

Streams of Compassion

Response of the Catholic Church
to HIV/AIDS in India



CBCI
Health Commission



USAID
FROM THE AMERICAN PEOPLE



POLICY Project
Futures Group



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Abbreviations

AIDS	Acquired Immuno Deficiency Syndrome
ART	Anti-retroviral Therapy
BCC	Behaviour Change Communication
CBCI	Catholic Bishops' Conference of India
CCDT	Committed Communities Development Trust
CHAI	Catholic Health Association of India
ESAF	Evangelical Social Action Forum
ELIZA	Enzyme Linked Immunosorbent Assay
HIV	Human Immunodeficiency Virus
HAART	Highly Active Anti Retroviral Therapy
IEC	Information, Education and Communication
JCC	Jyothis Care Centre
JCT	Jyothis Charitable Trust
JTCC	Jyothis Terminal Care Centre
KSAPS	Karnataka State AIDS Prevention Society
MDACS	Maharashtra District AIDS Control Society
MGM	Mahatma Gandhi Mission
NGO	Non-governmental Organization
NIMHANS	National Institute of Mental Health and Neuro Sciences
OBGYN	Obstetrics Gynecology
OIs	Opportunistic Infections
PLHA	People Living with HIV/AIDS
RTI	Reproductive Tract Infections
STI	Sexually Transmitted Infections
SD	Sisters of the Destitute
VDRL	Venereal Disease Research Laboratory
WB	Western Belt

Introduction

The rapidly escalating HIV/AIDS pandemic in India poses a threat not only to the individual, but also to the community at large. This has elicited a multi-sectoral response from the public sector, private sector, non-governmental organizations, donors and faith-based organizations. The latter, in particular, are regarded in the community with respect and trust in their commitment to the well being of people. Thus there has been significant interest on the part of governmental and multilateral agencies to increase the function of faith based organizations in the efforts to fight the scourge of HIV/AIDS.

Being a diverse country, India encompasses various religious communities offering spiritual solace to people. Within the Christian community, the Catholic Church in India has a long history of providing healthcare services to underprivileged populations in medically underserved areas. Since the beginning, the Catholic Church has been involved in delivering healthcare services and spiritual counseling, with HIV/AIDS now becoming an additional area of intervention. To guide its operations, the Catholic Church felt the need to have an HIV/AIDS policy. With technical assistance from the United States Agency for International Development (USAID) funded POLICY Project/Futures Group, the Catholic Bishops Conference of India (CBCI) Commission for Healthcare initiated a process to help develop the HIV/AIDS policy of the Catholic Church in India.

The principles followed in the policy development process included policy dialogue, broadened participation of stakeholders and policy relevant research. A series of research studies were conducted with the aim of providing evidence-based decision making for developing the HIV/AIDS policy of the Catholic Church. One of the activities undertaken was to research and document the interventions by church-based organizations working on different aspects of HIV/AIDS.

The objective of this study is to develop a knowledge base of the interventions by church-based organizations and identify the strengths and weaknesses of the interventions. Each of the interventions studied exhibits a uniqueness in terms of the integration of spirituality with the differing intervention approach, and additionally reveals the strengths and constraints of that particular approach. This initiative also aims to serve as a 'good practice' model for faith-based organizations when working with People Living with HIV/AIDS (PLHAs).

Based on expert judgment, eleven church-based interventions were selected for the case study. These included St. Joseph's Hospital and St. Ann's Snehasadan (Andhra Pradesh), Snehadan and St. John's National Academy of Health Sciences (Karnataka), Jeevan Jyoti Hospice (Tamil Nadu), Bel Air Hospital, Jyothi's Care Centre and Niramay Niketan (Maharashtra), St. Francis Hospital (Rajasthan), Sneha Bhavan (Manipur) and Amala Hospital (Kerala). Each institution that was studied was unique, in many ways, as can be seen in the following pages. So were the experiences of people receiving care from these institutions as well as those serving in them.

The study followed a case study method. An interview guide was developed that indicated broad areas for exploration and observation. Selected organizations were visited and data collected through observation and interviews with the management, staff, clients and other key informants. The studies were conducted with the help of independent consultants.

Information was collected on the organizational background, nature of interventions, services offered, clients, availability and mobilization of resources and management of the organization. Efforts were made to examine the actual provision of care and treatment and look into adherence to universal precautions.

The study also looked at the day-to-day management and services available to clients in terms of psycho-social support, nutritional support, legal assistance in addressing stigma/discrimination, property rights and other human rights issues. Efforts made by the organizations towards creating

an enabling environment were examined by looking at their advocacy initiatives, networking activities and addressing of policy issues.

In brief, the unique feature discovered about each institution is as follows:

- ◆ Amala Cancer Hospital Research Centre follows a two-pronged approach, intervention–research and treatment, each complementing the other. The research team at the Centre envisions extending the services to a wider section of people as ayurvedic drugs can provide alternate life prolonging therapies at a low price, and in addition, the drugs do not produce any adverse toxicity. The Centre provides a good treatment model, with a viable model for making a low cost alternate system of medicine available to people.
- ◆ Bel Air Sanitarium and Hospital has provision for providing care to children orphaned and made vulnerable by HIV/AIDS.
- ◆ Jeevan Jyothi Hospice is located in Theni district, which is one of the high HIV prevalent districts of Tamil Nadu. The hospice is distinguished by its provision of holistic and comprehensive care to PLHA. Palliative care is provided to people within the community in which they live, thus resulting in acceptance and rehabilitation of the affected persons. The treatment process integrates allopathic medication with ayurveda, siddha and herbal treatments.
- ◆ Jyothi’s Charitable Trust provides institutional care and support programmes under its aegis, namely Jyothi’s Terminal Care Centre and Jyothi’s Care Centre. The trust also supports a rehabilitation home for women, which, in addition, undertakes activities for their capacity building.
- ◆ Eduljee Framed Allbless Niramay Niketan is a hospice supported by St. Vincent de Paul Society, a lay people’s organization, which traditionally engages in developing healthcare services and programmes to meet identified community needs.
- ◆ Sneha Bhawan is a rehabilitation centre for chemically dependent women. It supports a short stay home for widows infected or affected with HIV/AIDS, along with a drug de-addiction and rehabilitation centre. It works towards empowerment of communities at the village

level so that people have access to available services. It also seeks to provide educational support to children affected by HIV/AIDS.

- ◆ Snehadan provides ambulatory, psychiatric and paediatric care and treatment and supports a unique programme of providing placement assistance to people affected by HIV/AIDS.
- ◆ St. Ann's Snehasadan was started as a tuberculosis training centre for the student nurses of St. Ann's hospital, Vijayawada. Today the centre is providing dedicated and compassionate service to PLHAs.
- ◆ St Francis Hospital has the distinction of being a multi-specialty hospital. The intervention programme components include prevention, care and support implemented along with Asha Niketan (institutional care and support centre) and Jiwan Dayani Project (community based preventive programme).
- ◆ St. John's National Academy of Health Sciences is a tertiary care unit with different departments. The HIV/AIDS interventions include: treatment to PLHAs, training of medical professionals and conducting outreach activities through the community health department.
- ◆ St Joseph's Pratipadu is the first care and support centre for HIV/AIDS in Andhra Pradesh. Special attention is paid to female children of PLHAs and various skill-building trainings are organized for them. A unique feature of the hospital is that all patients, whether infected with leprosy or with HIV/AIDS, live in a common wing with separate wards so that they do not feel isolated, secluded and discriminated against. People infected with leprosy act as cheerleaders for PLHAs.

Common themes like providing compassionate care and support along with spiritual assistance to the PLHA underpins the case studies. The institutions studied here exhibit unique interventions aimed towards mitigating the impact of the HIV/AIDS pandemic by providing treatment, care and support services to people of various social strata.

The major themes that emerge from the study are as follows:

- ◆ The studies indicate the need for training in counseling and an increase of instructional staff, as majority of the centres have minimal staff strength.

- ◆ Not many centres advocated the use of condoms, although some did provide counselling on condoms as a means to prevent HIV/AIDS.
- ◆ The high cost of anti-retroviral therapy limits the availability of the treatment in many centres.
- ◆ A major problem faced by the centres is when a patient's death occurs. Often nobody, including family members, comes forward to claim the body. However, the administration finds that several claimants appear for the property and valuables of the deceased. This often poses problems and calls for legal redress.
- ◆ PLHAs in the hospital are visited by chaplains and support is provided through prayers and counselling.
- ◆ Most centres adhere to universal precautions of safety while dealing with blood and body fluids while operating and disposing of the dead.
- ◆ It is encouraging to observe that PLHAs themselves, when able, provide assistance in hospitals and hospices, which also enhances their self-esteem.
- ◆ Abstinence and staying faithful are preached in all the centres.
- ◆ The vulnerability of PLHAs is addressed through improved livelihood skills and better access to social and healthcare services.

"The moment I heard I was positive I felt that I am dead. My brothers took me to St. Johns and helped me to get treatment. But I believe it as too late and my condition was really bad. On the advice of the doctors in the hospital I was brought to Snehadanaan. Since then my condition has improved".

The perceptions presented in this volume highlight the importance of a compassionate and enabling environment that is critical for promotion of physical and mental health, dignity, self respect and thus longevity and inner peace of people living with HIV/AIDS.

"The love care and the treatment I got from them has kept me going, in fact I owe my life to the fathers who gave me rebirth. I was scared of death but now I am not".

Two common things among the people serving and the people receiving the services are 'love' and 'hope' – the experience of being loved and of loving and the experience of hope and giving hope. The studies have tried to capture their voices directly.

Analysis of the data clearly shows the effectiveness of religious institutional strategies, approaches and support for people living with HIV/AIDS. The surveyed institutions are seen to ably fulfill the healing mission of the Church by providing compassionate care and service.

Let us take this opportunity to thank the management and staff of the institutions studied for giving us their valuable time, and also the people living with HIV/AIDS for sharing with us their thoughts and experiences. Furthermore, our thanks are due to our consultants for carrying out the research and providing us with the results.

It is our hope that this volume presents valuable information and examples of how faith-based institutions can best provide care and support for people living with HIV/AIDS.

Gadde Narayana
Sherry Joseph
Kavita Chauhan

Amala Hospital

M. Retna Raj

The vision of Amala Hospital is based on the last words of Jesus Christ 'go and preach the good news and heal the sick' and healing the sick has been accepted as the major mission of Amala Hospital. It is a registered society and Carmelites of Mary Immaculate, Devamatha Province, Thrissur is its trustee. It was formally inaugurated on April 25, 1978 by the then President of India, Shri Neelam Sanjiva Reddy and was established as a non-profit, charitable institution.

Preaching the gospel of Jesus through human development services is the basic vision of Congregation of the Carmelites of Mary Immaculate, which has established a network of institutions for learning, social service and healthcare in India, including several in Kerala.

The Congregation was started in 1829 by two priests, Fr. Thomas Palackal and Fr. Thomas Porukara of the Vicariate Apostolic of Verapoly in Kerala. Its work consisted of arranging retreats, organizing seminaries, training priests, educating the youth and disseminating Christian literature. It undertook works of mercy and started charitable institutions.

A broad-based committee, consisting of Trustees and the Executive Body (including representatives of beneficiaries and experts from other cancer centres), formulates policies and lays down norms of operation for the institution. An apex Executive Committee consisting of seven members looks after the day-to-day management of the institution. The hospital has six complementary medical systems namely – cancer hos-

The hospital has six complementary medical systems namely - cancer hospital, general hospital, medical college, cancer research centre, ayurveda hospital and homeopathy centre.

pital, general hospital, medical college, cancer research centre, ayurveda hospital and homeopathy centre. *“Bethany,”* a home of the aged, also functions in the campus. In 2003 Amala Hospital was elevated to the status of Amala Institute of Medical Sciences (Medical College).

The hospital has diagnostic, therapeutic and research facilities to combat HIV/AIDS, cancer and other major ailments. This is a 600-bedded hospital complex, which is unique in having principal systems of medicine, allopathic, ayurveda and homeopathy in the campus.

The cancer hospital offers a range of modern facilities required for cancer patients. The comprehensive therapeutic services are comprised of chemotherapy, radiotherapy and cancer surgery. Its wards and private rooms accommodate 280 inpatients at a time. It serves an average of 30,000 outpatients and 6,000 inpatients annually. The National Board of Examinations has approved Amala to conduct a diploma course in radiotherapy and surgery. The centre also has a palliative care unit.

