

ANALYSING THE HUMAN RIGHTS OF PATIENTS WITH HIV/AIDS IN DEVELOPED COUNTRIES

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Author: Aparna Bhatnagar, 1st year student at Maharashtra National Law University, Mumbai.

ABSTRACT

Human Rights are understood to be claims which obligate the State to uphold, protect and respect certain legal rights inherent to every individual. The Office of the High Commissioner of Human Rights (United Nations) describes a threefold relationship between HIV/AIDS and human rights. Firstly, the disenfranchised status of certain sections of the population makes them more vulnerable to contracting this disease, thereby violating their right to equality, education and health. Secondly, the discrimination faced by such patients at the hands of State authorities as well as individuals leads to delays in treatment, resulting in a denial of right to life. Lastly, the stigmatization of people with HIV/AIDS leads to difficulties in their rehabilitation and can often have long lasting effects on their mental state. This research article attempts to situate the rights of patients with HIV/AIDS within the broader framework of Human Rights. In this context, it aims to analyze the evolution of these rights in various developed nations by means of a case study. The research article will focus on four countries from distinct geographical and cultural setups in order to build an inclusive understanding of the subject. The countries include the United States of America, United Kingdom, Australia and Japan. Further, the article also aims to compare the status of patients with HIV/AIDS in these jurisdictions and draw relevant conclusions.

The main research questions of this article include-

1. How are the rights of patients with HIV/AIDS placed under the ambit of Human Rights?
2. What are the measures taken by various jurisdictions for recognition of the rights of people with HIV/AIDS?
3. How has the existence of these safeguards translated in the realization of justice to patients with HIV/AIDS?

INTRODUCTION

Human Rights are basic freedoms that are inherent and inalienable to all humans, regardless of nationality, sex, national or ethnic origin, colour, religion, language, or any

other status.^[1] These rights are protected under the [International Bill of Rights](#)- comprising the International Covenant for Civil and Political Rights, and the International Covenant for Economic, Social and Cultural Rights. All human rights are underpinned by the values of fairness, respect, equality, dignity and autonomy. Although human rights are said to be 'inalienable', they can be limited by governments in exceptional situations, subject to stringent legal tests.

Policy frameworks seek to protect human rights in two ways. Firstly, these enable individuals to access human rights courts or tribunals in cases of violations. Secondly, the policies promote a 'culture of human rights' by ensuring that human rights undergird the workings of government and public authorities. This is done by placing a threefold legal obligation on these entities to respect, protect and to fulfil these rights. Respecting a right entails abstaining from interference with another's enjoyment of their rights. Protecting a right necessitates prevention of other parties from interfering with the exercise of other's rights. And lastly, fulfilment of a right means calls for active steps to establish laws, policies, institutions and procedures, including the allocation of resources, to enable people to enjoy their rights.

Human rights are inextricably linked with the prevalence of HIV/AIDS. The chronic nature of this disease, its particular vulnerability towards certain disenfranchised population groups, as well as its stigmatized constitution, all culminate in the gross violations of human rights of people with HIV/AIDS. The Office of the High Commissioner of Human Rights of the United Nations outlines three areas of intersectionality between HIV/AIDS and Human Rights. First, lack of information and access to services escalates the vulnerability of marginales sections of the society. Women form the largest of such categorizations to be denied sexual autonomy, as well as marginal negotiating power. Second, the evils of stigmatization and discrimination attach themselves to the patients of HIV/AIDS, resulting in a violation of a myriad of other rights, such as the right to employment, housing, etc. Vulnerability to HIV/AIDS is augmented by violations of human rights, such as infringements which create gender hierarchies and sustain poverty. Lastly, discrimination faced by communities not only violates their civil rights, but obstructs their access to treatment and care services.^[2] The interplay of these varied levels of discrimination undercuts and impedes the very notions of 'inalienable' Human Rights.

There is now an emerging consensus that public health interests do not conflict with human rights. On the contrary, it has been recognized that protection of human rights leads to fewer infections as well as a more dignified existence to those living with the disease. when human rights are protected, fewer people become infected and those living with the disease are allowed a better standard of living.

