

Health Rights in the context of HIV infection and AIDS

Christian Medical Association of India and Lawyers Collective

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HIV/AIDS is a developmental issue that calls for social and political action. It is also a public health issue that requires people-oriented health and medical interventions. Such responses require democracy, pro-people inter-sector policies, good governance, people's participation and effective communication. They should be rooted in internationally accepted human rights and humanitarian norms ['People's Charter on HIV/AIDS' by People's Health Movement].

The widespread abuse of human rights and fundamental freedom associated with Indian constitution has emerged as a serious issue in the last two decades after the origin of epidemic in India. Protection of human rights is essential to safeguard the human dignity in the context of HIV infection and AIDS. This paper draws upon five important areas where violation of human rights in the context of HIV infection and AIDS in health sector has been reported in India.

1. Universal Access to Treatment for PLHAs through Public Health System

Providing equitable access to comprehensive treatment for HIV infected people is crucial to the overall HIV infection and AIDS scenario in India. Comprehensive healthcare for those who have infected with HIV/AIDS include opportunity for them to lead healthy lifestyle which include cost-effective nutritional input, psycho-social support ect., access to treatment for the opportunistic infections and access to anti-retroviral therapy. The inability of people living with HIV/AIDS to access treatment is violating the 'Right to Life' under the India's constitution. The 'Right to Life' guaranteed by the constitution has been interpreted by the Supreme Court to include the "Right to Health' [Eg. Vincent Panikulangara Vs Union of India, 1987]. Many international commitments for which we are a signatory also mandate the state to provide access to treatment for those who are affected by HIV/AIDS [Eg. UNGASS Declaration of Commitment].

The Alma Ata Declaration of 1978 promised health for all by 2000 through primary health care approach. Verticalisation of public health systems, changing economic priorities, invasion of private interests into political

decision-making and lack of political determination lead to undermining of our public health system. This breakdown of public health and primary health care systems over the last two decades has proved to be highly detrimental to the capacity of our health system to cope with the treatment and care of HIV/AIDS.

One of the important components of treatment for the HIV/AIDS infected people is Anti-retroviral Therapy. Effective therapy inhibit the viral replication and reduces the viral load. This results in lower frequency of opportunistic infection and helps the infected people to lead more productive lives. The decision taken by the Government of India to provide treatment to one hundred thousand people starting from 1st of April 2004 in six high prevalence states was an important step. However the majority the people who require anti-retroviral therapy are outside this commitment. It has also been noted that the pace at which the programme is rolling out even in the identified states is not at a desirable level and also some of these states are facing logistic problems. One major reason for this is the collapse of our public health system which make it handicapped to handle and monitor Anti Retroviral Therapy. Though the programme has been announced as free of cost, it is totally objectionable that certain elements of cost recovery from users have nevertheless been brought into the public provision of Anti-Retroviral Therapy through the back door. The present programme does not offer any second line therapy making people who fail in the first line therapy highly vulnerable.

Informed consent and proper counseling of patients is essential and should be mandatory before starting the treatment. The counseling should include detailing the nature of life long treatment, possibility of resistance, toxicity of anti retroviral drugs. Provision of anti retroviral should ensure maintaining and respecting the right to confidentiality of the PLHAs, proper monitoring of the patient clinically and also providing necessary psycho-social support. Another important point of caution is the likelihood of abuse of Anti-retrovirals by the unregulated private health sector in India [as in the case of tuberculosis treatment where hundreds of different treat regimes, most of which are irrational are being practiced by the doctors]. This should be avoided as such a practice can result in drug resistance as well as exploitation of the patients.

Increased cost of anti-retroviral drugs decreases government's ability to procure medicines. The impact of TRIPS on cost of drugs will be one aspect that will make treatment out of reach for most of Indian PLHAs. Government of India should make maximum use of the provisions available within TRIPS and also pursue other options like overhauling and expanding system of price control of medicines. Revamping of public sector drug manufacturing units is another crucial step in making sure the availability of medicines at critical times.