The general hospital offers the services of 23 well-established departments-cardiology, pulmonology, plastic and reconstructive surgery, neurosurgery, cardio-thoracic surgery, surgical oncology, general surgery, neurology, urology, nephrology, medicine, orthopaedics, ear, nose and throat (ENT), oral and maxilla-facial surgery, dentistry, gynaecology and obstetrics, paediatrics, dermatology, radiology etc. The general hospital has inpatient facilities to accommodate 320 patients.

Amala Ayurveda Hospital was started in 1982. This is an independent and full-fledged complex having inpatient facilities to accommodate 68 patients. The ayurvedic unit consists of ayurveda general hospital, pharmacy unit, medicine preparation centre, herbal garden and research wing. The homeopathy hospital was started in 1989 for the research and treatment of cancer and other diseases. This unit functions with an outpatient department.

Amala AIDS Research and Treatment Centre

Amala AIDS Research and Treatment Centre is a combined effort of Amala Ayurvedic Hospital and Amala Research Centre. It is a recognized institution with pure research sections in several disciplines of modern medicine, and is endorsed by several Indian universities and Medical boards.

The intervention is two pronged which includes research and treatment. Both the services are complementary and can be termed as research-linked treatment and treatment-linked research via the application of ayurveda drugs on HIV positive people. Services related to treatment and research are also carried out in collaboration with other agencies engaged in similar services in the region. While prevention is not a concern of this intervention, partner identification, and efforts for reducing mother-to-child transmission and counselling services serve this purpose.

AIDS related treatment and research was initiated by Amala ayurvedic hospital in collaboration with Amala Cancer Research Centre in December 1992. The idea evolved at the All India Ayurveda Congress in Kochi in October 1991 when Dr. Rajagopal, the Research Director of the hospital presented a paper on the reference in ayurveda to a disease similar to AIDS. He spoke about the possibility of developing drugs in ayurveda to counteract AIDS and also announced Amala's intention to help AIDS patients. Soon Amala started getting inquiries from patients about ayurveda treatment for HIV/AIDS. A research team was formed, including Dr. Ramdas Kuttan and Dr. Kesavan, and Amala took up the challenge and developed an herbal treatment formula in 1992.

In the same year the first HIV positive patient to the hospital was referred by one of the cancer patients of the Amala Hospital. He was pleased that the hospital offered him treatment when many others had refused. Later his wife tested negative in the ELIZA test. This patient lives and works in Bombay and has stopped taking any medicine. However, he remains HIV positive. He still maintains contact with the Centre and according to the team, his association and co-operation, irrespective

All the services offered in the centre are related to treatment-linked research and research-linked treatment.

of the rumours and discouragements from many directions, has helped Amala tremendously in carrying out its present level of services to HIV affected patients.

The team explained the initial hurdles that they had to face. There were several misconceptions regarding HIV/AIDS. Even colleagues in Amala Cancer Hospital did not support the endeavour and were hesitant to conduct the ELIZA test. This test facility was available only in Amala at that time, and so the ayurveda doctor himself had to conduct the test.

Services in the Centre **Diagnostic Services**

All the services offered in the Centre are related to treatment-linked research and research-linked treatment. Amala Research Centre has the facility for doing diagnostic testing for HIV/AIDS. ELIZA and Western Blot analysis are done for the people and the VDRL testing facility for STI is also available. The CD4 and viral load tests are done for people in the research scheme. These tests are done at RANBAXY in Mumbai.

The facility for ELIZA test was made available in 1992 when it was available in only a very few centres in Kerala. As a result, several people from different parts of Kerala began to come to the Centre for testing and treatment. The WB analysis was initiated in 1994. The ELIZA test is done at concessional rates or even free of cost for the poor. A 10 to 20% concession is given to the poor people for WB analysis. The practice of sending samples for CD4 and viral load tests started in 2003 as part of the present research program and both the tests are done every six months to assess the impact of the treatment.

Counselling Services

Counselling service was initiated in 1999 and informal counselling is given to the people at the Centre three days a week. The Evangelical Social Action Forum (ESAF), which has been doing counselling and out-

reach services for the HIV positives in Thrissur city, lends its counsellor's services on a part-time basis for this purpose.

In the last two years 125 people have attended counselling sessions. Some of the people coming to the Centre do not wish to attend counselling sessions due to the fear of social ostracism. According to the opinion of the counsellor and doctors, counselling sessions prove to be more effective for those people who come from a supportive and favourable family environment. The counsellor focuses on the following components.

Post-test and Treatment Counselling

Post-test counselling is given in an informal way prior to the beginning of the treatment. At this time details regarding the ayurveda treatment are also given. Since most of the patients come to the Centre after being referred by others, most of them have prior knowledge of the mode of treatment followed in the Centre.

Healthcare Counselling

Healthcare counselling is given both to the people and their family members. The nutritional aspects and the relevance of giving a balanced diet to those affected are highlighted.

Awareness Counselling

Awareness counselling is extended to the client, the spouse and family members. The spread and infection aspects are stressed. The need for correct knowledge about HIV/AIDS is also emphasized.

Risk Reduction/Behavioural Counselling

The moral aspect is emphasized during risk reduction and behaviour counselling. The use of condom during sex is advocated however, they are also advised to abstain from sex until marriage. According to the opinion of the counsellor there have been fewer episodes of

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unprotected sex with multiple partners among the people who have regular contact with the Centre.

Mental and Spiritual Health Counselling

Efforts are made to boost the emotional balance of the people. This aspect is emphasized on the assumption that treatment can be more effective under a balanced motivational and emotional state. People are made to believe that HIV/AIDS is like any other normal disease and with life-style change, treatment and care, the lifespan of an individual can be prolonged. The patient is motivated to turn to prayer for emotional balance. According to the doctor and counsellor,

this aspect of counselling is crucial and integral because people are asked to respect the human rights of others as a moral obligation, and it is contingent on them to refrain from all acts that lead to the spread of virus to others.

There is much scope for strengthening behaviour counselling in the Centre. As long as vaccines to protect against HIV infections remain elusive, behavioural interventions continue to be best hope for slowing the AIDS pandemic. This type of counselling helps the widows to 'live beyond loss'. There are also cases with depressive symptoms and acute stress disorder symptoms which can be handled effectively only by a professional HIV counsellor. In addition, there is the need for mental health services for persons with HIV who have a difficulty in coping with the infection and AIDS related bereavements.

Treatment Services

Amala Ayurveda Hospital provides inpatient and outpatient service to general patients seeking treatment in ayurvedic medicine. However, only outpatient service is given to the HIV/AIDS patients. The absence of inpatient service is a major handicap in proving the efficacy of ayurveda drugs on the patients, since they are not exposed to the experimental situation in a controlled environment.

For effective management of ayurveda drugs the HIV infected cases are grouped into three categories and medicine is administered accordingly.

Carrier Stage Cases

Preventive medicine is given to those in the carrier stage of infection to prevent multiplication of the virus. Two sets of medicines are given to them and people in this category need to spend Rs.90 every month for the medicine (after 50% concession).

Symptom Stage Cases

Symptomatic care and treatment is given along with other drugs for HIV infection to those in the symptom stage. Four sets of medicines are given to such people along with symptomatic management of diseases. They need to spend Rs.150 every month for the medicine (after 50% concession).

Full-blown Cases

These cases are given four sets of medicines along with symptomatic management of diseases. According to Dr. Kesavan “there is no effective treatment in ayurveda for such cases and what they need is regular counselling and palliative therapy. As a result such cases are referred to palliative therapy centres”. However, those at the beginning of the full-blown stage are given treatment. This category of people needs to spend Rs. 250 every month for the medicine (after 50% concession).

Of the seven cases met by the researcher, one started taking anti-retroviral therapy three months ago because she found taking the ayurveda drugs to be very inconvenient. The spouses of three people are undergoing ART as they have several complaints. According to them *“once we start ART it becomes a suitable remedy for several other aids related symptoms as well and there is no need to take extra medicine for such symptoms. But in the case of those taking ayurveda medicine additional*

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The Ayurveda Centre has a medicine lab in the medicine preparatory unit, which is managed scientifically. The lab is linked to the treatment-cum-research process.

allopathic drugs are required for other aids related complex.” Those people taking ayurveda medicine said, *“the doctors in the Centre have also asked them to follow allopathic medicine in emergency situations”*. However, all the people and their family members met by the researcher appreciate the effect of ayurveda drugs on those in the early stage of infection, and many remain without even a minor complaint over a 10 year period.

The research team at the Ayurveda Centre has the vision of extending the treatment services to a larger number of people. According to them, at the end of the present research (2006) they expect to document the impact of the drugs and develop the medicine in encapsulated or tabulated preparations and find out the efficacy. This will help widen the clientele at the national and international level. Some of the agencies based in the U.S.A. and Sweden have already agreed to collaborate with this venture.

The Ayurveda Centre has a medicine lab in the medicine preparatory unit, which is managed scientifically. The lab is linked to the treatment-cum-research process. Herbal powder is combined and prepared based on the needs of the people under the supervision of the doctors. Raw materials are brought from outside and materials are made available from the herbal garden. However, the medicine prepared by the Centre does not have a patent. Therefore, the Centre is desirous of obtaining a patent after packaging the combinations in capsule form.

Management of the Centre

The research element, being the focus of the intervention, is planned, designed and executed at a professional level. A high-level professional research team with an inter-disciplinary approach monitors this element on an on-going basis. Many indicators have been evolved to monitor the change and progress that take place in the patients before and after the experimental treatment. Periodic tests are conducted at regular intervals to make timely assessments. Along with the clinical evaluation on all the

cases, a representative sample is chosen from the patients, based on selected criteria, and they are studied closely. The people are kept informed of the findings. The changes are recorded scientifically and documented properly for use in the next phase of scientific inferences to be drawn.

The basic steps of intervention design such as problem analysis and solutions, stakeholder analysis, project goals and purposes, performance targets and indicators, defined outputs, strategies and activities, however, are not properly executed. Many of the supportive programs that are supposed to be combined along with the AIDS prevention and treatment programme among HIV positive patients are not even initiated due to several technical and financial constraints. Therefore, in the absence of several other services, the research component itself is handicapped.

The HIV/AIDS related Amala Cancer Research Centre and the Amala Ayurveda Hospital jointly shoulder activities of Amala Cancer Hospital and Research Centre. The staff consists of a Research Director, Research Consultant, two Research Officers, two Assistant Physicians and a Counsellor who visit the centre three days a week on a voluntary basis. Other supportive services are also provided on a part time basis to the marginalized groups seeking treatment and care in the Centre. All the senior doctors have attended short-term training and workshops in alternative systems of medicine for persons involved with HIV/AIDS and have presented papers in intensive ayurveda treatment for HIV/ AIDS.

No funds are received from any specific agency for research in HIV/AIDS. A portion of the funds received from national and international agencies for Amala Cancer Research Centre is set apart for this purpose. Rs.10 lakhs is earmarked for three years for doing the present study. However, the Centre is expecting grants for conducting research-linked treatment in HIV/AIDS from some international agencies based in the U.S.A.

Many of the supportive programmes that are supposed to be combined along with the AIDS prevention and treatment program among HIV positive patients are not even initiated due to several technical and financial constraints.

Expenses incurred on providing free/subsidized service to the research cases are met from the funds obtained from the national and international agencies for research in alternate systems of medicine.

Expenses incurred on providing free/subsidized service to the research cases are met from the funds obtained from the national and international agencies for research in alternate systems of medicine. The subsidized service for other people is met from the profit made by Amala Ayurveda Hospital. The management sees to it that no patient stops treatment because of financial constraints.

Research Linked Treatment Programmes

Research in ayurveda herbal treatment is justified by the fact that even after the intensive research of the last one-decade, there have been no effective remedies for HIV/AIDS and the available allopathic drugs are costly. These drugs are not affordable and accessible to the affected persons in India. It is known that HIV mainly affects CD4 lymphocytes, and when these are destroyed it produces an immunological imbalance in the body and weakens the resistance to several opportunistic infections, subsequently leading to death. The medicines available at present produce a decrease of the viral load, but as they are immune suppressants they can produce deterioration in the patient's immunity. Hence a committed team in the Amala Cancer Research Centre is seeking for an alternative non-toxic drug that can stimulate immunity and thereby increase the body's ability to fight the HIV infection.

While HIV infection leads to depletion in the body's immunity, this immunological breakdown does not occur in every person in the same manner. According to body strength, an infected person may be free of symptoms up to 15 years. Hence the research team came to the conclusion that one might not get AIDS as long as the immune system is intact, even if the person is infected. *Ojas* (immunity) is the abstract of seven elements - *rasa*, blood, flesh, fat, bone, bone marrow and semen. So when there is adequate nourishment of elements (*dhatu*) the immunity is maintained in the body. Each *dhatu* is being nourished by the help of *dhatwagni*. The drugs for the HIV/AIDS had been selected keeping in mind the above principles and hypothesis known to both ayurveda and allopathic.

