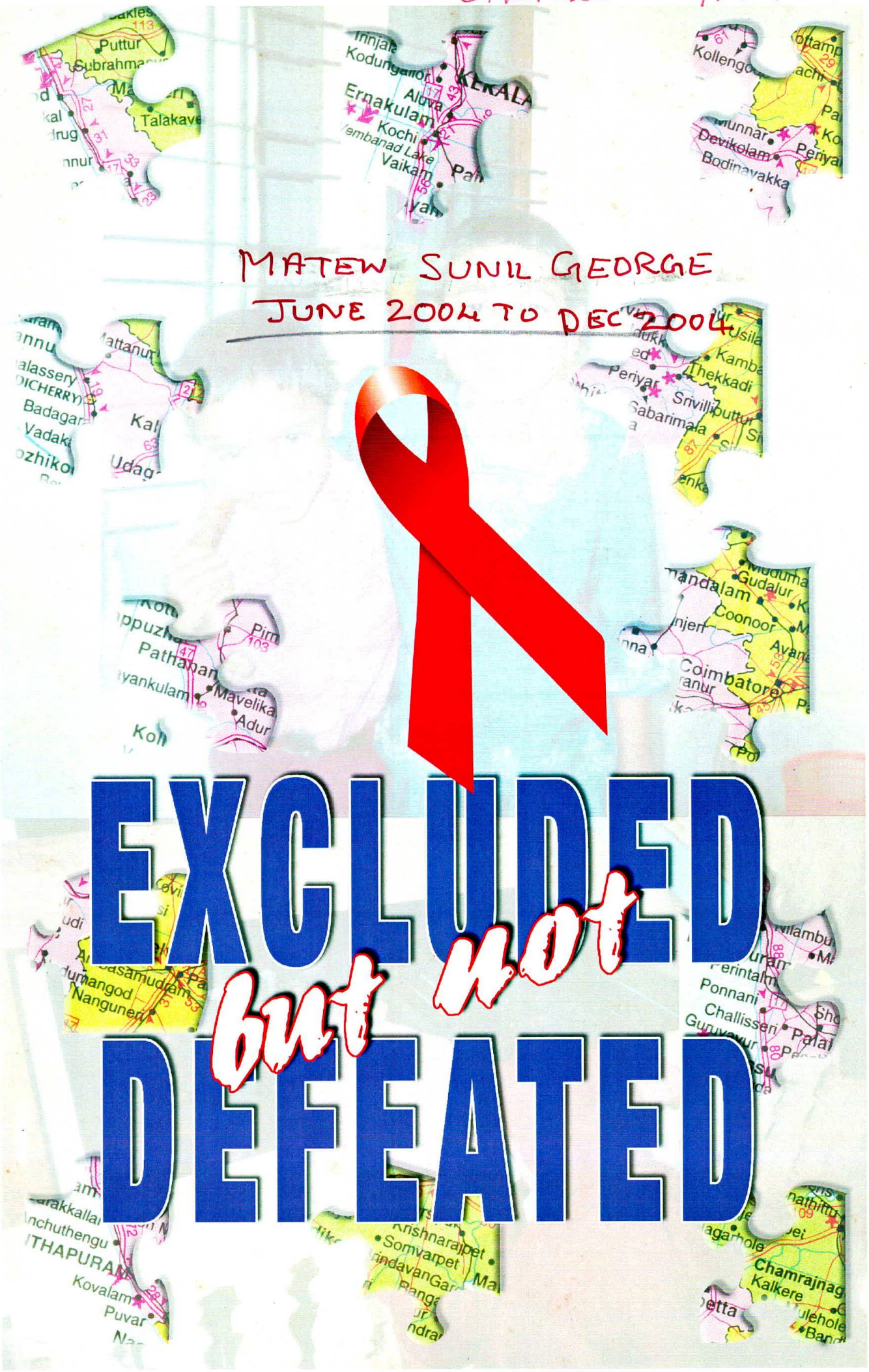
CMLP-2004-H/FR7



Report and Reflections of the Community Health Internship
June 04- Dec 04

M. Sunil George

Mentor
Dr. Ravi Narayan

Community Health Cell
Bangalore
30-12-04

Acknowledgements

In the journey of life we encounter many people and experience many events. Most of them fade away from our memory with the passage of time, but some of them make an indelible impression on our lives. When we look back we find that such encounters have changed our lives for the good. Our life would not be the same without them. The same could be said about the experiences that I have had during this internship. This would not have been possible if not for the help and support that I received from many people. As I compile this report and look back on the past six months, my heart goes out in gratitude to each one of them for what they have been to me.

Drs. Ravi and Thelma Narayan for their presence, support and guidance. If not for Ravi and Thelma much of what I was able to accomplish would have been impossible. The clarity and passion that I have today regarding my role with People Living with HIV and AIDS is in a large measure due to their mentoring.

Dr. C.M. Francis who like a *rishi* is a store house of wisdom and experience. *Thank you Sir* for your guidance, availability, and encouragement.

Dr. B. Ekbal who played a significant role not just during the time I spent in Kerala but also after that. *Thank you Ekbal sir* for your encouragement, the confidence you placed in me, and above all for the simplicity of your life that continues to inspire me.

My field mentors Mr. Augustine Kaunds and Fr. Antony Kunnel OSC. If I have had enriching experiences while at SPAD and Snehadaan it was because both of them took the time and personal interest to help me understand and assimilate what I saw and experienced.

Jose the Personal Care Manager at Snehadaan who continues to inspire and challenge me by the compassion and love that he shows for People Living with HIV and AIDS. I learnt more from him about how to respond to this pandemic than from any textbook or journal.

All the staff at Community Health Cell and the People Health Movement for the homely atmosphere minus the formality and red-tapism that characterizes many of our Indian offices.

Alphonse and Gayatri as well as Lloyd and Tina for being such wonderful friends and giving me time and space in their lives.

Dr. Mathew Abraham who identified and nurtured the spark within me with regard to HIV and AIDS.

Drs. Abraham Thomas, Neeta Rao as well as Rajendran for being wonderful friends and supporting me with their companionship.

The Bangalore Province of the Redemptorists, of which I am a member, for supporting and encouraging me.

The Sir Ratan Tata Trust for financially supporting the Fellowship/Internship programme.

All the positive people who have shared their lives with me and in the process made me more humane and alive.

Mathew Sunil George
Dec 2004, Bangalore

Table of Contents

Section III
Care and Support of People Living with HIV/AIDS

Section IV
Stigma and Discrimination

Section V
Other Exposures

Section VI
Reflections and Conclusion

Section VII
Annexures

SECTION 1

It was the 22nd of July 1978 a young woman in the last stages of her pregnancy had developed labour pains and was being rushed in a taxi from her village to Lissy Hospital in Ernakulam. Being the first child the entire family was praying for the mother as well as the unborn baby. Early the next day the agony that she went through in giving birth to her first born turned to ecstasy as she saw the face of her first born son. It was the 23rd of July 1978-the day I began my journey in this world. Over the past twenty six years this journey of life has taken its own ups and downs. As I look back on my life certain events, decisions and people stand out for the impact that they have had on my life and the direction it has taken-the internship in Community Health being one of them

Journey to the Congregation of the Most Holy Redeemer

One important decision that I took was to join the Redemptorists[1] in the year 1999. All who knew me had never expected me to do such a thing as joining a religious congregation. In fact, a few years before that even I would not have imagined such a thing! Having been very good in academics, my 12th standard results came as a rude shock to me. The mark sheet that I held in my hands kept on telling me that I wasn't going to make it big in life. Missing the *'cut off'* mark for an engineering seat only added to the despair that I was going through. With no other option I entered Loyola College to study for a B. Sc Degree in Physics. The dreams of settling into a well paid job, settling my family's debts, having my own house and car and marrying a pretty girl all seemed to fade away. Listening to lectures that every force has equal and opposite reaction and trying to prove it the laboratory wasn't something I had hoped to do. Soon I joined for a three year Post Graduate Diploma (GNIIT) in Software Management and was hoping to make it big this time around. As my old dreams began to take wings again something unexpected happened.

[1] A Congregation in the Catholic Church that works for the most abandoned poor

Encountering God

An innocent suggestion by a friend that I could attend a retreat being held at Stella Maris College saw me spending three days listening to talks and sermons. At least they were better than those boring lectures in quantum mechanics and nuclear physics! The primary reason why I went for the retreat was to strike the following bargain with God,

'If I cleared the CAT for the IIM's the following year then I would be a dutiful son of his.' After the disappointment of losing out on an Engineering seat this was the least I hoped God would do for me. After all I was preparing for it for almost a year by then; surely he can help me. But the Sunil who entered the campus was not the one who left it at the end of three days. CAT was not my primary concern. I knew for the first time in my life that God was alive and active and that he loved me beyond my wildest imagination. In the months to come, my interest in the CAT would die and I started to dream of other things- things beyond my wildest imagination! I knew for sure that God was alive and active in my life! A realisation that gave me more joy than anything else. This led me to apply to the Congregation of the Most Holy Redeemer in March 1999 and joining the Redemptorists in June 1999.

Exposure to HIV&AIDS

Just before I joined the seminary I heard the story of someone whom I knew well. She came from a well to do background. She was working as a teacher in a very prominent school. Several years back she had an operation and had to undergo blood transfusion. Later she was falling ill quite often and had been diagnosed as HIV+ve. Her cry "Why did this happen to me?" is still fresh in my mind. It is something I will never be able to forget. A few years later I came to know of a relative who had been diagnosed as HIV+ve as well. HIV&AIDS was no longer a distant, other man's problem for me. When I was studying philosophy in Bangalore, I would watch the hearse van go with unfailing regularity to Freedom Foundation that was situated just behind our residence. The cry of that young woman kept coming back to me. Occasional visits to Freedom Foundation gave me a brief glimpse of the isolation to

which People living with HIV&AIDS are condemned! I continued my studies and reached the stage of theology. During this course, all of us had to take a year off in order to immerse ourselves with the struggles of abandoned people. My personal interest in HIV&AIDS and the guidance of Mathew Abraham who was a fellow last year saw me applying for an internship this year. The interviews with Drs. Ravi, Thelma, C.M.Francis and Paresh went on for quite some time and finally I received the news that I had been selected to do an internship with Community Health Cell under the programme supported by Sir Ratan Tata Trust.

Internship Objectives

These objectives were fixed keeping in mind my personal interests as well as the objectives of the internship programme.

1. Understanding the various interventions undertaken by an organisation working in the prevention and awareness promotion of HIV&AIDS.

2. A general idea about the stigma and discrimination against HIV+ve individuals.

3. To ascertain whether HIV&AIDS is as common as it is reported to be.

4. A lived–in-experience that would give me a clear understanding of the HIV pandemic-the disease itself, precautions for caregivers, possible guidelines when dealing with the issue at the individual and community levels, the social issues arising out of the pandemic.

5. Deepening my empathy for those living with HIV&AIDS.

6. Leaving behind my fears and developing a strong conviction to work for people living with HIV&AIDS

Different Faces of HIV&AIDS

The UNAIDS global report on HIV&AIDS for the year 2004 states that in India alone around 5,60,000 confirmed deaths have taken place due to AIDS in the year 2003[2]. This is not counting the innumerable deaths that go unreported. The estimated people living with HIV in India by the end of 2003 according to the same report is around 76,00,000. Most of those who suffer on account of HIV&AIDS, as I have seen in the past six months, are the poor and the most abandoned. While the virus makes no difference between rich or poor, it is the poor who can't afford treatment or care and hence suffer the most from the consequences. During the past six months I have been exposed to various faces of the pandemic.

a. Prevention and Awareness building with Truck Drivers and Sex Workers (SPAD)

b. Care and Support of HIV+ve and AIDS patients (Snehadaan)

c. Stigma and Discrimination against people who are HIV+ve (Kerala)

---

[2] UNAIDS, ***2004 report on the Global AIDS epidemic: 4th Global Report*** (Geneva: UNAIDS, 2004), 23.

SECTION 2

Prevention & Awareness

Society for People's Action for Development (SPAD)

'We are sitting on top of a volcano. How can one keep quiet?'

Ms. Usha Bhasin

Learning Objectives

When I began this exposure my objectives were as follows,

1. Understanding the various interventions undertaken by an organisation working in the prevention and awareness promotion of HIV&AIDS

2. Personal interaction with truckers and Commercial Sex Workers in order to understand more about their lives and the social and economic factors that make them susceptible to HIV.

3. A general idea about the stigma and discrimination against HIV+ve individuals

4. To ascertain whether HIV&AIDS is as common as it is reported to be

5. Gain confidence in interacting with people who are working in this field

Background

The Society for People's Action for development (SPAD) began in 1993 out of the concerns and efforts of a group of young Social Work professionals. Initially in addition to working for truckers, there were programmes for dalit empowerment etc. The present focus of the group is to respond to the problem of HIV&AIDS. In responding to this, they have chosen to focus on those considered traditionally as high-risk groups such as Truckers and Commercial Sex Workers. A new project aimed at Commercial Sex Workers working in slums, known as the MILAN project, has been started recently.

Healthy Highways Project

The following Centres are located in Bangalore

1. Mysore Road (VRL Truck yard)
2. Chamrajpet
3. Kalasipalayam
4. Bhattarahalli

Note:

A fifth centre at Makhli has been taken up recently.

Interventions

The intervention programmes with truckers aim at the following,

1. **Behaviour Change Communication (BCC)**

   In this there are seven steps,

   a. Being unaware of HIV&AIDS.
   b. Becoming aware of HIV&AIDS.
   c. Concern about HIV&AIDS.
   d. Motivation.
   e. Willingness to change risky behaviour.
   f. Trial
   g. Sustained use (of condoms) –no risk behaviour.

2. **Quality STD Treatment**

   This involves the following,

   a. Treatment
   b. Counselling to avoid risky behaviour
   c. Partner treatment
   d. Reduction of multiple partners

3. **Condom Promotion**

   This consists of,

   a. Promotion of condoms during one-one or one-group interactions by the field staff. It consists of a demo of the correct usage of a condom by the staff as well as a re-demo by the individual or members of the group that participated in the interaction.

   b. Social Marketing of Condoms

      This ensures that condoms are freely available, especially, for those who indulge in high-risk behaviour. Partners who are roped in for this include medical shops, petty shops, general stores in the area etc.

4. **Enabling Environment**

   In order to build a positive atmosphere, the following groups are sensitised and involved in the process.

   a. Transport Associations
   b. Local Community
   c. Medical Community
   d. Civic Bodies (e.g. BMP)
   e. Police
   f. Other NGOs (Networking)

Interventions at the various centres in Bangalore

1. **<u>VRL Truck Yard, Mysore Road</u>**

   Situated on the outskirts of Bangalore, Vijayanand Road Lines is the 2nd largest transport corporation after Transport Corporation of India (TCI). The intervention here is well organized and systematic. The two field staff interact with the truckers, cleaners and hamalis who come to this truck yard. The intervention began with SPAD field staff coming in their mobile clinic (van) and conducting awareness programmes for truckers in the area. On seeing the

good work being done by SPAD, the management of VRL decided to allot a permanent place for the staff from SPAD inside their truck yard. This led to the first drop-in-room initiated by SPAD. The average number of truckers in this truck yard ranges from 500-600 per day (this is a rough estimate).

Drop in Room

The drop-in-room is a rest room used by the truckers during their free time. On the walls pictures' explaining what HIV&AIDS is all about, the modes of transmission as well as how HIV&AIDS is not transmitted, symptoms of STDS, correct usage of condoms, flip charts containing messages about safe sex practices are displayed. Addresses of outlets where condoms are available in the surrounding areas as well as names and addresses of referral doctors in the area are also displayed for the benefit of truckers who come here. In addition to this there is a snake and ladder game containing messages about HIV&AIDS, which seems to be popular among truckers.

The two field staff present here interact with the truckers both on a one-one and one-group basis. In addition to the staff from SPAD, there are two peer educators from the staff of VRL as well as a couple of long distance truckers who spread awareness about HIV&AIDS.

Doctors are available for free consultation on weekdays both for general health check ups as well as for STD treatment. VRL pays for the doctors while on one day of the week (Wednesday), the doctor who works for SPAD comes here. This has been stopped of late as part of the phased withdrawal from this centre. The doctors as well as the field staff who have been trained to counsel as well as collect blood samples from the truckers in order to test for the presence of HIV. The blood samples are taken to the testing centre that is operated by SPAD at Chamrajpet. Much emphasis is laid on the confidentiality of the results during the interaction. The drop-in-room is open 24 hours, seven days a week. Truckers who come here to take rest can get information about STIs/HIV&AIDS from the pictures that are displayed on the walls.

Interaction with Truckers

The venue of the interaction can be either in or around the drop in room and sometimes inside the cabin of a truck. The interaction usually begins with the field staff assessing the knowledge levels of truckers, cleaners etc about HIV&AIDS. During this time most of the myths and misconceptions about HIV&AIDS come forth. While there is awareness about the existence and prevalence of HIV&AIDS, most truckers whom I met had several misconceptions about HIV&AIDS. Building on this the field staff proceed to explain what is HIV&AIDS, the modes of transmission, how it is not spread. The interaction then proceeds to a condom demo and re demo. Each trucker is then given a condom flyer containing messages on how to use a condom as well as a condom. The field staff also tries to install amongst the truckers the importance of not discriminating against those who have HIV&AIDS. Leaflets containing messages on HIV&AIDS are also distributed.

From being referred to as an AIDS doctor/staff by the truckers, today there is openness even to discuss issues such as their sex lives, ask for condoms etc.

HIV/STD Cases

A few HIV+ve cases have been detected among some of the truckers but in keeping with the emphasis on confidentiality, they are kept anonymous. While the staff of SPAD give them counselling on how to lead a healthy life with emphasis on personal hygiene and nutritious diet, the extreme mobility of truckers makes it difficult to follow up. Another issue is the near impossibility of getting their partners for testing since most of them are from rural areas and are afraid to reveal their status even to their families for fear of stigma and discrimination. An average of sixty STD cases per month has been detected here.

