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Research Article

Politics of HIV/AIDS: Layers of Exclusion

Seema Rani Bohet[1]* and Neena Pandey[2]

[1]Ph.D. Student, [2]Associate Professor, Department of Social Work, University of Delhi, India
*Corresponding author email id: seemarsdu@gmail.com

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ABSTRACT

Politics of any country claims to work for the development of people. Political will and commitment are essential key components of an enabling environment for the implementation of right-based policies. One of its kinds has been human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) prevention, care and support programmes that claimed attention globally and nationally during the late nineties to 2015 capturing attention of Millennium Development Goals (MDGs). HIV is a disease of social-relational nature and it is not merely a social disease. The epidemic is still largely concentrated among key populations at higher risk such as female sex workers, Injecting Drug Users (IDU), migrant labourers, Men who have sex with men (MSM) and other sexual minorities, that is, Lesbian Gay Bisexual Transgender and Queer (LGBTQ). The ecological perspective suggests that health is affected by different social structures and aspects. This paper is an attempt to highlight the political factors which determine the disease and also the issues pertaining to funding which makes the disease less discussed in public nowadays. The funding of this sector (HIV/AIDS) has really gone down which raises several questions with regard to the spread of the disease vis-a-vis Indian diverse population. It is important to look at the government's initiatives in contemporary times towards addressing treatment and adherence issues. It is found that there are issues that need to be addressed such as HIV prevalence, non-adherence, accessibility and availability of medicines and services, etc. Politics may play a crucial role in providing non-stigmatised, non-judgmental and enabling environment. India's strength is its young age and its youth and majority of the population are below the age group of 25 and hence it is all the more crucial that proper focus on prevention and awareness of this behavioural disease.

Keywords: HIV/AIDS prevalence, Politics, Adherence, Marginal sexuality

INTRODUCTION

'We cannot become complacent in our efforts, because failing to reach out to each of the estimated PLHIV and putting them on ART threatens to reverse the progress made in fighting AIDS'. Gilada, one of the experts in treatment and management of HIV/AIDS programme from last three decades cited in Somashekar (2018).

The epidemic of HIV/AIDS is understudied in political domain. HIV issues and concerns are increasing as other social developmental issues that equally demand political attention (Singer, 1994). HIV/AIDS has remained in discourse in the last decade with strong commitment of halting and beginning to reverse the spread of HIV/AIDS by 2015 through the Millennium Development Goal (6). It was also targeted to ensure access to treatment among those in need of ART treatment by 2010 (Prendergast *et al*., 2014).

Given the almost universal lack of access to HIV testing, prevention and treatment for children in high prevalence countries in 2000, the achievements of the past 15 years have been extraordinary, fuelled by massive donor investment, strong political commitment and ambitious global targets India is committed to achieve the 17 SDGs and the 169 associated targets, which comprehensively cover social, economic and environmental dimensions of development and focus on ending poverty in all its forms and dimensions (SDG Index, Baseline Report, 2018).

The 2030 Agenda is the universal call for action for better health, end poverty and ensure that all people enjoy peace and prosperity. Sustainable Development was to scale, what the AIDS response has been working with people to access high-quality HIV and health services without discrimination? It has revealed that AIDS itself is a disease of social relationship not merely a social disease, but a disease of modern social order as it is constituted as a complexly stratified and widely oppressive structure. In many parts of the world, the greatest problems are a compound of a lack of political will, the existence of barriers (usually religious or cultural in origin) against admitting the causes of infection and addressing them in practical ways, the severe stigma directed against both those with HIV and those from groups associated with AIDS (sex workers, needle-users, homosexuals, etc.) and-often underlying all of these-the pressure for survival on large numbers of people who are poor, homeless, and ill-educated. Has Political will, technical expertise and robust institutional mechanisms are cornerstones of a country's response to HIV and AIDS. Political will is key to agenda setting, generating and sustaining a full-fledged response to the epidemic, strengthening policy and the legal environment, mobilising resources as well as promoting multi-sectoral approaches to tackle the epidemic. Strong political leadership plays an important role in addressing the stigma both against people living with HIV (PLHIVs) and the key populations at higher risk, who have traditionally been a marginalised group.

