CHAPTER IX

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CHAPTER IX

CONCLUSIONS & RECOMMENDATIONS

9.1.1. Care & support of PLWHAs

For sustainable behaviour change to occur, there has to be a belief in future, or at least a reason for hope. This comes about when communities and individuals become involved in the care of those living with HIV. We know that this care has to be with compassion and caring, with rich and valuable human attributes which are at the centre not only of the response to the epidemic but of human development itself. For there to be a future in the face of this terrifying epidemic, the infrastructure required by communities must continue to function. The existing infrastructure must be able to include these new areas too within their ambit in a multi-disciplinary holistic way.

9.1.2. Education & Support for caregivers

Caregivers are fewer in number in HIV field compared to many other areas. However as this is a rapidly advancing field, they cannot be placed behind any training. The current day trainings are to modified with more of person to person and region specific interactions. Proper training delivered by experts and covering areas
of behaviour change, attitudinal modifications and aimed at an improvement in practices might help a lot. The modus operandi of the content and methodology has to be revamped by experts in the field. Action must be taken to cover the burnout likely to occur in care givers too.

9.1.3. Education & Support for families

Families have to start recognizing their very important role as care givers and supporters to the patients. The role of family in modifying the behaviours of the next generation is also very important. The issue of confidentiality at family and community level (difficult to handle) must be addressed on a day to day and contextual basis.

9.1.4. Individual issues in HIV disease

Every individual has a right to dignity, health & life. Public health and interest of the community in the context of HIV epidemic depend upon respect for individual rights and recognition. This requires the empowerment of individuals and communities to protect themselves against HIV and that they must be free from all forms of discrimination. It is the responsibility of each individual, community and nation to live up to this cause through existing
means. Compulsory reporting, compulsory testing of certain population groups, immigrants and laws that compel disclosure of HIV status are all situations which are dangerous in a broader sense. The coercive nature of these directives which often impose criminal sanction for non-compliance, far from encouraging conduct that will reduce the spread of HIV, may actually impede all control efforts.

9.2. Education & Support for community

The important lessons from the first few years of the epidemic are that behavior change to stop the transmission of HIV can and does occur but that needs the support of the community and an enabling and supportive environment. Behaviour change is a process which must essentially involve changes in sexual norms and values, the availability of voluntary and confidential testing services and creation of an environment that encourages the possibility of open and honest discussion of sexuality and even dying.

9.3 Research & Policy Needs: Implications for policy, programming and future research

*With respect to policy development the following general points can be made:*

• Efforts to tackle HIV/AIDS-related stigmatization, discrimination and denial seem doomed to fail in the absence of a supportive legal
framework. It is not enough to spread awareness about HIV/AIDS, its transmission matters or even about legal rights. What is urgently needed is government anti-discrimination policy supported by a law that will ensure the protection of (HIV) positive people's rights. Laws can be enacted which require minimum levels of participation and representation of socially disadvantaged groups in the policy process. A need to harness the symbolism of the law in prospective, protective aspects and which can be instrumental to promote rather than impede the changes necessary to reduce the spread of HIV is the need of the day.

- Even where such laws exist, or where governments make active efforts to combat HIV/AIDS-related discrimination, it is vital to challenge popular myths, stereotypes and judgements that provide the ground upon which HIV/AIDS-related stigma can grow. At the policy level, prevention programmes should foster tolerance and social solidarity using, wherever possible, an approach which is non-judgemental and not based on fear.

- In both employment and health care, discriminatory policy needs to be developed to protect and safeguard the employment and health care rights of people living with HIV/AIDS. Central to this must be
principles of confidentiality and respect for human rights. People with HIV/AIDS should be given adequate information and advice about various lines of treatment and care options. They should be made to understand in clear terms that their future is also in their acts of today and tomorrow.

• Interventions targeting discrimination need to take place concurrent with the establishment of a supportive legal framework that includes generic anti-discrimination laws covering health care, employment, education, housing and social security, as well as effective enforcement mechanisms.

• Other important and complementary activities must include efforts to change attitudes through communication campaigns in the media, education and training.

• Efforts must be made to tackle the forms of felt and enacted stigma that make it difficult for people living with HIV/AIDS to be open about their serostatus. This secrecy causes them to withdraw from social life, and makes it difficult for them to play a full part in prevention and to benefit from care.
With respect to future research, more needs to be learned about:

- The overt and the more hidden and institutionalized forms of HIV/AIDS-related stigmatization, discrimination and denial that exist in different settings and at different stages of the epidemic.
- The determinants of these different kinds of HIV/AIDS-related stigmatization, discrimination and denial, and the circumstances and factors that lead to a reduction in stigmatization and its negative consequences.
- The positive responses to which HIV/AIDS-related stigmatization, discrimination and denial can give rise, the circumstances in which these occur, precipitating and supporting factors, and the key parties involved.
- The price that societies and communities pay for HIV/AIDS-related stigmatization, discrimination and denial, its impact upon family and community, health care systems, labour and productivity.
9.4. The Challenges

There are a number of challenges for communities and governments. The first challenge will be the type of behaviour change and policies adopted and the extent of resources directed to the epidemic in early stages. Choices will affect the number of people infected and hence the number of people who die. Even if all future cases of HIV infection are going to be prevented from today, every five percent of those already infected will develop AIDS and die.