Three types of ayurvedic herbal preparations were selected for initiating the research in order to counteract the *ojakshaya* in HIV/AIDS patients. They are 'Jeevaneeya" and "Bramhaneeyas" (meant for maintaining and improving the body weight) and "Panchaneeya" (for nourishing).

The first research was undertaken during 1995-96 with 11 participants funded by the Indian Council for Medical Research (ICMR). Thereafter, utilizing its own funds, the study was continued by the Centre. The study was conducted on patients in whom the HIV infection was confirmed through ELISA and Western Blot tests. CD4, and CD 8 ratio and other immunological parameters were checked before and after treatment at Christian Medical College, Vellore.

The selection criteria for the people were as follows – a minimum of five years of contact period, having AIDS related symptoms and never having taken any medicine specifically for HIV/AIDS. Patients were categorized into two groups for the purpose of detailed study. 45 AIDS-symptom patients were included in group one and 11 AIDS patients were included in group two.

The initial weight of the patient as well as history, duration of contact and prior medication were recorded. Patients were given three types of medications that were formulated in the Centre and coded as NCV-I, AC II and S.G.III. The general findings of the study revealed the effects of ayurvedic drugs on HIV patients with aids related symptoms. Medication produced satisfactory relief of opportunistic infections and physical ailments in the patients like fever, diarrhoea, joint pain, herpes zoster, itching, insomnia etc. The medicine was found useful in improving the immunological status in HIV patients taking anti-retroviral therapy drugs as well as among those with the early stages of AIDS. Drugs were found to increase the lifespan in many patients and did not produce any adverse toxicity in them. Medication also produced positive improvement even among the patients who had been discharged from the medical college hospital for palliative therapy. However, Western Blot analysis of the patients before and after treatment did not show any significant change and all patients remained sero-positive after the treatment.

The people who had been selected for the study were informed about the merits and demerits of the treatment being given to them. In addition, the purpose of study was clearly indicated in advance to them and to their family members.

Body weight analysis of HIV patients before and after treatment indicates that there was significant improvement in most of the cases. It was found that the body weight positively increased during the first six months for most cases. In some cases body weight decreased drastically due to increased activity of the patient or decreased food intake.

A significant finding of the research done on two categories of AIDS patients reveal that the special ayurvedic drugs formulated by the centre have been found highly effective in substantially improving the immune system, resulting in the complete disappearance of most of the symptoms of AIDS, though the patients continue to be HIV positive when tested. The people who had

been selected for the study were informed about the merits and demerits of the treatment being given to them. In addition, the purpose of study was clearly indicated in advance to them and to their family members. Informed consent was taken before doing the diagnostic tests and they were kept informed of the results of each test.

The present research was initiated in 2003 and it is for a period of three years from 2003-2006 and the chief objective of the research is to assess the efficacy of ayurveda drugs in bringing changes in the viral load and CD4 count. 30 patients have been selected for the present study based on the following criteria - those at the carrier stage of HIV with minor symptoms, those having minimum of three years of infection and those who have not begun to take ART.

Parameters like CD4, total viral load, hepatic function test and haematological evaluation are assessed to measure the effect of the drugs on the patients. Thereafter the tests are conducted once in six months for a period of three years in order to assess the efficacy of ayurveda drugs. These tests are conducted in RANBAXY, Clinical Reference Laboratories, Mumbai. The tests also provide valid evidence for documentation.

As per the records the Centre has extended service to more than 800 HIV positive patients till August 2004. However, over the years some have shifted to allopathic treatment and ART for various reasons. While around 100 of the people have died, some have discontinued the treatment. According to Dr. Kesavan "around 50 have stopped medicine because of stable health conditions. And they do not have any AIDS related complaints".

At present 250 people regularly seek healthcare from the Centre. Some of them do not come to the hospital regularly in person and as long as they do not have any complaints, they get the medicine every month through family members or other third parties. However, they do present themselves periodically for direct clinical evaluation. 29 out of 30 cases that are included in the research scheme maintain contact with the Centre at regular intervals.

Majority of people seeking treatment are from a poor socio-economic background. Most of the people coming to the Centre are in the carrier stage of infection because ayurveda is found to be more effective at this stage. 294 showed symptoms of AIDS and 93 were reported to be full blown AIDS cases and 73 people have been reported dead as of December 2003.

The maximum numbers of people were in the age group of 20-40 years. 8% cases were from the 40-50 year age group, 2% were above 50 years of age and 2% were below 20 years of age. In 83.71% cases the infection was caused by sexual contact. 8% of infections were due to blood transfusions and injecting, less than 2% from parent to child transmission, and in 6% of the cases the source of infection was unknown. Sex classification revealed that 75% were male patients. 68% are married. The majority of the women people are housewives. Drivers are the single largest occupational group.

Most of the people are from Trichur, Palghat and Malapuram districts of Kerala but they also come for treatment from Andhra Pradesh, Bombay, Mangalore and Goa. Some authors who have written on HIV/AIDS in Kerala have pointed out the availability of treatment facilities for HIV/

The majority of the people come to the Centre through referrals from other diagnostic centres, doctors and hospitals. As a result, most of them come with a positive test result.

AIDS in Amala hospital. For example Dr. Ajesh Sankar and Dr. Kanam Sankarapillai in their book "AIDS in Kerala" reported that upto 1995 there were 242 HIV positive patients who had undergone ayurveda treatment in Amala. 26 were from other states of India and 4 from other countries like Muscat, Oman and Bangladesh.

The majority of the people come to the Centre through referrals from other diagnostic centres, doctors and hospitals. As a result, most of them come with a positive test result. Very few cases are detected by the Amala hospital itself.

The prime mandate of the Centre is research-oriented treatment for the HIV positive patients and there is continuous monitoring of the treatment of the 30 current test cases. However, the Centre feels that it is time to advertise again in the regional and national dailies, so that it can get more new people, preferably those with infection at the primary stage.

People have come to the Centre for three reasons: the beneficial effect of treatment among those in the primary and secondary stages of infection, the significant impact seen in the bodyweight and in the CD4 counts and the treatment cost per month of Rs.150-250 after the concession. Those patients included in the research scheme get the medicine and related services free of cost. Also confidentiality is maintained with regard to their treatment. Since the clinic is run along with the general hospital set up and part of the ayurveda clinic, there is no stigma associated with the treatment for HIV/AIDS.

According to the doctors, the infected persons read a lot about HIV/AIDS, its spread, prevention and treatment aspects. However, the women who got infected from their husbands did not have much awareness about HIV/AIDS initially and had many false perceptions as well. They are given the correct information about the spread of the virus and its treatment during clinical verification and counselling sessions. Interviews with the people validate this statement of the doctors. While

people are found to have correct knowledge of HIV/AIDS, the majority of the family members of affected persons continue to have several misperceptions regarding the spread of HIV/AIDS. Some people consider their infection to be fate and do not bother to take their treatment seriously, and as a result they have not undergone much behaviour change and continue to indulge in multi-partner sex. Others, especially the housewives and widows say, *“anyway we are infected let us lead a fruitful life so that others do not get infected from us.”* Such people take the full course of the treatment and come regularly to the centre and advise others with the infection to pursue treatment at an early stage. These people are from families that treat them with care and concern.

The outpatient service is given to the people six days a week, while counselling service is given to the people three days a week. The majority of the people visit on the days on which Dr. Kesavan attends to patients in the outpatient department. However, both the senior doctors are available in the Centre on all the six days.

The researcher’s interaction with the people and their family members indicates that the relationship between the Centre and the people is personal and intimate. In the words of some people, *“the congenial atmosphere of this Centre makes us visit the Centre quite often and we prefer to spend longer hours in the Centre. We feel consoled when we spend 30 minutes with the counsellor.”* Since Amala Ayurveda Hospital caters to the general health needs of patients the Centre is very busy and some people feel that they are not getting much attention on certain occasions. They are desirous of having the services of the counsellor for six days in the week so that they can visit the Centre for guidance - both emotional and medical whenever they feel the need for it.

During the initial month the patients are asked to come once in 15 days and are given medicine for 15 days only. This is to understand the response of the body mechanism to the medi-

The outpatient service is given to the people six days a week, while counselling service is given to the people three days a week.

Periodic awareness programs are conducted through the Amala fellowship centres which is a voluntary association initiated in 1982 through public initiative.

Thereafter people are asked to come once a month and medicine is given for one month. If the people are from distant places and if they do not have any AIDS related symptoms they are asked to come once in two or three months' time. However, meeting the doctor once a month is the desirable frequency.

Amala Ayurveda Centre does not have treatment facilities for STIs. However Amala hospital has a department in Dermatology and two qualified doctors provide treatment and referral services to the concerned patients. The hospital has a full-fledged laboratory and is equipped for doing

VDRL tests. Follow up treatment is given based on the test result. However, there is no facility to conduct pre-test and post-test counselling sessions. Those patients who test positive in VDRL are given informal guidance. According to the doctors in the department of Dermatology 2 to 3 cases test positive in the VDRL every month and the patients take the full course of treatment. No case has so far been referred to the Ayurvedic Centre for treatment in HIV/AIDS. The syndromic management of STIs is done by the Centre and one doctor has undergone training in this regard.

Prevention Programme

Developing and maintaining a comprehensive HIV prevention programme necessitates a multi-disciplinary approach. No clear-cut strategy has been designed and followed with regard to the prevention of HIV/AIDS. The Centre does not do much in this matter.

Periodic awareness programs are conducted through the Amala fellowship centres which is a voluntary association initiated in 1982 through public initiative. The fellowship has 26 units in various districts of Kerala. These fellowship centres are used as platforms to conduct awareness programs on various topics including HIV/AIDS and cancer. The various services offered by the hospital are also made known to the public through these fellowship centres.

A morality-based prevention strategy is generally followed. Not many indicators have been developed to assess the efficacy of such strategy among the people. However, it is generally believed that such a strategy has been effective among females.

Partner Identification and Treatment

Partner identification and treatment is done on an on-going basis. Once the HIV status of the client is confirmed he/she is asked to bring the marital partners. Then the partners are asked to undergo the ELIZA test and if tested positive they are asked to initiate the treatment. If the partner tests negative he/she is given the necessary guidance regarding safety practices and the care and support that need to be extended to the partner. For the partners and children the ELIZA test is done free of cost. No records regarding partner-treatment are kept and the follow up aspects of their treatment and behaviour are not clearly documented.

Out of 700 people, 300 have been identified through the process of partner identification. Four out of the seven cases interviewed by the researcher had been identified through the partner identification process and three of them are widows now. Mother-to-child transmission has been drastically reduced because of this partner identification and as a result only 3% of the children of the people have had the virus transmitted to them. Not much effort has been made to identify the sexual partners of unmarried people, except for some cases of men having sex with men. However, the unmarried people are told of the possibility of infection to their sexual partners.

Voluntary Counselling and Testing Centre

The ELIZA and Western Blot analysis are done at the Amala Research Centre. However, very few cases come to the Centre for the purpose of testing to find out their HIV status. They mostly come for treatment already armed with the test result. All people are given informal counselling in the Research Centre. If they test positive they are referred to the Amala Ayurveda Cen-

Mother-to-child transmission has been drastically reduced because of this partner identification and as a result only 3% of the children of the people have had the virus transmitted to them.

tre for treatment. Post-test and pre-treatment counselling is given at Amala Ayurveda Hospital. Most of the people are referred by private hospitals and private diagnostic centres. Research studies are carried out with financial assistance from some national and international agencies.

Currently Amala does not carry out any outreach activities for HIV positive persons and their families, but it is proposing to initiate such activities through Amala fellowships centres. ESAF, which networks with Amala Ayurveda Hospital and carries out some extension and outreach activities, is making conscious efforts to understand the problems of the HIV positive persons and their families, in order to extend possible services to them. This would also help Amala Ayurveda Centre to maintain the goodwill it enjoys among affected families.

Blood Safety

Amala has a complete range of test and investigation facilities necessary for a modern multi-specialty hospital. Improved techniques are used to ensure blood safety. The screening for HIV-antibodies, anti-HCV and Hepatitis B surface antigen is done by the ELIZA method using Vitros kits of Johnson and Johnson. Screening for syphilis is done by the Rapid Plasma Reagin (RPR) test using carbogen kits. Units tested positive by the ELIZA method were retested using a duplicate kit. All the surgical and delivery cases are screened on a routine basis. Similarly all blood donors are screened. Trained doctors and technicians provide leadership for this process.

