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## **Changing social relations of HIV infected people with families and communities in Punjab, Pakistan**

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**Abstract**--Background: It is observed that HIV infected people are facing multidimensional stigma, discrimination, blames, restrictions, ban, loathing and hateful behavior by their own families, community members, neighbors, and many more people who comes in daily contact with them. The objective of the study was to determine the problems of changing social relations that HIV/AIDS patients experiences in the families and communities. Materials and Methods: The study was qualitative and cross-sectional in nature. The participants of the study were HIV infected people registered with Punjab AIDS Control Programme and enrolled at Public Hospitals and

their key informants i.e. family members and medical practitioners. Purposive sampling technique was used to select the representative sample. A sample of 50 HIV infected people, 50 family members and 20 medical practitioners were interviewed. In-depth interviews were conducted with HIV infected people, family members and medical practitioners. The collected in-depth and enrich information was analyzed thematic analysis. Results: The diagnose of HIV reshape the identity of individual in the family and community. The social relations of HIV infected people change with the family and friends. The AIDS epidemic has caused adverse psychosocial and economic consequences leading to change in the family structure, and thus disturbed the capacity of the nuclear and extended family to respond to the needs of members afflicted by HIV and AIDS. Most of the participants revealed that social exclusion, stigmatization, myths and loathing trigger the socio-phobic and psychological distress. Importantly, members of community perceive that HIV infected people are morally degenerated and they deserve to social isolation and different treatment. The health professionals and medical practitioners stated that HIV infected people should be brave, fearless and emotionless to counter the negative social response of family and community. Conclusion: The findings of the study can be concluded that HIV/AIDS affect the social relations of infected people with families and communities. Most of members of the family (blood relations) provide moral, social and financial support to the HIV infected people. On the other hand, community and peer group treat differently to HIV infected people which cause the social exclusion and discrimination. It is suggested that there is need to disseminate awareness regarding the prevention and spread of HIV/AIDS so that HIV infected may treat in a positive way in the family and community.

**Keywords**--family treatment, social relations, HIV/AIDS, antiretroviral therapy, social response.

## **Introduction**

Acquired immunodeficiency syndrome (AIDS) is one of the most significant health and social problems facing the world today. Generally, an HIV diagnosis is a traumatic experience that significantly changes a person's life (Pourcher et al, 2020). Commonly, the patient does not reveal their diagnosis at all or only reveals it to a limited number of people. A previous study determined that the most common reason patients hide their diagnosis is fear of stigma and exclusion (Kim and White, 2018). Because of the stigma associated with HIV, the patient and their family may face psychosocial problems during diagnosis, treatment and progression (Nlooto, 2017). In previous studies, it has been shown that having a family member diagnosed with HIV can affect family members in different ways and affects social relations (Sargolzaei and Mohebi, 2018).

It is observed that HIV infected people are facing multidimensional stigma, discrimination, blames, restrictions, ban, loathing and hateful behavior by their

own families, community members, neighbors, and many more people who comes in daily contact with them (Fasoulakis, 2017). In schools, colleges, work places, public places, even at hospitals HIV infected people have been facing uneven problems (Saki et al, 2015). However, the social relations have not been found same as they are changing gradually. Behavioral change of families, community members and the public people has altered the perceptives to look at the HIV infected people (Salih M et al, 2017). As a consequence, HIV infected people are facing the problem in multidisciplinary sectors of social life, namely at educational institutions, health sectors, market and the public sectors of social life (Rendina et al, 2019). The problem associated with HIV and AIDS related illness has caused discontinuation of study, restriction in getting health facilities at hospitals, creating problem to run occupation and hold a job. This has made the survival of the respondents more difficult (Ribeiro et al, 2015).

Although changing in size, structure and function, the Pakistani family has persistently maintained its place as the central human social unit. Beyond the traditional Pakistani family, whether in the nuclear or the extended form, is a network of people, most of whom are connected by kin or blood relationships, termed the clanship system. Patterns of family treatment and care are deeply embedded in this wider Kinship system. The AIDS epidemic has caused adverse psychosocial and economic consequences leading to change in the family structure, and thus disturbed the capacity of the nuclear and extended family to respond to the needs of members afflicted by HIV and AIDS (Arshad, 2017).

### **Statement of the problem**

Increasing stigma and discrimination turning the survival, livelihood, empowerment of people living with HIV and AIDS to the deep trench of inhumane practices and survival has been turning to difficult mode of social life. Since the beginning of HIV and AIDS epidemic, stigma attached to it has been widely recognized as a significant hindrance to the provision of care and preventive efforts. People living with HIV have faced Stigma, Discrimination, violent attacks, and harassment, been rejected by families, spouses and communities, been refused medical treatment, and even in some reported cases denied the last rites before they die. Negative attitudes from health care staff have generated problem among many people living with HIV. As a result, many keep their status secret. The study tries to focus on changing social relations of these people. This is very sensitive issue.