Recommendations

1. Governments should develop and strengthen health system based on comprehensive Primary Health Care principles and include the treatment and care interventions for peoples living with HIV and AIDS under it.
2. Government should ensure free and universal access to treatment for opportunistic infections, provision of anto-retrovirals whenever necessary and required monitoring tests to all people living with HIV and AIDS. Make nutritional inputs and psychosocial support part of HIV and AIDS care. Special attention should be paid to gender issues and treatment access of women living with HIV infection. There is increasing number of children living with HIV/AIDS and their need for treatment should be also be attended to.
3. Cost recovery elements in the present programme to provide anti-retroviral therapy in select high prevalence states should be stopped.
4. Treatment protocol required for the administration of anti retroviral drugs and drugs for opportunistic infection should include guidelines for counseling and informed consent. Take necessary steps to ensure that the same protocols are followed by the private sector.
5. Ensure the availability and affordability of all essential medicines including those required for the treatment of people living with HIV and AIDS, by expanding the DPCO and making the process of price control transparent.
6. Make use of the flexibility available with in TRIPS agreement and include supporting provisions in to the amendment to the patent Act. Accessibility and availability of medicines should be ensured by limiting patents to new chemical molecules and revamping the existing compulsory license mechanisms.
7. Revitalise the public sector pharmaceutical manufacturing units so as to cater to the needs arising out of situation under TRIPS.

2. Prevention of Parent to Child Transmission

Perinatal transmission of HIV infection accounts for about 2.74% of all HIV infection in India. In the absence of any preventive steps, the risk of vertical transmission from an infected mother to child is about 30 to 35%. Historically the prevention of parents to child transmission was looked only as a technical/clinical issues of treating the mother and child to prevent vertical transmission. However it needs to be viewed from a rights perspective of all the people in child's life whose well being will enable fulfillment of child's life.

Unfortunately our weak health system provides limited access for anti-natal care leaving many who require preventive measure against vertical transmission out of reach. Unless the health systems are equipped to provide

ante-natal care services to most of pregnant women, the chances of most of the infected pregnant women accessing Voluntary Counseling Testing [VCT] and Prevention of Parent To Child Transmission [PPTCT] are rare. The availability of VCT and PPTCT should be universal by making it part of health systems based on primary health care strategy.

Right to autonomy and bodily integrity is recognised in all law including the fundamental rights in the constitution - article 21 - right to life and personal liberty. However despite the recognition of the right to autonomy and bodily integrity in the law, large number of women visiting the ante natal clinics in India are routinely prescribed HIV test as part of a battery of tests. In India a number of cases have already been reported where pregnant women are subjected to HIV screening without proper pre test counseling and on diagnosis of HIV infection, they are denied post test counseling. It should also be ensured that HIV infected pregnant women are not coerced into abortion by health system staff or relatives and the choice should be given to the pregnant women. Availability of voluntary testing facilities with compulsory provisions for pre and post test counseling is a must for safeguarding the mothers right to take an informed decision regarding testing, continuation of her pregnancy and also for receiving treatment for PPTCT.

PPTCT programme which look only at the right of the child and ignoring the rights to life of people connected with the child is unacceptable. Treatment and care should also be made available to HIV positive mothers and other infected members of the family. Adequate support systems need to be built within the community for the affected and infected children.

The risk of transmission of infection to child through breast milk is about 15 percent. But given India's high infant mortality rate, the protection benefits of breast feeding against Diarrhoea and other life threatening infections far outweigh the risk of transmission through breast feeding. Every HIV positive women has the right to an individual evaluation of the best feeding option for her child. If she decides so, all required support should be made available to enable this.

