

HIV Positive Patients' Experiences on Receiving an HIV Positive Test: An Iranian – Qualitative Study

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Abstract The main objective of this current study is to provide information about HIV positive patients' experiences toward realizing HIV test results by using qualitative method. Ten HIV positive patients participated in 30- to 60-min semi-structure interviews which involved open ended questions. Five main codes were identified. The findings revealed reasons for HIV testing including: emotional reactions in time of realizing HIV status, physical reactions towards understanding of HIV status, mitigating factors, aggravating factors. Based on the findings of this study, it is suggested that HIV service providers should consider post-test counseling for HIV positive patients. This counseling might be more helpful when done by a HIV specialist and trained HIV positive patients.

Keywords: HIV positive patients, experiences, HIV test

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1. Introduction

A positive HIV test result can be a very stressful experience and can lead to both physical and psychological health consequences [1]. Sadness, shock, disbelief, depression, thought about death and contemplating suicide could be the immediate reactions to receiving a HIV positive results [2].

HIV testing and counseling have been recognized as effective interventions for secondary prevention of HIV in individuals. [3] Moreover, these interventions can be used to influence in countries progress towards HIV/AIDS prevention. If utilized effectively, these strategies can assist countries to reduce the incidence of new HIV infections leading to reduction of HIV-related morbidity and mortality [4]. Studies from across the world have demonstrated substantial reduction of high-risk sexual behavior after under-going HIV testing including pre and post-test counseling (PTC) [5,6].

International guidelines inform effective communications strategies to provide information to patients who are undergoing HIV testing. It has been described that HIV testing and counseling (HCT) are essential gateway to HIV prevention, treatment and care and consist on five key components (5Cs) including: (i) consent (ii) Confidentiality (iii) Counseling (iv) Correct test results

and (v) Connection/linkage to prevention, care and treatment [7]. Counseling as one of the most important components among "5 Cs" is defined in two parts pre-test and post-test counseling. Pre-test provides information regarding the HIV test and the confidentiality of test results, moreover, the HIV transmission routes and how protects him/herself. Post-test counseling includes revealing HIV status to patients and is considered the main part of post-test counseling process. Counseling requires time and special skills and it can be harmful if not conducted effectively. In their study, Hult and colleagues, describe that effective delivery of HIV test results by health care providers is necessary for effective prevention of HIV and is an essential part of testing process [2].

Similar to many other countries, Iran has been experiencing high prevalence of HIV infection among high risk group such IV drug users and low prevalence of HIV testing [8]. There is limited or no data that report HIV testing prevalence among general population or High risk groups. Additionally, there is lack of data regarding the quality and effectiveness of post-test counseling in Iran. In order to understand HIV testing and counseling and the impact of these for future preventive and treatment behavior of a HIV positive patient, it is important to understand the current experience of receiving a positive test result. This understanding can inform the development policies and programs that are responsive to the needs of those testing positive. The aim of this study was to gain

information about HIV positive patients' experiences when receiving HIV test results.

2. Method

This paper reports findings from semi-structured interviews which were conducted with 10 (6 males and 4 female) HIV positive patients between November 2010 and December 2010. Participants were members of the Iranian Research center for HIV/AIDs (IRCHA) "Positive Club.

Interviews questions explored: (i) reasons for HIV testing, (ii) Their feeling at the time when they received HIV status results, (iii) physical and emotional reactions towards the results, (iv) and mitigating factors and aggravating factors towards of understanding HIV status.

Interviews tool approximately 60 minutes and were anonymously conducted at the "Positive Club. Interviews were conducted in Persian language which is the formal language in Iran and spoken fluently by both participants and the principal researcher (BMD).

2.1. Analysis

All transcripts were analyzed by both chief investigators using the framework described by Braun and Clarke [9]. Texts were read several times to identify interesting features and relevant data were collated and coded. Related codes were collected into potential themes that illuminated the understanding of issues narrated by participants. Emerging themes were refined and further analysis performed by moving back and forth between 'the parts and the whole' of the transcribed texts to identify structures of the main themes. All themes were reviewed, analyzed, and related to the research question.

Participants were also given the opportunity to check the validity of findings.

2.2. Ethical Considerations

All participants provided informed consent and allowed their responses to be recorded throughout the discussions and conversations. Focus group discussion notes were also taken. All notes, transcripts and recordings were anonymous and stored in secure facilities.

The study was approved by The Research Ethics Board of the AIDS Research Centre, Tehran University of Medical Sciences, Iran.

