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Right to Privacy Vs. Right to Know: With Special Reference to HIV/AIDS in India

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ABSTRACT

HIV/AIDS is a sexually transmitted disease with stigma attached to it in our country. It is a violation of the right to privacy guaranteed under Article 21 of the Constitution through various judicial pronouncements if any hospital reveals the patient's identity and nature of their disease to any third party without the patient's permission.

Under Article 21, Supreme Court has also guaranteed the right to public health through judicial pronouncement. Under the right to public health, the state must ensure protection to the people from the spread of HIV/AIDS in the country. When a person marries, it should be their right to know if their partner is suffering from such sexually transmitted disease or not. The state cannot deny that person's right to health to protect the person's right of privacy suffering from the disease.

To make an informed choice, they must get the right to information as a constitutionally guaranteed right. It has also discussed how the right to information is fundamental for a democratic country. Supreme Court has pronounced in judgment that Article 19(1)(a), which talks about the right to freedom of speech and expression, also includes the right to information.

When Court guarantees two distinct rights to the people which are contradictory to each other, the judiciary must strike out a balance between the two whether public interest overshadows the Right to privacy guaranteed under Article 21 of the Indian Constitution. We will refer to international law or principle to decide between the right to privacy and the right to know. If we want that right to health and information to be kept above the right to privacy, we need legislation governing this to protect public rights. The need is to create a fine balance between both rights.

Keywords: HIV, Privacy, Fundamental Rights, Consent, Dignity.

I. INTRODUCTION

AIDS/HIV is a sexually transmitted disease transmitted from one person to another through sexual intercourse primarily. There are also ways to communicate it, like through transfusion of blood which is infected, using nonsterile and HIV infected needles and syringes. It is also

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transmitted to the unborn child if their mother suffers from such disease.

There are also many misconceptions about this disease and the medium through which it can get transmitted. Some people have the perception that it is transmitted only by touching an infected person or using the same washroom which an infected person has used. These are false misconceptions that have majorly played a role in stigmatising this disease in society. Society often questions the character of the person infected with this virus as they have the option that it is transmitted only when you have sexual intercourse with an infected person or when you have multiple sex partners. Thus, it is considered confidential whether they have AIDS because of such stigmatisation. It becomes the doctor's duty under medical ethics that he should not disclose the HIV status of the patient to the public at large as it would demean their character in society, and it will become difficult for the patient to live in the society with dignity. It is a matter of privacy of the human body that should be preserved.

But there are certain circumstances when it is necessary to disclose such information of the patient to another person. Those necessity conditions include the spouse or would-be the spouse who should know the HIV status of the patient to whom they are going to have sexual intercourse because nondisclosure in such situation amounts to a violation of the Right to information and Right to Health which has been established as a fundamental right of every citizen with various judicial pronouncements. In such cases of necessity, it is a choice between the Right to privacy and the right to information and health.

The HIV/AIDS Bill 2007 has not been passed yet. Still, we will discuss the problem and suggestions in light of various international cases, legal provisions given in the International Conventions, the legal provision in Indian laws (INDIAN MEDICAL COUNCIL ACT, 1956 (Professional Conduct, & Ethics) Regulations, 2002 and IMMORAL TRAFFICKING PREVENTION ACT, 1986) and National Policy on HIV/AIDS and the World of Work" Policy.

(A) Literature Review

An article '**RIGHT TO INFORMATION in CONSONANCE with RIGHT TO PRIVACY**' written by '**Vartika Phogat**' published on the 'Central Information Commission' website discussed many countries that had recognised the need for the right to information and its need in recent years. To make informed choices, they must get the right to information as a constitutionally guaranteed right. It has also discussed how the right to information is fundamental for a democratic country. I will be discussing in my paper that how the right to information as a fundamental right requires the medical professional to inform the patient about

the patient who is suffering from disease like AIDS so that the patient can make an informed choice whether to go further with the sexual relation with such AIDS patient or not. It should be an informed decision made by the person only and should not be deprived of such information.