Recommendations

1. Ensure that women visiting antenatal centres are not targeted and taking informed consent and pre and post test counseling should be part of any screening for HIV infection in pregnancy.
2. Accepting or refusing testing should not have detrimental consequences to the quality of prenatal care offered.
3. Access to PPTCT should be universal. It should not be viewed in isolation as a procedure to prevent vertical transmission and all people related to the life of the child especially the mother should get anti-retroviral drug therapy, if required

4. Women's reproductive health rights should be respected in aspects of the programme to reduce the risk of parents to child HIV infection. Woman's decision based on proper informed consent should be mandatory for all important decisions including continuation of pregnancy, PMTCT intervention, breast feeding of the child etc.

3. Consent and counseling issues related to testing/screening for HIV

The principle of consent is based on the fundamental principle of autonomy of an individual, which has been recognised within the meaning of the right to life and personal liberty under Article 21 of the Constitution of India. Based on this principle, the most important reason for taking consent from a person before testing and treatment is to respect human dignity and bodily integrity. Another reason for taking consent is clinical; as the efficacy of any treatment improves substantially through a patient's co-operation, faith and confidence. For those delivering treatment, obtaining consent also provides a defense to a criminal charge of assault or battery or a civil claim for damages or trespass to a person. Therefore, it is necessary for a health care worker (including counsellor) to take consent and explain the implications and risks involved as part of the duty to care. Mandatory testing, which is not based on informed consent, is a violation of the right to autonomy and has had have negative public health consequences and has proven to be detrimental to HIV prevention efforts.

The concept of consent has three discrete but equally important aspects: first, consent is valid only if the person giving it is competent to do so; second, consent must be properly informed; third, consent must be given voluntarily. The patient/client has a right to all the information relevant to the decision of whether or not to consent to a particular diagnostic test, a test to determine the line of treatment or the line of treatment itself. Informed consent implies informing the patient/client of the implications of the tests and treatment and risks involved in the treatment prior to taking consent from the patient. Therefore, consent for necessitates (a) a duty on the health care worker to take informed consent from the patient, as a part of the duty to care; (b) a right of the patient to have knowledge and information of the options available and the risks involved in testing and treatment, so as to enable the patient to make an informed choice.

The question that arises is how much should be disclosed to the patient to ensure that consent is informed. In England, the standard of care which a doctor is required to exercise in discharging her/his duty to inform the patient of risks inherent in the treatment is the same as that required by a doctor in his diagnosis and treatment, namely to act in accordance with a practice accepted by a body of skilled and experienced medical professionals. In the U.S., the doctor must disclose all "material risks"; what are material risks is

based on the "prudent patient" test i.e. a risk is material "when a reasonable person would attach significance to the risk." In Canada, the doctor must disclose known, probable, special or unusual risks. The law requires that objective and subjective factors be taken into consideration. The objective factors are what a reasonable patient would complain of, the subjective factors are the "particular concerns" and "special consideration affecting a particular patient" to determine whether the patient would have refused treatment if informed of possible risks. In Australia, the doctor has a duty to warn the patient of a material risk inherent in a proposed treatment. It would be a material risk if a reasonable person would attach significance to it. This duty is subject to therapeutic privilege. In India the concept of consent is not fully developed in tort law and references may be made to the principles laid down in the Indian Contract Act and the Indian Penal Code.

There are situations where consent cannot be taken from the patient and is taken from the next of kin or guardian of the patient. This is also referred to as proxy consent and is particularly relevant in the case of children. Consent for diagnosis and treatment of children is generally taken from the parents or an adult next of kin of the child. However, in certain circumstances law recognises that a child may consent depending on the age of the child and the ability of the child to understand the nature of the diagnosis or treatment. In England, a young person of 16 years of age may be treated as an adult and is presumed to have the capacity to decide. In most states in the U.S., minors who are at least 12 years of age can consent for an HIV test or treatment. The paramount consideration remains the best interest and welfare of the child when evaluating which actions are permissible, even if consent is taken from the minor. However, under the NACO Policy consent for testing has to be taken from the minor's guardian. Studies and experiences have indicated that a large percentage of minors are sexually active and take drugs and need services related to sexual health and HIV etc. Experiences have also shown that minors are unwilling to access services with a guardian. Many minors such as those living on the streets have no guardians and want to access services independently.

