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International Journal of Current Research
Vol. 4, Issue, 05, pp.211-215, May, 2012

INTERNATIONAL JOURNAL OF CURRENT RESEARCH

ISSN: 0975-833X

RESEARCH ARTICLE

RIGHT TO PRIVACY AND CONFIDENTIALITY AMONG ACQUIRED IMMUNO DEFICIENCY SYNDROME CASES – PUBLIC HEALTH VS HUMAN RIGHTS PERSPECTIVES

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ARTICLE INFO

Article History:
Received 20th February, 2012
Received in revised form
26th March, 2012
Accepted 19th April, 2012
Published online 30th May, 2012

Key words:
HIV-AIDS cases
Medical limitations
Social and legal
Dimensions.

ABSTRACT

HIV/AIDS, since from the time of its first detection, has a medical issue with both social and legal dimensions attached to it. Paper highlighted few dimensions such as compulsory treatment and testing; drug dependents; protection of confidentiality and privacy of clients; right to seek treatment; right against discrimination at the work place; right to marry and right against disclosure to the spouse/sexual partner. In view of the existing socio-demographic barriers to effective prevention of HIV, and medical limitations in curing HIV-AIDS cases, paper also advocates the need of an inclusive legislation framework that could integrate all issues concerning HIV and AIDS.

INTRODUCTION

Though the first case of Acquired Immuno Deficiency Syndrome (AIDS) in India was detected in 1986 in the then city of Madras, there was hardly any appreciation of the legal dimensions in preventing the spread of this disease. Well over a decade after the inception, on April 3, 1997 Justice Tipnis and Justice Trivedi ruled that a Human Immuno-deficiency Virus (HIV) positive person is entitled to employment if he/she is otherwise fit for work and that he/she can approach a court of law by keeping the identity suppressed[1]. It represented a significant sensitization of the judiciary on the vexed issue of the rights of HIV positive people, as also highlighted the fact that HIV is both a medical issue with social and legal dimensions attached to it.

In 2006 UNAIDS estimated that there were 5.6 million people living with HIV in India, which indicated that there were more people with HIV in India than in any other country in the world[3]. In 2007, following the first survey of HIV among the general population, UNAIDS and NACO agreed on a new estimate – between 2 million and 3.1 million people living with HIV[4]. In 2008 the figure was estimated to be 2.31 million[5]. In 2009 it was estimated that 2.4 million people were living with HIV in India, which equates to a prevalence of 0.3%[6]. To put the words of Kofi Annan, the former Secretary General of the U.N, "Every day more than 8,000 people die of AIDS. Every hour, almost 600 people become infected. Every minute, a child dies of the virus". The number of AIDS orphans, that is, children below the age of 18 years who have lost their mother or both the parents to HIV/AIDs, is increasing rapidly.

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The escalating AIDS crisis is leaving an unprecedented number of children orphaned with little or no adult protection and care. The proportion of orphaned children is expected to double in the next five years and remain exceptionally high until 2020[7]. According to UNAIDS there are already over 8 million children who have lost their mother due to AIDS[8]. There are important human rights perspectives of HIV/AIDS cases, such as, compulsory treatment and testing, drug dependents, protection of confidentiality and privacy of clients, right to seek treatment, right against discrimination at the work place, right to marry, and right against disclosure to the spouse/sexual partner. In the context of existing prevalence trends of HIV, resultant orphanage and social discrimination, it is essential to decipher four important relationships between health and human rights: (i) public health policies, programs and practices affect human rights; (ii) violation of human rights has health impacts; (iii) promotion and protection of human rights is linked to that of health and finally, (iv) human rights can serve as "code of ethics" of public health. Equality, fairness and opportunity are good not just in themselves but also for public health.

Law and HIV-AIDS

While 21st Century continues to have policies that would debate about public health vs individual rights, the importance and innateness of delineation of legal rights and duties ought to be an essential part of any policy discourse, today. Reports of serious encroachment on the civil liberties of people with HIV have established beyond doubt that law has a major role to play in HIV policy. Some of the important issues that automatically emerge out of this are: (i) how legislation on HIV/AIDS can protect the interests of HIV infected and assist

in strategies for the care and treatment; (ii) what has been the experience, two decades into the epidemics?; and (iii) would legal sanctions be helpful in bringing about necessary social changes to respond effectively to HIV/AIDS?. Law operates upon different layers through multi-faceted channels. The traditional proscriptive modes penalize certain forms of conduct, whereas protective laws tend to uphold the rights and interests of the needy segments. Yet a third, integrated model, seeks to actively promote the changes in the values and patterns of social interaction - the distinction among the three is not always clear, and could overlap, though. For instance, the two groups most affected by HIV (homosexuals and drug users) could invite criminal proceedings under many jurisdictions across the globe. In India, Art. 377 for Sodomy and Narcotic Drugs and Psychotropic Substances Act of 1985 are the examples of legal remedies for these offences[9]. In another example, the sale of condoms in Ireland was considered an offence until 1990s[10].

