VII Sir Dorabji Tata Symposium

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Panel Discussion

Towards the Social Vaccine – research challenges on the social / determinants of HIV / AIDS

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1. INTRODUCTION

The HIV / AIDS pandemic is one of the greatest humanitarian crisis of our times and also one of the most complex research and programme challenges in public health practice today. While new drugs and vaccines and other ‘magic bullets’ need to be developed, as researchers work on the bio-medical aspects of HIV-AIDS leading into the frontiers of molecular biology, pharmacokinetics and other related areas, there is urgent need for researchers to also study the social determinants of HIV / AIDS and explore the social, economic, political, cultural and other factors that contribute to the evolving socio–epidemiology of HIV / AIDS and affect the health systems response to it. This alternative area of research is not just ‘operations research’ or ‘evaluation and health systems management of public health programmes’, but an area of research that could lead to a deeper understanding of the complexity of the pandemic and the complexity of the socio-medical response required to address this complexity. Without progress in this area of research leading to perhaps a more comprehensive programme that could be entitled a ‘social vaccine’, there is a danger that we may loose the battle against this new health challenge and the loss would represent a failure of research methodology rather than a programme failure in public health. A panel discussion at the VII Sir Dorabji Tata Symposium on March 11, 2006, tried to explore these social determinants – so that discussion, debate, research and response towards a ‘social vaccine’ could be stimulated.

The Panelists on this session discussed this theme in three different ways:

a) Dr. Ravi Narayan identified the larger social determinants of HIV-AIDS that are emerging from health systems and health policy research.

b) Ms. Sanghamitra covered some experiences from North Karnataka focusing on determinants which include both positive and negative experiences of sexuality and sexual behaviour. She also emphasised that responsible sexual behaviour, involves both individuals and communities and that there is evidence that social norm change is not only possible in these areas, but may be one of the most effective ways of halting and reversing the HIV epidemic in India.

c) Prof. Jayashree Ramakrishna, (who unfortunately could not attend the panel) sent a presentation that focussed on stigma and discrimination and the association of this with our notions of sexuality and morality. The presentation also focussed on the relationship between structural factors such as gender and socio-economic class on the ability to manage stigma, drawing upon studies in Bangalore and Pune. It highlighted that the language of scientists and public health specialists often contribute to stigma and changing attitudes of health care providers can go a long way towards mitigating stigma.

d) Dr. Narayan then integrated all the components of actions that emerged from the above reflections on social determinants into the concept of a social vaccine. This consisted of a series of potential programme components. He also made a plea for a greater paradigm shift in medical and health research to take this line of research and public health system development further.
2. SOCIAL DETERMINANTS OF HIV-AIDS (RN)

A review of public health literature on the research and health challenges of HIV-AIDS is increasingly focusing on a large number of social determinants that affect the evolution and spread of the disease as well as affect the access, response and outcome to programmes evolved to meet this health challenge. These include:

1. Poverty and equity
2. Class and caste differentials in society
3. Gender relations and discrimination
4. Access to primary health care
5. Sexuality, sexual behaviour and norms
6. Stigma and discrimination
7. Levels of community awareness and mobilization
8. War and social conflicts
9. The state of development of medical ethics and the concept of patient rights in society.

In addition, the new economic paradigms are leading to changes in health system responses that affect indirectly the spread of the HIV-AIDS epidemic or our ability to respond to it in systemic ways. These include the following:

1. Erosion of public health systems
2. Privatization and commercialization of health care
3. Inadequate occupation health and safety
4. Enhanced migration and displacement due to unplanned or inadequately evaluated development strategies
5. Social aspects of natural and man made disasters
6. Provisions of WTO and TRIPS and its effect on drug policies and availability of essential drugs
7. The continuing debt crisis of national and state governments, and
8. The global macro economic policies and international financial trends affecting national economic policies and health budget.

All these factors have been identified by a People’s Charter on HIV and AIDS that was developed through an active participatory process involving people from various walks of life, including persons living with HIV/AIDS (1).

3. COMPLEXITY OF RESEARCH CHALLENGE (RN)

While the current symposium has been primarily discussing bio-medical and molecular biological challenges of HIV-AIDS treatment and prevention including HIV Virology; tissue pathology; clinical and laboratory monitoring; opportunistic infections including fungal and visceral leishmaniasis; ARV therapy; HIV drug resistance; therapeutic vaccines; preventive HIV vaccines; microbicides and non human primate models – there is urgent need also to study the larger social determinants mentioned above. The research challenges in
HIV/AIDS should ideally include work at both levels so that we understand better the complexity of HIV/AIDS as shown in the diagram below.

