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A dual battle for people living with HIV/AIDS: Fighting HIV/AIDS and discrimination

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Abstract

Thirty-six years have passed since the first case of HIV infection was detected in India in 1986. Around 2.1 million people are living with HIV/AIDS in India. This number makes India the third-worst affected country in the world. Globally, we have made tremendous progress in converting it into a chronic manageable illness. Though the incidence of HIV/AIDS is also declining in India since 2001 but the stigma and discrimination associated with it are still candidly prevalent in many parts of the world and in India too. India has enacted legislation to do away with discrimination but still, there are miles to go. A study was conducted to study the lives of children living with HIV/AIDS in families and in institutional setup. Thirty families and thirty children residing in residential institutions were selected for the study depending upon the willingness of the families to participate in the study and access to the researcher. Unstructured interview guides, theme-based group discussions, observations of the family dynamics wherever possible, and narratives of caregivers and children were used to elicit the information. The study revealed the prevalence of discrimination and stigma in explicit and in subtle forms in the lives of people living with HIV/AIDS and the need to devise strategies to tackle it effectively.

Keywords: HIV/AIDS, children, discrimination, stigma, bullying, awareness

Introduction

Media content during the early phases of HIV/AIDS on persons affected by HIV reads as follows:

- “Schools show the door to HIV kids”
- “An HIV positive girl was made to sit alone on the last mat in the class and her teacher also instructed other children not to play with the girl as they may also get the disease in Tamil Nadu”.
- “A three-year-old kid was left hanging from a tree for seven hours, all because he was HIV Positive”.
- “A couple in Orissa was not allowed to be cremated for the fear that smokes from the pyre would pollute the entire village”.
- “Hospital shuts doors to a pregnant lady”.

These stories are the harsh realities that are faced by people living and affected by HIV. Human Rights Watch in 2004 reported rampant discrimination of children living with HIV/AIDS. A lot of children with HIV-positive status were either segregated from HIV-negative pupils, expelled from the schools, or denied admission in schools altogether.

The lack of awareness and incorrect and incomplete knowledge create stigma and discrimination related to HIV/AIDS. A family living with HIV/AIDS dies a social death much before their physical death. An intimate partner infects his friend or spouse with the virus because he keeps it a secret. Parents leave their infants to die before s/he has taken his/her first independent breath. These are examples of unequal power relationships between health providers, parents, intimate partners, and society. HIV/AIDS thrives and exposes every weakness of society.

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The Legal Provisions

The Indian Supreme Court, 2014 recognized transgender people as a separate gender. Since then, the government and non-governmental sectors are being set up to meet their specific health needs. Even with the creation of favorable legal environment, transgender people face massive stigma and violence. A study done in 2017 using the interview as the study tool on around 70 transgender sex workers in Maharashtra revealed that most had experiences of stigma, discrimination, bullying and violence (Ganju and Saggurti, 2017) [4].

On 5 May 2017, Supreme Court held that children living with HIV/AIDS (infected and affected- children who themselves are HIV negative but whose parent(s) is HIV positive) should be afforded protected status and included as a 'child belonging to a disadvantaged group' under Right of Children to Free and Compulsory Education (RTE) Act (2009). The bestowment of protected status to children living with HIV means that they are now entitled to special protections and measures, under the terms of the RTE Act (<http://eoc.du.ac.in/RTE%20-%20notified.pdf>). It eliminates discrimination with respect to admissions including denying or limiting access to sports facilities, playgrounds, canteen, common areas, or any other amenities being available in the school. It also protects them from financial extortion or forced expenditure on any pretext. It also guarantees that private schools will reserve a minimum of 25% of seats in each class to children from disadvantaged groups. Special mechanisms are available for complaints of discrimination if encountered any (40_0.pdf (education.gov.in).

In 2018, HIV AIDS (Prevention and Control) Act 2017 was implemented. The law makes it a punishable act to discriminate against people living with HIV and AIDS. This includes all settings like including workplaces, healthcare settings, educational places, public places. It also protects their property and insurance rights.

The Supreme Court decriminalized homosexuality between consenting adults in 2018. This enabled the access of HIV services within the reach of many men who have sex with men.

Despite bringing changes in the legal environment of India, men who have sex with men remain extremely marginalized and face widespread stigma, homophobia, and discrimination.

Discrimination

Discrimination or bullying is a form of abuse. It can be emotional, verbal, or physical, and/or a combination of all. Many times, it involves subtle methods of psychological manipulation. It shows that one group or person's power over another group or person, thus an "imbalance of power" or unequal power relations. It may be social power and/or physical power. Bullying can occur in any context in which human beings interact with each other. This includes school, religious place, family, the workplace, home, and neighborhoods.