Socio-economic Status of Truckers

Most of the truckers who make use of this truck yard come from North Karnataka especially the districts of Hubli and Dharwad. Almost all of them come from very poor families and illiteracy is very high among them. Most whom I interacted with had studied up to a certain class and had to discontinue primarily on account of financial reasons. Many took to this profession as cleaners and later on went on to become drivers. When queried as to why they became tuckers most of them replied that it was because of economic reasons. Some of them had agricultural lands but farming had become financially not viable and hence they turned to this profession. There is a very strong stigma attached to being a trucker. Some of the truckers said that being a trucker was almost synonymous to being a person of loose morals, especially in the villages. This not only leads to anger and depression amongst the community but also has practical difficulties for truckers especially in getting married.

In addition to VRL, where most of the work is focussed, the staff also go to meet other truckers in the area. While all the medicines were provided free by the management initially, this has been stopped of late on account of a stir by the hamalis association.

Alcoholism

Many of the truckers take to alcohol as they believe that it helps them to overcome the stress they face due to loneliness and separation from their families in addition to the demands of their profession. A good portion of their earnings are spent in this manner.

Interaction with Peer Educators and Management

In my personal interaction with one of the peer educators I brought up the issue of sustainability of the project once SPAD leaves the centre. To my pleasant surprise, I found that this person was quite confident that they would

be able to run the centre to a large extent. His confidence also stemmed from the fact that he regularly conducts awareness programmes among truckers in the absence of SPAD staff in the evenings, once his work in the office is over. The manager in charge of the truck yard was emphatic about the positive influence of SPAD on the employees of VRL. On the question of restarting distribution of free medicines he was confident that they would begin it once a few internal issues were settled.

2. **Truck Yard, Chamrajpet**

Unlike VRL, this truck yard is open to truckers of various transport corporations operating in and around Chamrajpet. The methodology adopted here, while following the broad outline of that adopted at VRL, is customised to serve the area and needs of the truckers here. Unlike VRL truck yard there is no drop in room here. A private person owns the truck yard here and trucks are charged a fee depending on the time elapsed between entry and exit.

Wall painting

Opposite the offices of the transport corporations, is a wall painting explaining the modes of transmission of HIV&AIDS, how it is not spread, common symptoms of STDs as well as VCTC. The explanation is given both in Kannada and Tamil. Being just opposite many of the transport companies/agents in the area, many of the truckers stop and read the messages and information that is displayed.

Laboratory

In collaboration with the management of St.Mary's Hospital, SPAD has an arrangement by which a portion of their lab had been given to SPAD for testing for HIV. The blood samples collected by the field staff from all the centres in Bangalore are brought to this lab where ELISA and Western Blot tests are done by one of the staff from SPAD.

VCTC is provided at a subsidized rate of Rs. 100/- for truckers. Thos who can't afford this are taken to Victoria Hospital where they are charged Rs. 10/- A counsellor from SPAD is present at the hospital in order to facilitate VCTC.

Interaction with Truckers

This is done at the truck yard, where it is both one – one as well as one-group and in offices and rest rooms of the transport companies/agents, where it is primarily a one -group interaction. The peer educators who have been identified and trained from among the staff of a few companies help to gather as the truckers well as participate in the interactions whenever possible.

Secondary stakeholders such as salesmen, shop owners and hamalis who are close associates of drivers and cleaners are also targeted in order to make the interactions sustained as well as effective.

Weekly Clinic

Unlike VRL truck yard, there is no permanent clinic here at Chamrajpet. A mobile clinic caters to the truckers every Monday.

Socio-economic Status of Truckers

The social and economic status of the trucker community remains the same by and large whether they come from Karnataka, Tamil Nadu or any other part of India. Most of the truckers come from the districts of Dharmapuri and Salem in Tamil Nadu. Even they had similar stories of discrimination to relate as their counterparts in the other centres. *(Refer to issues/case studies)*

Interaction with Peer Educators and the Management

During my personal interaction with peer educators in the absence of SPAD I tried to ascertain the goodwill that SPAD had generated among the community. The two whom I interacted with were very happy about the involvement of SPAD with their community. The field staff enjoy a good

rapport with the employees of the various transport companies. These companies are ready to allow their offices and restrooms to be used for interactions. One of them has even come forward to sponsor VCTC for its employees.

3. SPAD Health Care Centre, Kalasipalayam.

The clinic operates out of a room arranged and sponsored by the 'Moti Nagar Local Lorry Owners Association.' This clinic serves as a nodal point for the staff of the Truckers as well as the CSW and MILAN project. While two of the field staff focus on truckers, the entire field staff of the CSW as well as MILAN project also gather at the clinic. This initiative had similar beginnings as the others as a mobile clinic and has developed into a regular clinic today. In addition to the truckers operating from this area, a large number of Commercial Sex Workers make use of this clinic on account of its location. The truckers come from Tamil Nadu, Karnataka and also from parts of North India

Clinic

The Medical Interventions focus on General health problems as well as STDs. While majority of those who make use of this clinic are CSWs, Hamalis and Truckers, a very small number from the general population also make use of the facility. There is an element of stigma attached among the Muslim community of the area (youth) in coming to this clinic. The primary reason being, fears of being taunted or stigmatised by other members of the community as being of loose character. Most of them belong to the lower economic category. A registration fee of Rs. 5/- is collected per person. General medicines are purchased and sold at the cost price whereas, STD drugs are bought through KSAPS funding.

Interaction with Truckers

This is conducted in the offices of the transport corporations. Peer Educators who have been identified and trained, help in gathering the truckers as well as participate in the interactions. The interactions follow the same outline as described above.

Hamalis

Due to its proximity to the City Vegetable Market, a large number of hamalis are found in this area. Their work consists of loading and unloading the trucks that come to the market. Most of them are economically poor and quite a few HIV+ve cases have been identified in this community.

On seeing the work done by SPAD amongst the truckers, the office bearers of the Hamali Association (the number of members is around 7000), approached SPAD and asked them to help them with a clinic for them. The proposal to build a two storeyed building consisting of a clinic on the ground floor and a lab and counselling centre on the 1st floor was formulated. This was then taken up with the Special Commissioner of the Bangalore Mahanagara Palike. Approval has been granted recently and this is about to be constructed at the site of an abandoned police check post at the entrance of the vegetable market.

The Hamali Association itself is raising the funds for construction of this clinic. They will also be paying for the services of the doctor and the other staff who would be working at this clinic. The entire process was facilitated by SPAD and they are in the process of identifying an institution like Rotary Club or Infosys for financial assistance for constructing the building so that the funds raised by the hamali association could go towards the operational costs of the clinic.

Rapport with Transport Companies

The owner of a transport corporation from Bhattarahalli who happened to be visiting one of his friends in the area decided to accompany the field staff and speak about SPAD to his friends in the area. This was a very positive feature

and as an owner he was able to get a very good response from other owners of transport companies.

4. Truck Yard, Bhattarahalli.

This is located on Old Madras Road, around six kilometres from Krishnarajapuram. The drivers making use of this truck yard are primarily from Andhra Pradesh. The present interventions include a mobile clinic on Tuesdays and Saturdays, drop-in-room on the lines of the one at VRL and using the same methodology for awareness building about HIV&AIDS. Peer educators who are identified interact with the truckers in addition to the staff from SPAD.

An initiative to start a regular clinic was stalled on account of conflict between two truck company owners. This project has been shelved temporarily.

Intervention among College Students

In addition to focusing on truckers, the team is also looking at building awareness among college students in the area. The college identified is Garden City College with whom discussions are on to decide on the best mode of delivering the message about HIV&AIDS. The medium that is currently planned for as of now is a street play for which the staff have been trained. *However the content has to be modified considerably, especially the messages with regard to prevention (moving from safer sex to responsible sex); in order to adapt it to the specific needs of college going youngsters.*

5 Other Interventions

In addition to the above-mentioned interventions, the following interventions take place at regular intervals,

a) Street Plays

This is performed by al the members of the Healthy Highways Project. The street play begins by explaining in a very clear and simple manner the role of the immune system and how it protects us. It then goes on to show what

happens to the immune system once the HIV virus enters the body and the modes of transmission. A message against stigmatising HIV+ve people winds up the street play. At present this street play is performed in Kannada and Tamil at regular intervals at the various truck yards as well as slums where the MILAN project is functioning.

b) Infotainment Project

This project seeks to make use of traditional folk dances art forms in order to convey the messages about HIV&AIDS and the create awareness. At present this project covers the districts of Hassan, Kodagu and Tumkur.

c) Billboards/Hoardings

Efforts are being made to get permission as well as sponsors to erect hoardings billboards displaying messages about HIV&AIDS at various check posts around Bangalore. Permission for a few of the check posts has come through.

In addition to the interventions made at Bangalore, there is a team working in Chitradurga district. Also occasional visits are made to other districts such as Hubli in order to spread awareness about HIV&AIDS. Meetings are held at regular intervals for the Referral Doctors working with SPAD as well as the Social Marketing Outlet Owners

Case Studies/Issues

1. ***"If HIV affects everyone, then why do you focus only on truckers?"***

-Driver from Hubli

This question raised the issue of how we approach a problem. While it is good and at times even necessary to talk of target/high risk groups so that our interventions can be focussed, there is a need to re look at this approach. It is in a sense misleading to talk of high-risk groups with regard to HIV&AIDS because,

- Anyone indulging in high-risk behaviour can contract the virus. Hence from *high risk groups* we need to focus our attention on *high risk behaviours.*

- This indirectly leads to stigma and discrimination of groups' of people who are already marginalized and stigmatised. It also leads to the moral stigma attached to HIV&AIDS.

- The clients of a CSW who belongs to the so-called high-risk group also come from the general population such as students, software professionals etc.

2. ***"In Namakkal district, it s very difficult to get a bride if you are a driver, cleaner or owner of a truck."***

-Truck driver from Tamil Nadu

"My elder sister would not give her daughter to me in marriage since I was a truck driver. In the end I threatened to elope with her only then did she give her daughter in marriage to me.

-Truck driver from North Karnataka

The trucker community has become identified in certain areas with the spread of HIV&AIDS. To be a trucker today is to become synonymous in many areas with HIV. This is turn leads to stigmatisation and discrimination of an already marginalized group. Again it points to the pitfalls in identifying a particular group or community as high-risk.

3. ***"Why are you laughing? Is this a laughing matter they are talking about?"***

-Truck driver from Tamil Nadu

This was the response of a trucker when one of his companions laughed while watching a condom demonstration. This response in a sense imaged the concern that prevails among truckers about HIV and the desire to protect themselves against the disease.

4. ***"I have just begun my life as a cleaner. I took to this job because we have a lot of debts to be paid off and I am the eldest son in my family."***

- Cleaner from Dharmapuri, Tamil Nadu

When I interacted with this young boy who said that he was 15 years old, he was still wearing what looked like a typical school uniform. From my conversation with him it was very clear that he did not take to this profession on account of his own choice. It was due to financial difficulties at home. In few cases truckers and cleaners were formerly engaged in agriculture and had turned to truck driving because agriculture had proved to be an economically unviable option for them.

5. ***"What is the use of someone who has HIV? He is going to die anyway. Why bother about such people?"***

- Driver from North Karnataka

This was a question raised during an interaction. The impression that once a person gets infected with HIV he or she becomes fit for nothing is very common among truckers. Part of this problem could be non-availability of ARVs for those who are infected making them socially and economically useless. Also the initial approach to HIV&AIDS as a fatal (showing the skull and two bones on some ads), non-manageable disease could have contributed to such an impression.

6. "***HIV can be spread through mosquito bites. A doctor in my village told me this. Because of this I kept away from a friend who had HIV."***

- Driver from Hubli

While awareness about the existence of HIV was fairly widespread, most of the drivers were not very sure about the modes of transmission and how HIV is not spread. The above statement in a way images the misconceptions that still exist in the minds of many (probably even doctors) especially in rural areas. Such misconceptions lead to stigma and discrimination as well.

7. "***Before this problem, truckers used to visit Sex Workers regularly. They were also freely available on the Highways. In fact I have seen many truckers line up outside brothels and wait to get their turn with the sex workers. Now no one goes because of fear of catching this HIV."***

- Driver from Salem, Tamil Nadu

Fear of HIV is widespread among the trucker community. This fear could have contributed to the above statement on change in the behaviour of truckers in general. Also almost all the truckers whom I had an opportunity of interacting

with related the story of someone whom they knew who had died due to AIDS. Many of them felt that sharing the same clothes as well as eating from the same plate could transmit the virus. Misconceptions and wrong information led to discrimination against those who were supposed to have HIV.

8. ***"You are talking about HIV. In my village you don't have to have HIV to face discrimination. You just have to be a member of the backward caste."***

-Driver from North Karnataka

This statement was an eye-opener to the harsh reality that discrimination based on the caste system continues to exist quite strongly especially in the rural parts of our country. For me it was a move from knowing this via text books, lectures and discussions to facing this myself.

Learning Points

1. This was the first time I was exposed to the harsh reality of life as experienced by marginalised groups such as Truckers, and to an extent Sex Workers and hamalis

2. The reality of HIV&AIDS which is not a distant pandemic happening in some African Country but very much present in the place where I live.

3. The human side of the life of a trucker or Sex Worker-the pain in their lives, the difficulties they encounter.

4. The need for an integrated all out approach to combat HIV&AIDS if we need to reverse the pandemic.

5. That HIV&AIDS is not a disease/concern of just others (certain groups termed as high risk) but of everyone.

6. The stigma and discrimination surrounding members belonging to the so called high risk groups.

7. The importance of approaching any group with a non-judgmental attitude.

8. The challenges in working with and for those who are marginalised

SWOT Analysis

Strengths

1. Highly Motivated Team
2. Proactive Approach
3. Goodwill among target groups
4. Good Networking

5. Openness and desire for feedback and improvement
6. Withdrawal strategy planned
7. Non-creation of dependency to a great extent
8. Involvement of the local community wherever possible.
9. Involvement of various stakeholders (truckers, owners, officials, etc.)
10. Good team spirit
11. Regular reviews among all the staff
12. Good method of feedback to field staff

Weakness

1. Need to address allied issues that lead to high risk behaviour among target groups (e.g. Alcoholism not only drains truckers financially but also contributes to high risk behaviour)
2. Working at larger issues that contribute to the spread of HIV&AIDS such as structures that create poverty, force a woman to enter prostitution etc.

Opportunities

1. Greater focus on rural areas of Karnataka where myths and misconceptions about HIV&AIDS is widespread and the prevalence of HIV is common.
2. Creative interventions to promote awareness such as card packs which are printed with messages about HIV, carom boards printed with similar messages could be employed with regard to the trucker community.
3. More involvement of the local community (truckers and CSWs) in programme formulation.

Threats

With the openness shown by SPAD and the timeframe of my involvement, I have been unable to identify any major areas of threat.

SECTION 3

Care and Support of People Living with HIV/AIDS

SNEHADAAN

CARE AND SUPPORT CENTRE FOR PEOPLE LIVING WITH HIV&AIDS

"How can we say no to People infected with HIV? Every person infected with HIV is Jesus amongst us and we cannot say no to Jesus"

Mother Teresa

Learning Objectives

1. This lived-in-experience should give me a clear understanding of the HIV pandemic-the disease itself, precautions for caregivers, possible guidelines when dealing with the issue at the individual and community levels, the social issues arising out of the pandemic.
2. Through my personal contact with HIV&AIDS patients, I hope to deepen my empathy for those who are HIV positive.
3. At a personal level, I still have some fears primarily because this is the first time I would be involving myself at this level. I hope that this experience will help me to leave behind these fears and develop a strong conviction to work for people infected with HIV&AIDS.

Background

Snehadaan is a care and support Centre for PLWHA. Snehadaan belongs to Sneha charitable Trust ® which aims to carry on its service and care to the sick, especially the most neglected sick of our society. The organisation that administers Snehadaan is called Camillians. When they began their work they had decided to take care of the most abandoned sick. However as destiny would have it, the first person that they picked up from the streets turned out to be HIV positive himself. The organization has a preferential option to take care of PLWHA and as a result of this Snehadaan was formally started on 14th July 1997. Snehadaan is situated in outskirts of Bangalore. Snehadaan is primarily involved in cares for the HIV infected, palliative are of AIDS patients, value based education on prevention of HIV infection and support and train the family members to care to their loved ones who are sick. It also provides training for Doctors, Nurses and health care workers, nurse trainees, social workers and

medical students on medical management and cases of HIV&AIDS. Snehadaan can care for 52 people men, women and children.

General Objectives of SNEHADAAN

- To provide holistic care to persons to enhance the quality of living
- To provide compassionate care to those who are in the end stage of HIV&AIDS
- To help PLWHA maintain their personal dignity and worth even when they are physically very sick.
- To extend psycho social and spiritual services to PLWHA.
- To facilitate rehabilitative services to PLWHA.
- To prevent the occurrence and spread of HIV&AIDS through Counselling and informational support.
- To train health care professionals in the management of HIV&AIDS.
- To network with other organizations working in the field of HIV&AIDS.

The Approach

From its experience in working with PLWHA, Snehadaan has developed a holistic approach. It realizes that the most effective way of care and support is that of an integrated approach. This means that its work incorporates care and management of PLWHA, prevention training, care and management training, forming peer groups, counseling support, rehabilitative services, exposure for visitors, networking, home visit and coordinating with state agencies and NGOs, both local and national. In all its activities, it strives to promote the active participation of all the stake holders.

The Vision

To be the best, comprehensive and holistic health care providers to People Living with HIV&AIDS.

The Mission

To help people accessible to quality health care.

