INFLUENCE OF DEMOGRAPHIC CHARACTERISTICS ON DISCLOSURE DECISION OF HIV-INFECTED INDIVIDUALS IN PAKISTAN

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ABSTRACT

Background: People infected with HIV have to deal with not only the challenges of living with an incurable condition but also the dilemma of whether to disclose their medical condition to their families, friends, colleagues, and other stakeholders. The disclosure decision of HIV-positive serostatus also depends on an individual's basic demographic characteristics.

Materials & Methods: This study utilizes the data obtained from in-depth interviews with HIV-infected people in Pakistan to identify trends based on the demographic characteristics, such as gender, age, religion, and household status, of the participants.

Results: Based on the in-depth interviews with HIV-infected people, this study describes how their disclosure decision is affected by their demographic characteristics. In particular, the respondents illustrate that their disclosure decision is influenced by the complexities of a joint family setup, social responsibilities associated with age, and personal religious belief. Moreover, women participants face additional social pressure, leading them to conceal their HIV status.

Conclusion: This study advances the understanding of the disclosure decision of HIV-infected individuals in a culturally conservative setting, such as Pakistan, by elaborating on how demographic and cultural factors influence this decision.

Keywords: Disclosure decision, HIV, demographic characteristics, culture, Pakistan, interviews

Citation: Farooq S, Mughal U. Influence of demographic characteristics on disclosure decision of HIV-infected individuals in Pakistan. Gulf Medical Journal. 2016;5(1):48–54.

INTRODUCTION

The human immunodeficiency virus (HIV) infection within the Asian population has attracted comparatively minimal attention in treatment literature. Very few studies examine how Asian cultural values affect the disclosure of infected status[1, 2]. Such information is necessary to help healthcare professionals as numerous studies have described the positive impact of emotional support on health outcomes[1, 3]. With an understanding of these culturally driven factors, healthcare practitioners may be able to devise practical, culturally appropriate, and acceptable programs.

Although we have gained significant ground in understanding the factors influencing the disclosure decision of HIV-infected individuals living in different regions of the world, few research studies exist in different cultural settings, particularly in resource-limited Muslim-dominated countries such as Pakistan. The disclosure practices in Asia differ from those in other countries because of cultural differences[4, 5]. Qualitative research can be used to identify culturally specific factors that influence disclosure decision in new settings, and lay the foundation for devising culturally appropriate intervention strategies.

According to official reports, less than 0.1% of Pakistan's population is infected with HIV, but the infection rate is increasing in high-risk

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groups, such as injection drug users, bisexuals, and commercial sex workers[6]. With regard to HIV, Pakistan has transitioned from a 'low prevalence, high risk' state to a 'concentrated epidemic' state. Since the first HIV-positive case in Pakistan was identified in 1987, the number of HIV-infected individuals has gradually increased. The official number of reported HIV cases in 2002 was 1,913, which rose to 120,000 by 2014. Of these HIV-positive patients, just 7,819 (6.5%) registered themselves with governmental agencies, an indication of the low disclosure rate in Pakistan. Although the occurrence of HIV-positive cases decreased 3.92% during 2002–14 at the global level, it increased 15.09% in Pakistan. In addition, the mortality rate of HIV-positive individuals in Pakistan rose 11.47% during the same period, whereas the mortality rate fell in the rest of the world. The lack of awareness among the general public and health professionals, religious beliefs, and social stigma attached to HIV are some of major causes attributed to the increasing rate of HIV-positive cases.

Given the prevalence of HIV in Pakistan, this study explores the extent to which basic demographic factors, such as age, gender, household status, and religious beliefs, influence the disclosure decision of HIV-infected individuals. We conducted a qualitative study consisting of in-depth interviews with 13 people infected with HIV. Thereafter, we carried out a thematic content analysis to identify the trends emerging from these interviews.

MATERIALS & METHODS

Persons infected with HIV are socially marginalized in Pakistan, making it difficult to approach them. In addition, it difficult to identify individuals in Pakistan infected with HIV as they do not disclose their infection status. Moreover, societal prejudices and institutional policies that perpetuate discrimination against people with seropositive status have isolated them from the mainstream society. We conducted interviews with 13 individuals visiting an HIV clinic at Pakistan Institute of Medical Sciences (PIMS) in Islamabad between October 2014 and March 2015. The HIV clinic serves as a regional distribution point for free anti-retroviral drugs, and attracts a largely rural population residing in the suburbs of Islamabad and Rawalpindi. The interview participants were individuals who visited the treatment center. The participants were selected using purposive sampling, a widely used qualitative research technique that involves selecting the subjects based on specific characteristics and attributes to ensure that a range of perspectives is represented[7]. All interviews were conducted face-to-face and recorded within the anti-retroviral therapy (ART) clinic premises. The duration of the interviews was about 90 minutes.