This article is an attempt to delineate, compare and analyse the policy frameworks of developed nations, and from varied cultures.

INTERNATIONAL LAW IN CONTEXT OF HUMAN RIGHTS OF PEOPLE WITH HIV/AIDS

International Human Rights law was born with the establishment of the United Nations in 1945, against the backdrop of mass human rights violations during the Second World War. Emanating out of the need to address, prevent and punish the ghastly ‘crimes against humanity’ in Nazi Germany, Russia and many more places, the UN Charter recognized that ‘non-interference in their internal affairs is a principle that can be overridden where international peace and security are threatened.’^[1]

Today, there exists a strong and comprehensive body of international treaties, customs, covenants and guidelines, which, albeit customary in nature, carry the voices of state leaders, international organizations, and people across the globe. This section details some of the International law treaties that recognize the rights of people with HIV/AIDS.

International law on human rights is rooted in a ‘rights-based approach’^[2] to public health in general, and rights of people living with, or vulnerable to, HIV/AIDS in particular. A ‘rights-based approach’, as contrasted to a ‘needs based approach’, places emphasis on recognizing and fulfilling the rights of the socially, economically and culturally marginalised communities, and not the mere satisfaction of their basic needs. It seeks to reinforce the capabilities of duty bearers (usually governments), and ‘aims to approach development issues holistically, taking into account the relations between individuals and their interactions with institutions of power.’^[3]

A major step in this direction was the recognition of the Human Rights Based Approach (HRBA) framework as one of the six Guiding Principles of the [United Nations Sustainable Development Cooperation Framework](#).^[4]

David Patterson and Leslie London note that the rights-based approach also connects to social movements that use the same language, such as the women’s movement and the struggles of indigenous peoples.^[5]

The United Nations Centre for Human Rights, in collaboration with the World Health Organization, hosted the first International Consultation on AIDS and Human Rights in Geneva in 1989.^[6] This formed the bedrock for the building of a stringent human rights

framework for people with HIV/AIDS. The Second International Consultation on HIV/AIDS and Human Rights was held in Geneva in September of 1996, by the United Nations Centre for Human Rights and the United Nations Programme on HIV/AIDS (UNAIDS). The 'International Guidelines on HIV/AIDS and Human Rights' were included in the report of the consultation tabled at the 53rd session of the Commission on Human Rights in 1997. These guidelines were the product of careful deliberations by health experts, world leaders and human rights groups at this conference. Forming an imperative for state action, these guidelines included- 'establishing an effective national framework for their response to HIV, ensuring political and financial support, reviewing and reforming public health and criminal laws, strengthening anti-discrimination and other protective laws, implementing legal support services, promoting the distribution of creative education'^[10] and so on.

The third International Consultation on HIV/AIDS and Human Rights held in Geneva from 25 to 26 July 2002 recognized the limitations on certain personal freedoms allowed within the framework of international law of human rights. Any such limitations were, however, are subject to strict legal processes and must be in consonance with "public health rationale" for preventing discrimination against people living with HIV/AIDS.^[11]

Other developments that further developed the cause were the inclusion of 'combating HIV/AIDS, malaria and other diseases' in the Millennium Development Goals^[12], UN General Assembly Special Session on HIV/AIDS in 2001, and Commission on Human Rights resolutions on the right to the highest attainable standard of health and access to medication.^[13]

The Executive Committee of the World Trade Organization issued a statement in November 2001, declaring that the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) "does not and does not prohibit members from taking steps to protect public health."^[14]

The International Labour Organization's (ILO) HIV/AIDS Programme (ILO/AIDS) was instituted in June 2000, as an outcome of the passage of a resolution by the International Labour Conference. In 2001, the 'ILO Code of Practice on HIV/AIDS and the World of Work' was adopted during a Tripartite Meeting bringing together governments, employers, and workers from across the globe.^[15] The code establishes for the prevention, treatment, care and support in the workplace in context of HIV/AIDS and enumerated rights such as non-discrimination and equality before the law, right to health, privacy,

social security etc.