Blood Donation Policy

The blood bank is managed by the Department of Pathology. All the World Health Organization (WHO) norms are followed in order to maintain blood safety. The incidence of HIV was 0.13% among donors. This result is from the screening of 246,781 cases from March 1999 to December 2003. However, only 3% of the donors are voluntary donors and 97% are replacement donors. The lower prevalence of infection may be due to the donor selection procedure followed by the hospital. The prevalence of VDRL positivity was 0.13% during this period.

All surgical and pregnant cases are screened on a routine manner as part of the policy of the hospital. This helps to identify HIV infected cases among such people. If a pregnant woman tests positive she is immediately referred for ART. Since the doctors of Amala Cancer Hospital are not trained in ART, the patients are referred to other hospitals. They are also advised to conduct delivery through surgery and not to breast-feed the newborn child. Thus the chance of mother-to-child transmission is reduced to 3%. On ethical grounds doctors in the Centre usually take a neutral stand on matters relating to abortions.

All surgical and pregnant cases are screened on a routine manner as part of the policy of the hospital. This helps to identify HIV infected cases among such people.

Treatment

According to doctors and counsellors HIV/AIDS prevalence is high in the locality. The majority of the people coming to the Centre are from Thrissur, Palghat and Malappuram Districts. The Centre has identified three risk groups as sensitive to HIV/AIDS viz. truckers passing through the border areas of Palghat and Malappuram districts, diamond workers of Thrissur district and families of those employed in the Gulf from Malappuram and Thrissur districts. However, the Centre has not initiated any prevalence study or situational appraisal study among these risk groups. Research being the mandate of the Centre, no conscious effort is made to identify the HIV/AIDS patients among these groups.

Care and Support

Care and support component is not provided by the Centre, several people approach it for just such a service and several reasons have been cited by the management for not initiating inpatient service for HIV positives. The present mandate of the Centre is research-linked treatment for developing ayurveda drugs suitable to counteract HIV/AIDS. The ayurveda treatment has been found effective among those people who are in the initial and secondary stages of infection. The full-blown cases and those in need of palliative therapy do not have much to gain from ayurveda and, therefore, such cases are referred for ART.

The Research Centre shows evidence that ayurveda drugs can provide alternate life prolonging therapies like ART at a low price and in addition the drugs do not produce any adverse toxicity in the patients.

The Research Centre shows evidence that ayurveda drugs can provide alternate life prolonging therapies like ART at a low price and in addition the drugs do not produce any adverse toxicity in the patients. This provides a treatment model for countries like India. It also provides a viable model for distributing medicine free of cost to affected persons. However, this will be possible only when it is feasible to produce the herbal combination in a capsule form.

The ayurveda drugs also prove to be effective in reducing a person's infection and managing the stress coping mechanism. Patients being treated in the centre have an increased sense of well-being. It has proved that intervention at the earlier stages of infection produces benefits and expected results. In the words of the doctors of the Centre "there is dramatic fall in AIDS deaths over last five years among the people who undergo treatment."

The results of Amala's research provide information relevant to clinical objectives including the effect of certain ayurveda preparations in the treatment of HIV; identifying cases that are most likely to benefit from such research findings; and identifying the supportive services that an organization like Amala needs from a funding agency. Integrating several other supportive services will strengthen the research linked treatment services of Amala Cancer Research Centre and will definitely produce a successful intervention model for use among HIV patients.

Bel Air Sanatorium and Hospital

Gracy Bibiana Fernandesaj

Situated in Panchgani, Satara District in Maharashtra, the geographical coverage of Bel Air Sanatorium and Hospital includes the rural and urban areas of Satara. HIV/AIDS Community Care Centre at Bel Air was started in 1994 when Fr. Tomy, MCBS, took over as the Administrator of the Bel Air TB Sanitarium. Prevention, treatment, care and support are the Sanitarium's intervention themes for HIV/AIDS victims.

Going back to the early days of HIV/AIDS care at Bel Air, in 1995, Fr. Tomy talked about the fear of and negative response to, PLHA at the time. When first confronted with having to admit patients who were HIV positive, "we simply could not do it," he said, adding, "At the same time, our conscience did not permit us to reject these people either." The hospital, already having been in the field of TB care, stumbled upon HIV, as TB is one of the most common opportunistic infections of HIV. Therefore, "our work," Fr. Tomy states "began in an unplanned and non-strategic manner, rather than a well planned project." The early period of the hospital's work with HIV/AIDS also marked the beginning of dispelling various myths surrounding HIV/AIDS.

Between 1995 and 1996 the number of HIV patients went up more than six times. This quantum leap forced the sanatorium management to look at well-defined ways to tackle the problem. The hospital strictly adheres to the policy of not admitting a patient unless accompanied by a relative. What may sound harsh is actually seen as pragmatic by the hospital. "We're not looking for unwanted people," said Fr. Tomy. There are instances when family members do not return and the patient is simply

According to hospital statistics, the number of people infected with HIV/AIDS has increased about 35 times in the first seven years of the intervention.

sent back home. However, in case the patient is ill, the hospital continues to provide care and treatment.

An important incentive to keep a family member as a bystander (a care giving attendant) in the hospital is the free board and lodging provided to this person. It helps in those situations where the families face financial hardships due to the affliction and, more importantly, it provided emotional support to the patient, as having a

family member to nurse the patient or to bond with emotionally, helps in dealing with their volatile physical condition.

According to hospital statistics, the number of people infected with HIV/AIDS has increased about 35 times in the first seven years of the intervention. What began with a mere eight patients in 1995 rose to 283 in 2002. At the same time, due to its HIV/AIDS community intervention, the hospital's general admissions registered a decrease in patients. However, Fr. Tomy continued to maintain that HIV/AIDS care should be integrated with general healthcare, rather than be conducted in an isolated manner.

While those who "can afford to pay" are charged for treatment, bed and food is free for all. The costs of expensive investigative tests like the CD4 count have to be borne by the patients themselves. Some patients have paid admission fees between Rs 3,000 to Rs 5,000, though part of this could be refunded at the time of discharge.

HIV Positive Volunteers

The hospital has a band of 15 volunteers all of whom are seropositive. All of them have been hospitalised there in the last few years for AIDS-related complications, and had returned to serve as volunteers, for which they were paid a stipend of Rs 3,000. Of this, Rs 2,000 was deducted towards their board, lodging and ART, if the latter was required. Most of the volunteers happen to be on ART.

Several tasks are allotted to these volunteers at the hospital including, fetching the food from the hospital kitchen to the wards; bringing patients medication; assisting patients to the community hall for yoga sessions; informing patients about activities; offering moral support to the families of patients; and, lastly, preparing the body of a deceased patient. The 15 HIV infected volunteers, do not receive any formal training rather they learn skills on the job. Doctors, while on their once-a-day rounds, train the relatives of patients who function as bystanders. The hospital's nurses working with PLHA, attended training by means of the training programmes in Basic HIV/AIDS Care conducted for general practitioners.

The hospital works with both the general population and the vulnerable groups like women and children. The hospital records revealed a disturbing fact that PLHAs are typically in the prime of their lives, in the 25-40 year age group. As for the women infected, "Most of them are the younger ones, given that they fall in the more sexually active category," said the hospital gynaecologist.

Most of the HIV infected women seeking service in the hospital belong to the lower socio-economic strata of society and many of them are wives of policemen, fruit vendors and petty shopkeepers. The men admitted to the hospital include mostly poor, casual labourers or farmers, truckers, migrant workers, lower cadre army personnel and police constables. The majority were forced to quit their work, as a result of getting physically worn out, thus making them fully dependent on their families for sustenance. A social worker of Bel Air said, "hardly 20 percent are literate or semi-literate."

Though patients often came to the hospital with their HIV status report, this did not always translate into an awareness of the true implications of HIV/AIDS. But even though information about HIV/AIDS is imparted, as one doctor commented, the knowledge of the patients is still "poor." Added to this, is the

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Word of mouth helps draw clients not only from Panchgani, but from other districts of Maharashtra like Solapur, Nasik, Dhule and faraway places in Karnataka State.

difficulty in coming to terms with their condition. The doctor added “Many of them are unable to accept the fact that they have HIV. They want a guarantee that they will be fine,” she added.

Private doctors and patients who have been treated in the hospital refer other people seeking treatment and care in a hospital. The hospital’s drop-in centre in Satara also serves as a referral point. “If the patients coming to the centre are found to be in a serious condition, they are referred here,” commented a social worker. Follow-up treatment is also done through this drop-in centre.

Word of mouth helps draw clients not only from Panchgani, but from other districts of Maharashtra like Solapur, Nasik, Dhule and faraway places in Karnataka State. Another important referral route is the Basic Management of HIV/AIDS Care training programme for general practitioners from around Satara conducted by the hospital. “Many of these doctors refer their AIDS patients here as they would not like to keep them in their own hospitals,” said a doctor.

Countering Stigma and Discrimination

Stigma is something that many of the PLHAs experience, in some form or the other. As Fr. Tomy notes, “it is the single most important obstacle in the treatment and care of HIV/AIDS patients, since the very beginning.”

A female HIV infected volunteer talked about how she had stopped receiving invitations to village functions after it was known that she is HIV positive, and another infected person had been thrown out of the village, once it was known that he suffers from AIDS. All the volunteers said their families had been aware of their HIV positive status, except one who said she had not disclosed to her in-laws that she is seropositive. Only two out of ten volunteers said that they had not faced any

stigma back home. One of them, a man in his late twenties, used to be a trucker before being admitted to the hospital said, “My friends knew about my being HIV positive, but are absolutely normal with me.”

A common feature noted at the hospital, is the discriminatory treatment meted out to the women patients by their husbands and in-laws, even though most of them contract the virus from their husbands. Two of the women patients in the hospital are those who have cared for their husbands when they were in a critical state, only to be shunned by the families of the very men who were responsible for their plight. As a result, “Many of these women have to be looked after by their own families” said a social worker.

In trying to achieve stigma reduction, the volunteers have played an important role. Through first-hand experience, they have demonstrated to the patients’ attendants that a PLHA is no threat to non-infected people and can go about leading a normal life.

Enforcing the rule of a patient accompaniment, according to Fr. Tomy had served as a catalyst in stigma reduction. “Seeing us touch, clean and treat the patient takes away fear from the family members,” he said, adding that “the biggest hindrance to the well-being of a PLHA is the trauma of rejection, especially that from loved ones.” Having a loved one at the bedside, he stated, had resulted in “miraculous cures.”

Problems posed by the community to the hospital in the earlier part of its HIV/AIDS intervention is also decreasing. As Fr. Tomy mentioned, “We had to erect a screen around our mortuary (which is visible from the main road), to prevent the light (which is kept on when there has been a death in the hospital) from being seen. While keeping the light on at such times was not an unusual practice, the people in the neighbourhood, already aware of HIV/AIDS being in their vicinity, would get suspicious and come and pose several problems for the hospital. We no longer have to do this.” Things have also improved at the local crema-

Enforcing the rule of a patient accompaniment, according to Fr. Tomy had served as a catalyst in stigma reduction.

torium, which, as Fr. Tomy said, “would insist on us washing the place following the cremation of a PLHA.”

Caring for Children Orphaned and made Vulnerable by HIV/AIDS

Many of the villages in Satara have witnessed a growing number of children orphaned and women widowed by AIDS. These children were treated as outcasts, even if they were not HIV positive. “There have been instances where nobody would like to sit next to them in school,” Fr. Tomy indicates.

Orphans with or without HIV bear the brunt of discrimination. As one social worker said, “nobody wants to care for them.” And then when they did find care, it often comes with varying degrees of mistreatment. One recently orphaned child adopted by his uncle and aunt, was sent to work, to supplement the family’s income. There is also the problem of gender discrimination. In a case where a young girl and boy were orphaned, the paternal grandparents took the boy (not HIV positive), while the nine-year-old girl (HIV positive) was left behind. After a few months in the hospital, she was adopted by her maternal grandmother.

The hospital’s outpatient department has treated 15 to 20 seropositive orphans. The hospital refers some of the seropositive orphans left behind by their patients to the Jyotnis HIV/AIDS Care Hospice in New Bombay, which is run by the Sisters of the Destitute.