Target Groups

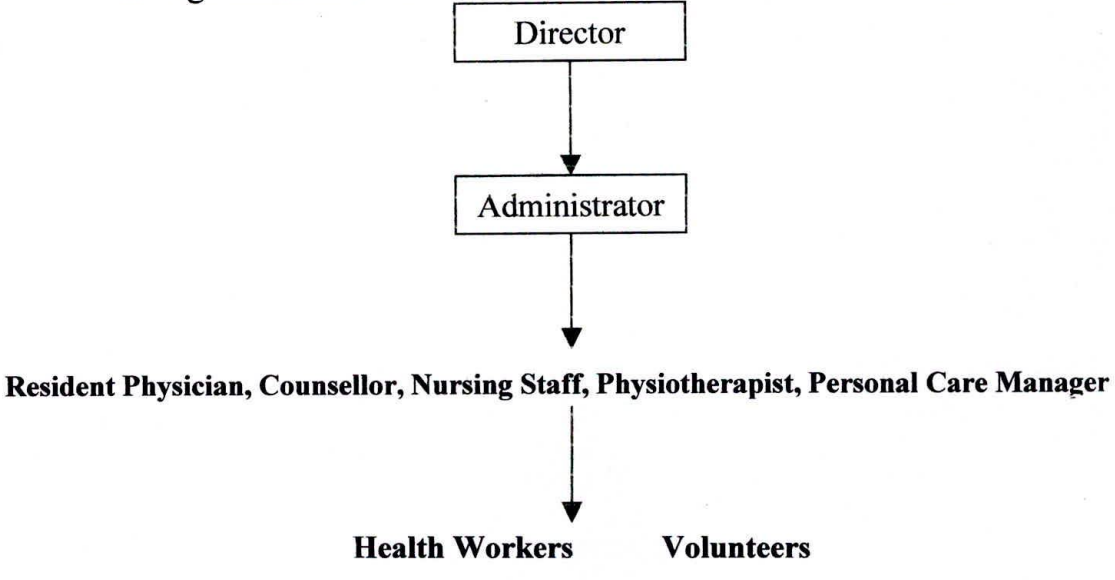
1. People Living with HIV&AIDS who need Medical / Nursing care.
2. People living with HIV&AIDS who require Psycho-spiritual (counselling) care
3. Children and orphans affected with HIV&AIDS
4. People with HIV&AIDS who stay at home with their families.

The Goal

To enhance the dignity of the HIV&AIDS infected persons by enabling them to living a quality life and also caring and supporting the terminally ill persons with HIV&AIDS.

Organisational Structure of Snehadaan

The organisational structure of Snehadaan follows the following pattern



Summary of the Major Activities at Snehadaan

1. **Residential Medical and Nursing care**

   The quality of care of the PLWHA is ensured by Snehadaan with its professional team of Doctors and Nurses. Medical and Nursing management is also offered to by St. Johns Medical College and NIMHANS. The plan of treatment is designed by the Medical and Nursing team in consultation with the Counsellor and Personal Care Manager.

2. **Professional Counseling**

   Counselling to the PLWHA is the integral part of the Snehadaan's care plan. Snehadaan with its one full time counsellor and a Residential Counsellor does individually and group counselling. The unit of Family Counselling is vital to Snehadaan's care and support to PLWHA. Rehabilitative counselling is doing an outstanding service to the persons who are discharged and begun their normal, ordinary life in the society.

3. **Physiotherapy Unit**

   One part time physiotherapist is engaged in the pain management and support of PLWHA. Those PLWHA who suffer due to physical disability; reduced sensation and mobility are given regular physical exercise for the purpose of comfort and pain reduction and management.

4. **Nutritional Support**

   A major area of care is given through adequate nutritional support that is rich with protein and other minerals that enhances the overall health and immune system of the residents. In fact every meal has some food type that is rich in protein. A nutritionist makes assessment on individual patients in consultation with the nurses to provide special diet to certain patients who are in need of them.

5. **Spiritual Support**

Snehadaan is a faith-based organization and integrates spiritual care along with other needs of the residents. They believe that through the support of spiritual resources from their unique faith traditions PLWHA can address many existential issues like meaning of life and death and the questions of suffering. Even though the residents belong to the various faith traditions or no traditions at all, they all seem to tap the spiritual atmosphere that is present at the centre for their benefit. Spiritual support is crucial with the issues of forgiveness, guilt and reconciliation of relationships. They offer great support at the time of death, to help them die with a sense of peace.

6. **Enabling Environment Workshops for PLWHA**

Enabling environment workshops aims at empowering them with information and plan of further actins in their living. In these workshops PLWHA are enabled to meet the challenges of life as positive persons. These workshops provide them with an opportunity to sit and discuss together the possibility of quality of life in their work place.

7. **Education and Learning Support Service**

Snehadaan not only cares and supports PLWHA, but also serves the society by educating and offering training various categories of people. Such as

a. Doctors, Nurses and Paramedics in the care and management of HIV&AIDS.
b. Offering the library facility to students who come here either for research or as part of their block placement assignment.
c. Information Dissemination and Publication

The care and support team in Snehadaan has extended its services by way of information dissemination and also publishing some notes/articles on the issues of HIV&AIDS. This provides the people with the correct

knowledge on the health issues of HIV&AIDS, and also brings about the social acceptance of the PLWHA. There are outreach programmes and sub-units of Snehadaan working in different parts of India. E.g. Snehatheeram in Eranakulam, Kerala, HIV&AIDS information centre, Eluru, A.P.

8. Conscientation and Prevention Campaign

Controlling the further spread of HIV virus has been one of the social concerns of Snehadaan since the beginning. The goals of this prevention training campaigns are;

- To reduce the rate of HIV infection and risk behavior in young people,
- To build positive attitude among the public,
- To promote acceptance,
- Assistance and understanding to peoples with HIV&AIDS.

Realising that more and more young adults are getting infected and innocent women are becoming victims of the HIV, Snehadaan begun its conscietation and prevention campaigns especially in the northern part of Karnataka, in the region of Bijapura, Raichur as well as Kollegala, B.R.Hills, and Bangalore rural Sarjapura Taluk. This is done on a regular basis from time to time.

9. On-line telephone Counselling

Telephone counselling is available to families and people with HIV&AIDS on all days of the week. These people who are located far from the centre, do get this facility on a regular basis. This also forms an important part of the follow up programme of those who have been discharged.

10. Home Based Care

Snehadaan is a day-by-day realizing the need of the home-based care due to the increasing number of the HIV&AIDS cases in and around Bangalore. So

Snehadaan has a unit that looks after home based care for PLWHA who are discharged from the centre. The nurses, social worker and the counsellor visit the homes of PLWHA according to the need of the patient.

11. Network co-ordination with other NGOs and Care centres

Network co-ordination with NGOs and Care Centres is yet another activity conducted here. This mutual sharing of the resources and references is important in strengthening the front against HIV&AIDS. In collaboration seminars, workshops, training programmes, positive persons meets etc are organized.

12. Job Placement for PLWHA

The social work department at Snehadaan looks into the on going economical support of the discharged patients. It tries to find some short-term job placement to PLWHA who are able to work. While working they learn to manage their minimum needs and have access to Snehadaan for their needs at any time.

13. Out Patient Care

Upon diagnosed HIV positive, many are crestfallen and unable to cope up with the mental and emotional trauma. Such persons are taken care of by Snehadaan as out patients. Up on their visit to Snehadaan they are counselled about leading a positive life and given medications for their physical and emotional well being.

14. Advocacy

'***My friend with HIV&AIDS is still my friend.***' This theme is the background for the advocacy work taken up by Snehadaan. The centre deals with the Human rights issues of the HIV&AIDS infected. In its advocacy efforts it takes the concerns of the positive persons to the government bodies and other

state, national and International agencies and organizations. The staff from Snehadaan have also participated in National consultations on the Human rights issues of HIV&AIDS infected persons.

15. Project Management, Monitoring and Evaluation

Documentation is done both Monthly and Yearly. The Annual Evaluation Report contains all the activities of the year.

a. Monitoring and Management

To ensure continuing experience of the operation and management, Snehadaan encourages a collective management system in which all concerned staff members are encouraged and supported to take part in planning, decision making, evaluation, sharing of experiences, and so on. The project co-ordinator helps to co-ordinate and monitors the work of all programmes, so that Snehadaan will be able to provide effective and efficient services to all its target groups. Apart from collective activities on staff development and monitoring, small group discussions under each programme/activity are also promoted to regularly monitor its work

b. Annual Evaluation Meeting

Snehadaan holds an annual evaluation meeting to look at its operations in the past year as well as to plan for the following year. Each programme/department presents the work done in the past year to the floor and the staff members will discuss and analyze the work and its outputs, give recommendations, and so on. The results of this evaluation meeting will be used for improving the work in the coming year. New initiatives may also crop up in this evaluation session. The results are documented as progress reports for donor agencies. In this evaluation, Snehadaan may invite resources persons from outside to help look at its work.

Experiences at Snehadaan

My stay at Snehadaan was an intense period in my life. The fifteen days or more that I spent here was a time of immersion into the lives and struggles of PLWHA. Every day I encountered something different that challenged, pained or inspired me. While I did keep at diary in which I had recorded my experiences in detail I would refrain from actually recording them here for the sake of confidentiality. I would like to look at my experiences as follows

The Most Difficult

This incident happened a few days after I was at Snehadaan. I was part of the counselling team that broke the news to a person who had tested positive for HIV. It was a very difficult and painful thing to do. It took us a very long time to prepare him to accept the news. From confidence to doubt to despair, he was a broken man in a few minutes. His first impulse was, "Why should I live anymore?" The next day I accompanied him for breakfast and while we had breakfast he asked me with tearful eyes if he could ever life a normal life. Whether he will be able to live as before? The whole of that day he was asking me the same thing. I found it very difficult to answer his question. All that he wanted to hear from me was a simple and clear 'yes'. But I just couldn't do it, even when I wanted to.

The Most Human

Anil (name changed) and I became friends during my stay at Snehadaan. The following lines are extracts from my diary

His bright twinkling eyes caught my attention. Playful and noisy, he was such a welcome distraction for me. I was standing by the side of his father who was in the final stages of AIDS. Hardly responding, he was just a bundle of skin and bones-a wasted frame. His wife was trying to make him take his medicines and met with partial success

A little later I met him again in the corridor and waved to him. With curious eyes he observed me. Who is this who calls out to me? A few minutes of persistent

efforts broke the ice and soon we were sitting side by side and chatting about many important things. From his liking for Diary Milk Chocolate, the subjects he studies, to his preference to the Pakistan cricket team and his fear of going to the National park on account of the elephants that are there (some of them have destroyed the huts nearby he says). Suddenly he began to speak about his father. With childlike innocence he told me that his father no longer speaks to him and that he will never get well! I felt uncomfortable talking about death to a small child like him and tried to distract him but he continued. He knows that his father will die very soon. In fact, his uncle died the same way, he says. Childlike innocence I encountered here! At the suggestion of a walk to the gate and back, his face lights up. Soon he is running down the path and enjoying himself. Watching him is enriching me as a person. We decided to spend sometime watching the birds and after having given me a few lessons about their behaviour and food habits (in fact he even tried to demonstrate this for me), he decided to go and meet his mother.

An hour later I was told by one of the inmates that someone was looking for me. I was wondering who it could be, but not for long. From behind a pillar I could see my new found friend Anil smile at me. He enquired if I had taken my food. When I told him that I would be taking food soon, he insisted that I have food with him. He even refused to take food if I did not have food with him. Not knowing what the rules are, I asked him to go back and have food with his mummy. After much cajoling, he relented but only after being assured that I will be taking my food soon. The next day I went out to meet someone. When I returned I was told that Anil had left.

A week had passed since then and I was mopping the floor in the morning when I saw his mother rush in. Tears were streaming down her face and from behind her I could see him peep. Soon we rushed to the auto and lifted his father who was sinking. Within seconds he was on a stretcher, an I.V. was started and attempts were made to revive him. He was gasping for breath and we took turns to be by his side. When I was relieved, I went out and on seeing him said Hi! He was silent; his bright eyes avoiding mine. May be he is upset I said to myself. After a while I went back to take my turn at the ICU. An hour later I realised that his dad was gasping all the more

...it was over. Within a few seconds silence descended and it was over. While transferring the body to the mortuary, I saw Anil playing. When he saw us he asked me "Isn't this my 'daddy' you are taking? I know this is my 'daddy' A little later he was with his mother looking at his father's body.

Later in the afternoon we sat together and chatted a lot. He refused to leave my side, even standing at a distance and watched me wash my clothes. "Anil go back to your mummy. I'll come later" I said. "No" he replied, "You come now or else I'll wait for you." Suddenly I saw him take a small container fill it with water and go. "Where are you going?" "I am going to water the plants in front of your room and then they will give nice, big flowers. Then your room will look very nice when there are flowers in front of it isn't it!"

Most Painful

These were written after I encountered a young woman who had just tested positive

What will I write today? What can I write tday? After seeing her here, what can I write? It is of no use to her and probably for many like her. I saw her early this morning. Oh must be the relative of someone here, I thought. But why is she coming along with the other inmates for her food? No she can't be! My hopes for her were dashed in a few minutes when I came to know that she was positive as well!

Four months ago she was married. When the proposal came, someone suggested that they should get a screen the groom for HIV. It was of course brushed aside. Recently when she went for her first AnteNatal check up it was discovered that she had tested positive for HIV. When an abortion was suggested she decided against it. She goes around in silence, occasionally talking to the other women. At times a rare smile does make an appearance. I find it difficult to even look at her. She seems younger than me, has never indulged in risky behaviour, has been faithful to her spouse, doesn't belong to any of the so called hi-risk groups. She is not the only on here. Another inmate has the same story to relate. In her case her husband passed away a few weeks ago at this very place.

Should premarital testing become mandatory? But when something is made mandatory people always find a way out. Unscrupulous elements will always provide a clean chit for a bribe. What is marriage? If it is a genuine giving of oneself to another in love then there is no problem. No need for any mandatory laws.

This evening I was burning with anger. Why did this happen to them and why is this happening to many such innocents like them? Can't I do something to restore the joy that has been robbed from their lives? My questions came against a huge wall that I was unable to scale. I fell down defeated and disgusted. Then I spoke to Jose late in the evening and in his words I found light,

"We can do absolutely nothing about the past. The only thing is to minimise their suffering and try to make them happy for the rest of their days."

Yes and that is my call, my destiny.

The one that really angered me

Stigma and discrimination has been the lot of anyone who has tested HIV positive. Many of the residents here have been rejected by society and at times even by their families. The following extract is about one such person

I came back in the evening after visiting the office of the Peoples Health Movement and as I passed the ICU on my way to the refectory, I saw that one of the beds was empty! Where was he? Did he get better? Has he been shifted to the ward? Or… I proceeded to the refectory with these thoughts. A little later, the sister who was serving food along with me told me what had happened. He was no more. He had succumbed to cyptoccocal meningitis.

A sad note was what had happened when it was diagnosed that he had cryptoccocal meningitis. The treatment would cost more than Rs. 5000/-. When his brother was asked if he could chip in some money, he came and met him, gave him 500/- and asked him consume poison and die! For the next two days he would tell everyone who cared for him that his brother was right in telling him that he was useless and it was better for him to die than to survive. The temptation for me is to

say, "Oh how could he be so cruel?" But it is just a fraction, a glimpse of the cruelty that society shows to people who are infected with HIV. "***He/she deserves it***" is a common response. A person working as a counsellor one shared with me the following,

> Once I was talking to a religious leader. When he heard about my work with people infected with HIV, this was his response, "If you want to become a Mother Theresa, go and help cancer patients, not these. They deserve it."

Who deserves what? And who am I to pass such a righteous judgment? Who gave me the authority and what is my credibility?

Bringing Dignity to the Dying

I met Jose at the Care and Support Centre where I stayed. The way he respects and takes care of patients who are in their last stages is just out of the ordinary-more divine than human. The condition of some of these patients can be forbidding and difficult to even behold. But for him every person is to be respected no matter what his physical or mental state is. Even when we went to clean and pack the body of the person who had died, the first thing he told me and two of the brothers who had come to assist him was, "Even though this is only a dead body, we need to show utmost respect and care." The same love and care is shown even to those who do not cooperate and rebel. When I asked him about it he told me, "See they are not well, some are not normal. But we are healthy and normal. They can get angry or rebel but we shouldn't. If we also do the same then what is the difference between those who are sick and us?

It has been almost five years since he has been bringing joy and dignity to the last days of many of these abandoned people. Even they are glad to see him come. Those who are in agony will listen to him and allow him to care for them.

An inmate told me,

> "Even my brother would stand outside my room and talk to me, but these brothers touch us, clean us and take care of us so well. We are not related to

them by blood but they take care of us as though we are their own brother and sisters."

I had an opportunity to talk to Mr.Jose about his work, he pointed out to me that the basis for all the work that he is doing was his faith in God. His example is more potent than a thousand well researched and well delivered sermons and seminars. There are many such people in this world caring for the dying and unwanted. Most of them go unnoticed but with their lives of sacrifice they make this world a better place for all of us. They are living saints and heroes!

Sandeep

Sandeep was yet another young friend I came to know when I stayed at Snehadaan. In a span of 15 days we became close friends that it was difficult for me to say bye to him when I left Snehadaan. The following extracts are about him and his presence in my life. The first one was written a few days before I left Snehadaan and the second on the last day

One night towards the end of my stay my little friend Sandeep (name changed) came and wished me "goodnight *anna.*" He is four years old and HIV positive. His parents are also HIV positive. Full of life from dawn to dusk, he is all over the place. We played, chatted, fought and argued all these days. Thanks to him I have been able to rediscover the child within me. As I planted a kiss on his cheek I the realisation that I would be leaving this place in a few days dawned on me. Will I see him again when I come back to Snehadaan later? Will he get to experience the joys and sorrows of childhood like others? How long before his tender body succumbs to a killer that doesn't show any mercy to an innocent child like him who has been infected for no fault of his?