People living with HIV/AIDS have faced direct attacks of bullies such as hitting, throwing things, slapping, choking, punching and kicking, beating, stabbing, pulling hair, scratching, biting, scraping, and pinching. Name-calling, teasing or taunting, threatening, stalking, coercion, stealing, etc., and indirect attacks such as spreading rumours i. e. malicious gossiping, demeaning, intentional exclusion or trying to make others reject or isolate someone. This isolation is achieved through a wide variety of techniques like refusing to socialize with the victims (families living with HIV/AIDS),

criticizing their mannerisms, and other significant social markers. It negatively impacts every member of the family. They may feel tense and afraid. They may suffer from long-term emotional and behavioral problems like loneliness, depression, anxiety leading to low self-esteem and increased vulnerability to illness. They may take drastic actions like committing suicide. Bullies may also be present in the family. A male partner may bully his female partner or vice versa.

Methodology

A study was conducted by the author from 2006-2011 to study the family dynamics of people living with HIV/AIDS in Delhi. Thirty children in the age group of 07-14 years living with HIV/AIDS in residential institutions and 30 families living with HIV/AIDS were selected from Delhi and NCR for the study depending upon their willingness to participate in the study and access to the researcher. Unstructured interview guides, theme-based group discussions, observations of the family dynamics wherever possible, and narratives of caregivers and children were used to elicit the information. Relevant narratives from the study have been incorporated in the present article wherever necessary to portray the lucid picture of being discriminated or bullied by and because of HIV infection (Jain, 2011) [7].

Results and Discussion

Discrimination at macro and micro levels of society: Some of the salient aspects responsible for increasing the susceptibility of women and girls to HIV infection in India is blatant gender discrimination, poverty, early marriage, low status of women, migration, lack of education, trafficking, and sex work.

Women are treated very differently from men in India where they are economically, culturally, and socially disadvantaged. They are sometimes mistakenly perceived to be the main transmitters of HIV. The poor economic status and educational opportunities lead to women and girls being deprived of information about HIV and AIDS, this is true of most countries but especially true in India.

One of the married women from the sample reported, "I thought, it would be better to commit suicide than to die from his beating or live with them, so some time back I attempted suicide but failed". (Jain, 2011) [7].

The unequal gender status is revealed in the sexual relations between a husband and his wife. For millions of Indian women, sexual intercourse is not a question of choice but of survival and duty. It is a source of identity for married Indian women. A married women's morals and faithfulness are questioned when she tries to negotiate safer sex even if she suspects her spouse's behavior as risky. Women do not have a right to demand safe sex and ask men to use a condom. There is also a lack of availability of female-controlled HIV preventive methods. Secondly, the cultural norms and attitude of overlooking male behavior of multiple partners/ pre-marital or extra-marital sexual affairs of men in the society proliferates women's chances of getting infected with the virus.

One of the women narrated, "My husband died of AIDS in 2007. He was 30 years old. He was an alcoholic and had extramarital affair with a girl near his home. I knew of his relationship and objected to it. He used to fight with me and hit me if I said anything against that relationship. He used to threaten me with divorce (Jain, 2011) [7]."

Women with HIV are subjected to various forms of violence and discrimination based on gender. They are thrown out of

the house, denied a legitimate share in the property, denied treatment and attention, or accused of a husband's HIV diagnosis. In cases where a husband has admitted he had sexual relations with sex workers, the burden of the blame still falls on the wife for failing to 'satisfy' her husband. Women with the virus may also be physically abused. Also, during pregnancy women are first to be tested for HIV and hence blamed for having HIV, even though their male partners could be the true source of infection (Jain, 2011) [7]. In comparison to HIV-positive men (68%) HIV-positive women (87%) are significantly more likely to be diagnosed, this happens due to the prevention of mother-to-child transmission and the number of women being tested for HIV (Bhattacharya, 2018) [3]. This also deems them culprits and labeling occur. The overall HIV prevalence is more among men than women, with 0.25% of males and 0.19% of females living with HIV as of 2017 (Ministry of Health and Family Welfare, 2019). This is because key populations such as men who have sex with men, drug users, and migrant populations are largely male.

The social responses to people with AIDS have been devastatingly undesirable in India. A study has shown that 36% of people felt it would be better if infected people killed themselves, and the same number stated that these people deserved their fate. Also, 34% said they would not associate with people with AIDS and one fifty stated that AIDS was a punishment from God (UNAIDS, 2001) [10].