Prevention Programme

In the case of patients who are married, “we insist on testing (free of charge) the wife in the hospital,” said the hospital gynaecologist. This testing is both preceded and followed by counselling. The results more often than not show the woman to be infected. “It is very rare that the woman whose partner is infected turns out to be negative,” she added. Partner identification, however, remains restricted to married PLHAs and, was restricted to the spouse of the patient. In a situation where most

of the patients had been either truckers or migrant labourers, the fact that there are numerous others who had been infected by these patients was a matter of grave concern.

Patients were informed about the pros and cons of condom usage as a preventive measure at the post-test counselling session. At the time of the patient discharge from hospital Fr. Tomy said, "It is mandatory for the patient and the spouse to demonstrate the usage of the condom in the presence of a male and female counsellor." "We repeat the information given at the time of post-test counselling," said the social worker. "It is important to focus on spreading AIDS awareness on seropositive people in order to keep the virus in check."

Patients were informed about the pros and cons of condom usage as a preventive measure at the post-test counselling session.

Prevention of Mother-to-Child Transmission

While the hospital does not have a Mother-to-Child Transmission programme, it does advise HIV positive mothers on ways they can protect their baby from the transmission of the virus, such as avoidance of breast-feeding if baby formulas can be afforded. "Another important factor in trying to reduce the risk of mother-to-child transmission is balanced nutrition."

Equally important is the avoidance of the stress factor, as it could result in the tearing of the placenta and the consequent mixing of the blood of the mother and the baby. Elective caesarean surgery is also advisable because it allows for the anti-retroviral drug AZT to be administered to the woman between the 34th and 38th week of her pregnancy. To further minimize the risk of contracting HIV, the newborn can be started on AZT syrup at six weeks of age. After explaining the pros and cons, "The decision is left entirely to the patient," said the doctor. In most cases the parents-to-be opt for caesarean delivery in their eagerness to safeguard the baby. However, if they chose not to go in for a C-section, it is due to "financial constraints," she said, as a caesarean surgery in the hospital would cost between Rs. 2000 to Rs. 3000.

Stigma may also be carried into death, where in some cases, the relatives have refused to claim the body of their family members who were PLHAs, out of fear.

Outreach Programme

The hospital conducts its outreach programme through its sub-centre in Satara District. The sub-centre staff includes two counsellors, a programme coordinator and a health worker. One of Bel Air's counsellors said, "The focus of the hospital's social workers is on counselling, and home visits only form a small part of the work, namely four to five visits a month, as against a total of 20-25 monthly visits to the different villages in Satara by the social workers from the sub-centres."

These home visits can serve as follow-ups if a patient on ART does not visit the hospital after discharge, if a patient is in need of any help or hospitalization or if the person experiences stigma for being a PLHA. "There have been reported cases of PLHAs being stigmatized either by their fellow villagers or family, even after they have returned home, following their treatment in the hospital," said Fr. Tomy. "In one village we found that a seropositive person was made to sleep in the cowshed at night." Stigma may also be carried into death, where in some cases, the relatives have refused to claim the body of their family members who were PLHAs, out of fear.

Another deterrent to the interests of PLHAs in the villages is, as Fr. Tomy notes, "the absence of confidentiality." He added, "Every one knows that a person is HIV positive even before he comes to the hospital. Even the doctors and lab technicians there disclose information that a certain person is HIV positive. It is not an important issue there."

Networking and Linkages

In attempting to combat stigma, the village sarpanch (elected headman) can be a co-operative and effective partner. As a social worker said, "We visit the village and have a dialogue with the sarpanch, in addition to the family members and the villagers." These 'sarpanch' (local elected leaders) are open to discussion and in a few instances even visited the patients in hospital.

The other modes of stigma reduction in the villages have been through HIV/AIDS awareness programmes, namely street theatre, staged by volunteers at the village level, slide shows, question and answer sessions and the distribution of HIV/AIDS awareness literature in Marathi - the mother tongue of the villagers.

While the sub-centre staff was invited by the tarun mandals (youth groups) in the villages to conduct HIV/AIDS awareness programmes at time of festivals, as Fr. Tomy notes, the team visited the villages even uninvited.

The process of sensitization of the villagers to the issue of HIV/AIDS is an ongoing one and was initiated around the early days of the project. "Sometimes some of the villagers are brought to the hospital to be trained in HIV/AIDS awareness. This has helped greatly in the reduction of discrimination," said Fr. Tomy. The hospital also networks with other organizations in Satara, Pune and Mumbai in seeking treatment, and support in financial, domestic and legal issues. The hospital is also attempting to get the PLHAs to network with the support group, Networking with Positive People.

Healthcare

Surgery on Persons Infected with HIV

The first surgery was performed on a patient who had suffered multiple fractures and had arrived at Bel Air after following a circuitous route to hospitals in Pune, Satara and Phaltan where he was rejected. While the hospital's orthopaedic surgeon agreed to operate on the patient, the anaesthetist flatly refused to provide his services. This prompted Fr. Tomy and his team to identify a senior anaesthetist from within the state, but then the hospital matron announced that her nurses would not be assisting in the surgery as they were terrified of getting infected. However, as a result of Fr. Tomy's intervention, the nurses agreed to be a part of the surgical team and the man was successfully operated upon.

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Another instance in the hospital's early history of positive interventions was when a 25-year-old patient from Satara, in need of a minor surgery.

Another instance in the hospital's early history of positive interventions was when a 25-year-old patient from Satara, in need of a minor surgery. This patient too had visited a number of civil hospitals. Fr. Tomy explained, "The hospital in Satara had certified his HIV status in writing (which is unethical), referring him to the state run Sassoon Hospital in Pune. At Sassoon, he was discharged on the pretext of their not having the 'required' facilities for the treatment and surgery of the patient." The patient ended up in Bel Air where surgery was performed, but unfortunately the delay in treatment resulted in his demise.

In the last year, Bel Air's gynaecologist has conducted eight caesarean surgeries on seropositive women performed by its gynaecologist. Incidentally, she first overcame her own fears when called to perform a complicated surgery in 1999 on an HIV positive pregnant woman in Ghana who was haemorrhaging. "After that experience," she said, "I knew no fear."

Sexually Transmitted Infections

The question of the incidence of STIs in the hospital drew mixed answers. The hospital gynaecologist who was involved in a study on STIs in women, said she had not come across a single case among the 45 PLHAs in the hospital whom she had investigated. She concluded that most of the patients, by virtue of being old cases of AIDS, would have already been treated for STIs at some point in the past. Besides, "Most of these women," she added, "had lost their husbands to HIV and were no longer sexually active."

However, another doctor who treated both, the male and female PLHAs in the hospital said that manifestations of STIs in the form of syphilis were commonplace which are treated through medication. Hospital records, however classified STIs under the 'other infections' category. As a rough estimate, a hospital social worker put the incidence of STIs in 'serious' patients between 30 to 40 percent.

All the PLHAs in the hospital are at different levels with regard to their physical condition, but all these people, no matter what their condition was, said they are happy with the treatment provided by the hospital. Most of the patients come in the terminal stage, when their CD4 counts had dipped way below 50. The prognosis is very poor and the condition goes through a constant state of flux, marked by convulsions, bleeding, sinking into coma or simply collapsing into a state of no return.

Anti-retroviral Treatment

The hospital had 25 patients on ART as of September 2004. Fifteen of these patients were volunteers. According to Fr. Tomy, to get started on ART, the patient has to have a CD4 count of 200 or lower. This requirement, according to him, was easy to meet as between 75 to 80 percent of the patients in the hospital have a CD4 count which was way below 200.

Another determinant for starting a patient on ART, according to Fr. Tomy, is the patient's "level of motivation." This was especially important, given the chances of backsliding, as a result of the side effects which could be extremely painful.

Fr. Tomy, expressing views that were strongly in favour of ART, said there have been a "high success rate among the hospital's patients who have opted for it" (ART). This, he said, has been especially true of the volunteers, in whom "there has been a marked resurgence. Some of them were admitted to the hospital in a state of semi-consciousness. Many had weighed even below 45 kg," he added. The hospital's gynaecologist said, "ART has certainly worked. Many of the volunteers have benefited immensely from it." One valuable quality of ART, the doctor emphasized, was that it enabled the quality of life to be good rather than simply prolonging it.

All the PLHAs in the hospital are at different levels with regard to their physical condition, but all these people, no matter what their condition was, said they are happy with the treatment provided by the hospital.

The severe side effects that the volunteers described, namely nausea, headache and skin infections were said to put the patient off the treatment.

The severe side effects that the volunteers described, namely nausea, headache and skin infections were said to put the patient off the treatment. Therefore, Fr. Tomy said, "It is important to administer the treatment under proper medical management and constant motivation." The patients, he added, were monitored every month.

A strategy that the hospital had devised, to ensure adherence at least in the initial stage of the treatment, as Fr. Tomy said, was to "force patients starting ART to stay in hospital in the initial 15-20 days, as this is the crucial period in the treatment." This period was also marked by tremendous agony.

"Peer support is another factor that could work as a catalyst in keeping the patient on ART," says Fr. Tomy. There are some lucky ones, he added, who do not suffer any side-effects. Among the volunteers, the CD4 counts were reported to have touched new highs. One of them saw a jump from 82 to 800 since being on ART. Those who have tried ART have seen that it comes at a price. "The cheapest regimen could cost between Rs.1000 to Rs.1200, something that only 10 per cent of our patients can afford," said Fr. Tomy.

The volunteers hoped for the day when ART would be available at more affordable prices. Fr. Tomy on his part has been working towards getting ART free of charge at Bel Air, as part of the state government's free ART distribution programme.

But until that happens, patients who are desperate to hang on to life resorted to all kinds of means to buy what they thought is a 'life saving' cocktail, often ending up in dire financial straits. This reflected on the patient's mental and physical state. "If a patient on ART is under severe stress, caused by a financial strain ART does not work well," said Fr. Tomy.

Medical experience at the ground level has sounded another note of

caution, a point that was either ignored or unknown by the patient fraternity. As one doctor warned, “It is advisable to start ART if the patient does not have too many opportunistic infections, which need to be treated first. As far as critical patients go, it is not at all worth trying ART. This is especially so if HIV takes its toll on the Central Nervous System (CNS).”

Clash Between ART and TB Treatment

Another reason for putting ART on hold, the doctor added, is if the patient is undergoing treatment for TB. The two drugs, Rifampicin (anti-TB treatment) and Nevirapine (ART) do not work when taken together. Therefore, to get results, Effavir, another very expensive drug has to be taken alongside.

So if ART is combined with the anti-TB treatment (which could last between six and nine months) the patient could be set back by about Rs 15,000 to Rs. 20,000 a month for that period, said the doctor. In the case of multi-drug resistance, a common villain in TB treatment, the cost could go even higher as new lines of treatment cost much more than the original one.

Given the fatal potential of TB, the doctor said, “It is absolutely imperative to control TB, because if it spreads, death is sure to follow.” This, she added, is also true of any other opportunistic infection, which goes untreated. Therefore, “it would be more advisable to deal with opportunistic infections, rather than resorting to ART,” she added.

ART and Discrimination Against Women

Women are at the receiving end not only in the transmission of HIV, but even in its treatment. Social workers and the doctors agreed that when both the partners are infected, the husband is given preference over his wife in getting treated. The decision as to who should get treated first is taken either by the couple themselves or as is often the case, as one doctor says, “by the woman’s in-laws.” This was especially true in the case of ART. Hospital records revealed that those who had undergone ART during January 2003-2004, included 390 men, in contrast with 110 women.

The hospital used disposable syringes. Needles and other materials were destroyed either by deep burial or in a metallic incinerator situated on the periphery of the hospital.

Adherence to Standard Precautions

There have been instances in the hospital where nurses have sustained pricks from needles used to inject the PLHAs. These nurses had been put on ART. None of these staff members, the hospital said, have become infected with HIV.

The hospital used disposable syringes. Needles and other materials were destroyed either by deep burial or in a metallic incinerator situated on the periphery of the hospital. However, as a doctor said, "This is not an ideal incinerator. The hospital needs a very good one."

During surgery performed on PLHAs, the protective gear included: double gloves, foot protection over sandals and protective goggles which helped in case of fluid splashes, especially common in caesarean operations. The linen used during surgery is washed in a special disinfectant called Dakins Solution (sodium hypochloride).

In handling patients having wounds, doctors and health workers wear gloves. "When around TB patients, we wear masks," said one doctor. If the spouse caring for the patient is not HIV positive, he or she was compelled to use gloves in order to avoid any direct contact with the body, which could result in the contraction of infections.