### **Significance of the study**

This study therefore, is an effort to contribute to an understanding of how HIV and AIDS related stigma is constructed in the families and communities. This study is highly significance in order to provide counseling and support to families of people living with HIV and AIDS. Through their involvement in communities will be encouraged to discuss openly around sexuality, HIV and gender related issues by building positive norms through community involvement in discussions about these issues and creating environments where such issues can be discussed without violating the society's norms. The present study also highlights the socio-cultural factors at a wider scale to gain an in-depth understanding that

can help to come up with solutions to reduce stigma. The findings of this research also draws the attention of religious institutions in the fight against HIV and AIDS epidemic.

### **Objective of the study**

To determine the problems of changing social relations that HIV/AIDS patients experiences in the families and communities.

### **Research questions**

- What is awareness' level and perception's about the People living with HIV positive in the family and community?
- How does HIV affect the lives of people in terms of changing social relations with families and communities?
- Which types of segregation, stigma and discrimination are faced people living with HIV in families and community life?

### **Materials and Methods**

The study was qualitative and cross-sectional in nature. The participants of the study were HIV infected people registered with Punjab AIDS Control Programme and enrolled at Public Hospitals and their key informants i.e. family members, community members and medical practitioners. As seen in the literature, a significant issue in AIDS research revolves around ensuring confidentiality; thus, it is not possible to obtain a 'representative sample'. Therefore, a purposive sampling technique was used. The participants were recruited as per the inclusion criteria i.e. the participants were diagnosed as HIV positive, aware of their HIV status, mentally capable of with voluntary informed consent, and willing to participate. The patients were also asked to bring a family member of their choice to the meeting. All the participants were 18 years of age or older. The sample of 50 HIV infected people, 50 family members and 20 medical practitioners were interviewed. In-depth interviews were conducted with HIV infected people, family members and medical practitioner. The collected in-depth and enrich information was analyzed thematic analysis. A code list was developed for the data and used to rate each of the participant's note. Regarding the practical ethics and moral research practice, the researchers uncovered the purpose of research to the participants and ensured confidentiality. Researchers were concerned to produce a moral and ethical research.

### **Results and Discussions**

Table 3.1  
Demographic Characteristics of HIV Infected People

Demographic Characteristics		Frequency	Percentage
Age	21-30	13	26
	31-40	20	40
	41-50	17	34
Gender	Male	32	64

	Female	18	36
Marital Status	Un-Married	14	28
	Married	34	68
	Divorced	2	4
Educational Status	No Education	5	10
	Primary	8	16
	Middle	8	16
	Matric	7	14
	Intermediate	6	12
	Graduation	10	20
	Master and Above	6	12
Occupation	Un-employed	16	32
	Housewives	18	36
	Self employed	10	20
	Private Employee	6	12
On ARTs	Yes	34	68
	No	16	32

The above table represents the demographic characteristics of the HIV infected people. Most of the participants (40%) aged 31-40 years, 34% of the participants aged 41-50 years and 26% of the participants aged 21-30 years. In this study, 64% of the participants were male and 36% of the participants were female. Regarding marital status, 68% of the participants were married, 28% of the respondents were un-married and 4% of the respondents were divorced. 10% of the participants were illiterate and 90% of the participants were literate. All of the female participants were housewives, most of the male participants (32%) were unemployed, 20% of the participants were self-employed and 12% of the participants were involved in private jobs. 68% of HIV infected people were on ARTs and 32% of the HIV infected people were not using ARTs.

### **Research Questions 1: Awareness' level and perception's about the People living with HIV positive in the family and community**

Families and communities had limited level of awareness about the spread of HIV. It was observed that family members and social capital of HIV infected people think that infected person are characterless and morally degenerated. They had no proper awareness about the viral infection of HIV/AIDS. One of the family members indicates that:

*"I am the elder brother of this HIV infected person. It is a will of God, my brother was not involved in any kind of immoral activity. Sadly, unconscious people blemish the character and identity of my brother".*

Most of the family members stated that HIV infected persons are treated differently in the family and community. The fear of stigma and discrimination create the element of socio-phobic among the HIV infected persons. Another family member revealed that:

*“Prejudgments and bad treatment with HIV infected persons leave them alone. Exclusion from family and general community trigger the anxiety and panic disorders. Basically, it is perceived that the cause of HIV/AIDs is only having sexual relation with multiple partners/prostitution. Such misinformation and perception shape the attitude of family and community towards HIV infected persons”.*

It has also been observed that family and social support is highly integral for the HIV infected people. Due to lack of social and moral support, most of the HIV infected people do not disclose their disease. One of the family members also shared that:

*“This (HIV infected person) is my younger brother and he is unmarried. When we come to learn that he is infected from HIV, it was a shocking news for our family. My family provides social and moral support to him. Our relatives showed negative response but we left them. Due to lack of awareness, no girl is ready to marry him”.*

It is very difficult for female to survive with HIV infection in family and community. Social discrimination, isolation and character assassination weak the existence of female. One of the female family members revealed that:

*“She (HIV infected person) is my elder sister, she has three children. Her husband left her, when HIV diagnosed. Now, she used to live alone with her children. No body care about her, she lives in isolation. Our family support her morally and financially. She also tried to take her life due to the different and unusual behavior of in-laws and community”.*

One of the medical practitioners also shared that:

*“HIV infected people need social and moral support. Living alone and being discriminated in the family and environment increase their psychological stress and disorders. In this regard, patient doctor relationship is highly important to support the HIV infected people. There is need to disseminate the awareness that how can people get HIV, how to take care of it and how people can live with HIV infected people. I advise that HIV infected person should behave like brave, fearless and emotionless to counter the negative response of community”.*

### **Research Question 2: Changing Social Relations of HIV Infected Persons with Families and Communities**

HIV affects the lives of people in terms of changing social relations with families and communities at large. HIV reshape the individual identity and relations with families and communities. Due to fear of stigma and discrimination, most of the people do not disclose to families and friends. One of the male HIV infected revealed that:

*“I am treated differently in my family and peer group. I live in house but most of the members of family refrain me in many ways. They treat me in a derogatory way. I am excluded from my family, relatives and community. Even, there is no acceptability of my family in the community”.*

One of the female HIV infected shared that:

*“I was a working lady before diagnose. When I diagnosed HIV, company fired me from job. People associate and label me with prostitute. People are unconscious about the spread and treatment of HIV. There are myths and prejudgments about the HIV/AIDS, and cause the social exclusion and character assassination. At present, I am facing financial and psychological problems.*

Another female HIV infected stated that:

*“My husband divorced me after diagnose of HIV. He abused and blamed me for involvement in the profession of prostitution. By God, I never met any other member except my partner. Due to unfavorable circumstances, I left my home and settled in a rented one room with my one kid. Even, my brothers never met me. I am living alone and counting my days”.*

Another male HIV infected said that:

*“I disclosed my disease to some close friends. They all left me in a difficult time. My family provide me moral, social and financial support. My wife is living with me. We use condom while having sex. We live a normal life by taking the considerable measures. Regarding the attitude of peer group, they treat differently. I run my own business without disclosing my disease”.*

Another male HIV infected shared that:

*“I live with my mother and father. All other family members especially my brothers left us. They forced my parents to leave me alone but my parents refused. My sisters come to see me. There is no social acceptability of HIV disease in the community. People label and stigmatize disease with immoral activities”.*

One of the medical practitioner shared that:

*“Most of the people are unconscious and they have little knowledge about the HIV/AIDS. Even, most of the health professionals treat differently. There is need a friendly dealing with the patient of HIV. They are emotionally sensitive people, they need care and attention. So, there is no need to change social relations with them.*

Another medical practitioner suggested that:

*“There is need to conduct and arrange awareness camps in the colleges, universities and communities with the collective efforts of government and civil society to breakdown the myths and prejudgments. In fact, attached social stigmatization and labeling exclude the patient of HIV from the social settings. There is also need to conduct counselling sessions with HIV infected persons, family members and community members to manage the disease in a better way”.*

**Research Question 3: Types of segregation, stigma and discrimination are faced people living with HIV in families and community life**

No one can deny the fact that people living with HIV face the segregation, discrimination and stigmatization in many ways. The prejudgments and misconceptions about the HIV unleash the negative social response. One of the female HIV infected revealed that:

*“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”.*

She also stated that:

*“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”.*

Another male HIV infected shared that behavior of medical personnel during the treatment:

*“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”.*

Another female HIV Infected told that:

*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.*

Another male HIV Infected stated that:

*“I haven’t had any sexual intercourse for 14 years. I don’t want it. Anyway, I can’t find anyone like me. It’s difficult, especially in this country”.*

One of the medical practitioners shared that:

*“Depression and anxiety are also common in these patients. Fear of the disease and stigma leads to depression and anxiety and it is necessary to provide psychological support for patients to prevent rejection from society and its consequences: “They have to be accepted by their families, because if they would be isolated and ostracized, especially if they have underlying psychological problems”.*

One of the family members also revealed that:

*“The disease leads to depression in patients and their families. His disease affects me more, because I have got mental disorders and depression.”*

Another family member of HIV infected people shared that:

*“Though my daughter is a medical doctor; she asked that what we are 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”.*

One of the health professionals stated that:

*“A large amount of social problems are due to rejection by other people and society. He believed that the most important action is to inform and train people to accept them and to facilitate patients’ marriage which is a fundamental issue. In addition, infected people are facing employment problems: Several steps must be taken to facilitate their employment. Nothing has been done yet to solve the problem. Employment and meeting their basic needs can solve their medical problems as well.”*

## **Conclusion**

It is an admitted fact that HIV infected people suffer many problems in terms of changing social relations with families and communities. Members of family and community treat them very badly in many ways. Most importantly, social exclusion, stigmatization and labeling trigger the psychological and mental ill-being among the patients of HIV infected. Symbolic stigmatization and character assassination of the HIV infected people create the situation of socio-phobic. The findings of the study reveal that HIV infected people need social and moral support from the family and community to fight against the disease. There is need to breakdown the prejudgments and myths about the spread of HIV/AIDS. There is need to provide the counselling services to the members of family and community regarding the how can they get it (HIV), how to take care of it and how can you live with it. Most significantly, media and civil society play collective role for the dissemination of awareness regarding the prevention of HIV/AIDS.

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