HIV/AIDS in India is not merely a medical issue. It is a multifaceted issue a social/a human problem. In India, as elsewhere, HIV infection is often seen as the disease of those whose lifestyles are considered deviant. This may be because the disease was first found among high-risk groups (homosexuals, sex workers, injecting drug users, etc) and our prevention efforts were directed towards them only. At present the HIV infection has moved into the general population, the epidemic is still misunderstood by the general public. The mental agony of a woman can be felt from her narratives, "I am HIV positive. My husband is HIV-negative. He is a 'pujari' (priest) by profession. It is our second marriage. My husband has three children from his first marriage. I am pregnant with our third child. I have the feeling that this time I will not be able to see my child. I was diagnosed with HIV in 2003. I did not take medicine for about a year. There is a lot of marital discord between us. He hits me. My husband always taunts me for the disease. He never takes any precautions during sexual intercourse to protect him. He feels that he has not done anything wrong, so God will not punish him with the disease. I have suffered from many diseases like TB, piles, etc. I remain awake during nights". (Jain, 2011) [7].

Hence, HIV/AIDS reflects and reinforces social inequalities.

HIV and abandonment of children

A significant number of children are abandoned or rendered destitute due to their HIV-positive status at birth. The children are often born to socially underprivileged families who receive no support to permit them to care for their children. The children have to face similar discrimination and incredible barriers to access social and medical services that would enable them to care for themselves and their children in their family environment. As a result, the mothers relinquish their parental rights. The expansion of residential services in several countries including India at the time the author was doing her fieldwork often created a pull effect. Families were inclined to give up their children for a better future. State

support could have allowed children to grow up within their families. Born to HIV-affected mothers, even if they themselves do not test positive they are often abandoned by their families. Adoption data indicates that even if blood tests on infants indicated that the child was negative for HIV, very rarely would an Indian family come forward to adopt the child. The maternal history became baggage for the newborn child. Thus, abandonment or surrender of this child renders this child without the right to a family and a future full of challenges. Infants are relegated to state institutions or orphanages, which have highly negative long-term developmental outcomes (Bhargava, 2005) [2].

"Their removal from their mother, their family and community is an expression of both the stigma surrounding the HIV disease and of the multiple hardships that overwhelm many disadvantaged women" (UNICEF, 2010a:7) [14].

There is a prevalent belief among social workers that foster care cannot be an option for children living with HIV. Within the residential care system, it is argued that children with HIV have specific psychological, academic, nutritional, and medical needs that require them to be segregated. This practice not only leads to children being placed in residential care but also affects the types of facilities they go into. In India, this argument was used as a justification for the segregation of HIV-positive children (Jain, 2011) [7].

Discrimination in health care settings: Research of hospital staff in government and non-government clinics in Mumbai and Bengaluru found prejudices were rampant (NACO, 2017). This included a preparedness to forbid women affected with HIV from having children (55 to 80%), authorization of compulsory testing for female sex workers (94 to 97%) and surgery patients (90 to 99%), and asserting that people who developed HIV 'got what they deserved' (50 to 83%). There is an almost phobia of HIV/AIDS at all levels, from the administration, the doctors, the sweeper, and ward boys, which forces them to refuse to deal with an HIV positive patient. Stigma and discrimination are very common within the healthcare sector. One of the families recollected the hurtful words of medical staff,

"Nowadays discrimination has become very subtle. In 1998-99, discrimination was very rampant. Once one of the doctors at the government hospital told me, "Agar tumako apni bimari batane mai sharam aati hai to chehre par poster lag walo" (If you feel ashamed of your disease, then get a poster pasted on your face). I have to undergo uterus removal operation (Hysterectomy). Doctors are avoiding my surgery on one or other pretext" (Jain, 2015) [7].

Discrimination was rampant during the eighties and is now subtle in health care settings. It has generated anxiety and fear in the general public about people living with HIV and AIDS. Many families living with HIV/AIDS keeps their status secret because of their traumatic experiences in health care settings. A woman reported, "The sweepers and ward boys wore extra gloves when they had to do anything for my husband and kept staring at us. They never did dressing. Instead, they gave me cotton gauge, medicine, and dressing. We used to do it on our own. Doctors never touched him while doing the check-ups". (Jain, 2011) [7].

Experiences of children being discriminated

In the majority of developing countries, families are the primary caregivers when somebody falls ill but, HIV-infected members of the family can find themselves stigmatized and discriminated against within the home. They are maltreated

by their own family members. A twelve-year institutional child reported, "My bhabhi used to keep me away from her children. She used to ask me to sleep on the staircase outside the home. If I had a mother, then my mother would not have discriminated like this. She used to tell her children not to share food with me. She used to ask me why have you come here". (Jain, 2011) [7].