Globalisation has its impacts on HIV/AIDS. It is multi-faceted and impacts sexuality in all three ways. Economic changes mean that sexuality is increasingly commodified, whether through advertising or prostitution, which is closely linked to economic dislocation and change. Cultural changes mean that certain ideas about behaviour and identity are widely dispersed, so that new ways of understanding oneself become available that often conflict bitterly with traditional mores. And the political realm will determine what forms are available for sexual expression. The first attempt to relate HIV/AIDS explicitly to globalisation came in a 1990 paper by John O'Neill, who referred to AIDS as 'a potential Globalizing panic on two fronts; namely (a) a crisis of legitimating at the level of global unisexual culture; and (b) a crisis of opportunity in the therapeutic apparatus of the welfare state and the international medical order' (O'Neill uses the term, 'a global unisexual culture' to mean 'a same-sex culture whose technological infrastructure is indifferent, benign or emancipated with respect to its male and female protagonists', an odd use which need not detain us (O'Neill, 1990, p. 334).

HIV, ART TREATMENT PROGRAMMES

According to the UNAIDS Report (2017) In India, 2,100,000 people are living with HIV. 88 000 people were newly infected with HIV. 69 000 people died from an AIDS-related illness. There has been progressed in the number of AIDS-related deaths since 2010, with a 56% decrease, from 160 00 deaths to 69 000 deaths. The number of new HIV infections has decreased, from 120 000 to 88 000 in the same period. The 90–90–90 targets envision that, by 2020, 90% of people living with HIV will know their HIV status, 90% of people who know their HIV-positive status will be accessing treatment and 90% of people on treatment will have suppressed viral loads. In terms of all people living with HIV, reaching 90–90–90 targets mean that 81% of all people living with HIV are on treatment and 73% of all people living with HIV are virally suppressed. 79% of people living with HIV knew their status. 56% of people living with HIV were on treatment. Of all adults aged 15 years and over living with HIV, 56% were on treatment. Totally 60% of pregnant women living with HIV accessed antiretroviral medicine to prevent transmission of the virus to their baby, preventing 3500 new HIV infections among newborns. Early infant diagnosis-the percentage of HIV-exposed infants tested for HIV before eight weeks of age-stood at 23% in 2017. Of the 2,100,000 adults living with HIV, 880 000 (41.9%) were women. HIV treatment was higher among women than men, with 63% of adult women living with HIV on treatment, compared to 50% of adult men. We are living in the current year of 2020 and we are lagging far behind the 90-90-90 target. It is important to gaze the efforts to meet the targets or it is significant to highlight the extra efforts required to meet the said target of treatment and management of HIV/AIDS.

The HIV/AIDS epidemic has, over the past decade, evolved into a more complex one necessitating operational research, effective health delivery systems and a trained and motivated workforce. The ART Programme has adopted a public health approach for provision of ART. This implies a comprehensive prevention, care and treatment programme, with a standardised, simplified combination of ART regimens, a regular secure supply of good-quality Anti-Retroviral (ARV) drugs, and a robust monitoring and evaluation system. The care, support and treatment programme aims to provide care and treatment to as many people as possible, while working towards universal access to care and treatment.

The ART centres were established mainly in the medicine department of medical colleges and district Hospitals in the existing public health facilities. But over the years, some ART centres have also been established in sub-district and area hospitals, especially those in high prevalence states to improve access and decentralise treatment services. The centres were selected based on prevalence of HIV in the district/ region, number of PLHIV detected and capacity of the institution to deliver ART related services. It was decided that the centre will be led by the head of the department of medicine and National AIDS Control Organisation (NACO) shall support additional personnel (doctors, counsellors, nurses, pharmacists, data managers and community care coordinators) at these centres based on patient load (NACO 20).