Law provides for exceptions in certain circumstances. Thus, if a person is unable to give consent because s/he cannot understand the nature and consequence of the diagnosis or treatment due to mental incapacity, medical practitioners are under a duty to act in the best interest of the person. In England, no person can give or withhold consent to treatment on behalf of a mentally incapacitated patient. The medical practitioner has a duty to assess the capacity of the patient and make an informed decision about the treatment. If the patient lacks capacity, then the medical practitioner is to act in the best interest of the patient. Similarly, during an emergency where, for instance, obtaining consent from an unconscious patient would not be possible, the medical practitioner can lawfully treat the patient and is required to act in the best interest of the patient so as to preserve life.

In light of the above, it is indicative that health programme that does not maintain the dignity of patients or deprives them of their basic rights is violative of their fundamental and human rights. No individual should be made to undergo a mandatory test for HIV. A person, who has the mental and physical capacity to make a decision, has an absolute right to choose whether to consent to testing and/or medical treatment, to refuse it or to choose an alternative. It is also important that informed consent is taken in writing after explaining to the patient, in a language that s/he understands, the risks and implications of a particular test or treatment. The patient has a right to refuse and/or withdraw consent prior to the test being conducted. Principles relating to consent also mandate pre and post-test counselling as fundamental to any process of obtaining informed consent.

Recommendations

1. Ensure that consent to testing for HIV has to be accompanied by pre and post test counselling.
2. Ensure that consent for HIV testing, treatment and research is taken in a language and manner that is best understood by the person.
3. Ensure that the counselling is of a high quality and that it is done in a non-judgmental and sensitive manner. The protocols for pre-test and post test counselling and training of counsellors should be reviewed through a consultative process.
4. Ensure that every institution involved in HIV related testing, treatment and research should develop counselling protocols for women and children to ensure that decision-making is independent and informed.
5. Ensure that persons between the ages of 12 and 16 years be allowed to consent for a HIV test and only in cases where the health care provider evaluates in writing that the person lacks the capacity to consent should consent be taken from the parent/guardian. A clear policy needs to be developed for the same.
6. Ensure that that protocols for taking consent for treatment is developed that includes giving information in a language and manner best understood by the person, on risk and benefits of the proposed treatment the alternatives that may be available, including the nature of the HIV disease, the treatments available for it (including the possible failures, toxicity etc), the stages when they can be administered, their duration, the likely expenses, the when they can be administered, their duration, the adherence requirements.
7. Formal training of counsellors should be made mandatory and training facility should be made available at various regions of the country.

8. Norms for testing and counselling should be part of 'code of medical ethics' prepared by the Medical Council of India [MCI] and MCI and state medical councils should take action against those registered medical practitioners who are violating the norms.
9. Ensure that any proposed research on HIV/AIDS is thoroughly examined for ethical standards and that consent protocols are developed to inform the potential research subject in a language and manner best understood by him/her of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study, the discomfort it may entail and the right to abstain from participation in the research or to withdraw consent to participate in the research at any time.

4. Stigma and Discrimination in health care settings

Discrimination lies at the root of all legal and human rights issues in the HIV/AIDS context. It is because of the fear, ignorance and stigma associated with HIV/AIDS that PLHAs are treated prejudicially and unequally.

However the reality is quite different and discrimination is rampant vis-à-vis PLHAs in the healthcare setting. This is further accentuated for certain marginalized populations. For instance women, sex workers, drug users and prisoners find themselves discriminated in healthcare irrespective of their HIV status. The positive status of such individuals/groups, however, further marginalizes them and decreases access to health services even more. Those who do not fall within these populations but are HIV+ also suffer immense discrimination in healthcare. Not only would increase in access to healthcare benefit PLHAs, it would have a positive public health impact on society at large in preventing the spread of the epidemic.