The second challenge will be the extent to which the community response is integrated into and complimented by the govt. response. Affected communities have already begun certain initiatives. They must be given the political and social support. Community leaders, women’s organisations, health professionals, employers, trade unions, religious and political bodies are all players in this community response.

A third challenge will be the extent to which the governments assist the affected, their families and carers and those who survive them to remain an integral part of their communities. It will be essential to create a climate of acceptance and support for the policies.
There is a further critical challenge which occurs at the global level. The free working of the global market tends to increase the disparities between rich and poor nations. The current system of development assistance is the only alternative to this. But if it is able to serve as a social safety net, it will have to be based on principles requiring that aid should be directed to priority concerns.
9.5. Objectives and Assumptions recalled.

The objectives were listed at the beginning of the study as follows

1. The first objective was to map the socio demographic profile of the disease in Kerala. This objective could be satisfied through the systematic study of more than 1500 cases which represent the various types of cases. This is perhaps the largest number studied at any time in our state. As both HIV infected and AIDS cases were included, all stages of the disease could be studied. The clinical features, ways of presentation and survival patterns have been observed. It was observed that this state has a good share of all clinical problems as seen in any part of the world. Even when tuberculosis is getting controlled in all parts of the world, with the advent of HIV epidemic, it has staged a comeback. Tuberculosis happens to be the commonest problem in our state too. The existence of a non hygienic environment paves the way for many infectious diseases in these people. Protecting them from these infections can make their survival better. The number of children infected from their mothers and spouses infected from their monogamous partners has been documented. The increase in the number of women and children becoming infected is also noticed.
2. The second objective was to identify and enlist the problems faced by PLWHAs and their relatives in the hospitals, family, community and workplace. Even though the media had been pouring materials on this aspect, systematic studies were few. Whereas this is an area of focus in many developed countries, the problems faced by PLWHAs are many a time labeled as natural outcomes of their behaviour. We could categorise these problems and identify areas where positive changes are extremely urgent. The identification of a proper way to reveal the HIV status, to discuss the issues with spouse, to inculcate friendship relationships into the betterment of emotional life of PLWHAs is a very urgent step. The issues of confidentiality and unnecessary breaches spoil the morale of PLWHAs and prevent them from accessing health institutions. The instances of health staff acting against the interests of these persons are also documented. The reactions from the community also leave a lot to be desired. There have been instances where the PLWHAs were more comfortable with friends rather than relatives. But in many instances, revelation of the status to a friend has been fraught with breach of confidentiality too.
3. To enlist the forms of stigma and discrimination in our state. This disease affects all categories of humans, barring social, economic and educational barriers. It has however a tendency to concentrate in the lower strata of the society, where the consequences are more gruesome. Thus the lack of power in these categories makes them more vulnerable. Stigma and discrimination are almost always directed against the helpless groups. The rich are privileged here too. Hospitals, family, community, schools and workplace have all been incriminated as palaces of discriminatory behaviour. Many subjects have described painful stories of discrimination even in religious places. Similar incidents have taken place not only in public sector but also in non governmental voluntary sector as well. This has surprised many as these are the institutions where bureaucracy and tradition should have given way to voluntarism and courtesy. Instances where uninfected persons have been discriminated are disgraces to the society. Stigma and discrimination should disappear from current world, as these are the remnants of pre civilisation period and have no place in the educated world of today, especially in a state like Kerala.
4. The next objective was to consolidate the existing response patterns from society. This has been done through the questionnaires and observations in direct interviews, focus group discussions and personal observations and analysis. These responses have been summarized in the chapter on Observation and Case Studies. Each of the case studies depicted a peculiar group and the response that is elicited by a person and his interaction with the surroundings. We could consolidate these responses and compare them across various groups studied. Based on the response, three broad categories evolved. These are ‘negative’ ‘indifferent’ and ‘positive’ responses. These categories are not water tight compartments. The subjects have experienced the sliding responses from families too. Even though no person in this study had been thrown out, many cases have been noted where they have been told that the family can not support them anymore. In many such instances, the household dynamics were already disturbed and the presence of HIV in one member served to further polarize them. Positive responses like remarriage of widows and families taking care of orphans have also been documented.
5. To identify the changes happening, with the introduction of better care. Along with an increase in the number of cases, newer developments are also happening. The world has become smaller on many grounds. Many new drugs and updates on therapy available in the western world are no more monpolies. Indian pharmaceutical companies have shown the way in contesting some of the selfish interests of multinationals. This gave India a lead in introduction of new therapies. Even though our state was a little hesitant to accept these initially, now things are turning for the better. Drugs for OI treatments and prevention are now freely available in many hospitals. Anti retro viral therapy is gradually coming in. This paved the way for a change in attitudes and thought processes even in the minds of professionals. The documented changes in knowledge and attitudes over the short period of this study tells us in certain terms that improvements in care has made life easier for all involved in this epidemic. The issues associated with the initiation of treatment are likely to come out soon. It may then warrant a detailed study about the consequences of rapid introduction of newer drugs and modalities in an unprepared world with lot of pre existing problems.
6. The last objective was to propose remedial measures. This is a need of the day. There are measures to be adopted by the PLWHAs, health care providers, social leaders, community, family and the state at large. The study puts forth these recommendations in clear terms. The implementation these are not easy. But they are mandatory for a progress towards a better tomorrow. The remedial measures should take into consideration the needs of the next generation. These cover broad areas like individual rights, sex and sexuality, care and support, normalization of the patterns as well as legislation. We need a strong political will to make things happen. Some of the remedial measures are short term and many are long term. Many of them can be introduced at smaller levels like family, workplace etc. But the approach has to be holistic and multi dimensional in the case of state. We have to learn from examples, good and bad in the past and from the west and east. The lessons from countries like Thailand can definitely lead us.