It was felt that medical institutions are needed which shall deliver high quality of care, treatment and support to People Living with HIV (PLHIV). Complex treatment schedules and patient management require constant training and upgrading of skills among service providers. At the same time, being a lifelong therapy, it requires a comprehensive care approach that meets the range of needs of PLHIV as well as high levels of drug adherence for antiretroviral treatment. It became essential that there be institutions of repute and standards, motivated and encouraged to accord more serious attention to this disease. Hence Centers of Excellence (COE) in HIV care were established. These COE are model treatment centres, provide second line and alternative first-line ART treatment, impart high-quality training and help in capacity building of health care providers. Most importantly, they will monitor and mentor other institutions in technical issues. They will also be primary sites for undertaking operational and clinical research. Similarly, the regional paediatric centres were upgraded as paediatric COEs. Both COEs have been provided with additional staff like research fellows, SACEP (State AIDS Clinical Expert Panel) coordinator, data analyst, training and mentoring coordinator, nutritionist, and outreach workers to carry out these responsibilities. In short, effective AIDS interventions depend upon a number of variables most of which are outside the control of those immediately concerned with HIV/AIDS programmes and their delivery. These centre

around the resources available to mount both prevention and care programmes, resources, in this case, encompassing cultural and political factors as much as economic.

There was increased involvement of other UN agencies, especially the United Nations Development Program and more recently the World Bank during the 1990s. A number of donor countries proposed the creation of a 'joint and co-sponsored program' of the United Nations, UNAIDS, which began operations in 1996. UNAIDS is meant to coordinate the activities of seven of the international agencies involved in AIDS work-the World Health Organization; the United Nations Development Program; the United Nations Children's Fund; the United Nations Population Fund; UNESCO; the World Bank, and the UN International Drug Control Program. As its Mission states, UNAIDS is meant to act as 'the main advocate for global action on HIV/AIDS' (Altman, 2001). Despite numerous efforts taken under international and national initiatives, certain categories faced exclusion due to their identity they belong to. This was because of the cultural understanding and their acceptance in the specific frame by the society and making them less important even in the health services meant for everyone irrespective of their caste, class, gender, region and religion. One cannot ignore the exclusionary processes which were present in the course of addressing the issues of HIV/AIDS. This was faced at both macro and micro level. The macro issues could be understood through the politics of funding and the micro issues can be understood while reviewing the impact of cultural characteristics in distribution of health services with regard to HIV/AIDS.

POLITICS OF FUNDING

The access to effective treatments is increasingly a matter of economic resources and access to expensive and sophisticated pharmaceuticals. Recent advances in AIDS treatments have emphasised the gulf between rich and poor, with a minority of people with HIV now seemingly able to live for long periods without major disease, while the majority of infected people face a series of debilitating and painful illness unrouted to a reasonably rapid death. A report for the World Bank has warned that antiviral therapies are both expensive and uncertain, claiming that even if the costs were reduced to one-hundredth of current costs. They would still be several times the total annual per capita expenditure on health in many low-income countries. One should note that most people with HIV do not have access to even common drugs used to treat opportunistic diseases nor to palliative and terminal care. Clearly, the resources available for HIV/AIDS prevention and treatments will reflect larger economic and political realities. The economic crisis in some southeast Asian economies from the end of 1997 has meant severe cuts in HIV programmes, to the extent that in Indonesia screening of blood supplies has been affected because of the cost of imported. The World Bank putting increasing sums of money

into AIDS work in countries such as Brazil and India where the Bank's own policies had helped weaken the health structures that might have already helped prevent the spread of HIV. AIDS policy, such as educational interventions and prevention of discrimination, the correlation between 'development' and policy options is less clear Altman (1999). It is significant to analyse the funds allocated for HIV/AIDS in the last 15 years from 2015. The mega projects like Global Fund which had several rounds of funding in India to combat HIV/AIDS was closed. During National AIDS Control Programme (NACP) phase three the Targeted Intervention popularly known as TI Project was at the core of the national policy which was executed in a strategic manner with the help and support of civil society Organisations and NGOs. This too helped to reach the target to halt the cases of HIV was working out very well with HRGs. All such initiative became secondary due to structural decisions of minimising the funds allocation to the projects of HIV/AIDS. Such structural changes created macro-level exclusions like the developing countries like India were hard affected due to lack of funds to the said sector. Many ongoing programmes were put to forced closure.