Double orphans (children who had lost both parents because of HIV/AIDS) living in institutional setup reported that they were bullied by single orphans (children who had lost one parent due to HIV/AIDS) and children from poverty-stricken homes but had parents. A double orphan reported, "Many times during fights "Ghar wale bachhe "(children having a home) call me as 'anaath' (orphan) (Jain, 2011) [7].

A mother reported, "My husband died of AIDS. He once had a premarital sexual relationship with somebody just once. He contracted AIDS from there. I am also HIV positive. My son is HIV-negative. I shifted to Delhi in search of work. At present, I am working as an "outreach worker". Because of long hours of working and the absence of any member at home, I placed my son in a residential institution. Once I conducted an awareness programme on HIV at his institution. Now my son is nicknamed as "HIV" by the institutional children". (Jain, 2015) [8].

Research has begun to scrutinize the effects of childhood bullying on physical health outcomes. There is a significant association between childhood persecution and high levels of lasting physical suffering, including somatic and physical complaints. Common illnesses in adolescence such as eczema, asthma, sore throat, headache or shoulder pain, and lower respiratory tract infection were significantly related to negative life experiences including being bullied at school. In a meta-analysis of recent studies, the risk for psychosomatic problems was significantly higher among those victimized by bullying. Thus it is evident that HIV stigma and bullying would be associated with major depressive disorder and high-risk suicidality as found by Ashaba *et al.* (2018) [1].

Conclusions and Recommendations

From the study, it was evident that discrimination and stigma were widespread in every setting of society against the people living with HIV/AIDS. The families living with HIV/AIDS irrespective of their infected or affected status faced discrimination not only outside the family but also within the family by their closest relatives. Bullying, discrimination, stigma against women and children were also fuelled by already existing social and gender inequalities.

Combating bullying against people living with HIV/AIDS by the general population is a mission that requires cooperation between everyone involved. Parents, the school, and the community must work together to generate awareness, stop the stigma, labeling, and hence bullying. Stigma and discrimination will continue to exist so long as societies as a whole have a poor understanding of HIV and AIDS and the pain and suffering caused by negative attitudes and discriminatory practices.

A comprehensive intervention plan with candid knowledge of the etiology of HIV/AIDS for all would help ensure that all people living with HIV/AIDS in general and children living with HIV/AIDS, in particular, can live and learn in a safe and fear-free environment. We should all strive towards developing a social including school climate where bullying towards families living with HIV/AIDS is conspicuous by its absence.

Availability of Anti-Retro Viral medicines to all eligible HIV-

infected people including children and hundred percent adherence to ARV will reduce the viral load to undetectable levels and this would make it nontransmissible HIV infection to others and would help in eliminating the disease from the globe. Nontransmissible status of HIV would also greatly help in combating stigma and discrimination against people living with HIV/AIDS.

The core of HIV/AIDS discrimination is the fear that needs to be tackled at the community and national levels. This fear can only be reduced with AIDS education on a war footing. A more enabling environment needs to be created to increase the visibility of people with HIV/AIDS as a 'normal' part of any society. The presence of treatment makes this task easier; where there is hope, people are less afraid of AIDS; they are more willing to be tested for HIV, to disclose their status, and to seek care if necessary. The mission needs to confront the fear-based messages and prejudiced social attitudes, in order to reduce the discrimination and stigma of people living with HIV and AIDS.

Safe prenatal, antenatal and post-natal medical services need to be made available to all women of childbearing age. Institutional deliveries should be promoted in a mission mode to prevent transmission of the virus from parent to child. Counselling services should be made available to people including children living with HIV/AIDS as and when required by them. Efforts should be made to improve the quality of life of people living with HIV/AIDS. Another prevention tool being developed is microbicides; which women could apply vaginally as gels without their partners' knowing to prevent sexual transmission of HIV. Women-controlled barrier methods like female condoms and vaginal microbicides etc will enhance women's ability to protect themselves from HIV and other sexually transmitted diseases. HIV/AIDS-related discrimination cannot be fought with policy or laws alone. Strong political commitment and leadership are prerequisites for setting the agenda and driving a potentially effective response. India must ensure that the social, economic legal, medical, and regulatory frameworks and their implementation are in line with international, regional, and human rights standards so that people living with HIV can enjoy their rights to non-discrimination, human dignity, privacy, confidentiality, and health.

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