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Psycho-Social Problems Faced by the HIV/AIDS Patients

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Abstract: ***HIV, as is well known, is not random in its spread and its impact is disproportionately high on those who are socially, sexually and economically vulnerable. The vulnerability is mostly in low socio economic families. The persons having HIV infection suffers various problems not only physical but also strikingly psychological and sociological. The present study was conducted on 'Psycho-Social Problems of HIV/AIDS patients and to assess gender difference among HIV/AIDS patients at ART centre of SMS hospital, Jaipur, India. Required information was gathered by using a self prepared questionnaire. 15 males and 15 females (n-30) HIV/AIDS patients were contacted to collect data. Case study method was used to seek in-depth information for depicting the results. On the basis of obtained information and observation, it was concluded that most of the HIV/AIDS patients had to face more social problems than psychological problems. Female patients showed lack of awareness level regarding HIV infection and AIDS than male patients and are facing the daunting challenge of life after HIV infection. It was also observed that majority of the females got this infection from their husbands, but male respondents were more vulnerable to receive this disease due to unsafe sex and extra marital sex. The sociological problems are facing more in illiterate females as compare to male like rejection from the family member or negative behavior with them, but all over the social conditions are worse for HIV/AIDS patients.***

Keywords: Psycho-Social Problems, HIV, AIDS

1. Introduction

"HIV infection is now common in India; exactly what the prevalence is, is not really known, but it can be stated without any fear of being wrong that infection is widespread… it is spreading rapidly into those segments that society in India does not recognize as being at risk. AIDS is coming out of the closet (Nath L.M., 1998). AIDS is the most dreaded enemy of the human race which is going epidemic dimension gradually all over the world. It has entered the Indian soil with disastrous implications on millions of people living in rural, urban and tribal communities. Every state in the India is experiencing a snow balling increased in the transmission of HIV. Since young people are the easily approachable targets of HIV/AIDS.

2. Estimation

India has a population of one billion, around half of whom are adults in the sexually active age group. The first AIDS case in India was detected in 1986 and since then HIV infection has been reported in all states and union territories. India is one of the largest and most populated countries in the world, with over one billion inhabitants. Of this number, In 2006 UNAIDS estimated that there were 5.6 million people living with HIV in India, which indicated that there were more people with HIV in India than in any other country in the world. In 2007, following the first survey of HIV among the general population, UNAIDS and NACO agreed on a new estimate – between 2 million and 3.1 million people living with HIV *(UNAIDS, 2007).* In 2008 the figure was estimated to be 2.31 million. In 2009 it was estimated that 2.4 million people were living with HIV in India, which equates to a prevalence of 0.3%. While this may seem low, because India's population is so large, it is third in the world in terms of greatest number of people living with HIV. With a population of around a billion, a mere 0.1% increase in HIV prevalence would increase the estimated number of people living with HIV by over half a million. The spread of HIV in India has been uneven. Although much of India has a low rate of infection, certain places have been more affected than others. According to the Rajasthan State Aids Control Society, transfusion of HIV-infected blood is also a major reason for transmission of the virus. In 2008, around 3,90,899 people had donated blood out of which 764 were HIV positive, and in 2009 the figure increased to 808, in the same year 3,94,917 people had donated blood.

3. Stigma and Discrimination

In India, as elsewhere, AIDS is often seen as *"someone else's problem"* – as something that affects people living on the margins of society, whose lifestyles are considered immoral. Even as it moves into the general population, the HIV epidemic is still misunderstood among the Indian public. People living with HIV have faced violent attacks, been rejected by families, spouses and communities, been refused medical treatment, and even, in some reported cases, denied the last rites before they die.

AIDS related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment towards people living with HIV and AIDS. The consequences of stigma and discrimination are wide-ranging by family, peers and the wider community. An erosion of rights, psychological damage, and a negative effect on the success of HIV testing and treatment. Stigma not only makes it more difficult for people trying to come to terms with HIV and manage their illness on a personal level, but it also interferes with

attempts to fight the AIDS epidemic as a whole. On a personal level it can make individuals reluctant to access HIV testing, treatment and care.

The majority of developing countries families are the primary caregivers when somebody falls ill. There is clear evidence that families play an important role in providing support and care for people living with HIV and AIDS. However, not all family responses are supportive. HIV positive members of the family can find themselves stigmatized and discriminated against within the home. There is concern that women and non-heterosexual family members are more likely than children and men to be mistreated. As well as adding to the suffering of people living with HIV, this discrimination is hindering efforts to prevent new infections. While such strong reactions to HIV and AIDS exist, it is difficult to educate people about how they can avoid infection. AIDS outreach workers and peer-educators have reported harassment, and in family sometimes face negative reactions from the parents.