Based on a qualitative approach, we conducted semi-structured interviews that contained open-ended questions related to the disclosure of their HIV status. We asked probing questions in these interviews to elicit descriptions and interpretations of their experiences. All participants were infected with HIV and were using anti-retroviral drugs. During the interviews, the participants were made comfortable. We ensured that the participants trusted us by making an oral commitment to them regarding their privacy. We shared details about the research during informal chats, and subsequently requested them to participate. However, few (four) individuals declined our request because of privacy issues. The interview process started with enquiring them on certain health conditions, their job status, and organizational affiliation. The subsequent questions delved into their experiences of being infected with HIV and how they managed the stigma in the organizational and social domains. The interview process was flexible, permitting individuals to digress from the list of questions and discuss issues of interest to them. This allowed us to gather enriched data. After the data was gathered, we carried out a thematic analysis using NVivo, a qualitative data analysis tool developed by QSR International. As this study is a qualitative study, none of the statistical procedures and analyses were used.

Validity & Reliability

In this study, as the participants are infected with HIV and face the issue of disclosure decision each day in their lives, we provided them the opportunity to freely express their true self, feelings, and experiences to ensure the validity of the research.

Table 1. Participants' characteristics

Gender	Age	Education	Marital status	Disclosure level
Male	52	MBA	Married	Concealed
Male	48	MSc degree	Married	Concealed
Female	44	Matric	Married	Concealed
Female	27	BS (CS)	Married	Revealed to husband
Female	30	BBA	Unmarried	Concealed
Male	28	Matric	Unmarried	Concealed
Male	49	BA	Unmarried	Revealed
Male	54	MS	Married	Concealed
Male	32	MA	Married	Concealed
Male	44	MA	Married	Revealed
Male	41	MSc	Unmarried	Concealed
Male	26	BS	Unmarried	Concealed
Female	33	MCom	Unmarried	Revealed to parents

Note: Most participants were university graduates and working in various organizations. The participants were not enquired about their source of infection. As one of the main reasons for HIV infection was sexual activity, we were not very open about it to keep the participants at ease and make them comfortable during the interviews.

ANALYSIS

Household Status

The joint family structure, which is prevalent in many Asian cultures, is a significant factor that influences the disclosure decision of HIV-infected individuals in Pakistan. The fundamental basis of this social organization is collectivism, which is reflected in a greater willingness to collaborate with extended relatives on decisions affecting most aspects of an individual's life. In a joint family setup, people tend to value interdependence and social hierarchies. Thus, if one has to make a decision to reveal his/her HIV status, it may risk losing family ties. As narrated by one of the respondents,

"There are pros and cons of having a joint family setup. A beautiful thing about it is we are tightly integrated; we are one unit in anguish and contentment. But there is a lot of judgment. There is a pre-defined standard of who you should be and what you should do. It is very difficult to go against it and you cannot ignore the expectations of your relatives."

Some participants indicated that,

"We are living in a joint family. My cousins somehow suspected my medical condition and spread it to the extended family. Everybody was kind of shocked. Instead of understanding my medical problem, they considered me a sinner and thought that I might be indulging in unethical activities, and so they started to check routinely my daily activities, kept pushing me to change my lifestyle, and concurrently kept threatening me that they would tell everybody about it if I do not change. A lot of psychological distress was caused by this."

One participant mentioned another drawback of a joint family setup,

"I think concealing a secret inside the joint family is not an easy task because most family members share the same space. If they know about your seropositivity, it becomes a 'headline' during social gatherings, including weddings, funerals, and family gatherings. One of my uncles suspected that there is something wrong with me. He tried to find out about it by following me whenever I stepped out of the house. That is unacceptable. I am undergoing ART and need to go to the clinic. I just wish my space is respected."

In Pakistan's joint family setup, gossip culture in highly prevalent and negatively impacts the life of individuals infected with HIV. As mentioned by one participant,

"I do not want people to gossip about me. It is evident from my family background that one of my openly HIV-infected cousins was spoken of as being promiscuous, a man who deserved to be excluded from the family. I know when someone's weakness is pointed out, it becomes everyone's business to discuss his/her character in every family gathering. I do not want to be perceived as being promiscuous by others or become the topic of my relatives' conversation."

Age

The desire to protect their relatives from the pain of knowing about their medical condition motivated middle- and old-aged participants not to disclose their HIV status. In particular, this concern was evident in their decision to disclose their status to children, especially if the children were too young or if they feared that the reality would be too painful and agonizing for them. A married male participant, aged 52 years, explained that,

"I have not revealed my HIV-positive status to my daughter as I know that she would not be able to bear the reality. I do not think she has to worry about me because I feel okay. To keep a secret will also be a burden to her and I do not think that is healthy for her."