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> According to UNAIDS report (2016, p. 1):
> There has been great fall observed in the budget from government donor since 2010. The 2016 decline is due to several factors: actual decreases in both bilateral and multilateral funding, accounting for an approximate net 50% of the decline; exchange rate fluctuations (20%); and the timing of U.S. contributions to the Global Fund to Fight AIDS, Tuberculosis and Malaria (30%), due to U.S. law that limits its funding to one-third of total contributions to the Global Fund'.

The future outlook of donor funding for HIV remains uncertain, which is an alarming concern especially for developing countries given recently proposed cuts to HIV funding by the U.S., amidst other competing demands on donor budgets more generally.

THE POLITICS OF GENDER

It is a well-known fact that gender is pervasive and universal. The concerns of HIV/

AIDS have also faced the impact and influence of gender in every aspect. The woman's body is considered to be receptive and conducive for the survival of HIV because of the biological and anatomy of women physiology. Arkell (2016) documented

> there are several inherent biological factors that may explain an increased vulnerability to HIV infection in the female genital tract, including physical characteristics and the immune system.

She further cited Boily *et al*. 'On average, the risk of HIV transmission through vaginal sex may be about two times higher for females than for males'. It is an irony that intimate partner violence, inequitable laws and harmful traditional practices reinforce unequal dynamics between men and women. As a result, these dynamics limits women's choices, opportunities and access to information, health, social service education and employment (Avert Report, 2015). Politics can be identified through the issues of Gender Disparities in HIV related matters. Gender has always been a prominent issue in HIV/AIDS and support. HIV deaths are higher for women than for men. UNAID 2004 report documents,

> at its heart, this is a crisis of gender inequality, with women less able than men to exercise control over their bodies and lives. Nearly universally, cultural expectations have encouraged men to have multiple partners, while women are expected to abstain or be faithful. There is also a culture of silence around sexual and reproductive health. Simply by fulfilling their expected gender roles, men and women are likely to increase their risk of HIV infection. (p. 7)

The study by Joint United Nations Programme on HIV/AIDS (2000) based on Human rights and gender Botswana, Lesotho, Mozambique, South Africa, Swaziland and Zimbabwe revealed that these countries failed in eliminating all forms of discrimination against women due to common and customary laws that encourage gender discrimination. In a critical view, Richey (2003) maintained that, the issues of HIV/AIDS are less talked among women. It remains in the shadow of reproductive health interventions; it does not lessen the impact of the disease on people's lives. HIV/AIDS cannot just be a part of family planning programme, and termed as 'reproductive health' programmes rather it should be comprehensively spoken. Women living with HIV face various problems in practicing safer sex, communicating about her HIV status to partners and to make plan to have children and to avoid pregnancy. Ironically condom management programmes also put the onus upon women to convince the man for condom usage as the ratio of availability of female condoms is much lesser than the male condoms. Furthermore, if the female condoms are available, then their prices are much higher than the ones being manufactured for male condoms.