Resistance of Bystanders to Wearing Masks/Gloves: However, the hospital had not been successful in getting the bystanders of these severely infected patients to wear either gloves or masks when around their loved ones. "Some of the very illiterate women do not listen to these instructions. They are either not fully aware of the seriousness of the problem or they are reluctant to make the patient feel isolated."

On the other hand, not all of the patients were seen wearing masks. This, the doctor felt, was unsafe for the patient, "given the abundance of micro organisms floating around."

Equally at risk were the hospital's medical staff and the counsellors who had to be sitting with patients for prolonged stretches. "We are at a high risk as many of the patients we see are in advanced stages of TB," said one counsellor. However, "it would feel awkward to wear a mask before a person who is confiding personal details in you." he added. As the hospital has no blood bank of its own, it had to resort to getting blood from the nearest blood bank in Wai that was six to seven km from Panchgani. "Not having a blood bank poses difficulties during emergencies," said a doctor.

Care and Support

Counselling to Family of the PLHA

Counselling is also extended to family members not just in the areas of home based care but also in that of any further damage control. As a counsellor said, "Parents of patients who talk of getting their HIV infected sons or daughters married are enlightened on the demerits of getting an HIV positive person married."

In case of PLHAs who suffered with cancer, the hospital referred them to other hospitals equipped to handle the cases. Sometimes PLHAs were also referred to government hospitals in their vicinity. For follow-up treatment, patients were referred to doctors in their vicinity through the sub-centre staff, who in turn visited these doctors as part of the patient's follow-up. HIV/AIDS awareness literature in Marathi, produced by the Maharashtra AIDS Control Society (Maharashtra District AIDS Control Society) is given to patients before being discharged from hospital.

Counselling to Patients

In the counselling room attached to the ward, the two counsellors are continually brought face to face with very real and grave fears of life and death. One of them said, "They (the patients) make quick connections between HIV/AIDS and death. We explain to them that HIV

HIV/AIDS awareness literature in Marathi, produced by the Maharashtra AIDS Control Society (Maharashtra District AIDS Control Society) is given to patients before being discharged from hospital.

The Alcoholics Anonymous chapter from Pune has been invited to conduct monthly meetings for patients who had a drinking problem.

is the first step and AIDS is the last stage and that death does not necessarily come fast.”

As part of a daily workload, a counsellor would typically see five to six patients a day. Besides the times when patients may simply want to unburden themselves by talking, there are the pre- and post-test counselling sessions. According to Fr. Tomy in 90 per cent of the cases of PLHAs who come to the hospital, the route of HIV trans-

mission has been through sex. However, he notes, “During counselling, we avoid delving into the patient’s sexual history.”

Many of the patients, being addicted to smoking *beedis* (tobacco wrapped in bay leaf) and chewing tobacco, were helped to try and quit through group counselling, which was held once a fortnight. The Alcoholics Anonymous chapter from Pune has been invited to conduct monthly meetings for patients who had a drinking problem.

Human Rights Issue

One of the hospital’s interventions in rendering justice to a PLHA was in the case of an HIV positive woman who was being refused the post of her deceased husband who had died of AIDS-related complications. Finally, following the intervention of Fr. Tomy the organization for which her deceased husband had worked, agreed to allow her to take her husband’s job on the condition that she produce her HIV test report. In handling cases of stigma related injustice to PLHAs and their families, Fr. Tomy said he is forced to resort to applying “political pressure.”

Vocational Training

For most patient volunteers, working and staying in the hospital offers them advantages that life outside would not. “If we go out we won’t get work,” they said. “Here in the hospital we get both work and immediate care.” Some of the women volunteers suggested that there could be a wider scope to keep them better and more gainfully occupied through vocational training programmes like candle making.

The hospital has no faith-based programme with any organised religion as its focus, said Fr. Tomy. Instead, meditation and yoga were chosen as the preferred approaches to help instil a sense of calm and balance in the patients. “The patients recite ‘OM’ and have prayer sessions,” he added.

Before the body of a deceased patient is handed over to the family for cremation, the hospital’s PLHA volunteers help in readying the body by spraying it with a herbal disinfectant and wrapping it in a white sheet.

Being in a situation where one was confronted head-on with death, hope is all there is. Speaking of Fr. Tomy one patient said, “If not for this priest, I would have lost hope in living a long time ago. He has been working towards getting the very best treatment for us. I hope to leave the hospital without the virus. This hope has also lessened the depression and worries, making me feel ‘normal’.”

Committed and dedicated personnel in the hospital continue to provide and promote mental and physical healing of the PLHAs through reuniting bonds with their families and friends.

Jeevan Jyothi Hospice

Sateesh R Chandran

“I am but a passerby of this world and that will be for once and for all, therefore if there is any good thing that I can do, or any kindness I can show to any fellow creature, let me do it now, let me not defer it nor neglect it for I shall not pass this way again.”

This motivation seems to be true in the life sisters in Jeevan Jyothi.

The Presentation Sisters in India are part of the worldwide Association of Presentation Sisters numbering 3,500 and working in 27 countries. In India, the Presentation Sisters started their work approximately 130 years ago in Chennai. Administratively, the congregation is divided into four provinces defined as North, South, South-east and South-west. The Indian headquarters of the congregation is at Delhi and there are about 250 Presentation Sisters in total working all over India.

Holy Redeemer Hospital, Theni, locally known as “Convent Hospital’ was started by the Presentation Sisters in 1933 to take care of the health needs of the poor and the needy. Started in a small way, the hospital now has a capacity of eighty five beds with maternity, medical and paediatric wards. It also has a well equipped operation theatre, laboratory, pharmacy and facilities for ultrasound scan. In 1985, the Sisters realized that institutionalized care was not an efficient strategy to cater to the health needs of the rural people and, therefore, started a community health centre. Primary health is the leading concern of the community health centre. It emphasizes the preventive and curative aspects of health by organizing different awareness generation activities, medical camps and health education programmes in the community, thereby reaching out to the people who

would otherwise have been denied access to healthcare. Presently the staff of the health centre is working in 20 slums, organizing women's sangams (groups) and performing other related activities.

Various sources of information such as observations during field visits, house-to-house surveys and records in the hospital and laboratory revealed that the incidence of HIV/AIDS in Theni was increasing. Thus the congregation started preventive interventions such as awareness camps and campaigns, pre- and post-test counselling, medical care, home care and nutritional supplements.

Thereafter the Sisters were struck by the plight of the HIV infected people rejected by family and society, and the misery of the poor infected people who did not have access to treatment, care and support. They felt the need for a community-based centre where good quality care and rehabilitation could be provided to People Living with HIV/AIDS (PLHA). [This was one of the objectives listed in the 1996 Chapter of the General Assembly and of the General Assembly in 2001.] The Southern provinces of the congregation decided that a centre for HIV/AIDS infected people should be established at the earliest assessing the need of a place.

"It was a dream come true, opening up new avenues of service, through relentless efforts, assisted by unlimited generosity - a hospice providing quality care and support to people infected with HIV/AIDS especially the terminally ill" Sr. Anasthasia.

Theni is one of the districts reporting the highest HIV prevalence in the state of Tamil Nadu. As per reports from VCTC, the prevalence rate of HIV in the district is 1.8 per cent and the major route of transmission is sexual. Located near the state of Kerala, and being a hub for commercial activities, the population mobility in Theni is high. Most of the slum areas in the district have large concentrations of migrant populations from the nearby districts. In addition, other factors that contribute to the high prevalence of HIV in the district are low socio-

Presently the staff of the health centre is working in 20 slums, organizing women's sangams (groups) and performing other related activities.

Early marriages are usually attributed to fear of exploitation of women by neighbours and employers, high level of promiscuity, low socio-economic status, illiteracy and societal pressure.

economic status, a low level of knowledge of HIV/AIDS, poor health seeking behaviour, increasing number of sex workers and an increase in the number of widows.

Theni, is a conservative area and people, especially in the lower economic strata, strictly follow the social norms. Most marriages take place within the close family network and early marriages are also very common. Early marriages are usually attributed to fear of exploitation of women by neighbours and employers, high level of promiscuity, low socio-economic status, illiteracy and societal pressure.

Sr. Anasthasia, Head of the Community Health Department took the initiative in setting up the Jeevan Jyothi AIDS Hospice. On 31 October 2002, the foundation stone of Jeevan Jyothi Hospice was laid and the construction work was started at Nagle Gardens, (situated between Theni and Periyakulam towns) and well connected by road.

Jeevan Jyothi Hospice was blessed by Most Rev. Dr. Antony Pappasamy, the then, Auxiliary Bishop of Madurai Archdiocese. With a provision for 24 beds along with two cottages, which can accommodate up to 12 children, it was formally declared open on September 10th, 2003 in the presence of state government ministers, the District Collector and various other dignitaries.

The vision of Jeevan Jyothi Hospice is to provide holistic, comprehensive and quality healthcare to the sick - with special preference to the people infected with and affected by HIV/AIDS. Jeevan Jyothi stands for offering life and light, care and support, to those infected and affected by HIV/AIDS. Since its inception it has provided care to around 300 HIV/AIDS affected individuals from different parts of the state.

The mission of the institution is to be an effective instrument in offering quality, holistic, palliative institutional care aiming at psycho-social and

spiritual support to PLHAs within the community they live, thus resulting in the acceptance and rehabilitation of the affected persons in the communities.

Objectives

- ◆ To raise the quality of life of People Living with HIV/AIDS (PLHAs) and provide them access to quality clinical care.
- ◆ To provide compassionate care to PLHAs especially in the terminal stage of disease.
- ◆ To give psycho-social and spiritual support to PLHAs.
- ◆ To offer spiritual solace (in conformity with their religious convictions) to people in the terminal stage of disease.
- ◆ To provide worth and dignity to PLHAs.
- ◆ To facilitate support and loving care by the family by offering family counselling.
- ◆ To offer care and support to children infected with and affected by HIV/AIDS through medical and educational assistance.
- ◆ To provide quality care and support to those suffering from opportunistic infections.
- ◆ To train healthcare personnel in the management of HIV/AIDS.
- ◆ To help prevention of the spread of HIV through counselling and awareness programmes.
- ◆ To network with NGOs, Governmental Organizations for preventing HIV transmission and rehabilitate (PLHAs.)

The people accessing service from Jeevan Jyothi Hospice centre consist of persons mostly from the nearby slums and villages. The socio-economic status of the majority of the beneficiaries is very low. Most of the people were identified by the field staff through community visits and were brought to the centre. Some were referred from Holy Redeemer Hospital and other agencies working in the area. They reach the centre in a severely malnourished condition, unable to work and earn a living. In most of the cases the infected wife, without disclosing her status, becomes the prime earning member of the family.

Since Jeevan Jyothi is an institutional care and support centre most of the

People affected with HIV/AIDS approach Jeevan Jyothi at a stage when their physical and psychological health is very weak.

PLHA coming to the centre are at the terminal stage of life. So far, more than 300 people have availed of the services of the centre. The centre has witnessed about 80 deaths since its inception. In situations where the family refuses to accept the body of the deceased, the centre takes the initiative to dispose the dead in accordance with his or her faith.

The community in general recognizes the need of a care and support centre for people living with HIV/AIDS and accepts the services offered by Jeevan Jyothi. The number of people infected with HIV/AIDS needing care and support are increasing day by day. Therefore, developing appropriate systems and mobilizing adequate resources to meet this expanding need will be a challenge for Jeevan Jyothi in the coming days.

Holistic Care

Sister-nurse Lucy, with 25 years of work experience says: "A socio-medical approach need to be adopted in the care and support programmes for people living with HIV/AIDS."

"I came here with my mother 3 months back, she died one Sunday. Now I don't have anyone. But the centre takes care of me. I like studying and I want to become a doctor so that I can take care of sick people. Moreover I can give them life as the Sisters are doing here. I want to work in this hospital". Prem Kumar, 13 years old lost his family to AIDS.

People affected with HIV/AIDS approach Jeevan Jyothi at a stage when their physical and psychological health is very weak. They are provided symptomatic treatment for opportunistic infections with the required doses of antibiotics, intravenous fluids and other medicines. The treatment process adopted by the centre integrates allopathic medication with Ayurveda, Siddha and Herbal treatments. If the health condition of the inmates is critical and needs an expert opinion or further investigations, the Sisters

take them to specialist medical practitioners for such expert opinions and treatment.