An article '**Rights of HIV/AIDS patients in India**', published on '**Helpline law, legal solution worldwide**', has discussed the HIV/AIDS Bill, 2007. It has talked about the various kinds of discrimination against patients who have HIV based on HIV status. In the bill, they have talked about the confidentiality of the HIV status of a person, and there are exceptions given under which it is allowed to disclose the HIV status by the medical professionals, which are an ideal state according to the author of this research paper. According to the Bill, every person has the right to information and education relating to health and protecting health from the State. The major focus of the Bill is upon women and young persons. It puts an obligation upon the State to institute IEC programmes which are evidence-based, age-appropriate, gender-sensitive, non-stigmatizing, and non-discriminatory. It is necessary to create a balance between privacy and information, which is also the main theme of this research paper.

An article '**Privacy in Healthcare: Policy Guide**', published on '**the centre for internet and society**', has discussed **privacy**. They have talked about the fiduciary relationship between the doctor and the patient. As per **the Indian Medical Council Act of 1952**, there is a reasonable expectation of mutual trust between the doctor and the patient from which this fiduciary relationship has been established. Under **section 20(A)** of the Act, there is a code of ethics expected from the doctor that they will abide by the same. Privacy within the healthcare sector includes several aspects, including but not limited to informational privacy (e.g., confidentiality, anonymity, secrecy, and data security); physical privacy (e.g., modesty and bodily integrity); associational privacy (e.g. intimate sharing of death, illness and recovery); proprietary privacy (e.g., self-ownership and control over personal identifiers, genetic data, and body tissues); and decisional privacy (e.g., autonomy and choice in medical decision-making). Thus, this article will help understand the scope of privacy and explore whether this privacy can be denied under certain special circumstances, which will be discussed in the research paper in detail.

An Article '**Right to Health as a Fundamental Human Right in India: Constitutional and Judicial Responses**' published on '**Sodhganga**' website has discussed fundamental rights, i.e. guaranteed under **Article 21** of the Constitution of India, i.e. Right to life which puts an obligation upon the state to take every measure to preserve life. The court has said that the welfare state has a primary duty to ensure that medical facilities are adequate and available to

provide treatment, and for the violation of the right to life of the petitioner, compensation was awarded to him. In 1991, in **CESC Ltd. vs Subash Chandra Bose**², the Supreme Court relied on international instruments and concluded that the right to health is a fundamental right. This will help establish that health is always above any confidentiality in this research paper.

II. HIV JURISPRUDENCE AND RIGHT TO PRIVACY IN INDIA

The Indian judiciary has conservatively developed jurisprudence, resulting in the stigmatisation of the medical condition. In **Dominic D'souza's case**, an employee was fired from the job when her HIV status was disclosed at the workplace and refused to get treatment by doctors.³ The state justified the action under Section 53 of the Goa Public Health (Amendment) Act, 1987, under which HIV positive person has to be isolated to protect public health.⁴ The Court held that such provision is not unjust and arbitrary but for the patient's safety. However, the court-ordered release from confinement and made it discretionary rather than mandatory to detain under section 53 of the Act.⁵ The Bombay High Court passed an order to arrest a mass of female sex workers to prevent the spread of HIV.⁶ Court also directed to make raids a regular feature of public policy as long as the spread is reduced in states.⁷ The Court referred to the medical welfare of the citizens with good health, which depends upon a legitimate system and doesn't exploit vulnerable sections of the society.⁸

HIV/AIDS is a sexually transmitted disease, so it is stigmatised. The information regarding the HIV status of the patient is considered positive information as it results in discrimination against the patients. Right to privacy, in this case, amounts to non-disclosure of the HIV status of the patient to any third person by the doctor. There is a lack of privacy regulations, resulting in fear in the patient's mind. Many people in India are not getting them tested because of the fear that the information will be leaked as there is no privacy regulation, which could lead to a breach of patient confidentiality.⁹

² AIR 1992 SC 573,585

³ Souza v. State of Goa, A.I.R. 1990 BOM 357.

⁴ Julie Hamblin, People Living with HIV: The Law, Ethics and Discrimination, UNITED NATIONS DEVELOPMENT PROGRAMME (1992). <http://www.undp.org/hiv/publications/issues/english/issue04e.htm>.

