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Stigma and Discrimination Experienced by People Living with HIV/AIDS at Health care Facilities in Karachi, Pakistan

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Abstract

Stigma and discrimination have always accompanied the HIV/AIDS epidemic, resulting in prejudice against those living with HIV/AIDS, as well as the groups that are considered 'high-risk'. Healthcare settings are the most significant context for stigma and discrimination as it greatly hampers HIV/AIDS testing, treatment and prevention. This study was done to assess the nature and prevalence of discriminatory practices and attitudes towards People Living with HIV/AIDS (PLHA) in the health sector in Karachi, Pakistan.

A descriptive cross sectional study was conducted in Karachi, Pakistan. Trained interviewers

used a semi-structured questionnaire to interview 102 HIV-positive adults to collect information on socio-demographic characteristics, HIV testing, reactions upon receiving a positive test result, and their experiences accessing the healthcare services The data were analyzed using SPSS version 18.

Majority (67%) of the participants were aged between 21 and 40 years. More than one-third (35%) were illiterate and 65% reported a household income between Rs1000 and Rs5000 per month (USD12 and USD54).

Average time since diagnosis was 2 years. 42% of the participants were tested without their knowledge. Post-test counseling was provided to 75% individuals.

35% participants reported discrimination at the hands of the healthcare providers. This included rudeness, blaming and denial of treatment.

This study reveals the existence of stigma and discrimination at health care facilities against PLHA in Karachi. In addition to HIV/AIDS related education and training, the healthcare providers also need to be targeted in HIV/AIDS intervention programs.

Key words: PLHA, HIV/AIDS, Stigma, discrimination, healthcare facilities.

Introduction

For nearly three decades, the world has struggled to control the HIV/AIDS epidemic. The fact is that poor understanding of the related issues of stigma, discrimination and denial have hampered national and international programs. [(1)]

HIV-related stigma and discrimination has been described as a devaluating process of people living with HIV/AIDS (PLHA), whereas discrimination is enacted stigma comprising unfair treatment of PLHA and it is most debilitating for already marginalised populations. [(2)]

Although discrimination occurs in multiple settings, this study focuses on the healthcare context. It is the healthcare facilities where the PLHA discover their HIV status, can get information about the prevention and care, and receive treatment. Therefore, it is particularly important to study HIV/AIDS related stigma and discrimination faced by PLHA in this setting. Studies report that stigma and discrimination predominantly occurs in the healthcare sector and is the most commonly reported by PLHA. [(2,3,4)]

Studies have reported practices including denying treatment, HIV testing without consent, lack of confidentiality and denial of hospital facilities and medicines to PLHA. [3,4] Stigma and discrimination in healthcare settings receives little attention in HIV related policy and programs[3] therefore there is a need to identify it to provide an evidence base for program and policy makers.

Stigma and discrimination can result in negative health outcomes for PLHA. Internationally, stigma has been described as a major barrier to accessing HIV treatment. [3] Research suggests that health care workers often hold negative views of people with HIV and that their views tend to mirror those of the general public. [5]

Globally 35 million people were living with HIV/AIDS at the end of 2013. [6] Out of these, 4 million PLHA were living in Asia [7], the highest outside Sub-Saharan Africa. According to a UNAIDS report in 2013 [7], Pakistan is among the 12 Asian countries that account for almost 90% HIV cases in the Asia Pacific Region. In Pakistan, the first case of HIV/AIDS was reported in 1987.[8] Pakistan is considered a high-risk, low prevalence country regarding HIV/AIDS. In 2012, there were an estimated 50,000-160,000 PLHA in Pakistan. [9] and currently the HIV prevalence rate in Pakistan is 0.1% among the general population. [5] Although this is low, yet Pakistan is facing the risk of concentrated HIV/AIDS epidemics in high-risk groups with a threat of spilling over to the general population. [10] The groups identified for this spread are commercial sex workers, Intravenous drug users (IVDUs), individuals who received blood transfusions [8] and Pakistani workers deported from abroad.[10]

Pakistan is the world's sixth most populous country with 21% of its population living below the International Poverty line of US$1.25/day. [11] Pakistan is also very low on human development index including literacy. [11] These factors make it highly vulnerable to HIV/AIDS and its related stigmas.

Although HIV/AIDS related stigma and discrimination have been extensively researched globally, limited literature addresses the situation in health care facilities in underdeveloped countries like Pakistan ,[12] despite its social and organizational implications.