The nutritional needs of the patients are adequately taken care of in Jeevan Jyothi. The morning starts with a herbal drink early in the morning followed by a cup of coffee. Breakfast and lunch are fixed healthy meals and fresh vegetables from their garden form a part of lunch almost everyday. Meat, fish or eggs are also served thrice a week. Evening tea and snacks are followed by porridge (prepared out of nine types of grains and cereals and 10-15 types of herbal medicines at 6 pm). Dinner is served followed by a cup of milk and this dietary plan is strictly followed in Jeevan Jyothi. This nutritious diet helps the PLHAs to increase their immunity and regain lost body weight in a short period of time. The patients are very appreciative of the quality and quantity of food served in Jeevan Jyothi. Kanmani, a transgender says: "I had lived in other HIV/AIDS care centres, but the food one gets here is really in good quality and quantity."

The centre offers counselling services to help people cope with their psycho-social problems and to increase their self-confidence and self-acceptance. It also helps clients to increase awareness of HIV/AIDS, its modes of transmission, methods of prevention, and life skills to cope with the current health and family situations. Family counselling is also provided whenever possible, so the clients are accepted better in their families and have access to good care at home.

One of the objectives of the Hospice is to psychologically prepare the terminally ill patients for a dignified peaceful death. Prayers and spiritual support-another component of the holistic care is also provided in Jeevan Jyothi. Prayer service/meditation, universal to all religions, is conducted daily to help them deepen their relationship with God. Patients who regain health are encouraged to care for those people who are unable to help themselves. This helps to develop concern and care towards the suffering and the helpless, and also create a sense of belonging to the Jeevan Jyothi family.

Family counselling is also provided whenever possible, so the clients are accepted better in their families and have access to good care at home.

A special programme to Prevent Parent-to-Child-Transmission was initiated through Holy Redeemer Hospital in December 2003 with support from the Tamil Nadu State AIDS Control Society.

Recreational activities, a part of the routine in Jeevan Jyothi centre, help the patients to relax. In addition, the PLHAs are taught simple relaxation techniques and exercises to keep their bodies and minds healthy. In the evenings the patients go for a walk around the campus. Healthy PLHAs are also encouraged to participate in kitchen chores, help in gardening and cleaning, in order to keep themselves engaged. Like in a family, many cultural and traditional festivals are celebrated with the patients of the Hospice.

During field visits and family counselling, the doubts of the PLHAs on inheritance, property and human rights issues are also clarified by the team members. In a few cases they have been assisted in accessing legal help from professionals. With the quality of care and support offered in the Hospice, most of the PLHAs regain lost body weight and develop better self confidence. Once their health is better they are discharged back to their homes. After discharge the PLHAs are encouraged to come back for regular follow-up visits every fortnight.

A special programme to Prevent Parent-to-Child-Transmission was initiated through Holy Redeemer Hospital in December 2003 with support from the Tamil Nadu State AIDS Control Society. The set of services that is offered under the PPTCT programme includes pre- and post-test counselling, HIV testing, treatment with the recommended dose of Nevirapine for the mother and child, and provision for safe delivery of the mother. Women who have been identified as HIV positive in the antenatal clinic are counselled and advised to have an institutional delivery. So far, five deliveries of HIV positive women have been conducted in the Hospice. All babies, except one, were found to be HIV negative. One laboratory technician and one female counsellor are involved in the PPTCT programmes.

Community-Based Care and Support

Community-based activities conducted by the Jeevan Jyothi include peri-

odic home visits, awareness generation activities, developing volunteer and support groups in the community, organizing community health camps, identification of poorest of the poor, pre- and post-test counseling, health assessment, referring terminally ill people to the Hospice, follow-up of the people discharged from the Hospice and providing supportive services to people living with HIV/AIDS.

Regular follow-up visits are undertaken by the Jeevan Jyothi field workers, especially to those who do not come back to the Hospice for follow-up. The field workers visit the homes of PLHAs discharged from the Hospice periodically and interact with them and their family to ensure that they are following the instructions provided by the centre, and are following a healthy lifestyle. The field visits also give an opportunity to address the concerns regarding family support and healthcare needs of PLHAs. In addition, these visits also help to identify new cases within the community that require support.

In Theni, the rate of Sexually Transmitted Infections (STIs) among the general population is reported to be 4.75 percent. A high incidence of STIs is also reported among the people admitted to the Jeevan Jyothi Hospice centre and priority treatment is accorded for this. During awareness programmes, knowledge on the STIs, its links with HIV, the need to complete the treatment regimen and partner treatment are conveyed to the people through individual and group sessions.

The prevention programmes mainly focus on information dissemination on HIV/AIDS/STI transmission and prevention.

Information on treatment and support facilities are also conveyed to the community. Regarding the prevention aspects, focus is given to value-based education. Information on condoms as a means of prevention is also provided, though condoms are not distributed.

Jeevan Jyothi obtains HIV/AIDS educational materials from various agencies, including the Tamil Nadu AIDS Control Society, and distrib-

Regular follow-up visits are undertaken by the Jeevan Jyothi field workers, especially to those who do not come back to the Hospice for follow-up.

utes it in the slums and communities in a need based manner. It has also initiated an awareness programme with barbers to prevent transmission through contaminated blades. Good cooperation has been obtained from the Barbers' Association and the practice of sharing blades has decreased. The Sisters have been able to gain the confidence of the community in implementing prevention programmes. The community listens and respects team members of the Jeevan Jyothi centre and similar need based community-oriented programmes are also in the pipeline.

Jeevan Jyothi has identified the children of HIV/AIDS affected individuals who need assistance for education and nutrition. Fourteen such children have been admitted to boarding schools run by Reach the Unreached Trust.

PLHAs who are unable to withstand the rigors of daily life and lack confidence in working in other places, are offered work in the Hospice itself. Jeevan Jyothi also explores employment opportunities in and around Theni for them and places them according to their potential and abilities. The centre has also initiated a scheme that provides economic assistance for income generation activities and/or gives family assistance to the deserving.

Community mobilization is effected through the formation of self help groups, youth clubs and childrens' units-all mechanisms for providing ongoing support to them. Programmes are comprehensive in nature addressing all the health care needs of the community. Those people who have been identified with STI and tuberculosis (TB) are motivated to go for pre-test counselling and services which will be provided free of cost.

Creating an Enabling Environment

Another Jeevan Jyothi intervention area is to develop a supportive environment for PLHAs. The programmes related to an enabling environment are developed based on the premise that some human behaviours are instinctive but may lead to difficulties and hazards at a later stage in life. Even though some people may find it difficult to control these hazardous behaviours, an enabling environment

can reduce the risk associated with these behaviours.

Stigma and discrimination against PLHAs are major obstacles in carrying out programmes in the community. It seems that in the community, isolating PLHA and discriminating against them happens because of irrational fear and stigma attached to the disease. During one of the interviews, Gopal, who stays in the Hospice along with his infected wife, said that, "When I came to know about my status, I didn't outwardly express any frustration. On the contrary I presented myself as a cheerful and happy person though I was under great stress ... I had seen my neighbour committing suicide after knowing his HIV status and was afraid of the community's reaction."

Stigma and discrimination against PLHAs are major obstacles in carrying out programmes in the community.

The outreach workers of Jeevan Jyothi, through regular community visits and interaction with the family members, make all conscious attempts to create an enabling environment in the family and the community. By organizing meetings of youth clubs, mahila sangams and self help groups, community support is mobilized for the programme. The centre also maintains a good relationship with the government authorities and other agencies in and around Theni.

Infrastructure

Jeevan Jyothi Hospice centre functions in a separate campus, built on the land provided by the Congregation of Presentation Sisters. The complex has five blocks. The main block consists of wards for the PLHAs, an antenatal clinic, nursing room and clinical examination room, along with the kitchen, dining, prayer and meetings rooms.

The second block has facilities for outpatient consultation, a training hall, doctors' residence and dormitories. The Chapel and the residence of the Sisters are in the next block. The accounts and administration block and the residence of nursing staff are in the remaining blocks. The hospice also provides ambulance facility.

Almost all members in the care giving team were qualified in accordance with their job requirements.

The campus has good electricity connection and water supply. A well-maintained garden, waste recycling unit, solar cooking facility and productive agricultural activities are unique features of Jeevan Jyothi. The centre conducts periodic quality check on cleanliness, hygiene, medical care, caring and nutritional support.

The centre also has an intensive care unit, antenatal care facilities, an outpatient department for general medicine and centre for HIV testing based on ELISA test (only on Fridays).

Human Resource Profile

“Witnessing death is not a new thing in the nursing profession, but caring for a person, knowing that death is closer to him/her is painful.... When you experience these daily, it affects you emotionally,” said Sr. Lucy.

The situation might be the same with most of the caregivers in Jeevan Jyothi. The discussion with the caregivers reveals that it is not by ‘chance’ they have taken up this vocation, but it was a ‘conscious choice’. Since it is a choice, their likes or dislikes are of very low priority. The emotional attachment and commitment to the basic cause drives them in delivering quality services.

The project team in Jeevan Jyothi consists of a project director, a nursing matron, part-time doctor, administrator, accountant, two outreach workers, a field worker/counselor, three staff nurses and three support staff. In addition to this, the centre receives human resource support from the congregation from time to time. Almost all members in the care giving team were qualified in accordance with their job requirements. They have also received proper training from external resource persons. Additionally, the centre has its own in-house training systems, which cater to the training needs of the team.

Sr. Anasthasia is the backbone of the institution and for the last six years she has been associated with HIV/AIDS related programmes. Sr. Lucy

also provides ample support and other team members accept the leadership and function as an effective team. A team of resident nurses are the primary caregivers in the Hospice. A part-time doctor visits the centre daily and offers medical assistance and advice. Besides them, healthy PLHAs help in taking care of other patients who are usually without any attendants (family caregivers).

In their endeavour to provide quality care and support to people infected with and affected by HIV/AIDS, Jeevan Jyothi has got support from the congregation, Miriam Dean Trust of United Kingdom, Reaching the Unreached Trust and the Tamil Nadu State AIDS Control Society.

Sr. Anasthasia on availability of resources states, “We will work, as long as we have the physical strength to do so. It is our conviction, not a conceived idea.” The supporting agencies also understands the spirit in which Jeevan Jyothi works and so extends whole hearted support.

Networking and Collaboration

Involvement of the community in an effort to bring physical and psychological comfort to PLHA has been achieved, to a certain extent, through networking and collaboration with various groups and institutions.

Reaching the Unreached Trust offers support to Jeevan Jyothi in every possible way, making the delivery of services possible and meaningful. The support of the congregation of Presentation Sisters, especially at Holy Redeemer Hospital, through regular visits gives encouragement and support for the sick and suffering. Holy Redeemer Hospital remains a solid support when the Hospice has to refer PLHA for further investigation and diagnosis.

Members of Malligai Mahalir Mantram make frequent visits to the Hospice and they donate cereals every month. They celebrated Women’s Day on March 8th in the Hospice and interacted with the inmates. During this occa-

Reaching the Unreached Trust offers support to Jeevan Jyothi in every possible way, making the delivery of services possible and meaningful.

To productively utilize the learning experiences of the Hospice centre and its team members, plans for package trainings are also in the pipeline.

sion, they also shared sweets and donated bed sheets.

Nalam Naadum Nanbargal Kuzhu is a group of well-wishers including doctors, professors, government employees, business people, members of Mahalir Mantrams and clubs, who are interested in the issue of HIV/AIDS. Regular meetings are held with this group and their suggestions and assistance are valued immensely.

As mentioned earlier, Jeevan Jyothi, through the community health centre is working in 5 villages. The field workers have contacted important and influential people in these villages and formed support groups. These support groups will function as a back-up system that may help to identify new cases, follow-up old cases and address the concerns of the infected and affected people in the community. Jeevan Jyothi is also a member of Vaigai Network, a network of organizations dedicated to the social and economic uplift of the sick and weaker sections of the society in Theni District.

Way Forward

Jeevan Jyothi Hospice is in the process of establishing itself as a separate legal entity. There are plans to construct one more floor in the main block so that an additional 24 beds can be added. An outpatient department which will address the general health needs of the neighbouring community is expected to start functioning in November 2004. This will increase the scope of community health interventions which will be expanded to 5 more villages.

To productively utilize the learning experiences of the Hospice centre and its team members, plans for package trainings are also in the pipeline. The institution plans to rent out the infrastructure and facilities to other like minded organisations at a minimum cost for short term programmes and activities. This will help to generate additional income to support its programmes.

Even though efforts are made to address issues of stigma and discrimination, it is important to create and strengthen community structures to address these issues more effectively. More structured programmes focusing on prevention need to be planned and implemented, for which external technical support might be useful. Currently, the resources for the programme are accessed through individual efforts. The current flow of resources may not continue for long. Alternative resource mobilization strategies and systems then can sustain and individual efforts have to be identified and implemented. There is also a need to strengthen the documentation system of the agency. The management, through appropriate means, should disseminate the learning experiences of the centre for the benefit of other faith-based initiatives in the field of HIV/AIDS.