4. BEYOND THE VIRUS – NAGGING QUESTIONS ABOUT THE HOST (SI)

As antiretrovirals suddenly brought hope and new life to many, we are hopeful of the advances in Science in new areas and the new research in Microbicides and the AIDS vaccine. Every effort is being made to speed up these advances, and there is a feeling of optimism.

At a time of such hope and expectation, we also need to listen to those nagging voices from the community, which repeatedly ask the following questions:

1. Is a Clinical Vaccine or Microbicides alone the answer to halting or reversing the HIV pandemic?
2. Do we need to go beyond the agency of the virus to look at agency of the host?
3. Is the interaction between the virus and the host merely clinical?

These questions are serious ones. They raise the forgotten issue of human agency and how HIV is more than a medical issue. Its social and behavioural dimensions, which we tend to forget in the excitement of scientific advances in microbicide and vaccine trials, come back to haunt us.

Ethical issues surrounding access, availability, use and misuse of the vaccine still need to be resolved. Women’s groups are hopeful of the microbicide but concerned about the impact of the vaccine. Whether its protection will extend to women? whether it will extend only to consensual acts? or would it encourage co-ercive acts against women? Would gender inequities and gender violence be addressed, or swept under the carpet with the availability of the vaccine or microbicides?
These questions need deliberation. As a society, we are looking at quick fixes. At a recent Psychotherapy Conference in New York, O'Donohue took the audience by storm. He totally lifted them out of their existing paradigm of thinking and questioned the “ever briefer, more technical, symptom-focused, evidence-based, standardized therapies” making ever greater use of psychopharmacological agents. Analysing the phenomena of his astounding appeal, Mary Sykes(2) found that contemporary professionals were struck by the critical areas, that were neglected in the “highly logical” approach, that they had been taking. Respecting the inner agency of the individual, “helping people retrieve what had been lost to them; wakening and bringing home their fundamental wholesomeness.” was the old mantra which had been brought back with an exhilarating sense of personal possibility.

We, in HIV prevention, have fallen into the same rut. We feel that as clinicians, health educators and scientists we can change the behaviour of individuals with drugs, vaccines or didactic health education. Whatever tools for prevention we may use, we need to look at other factors that affect the individual’s ability to use them. For example, issues of gender-power inequities which make women vulnerable have to be addressed, not just provision of means to protect them in a coercive interaction. We need to recognize that HIV transmission is embedded in a context of denial, taboos and power inequalities. Most of the sexual transmission of HIV takes place in privacy, intimacy and secrecy. In this context of secrecy, there is no accountability. It is known that all behaviour change, whether it is the practice of safe sex or taking a vaccine when it is available, is dependent on the responsible behaviour of individuals. Therefore, the issue is about not just advocating responsible behaviour, but ensuring it.

When sexual activity is hidden and there is no discourse around it, responsible behaviour becomes difficult to enforce even through social pressure. What is required then, is to talk about the factors influencing HIV spread such as the lack of open and free discourse on sex and sexuality; and the social, legal, moral and cultural taboos on forms of consensual sexual interactions outside marriage.

We have forgotten the forces that have shaped individuals’ social and sexual behaviour; the family, their peers and their community. If responsible sexual behaviour has to be achieved, these forces have to be harnessed again. Larger social norms have to be addressed, so that behaviour change is sustained and sexual behaviour like social behaviour is held accountable.

Indian society is in transition and study after study quotes the high level of sexual partner change in both rural and urban India.(3,4,5,6,7). Samraksha’s own study of Sexual Networks, Risk and Vulnerability across 5 districts of North Karnataka with Synovate’s Social Research Wing (8), revealed that of the 2500 men interviewed (selected through a random sampling of households), 41% reported having had multiple sexual partners. They were from all walks of life, all occupations and all ages between 18 – 60. People spoke freely but asked for confidentiality, which signified a lack of social sanction. Most were consensual, but coercive acts were also reported. These included both paid and unpaid sexual acts. What was significant was the reason given for having many sexual partners. Topping the list was “I have money” followed by “Anonymity and easy access”

These highlight clearly the gender-power dimension as well as the loss of accountability structures in the anonymity offered by modern living.