The last day has dawned! How fast these days went by! I spent this day talking to those who had become close to me. In the morning around 11.30 my little friend Sandeep came looking for me. In his tiny hands he was holding a brown envelope. Standing besides me he carefully opened it taking utmost care to reveal the contents

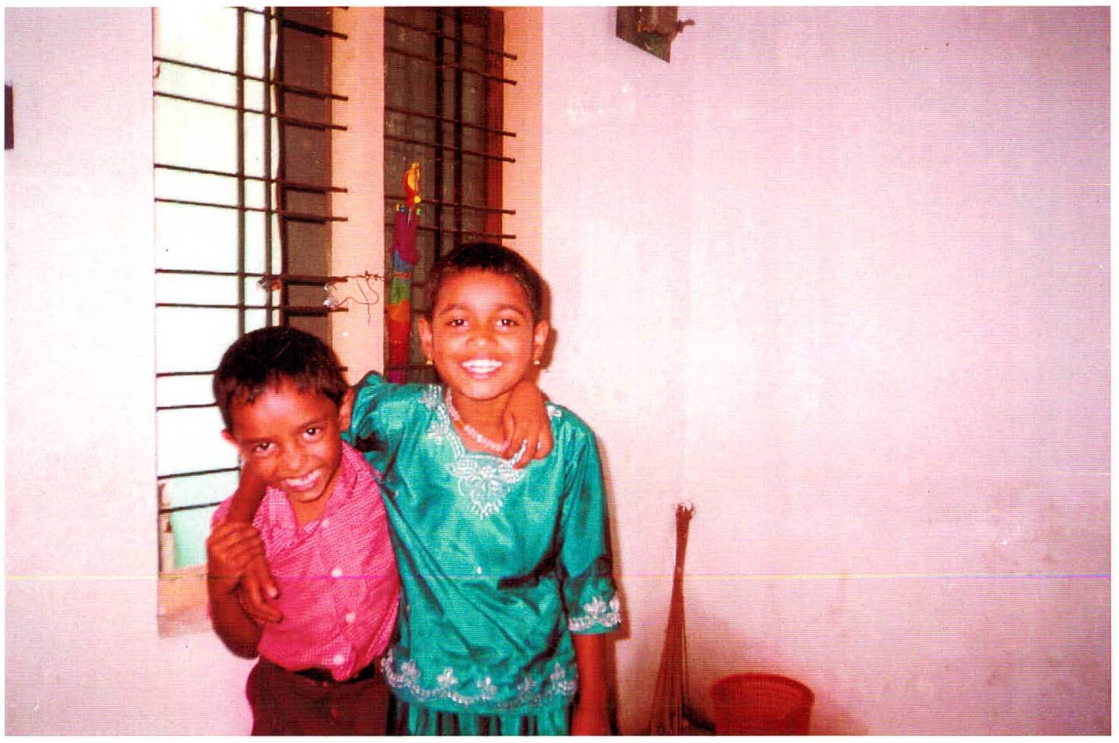
to me alone. They were his photographs. He placed one in my hand and asked me to keep it safely. He then rushed off instructing me to give the envelope to his father when I see him. In his broken Tamil he told me to keep it safe and to look at his picture whenever I think of him! I feel pained to leave Sandeep not knowing whether I would see him again. Knowing that a killer resides within him who is doing his job silently and ruthlessly. Knowing that in a few years may be a painful death awaits him. In these few days he gave me love and friendship. I will surely miss him. The photograph which I now carry reminds me of his innocent looks, the days when I carried him in my arms, when we played together as friends and equals. But a better life awaits him when you will carry him in your arms. And I pray he remembers me to you and whispers a prayer for me in your ears.

Conclusion

The experience at Snehadaan was a very deep and moving one. In a span of two weeks I had experienced suffering and death like never before in my life. I was part of the joys and sorrow of PLWHA like never before. I came to understand the struggles of PLWHA like never before. My involvement in Snehadaan included personal care, cleaning rooms, listening to PLWHA, talking to them, playing with them, preparing the bodies of persons who had succumbed to AIDS for their funeral etc. The most important learning that occurred to me at Snehadaan was that I was cured of my own fears about HIV&AIDS. When I look back Snehadaan was about all a spiritual experience. In the midst of all the suffering I encountered, the silver lining was the commitment and dedication of the staff at Snehadaan who, despite the demanding nature of their work and the stigma they faced continued to bring joy and dignity to the lives of those PLWHA. Recently I went back to Snehadaan and in the corridor I met a resident who was very ill when I was there. He had put on weight and had become healthy enough to take care of himself. When he saw me he gave me a big smile. It is such smiles that give me hope that some day mankind will win this war against HIV&AIDS.

SECTION 4

Stigma & Discrimination



Study on Stigma and Discrimination against children who are HIV positive in Kerala

"Sometimes I have a terrible feeling that I am dying not from the virus, but from being untouchable."

Amanda Heggs, PLWHA

Introduction

The idea of this study came from Dr. B. Ekbal who is the national convenor of the Jan Swasthiya Abhyan as well as the former Vice Chancellor of Kerala University. I had the opportunity to interact with Dr. Ekbal during one of his visits to Community Health Cell. On coming to know that I was working on various aspects related to HIV&AIDS, he asked me whether I would be interested to do a study on stigma and discrimination against children who were positive. The incident which he was referring to was the case of two children in Kerala who were denied education because of their status as HIV positive. I followed this up with him as well as my mentor Dr. Ravi Narayan and conducted this study during the month of October.

HIV+ve children, Kottiyoor

Kottiyoor is a small village situated in the eastern part of Kannur district in Kerala. The nearest railway station is Thallasery which is 64 kms away. Hills, forests and a noisy river that flows through it makes one feel that this is indeed God's Own Country. The annual festival of the Shiva Temple draws pilgrims from all over Kerala. After the festival which last for about twenty-seven days the village settles back into it quiet peaceful routine for another year. However the year 2003 witnessed something different. People from all over Kerala and even the neighboring states started to come to this village, Soon Kottiyoor became well known both in Kerala as well as outside the state. All this was happening even after the festival had come to an end. The reason was far removed from the Shiva temple or popular religiosity. In fact Kottiyoor was now becoming famous on account of the discrimination that was being meted out to two children who had turned out to be HIV positive.

The story of Rema and her children:

Shaji and Rema belong to a lower middle class family. They had three children Athira who is eleven years old, Akshara who is eight years old and Ananthakrishnan who is six years old. Shaji Kumar, the father of Akshara and Anantakrishnan was a motor mechanic who worked in Mumbai and Goa. Shaji returned to his native village Kottiyoor after having fallen ill a few years back. When he was taken to Pariyaram Medical College, Kannur for a check up, it was found out that he was HIV+ve. The doctor who was treating Shaji informed him and Rema his wife about this and asked them whether this should be informed to anyone else. However even before they reached Kottiyoor after being discharged from Pariyaram Medical College, the news that Shaji was HIV+ve spread like wildfire. When they returned people did not ask them directly about this but there was a visible change in their behaviour. Some of them would prevent their children from coming to their house. Soon Shaji began to loose weight (the opportunistic infection in his case was tuberculosis) and people began to ask Rema if it was true that he was HIV+ve. To this Rema replied in the negative and told them that he had T.B. not HIV. Meanwhile Shaji was taken to a hospital at Peravoor where he was treated for opportunistic infections.

Shaji's family then arranged for him to be transferred to Pratyasha Bhavan, Kannur. However this was done without the knowledge or consent of either Shaji or Rema and as a means of reducing the embarrassment that they were facing on account of the social stigma. Only on reaching Pratyasha Bhavan did they realize that they were brought there to be admitted. Since he did not want to stay there and at the same time not quarrel with his relatives, Shaji requested Rema to come back after a week and take him home. Later on when Rema tried to take him home, Shaji's brother and family opposed it saying that the villagers would not allow Shaji to enter Kottiyoor. In spite of this Rema got Shaji discharged from the hospital and took him home as per his wishes. By then Shaji had become quite weak than when he was admitted and Rema was confident that she could take care of him at their home in a better way. Shaji passed away on 9-06-2003. Very few people turned up for his funeral on account of fear of contracting HIV. *It is interesting to note here that Shaji is not the*

first person to die from HIV in Kottiyoor. When the first death occurred the doctor who was involved in treating the person told the family to buy two quintals of powdered (slaked) lime and bury him in that! This was verified with various people in Kottiyoor and found to be true. Seeing and hearing about this created a fear psychosis about HIV&AIDS among the villagers. When Shaji died the local health department workers who handled his body not only sprinkled powdered slaked lime but also warned those who were present not to touch the body or come near it! The question that people ask today is, "If HIV is easily destroyed as you say then why all this fear even among the health department and doctors" After Shaji's death a few institutions notably St.Camillus sisters had offered to take Rema and her children to a Care Home for HIV+ve people in Bangalore as well as at a few other places. However, since Rema desired to stay in Kottiyoor she declined these offers. Rema's contention was she had a house in Kottiyoor and both she and her children were healthy. Hence why should they go and live in a care home? The locals who stood by Rema also contented that if every one who is sick is being taken to Bangalore or another place soon that place would be full of HIV+ve people! They decided to settle this issue at Kottiyoor itself.

On account of the death of her father and the situation at home Akshara did not attend school for sometime. Meanwhile some members from the school management/SNDP unit approached Rema and asked her not to send her to school, till the issue settled down a bit. Meanwhile Ananthakrishnan continued to go to the local anganwadi and as a reaction to his presence the parents pulled out their children from the anganwadi. Soon Ananthakrishnan found himself out of the anganwadi as well!! Athira was required to produce a certificate concerning her HIV status and once that was done she was allowed to continue her studies in the nearby Upper Primary School. Initially there were rumours among the parents of that school that she was also sick but the teachers have been clear that she was HIV-ve and hence the question of her leaving the school doesn't arise.

Having neither a job as well as facing social alienation, Rema and her children (Athira, Akshara and Ananthakrishnan) had to depend on the charity of a few locals

and at times Shaji's family as well. Around this time, Navajyothi a local NGO came to know of the situation and stepped in to help them. They have given Rema employment in their office as a positive speaker and have been involved in the struggle to obtain educational facilities for her children, Akshara and Ananthakrishnan.

With the intention of getting the children back to school, Navajyothi approached the Education Department (offices of the AEO and DEO). An official order was also issued by the District Collector to ensure their readmission to the school. When approached, the school authorities pointed out that they could not readmit Akshara since she was absent for a very long time without giving any proper reason. Taking into account the prevailing social situation at that time, Navajyothi decided not to press the matter further that year. The next year (i.e., 2004), they started to get in touch with the school from February onwards. In the month of March, a written request was sent to the school asking them that a decision be taken with regard to admitting both the children and if this was not possible to specify it (that) in writing. A clear answer was however not coming and the school authorities pointed out that they could reply only after a meeting of the PTA. which would discuss this issue.

With the school refusing to admit Akshara and Anantakrishnan and no proper reply coming forth, Rema decided to go on a strike along with her two HIV+ve children in front of the Secretariat in Thiruvananthapuram. This was resorted to after all local possibilities of reaching an amicable solution were exhausted. The Chief Minister who saw the two kids on a dharna outside the legislature inquired about the issue and requested them to come to his office. He immediately passed an order that the children be admitted back to the school and also gave them a financial assistance of Rs. 25, 000/-. Along with Rema and her children, a Deputy Director of Education Mr.Sashidharan was sent to see that the order was implemented. On reaching Kannur, the Headmistress and the school Manager were summoned by the D.D.E to the collectorate and asked to make the necessary arrangements in order to admit the children by 2.00 pm. At 2.00 pm, the D.D.E, D.E.O., A.E.O. and the children arrived

at the school. The Headmistress was however absent. The manager of the school said that it was not possible to admit the children due to the prevailing social situation. Around 100 parents had meanwhile arrived with the intention of physically preventing the children from entering the school. Meanwhile the D.D.E. decided to wait for the Headmistress who arrived by 4.00 pm. She once again refused to admit the children citing the same reason- opposition from the parents of the other children. She was asked to give this in writing and placed under suspension.

Soon after this incident the manager of the school filed a writ petition against the order of the Chief Minister at the Ernakulam High Court. In this he stated that since children having communicable diseases cannot be admitted in a school and since HIV can be spread through saliva and blood, hence a communicable disease, the children can't be admitted. The judge who quashed the writ petition in his order stated,

> "Ignorance appears to be the root cause for the misplaced apprehensions raised in the writ petition."

He also issued order that awareness classes be conducted in Kottiyoor in order to remedy the situation. Having lost their case in court, the manager, the PTA president as well as the panchayat president approached the CM's office requesting the order be modified. In the meantime the PTA had met and placed nine demands if the children were to be educated at SNLP School. A procession was also organized by the PTA in which the other children studying in the school carried placards saying, "We do not want AIDS children in our school."

Some of the demands were

1. The children should be taught in a separate classroom that is located 500 meters from the school.
2. There should be no interaction whatsoever between Akshara and Ananthakrishnan and the school or the other children studying there.
3. None of the teachers in the school will teach these children.

The request to have a classroom 500 metres away was turned down and instead a separate classroom within the school compound was mooted as a compromise. Since none of the teachers were willing to teach them, the Department of Public Instruction was on the look out for a teacher who would volunteer to teach these children. Mr.Vinod Kumar who was teaching at Mulakunu U.P. School volunteered and was transferred to SNLP School Kottiyoor as a special teacher. Mr. Mohandass one of the locals who has been involved in getting Akshara and Ananthakrishnan back to school and his brother in law decided to send their children to study along with Akshara and Ananthakrishnan. While this was supposed to be a temporary solution leading to complete integration of the children, this is becoming a more or less permanent solution in the eyes of those concerned.

Current Situation

Are the children receiving proper education at SNLP School? The answer is both Yes and No. While a special teacher has been appointed and even other teachers are taking classes for these four children, it is a very artificial arrangement. These children long for the company of the other kids. Even if they get a five-minute break, they go and sit on the staircase overlooking one of the regular classrooms and observe what is happening there. Occasionally a few kids come and talk to them. While a few months back Akshara and Ananthakrishnan were not allowed to even mingle with others, today children have broken this barrier. The great myth that playing together can spread the virus is being broken day after day as some kids play along with Akshara and Ananthakrishnan.

But this is an uneasy calm. Rumours that Akshara and Anathakrishnan are moving around with syringes and blades in order to infect other children are very common in Kottiyoor. A teacher told me that one day a parent came and produced a syringe saying that it was brought by Akshara and given to her child! On investigating the incident this teacher found out that there was no connection between the syringe and either Akshara or Ananthakrishnan! Another child had brought the syringe in

question to school. When I was present, there was an incident of other kids taunting Akshara "HIV, HIV"

Rema's latest CD4 count is 298 whereas Akshara and Ananthu have a CD4 count of 860 and 839 respectively.

Many who are involved in this issue would like other s to believe that everything is fine at Kottiyoor. However this is far from the truth. When I asked Rema about this she told me the following,

"*I do not want to forcibly get my children to sit in a regular class. When the people realize that HIV will not be spread by my kids sitting along their children and ask me to send them to a regular class, only then will I send them. Till then let them study in a special class.*"

Bensy and Benson

The first case of discrimination against children in schools based on their HIV status that came into the limelight was of Bensy and Benson. Two years of struggle that included a hunger strike as well as the intervention of the President of India has got them back into school. However even today their grandfather Mr. Geevarghese John is not sure of what will happen to them after his death. In fact he told me that their lives would also come to a standstill once he passes away. Before I visited their home there were reports that their grandfather is making money by using these two children. It was also reported that he had misused the money that he had received from various quarters since he had an alcohol problem. While it may or may not be true what I was able to understand from the half a day that I spent with them was that he loved these children a lot. A fact confirmed by Bro. Joseph Charuplackal who did a detailed study of the situation in Benson and Bensy's case. When their HIV+ve status was known, Bensy and Benson had to discontinue their studies as the school where they were studying was not willing to let them continue there. At present they are studying in the local government school. From being asked to leave the school to being asked to migrate to some other state by the then local representative, Mr. Geevarghese John and these children have faced several forms of discrimination.

Today with the children becoming celebrities, everyone from political bigwigs, officials and others would like to be photographed with them and promote their cause. Mr John brought an album that was nearly empty and showed it to me. "It was full of photographs of these children and their parents but the people who came took them away and have never returned it." All that remains in that album is a picture of his daughter and her husband. Bensy needs to get admission in the U.P school next year in order to continue her studies. Mr. Geeevarghese John has fears whether they would manage to secure admission for her or if the whole cycle would repeat itself!

A report done by Bro Joseph Charuplackal into this issue throws some interesting parallels between the case of Benson and Bensy and Akshara and Ananthu.

In both their cases over exposure has been a factor that aggravated the problem. According the report by Bro Charuplackal, one Fr.Johnney Thottam who was involved on behalf of these kids went to the school along with media personnel and demanded that the two kids should be taught in the school no matter what the cost. If anyone had any objections they could remove their children from that school. However he also demanded that every child who left the school for this reason should be subjected to a HIV test to know his/her status. How can anyone make such a stupid, insensitive remark? Is it a surprise that the other parents would react as they did when the so-called protectors of the most abandoned hurt their sensitivities in such a crude manner? In one such meeting that was held to find a solution there were foreign media personnel veering the whole issue. Was their presence required? Did they contribute to vitiating the already tense atmosphere? It seems that their presence did more bad than good for Bensy When I went to meet Bensy and Benson, their grandfather told me that one of those who exploited them was this person called Fr.Johnney Thottam. My efforts to contact him personally did not yield any success and hence his opinion on this issue could not be obtained. But when an independent report as well as the caretakers themselves level accusations at him one wonders why Fr.Johnny got involved in this in the first place. Was it for the welfare of the children or his personal gain?

The locals interviewed by Bro Charu have said the following,

"The children were first sent out of a school run by their own community. Why can't they come forward and take care of these children. In that school the parents pay fees for their children's education and when they don't want them there is no problem. This school where they are studying is a govt. school where children of poor people like us study. We have no other option than sending our children to this government school. What about those who sent them away from their first school? They are considered good people, while we have become inhuman!"