The Right to Healthcare

The right to be treated equally and the right to health are fundamental rights guaranteed under the Indian Constitution and basic human rights found in all international human rights documents. In the Indian constitutional context it is the State's obligation to provide healthcare for all. However, the right of equality and healthcare is available only against the State and not against private bodies. Therefore, it is the widely felt experience of many PLHAs that they are discriminated against and refused treatment by private healthcare institutions due to their positive status. Even state-run healthcare institutions discriminate against PLHAs in many ways. These include an outright refusal to treat, physical isolation in wards, early and inappropriate discharges, delays in treatment, on condition of higher charges being levied and prejudicial comments and behaviour.

It has been held by the Indian Supreme Court, however, that both public and private healthcare institutions have a duty to treat all those in emergency situations although the latter is not obliged to treat persons in other circumstances. Yet, both public and private healthcare institutions continue to discriminate based on HIV/AIDS status.

Anti-discrimination Legislation

In certain jurisdictions medical standards prescribe that a healthcare worker must treat every patient as HIV positive and carry out medical procedures and take precautions based on this assumption. These jurisdictions also prescribe anti-discrimination legislation that makes treatment of PLHAs obligatory even on private healthcare.

In India however, there is an absence of anti-discrimination legislation. Therefore, private healthcare is free to refuse treatment to PLHAs, as it almost always does.

Manifestations of Discriminatory Practices

As mentioned above, many PLHAs are denied their basic fundamental right to health due to the discriminatory practices carried on by healthcare institutions. Discrimination manifests itself in many ways in a healthcare setting. For instance, PLHAs have their case papers often hung on their beds with bold and conspicuous notations on them indicating their positive status. This is done in order to 'warn' others and leads to prejudicial comments and mistreatment by healthcare staff.

Bodies of people deceased due to HIV/AIDS-related causes are treated in an undignified manner. Often healthcare staff refuses to handle such bodies. If they do, then the bodies are often dumped in plastic bags with 'HIV' written across the bags, which is unnecessary. Even after this the unclaimed bodies are not disposed off with dignity but are left to decay. Sometimes relatives are charged extortionate amounts for handling of such bodies.

Hospitals have been seen to refuse treatment to PLHAs stating that PLHAs can be treated from home and that admission in the institution is unnecessary. PLHAs are also discharged early by hospitals, prior to completion of treatment; on the pretext that the PLHA's health is improving and does not require supervision. Healthcare institutions sometimes grant a bed to the PLHA but discharge him/her in a few days without having analysed his/her condition or prescribed any treatment.

Sometimes PLHAs are treated by healthcare institutions and in the middle of treatment are asked to do an HIV test. Once the test results are seen as positive the PLHA is removed from the institution in the middle of treatment.

Pregnant women in private nursing homes are tested for HIV by a single, non-confirmatory ELISA test. If they are found positive, they are refused treatment at the nursing home, and are directed for delivery to public hospitals.

User charges are being imposed by public hospitals even though treatment in such institutions is meant to be free. Accessibility to treatment, therefore, is further reduced. Inaccessibility or denial of treatment causes PLHAs to access quacks instead, and to rely on spurious medications. The long-term consequence of this will be their worsened health condition and the increase of society's overall vulnerability to HIV infection.

Public hospitals too deny treatment to PLHAs. They often try to avoid surgical procedures on some pretext. This includes suggesting a non-invasive but inappropriate course of treatment. This method of treatment, and sometimes-outright refusal, is often meted out to PLHAs from certain marginalized communities such as injecting drug users and sex workers on the basis of their appearance. The only study done on patient-to-healthcare worker transmission by the Centre for Disease Control, United States Government indicates that the chances of such transmission are remote and the paramedical staffs is more at risk than the physician or surgeon. (CDC data shows that of the 52 cases 48 were of paramedical staff.) There are no similar studies in the Indian context but anecdotal data show similar trends. It may be pointed out that the results may be different considering the difference in the manner and context in which the health care sector functions.