The Special Rapporteur of the United Nations Sub-Commission on Prevention of Discrimination and Protection of Minorities on discrimination against HIV-infected people and people living with AIDS, in its report in 1993,^[15] upheld the importance of the right to health and education, with special focus on the vulnerability of women and children.

Other declarations upholding the rights of people with HIV/AIDS include-

- London Declaration on AIDS Prevention, World Summit of Ministers of Health, 1988- The conference released a statement that shifted international attention to three specific areas. First, the spread of AIDS could be prevented through national information programs. Second, the health care workers had to be educated for the struggle against AIDS. And lastly, that effective means-must be sought to inform and educate specific groups whose behaviors place them at high risk of infection.^[16]
- Paris Declaration, World AIDS Summit, Paris, 1 December 1994- The summit placed emphasis on increasing awareness about the spread of the HIV/AIDS pandemic as well as on the importance of actions taken at the local level to deal with the disease's social and economic consequences.^[17]

Both of these Summits were revolutionary for bringing the novel concept of information spread and socio-economic consequences in the public discourse.

STATUS OF HUMAN RIGHTS OF PEOPLE WITH HIV/AIDS IN DEVELOPED COUNTRIES

United States of America

In the United States of America, the civil rights of individuals living with HIV/AIDS are protected under the Rehabilitation Act of 1973^[18] and the Americans with Disabilities Act of 1990 (ADA)^[19].

While Section 504 of the Rehabilitation Act of 1973 prohibits discrimination by health care and human service agencies that receive federal funds, Title II of the Americans with Disabilities Act of 1990 (ADA) prohibits discrimination by state and local government entities even if they do not receive federal financial assistance.^[20] This effectively places an imperative upon private bodies to prevent discrimination and other abuses. The bodies governed by these legislations include health clinics, dental offices, social services

agencies, drug treatment centres as well as nursing homes, both public and private.

Title II mandates state and local governments to extend to persons with disabilities with an equal opportunity to engage in activities and receive benefits from such activities, programmes, or services. If an individual meets the essential criteria, he/she is entitled to the benefits provided and the denial of the same is treated as a grave violation of human rights. The ADA also protects other persons, such as family and friends, who are discriminated against because of their association with someone who has HIV.^[21] A strict compliance to these is regulated by the US Department of Health and Human Services (HHS).^[22]

Legislations which restricted entrance to the United States based on medical diagnoses were first combined into one formal body of law in the Immigration and Nationality Act (INA) in 1952. As noted by S.E. Winston in an excellent article, *"it was not the discovery of HIV alone, but the economic and political climate of the 1980s that led to the introduction of the ban."*^[23] The economic recession, surge in the number of immigrants as well as a growing burden on the medical infrastructure culminated in the passage of the impugned act.

In 2009, President Barack Obama signed the Ryan White H.I.V./AIDS Treatment Extension Act of 2009,^[24] lifting a 22-year-old ban on people who tested positive for the HIV virus from travelling to the United States. This was hailed as a much-needed step in the long journey for the establishment of a non-discriminatory and just system for people with HIV/AIDS in the USA.

In 2015, the US government widened the ambit of the national health insurance programme 'Medicare' coverage to include universal HIV testing for everyone aged 15 to 65-years-old, as well as pregnant women and people outside of this age bracket.^[25]

However, the growth for the rights of people with HIV/AIDS has not been linear. As of December 2018, 27 states of the United States of America had HIV criminalisation laws.^[26] The United States is the world's third-largest prosecutor in HIV-related criminal cases, behind only Russia and Belarus.^[27]

Under the Presidency of Donald Trump, in early 2018, the Department of Health and Human Services introduced a law that would grant healthcare providers and insurers the right to refuse to offer services to customers on grounds of moral or religious considerations. A new study found that the enactment of such legislation linked to a 46

percent rise in the number of LGBT people experiencing mental distress.^[28]

UNITED KINGDOM

The human rights of all the people in the United Kingdom are protected by the British Human Rights Act 1998^[29]. The Act, heavily influenced by the European Convention on Human Rights, enumerates the rights it seeks to protect- right to life, liberty, expression, conscience, fair trial, free elections, etc.