3. Findings

3.1. Participants' Socio-demographic Profiles

Ten participants mean age was 35.6 years (range 19-46 years). There was variation of mean age by gender with mean age among men being 32.3 years compared to women 40.5 years among females.

Participants and mode of transmission of HIV infections:

Nearly all participants knew how they contracted the HIV infections. Mode of transmission for male participants included: (i) intravenous drug use (4 participants), (ii) sexual relationships with an HIV positive person (1 participant), (iii) and unknown (1 participant) but he had history of high risk sexual behaviors. Four male participants were single and two were married. All females participants except one reported that they were infected by their husband. The female group consisted of two married women and two widowed women. Six participants were employed (five male and one female) and four were without job (one male and three women). [Table 1](#) below details participants' socio-demographic profiles.

Table 1. Demographic Information

	Gender	Age	Job	Marital Status	Child	Time after being infected to HIV	History of tuberculosis and Hepatitis	Membership in HIV positive club
1	Male	40	Shoe maker	Single	no	3years	Positive	Yes
2	Male	19	jobless	Single	no	2months	negative	No
3	Male	37	Self-employed	Married	no	3years	positive	Yes
4	Male	34	employee	Married	no	3months	negative	Yes
5	Male	27	Self-employed	Single	no	6months	Negative	Yes
6	Male	37	Car buttery specialist	Single	no	10 years	Positive	Yes
7	Female	46	worker	Widowed	no	1year	negative	No
8	Female	34	House-wife	Married	yes	5years	negative	Yes
9	Female	44	House-wife	Married	yes	2.5years	negative	Yes
10	Female	38	House-wife	Widowed	yes	11years	negative	Yes

3.2. Main Reasons for HIV Testing

Four out of 6 (66.7%) male participants reported that they had sought HIV testing because they had history of intravenous drug use and they were encouraged by friends or themselves to learn their HIV status. In some cases their physicians requested HIV testing due to elevated frequencies of hospitalization or having the symptoms of resistant stage of diseases. One of the male participants (no 4) realized his HIV status after a blood donation through Iranian Blood Transfusion Organization. Among the women, two participants were HIV tested because their husbands were HIV positive. Two were referred by a

physician for HIV testing because of bad general health condition. In general, all participants except one (No5) who had been an intravenous drug user for a long time, reported that they did not expect to be HIV positive

3.3. Emotional Reactions in the Time of Realizing HIV Status

Based on the level of HIV/AIDS knowledge, each participant had varied reaction sat the time of receiving their HIV status. These reactions included delirium, anger, guilt and denial. In some cases anxiety, consternation, fear of death, hopelessness, self hatred and embarrassment were reported.

“I was bewildered and I could not understand what happened” (No 4)

Two female participants (No 9 and No 10) who reported that they had been infected by their husbands, stated that upon receiving HIV positive test results, they felt hatred toward their husbands and they were very upset, and that they wanted to take revenge on their husbands.

Male participants (No 1 and No 6), who reported to have been infected by having sexual relationships with HIV positive person, also reported having feelings of wanting to take a revenge. They also reported to have felt very isolated and mad at themselves. They also thought that it was unfair that they were the ones to contract the disease.

“I thought that all were guilty except me and I wanted to take revenge of all” (No 6)

“I was isolated and I did not like to talk to anybody.....”(No 3)

“After hearing I am HIV positive, I kept asking “why me?””(No 3)

After thought following receipt of HIV positive test:

After receiving the test results, some participants reported to have contemplated suicide. However, most participants thought about how they would disclose this information to their family. Some participants felt guilty and some of them thought about death because of being HIV positive.

“I thought this is the end of the world (thinking of death)” (No 8)

3.4. Physical Reactions in the Time of Realizing HIV Status

In some cases, physical reactions were reported by participants. These reactions included: dizziness, increase heart beat, shouting, crying and feeling of choking.

“Suddenly everything turned around (dizziness)” (No 4)

“When I realized I was HIV positive, I felt like B someone was pouring boiling water down my back (be shocked)” (No1)

A female participant who reported to have been infected by her husband and did not have any HIV/AIDS knowledge in the time of realizing HIV status, she stated sentence below regarding her feeling in hospital when she realized she was HIV positive.

“I started having disoriented and I totally became mad” (No 10)

Thoughts about leaving and escaping to a different city, as well as thoughts of suicide, were a common occurrence among many of the patients.

“I felt so bad, I tried to find a syringe and kill myself there but I could not”(No 2)

3.5. Mitigating Factors

Participants reported different factors which helped them to manage their conditions after realizing their HIV status. These mitigating factors can be group into five levels or categories including: (i) societal (ii) individuals, (iii) family, (iv) friends, (v) and spirituality.