It was reported that doctors, well informed about the manner in which HIV may be transmitted, refuse to touch HIV+ patients, thereby increasing the stigma among less trained personnel and attending family members. Healthcare workers sometimes disclose the status of PLHAs to colleagues although the same is totally unnecessary. This sharing of information leads to discrimination by the entire healthcare staff due to the stigma surrounding the infection and already marginalized populations; separate wards, which can be in most shabby conditions, are maintained for PLHAs and also labelled as such.

Concerns of Healthcare Workers

There is a right in law of a health care worker to a safe working environment. Due to the fear, ignorance and stigma around HIV/AIDS, many healthcare workers are afraid to treat PLHAs. Such fear can be mitigated if healthcare workers are provided a safe working environment. This in turn may reduce the discrimination suffered by PLHAs.

It has been argued, even by public healthcare institutions, that providing basic universal precautions to healthcare workers is not a matter of priority. As such, it has been seen that these universal precautions, (including gloves and sheet,

and in the HIV context, post-exposure prophylaxis (PEP¹)), which ought to be considered an essential part of the functioning of healthcare institutions, whether dealing with HIV or any other condition, are not provided to healthcare workers. In these circumstances, it is contended that they are free to deny treatment to PLHAs.

NACO is supposed to reimburse expenses incurred on PEP and Universal Precautions to public healthcare institutions. Even though NACO policy envisages provision of PEP and Universal Precautions, in reality, the same is not available. Where available, red tapism prevents reimbursement of costs as assured. Also there is no proper government policy on universal precautions and this is not treated as a priority issue.

The healthcare workers argue that the institution owes them a standard of care, which necessitates provision of universal precautions. In the absence of these precautions would a healthcare worker be justified in refusing treatment, especially with public hospitals and their emergency wards being burdened as they are?

Certain other issues that require discussion arise in the healthcare context. For instance, whether the healthcare worker have a right to refuse treatment to a person who shows symptoms of HIV/AIDS but is unwilling to be tested. This is of special significance especially in the public healthcare setting where the duty of the state to provide health care is of paramount importance.

What are the rights of the healthcare worker in the event of being infected in the course of employment? In such an event the institution is bound to take care of the worker's medical needs, especially in light of the fact that the healthcare workers have a right to a safe working environment including universal precautions.

It is the experience of many persons that because of their positive status, healthcare institutions charge them large amounts of money, which are otherwise not charged to those with other illnesses. This is often done on the pretext that the healthcare worker needs to spend an extra amount for protective gear. Thus the burden of providing universal precautions falls on the PLHAs, making access to care even more remote.

Recommendations

- 1) The government should make efforts to ensure that discrimination of PLHAs and those associated with HIV/AIDS in both the private and public

¹ PEP is a combination drug regimen, which if administered within a certain time, can prevent the healthcare worker infected by needle stick injury from becoming HIV+.)

health sector is prohibited. This can be achieved through legislation and sensitization programmes with healthcare workers.

- 2) Ensure that health care workers including paramedical staff have the right to a safe working environment where they are provided with universal precautions, PEP etc for which protocols should be developed.
- 3) Ensure that health care staff is provided with training on the effective use of universal precautions, reporting in case of exposure and PEP administration.

5. Confidentiality issues in healthcare settings related to positive status

The concept of confidentiality is rooted in the fundamental human right of privacy - every person has the right to a sphere of activity and personal information that is exclusive to him/herself and that s/he has the right to disclose as s/he pleases. This is a right that has been guaranteed by both international human rights documents and under the Indian Constitution.

Confidentiality is an extension of this right of privacy and plays an important role in the HIV/AIDS scenario where stigma and discrimination are rampant. As discussed later, this is not only an issue of the individual interest but also one that actually serves the general public interest. In the context of confidentiality the main issue that requires to be addressed is whether a positive person has the right to confidentiality about his/her HIV status. It is important to note that confidentiality is fundamental in any public health strategy and especially important in a physician-patient relationship where trust is a foundation. After all, if such a relationship cannot guarantee confidentiality it will only lead to fewer and fewer people accessing health services.