In this dismal picture, Samraksha would like to share its experience of a new model of building a social force towards positive and responsible sexuality in the era.
This prevention model works with small geographical units eg a village or a town ward. With a highly intensive focus over a very short time, using the tool of perspective building on HIV prevention and impact reduction, Samraksha was able to achieve some significant results. The methodology has been to initiate community conversations on sex and sexuality, risk and vulnerability and protective mechanisms across every segment of that geographical unit. The strategy and activities have included letting communities question existing norms, explore newer ones, bringing in public discourse on taboo areas, creating cultural and social channels for that discourse, building gender, caste and economic perspectives, letting women examine power relations, risk and vulnerabilities. These were done through a range of interactive and reflective exercises and processes, using culturally appropriate media.

In the last 2 years, 680 villages have undergone a first round of the process. Over 400 villages have undergone a second round of that process. Process indicators are highly encouraging. Just to cite a few,

1. **A greater acceptance of risk and community support for behaviour change to safe sex practices:** seen through increased condom stocking in the community, at public places including Panchayats; increased condom acceptability by sex workers and an overall increased condom uptake
2. **Decreased denial of sexual practices/networks and increased tolerance for them.** This is seen though the changing language of public discourse; a shift from morality laden statements to condoms, education of school children and youth. From sex workers as the cause to personal risk acceptance by men has been a significant shift.
3. **Decreased blaming/shaming and decreased episodes of discrimination against people living with HIV and AIDS** denotes an acceptance of the community of the need to act on these beliefs

**Conclusion**

To conclude, an equal emphasis on social determinants of the epidemic is needed to respond to the epidemic on the social dimensions as well.

**Studies in understanding these determinants is critical,** as the paucity of research done with scientific rigour, leads to a neglect of important issues in planning interventions in the area of HIV and AIDS. If we acknowledge that HIV is a medical problem embedded in a social context, the medical research needs to be contextualised in a body of wider social science research.

Support of action research to initiate and measure interventions is also needed. There are numerous indigenous and culturally diverse responses to HIV/AIDS in India now. In order to measure their efficacy as well as draw out critical features that will lend themselves to be replicated, efforts will have to be made to document and disseminate these diverse and indigenous civil society led preventive responses. This is indeed important if HIV/AIDS research is to be holistic and comprehensive.
5. STIGMA AND DISCRIMINATION AND ITS ASSOCIATION WITH NOTIONS OF SEXUALITY AND MORALITY (JR)

“When the history of AIDS and our time is written, the inextricable links between health and social stigma, discrimination, human rights, and dignity may be recognized as our most important contribution”.

Jonathan Mann

HIV/AIDS Stigma and Human Rights

At one level Stigma and discrimination seems embedded and entrenched in society. It is built on the basic divisions of society that is used to categorise and make sense of social life – eg. Who is good and bad, what is valued, etc.. It rests on the fundamental divisions that we all draw between ‘us’ and ‘them.’ These societal categories are not fixed but change with time, place and situation. All of us are a part of a society and culture, all of us internalise values and morals, and we seldom question these.

Stigma and discrimination have been closely linked to health conditions. In fact, before HIV/AIDS, leprosy was seen as the *sin qua non* of stigma. However, it is with the advent of HIV/AIDS that there has been a refocus on the study of stigma, after the seminal study by Goffman (9) a social interactionist saw stigma as a product of social interaction and a deviant behaviour, it affected the very core of personhood, a person’s identity. Stigma represented a devalued and discredited identity. The pernicious aspect of stigma is that it is not only how others perceive the stigmatised but how the stigmatised perceive themselves. This causes untold anguish and suffering. Discrimination may be seen as ‘enacted’ stigma, where people are treated ‘differently,’

Morality, Sexuality and Gender

In terms of HIV/AIDS we need to look at the stigma of HIV/AIDS in relation to our notions of sexuality, our hesitancy to speak about sex, much less educate youngsters about it, the intimate link between gender and sexuality and differential moral standards. We only have to reflect honestly to recognise the discrepancy between popular rhetoric about ‘Indian” culture (as though there was a monolithic Indian culture) and the reality on the ground as evidenced by STI rates.

The agenda is to impose ‘moral’ standards. Whose moral standards? In India at least it is determined by the ‘middle class’ who draw upon ‘traditional’ Indian culture (which precludes art, dance, literature to which sexuality is central) and a ‘Victorian” legacy.