The women are confronted by the paucity of knowledge among both scientists and caregivers in the field of HIV-related gynaecological illness (Sherr *et al*., 1996). The

Connell's theory of gender and power can explain gender-related power differences, beliefs and reactions towards PLWHA. A central emphasis of this theory is that

> the analysis of gender involves a three-part structural model involving sexual division of labour (e.g. financial inequality), sexual division of power (e.g. authority), and the structure of affective attachments (e.g. social norms). These three structural models are the major elements of any gender order and operate with a logical complexity. Furthermore, these structural models exist at different levels (e.g. family, societal and institutional) and are maintained by social mechanisms. (Connell, 1998 as cited in Mbonu *et al*., 2010, p. 1)

Gender differences are not only prominent socially but medically also. It means how gender differences are mediated through health care professionals. A study conducted in South Africa, aimed at identifying the causes of gender-related differences in societal beliefs and reactions towards men and women living with HIV/AIDS in Port Harcourt, Nigeria. The study used in-depth interview schedule with Healthcare professionals and PLWHA (people living with HIV/AIDS). The study found that structures financial inequality, authority relations and social norms cause power differences between male and female PLWHA and power differences perpetuates the gender differences in family, society and health care systems and highlights their impact on the persistence of HIV and the care of PLWHA. The care-giving role of a woman in the family seems to be a priority concern for female PLWHA even when they are ill (Ngogi *et al*., 2010).

Speaking about the politics against sexual minority groups; Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQs) communities A joint report of USAID and UNDP has revealed the alarming human rights concerns of LGBTs in Indonesia Country. According to this report, there is not any provision in national laws to recognise and support the rights of LGBT people, even though homosexuality is not criminalised. Marriage and adoption by LGBT people are also not permitted. Moreover to this, there are no specific anti-discrimination laws that pertain to sexual orientation or gender identity (SOGI). Though considering Progress has been observed to gain LGBT rights due to the movement adopting universal human rights principles and strategies and with LGBT organisations and individuals participating in national human rights reviews and processes, In addition to this Discrimination against LGBT individuals in the workplace has also been noticed. It does not receive significant attention, and there is an absence of anti-discrimination laws as well as clear policies or statements related to LGBT people in the workplace. The report also claimed regarding Information and resources for the health and well-being for LGBT people which are predominantly related to HIV and STIs. Sexual and reproductive services are aimed at heterosexuals only. Therefore, there is a need for counselling and attention to psychosexual and sexual well-being issues for all LGBT people, information and support for transgender people are highly

required in relation to hormone therapy, and to expand and build on training for health workers to be sensitive to LGBT issues and people. A general lack of education on sex and sexuality in schools, and of issues specifically related to LGBT sexuality, combined with a lack of information and guidance from parents, is harmful to the self-esteem of young LGBT people. Professional social workers trained with guided principles, enriched with social and professional values can play a vital role in addressing human rights issues of LGBT s community (UNDP and USAID, 2014).

CASTE DISPARITIES

The people from lower caste (SC/STs) always has been a witness of social exclusion and being affected or infected with HIV makes them more vulnerable to access health services. According to Khan *et al*. (2015) 'Social exclusion is multidimensional, and can encompass a lack of access to employment, legal redress and markets; a lack of political voice; and poor social relationships'. It is clear that caste and ethnicity-based inequalities are major obstacles to achieving health equity. The study conducted in Nepal it was found that untouchables were least knowledgeable about HIV/AIDS disease, ART treatment and further assistance given by the government and non-government agencies (Atteraya *et al*., 2015). One of the research undertaken by Rani (2015) revealed in its findings that practice in ART treatment among people living with HIV reflected the plight and vulnerability of the people at the fringes who have been marginalised in every sphere of their life. The total number of HIV respondents interviewed were 200. Out of these 42% were belonging to lower caste and communities (SC/STs). Due to lack of awareness, illiteracy and inability to afford the ART and related required supplements Deeper study on caste factors among PLHIVs is recommended. Therefore sensitisation of these minor communities at political level is recommended (Rani, 2015). There are migrant workers who fall into the category of HRGs live an insecure life in cities as they are left with limited choices. The majority of the population of migrant workers is comprised of marginal castes as they move towards cities in search of jobs. They do not have options left for their livelihood in their local region. Once they reach in cities, they make all sorts of compromises with their life situations to save the earned money. Their attention to health needs becomes the aspect of lesser priority.