The objective of this study was to explore and assess the prevalence of stigma and

discrimination faced by adults living with HIV in the healthcare settings in Karachi, Pakistan.

Methods and materials

A descriptive cross-sectional survey was done from June 2013 to Dec 2013. The study sample was conveniently selected through VCT centers at three public sector hospitals in Karachi (Services Hospital Karachi, Civil Hospital Karachi (CHK), Jinnah Postgraduate Medical Centre) and three Non-government organizations (NGO) working with PLHA (VCT Centre of Marie Stoppes Society, Marie Adelaide Rehabilitation Centre, AMAL)

Sample size was calculated on the assumption that the prevalence of discriminatory practices reported would be 50% amongst the healthcare providers. The confidence level was set at 95% with a 10% acceptable margin of error. This required a sample size of 97, which was increased by 5 to allow for any dropouts or withdrawals. Therefore, a total of 102 PLHA were recruited for the study. Men and women who were at least 18 years of age, HIV positive and willing to participate in the study were considered eligible for inclusion.

A semi-structured questionnaire was used. Eight trained interviewers were employed to collect information on factors including socio-demographic data, HIV testing, how the participants felt upon receiving their test results, and their experiences accessing the healthcare services. The interviews were held at the VCT centers and the NGO facility that the participant was visiting. Each interview lasted about 45 minutes. The data were entered and analyzed using SPSS for Windows, version 18. Informed consent was obtained from each participant before the interview. They were fully informed of the nature of the study and the use of the data. They were free to withdraw from the interview at any time or refuse to answer any particular question. Participants were also ensured of confidentiality. Ethical approval for the study was given by the IRB of the Baqai Medical University, Karachi.

Results

Out of the 102 HIV-positive individuals interviewed, 95% were male. Most (67%) of them were 21-40 years old. Socio demographic characteristics are shown in table 1.

39% of the participants were living with HIV since 6-12 months, 49% since two years, 6% since more than two years, and 2% since more than 3 years. Half (52%) of the respondents HIV were tested at government run laboratories, 14% at private laboratories and 7% were tested through charitable /NGO facilities, while 26% were tested outside Pakistan.

42% of the participants were tested without their knowledge, while 4% were tested against their consent. Informed consent was obtained from 54% after pre-test counseling. Post-test counselling was provided to 75% of the participants.

The most common reaction on receiving the test result was disbelief (43%), followed by depression (22%), numbness (15%), shock (13%), fear (7%) and anger (1%).

A large majority (89%) of the respondents perceived their experience with health care providers as discouraging or unsatisfactory. Only 11% felt they were given the proper advice and treatment (Table 2).

As to the behaviour of the healthcare providers towards PLHA, 35% of the participants reported negative experiences due to their positive HIV status (Table 3).

Discussion

This study explored the prevalence of stigma and discrimination against PLHA in healthcare settings.

Poverty level was high among the study participants, with 21% reporting an income below the International Poverty line of 1.25USD per day, whereas another 44% were earning less than 2USD per day. This can both be a driver to get HIV/AIDS as well as a consequence of being HIV-positive. Poverty makes individuals vulnerable to HIV, while those who are diagnosed as HIV-positive are vulnerable to fall into poverty. [(14)]

Majority (67%) of the sample were aged between 21 and 40 years, which is economically the most productive age group. A report by WHO [(15)] has described HIV/AIDS as a challenge to both health and development.

One third of the respondents were tested without consent in this study. A study across Asia [(2)] reported that in China, Bangladesh and Sri Lanka more than 60% respondents had been tested without their consent. This is not only unethical [(16)] but it can also be detrimental to further

Table 1. Demographic Characteristics of the Participants (n=102)

Variable	Category	%
Gender	Male	**95**
	Female	**5**
Age (years)	Under 20	**9**
	21-30	**35**
	31-40	**32**
	> 40	**24**
Marital Status	Married	**41**
	Unmarried	**57**
	Divorced	**1**
	Widow	**1**
Ethnic Distribution	Karachi	**57**
	Interior Sindh	**18**
	Punjab	**14**
	KPK	**3**
	Baluchistan	**7**
	Foreigner immigrants*	**2**
Education level	Primary	**36**
	Secondary	**17**
	Intermediate	**7**
	Graduate	**5**
	Post-Graduate	**0**
	Illiterate	***35***
Household Income/month[+]	Rs.1000-3000	**21**
	Rs.3001-5000	**44**
	Rs.5001-10000	**19**
	>Rs.10000/month	**10**
	Unemployed	**4**
	No response	**2**