The main anti-discrimination law in Great Britain is the Equality Act 2010.^[30] The law empowers individuals with the right to 'not be unlawfully discriminated on the grounds of age, disability, gender reassignment, race, religion and belief, sex, sexual orientation, marriage and civil partnership, and pregnancy and maternity.' The violations of these rights are considered unlawful and it governs a wide range of situations, such as access to employment, education, and private and public services. Under the Equality Act, HIV is considered to be a disability from the point of diagnosis.

In Scotland, the Charter of Patient Rights and Responsibilities guarantees the rights such as the right to be involved in decisions, the right for your personal information to be kept confidential, the right to safe and effective care, and the right to be treated with dignity and respect while receiving treatment under the National Health Service.^[31]

In England, the National Health Services Constitution follows seven key principles, the first one being that the NHS has "... a duty owed to every individual that it serves to respect and uphold their human rights."^[32] Apart from that, it guarantees several rights such as the right to expect the National Health Service to determine the community health needs and to commission and implement services to address those needs if they are deemed appropriate and the right to get the best care and for the information to be kept confidential.

In Wales, the Health and Care Standards embody the importance to human rights in accessing health care services. Standard 6.2 specifically addresses protecting people's rights regarding recognition of population's diversity and human rights.^[33]

In Northern Ireland, the Northern Ireland Act 1999, Section 75^[34] covers all the equality and diversity issues. The Disability Discrimination Act, amended in 2007, makes specific reference to equal treatment of people living with HIV/AIDS.

HIV/AIDS continues to affect the marginalised sections of the population disproportionately. The prevalence of HIV/AIDS among heterosexual individuals is 1 person in 1,000. In stark contrast, around 25 out of 1,000 heterosexual men of African descent and 47 out of 1,000 heterosexual women of African descent are estimated to be living with HIV.^[35]

While trans people have comparable rates of diagnosis, care retention, and viral suppression as other HIV patients, they are four times more likely to experience mental health problems, according to a Public Health England (PHE) study released in 2019.^[36]

An 'opt out' scheme was launched by British prisons in 2018, where prisoners were offered voluntary standard HIV tests. These tests were provided to 71 percent of the new and relocated inmates; 33 percent of whom accepted these.^[37]

In 2011, the United Kingdom's government launched the first ever 'National HIV Testing Week', aimed at spreading awareness and addressing the disproportionate burdens placed on vulnerable communities.^[38]

AUSTRALIA

In Australia, the protection of human rights of people with HIV/AIDS against the main forms of discrimination comes under the ambit of the Disability Discrimination Act, which outlaws discrimination due to a disability.^[39]

Upholding an individual's right to information, section 70 of Queensland's Public Health Act 2005 expressly declares that doctors are obligated to notify AIDS diagnoses to the patients of the disease, except in cases where the test was carried out in a hospital, in which case the individual in charge of the hospital is responsible for notification.^[40]

On similar lines, the Public Health Act 1997 provides 'if a doctor or authorised nurse practitioner has reasonable grounds to believe that a patient has, or may have, a notifiable condition, the doctor or nurse practitioner must give the patient information about the transmission of the condition and how to prevent the transmission.'^[41]

In 2019, the National Association of People with HIV Australia NAPWHA held talks and deliberations, which lead to the development of 'the HIV resilience framework', the maiden national strategic framework to counter HIV stigma and prejudice, as well as to enhance the capabilities of People Living with HIV/AIDS.^[42]

Despite the enactment of several protective legislations, the HIV Futures 8 Report (2018), which surveyed 895 HIV-positive Australians from all states and territories, found that 15.8% of respondents had experienced less favourable treatment at a medical service as a result of having HIV.^[43] The violations of these rights impede the growth of fundamental rights framework.