⁵ Mitu Varma, India Health: Legal Luminaries Seek AIDS Legislation, Inter-Press News Serv, (1997) <http://www.aegis.com/news/ips/1997/IP971005.html>.

⁶ Yoshie Furuhashi, Rescuing" Sex Workers, in Compendium on Child Prostitution, SOCIO-LEGAL INFORMATION CENTRE (2000) <http://csf.colorado.edu/soc/m-fem/2000/msg01408.html>.

⁷ *ibid.*

⁸ Jayanth K. Krishnan, The Rights of the New Untouchables: A Constitutional Analysis of HIV Jurisprudence in India, HUMAN RIGHTS QUARTERLY, 791-819 (2003)

⁹ Aneka, Karnataka Sexual Minorities Forum, Chasing Numbers, Betraying People: Relooking at HIV Services in Karnataka, 24 (2011).

(A) In light of conjugal rights (confidentiality)

Among many other aspects of the right to privacy, privacy in the light of conjugal rights needs special attention because this is where the right to privacy comes in conflict with the right to information and the right to health. In these cases, even the disclosure of facts is considered a VA violation of the right to privacy because sometimes there is a conflict between one person's 'right to be let alone' with another person's 'right to be informed'. According to Lock's jurisprudence of right, Right is meaningless if the right holder doesn't get to make his personal choice as to where to go, what to say, and how to dispose of his property.¹⁰ Thus will and personal preference is key element of a right. But he said that such liberty doesn't include license, which means that man cannot harm or destroy anything, including himself.¹¹

(B) Mr. 'X' Vs. Hospital 'Z'¹²

The above case is the landmark judgment in light of the matter we are discussing: confidentiality. In this case, the issue was whether the HIV status of a person needs to be disclosed to their prospective spouse. Is it reasonable to breach the right to privacy to grant the right to health and information to the spouse for the public interest?

Court held doctor and patient confidentiality is just a part of medical ethics under Medical Council Act, and thus it is not enforceable. In these cases, there is a high risk of the spread of the virus to the prospective spouse, and thus it is reasonable to disclose the HIV status of the patient to the spouse. The consent to marry should be informed consent before marriage.

Court referred to the guideline issued by the General Medical Council of Great Britain, which mentioned that "doctor has the discretion to consider it as his duty to inform the patient's partner about the HIV status regardless of the wish or will of the patient himself".¹³

There is no privacy regulation or any other codification that determines what should be done in case of conflict between the right to information and privacy. It will be further determined in the research paper with the help of various case laws and landmark judgments delivered by the courts in India.

III. INTERNATIONAL LAW

US Supreme Court recognised the Right to privacy for the first time in 1965, where it held

¹⁰ Santiago-Nino C., *The ethics of human rights*, OXFORD CLARENDON (1991)

¹¹ *Ibid.*

¹² CA No. 4641 of 1998.

¹³ Diganth Raj Sehgal, *Privacy rights of AIDS patients in India*, IPLEADERS, (2021) <https://blog.ipleaders.in/privacy-rights-aids-patients-india/>

that patient's right to consult the doctor about contraception cannot be interfered with by the state.¹⁴

The International Covenant on Civil and Political Rights and the International Covenant on Economic, Social, and Cultural Rights are the conventions aimed at the goal that there should be no discrimination against patients infected with HIV. Apart from this, there are various other treaties, agreements, and declarations that India has signed. The idea behind signing these treaties is to protect the human rights of HIV patients and to prevent the spread of this disease in society.

The Universal Declaration of Human Rights declares that non-discrimination is one of the major principles under human highlights. There shall be no discrimination against people who have HIV due to the stigma and discrimination prevalent in society till now. Right to life, liberty, and security is also granted to people who have HIV, and because of these, no person should be compelled to any test or treatment. They also enjoy the right to work and participate in the community's cultural life. They are also entitled to equal protection by the law, and they are also equal before the law.

Article 25(1) of the declaration- right to adequate living standard, medical care, assistance, and all the necessary social services and right to security is also granted to HIV patients.