Thus all the listed objectives are satisfactorily achieved. It may be recalled that in addition to what we knew earlier about the epidemic at large, we could identify newer forms of human misdeeds and best practices.
The **major assumptions** at the beginning of the study were as follows:

1) **In spite of a very good model of education, literacy & awareness, Kerala's behaviour towards this epidemic is not appropriate. This can be overcome, if proper orientation, training and media orientation can be ensured. With better information transfer and changes in attitudes and practices, it would be possible to make this epidemic decelerate and reduce the deleterious effects on the life of the affected person.**

It has been an irony in the eyes of the world that Kerala has the best in education and perhaps the worst in human relations. What was needed was a thrust in areas like propriety in education, adoption of uniform standards and avoidance of hypocrisy. The availability of a very good interactive media group in Kerala is to be used for the good of the state. Information transfer should be associated with better attitudes and practices. However the thrust has to be on utility orientation. The silent revolution of introduction of footwears in Kerala communities is a classic example of how attitude change can occur without much information transfer. Role modeling may be important too.
2) Absence of treatment was a major obstacle in the social acceptance of the disease and once that barrier is lightened, care and survival of HIV infected persons and attitudes can improve.

This is a major point of thrust in all studies of the modern age. With the availability of health care facilities and providers across the state, the PLWHAs are surviving longer and longer. Particularly when this becomes known to the society at large, people are expected to be behaving a little better too. Even though it is a little too early to justify this assumption, the scene is set for a change. If this becomes just another chronic manageable infection, the outlook is definitely going to change.

3) Responses to HIV infected persons and the survival pattern of HIV infected persons are strongly influenced by the attitudes of health care staff and there are lots of lacunae in this field.

The health care staff belongs to a class in itself. The indifference of this class to suffering and death is well recognised. However HIV diseases offers a fantastic chance for them to improve. Changes have taken place in the infection control scenario. The first and foremost concern for anybody coming to a health facility is survival, but this should not be at the cost of civil rights and liberties. Many subjects in
this study had bitter memories about their place of shelter. There had been many instances where PLWHAs preferred no treatment and death to entering certain institutions. The most feared place for them was the health facility and most were scared about the breaches of confidentiality inside them. Ensuring access to health institutions which act as daunting barriers today is an immediate need. Change in behaviour is talked about much in the case of patients, but a constructive change in the behaviour of HCP is extremely needed.

4) The clinical pattern of the disease can be modified with proper therapy being given at the right time.

Almost all subjects in the study came to the hospital with a desire to live. The mere mention of availability of care changes their outlook. It has been documented that care of infected persons offer them a chance to survive to lead a healthy life. This is possible using the drugs and facilities available in the existing setup. Empowerment and strengthening of the existing machinery is never to be forgotten. The patients taking drugs are almost normal and back to their normal life, rather than being rehabilitated to a new unfamiliar environment.

It can be stated with confidence that major assumptions have been verified as true at the end of the study.
9.6. Conclusions  First, it is important to recognize that HIV/AIDS-related stigmatization, discrimination and denial can appear in a variety of forms, at a variety of levels and in a variety of contexts. Mapping these forms is the first step towards being able to identify their determinants. It may be important theoretically as well as practically to differentiate between individual, family-level, community and institutional determinants.