In the recent past in India and currently in the US and in the programmes funded by the US government, the ABC policy is espoused. Abstinence and faithfulness is propagated and the use of condoms neglected. Of course this might be a reaction to the perception that HIV programmes unduly focused on condoms. However this has adversely affected programmes for young people for whom the first two may not be realistic choices.

Morality and Power

I want to look at how the same stigma plays out in the international arena. It is not only a country’s policies that affect people in that country. The US administration in June 2005 notified U.S. organizations providing HIV/AIDS-related services in other countries that they must sign the pledge to be considered for federal funding opposing prostitution and sex trafficking. This notification conflated prostitution and sex
trafficking. Note the language the term ‘prostitution’ is used instead of sex work. The idea is to name them and shame them.

Many groups doing pioneering groundbreaking work lost their funding. However, on 19 May 2006 U.S. District Judge Emmet Sullivan ruled that a U.S. policy requiring recipients of federal HIV/AIDS service grants to pledge to oppose commercial sex work violates the groups' First Amendment right to free speech and was thus unconstitutional.

Public Health and Stigma

The language of public health can in itself be stigmatising. When twenty five years ago AIDS was recognised and the modes of transmission ascertained the focus at once turned to ‘high risk groups.’ A classic case of us and them. However, in time it was appreciated that it was high risk behaviour and not membership to a group that put one at risk. Still the notion persisted in form or another – ‘targeted interventions’, focus on ‘key groups’ etc. Areas of high prevalence were seen as epicentres, hot spots, these geological metaphors evoking images of disasters – earthquakes, volcanoes exploding, waiting to happen. The people who were infected were referred to in a dehumanising fashion as ‘vectors.’

The consequences of this stigmatising language are many.
1. In India at least it detracts attention from the ‘generalised’ epidemic, HIV infection in the general population – in people who do not belong to ‘high risk groups’ and some who do not even have ‘multiple partners.’

2. It serves to reinforce stereotypes, prejudices and biases that we all have. It cocoons us from the HIV patient as being among the ‘others.’

3. This notion of static groups also detracts attention from the dynamic nature of society. Eg., ‘brothel’ based sex work patterns may be changing, ‘family based,’ occasional sex work may be increasing.

Gender, Social Class and Disclosure

A study conducted in NIMHANS, by Prabha Chandra revealed that poor patients had little control over who learnt of their HIV status. This study was conducted before antiretroviral drugs became available. In contrast, a study conducted in Pune among middle class patients attending a NGO clinic, where antiretrovirals were available, showed they had more control over who they revealed their status to. Stigma management is thus related to access to resources and social class. The following tables show that even among the middle class women there is less control on managing information/stigma. (Table 1, 2, 3).
Table 1

Disclosure of HIV Positive Status to Men (48) and Women (29) by HCP (58) and Lab (19)

<table>
<thead>
<tr>
<th></th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lab</td>
<td>12.5</td>
<td>44.8</td>
</tr>
<tr>
<td>HCP</td>
<td>59.2</td>
<td>87.5</td>
</tr>
</tbody>
</table>

Table 2

Pattern of Disclosure of HIV Status to Men (42) and Women (16) by HCP (58)

<table>
<thead>
<tr>
<th></th>
<th>Patient only</th>
<th>Patient and spouse</th>
<th>Spouse</th>
<th>Natal Family</th>
<th>In-laws</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Series 1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Series 2</td>
<td>0</td>
<td>2</td>
<td>5</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 3

Disclosure of HIV Status by Laboratory Personnel to Men (6) and Women (13)

<table>
<thead>
<tr>
<th></th>
<th>Natal Family</th>
<th>Spouse</th>
<th>Patient and Spouse</th>
<th>Patient only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>25</td>
<td>20</td>
<td>30</td>
<td>30</td>
</tr>
<tr>
<td>Women</td>
<td>30</td>
<td>25</td>
<td>35</td>
<td>35</td>
</tr>
</tbody>
</table>
The National AIDS control policy explicitly states that pre-test and post test counselling is essential and the a competent person should reveal their status.

Can you tell why in the above table 45% women learn about their status from the lab as compared to 13% men? Why do most men learn about their status from health care providers. The difference between the gender in terms of the source of HIV disclosure is statistically significant at p = 0.002

Similarly, in the case of men, their status is revealed to them in private, while this happens in less than ten percent of the women as illustrated by the next table. A third of women learn of their status along with their spouse, or through their natal family, A surprising 25% men learn of their wife’s status before she knows her status. This might also be reflection of the fact that many married women contract infection from their husband, and HIV status may be checked in an antenatal care setting.