JAPAN

In Japan, groups particularly vulnerable to and most affected by HIV/AIDS include gay men, migrant workers and people engaged in sex work. Despite the enactment of the Anti-Prostitution Law in 1957^[44], there exists a large nexus of sex trade in Japan. A large number of non-Japanese women are particularly vulnerable to the virus, and issues such as 'language barriers further hinder access to adequate information on prevention and care and the workers lack of valid visas prevent them from applying for the health insurance that would enable access to treatment and medication.'^[45]

In the early 1980s, the blood scandal rocked Japan. Around 40% of the blood transfusions were infected, which led to several hundred hemophilia patients turning positive with HIV/AIDS. In 1989, Ryuhei Kawada filed a case against the government and pharmaceutical companies,^[46] and became the face of nationwide protests on the issue of human rights for HIV/AIDS patients. The current regulatory framework in Japan, based on social welfare coverage, promotion of basic and clinical research, and provision of medical care and treatment concerning HIV/AIDS has developed largely, from the reconciliation and confirmation notes exchanged as a result of the lawsuits.^[47]

The policy framework in Japan is set by the Ministry of Health, Labour and Welfare (MHLW), which also allocates funds out of the annual budget for special benefits for people with HIV/AIDS, supports research and promotes treatment programs. The implementation of these schemes is done almost solely by Japanese Foundation for AIDS Prevention (JFAP).^[48] The semi-governmental organisation was established in 1987 and is run by businessmen and politicians.

The domestic legal framework in Japan is made in consonance with Law Concerning the Prevention of Infectious Diseases and Patients with Infectious Diseases 1999. The law classifies infectious diseases into five categories, according to their infectiousness and the seriousness of their symptoms; HIV/AIDS is categorized as Type V.

The Ministry of Health Labour and Welfare has also announced the National Guidelines for

HIV/AIDS Prevention and Care to promote anti-AIDS measures and the AIDS Clinical Center (established in 1997) works towards developing potential cures and treatment.^[49]

CONCLUSION

Traditionally, the western developed countries of the world have tended to place more emphasis on civil and political rights, vis-à-vis socio-cultural and economic rights. This emanates from the notions of individuality, which can be traced back to the emergence of Enlightenment rationality in the early 1700s. It is against this backdrop that the present-day policies for recognising, protecting and developing human rights in the developed countries are built upon. It, then, comes as no surprise that several of the developing countries today reject such a straitjacking of the notions of rights within a strictly libertarian view. There is a growing consensus on the need to establish a holistic framework of rights, recognising the 'situatedness' of individuals within their societal and cultural contexts, and the interplay between these actors and those in power.

In recent years, there has been a tremendous growth in the development of science for the treatment and prevention of HIV/AIDS. However, countless surveys, reports and researches have found that this growth has not been complemented by a concomitant reduction in the hardships faced by patients of HIV/AIDS. The rights of the people living with HIV/AIDS (or the lack thereof), exist only in the minutes of International treaties. The social realities are such that in the absence of education and awareness, these rights are routinely violated. This article has made an attempt to describe the legal frameworks in developing countries regarding the status of patients with HIV/AIDS and draw parallels between them. The countries have deliberately been chosen from different continents, in an effort to bring in diversity of policy frameworks.

In the absence of a global dataset that comprehensively measures variations in HIV laws/policies across countries, it becomes quite difficult to draw valid conclusions. Nevertheless, there have been several cross country analyses and multidisciplinary studies. Some researchers have found a positive correlation between removal of parental consent clauses and an increase in HIV testing rates.^[50] Studies have also shown a reduction in the prevalence of HIV/AIDS among its population, in countries where sex work is regulated by legislations.^[51] Scholars have argued how race has played a major role in the politics of healthcare and AIDS, arguing that 'historical marginalisation of African Americans produced deafening quiet in political reaction to this stigmatized disease'.^[52]

Inspired by Malan's 'triangle of rules', Seye Abimbola has formed a 'triangle of rules',

describing the relationships in a health system's governance. The triangle connects “policy-makers, people and providers, who create, amend, and effectuate rules. These rules may be constitutional, collective and operational rules, and these rules in turn influence their actions, decisions and relations.”^[53] The real usefulness of such a representation is that it reinforces the centrality of these relationships in a public policy decision. It serves as a gentle reminder that though science has progressed in the affair of medical development, the fruits of these scientific developments can only be enjoyed equitably by everyone when basic human rights are achieved, for which policy decisions are an indispensable tool.

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