*Both were from Burma

[+]**Average Monthly Household income in Pakistan as reported by Household Integrated Economic Survey Pakistan (2007-8)**[(13)] Pakistan Rs 14456 (USD 172), Lower Income group Rs 8861(USD 105), Middle Income Group Rs 12200 (USD 145), Higher Income Group Rs 24659 (USD 294)

Table 2 Participant reported attitude of Healthcare providers (n=102)

Attitude of Health care providers	Percentage
Impolite and discouraging	7
Polite and referred to another doctor	43
Attended but could not understand the need	39
Sympathetic and provided proper advice/treatment	11

treatment and prevention measures. [(17)] Testing without consent can lead to lack of taking up treatment, prevention and support services. [(16,17)] This can make them more vulnerable to discrimination.

Table 3. Participant reported behaviour of healthcare Providers (n=102)

Behaviour of healthcare staff	Percentage
Sympathetic & caring	40
Rude and impolite	15
Humiliating and Blaming	11
Apathetic	09
Treated like ordinary patient	25

WHO defines key components for HIV testing services as informed consent, confidentiality, counselling (both pre and post-test) and direct referral to prevention, care and treatment services.[17] As a result of testing without consent, pre-test counselling is also missed. Our study data suggest that post-test counselling is more common than pre-test counselling. This is not an ideal practice, as one study from Uganda [16] concluded that both pretest and posttest counseling are needed to empower HIV-positive individuals to seek support within the community and thus handle stigma and discrimination in a positive manner.

On receiving a positive test result, disbelief was the predominant reaction among the participants. This can then lead to denial and therefore refusal to disclose, seek medical and social support. Thus becomes a driver for the spread of the epidemic.

The average duration since diagnosis for the study sample was 2 years, therefore most of the participants had enough experience of contact with healthcare providers after knowing their HIV positive status.

Only 11% respondents felt that their healthcare provider could understand their needs and their attitude was also good. Although a fair proportion reported that their doctor was polite to them yet they were either simply referred to another doctor or the healthcare professional did not understand their needs. Researchers observe that such findings reveal a gap in the healthcare providers' knowledge of HIV/AIDS management. [18] Referring HIV-positive patients to another provider may be due to fear related to the transmission of HIV/AIDS. [3,18] Further research is required to determine the possible underlying factors associated with the healthcare staff's attitude towards PLHA.

In our study, 35% reported discriminatory treatment at the hands of their healthcare providers. These findings are similar to a study done in nine Asian countries [2] where 54% participants had faced discrimination in the healthcare setting. However, a qualitative study in Iran [18] found that almost all the respondents had experienced stigma and discrimination by their healthcare provider. Such negative experiences can lead to negative consequences. PLHA have been found to react to stigma and discrimination by avoiding seeking healthcare [2,3,18], turning to alternative medicine or quacks [3] and in some cases even feeling violent and vengeful. [18] Therefore, they find non-disclosure as the best option to avoid the stigma and discrimination. [16] This means that those who are infected remain hidden thus making the efforts to stop the spread of HIV inadequate. Thus, even where HIV-positive people have access to health care, they may not experience better health and quality of life as a result of stigma and discrimination.[18]

Limitations of the study

Only 5% participants were female, therefore, the study might not reveal any gender differences related to stigma and discrimination faced by PLHA. Since all the participants were attending an HIV/AIDS Care Centre, the study findings may not be generalizable to those who do not have access to such facilities.

Conclusion

Our study shows evidence of stigmatization and discrimination in the treatment of PLHA in the Healthcare sector in Karachi, Pakistan. This is related to HIV testing without consent, being denied treatment and facing abuse. These findings highlight the need to educate the healthcare workers in order to reduce HIV-related stigma and discrimination.

Recommendations

- Further research is required in Pakistan to try and understand the underlying factors that lead to stigma and discrimination against PLHA in the healthcare setting.
- Continuing professional education for healthcare workers should not only include knowledge of HIV/AIDS, it must also emphasise the importance of ethics and an understanding of human rights.
- In Pakistan, research is required to understand the layering of stigma in marginalized groups that are considered to be high risk for getting HIV/AIDS. This will help inform policies that can address the entire spectrum of the stigma experience related to HIV/AIDS.
- Policies and programs also need to focus on multiple settings and not just the healthcare setting to combat HIV-related stigma and discrimination. Furthermore, it is very important to study HIV related stigma and discrimination in the sociocultural and economic context.

Conflict of interest: The authors declare they have no competing interests.

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Authors Column

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