The UNAIDS Guidelines, 1996

It acts as guidance to the states to find out the problems in making good strategies for the prevention of HIV/AIDS. It says that it is the states' duty to be involved in the legal reform of the nation. It focuses on enacting such laws in the state, which are aimed towards non-discrimination against the people who have been diagnosed with HIV positive in public and private sectors. The enactments should grant the rights like privacy and confidentiality.

European Convention on Human Rights, 1998- Article 8 of the convention- Based on this legal provision, the European court has held earlier that there is a prominent danger to life and health of the individual as a result of lack of information and to prevent such danger it should be the right of the individual to ask for information from the governmental bodies.

In another case, the European Court of Human Rights has held that the right to be informed is a right that exists with the public, and it should be granted even at the cost of disclosure of the private life of the public figures.

Thus, international lawmakers have also considered the right to life with good health while

¹⁴ Jonsen A., *The birth of bioethics*, OXFORD UNIVERSITY PRESS (1998).

protecting the right to privacy. The right to privacy cannot be protected at the cost of living and other people's health.

IV. INDIAN CONSTITUTIONAL FRAMEWORK

There is no law specifically for regulating the rights of the patients who have HIV and the state's duty to protect those rights of the people. We will deal with these issues with the help of rights that has been granted to the people of India under the Constitution of India. Equality to the people suffering from HIV and non-discrimination against them due to stigma in the society is to be dealt with by **Articles 14, 15, and 16** of the constitution, respectively.

Article 21 talks about the right to life, and there is another right that originated from article 21 with various judicial pronouncements and interpretations of the article. The right to privacy is one such right that has evolved from the right to life.

Article 47 is part of the directive principle, which imposes a duty on the state to improve and maintain public health. As a result of this article, it becomes the state's duty to inform the prospective spouse of the AIDS patient that that person they are going to marry has AIDS. After that, the consent will be considered as the informed consent of the partner. Marrying an AIDS patient worse affects the health of the person they are marrying as it is a disease that is transmitted sexually. Thus, with this provision's help, cases have been decided till now.

V. RIGHT TO PRIVACY VS RIGHT TO INFORMATION: CONFLICT AND BALANCE

In the case of marriages, whether the right to privacy of HIV patients should be considered or the right to information of the prospective spouse should be taken care of. This is where the conflict arises. Right to life under Article 21 includes the right to live a healthy life. It becomes the right of the spouse to know the status of the other party in terms of HIV and then decide whether to marry that person or not because the life of the spouse comes in danger after marrying a person who has HIV positive. It can never be considered a violation of privacy or confidentiality of the patient as it is the right of the spouse to make an informed consent about marriage. It becomes the public interest to inform the spouse, which supersedes the right to privacy which has been observed in various judgments discussed below:

(A) Mr Surupsingh Hrya Naik vs the State of Maharashtra¹⁵

In the above case, it has been held that whenever there is a conflict between the medical council code of ethics and RTI Act 2005, the RTI Act 2005 will supersede. An individual in judicial custody has health records, and they should be made available under the provisions of the Act.

¹⁵ AIR 2007 Bom 121, 2007 (109) Bom L R 844, 2007 (4) MhLj 573

There are only certain exceptional cases where the RTI can be valid reasons.

(B) Mr Surupsingh Hrya Naik v. the Thee state of Maharashtra¹⁶

In this case, the court also discussed whether the right to privacy should prevail over the RTI Act or not. Court held that confidentiality is only given under the code of ethics regulation. Thus they are not granted right while RTI is a right now, and it can only be denied in certain exceptional circumstances given under section 8 of the Act. Thus the medical records of a person in custody shall be made available to any person whosoever is asking for that information.

(C) Radiological & Imaging Association v. Union of India¹⁷

In this case se, the court has discussed the conflict between the right to privacy and public interest. There were PNDT Rules under which the collector and district magistrate issued a circular. Under those rules, it was required that the radiologist and sinologist submit an online form 'F', which was further challenged in the court that this requirement violated the patients' right to privacy. Court held that the form is submitted only to a collector in the presence of the radiologist. Thus there is no violation of the duty of the doctor about confidentiality. "There was declining sex ratio in the last five decades, which was considered compelling public interest that will supersede the right to privacy."