Discrimination is also alarmingly common in the health care sector. Negative attitudes from health care staff have generated anxiety and fear among many people living with HIV and AIDS. As a result, many keep their status secret. It is not surprising that for many HIV positive people, AIDS related fear and anxiety, and at times denial of their HIV status, can be traced to traumatic experiences in health care settings.

A 2006 study by NACO found that 25% of people living with HIV in India had been refused medical treatment on the basis of their HIV-positive status. It also found strong evidence of stigma in the workplace, with 74% of employees not disclosing their status to their employees for fear of discrimination. Of the 26% who did disclose their status, 10% reported having faced prejudice as a result. People in marginalized groups - female sex workers, kinners (transgender) and gay men - are often stigmatized not only because of their HIV status, but also because they belong to socially excluded groups. Stigma is made worse by a lack of knowledge about AIDS. Although a high percentage of people have heard about HIV and AIDS in urban areas (94% of men and 83% of women) this is much lower in rural areas where only 77% of men and 50% of women have heard of HIV and AIDS (*PEPFAR, 2008).* However, the real challenge lies with ignorance about how HIV is transmitted - for example the majority of men and women believe that AIDS can be transmitted by mosquito bites. In 2009, NACO carried a population based survey in Nagaland, where it was shown that 72.8% of people surveyed believed HIV could be transmitted by sharing food with someone (*PEPFAR, 2008).*

It is difficult to assess the accuracy of this statement as levels of stigma are hard to measure and a number of small-scale studies have shown that the relationship between increased access to HIV treatment and a reduction in stigma is not always clear. Some of these consequences refer to 'internal stigma' or 'self-stigma'. Internal stigma refers to how people living with HIV regard themselves, as well as how they see public perception of people living with HIV. Stigmatizing beliefs and actions may be imposed by people living with HIV themselves: Self-stigma and fear of a negative community reaction can hinder efforts to address the AIDS epidemic by perpetuating the wall of silence and shame surrounding the epidemic. Stigma also worsens problems faced by children orphaned by AIDS. AIDS orphans may encounter hostility from their extended families and community, and may be rejected, denied access to schooling and health care, and left to fend for themselves. Everyone has a right to information and education about HIV/AIDS and these facts of life will help young people to protect themselves from the infection of AIDS. An overwhelming section of our population is not aware about this dreaded disease, specially the women, illiterate and socially deprived people.

4. Methods

The study was conducted in ART centre of S.M.S. hospital, Jaipur. A group of 30 HIV positive and AIDS patients i.e. 15 males and 15 females were identified (n= 30) and contacted personally during OPD visits. In order to know about the psycho-social problems of HIV/AIDS patients a close-ended questionnaire was developed in Hindi language by the investigator with the help of related literature, reports and experts of the field. Majority of the patients were illiterate so they were interviewed after with the permission of SMS authority. The data were interpreted by Percentage and according to the nature of questions.

5. Results

Table 1: Awareness about symptoms of HIV/AIDS

S. No	*Symptoms*	*Male (n = 15)*		*Female (n = 15)*	
		f	%	*f*	%
1	weakness	3	20	2	13.33
2	pain	-	-	3	20.00
3	Fever	6	40	4	26.67
4	sore (pubic skin)	1	6.67	1	6.67
5	no response	5	33.33	5	33.33

Above table indicates that fever was recognized as the main symptom by the majority of the respondents i.e. 40% males and 26.67% females, least awareness was found regarding sore skin in the subjects. 33.33% respondents were not aware about symptoms of HIV/AIDS. Approximately 2/3rd of the subjects were aware about the major and minor symptoms of HIV/AIDS but in the beginning different patients experienced different symptoms. Since these symptoms are not very specific to HIV/AIDS, so the patients may not be serious about these symptoms in beginning.

Table 2: Respondents sharing secrets

S. No	*Responses*	*Male (n = 15)*		*Female (n = 15)*	
		f	%	*f*	%
1	Friends	4	26.67	-	-
2	Wife	6	40	-	-
3	Mother	3	20	11	73.33
4	No one	-	-	3	20
5	Friends	4	26.67	-	-

It is clear from the table 2 that majority of females (73.33%) shared their secrets regarding the diseases only with their mother. It may be due to the reason that either their husbands were staying away or they had lost their husbands,

so mother was the only close person with whom they could open hearts for help. On the other hand males were open to discuss and share with everybody including mother, wife, friends etc.