The above politics and disparities existed but many targets were achieved due to the global initiatives. The political history of the epidemic over the past three decades has witnessed some remarkable successes. HIV has been placed on the international agenda, with a specific UN programme, UNAIDS, created to coordinate the responses of different parts of the UN system to HIV, to inspire and inform the global response as well as to provide support to countries. The epidemic was the subject of a special meeting of the United Nations Security Council AIDS is specifically mentioned in the millennium

development goals (MDGs), and the creation of the Global Fund to Fight AIDS, Tuberculosis and Malaria has ensured considerable resources flow towards prevention and treatment. Set up in 2002, by 2011 the Global Fund had approved more than US$22 billion in grants, although, as is discussed later, spending is now slowing markedly. In some parts of the world, HIV has opened up space for discussion of sexuality and, to a lesser extent, drug use in quite unprecedented ways, and has meant considerable support for organisation and advocacy amongst marginalised and stigmatised populations (Kane, 1998; Kempadoo and Doezema, 1998; Altman, 2001). HIV has changed attitudes of health care providers and has created new paradigms of relationships between practitioners and patients that have affected other significant diseases. In short, AIDS altered existing balances of power. On the contrary, a study conducted in six highest HIV prevalence states Andhra Pradesh, Tamil Nadu, Karnataka, Maharashtra and Manipur aimed at providing the quality and quantum of debate and discourse among political leaders to gain an understanding of the level of awareness, commitment and interest among the elected representatives with regards to the epidemic and the populations most affected by it. It was found that most elected representatives appear to have insufficient information and knowledge about the epidemic. In parliament, hardly any questions were raised about the condition of high-risk population. Very few questions were asked on human aspect such as impact mitigation, stigma and discrimination or grievance redressal. Therefore minimum political will to address HIV is a major issue (UNAIDS, 2008).

To Conclude the above discussion; Political will and commitment form a key component of an enabling environment for implementation of a right-based HIV and AIDS prevention, care and support programmes. HIV does not receive significant privileged treatment by any one political party. Parliament and legislatures are the platforms for policy and legislation related debate but so far no policies on adherence have been found to be implemented. Secondly, the structural changes are required to be made such as; making available and usage of female condoms, focus on the issues of sexual minorities. The concerns related to affordability and accessibility of services like HIV testing, ART and counselling require to be addressed to the LGBTQ community. This requires acceptance of the society which needs a large amount of awareness and people's participation in all kinds of services associated with HIV/AIDS. A strong policy towards the health rights of sexual minority group is an urgent requirement. Such gaps will enable the country to achieve the stated Structural Development Goals (SDGs). The special services with regard to lower caste and class is required to be in place so that the needs of migrant workers can be addressed. The discourse merely touched on the policy dimensions of the epidemic. Considerable attention is required towards addressing treatment and adherence issues also as a huge amount is being spent annually. Though elected political

representatives are well placed to lead policy-level discussions, advocacy for HIV, they do not demonstrate a firm understanding of right sensitive approaches.

As far as political legislations are concerned few committed legislators who have demonstrated high level of sensitivity and understanding of issues related to key populations at higher risk and HIV. These concerns need to be brought to the forefront. The strategy for engagement of legislators is recommended to focus their role in policy processes and their action to decision-makers. In addition to this civil society organisations have a critical and vital role in facilitating interface between elected representatives and key populations who are vulnerable to enable them to understand the critical issues associated and preventive and caring measures. As 'HEALTH' is universal and human rights-based concept it should be linked with other developmental concerns of state (for instance in Manipur it is linked with youth and employment). A better prospects for research and action projects may be developed so that visibility and prominence to the subject are ensured and the appropriate context can be created to achieve the targets to meet the health rights of people. The LGBTQs communities, Migrant workers, marginal communities like SC/STs can be facilitated and enabled for better benefits of such opportunities to prevent themselves from stigma and discrimination, unemployment, lack of education and inabilities to access social services.

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