Mrs. Deepa Suresh the P.T.A president has said in the report that when they went to meet the District Collectors office to find an amicable solution to the problem, they were told that even if all the other kids left the school it will function for the sake of Bensy and Benson. Such a reply infuriated the other parents who had gone to meet the officials. Further conflicting opinions from doctors abut the facts of HIV had confused the parents. Moreover the report even says that few doctors told the parents that even though they knew the facts about HIV&AIDS, they would never permit their children to sit with HIV+ve children in their schools. If doctors themselves say such a thing then why portray simple people like us as being inhuman? She asks.

Sandhya and her children

Sandhya (name changed) is a young widow about twenty seven years. She stays in a village very close to the border of Kerala and Tamilnadu. I first met Sandhya at the office of an NGO in Thiruvananthapuram. Her husband had passed away three years ago. When it was discovered that they were positive, her husband suggested to her that they commit suicide. However keeping her children in mind, she refused to listen to him. One day he left the house under the pretext of going to meet his friends and later people discovered that he had consumed poison. He died while being rushed to the hospital. While she and her first child Anjali (name changed) are both HIV +ve, the other two children are HIV-ve. According to her while the locals know of her status as a HIV+ve person they are not very sure about it. Anjali was very sick and bedridden when she was very young. Today with Anti Retroviral therapy she is much

better but wants to know when her medicines will stop. Her mouth is full of blisters as a result of oral candidiasis but she longs to go to school and play with her classmates. When Sandhya's husband passed away she had to change the school where Anjali studied on account of opposition from some of her relatives who threatened to withdraw their children if Anjali came to the school. A member of the management even told her that sending Anjali to school would be one of the greatest harms that they would be doing to society! Anjali was sent to another school where the management was very positive and decided to admit her while keeping her status as HIV+ve confidential. Today while Anjali doesn't go to school on account of her poor health she still looks forward to the day when she can attend her classes! Sandhya's case is not an isolated one in her village there are reportedly nine families who were HIV +ve according to the volunteer who accompanied me.

For Discussion

Possible Reasons why Akshara and Ananthakrishnan are still being taught separately as well as certain important issues that comes to light from Kottiyoor.

1. **Division Fall**

   A division fall is a system whereby the posting of a teacher in a school is directly proportional to the number of students studying in the class. If the number of children falls below the prescribed limit then the junior most teacher gets transferred to another school. In the event of admitting Akshara and Ananthakrishnan to a regular class and other parents withdrawing their children out of the school division fall can occur. If this happens a few teaching posts will automatically get abolished in keeping with the strength of the students. In the coming year two posts are falling vacant at SNLP School, Kottiyoor. People who wished to remain anonymous claimed that the current rate for getting appointed as a teacher is around 5 lakhs. Hence if division fall occurs, certain individuals stand to loose.

2. Political Involvement

In a socially progressive society such as Kerala, political parties tend to get involved in almost all local issues. This trend has its advantages as well as disadvantages. The case of Akshara and Ananthakrishnan has received wide spread publicity and yet none of the major political parties have take a keen interest or a firm stand on this issue. Why?

Much after this incident at Kottiyoor, another case was reported at Cheruvathur in Kasargode District. The people there had initially asked for the 'Kottiyoor model'. However in Cheruvathur, it was reported that the cadres of a political party sent out a warning to the school authorities against any form of discrimination! The issue has been resolved completely while at Kottiyoor it still drags on. While there must be other reasons and interventions that resolved the problem the firm stand taken by a party seems to have aided the speedy resolution of the issue.

The present Panchayat president when interviewed said that the situation will resolve by itself with more children joining Akshara and Ananthakrishnan in their class! Such a response from a local political leader betrays the lack of interest in the early resolution of this problem. The involvement of any politicians so far has been with a view of trying to capitalize on this issue and gain as much mileage as possible from it.

Also the SNLP School is run by the SNDP that represents the ezhava community (ironically Akshara and Ananthakrishnan also belong to this community). No political party can afford to displease them without hurting their electoral prospects in Kottiyoor.

3. Teachers

When asked about their involvement, both the Headmistress and other teachers claimed that they neither have any problems in the children studying with others, nor teaching them. If this was the case, why did they refuse to teach

Akshara and Ananthakrishnan on being asked about this one of the teachers said that it was the PTA committee that took the decision and they are not to be held responsible for it! But the truth of the matter remains that in the initial stages, the teachers even refused to teach Akshara and Ananthakrishnan-a fact attested by many including the Panchayat president as well as the PTA president. During this problem the involvement of Kerala State Teachers Association was just to agitate to get the headmistress reappointed.

4. Medical Profession

Are doctors sufficiently trained to deal with HIV&AIDS? If one was to look for an answer to this question based on the events at Kottiyoor it is unfortunately a big **NO**! From asking for two quintals of slaked lime powder for burying a person who died of AIDS, to not being able to give clear answers to people during awareness classes and changing their stand on HIV&AIDS from time to time, doctors have definitely played a part in creating a fear psychosis about HIV in Kottiyoor. Moreover even nurses who have treated Akshara or Ananthakrishnan in the past have used gloves for administering even an injection! One of them even reportedly asked Akshara to swab spirit on Ananthakrishnan before administering an injection! Reports in newspapers about HIV+ve individuals refused treatment by doctors have confirmed the suspicion that HIV is a highly communicable disease. All along the locals asked me one question,

"If doctors who are all knowledgeable treat people like this, then what about us, why blame us?"

Today if there is any unanimity in Kottiyoor about HIV it is regarding the negative role played by the medical profession!

5. No Drug No Cure Campaign

Almost no one would believe me when I told them that medicines were available for treating HIV. Only when I was able to tell the names of a few

Anti Retrovirals, their prices etc did the people show some signs of belief. In the initial stages of the HIV pandemic both the government as well as various agencies involved in its prevention came out with a 'No drug, no cure' campaign. While there may have been reasons and even justifications for such an approach, it has had its own pitfalls.

Today with Anti Retroviral drugs HIV infection can be managed. This information has not yet seeped down to the common man. The question whether there are any medicines available to treat HIV infection was asked not only in Kottiyoor but throughout the length and breadth of Kerala by teachers, nurses and professionals.

Hence a campaign to consientise people that HIV is treatable could be thought of if not by the government at least by voluntary agencies working in the field of health. This would definitely go a long way in creating awareness among the general public as well as enabling HIV+ve individuals to come forward and seek treatment.

6. PTA

In the initial days when I was meeting people it was made out that all the blame lies at the door of the PTA. But as the PTA president Mr. O. Sebastian in his interview pointed out, it is neither a P.A nor a T.A, it is the P.T.A. which means everyone has played a role in the functioning of the PTA-parents, teachers as well as the management. Representatives of the management, parents as well as the teachers have signed the letter containing the demands if the children were to be admitted to SNLP School. In course of our discussions Mr. Sebastian agreed that touching or sitting together does not spread HIV. He even went to the extent of saying that he was willing to take care of Akshara and Ananthakrishnan in his own house! But at the same time he is not willing to allow them to study in a regular classroom! Why? When asked he said,

"Let a thousand HIV+ve children come here and study. But in that name we will not allow even a single innocent child to get infected!"

Is this perceived threat even a remote possibility? Even if it does happen (cuts and bruises) will HIV spread through superficial cuts and bruises?

He claimed that the PTA of a nearby government school had also refused to admit these children into their school. This was later on verified with the headmaster of the concerned school and found to be false. When asked whether his fears would be addressed if he could see for himself other schools where HIV+ve children study along with others, he said no. And finally he said that if others insisted on admitting these children into a regular class, they would withdraw their kids from the school!

Are these the stands of an individual or a few members of the PTA or of the whole general body?

Secondly is Mr. Sebastian alone or are others who want this issue to remain alive using him?

7. Immoral People

Why does HIV attract such levels of social stigma and discrimination? Is it only because of the absence of a complete cure? In case there was no sexual means of transmission of HIV would it acquire a degree of legitimacy?

In India the primary route of HIV transmission has been sexual. Sex and it related issues are considered taboo by many even today. Prostitution is considered to be the world's oldest profession and no society in history has been free from this social evil. When it comes to a public stand, people condemn prostitution while privately patronizing it. The HIV pandemic has exposed this pseudo-morality of our country most clearly. Today if a person gets infected with HIV, he is considered to be a bad person, an immoral person. HIV infection is seen as a just punishment for the sexual misdeeds of those who are infected. Even if an asexual mode infects a person he or she is termed immoral!

The same is true in the case of Akshara and Ananthakrishnan. Their parents were bad people and so the children are suffering from HIV was a common

refrain by many in Kottiyoor. Some even went to the extent of saying that the children should suffer for the sins of their parents!

What is the exact link between sexual morality and HIV? Can anyone say for sure that a person acquired HIV through sexual immorality when it s efficiency in this mode of transmission is said to be 0.1-1.0%. In Shaji's case it is said that years ago he had an accident and had received blood. Could it be possible that the blood, which he had received, was infected? We do not know. Even if a person acquires the infection through sexual immorality, does the physical, mental and emotional suffering that he or she undergoes on account of being HIV+ve justifiable as a punishment for it?

When I was in a care and support centre for HIV+ve people I came across this in a very strong and unfortunate way. Ramu (name changed) was in an advanced stage of AIDS. It was diagnosed that he was suffering from Cryptococcal Meningitis. The treatment being costly his family was approached if they could contribute something to his treatment. His brother gave him some money and told him to buy poison for it and end everything instead of being the pain that he was! A few days later he passed away. The one who took care of him shared that in the last two days before his death he was constantly talking about what his brother had told him! This is not an isolated incident. Many HIV+ve people who are on their death bed long for forgiveness and acceptance from their families and the society but alas it seldom comes and even if it does in many cases too late!

All the major religions of the world, Hinduism, Islam or Christianity talk about compassion, tolerance and forgiveness. Practice of these qualities is what makes one human and divine. But a HIV+ve person can be sure only of scorn and contempt not compassion or forgiveness.

8. Exploiting these children

A common cause for anger among the residents of Kottiyoor has been the so-called exploitation of the HIV+ve status of Akshara and Ananthakrishnan that

has turned them into celebrities! This they claimed was being misused for monetary gains by their family as well as others who are supporting them. It is true that there were a few instances where the children were called to inaugurate establishments, etc. The football match that they inaugurated was a special football match held between HIV+ve people and celebrities, not any football match! One also needs to look at their economic situation before condemning them. After Shaji's death, Rema and her children found it difficult even to have sufficient food. In such a situation any financial assistance even if it meant it involved inaugurating a shop was welcome and indeed necessary. Even today their house is one of the few houses in the locality that does not have electricity! The roof leaks at many places when it rains. The children wear torn clothes at times and have only one set of uniforms! Financial assistance has come from the Chief Minister, a few organizations and Suresh Gopi a cine actor. Those who came forward to help these children made sure that their act of kindness was well reported in the newspapers. This has caused a lot of resentment among the locals, most of who are economically backward, who look at this as an exploitation of the HIV+ve status of Akshara and Ananthakrishnan even by their own mother.

Both Rema and Mr.Johny the grandfather of Bensy and Benson told me that they went public with their stories just because they had no other choice. In both their cases if they had remained silent and continued to suffer they would have been chased away from their villages for sure.

Regarding this Dr. Ajith Kumar of Thrissur Medical College had this to say,

"Those who discriminated against these children are the ones who have made them celebrities. If they were accepted and allowed to continue their lives as before then there would have been no need for a hunger strike or publicity. Hence there is not point in blaming the children or their caregivers if they have now become celebrities."

9. Role of the Media

What has been the role of the media in this incident? It is true that if not for the coverage given by various newspapers and magazines to this issue, Rema and her children would have been driven out of Kottiyoor by now. If this has been a widely discussed issue it is because newspapers have played a proactive role. At the same time various write-ups and editorials written about HIV&AIDS with an intention of educating the people have been contradicting one another. Some of them have also given incorrect information about HIV, its modes of transmission, and precautions to be taken. This has caused confusion among the general public. Hence it is of utmost importance that what is published be verified for it genuineness- both the material as well as the credentials of the one who provides this information.

During my stay in Kerala, I came to know that the Kerala Government had decided to provide free Anti Retroviral Drugs for those who were in need of them. This is in spite of the fact that the funds for this had to be set apart by the state government itself since Kerala is considered to be a low prevalence state. However none of the prominent newspapers or magazines reported on this issue extensively or discussed this very positive step taken by the government. While stories of HIV positive patients being turned away from hospitals made good news items no one was willing to publish any instance of hospitals or physicians who were treating HIV+ve people. If this was done the public would have got a balanced picture. As of now all that remains in their mind is that even doctors are frightened of this disease.

10. Awareness and Prevention Campaigns

Awareness/Prevention campaigns that are conducted can and should definitely learn from the experiences of other nations. But blindly importing a

programme that doesn't take into account the local sensitivities can prove counter productive.

One of the locals claimed that during the previous temple festival at Kottiyoor, there was a poster campaign in order to promote the use of condoms. *The first poster showed a man waving a Fifty rupee note at a woman; the second showed a hundred rupee note, whereas the third showed a five hundred rupee note. All these advances were refused by the woman .However the fourth one had him waving a condom and in the fifth poster both were holding hands and walking!* What is the message that such a poster drive home? One of the locals asked me the following,

"So what everyone one is saying is to use a condom and do what you want. There is no problem as long as you don't get HIV. Is this the way to conduct an awareness campaign? Aren't all these NGOs who are doing these campaigns turning out to be agents of condoms manufacturing companies? At one house that I visited the parents told me that *after attending an awareness class their child came back saying that if we keep a condom in our pocket then we can be safe from HIV!*

Another person said,

"During the last festival here so many condoms were brought and distributed free by a condom manufacturing company. This is a sacred place and people come her to worship in the temple but if you just distribute condoms then you are destroying the sanctity of our village, isn't it?"

Even today people are not clear about the difference between HIV and AIDS. The greatest irony was waiting for me near the office of the State AIDS Control Society. Very close to it was a clinic cum laboratory which had prominently displayed the following on a board outside

AIDS Test
Hiv 1, Hiv2

While one can excuse an ordinary person of not knowing the difference between HIV and AIDS for doctors to display such a board is to add to the confusion and stigma that is already present.

Another issue to take note of is that health groups and health activists in general haven't show the same enthusiasm when it comes to HIV&AIDS. One possible reason could be the fact that many HIV&AIDS programmes have been donor driven. An average health group or a health activist works primarily out of a social concern and responsibility not for monetary benefits. Also a possible reason could be the fact that dealing with an issue like HIV&AIDS involves facing sensitive issues such as sexuality which are even today considered taboo in our country. Further more if HIV&AIDS attracts so much of stigma and discrimination from all sections of society, can health groups and health activists in our country be free from such a discriminatory attitude?

11. Overexposure

When hordes of media personnel officials and important politicians land in a remote village which has never seen such a crowd before it definitely leaves a lasting impression in the minds of the locals for good or bad. Both in Kaithakuzy (Bensy and Benson) as well as Kottiyoor (Akshara and Ananthakrishnan) overexposure has contributed it share to the problem. Dr. Prasanna Kumar of the Kerala State Aids Control Society who verified this fact said the following,

"When so much of attention is given then the people can't but believe that there is something special about this disease. Otherwise why are the children receiving so much of attention?" According to him this was the reason why the Kerala State Aids Control Society did not play a proactive role in the case of Akshara and Ananthakrishnan. During my stay in Kerala I also came across other children who were HIV positive as well as networks that had positive children on their roles. In many of the cases the management of the school

where they were studying was aware of their situation and decided to let the children continue their education in the school itself. This was verified by Dr. Ajit Kumar as well who said that even he was aware of personally aware of many schools where HIV+ve children where studying. While we can question whether this would be a positive thing to do in the long run, we should also take into account the current situation, as well as the need for these children to lead a normal life as far as possible. Today if all the children who are HIV positive were to come under the media glare then there will be more Bensys and Aksharas in Kerala.

12. Educating young people on sexuality

While I was in Kerala the main headlines in all the newspapers were about the Killiroor Sex Scandal and the Ice Cream parlour Sex Scandal. There is a great need for healthy and wholesome education and information on sexuality. If youngsters are not given the right information they will obtain what ever they can from where it is available. I am not suggesting that chastity should take a lower place in the hierarchy of values. But when it is an accepted fact that today youngsters are sexual more active then before and the tendency to experiment is very strong, an abstinence only approach is definitely short sighted. It is not true to say that the more children are informed of sex the more they will engage in sex. A report by the UNAIDS found evidence that demonstrated that sexual health education for children and young people that included promotion of condom use, promoted safer sex practices and did not increase their sexual activity.[3] To continue to ignore sexual education is to ask for trouble.

---

[3] UNAIDS, ***Impact of HIV and Sexual Health Education on the Sexual Behaviour of Young People: A Review Update*** (Geneva: UNAIDS, 1997), 15.

13. Migration

In all the three cases that I have mentioned migration seemed to be the cause for HIV infection. Even other positive people who I had met had a link with some other state where they claimed they have been infected. Traditionally Keralities have migrated to other states and countries in search of better opportunities. Unlike other communities migration her takes place on the levels of individuals; rarely as families. However most of the interventions that are presently on have continued to focus on the 'so called high-risk' groups such as sex workers, truck drivers etc. If inspite of high levels of migration Kerala is still a low prevalence state, it is due to the high literacy levels as well as the health seeking behaviour of malayalees. But to have a laid back attitude to migration as a route of HIV transmission in Kerala is asking for serious trouble in the future. Migration as a route of HIV transmission needs to receive high priority among groups who are working in the filed of HIV&AIDS with regard to Kerala.