Societal level factors:

In some cases support from the chief in a work place and becoming a member of HIV positive club (affiliated to Iran Research Center for HIV/AIDS) were helpful in reducing consequence of the news including the grief.

“After knowing I am HIV positive I have gone to work and I could not control myself. I was crying. My boss talked to me a lot and helped calm me down” (No 7)

Talking, consulting and support of a HIV specialist and also writinirg down the feelings were mentioned as ways to improve sense of bitterness

Individual level factors

Stopping intravenous drug use after being infected with HIV was one of the most important mentioned mitigating factors. Female participant also reported writing down their feeling as a way of gaining a relief

“by writing my feelings on a paper, I could become better” (No 8)

Family level factors

Family member support including spousal support was reported to be a significant mitigating factor. For example, wife support, as well as the wife’s HIV negative status, was two important mentioned mitigating factors.

“When my wife had tested and was negative my mind became calm” (No3)

Friends level factors:

Friends support and understanding seemed to be significant part of mitigating negative reactions that participants felt after receiving bad news of their HIV positive status. For example, male participant mentioned sympathy andsupport he received and from friends as a way to mitigate his feelings.

“Sympathy from a friend with the same condition (HIV positive) made me calm” (No 3)

Spiritual level factors:

The reactions perceived by participants when receiving news about their HIV positive status had emotional and spiritual sense. As such, spiritual thanking and praying to God were reported as ways to become calmer.

“My condition became better after finding a connection to God” (No 6)

3.6. Aggravating Factors

Participants reported several aggravating factors of sorrow and sadness after learning they were HIV positive. These factors have been grouped into categories including: (i) health providers, (ii) family, (iii) society, (iv) and individually.

Health provider factors

The most important mentioned reason, which increased negative feelings, was the negative behaviors from hospital staff and health providers.

“Because I told a dentist that I am HIV positive he did not extract my teeth, I do not like to lie”(No1)

Another health provider action that made most of the interviewees upset was how they were given information about their HIV test result.

“The person told my HIV result so bad and inconvenient” (No4)

Family factors

Participants expressed that they were worried and distressed that they could infect their family members including spouses and children. The worry of infecting their additionally, the majority of participants were worried about the disclosure of their status to the family. The fact that they needed to conceal of being HIV positive in society and their families have made them more upset about their condition. Furthermore, being infected by husband was another aggravating factor which was mentioned.

"I learned my husband was HIV positive and did not tell me and now I am HIV positive. I have so much anger."(No7)

Negative family behavior was mentioned as a reason to become more upset about their condition.

"Negative behavior of my husband's family made me feel guilty and completely disappointed of myself."(No 9)

Society factors:

Worrying about the negativity they will receive from society, as well as the society's lack of HIV/AIDs related knowledge were mention as significant aggravating factors.

"I was afraid of people thoughts and it made me feel so bad. They(people) do not know about this disease so they behaved in a way that I have done something wrong so I am sick" (No 6)

Individual factors:

Male participants (No 4 and No1) mentioned that they are so upset to tell lie to their friends and co-workers in their workplace and also they have had twinge for it. Moreover, drug use after learning HIV status was indicated as a factor that made interviewees upset.

"Before learning I was HIV positive I was clean (of drug), but after I realized I am HIV positive I started to use drugs. The drugs ended up making me feel worse." (No 6)

4. Discussion

The findings from this qualitative study revealed that individuals face different experiences at the time of receiving their HIV positive results..These experiences can be influenced by several factors. These factors can alleviate or facilitate the negative feelings that patients get upon the receipt of news about their HIV positive results..When analyzing the mode of HIV transmission among participants, the majority of men reported to be infected through intravenous drug use and all of female participants but one reported to have been infected by their husbands. These findings are interesting and vital in providing evidence that can be used to address HIV in the Iranian society. However, these findings are, are different from reported routes of HIV transmission in Europe. For example, in their study, Schrooten and colleagues investigated 1323 HIV positive patients, and reported that the mode of HIV transmission in approximately half of the participants was through homosexual contact [10].Findings also revealed important information including why participants sought to know their HIV status. A history of intravenous drug use and having a spouse who was HIV positive seemed to be significant reasons for participants to undertake HIV tests. Other factors including repeated hospitalization, poor general health outcomes were instrumental in pushing people to undertake the HIV test. In addition, incidental findings of positive test were also reported including finding of status after blood donation and routine medical checkup. Similar findings have been reported elsewhere. For example, in their study, Schrooten and colleagues reported that high risk behaviors (42%), physical complaints (35%),and HIV positive partner (21%) or a routine medical checkup(17%) were the top reasons that led an individual to taking an

HIV tested [10]. Moreover, Jackson and colleagues have found that the majority (61%) of HIV positive women who participated in the study were tested because they developed symptoms, or because someone with whom they were intimate, or their child, tested positive for HIV or became ill [11]. It seems high risk behaviors such as IV drug use, and/or having an HIV positive partner can be a strong motivation to undertaking an HIV test.

