Journey from victim to a victor—a case study of people living with HIV and AIDS

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INTRODUCTION

It will take a concerted and sustained effort globally to achieve UNAIDS' (United Nations Programme on HIV/AIDS) vision of zero discrimination, zero new human immunodeficiency virus (HIV) infections, and zero acquired immunodeficiency syndrome (AIDS)-related deaths.¹ Unequal treatment and increased vulnerability make women hapless victims of HIV/AIDS. Nearly 40% of HIV-positive people in India are women, according to United Nations Development Programme (UNDP). The UNDP states that nearly 80% of HIV infections among women in 2005 were the outcome of women contracting the disease from their husbands.² Gender plays a key role in the complex interplay between HIV-related stigma, moral judgement, shame, and blame. Women, whether married or single, divorced or widowed, sex workers or seasonal migrants or adolescent girls, are most susceptible to the negative impacts of HIV and AIDS. Further, women are biologically more prone to HIV infection than men in terms of any single act of unprotected sex with an infected partner. Gender disparities in terms of access to education, resources, income, political power, coupled with incidences of sexual violence, coercion, social dislocation in conflict situations like war etc. or owing to migration for work, serve to increase the risk of HIV infection to women through unprotected sexual intercourse.

For India, women account for about 39% of all infections despite the fact that >90% of them are in monogamous relationships. It is estimated that about 30 million men in India buy sex on a regular basis while the social and cultural limits placed on women's sexuality imply that a majority of women abstain from sex before marriage and postmarriage remain monogamous. Predictably, the inequality that characterises the social and economic spheres of society is often mirrored in sexual interactions, creating an unequal balance of power in sexual relations. As a result, majority of women have little or no control over the circumstances in which and with whom sexual intercourse takes place.³

There exists an inextricable link between human rights, gender, and HIV and AIDS. Men encounter more opportunities, owing to their indulgent and risky behaviour, to contract and transmit HIV. The right to make safer and informed decisions is still not seen as the prerogative of women and girls. Social restrictions also contribute to lesser healthcare for women, girls, and children. Women risk violence, abandonment, neglect of health and material needs, destitution, and community ostracism.

Violations of rights may worsen the impact of HIV, increase vulnerability, and hinder positive responses to the epidemic.⁴ A rights-based approach to HIV requires enabling, empowerment, and protecting people living with HIV so that they can live and thrive with dignity. Today, the majority of countries (89%) explicitly acknowledge human rights in their national AIDS strategies, with 92% of countries reporting that they have programmes in place to reduce HIV-related stigma and discrimination.¹

The greater involvement of people living with HIV and AIDS (GIPA) principle encourages the active involvement of people living with AIDS in policy-making, and in the development and implementation of programmes. Activities such as training and supporting people living with HIV as public speakers, educators, and counsellors have helped to reduce stigmatisation.

There is an urgent need to strengthen the response towards HIV among women. Rather than placing the onus of prevention on women, programmes must address the gender issues related to HIV and AIDS, at the socio-cultural and structural level. National AIDS Control Organisation III (NACP III) plan document reflects an understanding of such issues.

CASE STUDY

A case study is a research method common in social science. It is based on an in-depth investigation of a single individual, group, or event. Case study methods involve an in-depth, longitudinal (over a long period of time) examination of a single instance or event, a case.

This case study is about Anamika (name changed), a 35-year-old female who is an empowered HIV-positive and presently works as Community Co-ordinator at an anti-retroviral treatment (ART) centre. Her transformation from a victim of social stigma and discrimination due to her HIV-positive status to her present role has been possible due to her determination and social support she received from our medico-social workers. This case is being presented as a case study which shows the potential of effective social rehabilitation and exploring utilisation of HIV-positives as a resource in our fight against this medico-social epidemic of

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HIV/AIDS. A case report on process involved in rehabilitation of HIV-positive children was reported in 2006 by Verma et al.⁵