Thus, high-risk groups and those infected are reluctant to disclose their HIV status. The coercive nature of laws often imposing criminal sanctions against non-compliance does not help to act as instruments to prevent the spread of the disease, rather act adversely against it. The particular dynamics of HIV suggest that proscriptive models will not work. The Protective model on the other hand is viewed as a mechanism to protect and promote individual rights and legal protection in theory may not translate into practice, especially if the process is too cumbersome, time-consuming and/or costly. With regard to discrimination, breach of confidentiality etc one need to understand that these are mere symptoms of the problem and not the problem *per se*. The cause is deep rooted in the socio-cultural milieu of the society – prejudice and lack of sensitivity to the rights and needs of people with HIV/AIDS[11]. However, Instrumental model is an innovative combination of the earlier two. The most vulnerable people to this epidemic are those denied protection of their economic needs and sexuality. Thus the policy need to address the specific issues related to HIV in the context of overall social and economic fabric of the country.

HIV-AIDS and the work place

Protection of individual rights while safeguarding the public from a communicable virus has presented many unforeseen legal questions with regard to health law, insurance law, employment law, family and medical laws and civil rights. In fact, two epidemics emerged simultaneously: epidemic of transmissible disease of AIDS, and of fear, prejudice & stigmatization. An HIV infected person could possibly fall into three categories of (i) asymptomatic AIDS with Sero-positivity, otherwise medically fit, (ii) limited symptoms, otherwise medically fit to work, and (iii) too ill to work in the normal environment. Under law, no mandatory testing is required but law requires that the concerned person should be 'medically fit' to work in any organization[10]. Consequently, many employees are being tested for their health status – HIV being one of the components of testing. Many recruiters and even countries have mandatory requirement to disclose the HIV status on the part of the aspirant before taking up a job. Would this amount to invasion of privacy? Would it have an impact on the tenure of the employee? The guidelines of the International Labor Organization (ILO) and World Health Organization (WHO) lay down that, the employee should be able to work as long as medically fit for it; that s/he should be protected from stigmatization and discrimination; that there should be no obligation on the employee to disclose the employer regarding his or her HIV status; that no employee should be asked for mandatory testing; and that HIV positivity should not be the cause for termination of tenure of an employee who is otherwise fit to work[12,13,14].

RIGHT TO CONFIDENTIALITY

Mr. Justice Edwin Cameron, High Court of South Africa, notes that Confidentiality can be described as a concept encompassing a duty that inhibits the repetition to others of knowledge about another person or entity. The duty may be merely social or legally enforceable. We consider confidentiality here only in relation to natural persons. Confidentiality may attach to information about any aspect of another's life, past or present conduct, nature, or physical or psychological attributes. To attract confidentiality, the information or facts must be true - one cannot entrust to another for safekeeping in confidence an untruth about oneself. The publication of untruths therefore lies outside the concept. Not all accurate knowledge about another is confidential. As the semantics of the word suggest, confidentiality in its very essence entails that something is given in trust. For confidentiality to arise, there must therefore be a relationship between the subject to whom the knowledge pertains, and the bearer of the knowledge, of such a nature as to import a duty on the latter not to repeat it or to repeat it only in specified circumstances or on specified conditions[15]. In its very essence, confidentiality is thus not absolute. A number of factors bear on whether knowledge carries the stamp of confidentiality. These include the nature of the knowledge, the circumstances under which it was obtained, and the relationship between the person in possession of it and the subject of the knowledge.

Development of the Right to Confidentiality

In the Anglophone legal tradition, the right to confidentiality is most persuasively described as deriving from a right to privacy, which in turn stems from the right to dignity and autonomy. As a separate juridical concept, the right to privacy received its foundational academic analysis scarcely more than a century ago. In England and Wales, for instance, while judicial enforcement of informational confidentiality is highly elaborated the notion of privacy as a separately enforceable legal right is still in question[16]. The concept of privacy is underpinned by two powerful ideas. The first is, every human being is intrinsically entitled to some personal autonomy. Autonomy means the right to make decisions about and for one self. This encompasses "a protected field of decision-making within which the individual is free from the meddling of others". The second is the belief that respecting individuals' autonomy and thus their privacy is "a necessary condition for human flourishing". Privacy "is a fundamental value for everyone in a society which prizes freedom and individualism, not just for those with something shameful or immoral to hide". On the other hand, "The force of speaking of a right to privacy is not to say that it is absolute, but only to say there is a strong moral presumption in favour of privacy". The concept of privacy necessarily constrains the power of the

state. But it can also be argued that it is essential to the effective operation of the democratic state. The diverse values privacy protects has let to the distinction being formulated between the freedom "to make certain important decisions about what happens to one's own body" ("autonomy privacy") and the right "to keep personal information private" ("informational privacy"). The right to privacy finds recognition in international law. Article 17 of the International Covenant on Civil and Political Rights (1966) provides that "No one shall be subjected to arbitrary or unlawful interference with the privacy…"[17].