Reported emotional reactions after receiving a HIV positive in this study included delirium, not believing, denial, anxiety, consternation, fear of death, hopelessness, being mad of himself, embarrassment, introversion , grief and hatred towards spouses. These findings are consistent with Hult and colleagues's study where emotional reactions such as surprise, sadness, shock , disbelief, depression, thought about death and co contemplating suicide at the time of hearing the HIV test result were reported [2].

Physical reactions such as dizziness, increased heart beat, shouting, crying, feeling of choking and contemplating suicide were findings reported in the current study. Similarly, These findings were not dissimilar with Hult and colleagues's study where physical reactions including dizziness, numbness, having dry mouth , sweating , unable to hear anything and feeling suicidal were reported by their participants [2]. Interestingly, mitigating factors for a relief of negative reactions after the receipt of HIV positive news were based on multiple levels including the society, individual, family, friends and spirituality. These findings have implications including the providing knowledge that can be used to develop policies and programs that can assist patients with an HIV positive result. For instance, the most important factor mentioned was support from friends with the same condition (being HIV positive). By providing opportunities of talking or consulting with HIV positive patients , HIV service providers appeared to be important plays in helping individuals with HIV positive results to manage to their feelings effectively.

One of the most aggravating factors revealed in this study was the negative behavior of hospital staff on delivering the HIV status information. These findings are not dissimilar with Hult and colleagues study where health providers' methods of delivering bad news were implicated to making the testing process more difficult, upsetting, or disturbing for HIV positives individuals [2]. Similarly, a study conducted by Rahmati and colleague on 69 HIV positive participants showed that nearly all participants reported experiencing stigma and discrimination from their healthcare providers in a variety of contexts [12]. Refusal of care by hospital staff, due to fear of becoming infected, seemed to be one of the aggravating factors which made HIV positive patients more upset about their conditions. This refusal of care has also been found to Stigmatize and discriminate patients.

Stigma was first defined by Goffman (1994) as "an attribute that links a person to an undesirable stereotype, leading other people to reduce the bearer from a whole and usual person to a tainted, discounted one [13,14].

Discrimination has been defined as the process by which a member or members of a socially defined group is, or are, treated unfairly because of his/her/their membership of that group [15].

Stigma becomes discrimination when thoughts, beliefs or attitudes evolve into direct action.

Discrimination has been identified as an important determinant of health and there is a significant research literature on the negative effects of stigma and discrimination on health and wellbeing [16,17]. The findings of the current study suggest that discrimination and stigma influence health through multiple and complex pathways including stress and negative emotional reactions. There is also some evidence of factors that mediate the relationship between stigma/discrimination and health, such as drawing on social support, and taking action in the face of discrimination [17]. The attitudes of Health care providers were describe by participants in this study as discriminatory and seemed to increase HIV positive persons reluctance to seeking medical advice, further treatment refusing to disclose of their HIV status when they need medical care. Moreover, it is found that these groups of people may be experiencing emotional and psychological difficulties such as post - traumatic stress [18]. These findings call for clinicians and other health care providers to be more sensitive at the time of giving HIV test results to patients. Pergami and colleagues suggested that Satisfaction of HIV positive can be covered by perceived reassurance and sympathy and the quality of the information given by health care providers [19].

5. Conclusion

HIV pre and post test counseling are an essential step for helping HIV positive patients. On one hand it helps patients to face their infections and also it can also help patients feel more comfortable with seeking medical advice instead of hiding their diagnosis from medical staff. Post Test Counseling can be conducted by HIV experts and/or trained HIV positive patients. This study has found that the HIV service providers who revealed HIV testing results need to know their roles in the testing process. Service providers, through the means of post test counseling and through proper training of revealing HIV test results, can have a very strong impact on the individual's experience of testing positive. Consequently, HIV test counselors should receive specific training on providing positive test results.

Peer post test consultation may be helpful for individuals who have recently learned of their HIV status. As this study has found, the HIV service provider can provide the proper environment for trained HIV positive persons to talk with newly infected HIV patients. Although, this study utilized a qualitative methodology and on a limited number of HIV patients, its findings are highly transferable and will inform the formulation of HIV policies and practices across Iran and internationally.

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