Approaches to the Issues around Confidentiality

The debate over this issue has taken the form wherein two apparently polarised views have emerged - the rights of the individual versus the rights of the community. It is argued that by protecting the right of confidentiality of an individual the larger community is not made aware of the prevalence of the pandemic and is therefore at greater risk of getting infected. This should be remedied by full disclosure of the positive status of all persons.

The counter-argument states that the debate on the individual versus the community is a false debate and in reality protecting the rights of the individual strengthens the community itself. This argument posits that if confidentiality is maintained it engenders trust and faith in the public health system and assures people that they will not be exposed to stigma and

discrimination. This in turn encourages greater numbers to test themselves and access counselling and allied services thus having a positive impact on behaviour change and awareness. On the other hand if disclosure is made it will only discourage persons from accessing health care and testing themselves thus suppressing the pandemic and creating greater hurdles for control efforts.

It is therefore contended that maintaining confidentiality does not contribute to the spread of HIV/AIDS. Indeed, if employed in the appropriate context and in creative and culturally sensitive ways, confidentiality can help to decrease the spread of HIV/AIDS. For instance, in the Indian context, the principle of confidentiality may require to be adapted where voluntary testing centres function under tremendous space constraints and do not have the luxury of separate counselling areas/rooms. Systems need to be evolved to ensure that confidentiality is respected even in circumstances where a counsellor/healthcare worker is forced to discuss a patient's status in the presence of others, as is often the case.

Also, it is sometimes seen that a woman's test result is not collected by her, but by a male member of the family. Sometimes a patient is too ill to go to collect the test result him/herself and a friend or relative does so instead. In these circumstances the question whether the healthcare worker should give the results to the relative or whether s/he should insist on the patient collecting the results. Either choice raises different issues. For example, the situation at the patient's home may not be amenable to maintaining confidentiality. If the policy is that the relative may be given the result, a method of monitoring whether she/he has the informed consent of the patient to collect the result will have to be evolved.

Whether it is appropriate for the counsellor to make home visits despite the likelihood that family members may become aware of the patient's condition is a question that will have to be addressed in a culturally sensitive manner. This dilemma is compounded in cases where ART (Anti Retroviral Treatment) is being provided and follow up treatment is necessary, but where the person does not return for treatment.

Young people including adolescents are unable to access health care services including HIV testing and sexual health information because many health care providers do not view them as having rights equivalent to adults and therefore would often violate the principle of medical confidentiality. One of the key issues in testing and reporting of results is whether or not to involve a youth's parents/guardians in the process. Many young people may not wish to involve anyone in decisions relating to sexual or reproductive health services or HIV testing and treatment. In other countries the age at which a minor can access confidential testing varies between 12 to 16 years.

Breach of Confidentiality

Breach of confidentiality manifests itself in many ways. Due to the stigma and fear surrounding HIV/AIDS, it is the experience of many positive persons that once their status is disclosed they are denied many services especially in the healthcare and employment setting. Often test results are shared, without the HIV positive patient's consent, with other healthcare personnel, family members, relatives, neighbours, friends, colleagues and employers. Instead, maintaining confidentiality is seen to benefit and integrate positive people into mainstream society.

In the healthcare setting, it is seen that some hospitals have a practice of writing HIV in block letters on patient case papers. These papers go from department to department for tests etc. Also, it is common that these case papers are attached to the patient's bed. These practices are ostensibly to warn healthcare workers to be more wary of occupational exposure when providing services to PLHAs, but often result in discriminatory practices. Strategies need to be evolved so that the health services may be provided to PLHAs without compromising on either the right of health care workers to a safe working environment or the duty of confidentiality. Such strategies, it is suggested, would include mechanisms of ensuring availability of universal precautions (gloves etc) to health care workers and clear and enforceable rules regarding confidentiality.

Often hospitals assign separate wards to HIV/AIDS patients. This exposes positive persons to breach of confidentiality and discriminatory practices.

