Lessons from the HIV/AIDS literature. *Journal of Community & Applied Social Psychology*, 16, 418-425.
- Deacon, H., & Boulle, A. (2006). Commentary: factors affecting HIV/AIDS related stigma and discrimination by medical professionals. *International Journal of Epidemiology*, 36, 185-186.
- Dey, I. (1993). *Qualitative data analysis: A user-friendly guide for social scientists*. London: Routledge.
- Duyan, V., & Yıldırım, G. (2003). A brief picture of HIV/AIDS in Turkey. *AIDS Patient Care and STDs*, 17, 373–375.
- Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior*, 41, 50-67.
- Gagnon, J., & Simon, W. (1973). *Sexual conduct: The social sources of human sexuality*. London: Aldine Transaction.
- Giddens, A. (1984). *The constitution of society: Outline of the theory of structuration*. Berkeley, CA: University of California Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Hawthorne, NY: Aldine Publishing Company.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon & Schuster Inc.
- Greef, M., Phetlhu, R., Makoae, L. N., Dlamini P. S., Holzemer W. L., Naidoo, J. R., ... Chirwa, L. M. (2008). Disclosure of HIV status: Experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qualitative Health Research*, 18(3), 311-324.
- Herek, G.M. (1999). AIDS and stigma. *American Behavioral Scientist*, 42, 1106-1116.
- Herek, G. M. (2002). Thinking about AIDS and stigma: A psychologist’s perspective. *Journal of Law, Medicine & Ethics*, 30(4), 594-607.
- Herek, G. M., & Capitano, J. P. (1999). Sex differences in how heterosexuals think about lesbians and gay men: Evidences from survey context effects. *Journal of Sex Research*, 36, 348-360.
- Kasapoğlu, A., & Kuş, E. (2008). The role of gender in the stigmatization of people living with HIV/AIDS in Turkey. *Journal of Gender Studies*, 17 (4), 359-368.
- Link, B. G., & Phelan J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363-385.

- Ogden, J., & Nyblade, L. (2005). *Common at its core: HIV related stigma*. [Research report]. International Center for Research on Women. Retrieved from <http://www.icrw.org/files/publications/Common-at-its-Core-HIV-Related-Stigma-Across-Contexts.pdf>
- Parker, G. R., Easton, D., & Klein, C. H. (2000). Structural barriers and facilitators in HIV prevention: A review of international research. *AIDS, 14*, 522-532.
- Paxton, S., Gonzales, G., Uppakaew, K., Abraham, K. K., Okta, S., Green, C.,... Quesada, A. (2005). AIDS-related discrimination in Asia. *Aids Care, 17*, 413-424.
- QSR International (2006). *NVIVO 7* [computer software]. Victoria: Australia. Retrieved from <http://www.qsrinternational.com>.
- Quist, R. M., & Wiegand, D. M. (2002). Attributions of hate: The media's causal attributions of a homophobic murder. *American Behavioral Scientist, 46*, 93-109.
- Rudolph, U., Roesch, S. C., Greitemeyer, T., & Weiner, B. (2004). A meta-analytic review of help giving and aggression from an attributional perspective: Contributions to a general theory of motivation. *Cognition and Emotion, 18*(6), 815-848.
- Scambler, G. (1998). Stigma and disease: Changing paradigms. *Stigma of Mental Illness, 352*, 1054-1055.
- Schmitt, M. T., & Branscombe, N. R. (2002). The internal and external causal loci of attributions to prejudice. *Personality and Social Psychology Bulletin, 28*, 620-630.
- Siegel, K., & Krauss, B. J. (1991). Living with HIV infection: Adaptive tasks of seropositive gay men. *Journal of Health and Social Behavior 32*, 17-32.
- Strauss, A. L., & Corbin, J. (1998). *Basics of qualitative research*. London: Sage Publications.
- Warwick, I., Baharat, S., Castro, R., Garcia, R., Leshabari, M., Singhanetra-Renard, A., & Aggleton, P. (1998). Household and community response to AIDS in developing countries. *Critical Public Health, 8*, 291-310.
- Weiner, B. (1993). On sin versus sickness. A theory of perceived responsibility and social motivation. *The American Psychologist, 48*(9), 957-965.
- White, R. C., & Carr, R. (2005). Homosexuality and HIV/AIDS stigma in Jamaica. *Culture, Health & Sexuality, 7*, 347-359.

Author Note

Dr. Aytül Kasapoğlu is a professor of sociology in Ankara University Department of Sociology, Turkey. She has been a chairperson of the same department since 1999. She has been interested in social problems, health and disaster sociology as well as research methodology including qualitative techniques. She carried out many research projects and published 20 books and 57 journal articles. She is the Vice President of Sociology Association in Turkey and member of ESA and ISA. Correspondence regarding this article can be addressed to her E-mail: kasap@humanity.ankara.edu.tr

Dr. Elif Kus Saillard is an assistant professor of Sociology at Ankara University. Her academic interests include qualitative methodology, social identity, justice and problems of vulnerable groups who are exposed to stigmatization due to their illnesses.

Her current studies include stigmatization towards people living with mental illnesses in Turkey. She is interested in qualitative methodology as a subject in itself since she received her doctorate in sociology with her thesis “Computer Aided Qualitative Data Analysis”. She is teaching qualitative methodology, sociology of family and sociology of crime. Correspondence regarding this article can also be addressed to her E-mail: kus@humanity.ankara.edu.tr

Nilay Kaya (PhD, Durham,UK), is an associate professor in the Department of Sociology at University of Ankara, Turkey. Her main areas of work are gender and employment. She is particularly interested in rural and labour market studies (with a specific focus on gender), involuntary resettlement, human resource management, public health and education. She has carried out researches and published several journal articles on these topics.

Feryal Turan is an associate professor in the Department of Sociology at Ankara University. She received her PhD from Northeastern University. Her research interests are environmental sociology, social change, and underdevelopment. Recent publications include research on resettlement, economic crisis and environmental citizenship.

Acknowledgements

We would like to thank UNDP national and regional staff for their financial and technical contributions. We also would like to express our sincere appreciations to Sociology Association, Positive Living Association, HATAM and Numune Hospital for their sincere support. We are also grateful to all participants who made this research possible.

Copyright 2011: Aytul Kasapoglu, Elif Kuş Saillard, Nilay Kaya, Feryal Turan, and Nova Southeastern University

Article Citation

Kasapoglu, A., Saillard, E. K., Kaya, N., & Turan, F. (2011). AIDS related stigma in social relations: A qualitative study in Turkey. *The Qualitative Report*, 16(6), 1496-1516. Retrieved from <http://www.nova.edu/ssss/QR/QR16-6/kasapoglu.pdf>