Conclusion

From the above discussion and study results we have seen the intricate relationships between social structural factors that affect stigma and discrimination. Thus the strategies that we adopt to mitigate these need to take these factors into consideration and not merely focus on the individual.

6. COMPONENTS OF A PROGRAMME TOWARDS A SOCIAL VACCINE (RN)

Research on social determinants including issues such as poverty and equity, gender relations, sexuality, morality, stigma and other factors will help us understand the HIV/AIDS pandemic better. It will also help us identify programme responses that go beyond just the concept of ARVs and condoms. Many civil society groups and NGOs who are deeply involved in the HIV/AIDS pandemic are beginning to develop many programme responses based on this new understanding. These include:

a) Life skill education for youth and vulnerable groups on health and responsible sexuality - the focus being on building healthy and non exploitative relationships rather than only condom use for safe sex.

b) Local level peer educators and health promoters especially among youth and women to discuss the key messages of health and responsible sexuality and to help people make responsible and informed decisions.

c) Strengthening primary health care access to diagnosis, treatment, counseling and care with focus on women and marginalized sections of the community – who are often unable to access care even though they are most in need due to structural and other blocks in this health care system.

d) Community organisation, self-help groups and village health committees to strengthen local capacities to identify and tackle the problems.

e) Positive people’s networks to demand, empower, enable and monitor programmes responsive to their social, economic, cultural and political situations.

These programmatic shifts are taking place very slowly because of the dominant biomedical projects in international public health collaboration that is focus on highly selectivised, top-down vertical, distribution strategies of ARVs and condoms only. This has to change and this change will come only when researchers begin to shift focus of their research evidence and understanding of the problem.

7. THE NEW PARADIGM SHIFT IN RESEARCH (RN)

There is a Paradigm shift required to enhance research towards a ‘social vaccine’ which will be a much more comprehensive response to the HIV/AIDS problem building actively beyond the present pre-occupation with a bio-medically oriented vaccine / drug response to the epidemic.
The Paradigm shift for Research in HIV / AIDS

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Biomedical Approach</th>
<th>Social / Community Approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus</td>
<td>Individual</td>
<td>Community</td>
</tr>
<tr>
<td>Dimensions</td>
<td>Physical, Pathological</td>
<td>Social, Economic, Political, Cultural and Ecological</td>
</tr>
<tr>
<td>Technology</td>
<td>Drugs / Vaccines</td>
<td>Education, Awareness &amp; Social Mobilization</td>
</tr>
<tr>
<td>Type of service</td>
<td>Providing / Dependence Creating</td>
<td>Enabling / empowering / Autonomy building</td>
</tr>
<tr>
<td>Patient</td>
<td>Passive beneficiary</td>
<td>Active participant</td>
</tr>
<tr>
<td>Research</td>
<td>Molecular biology</td>
<td>Socio epidemiology</td>
</tr>
<tr>
<td></td>
<td>Pharmaco therapeutics</td>
<td>Behavioural sciences / social determinants</td>
</tr>
<tr>
<td></td>
<td>Clinical epidemiology</td>
<td>Social policy and political economy</td>
</tr>
</tbody>
</table>

As shown in the above diagram, this paradigm shift in research focus includes shifts in our attitude to the dimensions of research, to the type of processes to be organized; the type of service and our attitudes to the patients. It involves a focus on the community; a focus on education, awareness building and social mobilization; a focus on programmes that are enabling, empowering and autonomy building and a focus on people as active participants not just passive beneficiaries. Even within the Research agenda, the focus will move towards socio epidemiology focusing on social determinants and behavioural factors and additional research on social policy and political economy of health.

This paradigm shift will also require new partnerships between the medical / laboratory researcher and the public health researcher / activist. The quest for the social vaccine arising out of research activities in this new paradigm is an exciting prospect for the future.

**IS THE RESEARCH COMMUNITY IN OUR COUNTRY READY TO ACCEPT THIS CHALLENGE? IF SO, A SOCIAL VACCINE MAY DEVELOP SOONER THAN WE IMAGINE!!**

References

6. Akhila, Vasan; *Sex books and the Mediation of Masculinities*, [http://www.infochangeindia.org/index.jsp](http://www.infochangeindia.org/index.jsp)


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