Table 3: Respondents' reactions after declaration of HIV/AIDS

S. No	Responses	Male (n = 15)		Female (n = 15)	
		f	%	f	%
1	Negative Thinking	5	33.33	6	40
2	continued working as usual	4	26.67	1	6.67
3	commit suicide	1	6.67	2	13.33
4	Nothing	5	33.33	6	40
5	Negative Thinking	5	33.33	6	40

The table 3 shows that males (33.33 %) and females (40%) had negative reactions, after they came to know about this disease. Very few of them continued working as usual. The fact behind the negative thinking was that they were shocked to catch infection of such a fatal diseases and a few showed lack of coping up strategies and attempted suicide. While 33.33% males and 40% females were found neutral.

Table 4: Respondents having any other disease

S. No	Responses	Male (n = 15)		Female (n = 15)	
		f	%	f	%
1	Yes (T.B)	3	20	5	33.33
2	No	12	80	10	66.67

It is clear that very few AIDS patients under study i.e. 20% male and 33.33% females had tuberculosis, which is more frequently seen in HIV/AIDS patients while 80% Male and 66.67% females did not have any other disease because, they are still in the stage of HIV not AIDS.

Table 5: Source of knowledge of respondents about HIV/AIDS

S. No	Responses	Male (n = 15)		Female (n = 15)	
		f	%	f	%
1	Friends	-	-	1	6.67
2	T.V.	5	33.33	1	6.67
3	Radio	3	20.00	-	-
4	Any other	7	46.67	13	86.67
5	Internet	-	-	-	-

The table 5 shows that majority of the i.e. 46.67% males and 86.67% females were totally ignorant about this deadly disease. The reason being that most of the subjects were from low socio-economic status and they are busy in their work in making both ends meals staying away from families and men especially get involved in unsafe sex due to ignorance and dominating sex desires and pass on this disease to their wives. The rest of the respondents had some knowledge, which they received from friends, radio, T.V. etc. but they did not take seriously and ignored it for the momentary enjoyment of sex. None of the respondents have ever approached internet.

Table 6: Doctors Advice

S. No	Responses	Male (n = 15)		Female (n = 15)	
		f	%	f	%
1	Fully Following	12	80	14	93.33
2	To some extent	2	13.33	1	6.67
3	Don't follow	1	6.67	-	-

The table 6 indicates that almost 100% respondents were taking medicines regularly. Only one person has ignored doctor's advice due to low socioeconomic status but majority of them took care of medication and diet and few of them also adopted alternate therapies.

Table 7: Behavior of family members towards HIV/AIDS patients

S. No	Responses	Male (n = 15)		Female (n = 15)	
		f	%	f	%
1	Same	12	80	11	73.33
2	Better than before	1	6.67	-	-
3	Worse than before	2	13.33	4	26.67

This table 7 indicates very encouraging results that is males (80%) males and (73.33%) females had support of their families as usual while only 13.33% males and 26.67 females found negative change in behavior of family members, it may be because these females are widows and facing many problems since their families consider them burden and didn't want to support them.

Table 8: Problems faced by HIV/AIDS patients

S. No	Responses	Male (n = 15)		Female (n = 15)	
		f	%	f	%
1	Excluded from the family	-	-	3	20
2	Separation between husband & wife	-	-	-	-
3	Discharge from office work	-	-	-	-
4	Social boycott	-	-	-	--
5	Nothing	15	100	12	80

The table 8 shows that 20% females were excluded from the family after their husbands' death indicating the status of non working sick women with fatal disease in patriarchal society. The family does not want to carry their burden of expenditure on medication. Whereas 100% male patients and 80% female patients were staying in the family after diagnosis of the disease.

Table 9: Effect of medical and Psychological treatment (counseling) on the behavior and feelings of HIV/AIDS patients

S. No	Responses	Male (n = 15)		Female (n = 15)	
		f	%	f	%
1	positive thinking	5	33.33	2	13.33
2	increased interest in work	3	20	-	-
3	no change	4	26.67	6	40
4	wants to spend life happily	3	20	6	40
5	all of the above	-	-	1	6.67

Table 9 shows that medication and counseling plays a very major role in this disease, males (20%) have increased interest in their work and also 20% males and 40% females desired to live happily. one nice thing is that one female patient change her life in positivity and joined the job of counselor in ART center with the desire to do best for her children, surprisingly she was widow and accepting challenge.

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