Second, pre-existing local cultural practices and beliefs are both determinants and legitimators for HIV/AIDS-related stigmatization, discrimination and denial. These beliefs frequently establish categories of person or types of behaviour that are likely to be stigmatized (e.g. sexually “promiscuous” individuals, sex workers, drug users and homosexuals). The advent of HIV/AIDS frequently reinforces these already existing types of stigma, imbuing them with new and potent legitimacy.

Third, there is an important distinction to be made between “felt” and “enacted” stigma. Felt stigma arises from the real or imagined stigmatizing responses of others. It has an important role to play in “policing” the behaviour of people living with HIV/AIDS, causing some to deny their serostatus, others to conceal it, and all to
experience anxiety about telling others and seeking care. The consequences of both felt and enacted stigma undermine efforts to challenge HIV/AIDS-related stigmatization, discrimination and denial. Both prevent people living with HIV/AIDS publicly acknowledging their serostatus and playing their full and proper role in prevention and care.

Fourth, socioeconomic status and relative financial (and productive) security can influence the stigmatizing process. By enabling some families to “conceal” HIV/AIDS-affected members either within the home or in private medical facilities, some individuals are able to avoid being overtly stigmatized. At the same time, however, it may be especially shameful for wealthy individuals and their families to acknowledge being affected. More generally, socioeconomic status and wealth allow people to better manage the flow of information relating to HIV/AIDS and its impact upon family and household members.

Finally, it is clear that there is a strong gender bias in HIV/AIDS-related stigmatization, discrimination and denial. Women and men are not dealt with in the same way when they are infected – or believed to be affected – by HIV/AIDS. There is evidence that
men are more likely to be accepted by family and community. Women, on the other hand, are more likely to be blamed, even when they have been infected by their husbands in what for them have been monogamous relationships. This double standard exacts a terrible toll on women as mothers, as daughters, as care-givers and as people living with HIV/AIDS. HIV/AIDS-related stigma, and the discrimination to which it leads, therefore plays a key role in intensifying gender inequalities.

9.7 Recommendations summarised

Various recommendations have been listed during the discussion above. However they are summarized here

9.7.1 Care and Support for PLWHAs.

i. Provide good counseling centres.

ii. Broaden the scope of counselling in lifestyle issues.

iii. Provide subsidized and quality clinical care and medical advice.

iv. Strengthen existing care facilities in public sector.

v. Build supportive community environment for households.
vi. Provide the families of PLWHAs with opportunities for
group interaction

vii. Strengthen PLWHAs to reveal their status and speak
out. (become positive speakers).

viii. Develop appropriate care for women and children.

ix. Develop gender sensitive care and support programs

x. Strengthen existing NGOs to offer continuum of care.

9.7.2 Issues in Education and awareness.

xi. Design and develop credible and innovative IEC
messages.

xii. Normalise the disease as an infection.

xiii. Promote better understanding of sex and sexuality,
gender issues and norms in PLWHAs and society

xiv. Promote the networking of NGOs

xv. Ensure uniformity and consistency in messages
delivered at various levels.

9.7.3 Research needs

xvi. More of epidemiologic and intervention studies.

xvii. Provide qualitative and participatory, multidisciplinary
research.
xviii. Cross discipline (and cross border) initiatives to study medical and non medical issues

xix. New research to bridge the gaps in knowledge.

9.7.4 Policy and government levels.

xx. Legislation to be clear on the social interactions and social institutions like marriage, divorce, education etc.

xxi. Consultation with experts in the field before actions on any fields.

xxii. Prioritisation at various levels, taking into consideration the socio-economic realities.

9.8. The Ultimate Challenge:

The ultimate challenge rests with all of us. What is needed to cope with this onslaught is a determination from all alike in unison to decide that we will challenge the virus with all available strategies, in a totally holistic approach. We will have to incorporate Gandhian thoughts in this. We have to include culture specific content in all our endeavours. We have to offer the best for our next generation. The role models have to be generated on individual and community levels.
Kerala is definitely in a better position to do all this, with our strong heritage and cultural values. Streamlining is necessary without wasting time. We have to use the best resources in our state and outside to create a safer, better, healthier community tomorrow. Credible and innovative IEC tools are to be developed. Sex and sexuality must be understood in the proper context without fear messages. We have to link the household and community responses. We have to give a personalized face to the epidemic too.

The existing care facilities are to be strengthened. The magnitude and spatial and temporal aspects of the epidemic needs to better analysed. The unfortunate PLWHAs must be able to benefit from the holistic care models with inputs from research.

It is expected that we will need lots of research into many of these areas. The present study is one among them that can fit into the continuum of ongoing qualitative and quantitative and participatory interdisciplinary research.

Our hope lies in the centrality of the will to live, to stay together, to cope and survive at all levels – individual, families, communities, nations and internationally.