In the employment setting confidentiality is breached at various stages. During recruitment employers often insist on knowing the status of the prospective employee and doctors, working for the employer, divulge the same. This occurs even at stages of routine medical examinations during employment. The question that arises in such circumstances is whether a doctor is obliged to inform the employer and how this is balanced with the duty of confidentiality towards the patient. Some employers argue that the employee's immediate superior should be informed of her/his HIV status, to facilitate informed action in emergency situations. It has also been argued that the duty to maintain confidentiality would vary in circumstances where the employee remains regularly absent from work. Policy and rules with respect to these issues need to be clearly identified.

Breach of confidentiality is also seen in other situations such as at the time of an insurance claim. The question that arises often in this context is whether a healthcare worker is under an obligation to disclose the HIV status of a person to an insurance company enquiring into the cause of death or whether an alternative answer would suffice.

Exceptions to Confidentiality

The case for maintaining confidentiality limits non-disclosure. Although confidentiality is maintained between the healthcare worker and patient it is the duty of the positive person to notify his/her spouse/sexual partner/needle-sharing partner of his/her positive status. This is where counselling plays a vital role. However the argument in favour of disclosure sometimes goes to the extent of contending that the duty to notify the partner is not just the positive person's obligation but also extends to the healthcare worker.

It is important to note that the law does recognise exceptions to the rule of confidentiality. Such exceptions arise in a situation when the public interest to disclose outweighs the public interest to maintain confidentiality. It has also been held that disclosure is permissible (to another doctor) if it is for the treatment/interest of the patient. Confidentiality can also be breached when a person is compelled by law to breach it. Although there is no clear policy, some courts have held that where a special relationship exists (such as between counsellor and client) and there is a foreseeable danger to an identifiable third party, confidentiality can be breached by a healthcare worker. This reasoning could be applicable in a situation where, despite extensive counselling, a person continues to engage in high-risk activity for example refuses to practice safer sex with his/her sexual partner. In a situation where a person refuses to disclose HIV status to partner and is unable to have protected sex, the healthcare provider would need to assess if the client would face any dire consequence as a result of the disclosure and only then decide to disclose or not. For example women who test positive first might fear abandonment and violence on disclosure.

Beneficial Disclosure

Closely linked to the principle of confidentiality is the notion of beneficial disclosure. This implies disclosure that is made for the benefit of the affected individuals including the PLHA, his/her sexual and drug-injecting partners and family. Beneficial disclosure is voluntary, respects the autonomy and dignity of the affected individuals and maintains confidentiality as appropriate. Apart from beneficial results for the people affected, it is intended to lead to greater openness about HIV/AIDS in the community and meets the ethical imperatives of the situation where there is need to prevent onward transmission of HIV. Such beneficial disclosure maintains individuals' human rights, prevents discrimination, and improves public health in the form of prevention and care efforts.

Promoting beneficial disclosure with its elements of voluntariness and confidentiality serves a direct public health function, because it encourages people to access HIV prevention and care services. Beneficial disclosure also serves the purpose of opening up the HIV/AIDS epidemic. As more people feel able and willing to disclose their status, there grows a critical mass of individuals and families within a community, and indeed within a nation, who

are openly involved in dealing with the pandemic in positive and supportive ways. The challenge is to create an environment in which people will come forward for testing, counselling, prevention and care.

Recommendations

1. Information that is taken, disclosed, recorded in connection with HIV counselling, testing, treatment or research should be kept confidential.
 2. Ensure that disclosure of information imparted in confidence cannot be divulged unless with written informed consent.
 3. Make sure that Health Care Institutions institute data protection measures to protect confidentiality of PLHAs.
 4. Ensure that protocols are developed for disclosure to partner based on existing laws and policies. The protocols would need to address the issue of violence and abandonment that women might experience on disclosure. A health care worker notifying a partner should follow the protocols.
 5. Confidentiality of minors accessing HIV and related services should be ensured to improve their accessibility to such services. A clear policy should be developed for the same.
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