MEDICO-SOCIAL HISTORY

Anamika was born on 9 January 1975 as the youngest of three siblings to parents who belonged to rural Maharashtra. She lost her father in an accident during her infancy. The family including her mother blamed her ('you have heralded misfortune on the family') as being an unlucky omen for the family. She moved with her mother to her maternal grandparents where they lived in a joint family. She was neglected, ridiculed, and rebuked by her cousins who were always jealous and critical of her. She was made to do all household chores and even worked at fields. Once at 8–9 years of age she was sexually abused by a male working for the family in the fields. Despite these traumatic and unpleasant experiences in childhood she continued her education and successfully completed her matriculation in 1990. She always dreamt of becoming a working woman, who would be financially independent and show to the society that she is capable of better things in life. She believed that one is the master of one's destiny. She took science subjects in her higher secondary school against wishes of her family as she wanted to become self-reliant. She passed her senior school successfully in 1992 while rest of her classmates in the village had failed. Despite her resistance and unwillingness, her education was curtailed as she was forced to marry a farm worker in June 1994 at the tender age of 19 years. She was not lucky to enjoy marital bliss as her husband used to dislike her for not being so good looking. She knew of the extramarital exposures of her husband but she could not do much about it. Her husband used to tell her of his 'enjoyment' (sexual contacts) whenever he visited Pune city. After few months after marriage she started keeping unwell and she was advised HIV test by the doctor. Both Anamika and her husband were tested and found to be HIV-positive. She was devastated as she was an innocent victim of this deadly disease. They did not disclose their status to their family and friends for fear of stigma and social discrimination. Despite HIV infection she decided to go for pregnancy for two reasons. Firstly, there was a social and family pressure to produce a child to prove her fertility. Secondly, she was not very aware of the vertical transmission of infection from mother to foetus. During her first childbirth in January 1996, she went to a hospital where there was no doctor available and she was later transferred to another hospital where she delivered a neonate who died within 30 minutes of birth. During this delivery, she did not disclose her status to the hospital staff for fear of being turned out. During her second pregnancy she was fully aware that there was a possibility of children being HIV-positive. She however, always believed that children will not be affected as she had unshakable faith in God. She delivered in the vehicle while being transported to a hospital in March 1997. The child was negative for HIV. She became pregnant for the third time in September 1998. Later in 1998, her husband started keeping unwell and was being treated with

unknown medications and the family and society had come to know of their status. He got some treatment from medicine brought from Cochin and also at Pune. She is not sure if he ever received anti-retroviral therapy (ART). Her husband died on 9 June 1999 despite treatment after a downhill course. She used to be cursed by her in-laws ('you have killed my son; he has got the disease because of you'). Three weeks later she delivered a female child. During delivery she had been kept in a separate room in the hospital with another HIV-positive lady by the hospital staff. She was not exhibited any ART during these pregnancies. Her second daughter received nevirapine at birth. Her in-laws tried to get the second child eliminated. Fortunately, both children were born negative for HIV. She was now a widow who was HIV-positive with two daughters left to fend for herself with no social support from family and society. She was discriminated by the family and the neighbourhood. People used to cover their face while passing by their house; she was not permitted to enter kitchen and household of in-laws and was kept separately. Nobody interacted with her and she was not invited to attend any social function. The children from the village were not permitted to mingle with her children. She had a flour mill which had to be closed since people did not patronise it. During this phase of her life she felt like committing suicide and thought she should rather jump into her husband's pyre. She however did not do so because she thought about her two daughters. She decided to fight against her circumstances as she felt she was innocent victim of HIV and there was no fault on her side. She developed a defiant attitude to the discrimination she faced and wanted to prove to the world that she is capable of handling her circumstances and would not surrender without fighting it out. She decided that she will prove to others that she can overcome her difficulties with her determination. She was supported by her mother and brother. Her in-laws grabbed her savings and money obtained from selling flour mill. She was finding it difficult to make her ends meet. She even worked as farm labourer to earn her livelihood besides stitching clothes. She had received a sewing machine with the help of NMP+ (Network of HIV-positive people of Maharashtra) with whom she had registered. The children were admitted to the village primary school. She states that there was no discrimination against her children at school.