Government of Kerala

The government of Kerala has taken a very positive and bold step in providing free Anti Retroviral therapy for those in need in Kerala. This is the second instance, after Brazil, where a government has funded free ARVs for its citizens. In addition to this the state government has also come up with a policy to be implemented in all the schools regarding children and teachers who are HIV+ve which is again a step in the right direction. Kerala is an officially not a high prevalence state for HIV infections and hence it doesn't not receive any central funds for providing free ARVS. Despite of this the government has shown an example worth emulating. AT present this facility is available at the five Medical College Hospitals in Kerala. The idea is to make this facility available in all the Government General Hospitals at a later stage. Free testing of CD4 count is also being done at Thiruvananthapuram Medical College Hospital. This has helped a lot of HIV positive people who would

have otherwise found it almost impossible to undergo these costly tests in order to know their status. However if they are made available in all the Government Hospitals then more and more deserving people would be able to make use of them and thereby benefit from it.

Further more the Education Department in association with the Health Department and the Kerala State AIDS Society has come up with a government policy to be implement in all schools across the state. This policy document speaks not only of children who may be HIV+ve but takes into account possible cases of teachers who are HIV positive as well. The policy document admits that HIV&AIDS can turn out to be a major health problem in Kerala in the future. While the policy document categorically states that separate schools for HIV+ve children is unacceptable both at the national and international levels, especially since these children do not pose any health risk to the other children who study with them. The official order however talks of special facilities for children with HIV, which could eventually lead to discrimination. A health education programme for schools in the state that would include in addition to HIV&AIDS awareness about other blood born diseases such as Hepatitis B, C and the Universal Precautions that are to be taken in order to protect one from such diseases is also in the anvil.

Living Positively with HIV-David Perumayan

Out of the many HIV positive persons I had met David's story and his life touched me deeply,

David was working in Mumbai several years ago. One who would not care for anyone and a tough guy that he was he had never imagined that he would fall prey to the HIV virus. He has been infected for the past sixteen years but is still healthy and yet to start off anti viral therapy. He works as a positive speaker with an NGO. David helps those who are ostracized by their family and friends due to their HIV +ve status. Recently he got married to a HIV+ve widow. After

telling me about his work in helping people who were discriminated because of their HIV status, he summed up his life as follows,

"*I lived one part of my life in darkness and another in light. When I was HIV –ve I wouldn't bother about anybody. I never cared for anything. It was the time when I lived in darkness. But today when I get up in the morning I look into the mirror and tell myself, David see God has given you a day be good and do good for others, you may not get another day for yourself. At night before going to bed I look into the mirror again and say, so David the night has come. You don't know what will happen to night to you hence don't worry about anything. Just go to sleep. Today I am in the light. Now I read my scriptures and it makes so much sense for me. I am much more a human today than when I was HIV-ve* "

As I listened to these words I realized that my eyes were filling up with tears. Here was someone who could have been so negative about being infected with HIV but instead he was not only positive about himself but took it as his life mission to help others who were like him.

Conclusion

Kerala has been known as 'God's Own Country' all over. The levels of basic education, awareness, health seeking behaviour in Kerala are way above the national average. The Kerala Health Model, with its emphasis on decentralization of health services, is looked up to by health groups all over the country as a success story. But with regard to its approach to HIV, Kerala seems to be following the negative patterns of stigma and discrimination that have been noticed elsewhere. If people living with HIV&AIDS, especially children, continue to face stigma and discrimination it will not bring down the rate of incidence in Kerala. On the contrary it will only send the disease underground and make it an unmanageable epidemic. If Kerala does not take a positive and proactive approach in tackling the pandemic, the day is not far when it will find its place among the list of high prevalence states in our country. One of the

points made by the United Nations General Assembly Special Session on HIV&AIDS with regard to children is as follows,

> To ensure non-discrimination and full and equal enjoyment of all human rights through the **promotion of an active and visible policy of de-stigmatization** of children orphaned and made vulnerable by HIV&AIDS.[4]

If this has to be achieved then a responsible and combined effort by all stake holders (Government, NGOs, health activists, the media etc) is required. As the clock ticks more and more people are falling prey to this deadly disease, the lives that have already been lost in Africa and elsewhere, the painful lessons that the world has learnt after letting HIV wipe out whole generations should not go to waste. The HIV virus doesn't know the difference between a child and an adult; it has no compassion or mercy. It remains to be seen tell whether we will turn out to be crueler than the virus itself by our acts of stigma and discrimination. By reaching out to those living with HIV&AIDS each one of us has a chance to disprove it; whether we do so remains to be seen.

Epilogue

A few weeks back the PTA met and it was decided that Akshar and Anthakrishanan would be permitted to study in a regular classroom from the 1st of January 2005. However, the joy of this good news was short lived when we came to know that the management refused to allow the children to study in a regular class. This is inspite of the PTA taken a decision to permit the children to attend a regular class. The question that all of us have to face is, How many Aksharas and Ananthakrishnans do we require before children who are HIV positive are allowed to lead a normal life?

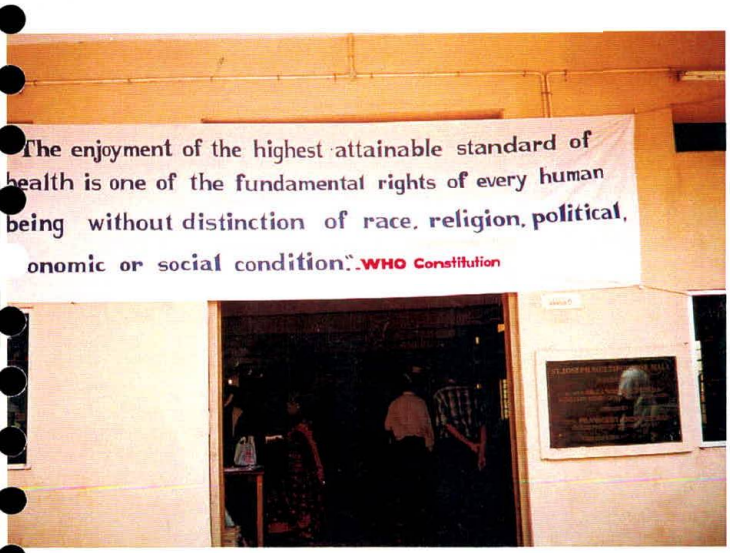
---

[4] Cf. ***UNGASS Declaration of Commitment on HIV&AIDS***, 2001. no. 66.

SECTION 5

Other Exposures

SVYM



Right to Health Care Campaign

SECTION 5

Other Exposures

Asia Pacific Peoples Alliance to Combat HIV & AIDS

Other Exposures during the Internship

1. Visit to H.D.Kote

The visit to H.D.Kote came at the end of our initial orientation at C.H.C. Though primarily with an intention to get an overview of the mission and objectives of the organization being translated into action, we moved to the tribal hamlets; it was more of a guided tour for us, primarily because we did not know much about the project to be able to demand and things were already planned for us! We did not confine our roles to mere visitors but also tried to critically analyse the project in the given context. Though there are active, preventive and promotive interventions the approach is basically medical/curative centric. We drove around 35 kms. to reach Hosahalli to get a feel of their education program

Education – We visited the Vivekananda Tribal Centre for learning. The school provides formal education and a platform for the holistic development of young children from tribal hamlets by encouraging sports. They also provide counselling for further education through Shikshavahini. It provides every possible facility to the children like well-developed library, computer education, well-equipped laboratory and above all committed and motivated teachers and an ambience, which promotes optimum learning. We interacted with primary teacher who teaches Kannnada language and sociology. His personal experience as a teacher was extremely good and he termed it challenging as he feels that the traditional system of teaching does not function successfully in those conditions. He has to follow up with the students and get them back to school and also ensure that they regularly come to school, which is a Herculean task. Over the years the enrolment has increased while the dropouts is minimal.

The following day we visited few haadis (tribal hamlet). The first one was ***Jaagankote haadi*** – We met an old man in his 50s but he appeared to be of late 60s. He had been evicted from the forest where he and his ancestors had been living a self-sustained life for ages. On eviction he was given some land & the government as

rehabilitation for the displaced tribal got a house of cement constructed for him. The forest department now claim that a portion of his land belongs to them and hence filed a case against him. He was subsequently arrested and imprisoned for a month. Dr. Bala got him rescued and is fighting for his cause though the case still remains pending. He got himself operated for cataract and due to the harsh environment in the prison he is unable to see through one eye. The food quality was also abysmally poor, which comprised of only cooked rice. He earns his livelihood through shifting cultivation, making baskets and earns around Rs. 15 per day, while by labouring on some other landlord's land he earns Rs. 30 per day. He occasionally travels to Coorg in search of work in the coffee plantation, which fetches him a better wage. Under the PDS for tribal they are entitled to buy grains at subsidy. Though the stock is generally available it is generally locked and the poor do not have financial accessibility to the available stock. The government-constructed house is made of low quality cement, which leaks, and hence the old man stays in a house made of leaves, wood and grass.

We then went to ***Brahmagiri haadi*** – This is the place from where Dr. Bala began his noble initiative. He practiced in a self-sufficient small place, which is now in dilapidated condition. We met a localite who was very agitated and unhappy with the SVYM system. He complained that well educated people visit the place and when they got used to their services they (SVYM) shifted out without a minimal consideration of what people would face who were now used to the services. We conversed with few teenage pregnant women and discovered that they both were less than 15yrs. and had to perform all the household chores, carry water around three to four times a day from ½ km. distance and as they have no toilet facility they have to defecate behind the bushes in the forest before dawn. The only intervention aimed at women like them were Iron and Folic acid tablets which they had to collect from the health centre while visiting for ANC. We spoke to a dai and discovered that almost 50% of the deliveries were home deliveries and there was no training imparted to these dais.

Gandantur – We met Jannakkamma a 35 yr. Unmarried women suffering from breast cancer from the past eight months. She did not reveal about her condition to anyone and only two months prior to our visit a health worker discovered this. The health worker spent her money to take her to Kenchanahalli hospital where she was admitted for two days. The gynecologist examined her and administered some symptomatic treatment. She discharged her stating that it is in its terminal stage and is incurable. It is a pitiable sight – Jannakkamma is unable to work or eat and is in agony, she does not even know what she is suffering from, thinking that it is just a wound she is hoping it to get cured. She hasn't even been taught of how to dress the wound, which is worsening day by day. As she is a non tribal the hospital is unwilling to provide her free service.

Learning from the experience –

- There is strong *gender discrimination.* The wages paid to women is par below that paid to men. Women are paid around Rs. 25 while men Rs. 35 to 40 for a day's labour. The clear difference in the nature of work both at home and in the field is also and evidence to this. SVYM hasn't tried to tackle this issue despite of several years of active intervention.
- *Equity* – More facilities are provided to the tribal by the organization, which might not reach all the needy. Thus people like Jannakkamma are denied treatment for being a non-tribal. On the other hand government hasn't been sensitive to the poor conditions of the people, the houses constructed by the government are in such a condition that the tribal don't prefer to live in them.
- *Schools* are functional but the syllabus that the children study take them away from their own reality and leave them half way by providing them education only up to higher secondary. Beyond that they are only counselled with no substantial help being extended to the poor. The bus pass to the far located college is Rs. 500 for a year (which is almost similar to the charges in city), which the tribal are unable to bear. 80% of the population consume tobacco and alcohol to combat with their stress.

From just being good doctors those in the SVYM have moved to education and other developmental activities. It was, despite the top down approach that we felt could be re looked, an excellent example of how people who are committed can bring about a change in the lives of the poor and the marginalized.

2. Involvement in the Public Hearing on the Right to Health Care at Bangalore as well as the Southern Regional Hearing at Chennai

My involvement in the Public Hearing both at Bangalore as well as in Chennai was restricted due to fact that I had to be hospitalised due to a road accident. The little involvment that I had was in preparing the case study on Mental Health for Basic Needs, India. What struck me the most at both places was the enthusiasm and courage of the poor and marginalsed who came forward to share their stories. This was inspite of being told that there would be no monetary compensation or for that matter even redressal was not the primary motive of the entire exercise! It was an excellent example of how both the Government as well as the Non-Governmental Sectors could cooperate in order to serve the marginalised sections of our country.

3. CMAI Conference at Pune

Date: **27th to 28th November, 2004.**

Venue: **U.B.S. Seminary, Bibewadi, Pune**

The annual meeting of the Christian Medical Association of India (CMAI) was also an occasion to coomemorate ten years of CACSAN, i.e., the Network of Christian Agencies to Combat Substance Abuse. The two-day seminar had presentations from various experts in the field of addiction and substance abuse. It also had presentations on HIV&AIDS and the role of religion. The presentation that impressed me the most was the one by Evangeline Booth Hospital. It was a refreshing change to see a HIV&AIDS presentation made without solely relying on PowerPoint presentations

and other latests gadgets. The health workers from Evangeline Booth Hospital performed a roleplay about their activities. The presentation that followed described in a brief and lucid manner the activites of the hospital in involving the community to respond to HIV&AIDS. Some of the creative initiatives that were presented were,

- Child counselling that seeks to help children understand and come to terms with the HIV positive ststus of their parents.
- Mapping of Comuntiy Concerns about HIV&AIDS by the communtiy itself
- Involving neighbours (Shared Confidfentiality)
- Orphan Visitation

The most encouraging example that they gave from their experience was about a family that had come to know of the HIV positive status of their inlaws after the engagement was over. In spite of it, the boy's family went ahead and got him married to the girl. This despite her father being HIV positive- a far cry from what we usually hear about people who are HIV positive!

4. APPACHA meet on HIV&AIDS and Governance New Delhi

Date: 2nd and 3rd December 2004
Venue: Jamia Hamdard University, New Delhi

Asia Pacific Peoples Alliance to Combat HIV&AIDS (APPACHA) is an initiative to forge an alliance that is as wide as possible n the fight against HIV&AIDS. The conference included representatives of Positive People's networks, governments and lawmakers, health activists, youth and student movements, trade unions, journalists, doctors, faith based organisations, sexual minorities, sex workers, funding agencies etc. This initiative supported by Action Aid was unique in bringing together people from varied interests and walks of life. As John Samuel the director of Action Aid Asia put it, "We need an alliance as broad as possible in order to triumph in our efforts against HIV&AIDS." In the two days of deliberations the various stakeholders

who had assembled had the opportunity to discus debate and take concrete steps to make this alliance a reality.

During my internship I have had to opportunity to live and work with PLWHA, activists and field workers, doctors and various professionals as well as representatives of various funding agencies. Can all of us work together as a team? Can peoples from such varied backgrounds come together to join hands in the fight against HIV&AIDS? From my experience I feel that it is possible and necessary. A healthy mix of activism and professionalism is better than the two extremes. And again both activists and professionals would do well to listen to what PLWHA have to tell us-after all the issue concerns them the most. APPACHA I feel is a move in that direction and would be a great contribution in the global fight against HIV&AIDS if this becomes a concrete reality.

Reflections and Conclusion

1. HIV and Health

Is HIV a physiological problem alone? Will a biomedical solution or a wonder drug solve the issues and problems that have risen in the wake of the pandemic? I am afraid the answer is no! HIV&AIDS is more about life and its complexities than just a tricky virus that has devastated mankind for more than two decades! A question that I have encountered and have been asked quite often is "How come with all the efforts that are on, the billions of dollars that are being pumped into HIV&AIDS the number of new infections shows no signs of abating? There can be many answers to this question depending on how one looks at the pandemic. A biomedical researcher would put it to the lack of a cure, a religious fanatic could point out that it is the wrath of God come upon mankind. As a health activist I look at the human person as a confluence of the mind, body and the spirit. HIV&AIDS has implications in all three areas and unless we address all these areas a complete solution will continue to evade us. The issues raised by this pandemic concern certain basic questions concerning mankind itself. Human sexuality, which is life giving and blood that has traditionally been a symbol of life in several cultures have become roadways to death. These are questions that concern everyone and hence to arrive at a holistic solution to this problem, it is only proper that everyone is involved in finding a solution. HIV&AIDS is not something that concerns a few doctors or NGOs or PLWHA or funding agencies. The moment we realize and move in that direction we will be closer to a wholesome answer to the pandemic. We may find a bio-medical cure in the coming years but we need to address the underlying issues that the pandemic has raised. Issues such as poverty that forces many young women into the sex trade, pharmaceutical companies that place profits above saving lives, drug cartels that play with the lives of millions and above all the culture of materialism that states that anything can be bought for a price. As long as we continue to look at HIV as a separate disease, the Human Immunodeficiency virus will continue to have the last laugh at us!

2. Alma Ata and our response to HIV&AIDS

- **'Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity'**

(cf. Alma Ata Declaration)

While the landmark declaration that health is holistic and not just the presence or absence of any disease is a favourite quote of many a health activist, we continue to be heavily in favour of a biomedical approach. This approach afflicts many community health activists including myself. Today HIV&AIDS is not curable in the physiological aspect but what about the physical, mental and social aspects? I am not trying to play light with a serious issue as HIV&AIDS but from my experiences with PLWHA I have come to the conclusion that approaching HIV&AIDS from these angles is more effective than just a bio-medical approach or just demanding access for treatment. We don't require any wonder drug to assure a person with HIV&AIDS that we still love him/her, it only requires a little compassion and concern on our part to treat PLWHA as normal human persons who share the same dignity as others. Even if a person has acquired the infection through socially unaccepted means, does our condemnation of such persons constitute a humane response? Do two wrongs make a right? The problem is that living values such as love and compassion especially when we think the other person doesn't deserve it is far more challenging than discovering a cure for the pandemic! Herein lies the challenge for all of us. Just like any crisis HIV&AIDS offers tremendous opportunities for mankind to redeem itself. It is precisely this reason why I feel HIV&AIDS is everyone's concern. You just can't claim to be a health activist and turn a blind eye to issues concerning HIV&AIDS. We may not be actively involved in the fight against HIV&AIDS, but the issues raised by this pandemic unlike others involve basic questions about how we view and live our lives.