(D) Sharda v. Dharmpal¹⁸

In this case, there was a divorce proceeding in which the party was compelled to go for medical examination to decide the issue of child custody. The party which was getting compelled for the medical examination gave the argument of the right to the private court said that the right to privacy is not absolute but has been conferred through the interpretation of article 21 of the constitution of India. In this case, privacy is limited because there is a greater question of the child's interest, which should not be jeopardised to protect the right to privacy. Thus the court has the power to compel the party for the medical examination for the best interest of the child involved in the case.

(E) M. Vijaya v. Chairman and Managing Director, Singareni Collieries Co. Ltd.¹⁹

The petitioner, in this case, has been infected with HIV because of the negligent act on the part of the hospital in the process of transfusion of blood. Court The court discussed public interest

¹⁶ AIR 2007 Bom 121, 2007 (109) Bom L R 844, 2007 (4) MhLj 573

¹⁷ writ petition no. 797 of 2011

¹⁸ AIR 2003 SC 3420

¹⁹ I (2002) ACC 32

in this case. The court has referred to article 47 of the constitution and said that the state must take all such steps to improve public health. Any law designed to achieve this public health objective cannot be held violative of article 21.

The roman principle of 'SalusPopuliestSuprema' states that when there is a necessity to protect public wealth, it is the highest law and will supersede over any other law.

(F) Justice K.S. Puttaswamy and Ors. V. Union of India and Ors.²⁰

This landmark judgment marked the importance of the Right to privacy in Indian jurisprudence; the right to privacy has been considered an integral part of Article 21 of the Constitution of India.

VI. EXCEPTION TO THE RIGHT TO PRIVACY

Considering all the above cases, we can observe the principle followed by the court in the cases where there is a conflict between the individual right to privacy and public interest. The Court has been following the “principle of utilitarianism”, which values larger public interest more than individuals' interest.

Thus the public interest in the exceptional case where the public's interest at large overshadows the right to privacy.

(A) Third-party information

Doctors have both positive and negative duties towards patient's, i.e. (1) positive duty to aid help and (2) negative duty not to bring any harm or risk to the people.²¹

Whenever a third party seeks information from the hospital regarding the HIV status of the person, it should not be rejected straight away to protect the right to privacy. The matter should be studied in-depth, and the reason should be checked because the third party is seeking such information. If it is found that it is in the public interest or for the health protection of such a third party, it should not be denied, but the information should be provided. The information can be provided with the consent of the patient or otherwise also when it is necessary.

VII. CONCLUSION AND RECOMMENDATION

The aim and objective of granting both the right, i.e. right to privacy and right to information, was to help the individual make the government and state accountable and transparent. There is a lack of enactment and legislation to govern this area and resolve the conflict between these

²⁰ (2017) 10 SCC 1

²¹ "The Hippocratic Oath" and "Principles of Medical Ethics (1980)

two rights. The term public interest needs to be defined to make it an exception to the right to privacy as it is vague right now and decided on a case-to-case basis. If we want that right to health and information to be kept above the right to privacy, we need legislation governing this to protect public rights. Policies to reduce discrimination and stigmatisation of HIV patients are necessary to protect the health of both patients and the public. The reason behind hiding their status is the fear of stigmatisation. The government should make pass bills to promote equal opportunity of employment and good work culture to remove their fear of coming out and disclosing their identity. AIDS should also be incorporated as one of the grounds of divorce under Indian legislation such as the Hindu Marriage Act, 1955, Indian Divorce Act, 1869 and Special Marriage Act, 1954 and Parsi Marriage and Divorce Act, 1936 to protect the right to health and personal choice of their spouses as well. The need is to create a fine balance between both rights. Value of dignity, rationality, interest element, and will element have to be taken together to form one powerful moral claim that we can apply in need of healthcare.²²

²² Y.M. Barilan and M. Brusa, Human rights and Bioethics, *Journal of Medical Ethics*,. 379-383 (2008)