The disclosure decision of middle- and old-aged HIV-infected individuals varied depending on their elderly parents and siblings to avoid unpleasant situation. A 48-year-old man revealed that,

"I am still a child for my parents. I do not want to pressurize my old parents or make them worry about my case. As my sister is a woman, you know she may not be strong to accept this hard fact, but she is very nice to me, very caring, loving, and too close. I think I cannot tell her."

A widowed female participant, aged 44 years, said,

"It would have adverse effects on my married daughter; her in-laws might create problems for her. They may break relations and behave badly with her as HIV is perceived as an immoral disease, which could spread within the family. In addition, my younger daughter is unmarried. I fear that disclosing my HIV-positive status may affect her marriage prospects."

Gender

In Pakistan, the disclosure decision for women is inextricably linked to their roles as mothers, caretakers, and nurturers. These obligations cannot be delegated easily. A fully closeted female participant from Rawalpindi illustrated this by invoking the perceived consequences of contravening family prestige:

"I belong to a Pashto-speaking family. I have heard stories of honor killing in my family. I have always heard about the primacy of preserving honor from my childhood. My family dwells on the family name. I think just disowning me would not be enough for my family to keep their face; they could definitely go beyond this. They can even kill me."

Emphasizing on family prestige and honor, one participant expressed her feelings:

"My family always tells me that being a girl I am the honor of the family. In particular, my father used to say, 'you have social and moral responsibilities. You cannot afford to do anything wrong because we have to live in the society. I have to face everybody every day. So just think how much pressure I have to live with'. My family is extremely important to me and I have always tried to avoid things that could put the reputation of my parents at stake. I will sacrifice myself for them, so that is why I never disclosed my seropositivity."

A 33-year-old female participant said,

"I have given signals about my seropositivity within the family. In return, my parents strictly asked me not to say a single word about it to anybody else. They think that I have brought shame to the family name, and therefore, they do not let me meet anybody in the neighborhood and extended family. They try to hide my HIV infection from everybody as it is a shameful secret."

Religious Factor

The social dynamics in Pakistan offer exclusive challenges to the disclosure decision of HIV-positive individuals. In Pakistan, religious taboos hinder the recognition of HIV as a sexually spreadable disease and restrict discussion on sexual health. According to one foreign-returned participant,

"I was very happy and content abroad because there I could talk about my HIV status. In Pakistan, I cannot do so because of religion and culture. You cannot talk about sex and safe sex. My experience there is that I did not care anymore. Most of my close friends there are comfortable with my seropositive status. I do not feel discrimination, but here the situation is totally different."

Another participant stated,

"Being diagnosed with HIV has strengthened my faith and increased spirituality in me. People often turn to religion to make sense of things and come to terms with being HIV infected. I did meditation, prayer, and other forms of religious activities to strengthen my faith and to cope with HIV/AIDS. I believe if I get closer to my religion, my sins will be forgiven and I will feel satisfied with my situation."

However, overall, the typical mindset of religious people in the Pakistani society is very conservative and they ostracize people infected with HIV. As one participant said,

"I wanted to keep in touch with religion; therefore, I regularly visited the mosque that is located in the neighborhood of my workplace for the Friday prayers. I used to be actively involved with my colleagues that are attached to the mosque. I am not involved anymore as they started asking questions and instead of understanding me, they started rectifying me through religious preaching. They looked down on me as if I am an unforgiveable sinner. I stopped going there because it could eventually affect our professional relationship."

DISCUSSION & CONCLUSION

The focus of this study was to investigate factors that influence the disclosure decision of seropositive status in Pakistan. The interviews with HIV-infected individuals in Pakistan confirmed that demographic factors significantly affect their disclosure decision. Several participants perceive that a collectivist society has a panoptic eye, an overarching omniscience that is continuously observing and judging their activities. This constant monitoring causes a persistent inner fear that any wrong step may reveal their hidden identity. The study revealed a prominent trend, which emerged from the impact of collectivism, that individuals belonging to close-knit families face more pressure to conceal their HIV-positive status. Importantly, due to the tightly integrated social system, the approach of 'don't ask, don't tell' does not appear to conceal one's stigma. In Western societies, a disclosure discourse may involve leaving the family and starting a life with a new identity[8]. In contrast, for HIV-infected people in Pakistan, leaving one's family is not possible as one is recognized through the family name. Moreover, individuals have a strong bond with their families and relatives.