In South Africa, the right to dignity, the source concept of privacy, is accorded express protection in the Constitution. But privacy itself is also expressly enshrined. The South African Constitutional Court in a decision observed that privacy was fundamental to protecting variant sexual orientations from unfair legislative intrusion. However, the constitutional rights to both dignity and privacy are not absolute and are subject to limitations by laws of general application "to the extend that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors", a number of which are expressly set out. This underscores that the right to confidentiality is not absolute as well. In India, privacy has long received explicit recognition as a fundamental constitutional right. The Supreme Court of India has time and again re-affirmed that the right to privacy is "an essential component" of the right to life envisaged by Article 21 of the Indian Constitution. The Court also held that the right is not absolute[18].

Confidentiality in Medical Context

In the medical context, confidentiality is often said to find its most ancient reflection in the oath formulated by Hippocrates in ancient Greece some 2400 years ago. This requires doctors to treat information acquired from a patient in a professional capacity as "sacred secrets", about which they must "keep silence". But there is evidence that the concept was first formally enshrined in the Indian sub-continent, nearly 500 years before Hippocrates, and that the Hippocratic Oath has antecedents in other ancient civilizations.

Confidentiality in the HIV-AIDS Epidemic

The HIV/AIDS epidemic has brought with it profound re-examination of the practical implications of the principle of confidentiality and of the tenets of medical ethics generally. This has triggered public and academic debates, primarily because infection with HIV invites conflict between an individual's right to limit knowledge of his or her health status, and the pressure to divulge that knowledge to others. Infection with the virus is life-long, incurable and, for those without access to the newest anti-viral combination therapies, probably fatal. It is therefore of great importance to anyone to attempt to avoid risk of exposure to infection, and to know if such a risk has nevertheless occurred. On the other hand, the risk of exposure occurs only in limited, known and well-defined situation. These exclude all forms of casual interaction, and almost all forms of professional contact. In South Africa, recognition of the need for confidentiality has formed one of the cornerstones of the official public health response to the AIDS epidemic. The National AIDS Plan (adopted on behalf of the government on 21 July 1994) expressly enshrines respect for confidentiality as a key concept. The South African Medical and Dental Council in July 1994 issued revised "Guidelines for the Management of Patients with HIV infection or AIDS. These emphasise that HIV test results "should be treated at the highest possible level of confidentiality". The federal Council of the Medical Association of South Africa in December 1992 published comparable "Guidelines for the Management of HIV/AIDS" which similarly underscore confidentiality. Regionally, the Code on HIV/AIDS and Employment, adopted as official policy by the fourteen nations of the Southern African Development Community (SADC), emphasizes that "persons with HIV or AIDS should have the legal right to confidentiality about their HIV status in any aspect of their employment", and that an employee "is under no obligation to inform an employer" of HIV/AIDS status. This point has been underscored by the observation of the Supreme Court of India in Dr X vs Hospital Z case that, after non-consensual disclosure of his HIV status, the appellant attracted "severe criticism" and was ostracized by the community, with the apparent result that he had to leave Nagaland, and start working in Madras.

On the other hand, none of codes or professional standards enunciates the duty of confidentiality in absolute terms. The SADC Guidelines require that HIV status should be treated "at the highest possible level of confidentiality", but they mandate disclosure to other health care workers who require the information. The Missouri Association of School Administrators (MASA) Ethical Guidelines permit doctors to divulge a patient's HIV status to a third party without the patient's consent only when an identifiable third party is a risk; the patient, after appropriate counseling, does not personally inform the third party; and the doctor has informed the patient that she or he intends breaking confidentiality under the circumstances. Confidentiality in relation to HIV/AIDS is thus not propounded as an absolute value. But the emphasis on it comes from three related reasons - each reflects the increasing link between public health and human rights, which has been one of the desirable by-products of AIDS. The first is respect for the intrinsic personhood of those who have HIV, which entails that their individual human rights should not be violated. The second is acknowledging attempts to contain the epidemic would invariably require respect for human rights. Justice Michael Kirby has called this "the HIV paradox". The realization that sound reasons rooted not only in respect for human dignity, but in effective public health planning, necessitate a just and non-discriminatory response to AIDS; that recognition of and respect for individual human rights does not impede prevention and containment of HIV, but actually enhances it[19]. The third reason is acknowledging the very concept and importance of confidentiality. This concerns the historical track of the epidemic. It stems from what Professor Jonathan Mann described as the "very intense, emotional, and personal" discovery, in the course of the 1980s, of empirical and theoretical connections between human rights abuses and vulnerability to HIV/AIDS. These considerations constitute the core of the most important international human rights policy response to HIV/AIDS. The epidemic has yet produced the International Guidelines on HIV-AIDS and Human Rights.