3. Looking to the future...with Hope

As I come to the end of this report, it is with a sense of joy and fulfilment that I look back on the last six months. This time of involvement on various issues related to HIV&AIDS has altered the course that the journey of my life was taking. HIV&AIDS and PLWHA have become an inseparable part of my life. After a few months of being an intern, my friends and collegues used to jokingly refer to me as *'HIV Sunil'*. These six months have helped me to commit my life to PLWHA and other issues related to the pandemic. Where I will be or what will be my exact role I do not know. But one thing that I am sure of is that I can make a difference for the better. I end this report with a favourite story from Rabindranath Tagore that embodies both my identity as a religious as well as my commitment to work on HIV&AIDS

'Upagupta the disciple of Buddha lay asleep on the dust by city wall of Mathura. Lamps were all out, doors were all shut, and stars were all hidden by the murky sky of August. Whose feet were those tinkling with anklets, touching his breast of a sudden? He woke up startled, and the light from a woman's lamp struck his forgiving eyes. It was the dancing girl, starred with jewels, clouded with a pal blue mantle, drunk with the wine of her youth. She lowered her lamp and saw the young face, austerely beautiful. Forgive me, young ascetic, said the woman: graciously come to my house. The dusty earth is not a fit bed for you. The ascetic answered, Woman go on your way; when the time is ripe I will come to you. Suddenly the black night showed its teeth in a flash of lightning. The storm growled from the corner of the sky and the woman trembled in fear. The branches of the wayside trees were arching with blossom. Gay notes of the flute came floating in the warm spring from afar. The citizens had gone to the woods, to the festival of flowers. From the mid-sky gazed the full moon on the shadows of the silent town. The young ascetic was walking in the lonely street, while overhead the love sick koels urged from the mango branches their sleepless plaint. Upagupta passed through the city gates, and stood at the base of the rampart. What woman lay in the shadow of the wall at his feet, struck with the black pestilence, her body spotted with sores, hurriedly driven away from the town? The ascetic sat by her side, taking her head in her knees, and moistened her lips with

water and smeared her body with balm. Who are you, merciful one? Asked the woman. The time, at last, has come to visit you, and I am here, replied the young ascetic.'[5]

[5] Rabindranath Tagore, ***Fruit Gathering*** (London: Macmillan and Co, 1951), 50-52.

Bibliography

Tagore, Rabindranath, ***Fruit Gathering*** (London: Macmillan and Co, 1951)

UNAIDS, ***2004 report on the Global AIDS epidemic: 4th Global Report***. (Geneva: UNAIDS, 2004)

UNAIDS, ***Impact of HIV and Sexual Health Education on the Sexual Behaviour of Young People: A Review Update*** (Geneva: UNAIDS, 1997)

UNGASS Declaration of Commitment on HIV&AIDS, 2001.

Annexure 1

Akshara's letter to the Chief Minster of Kerala

(Translated from the original in Malayalam)

From
Akshara Shaji Kumar
Kottenchira House,
Kottiyoor P.O.
Kannur District,
Kerala

To
Shri A.K. Antony
Chief Minister of Kerala

Sir,
I place this place in front of you for myself and my brother Ananthakrishnan. I am eight years old whereas my brother is five years old. On account of AIDS we have been thrown out of our school and anganwadi respectively. I was the first rank holder in my class last year. In between this my father who was in Mumbai several years ago was diagnosed as an AIDS patient. Daddy died soon after. Later when my mummy Rema was tested she was also found to be having AIDS. Later we were sent for HIV testing and both I and my brother were found to be HIV positive. This news came in the papers as well. With this I and my brother have become like captives. My mother has started to work with an NGO called Navajyothi located at Iritty from September 2003. We are surviving on the money that she gets from this place. We don't have any other source of income or anyone to turn to for help. If my mother goes to work which is 30 kms away, we have to remain within our house alone because of the exclusion we are facing from our relatives as well as the locals.
On account of the opposition of the locals and the school and anganwadi authorities, we have not studied anything this year. We are denied entry into the school and anganwadi. My name has been struck off from the rolls. My brother Ananthakrishnan has been expelled from the 8th anganwadi in Kottiyoor ward no 6. We have been denied admission into other schools and anganwadis as well. We want to study. Even if not a lot at least something general things in addition to being able read and write. We are healthy... We won't have any problems soon. The people came to know that we are infected from the reports in the newspapers and magazines. We had given petitions to the Kottiyoor Panchayat president as well as the Kannur District Collector. Even after trying to find a solution for several months, our problem remains unresolved. There has been no way for continuing our studies and all discussions have come to a standstill. Now what can we do? You must arrange for us to continue our studies. Even if we go to school or if anyone comes home we will remain aloof without touching anyone. Please open this closed world in which we find ourselves today. We heard that this is possible

legally. We need that. We make this plea so that we will get justice and be able to come out of this darkness and also the wall of our house to which we are presently confined. Since the efforts at the local and district level have failed we request you to take other measures. We hope you will take immediate action on this petition.

Signed by

Akshara S. Kumar

Annexure 2

Translation of the official govt order

HIV/AIDS Policy Statement (Guidelines)

1. The main purpose of this policy statement is to reduce the social, economic and developmental ill effects of HIV/AIDS in the educational field, while staying with the present educational system. The suggestion of starting special schools is not accepted at the national and international levels and there is no possibility of children who are infected with the virus spreading the disease to other children by the studying along with them. Hence there is no justification in keeping these children away from others.

2. In accordance with international standards, the Indian Constitution assures the right to primary education, the right against discrimination, the right to life, the right to ownership and the right to acquire knowledge, secure environment and circumstances conducive to the child's inclinations. Under these circumstances, there is a need for a State Policy Statement regarding these rights. In the light of HIV/AIDS becoming an important healthy problem in many states in India, it is likely to become an important health problem in Kerala also in the future.

3. HIV infected children and others remain healthy for long periods, even after the being infected with the virus. HIV infection does not spread to other children in the school through ordinary life styles. It is not correct to deny the right to education and through it the right to a meaningful life by discrimination against those virus affected children.

4. There is not possibility of HIV spreading to another person through ordinary social interactions in the educational establishments. It is also against the national AIDS policy to do compulsory testing for HIV. Students, teachers and other employees should not be denied entry into educational institutions in the name of HIV/AIDS infection

5. To prevent HIV infection and to remove fear about this disease and the unwarranted stigma and discrimination towards those affected by HIV, specific knowledge must be given to students, teachers and other employees. Practical information must be part of the syllabus. In addition, to prevent diseases transmitted through blood like hepatitis B, C, HIV, knowledge about them must be given and universal precautions must be taken to prevent the spread from one person to another.

Government of Kerala

Abstract

Order is released accepting the policy statement (guidelines) regarding HIV/AIDS produced by the Health/Family Welfare Department with respect to the students, teachers and other employees of educational institutions.

Health Family Welfare (FW) Department

S.V.(Ord) no. 3114/2003/HFWD Date, Thiruvananthapuram, 30.10.2003

Order

1. I order to overcome the difficulties encountered in the society by HIV infected persons, especially children, and to create suitable awareness among the people and others regarding this, the policy statement (guidelines) prepared for the purpose is accepted and is produced as appendix in this order.

2. In order to have special arrangements for the education of HIV positive children, an educational project should be prepared by the educational department.

By order of the Governor

Sd S.K. Bharatbhushan

Secretary

Copy to

Project Director, NACO

Project Director, Kerala State AIDS Control Society

Director, Public Relations

Director, Public Instruction

Director, Panchayat/Local Self Government

File/Office Copy

By Order

Section Officer

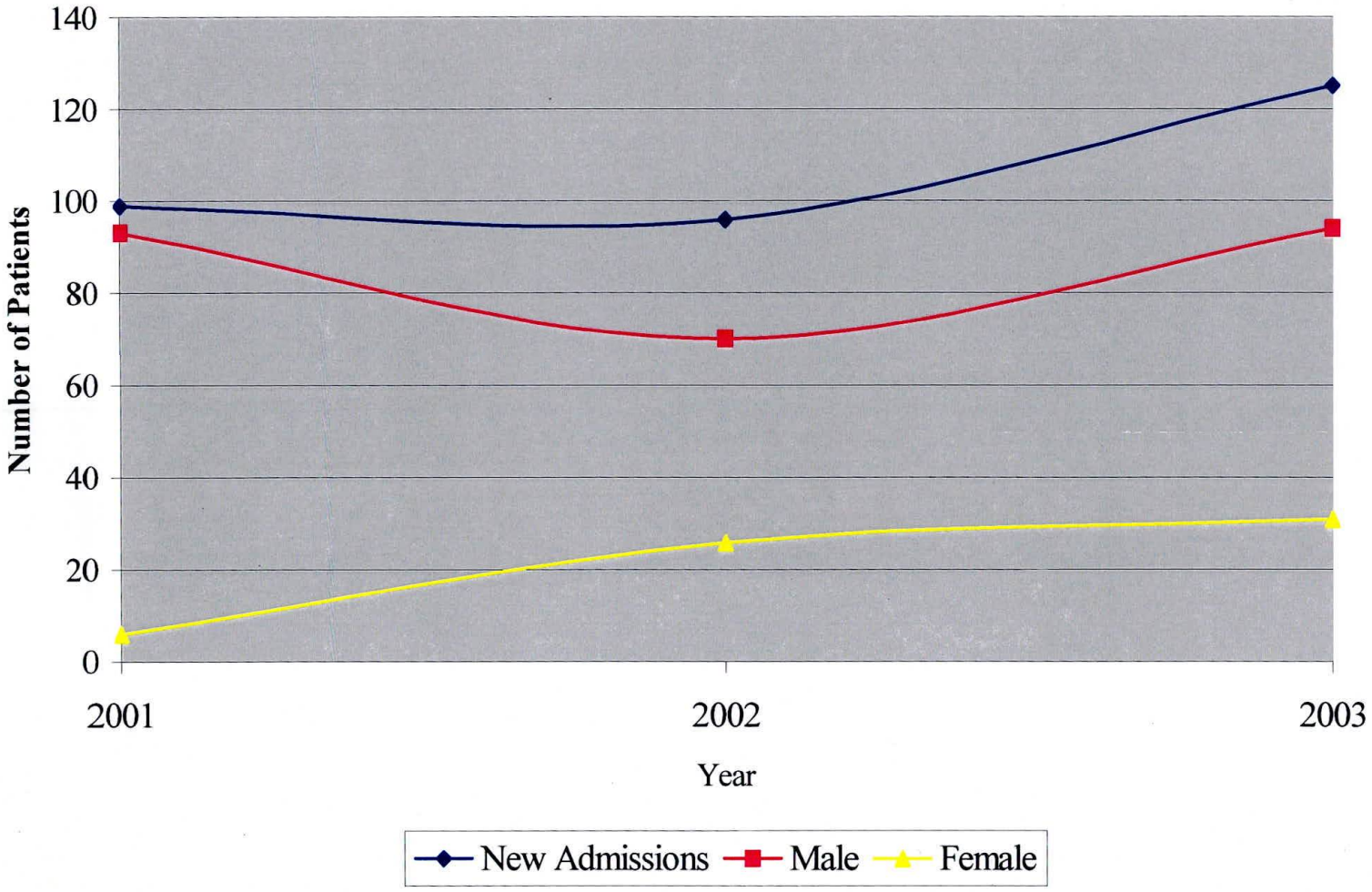
Copy to Additional Secretary, CAD (S.C.) Dept, item no. 2295