In 2006, during our routine visit to her village where rural health training centre of Armed Forces Medical College (AFMC) is located, she came in contact with our medico-social worker when her daughter needed surgery for chronic suppurative otitis media (CSOM). She was helped through Prayas Club (medico-social initiative of medical students) of AFMC for this treatment by arranging for her transport, accommodation, petty expenses, and food. She was then followed-up regularly. In 2007, being a widow she was befriended by a farm labourer from Punjab who was a migrant who came for work at her village with harvest machine and they developed sexual contact and she became pregnant. She was promised that he will marry her despite her seropositive status. She thought that she would get some companionship and support and would be more secure in the hostile world. She then consulted medico-social workers

of our department. She was advised to undergo abortion and discontinue her relationship as there was a chance for her being left high and dry after sexual exploitation by a migrant labourer. She was then counselled to get herself examined and enrol herself at the ART centre for follow-up. She expressed her desire to work and earn her livelihood. It was thought that economic independence would help her to fight out her social circumstances. Under Maharashtra State AIDS Control Society (MSACS) initiative ART centre in AFMC was started in March 2009. There was a post for people living with HIV and AIDS (PLHA) as Community Care Co-ordinator which was to be filled. Medico-social worker spoke to the officer-in-charge of ART centre and suggested that there was a PLHA who could be the right candidate for the job. Anamika had the requisite education, motivation, communication skill, and positive outlook, besides she had also participated in conference, seminar as PLHA spokesperson. She was thus interviewed, selected, and appointed as Community Care Co-ordinator. Since then, she has now become an advocate, spokesperson, counsellor, HIV worker, and a volunteer. She believes that she has been able to realise her dream of becoming a 'working woman' only because she came to Pune for her disease follow-up. She believes that HIV has come to her as a blessing in disguise. Her two children have been rehabilitated by putting them into a hostel run by a nongovernmental organisation working for the welfare of children. She regularly visits them. She has maintained good health and has not required ART so far for last 16 years that she has been positive. She attributes her maintained health to her positive and optimistic attitude towards life, tenacity to fight, not surrendering to challenges. She has sound spiritual health and unshakable faith in god. She has good health seeking behaviour and has access to good healthcare system. She consumes balanced vegetarian diet. She also takes supplements like iron, calcium, multivitamin, and vitamin C. She is also consuming some ayurvedic natural herb extracts like tulsi, ginger, mint, adulsa, belpatra, prajakta flower, and jaggery. She gets her medical follow-up done regularly.

She has been helped through various government schemes. She is a registered member of NMP+. She was gifted a sewing machine from Panchayat Samiti Zila Parishad which she utilised to earn her livelihood before taking up the present job. She has also benefited from Sanjay Gandhi Niradhar Yojna under which she being a widow receives a pension of ₹ 650 per month. She has done a computer course with the Help of Life Care Centre (NACO) Pune. She has been helped by Bal Kalyan Samiti under which her two daughters have been admitted to SOS Balgram (Home for Orphan children) where they are getting free education and where a family-based care is provided. She regularly visits her children and her children are doing well at school.

She is an empowered HIV-positive now working for HIV-positives. She feels empowered as she is now aware about the disease and has opportunity to work with professional people for the welfare of HIV-positives. She feels that this disease has given her an opportunity to serve people who are distressed and discriminated. She helps new PLHAs by motivating them with her personal example. She is a role model for PLHAs registered

at our ART centre. She is now economically independent. She feels this disease can be fought and won over if one has determination and gets the requisite social support. Her all relatives now call her for social functions and she is re-integrated into the society. She is now respected for her courage and conviction and she is no longer discriminated in the society. She says now even her in-laws have now started behaving with her appropriately. She has been given her share in the property, which was earlier denied to her by her in-laws. She is leading a life with dignity and pride as a PLHA. She now says that 'I am proud to be a HIV-positive person'.

INSPIRATION

Anamika, a lady from a rural background with a traumatic childhood gets infected with HIV from her husband. She is faced with the challenge of looking after herself and her two daughters. She has not only faced the death of her husband, social discrimination, and poverty but emerged stronger with her faith, determination, and resolve. She has been able to overcome her trials and tribulations due to her education, positive outlook, social support, and access to quality healthcare. She is now a role model for PLHAs. She is helping people with HIV infection to cope with their problems and able to give them a lot of hope and optimism by her personal example. This case study highlights the fact that a well rehabilitated HIV-positive person with social support and timely guidance can not only lead a healthy and positive life but also contribute significantly to the society. A great difference can be made to the life of a HIV-positive by small efforts from the society. The case portrays journey of a victim of HIV to a victor who is positive not only for HIV but also in life.

CONFLICTS OF INTEREST

None identified.

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