The pressure of disclosure varied greatly by age. The desire to protect their relatives from the pain of knowing about their medical condition was higher in middle-aged individuals, which motivated some participants not to disclose their status. This concern was evident in decisions about disclosing to parents, particularly if the parents were too old or in a frail health condition. Religious belief is another key factor influencing the disclosure decision of infected individuals. Our findings indicate that the participants who have strong faith experienced lesser pressure and accepted the medical condition as God's will. The participants who believed that HIV is a punishment from God were significantly more likely to conceal their status than those who did not express shame-related HIV stigma. Furthermore, the findings indicate that all HIV-positive women in our study actively hide their diagnosis, to a greater or lesser extent, from their husbands, children, and other family members. Based on the interviews, being a female motivated the patients to not reveal their infection status. Moreover, our findings are in line with the findings of H. Körner, whose study concluded that women disclosed to no one outside the healthcare system and were anxious to avoid any disclosure in the future[9].

Overall, our study serves as an important attempt to examine the socio-cultural and demographic factors associated with the disclosure decision among HIV-infected people. The HIV-positive status disclosure is vital for health promotion, social support, well-being, and prevention of the condition. The decision of disclosing one's HIV status to family members is a common concern among all individuals infected with HIV[10, 11]. However, our findings indicate that the decision to disclose HIV status is a personal and multifaceted undertaking, and usually not a one-step process. The decision to reveal to the members of one's religious community can facilitate emotional healing and support. Overall, our findings are in line with the studies of A.E. Arrey *et al.* and H. Körner[9, 12].

Our findings are in line with the findings of studies conducted in several other Muslim-dominated countries, such as Malaysia and Tanzania[13, 14]. Yonah *et al.* found that HIV-infected individuals in Mwanza, Tanzania, fear being stigmatized when they decide to disclose

their serostatus[14]. In contrast, S. Paxton found that public disclosure led to a reduction in discrimination, while decreasing stigma and stopping new infection cases were strong motivators to become community AIDS educators[13].

Our study offers a set of useful implication strategies to assist individuals struggling with disclosure. First, counseling on partial disclosure to a selected group, including sexual partners and people who are supportive, is essential. In addition, individuals with hidden identities need assistance in formulating a plan for disclosure to reduce the likelihood of negative consequences. Second, the perceived lack of awareness about the epidemic within the community is another important reason provided by the participants for not disclosing their status. Educating individuals who are the potential target of the disclosure decision about factual information on HIV, disease transmission process, treatment, and progression would facilitate them to respond positively. Third, strategies such as educating the targeted influential individuals within the communities are considered to be effective, as the United Nation AIDS Control Program identified education as being fundamental to the prevention, control, and treatment of the condition[6]. In this regard, local leaders, especially mosque imams, can play a crucial role in the promotion of healthcare services for people infected with HIV and reduction of the stigma associated with HIV. In a religious society such as Pakistan, men interact with imams on a regular basis to learn about their religion and follow the imam's instructions. In particular, during every Friday prayer, men of all ages gather to listen to a longer talk from the imam, where the imam can talk about primary health issues and enlighten them about the significance of HIV disclosure. Finally, theory and evidence-based efforts and interventions collectively promote ways that can help in reducing negative reactions to disclosure. Such interventions can focus on empowering women, developing disclosure skills, and providing information to disclosure targets by disseminating the research findings to a wide range of audience, including family members, business leaders, policy makers, and religious leaders, to reduce negative responses.

By exclusively focusing on culture, we are not negating the impact of wider structural factors within the society that influence the lives of HIV-infected people in Pakistan. The persistent problems of systematic social inequality, primarily manifested in social class and caste systems, may impact the decision about disclosure. Therefore, future studies should further extend this line of research among HIV patients across social classes to examine the possible similarities and differences in the disclosure decision.

LIMITATION OF THE STUDY

This study is sensitive in nature as people are not comfortable disclosing their personal lives and invisible social identities. These factors created some limitations for conducting the study in terms of finding more respondents. The main limitation was the difficulty to obtain a larger sample size. In general, HIV-infected people in Pakistan do not reside in a particular area or city, but are widely spread across the country. Thus, significant effort, finance, and convincing skills were required to approach the participants. Trust development was a critical issue; however, with the help of some doctors and other supportive patients, 13 people were successfully interviewed. The data collection process in this study was a time-consuming process. Hence, it was challenging to complete the data collection task within the estimated time limit.

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APPENDIX

We asked the following questions during the interview:

a) Name, age, occupation, designation and marital status
b) What are the factors that influenced you to conceal your HIV infection status from your family?
c) How important was family honor for you and how this factor influenced you to conceal or reveal your HIV status?
d) How collectivism, i.e., joint family setup and close-knit family structures, affects your disclosure decision, and what are the benefits and drawbacks of this variable?
e) Is marriage a social obligation, and what role does it play in your life?
f) How did religion influence your disclosure decision?
g) How do you manage your medical condition? How do you behave at home?
h) How do you maintain work–life balance?
i) How is your relationship with your spouse, parents, siblings, and colleagues? Does it affect your disclosure discussion?
j) What are the issues you may face after revealing your status?