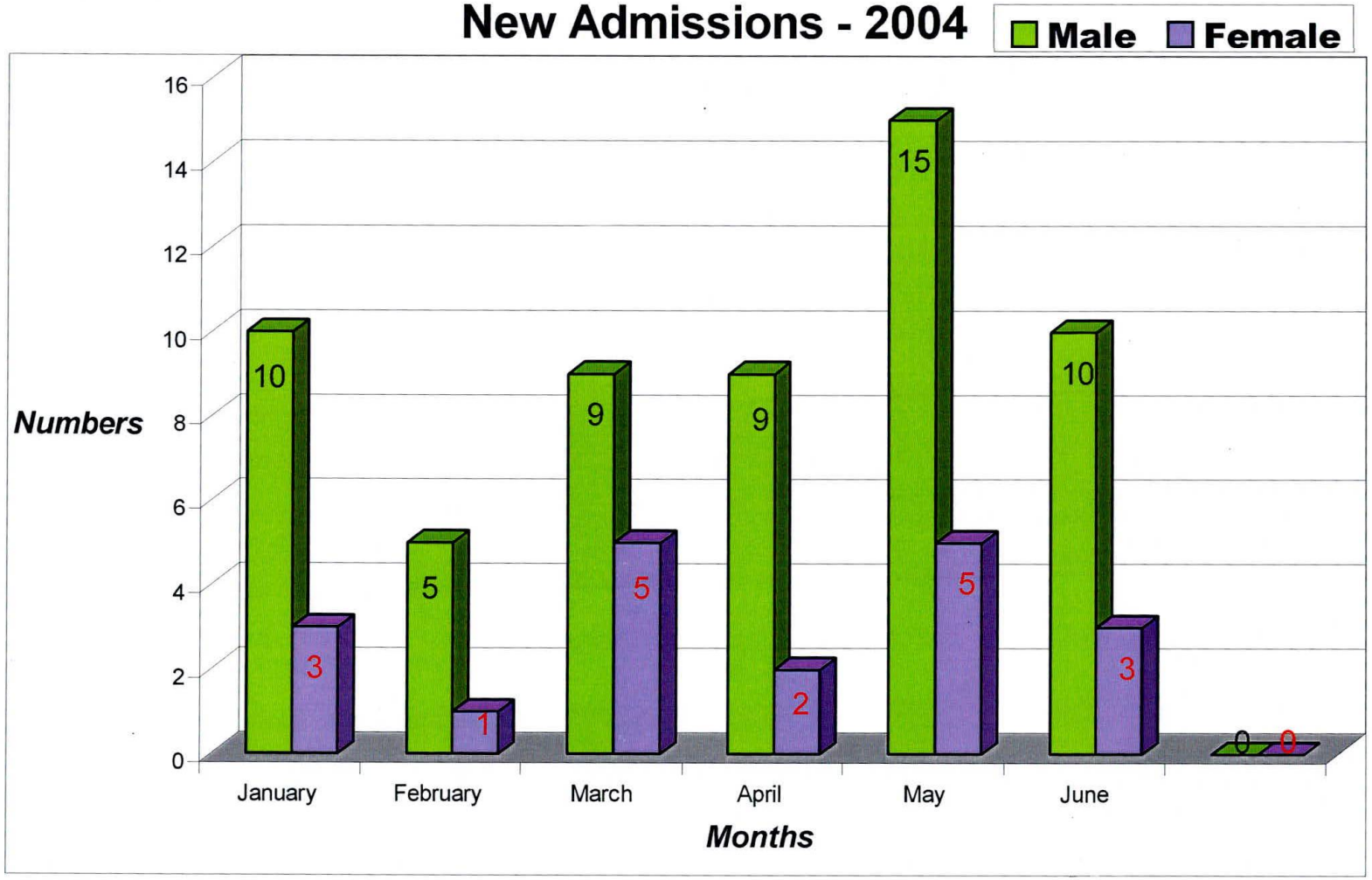
All Departments in the Secretariat

P.A. to the Health Secretary

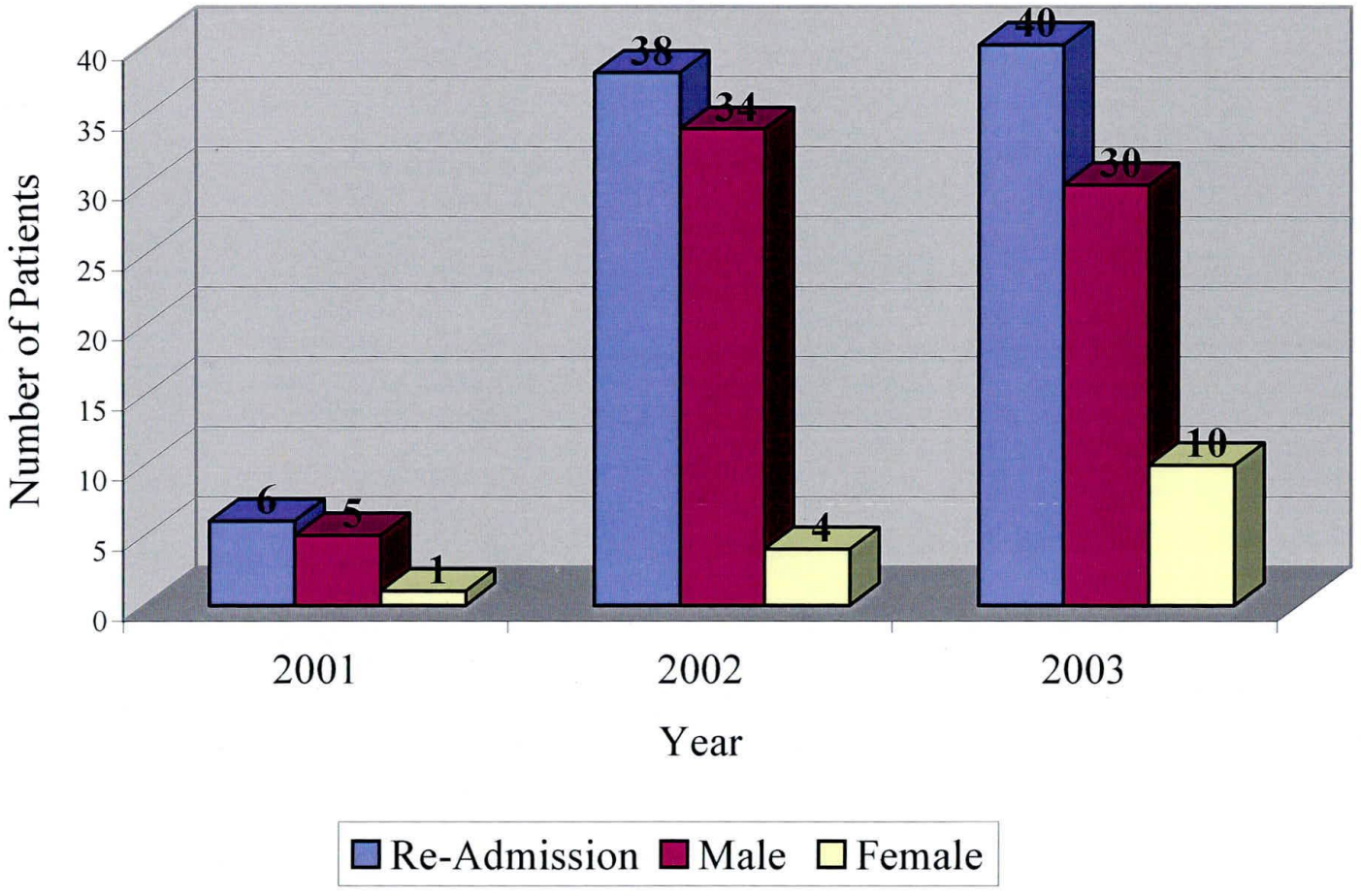
P.A. to the Additional Secretary

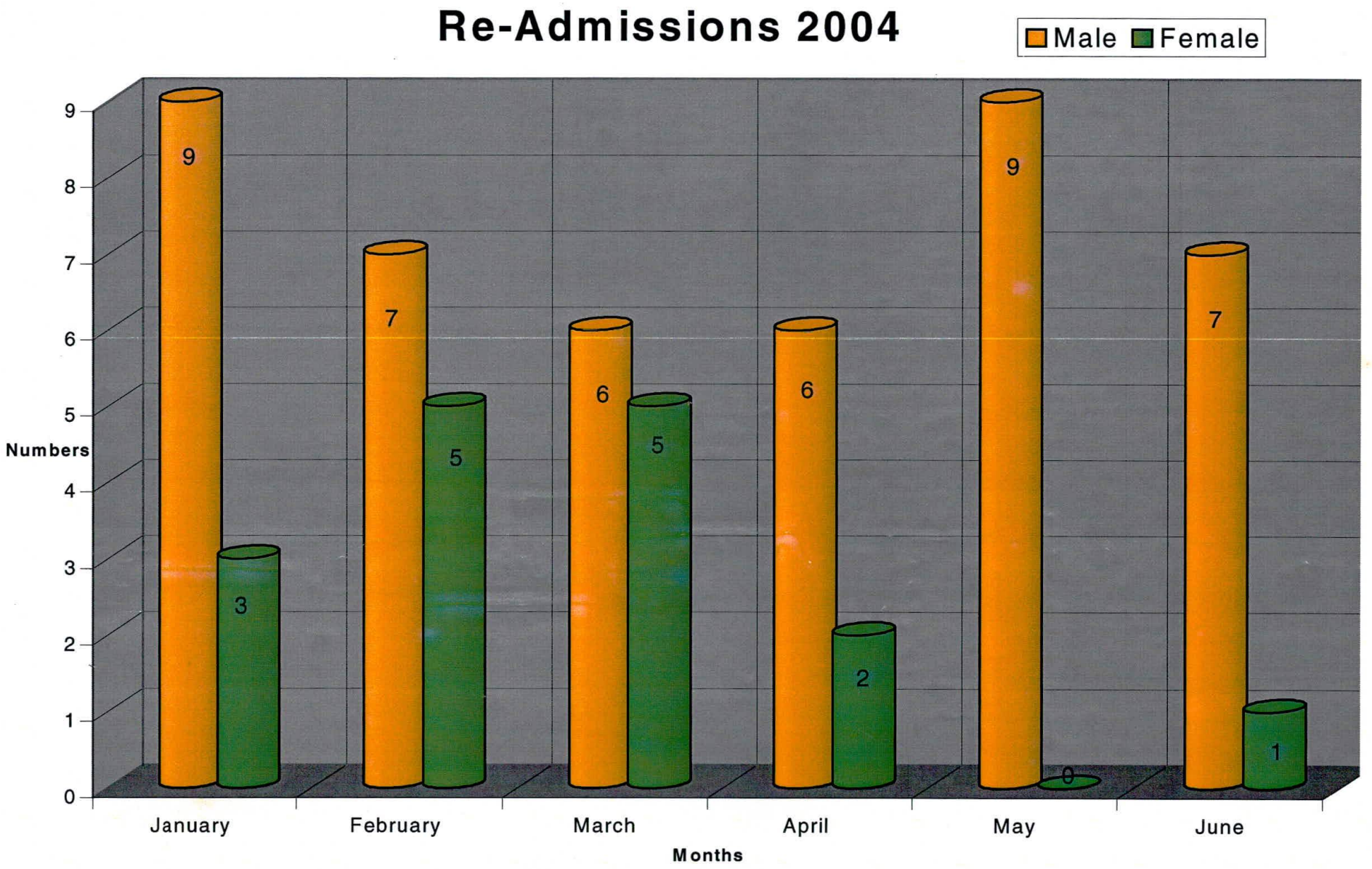
Patient Statistics: New Admissions (2001-2003)



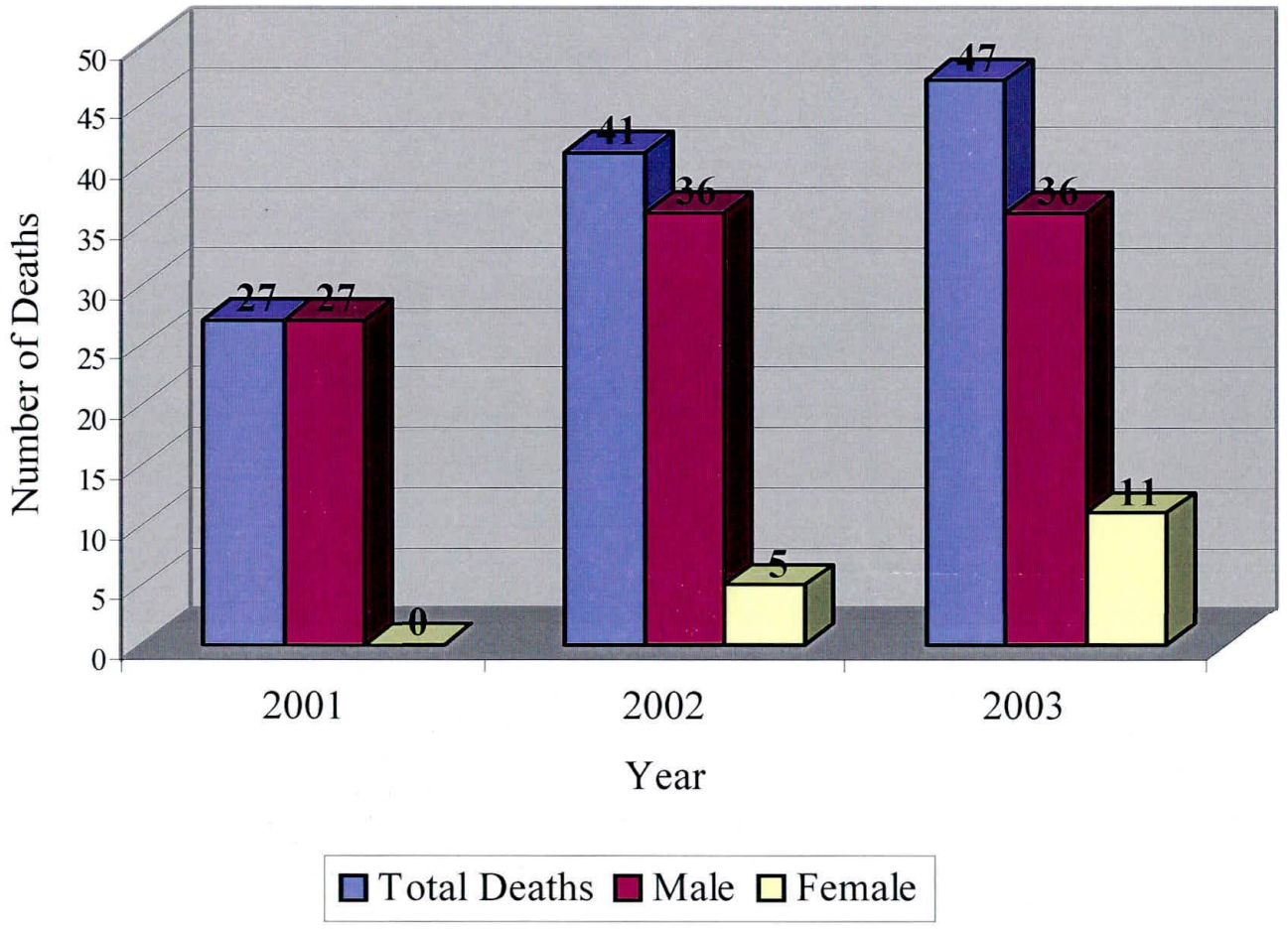

New Admissions - 2004
Male
Female
Numbers
16
14
12
10
8
6
4
2
0
10
3
5
1
9
5
9
2
15
5
10
3
0
0
January
February
March
April
May
June
Months

Patient Statistics: Re-Admissions (2001-2003)

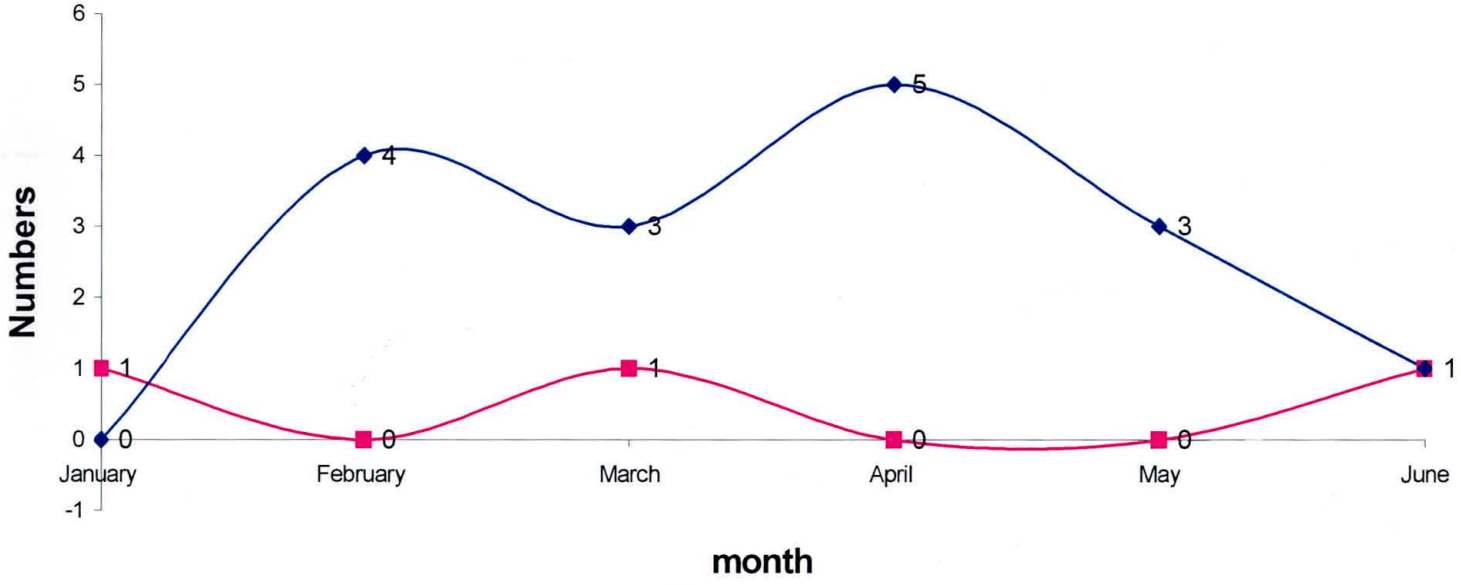



Re-Admissions 2004
Male
Female
Numbers
0
1
2
3
4
5
6
7
8
9
9
3
7
5
6
5
6
2
9
0
7
1
January
February
March
April
May
June
Months

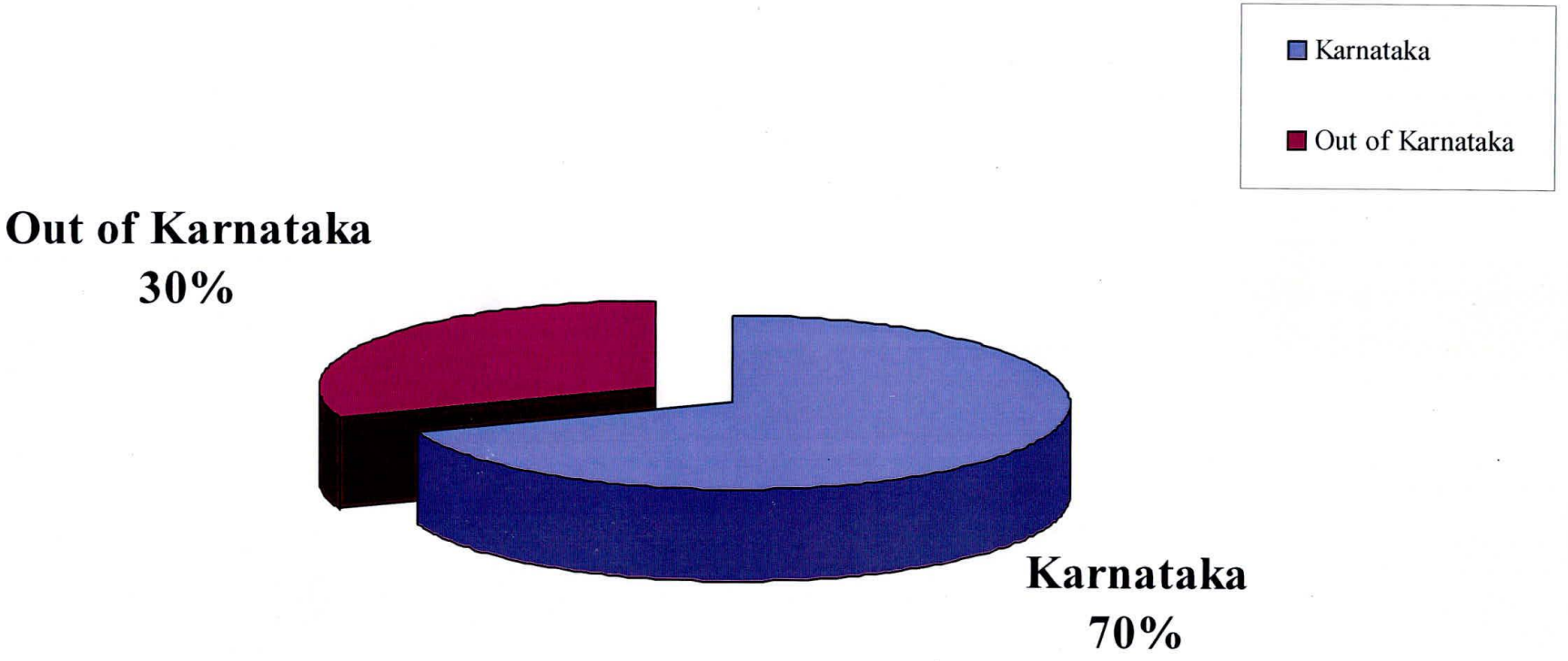
Patient Statistics: Number of Deaths (2001-2003)



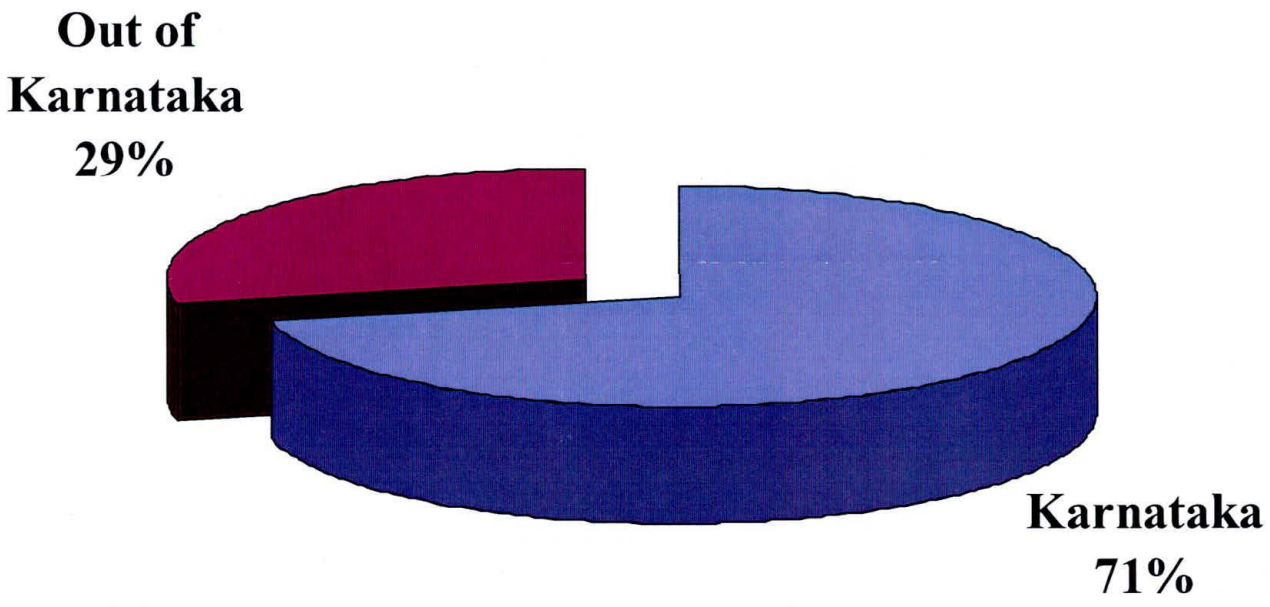
Patient Statistics: Number of Deaths (2004)



State of Origin (2001)



State of Origin (2002)



State of Origin (2003)