

Extended Abstract For Annual Research Sessions: Faculty of Graduate Studies, University of Colombo

Title: **“Right to Health of Sri Lankan People Living With HIV&AIDS (PLWHA)”**

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Background: The human rights of people living with HIV&AIDS are a sensitive and controversial topic in the current national context, due to society’s lack of knowledge, scarcity of resources and administrative issues within the healthcare field. This research assesses the right to health of Sri Lankans in terms of treatment, care and support from a rights based perspective. This assessment is to measure the national situation of HIV&AIDS and the level of enjoyment of right to health for people living with HIV&AIDS, against international human rights standards of disease management, as a benchmark to direct further studies on related topics from a human rights perspective. The existing status of Sri Lankan HIV&AIDS patients’ right to health is reviewed in the areas of policy, prevention, treatment and care, and stigma and discrimination compared to the relevant international standards.

Objectives: The general objective is to assess the existing status of the right to health of Sri Lankan HIV&AIDS positive patients and the factors associated with the current situation in comparison with relevant international standards. The specific objectives are to review the current status of policy directives and legal initiatives, and treatment and care in HIV&AIDS from the viewpoint of patients to ensure the right to health of Sri Lankan patients. The status of prevention interventions to stop further onward transmission of the virus and the status of stigma and discrimination reduction efforts in accessing healthcare are also examined.

Research methodology: This is a descriptive cross sectional study with a blend of qualitative and quantitative research methods. Different research methods and techniques were used according to the feasibility of usage in particular participant groups, circumstances or research settings. A hybrid approach that includes parts or all of multiple study types, such as in-depth interviews, focus groups, or non-participant observational techniques, was deployed in extracting information from patients and other program partners. The research proposal and tools were submitted for ethical clearance and approval was granted by the Ethics Review Committee of the Faculty of Medicine, University of Colombo. An independent and impartial sociological analysis was done through collection of an evidence-based set of information from all relevant stakeholders, including patients and human rights activists. The health care providers’ perspective was excluded due to administrative limitations imposed by national health authorities; hence the study depends on official data/information in appropriate references.

Key findings:

- The right to health of the focus population is secured by free ARV treatment, mental health care, counseling facilities, and family planning services which maintain good health. Though ARV is freely available, costs incurred in accessing healthcare such as transportation, clinical and laboratory services, drugs, essential vitamins, and adequate nutrition have put heavy financial burdens on patients. The nature, coverage, quality and quantity of social assistance they have received is at bare minimum level, even though patients need an adequate standard of living and social security and welfare benefits to enjoy the highest possible standards of right to health.
- Respondents' knowledge of patients' rights is satisfactory though there is not much concern about patients' responsibilities in maintaining their own health. Non-communicable disease management, addiction treatments, dietary and life style changes, exercise, treatment adherence, and the spiritual aspects of HIV management are serious concerns for longer life expectancy.
- Patients appreciate the specialised HIV & AIDS treatment staff who are thought to be friendly, polite and non-judgmental. Discriminatory treatments were experienced at other hospitals and specialized institutions where further treatment were required. Strong legal and administrative support systems have to be established at all hospitals for non-discriminatory access to healthcare to protect and promote the human rights of the patients.
- This study highlights the need for government involvement in managing PLWHA networks and drop-in centers through adequate financial support, technical assistance, rules and regulations, and a standard code of conduct to maintain the quality standards expected at these institutions.
- The emerging demographic trends of the Sri Lankan patient population show the growing need for enhancing the areas of pediatric and adolescent HIV, exercise, spiritual development, geriatric medical and disability care, and palliative care. All such improvements must conform to international standards of disease management to reduce the burden on healthcare institutions and individual households.
- The right to organize as interest groups has been ensured, and PLWHA forums are effective in promoting rights based thinking and safeguarding the security & privacy of members in claims of personal rights violations. Health promotion action is still limited to case based, but not cause based advocacy.
- The study indicates the need for reviewing existing program principles and strategies to promote

behavioural changes in the focus population. Rethinking and reviewing of partnership principles with PLWHA forums is essential for meaningful active participation of PLWHA in all related interventions. Capacity improvement of these forums in terms of policy, systems and management is an urgent issue that must be addressed through constant monitoring, progress review and evaluation to minimize long term harmful effects.

Conclusions:

- The right to health should be incorporated into the national constitution for judicial enforcement. Legal aid services must be established to address discrimination issues. Dismissal for wrongful conduct, through favorable policies for legal protection of patients, is a priority to end stigma and discrimination within healthcare settings.
- The existing socio economic and political realities and legal barriers negatively effect prevention interventions. The existing gap between theory and practice cannot be reduced until current punitive laws are changed. Instead of criminalizing behaviours, new prevention techniques and behavioural change modifications are demanded. Lifting of the ban on restrictions to prevention services for populations with high risk behaviours is essential. New prevention techniques like provision of harm reduction services will be feasible only in a barrier free environment. Until such time, the appropriateness of national HIV prevention intervention strategies is rather questionable given the context, factors, and reasons for onward transmission of the virus.
- More focused behavioural research is a dire necessity to understand and address the alarming risk of onward transmission of the virus. Irresponsible sexual conduct cannot be changed without financial and psycho social support which encourages responsible healthy living. Patients must be supported by holistic, tailor made, and appropriate prevention interventions that embrace economic independence, nutritional support, stigma and discrimination, free access of healthcare services, and favourable policy and legal measures which secure their human rights.

Key words: People living with HIV&AIDS (PLWHA), treatment, care and support, stigma,

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