The Guidelines contain twelve policy directives. These reflect the drafters' recognition that protection of human rights is essential not only to safeguard human dignity in the context of HIV/AIDS, but to ensure an effective, rights-based response to the epidemic. The Guidelines assert that public health interests do not conflict with human rights. Guideline 5 enjoins States to "enact or strengthen anti-discrimination and other protective laws", including those that "ensure privacy and confidentiality". International consensus therefore strongly points to the importance of respecting privacy and confidentiality as basic values in containing HIV/AIDS[20].

DISCUSSION

Country-specific measures had been taken to deal with the social and legal aspects of people living with HIV-AIDS. In the United States, by the mid-90s, virtually every State provided some degree of protection for the confidentiality of HIV information. Although these made a strong statement in favour of privacy, they varied considerably in their 'bite'. In Australia, the sero-prevalence amongst injecting drug users had stayed at about 5% for a long time. Where as in Manipur, rates increased exponentially since drug users were simply thrown into prison. Similarly, in Sonagachi, Kolkata, the Sexually Transmitted Diseases (STD) rates actually came down from 21% to 11% during 2000-2005. 5.17% of the 13,000 prostitutes in Sonagachi are estimated to be HIV positive as against 2.7 per cent in 1992, though have better treatment seeking behavior[21,22]. Where as in Mumbai, there were no program until the dawn of the century to protect the rights of Sex Workers.

The South African Supreme Court in Hoffman's case struck down the decision of the South African Airways not to recruit the petitioner as a Flight Attendant because of his HIV sero-positivity. The Airways had no other option but to appoint him. In 1999, in another case, an HIV positive person was denied work in the glass industry[23]. It was argued from the industry side that during working in the industry, injuries often occur to the workers and presence of an HIV positive individual in the work place would make other co-workers vulnerable to infection. The Industrial Court directed the complainant to get a certificate of medical fitness. J.J Hospital gave such a certificate of fitness to him. And in Dec. 1999, the Court passed Interim order, directing the industry to absorb the complaint to work and be paid full wages for his abstention from work during the pending of the case in the judiciary. Thus, a clear link between rights and levels of pandemics may be established.

During Justice Kirby's visit to India, about a decade ago, his opinion was sought on seclusion of HIV positive patients as a public health strategy to prevent spread of infection of HIV, to which he replied: "All I can say about seclusion is that while it might have been a strategy, perhaps way back around 1974, today there is no way it's going to work. You simply cannot seclude all the people infected with HIV/AIDS because you simply do not have enough barbed wire. The problem is too big to be solved by seclusion any more. Look at it-if anyone should have succeeded at seclusion it should have been Australia. We are an island. We do have strict controls over what comes in and goes out. We have a very effective Navy and Air Force policing our borders. But it did not. We could not control the problem by secluding people and you can't do that in India either. Of course…..Judges do think in regulatory terms. But that sort of response would simply not work in this case…..The individual rights matter because only if the individual is going to be sure about his rights will he be willing to consider being open about his disease"[19].

CONCLUSION

At present, in India we need an inclusive legislation framework that could integrate all issues concerning HIV and AIDS[24]. In the UK, the AIDS Control Act, 1987, provides for the collection and reporting of statistics relating to HIV infection and AIDS and the availability of facilities and staff for testing, consulting, treatment and other measures designed to prevent the spread of HIV infection. Section 23 of this Act prevented the sale, supply or administration of any equipment or reagents to detect HIV antibodies (test kits) in centres without medical supervision[25]. Similar legislation is needed in India to protect the rights of individuals. Further, Section 377 of the Indian Penal Code (IPC), which makes non-procreational sexual acts a criminal offence, may be taken as obsolete and deleted. Section 377 of the IPC seem to be violation of the constitutionally guaranteed rights of right to life, liberty and equality.

In view of the existing socio-demographic barriers to effective prevention of HIV, and medical limitations in curing HIV-AIDS cases, protection of their rights to privacy, right to willful testing and treatment and special rehabilitation support, such as, the doctrine of Reasonable Accommodation (job transferability to the most suitable department) and the doctrine of Compassionate Appointment (giving job to the spouse after death of the patient) are inadvertent[26,27]. We also need to have a concurrent legislation to uphold the rights of HIV positive people with special emphasis on women and children who are most vulnerable to exploitation. A comprehensive socioeconomic policy addressing the 'at risk' cases and infected individuals should be offered by the State, as to develop a sense of security amongst those in the brink of this all consuming menace.

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