Jeevan Jyothi Hospice centre has to a great extent been successful in providing **'life and light'** to people infected with and affected by HIV/AIDS in and around Theni district. The centre has been receiving moral and material support from the parent body, Presentation Sisters, and has an effective leadership. It also maintains a healthy relationship with the neighbouring communities and other stakeholders. The congregation should think about developing second level leadership, which will be helpful in expanding the scope of work of Jeevan Jyothi.

Jyothis Charitable Trust

Joy Abraham

The Congregation of 'Sisters of the Destitute' was founded on 19th March 1927 by Rev Fr. Varghese Payyappilly. It was started in Kerala at St. Joseph's Mount in Chunangamvely, Aluva in the Archdiocese of Ernakulam, Kerala. The Congregation was originally named 'Little Sisters of the Poor' which was later changed to 'Sisters of the Destitute', as a Congregation with the same name already existed.

The Congregation began with the aim "to continue Christ's redemptive Mission among the poor and the destitute, aged and infirm, unwanted and downtrodden abandoned in the streets or uncared for at homes." Immediately upon its founding, the Congregation started a home for the aged.

Sisters of the Destitute are engaged in various social, educational and health related programmes. Present activities of the Congregation include; Home for the aged, terminal care centres for cancer, Institutional care centres for PLHA, rehabilitation centres for physically and mentally handicapped children, day care centres for children, public health centres and dispensaries, hospitals and schools.

'Jyothis Charitable Trust' (JCT) was formed by the Sisters of the Destitute, Shantidham province in 1999 and registered it under the Bombay Public Trust Act, 1950. The trust was started with "*The aim of rendering service to the poor and underprivileged of the society irrespective of caste, creed and religion.*"

The main objectives of the trust include:

- ◆ Establish houses for the poor, destitute, the aged and the dying, and to establish homes for the rehabilitation of the physically handicapped and mentally challenged.
- ◆ Promote and assist in the enhancement of the physical, material, educational, intellectual, moral and civic welfare of the people.
- ◆ Establish, develop, maintain and administer medical institutions including hospitals, clinics, mobile clinics, health centres and rehabilitation centres.

The Centre provides palliative care services to both men and women irrespective of their religion, caste or cultural background.

Jyothis Charitable Trust has two centres providing institutional care and support programmes under its aegis namely, Jyothis Terminal Care Centre (JTCC) and Jyothis Care Centre (JCC).

Jyothis Terminal Care Centre

The rising numbers of people living with HIV/AIDS and the consequent increase in discrimination and stigma has led to family members deserting them and leaving them destitute, especially in the case of women. This motivated Sr. Redempta to start the hospice in Kalamboli in Navi Mumbai, (Raigad district Maharashtra), known as Jyothis Terminal Care Centre. The Centre was inaugurated on December 26, 1999. It is located 10 kms from Belapur, the business centre of Navi Mumbai, and also from Panvel, one of the fast developing suburbs of Navi Mumbai. The Centre is built on 1200 square metres of land purchased from CIDCO. The Centre has the capacity to admit 36 people, of which eight beds are currently reserved for men.

The Centre provides palliative care services to both men and women irrespective of their religion, caste or cultural background. On 29th of December 1999, the first clients were admitted at the Centre and since then a total of 680 people living with HIV/AIDS have received palliative care services. Palliative services include; residential, medical,

The majority of the people admitted come from the lower and middle socio-economic class.

nursing care, spiritual support, preparing the patients for death, and also providing post-death assistance to the families.

Jyothis Care Centre

From the centre's inception, the Sisters were faced with the challenge of dealing with the problems of women who were deserted by their family members or sex workers who had no place to go. In an effort to address this issue, with the help of the Japanese Consulate in Mumbai, JCT started a rehabilitation centre for women PLHAs in Taloja, known as 'Jyothis Care Centre' (JCC). The centre was inaugurated on 16th January 2003. JCC's objective is to provide these women with residential facilities as well as training in skills that would provide income generation opportunities. It has the capacity to accommodate 30 women. Currently 19 women either destitute or deserted by family stay at the centre. JCC is located 1.5 km inside on the old Mumbai-Pune highway and approximately 10 kms from Kalamboli in Navi Mumbai and Mumbra, one of the Central Railway stations. Services at both the Centres are completely free of cost. However, contributions from families who can afford it are encouraged.

Description of the Clientele

The PLHA are referred to the Centres by various organizations from Mumbai and other parts of Maharashtra and India. A significant number of PLHAs are also admitted directly by close family members and relatives. Nearly sixty per cent of the clients are residents of Mumbai and the rest from Thane, Navi Mumbai, Panvel and rest of Raigad. The majority of the clients are in the age group of 20 to 45 years.

The majority of the people admitted come from the lower and middle socio-economic class. Their occupational background shows that the men worked as labourers, drivers, hotel workers, contractors, marketing persons, vendors, farmers and businessmen. The majority of the women were housewives and others were sex workers mainly from Mumbai.

Since 1999, JCT has admitted 680 clients, fifty one percent being men and forty nine per cent women. Of these, 298 people died at the Centre and 333 were discharged after improvement in their health conditions. At present, there are 19 residents at JCC and at JTCC the number of patients at any given time is over thirty.

JTCC gives preference to terminally ill clients. However, very frequently, it is forced to admit those who are deserted by the family and have no place to go.

When JTCC started, it was planned to have an equal number of beds for men and women. However, the admission of males was terminated for a year and a half, from the end of 2002 to beginning of 2004, as the Sisters found it difficult to manage the mixed clientele. Nevertheless, they had to re-start admissions, as other Centres in Mumbai were overcrowded or provided only short-term care facilities. Currently there are eight beds for male PLHAs.

Clients prefer to come to JTCC, as it is the only Centre providing free services without any discrimination. Besides, the Centre is known for its high standards of hygiene and empathetic care. Clients express complete satisfaction and appreciation about the services at the Centre. Nevertheless, they require a lot of support to cope with the fear of imminent death, hopelessness and the feeling of being isolated by their families. Though they value the shelter, food and strength they receive from group prayers at the Centres, they are often sad and feel death is the only reality to which they can look forward.

Clients prefer to come to JTCC, as it is the only Centre providing free services without any discrimination. Besides, the Centre is known for its high standards of hygiene and empathetic care.

Care and Support Services

Institutional Care

JCT has flexible admission criteria. It provides services to clients who are poor, destitute, or referred by non-governmental organizations (NGOs), health care providers, relatives or

All the patients admitted to the JCT are given symptomatic treatment for opportunistic infections.

any responsible persons. Admission is open from Monday to Saturday from 9:00 a.m.–1:00 p.m. and 4:00–6:00 p.m. Both JTCC and JCC are institutional services based on charity and a missionary approach. They provide free food, medicines and accommodation to all the patients during their stay.

In the JCC admission is reserved only for HIV positive women deserted by their families or those with no place to go. There is no guideline regarding the duration of stay at JCC. It depends mainly on the health condition of the client and their family and support systems. Some of the clients stay at the Centre over a year. Even those who have been discharged are readmitted if there is a need.

Accommodation

There are six dormitory type rooms and each can accommodate up to eight patients. The rooms are well ventilated with windows covered with iron grills and mosquito nets. The Centre has two common halls for programmes as well as a prayer room (chapel). The dining area is attached to the kitchen, where able-bodied residents have their meals. It also has a television, so that patients can also see their favourite TV programmes during meal times. Though they miss their homes and children, most of the clients feel “the environment at the Centre is better than their homes.”

The day starts at 7.00 a.m. with physical exercise and prayers. Breakfast is followed by nursing care. Post lunch, the doctors take rounds to examine patients. In the evening recreational activities are held, followed by prayer and dinner. Besides the routine tasks, there is scope for clients to engage in-group activities and recreational sessions organized by volunteers and peers.

Medical & Nursing Care

All the patients admitted to the JCT are given symptomatic treatment for opportunistic infections. The common symptoms are body pain, weight loss, diarrhoea, weakness, skin infections and breathlessness. Sisters

Mr. V suffered multiple fractures after a serious accident and was admitted to a public hospital in Mumbai. As he needed an immediate operation, an HIV test was done and he tested positive. The hospital, without providing him with any treatment, sent him home, which was on the pavements at Santacruz. His wife, who is a domestic worker, took him to the JCT. According to sisters, when he came he had maggots all over his body, he was in severe pain and all thought he would not survive long.

The sisters nursed him daily, giving him nutritious food. They also helped his wife put the children in a hostel. Mr. V lived in the Centre for one year and most of his fractures healed. He also needed an operation, which was conducted at Bangalore by Snehadaan (at their cost). Today, Mr. V is back in society, working in a telephone booth.

visit the patients and provide nursing support such as dressing of wounds, administering medicines, recording temperature and blood pressure and feeding bed-ridden clients. The medical consultant visits the Centre three times a week. A doctor is also available if there is an emergency. The peer staff (staff who are themselves infected by HIV) help in sponging the bed-ridden patients and ensure timely intake of medicines and food.

At JTCC, any given time, more than fifty per cent of the patients are on tuber-

culosis (TB) drugs. The Sisters and peer staff do regular monitoring of medicine intake by the residents. JTCC does not carry out regular investigation and testing. This is mainly because, in the words of the medical consultant, "most of the patients are tired of investigations, so we do not do any, unless required." JTCC refers patients to nearby Mahatma Gandhi Mission Hospital and Medical College for investigations and specialized medical check-ups.

Currently, JCT does not have the resources for anti-retroviral therapy (ART). Only one peer staff gets the anti-retroviral drugs, which comes from an individual donor. Monitoring of treatment is done with the help of Bel Air Hospital, Panchgani, Maharashtra.

JTCC refers patients to nearby Mahatma Gandhi Mission Hospital and Medical College for investigations and specialized medical check-ups.

Most of the patients come on a stretcher or wheel chair and are unable to walk or do anything for themselves. Many such patients have returned home walking. The Sisters and peer staff shared some touching experiences about providing medical care. One such experience is narrated below:

JCT takes special care in providing nutritious food to the residents of its two Centres. One of the reasons for the improvement in health of the majority of the patients is the nutritional care they receive. As a resident said, "At home there are many mouths to be fed. My needs came last, especially when all knew anyway I would die. But here with proper food I have regained my health. I could not walk when I arrived at the Centre. Now I clean this place, help in cooking and also feed the sick."

Clients get vegetarian and non-vegetarian food. Breakfast and lunch are cooked with the help of Sisters, while the residents themselves prepare the dinner. Lunch consists of rice, curry, vegetables, salad, curd and fruits. Non-vegetarian items include fish, chicken and mutton. Eggs, milk and curd are served daily. The dinner mainly consists of roti/chappati and vegetables. The Sisters themselves serve the food. Residents can eat as much as they want. People with difficulty in swallowing food are given semi-solid foods or juices. According to the residents the "Food is always hot, fresh like home-made." The residents take turns in cooking, and one member said "There is also a competition among us as to who cooks the best, we feel good when others say the food was tasty." They said that doing these simple task gave them a "sense of achievement" and the feeling of making a "contribution to the Centre" which does so much for them when the whole world has disowned them.

Spiritual Support

Each individual is free to follow his or her faith in both the Centres. Spiritual support, in terms of regular group prayers, are conducted in the morning and evening. Group prayers, usually based on the Catholic faith, are part of daily routine. Discourses are also organized at times. All the residents find that group prayers, bhajans and bible reading revive

and rejuvenate them. Prayers and readings from the Bible are organized at the bedside of a dying resident, which has helped create a prayerful and peaceful environment at the moment of death. Some of the residents even stated that they have experienced the healing touch of god, as they had given up hopes of surviving.

All the residents find that group prayers, bhajans and bible reading revive and rejuvenate them.

Psycho-social Support

All the patients, along with those accompanying them, are given an orientation about the Centre to which they are assigned, and also its facilities. The Sisters attempt to spend time with each resident in order to listen, discuss their problems and to understand them better. They also provide guidance and support to the clients and their families. Issues relating to death and dying are discussed openly with the client to prepare them in the eventuality of death, especially those in terminal stages. Residents at both the Centres are burdened by psycho-social problems, which need to be addressed. A Sister from JCC provides counselling at JTCC once a week. Both the Centres have the potential for improving psycho-social support using the services of a full-time counsellor trained in HIV/AIDS counselling, and through group therapy and family counselling. JTCC, financed by Swargadwar, a non-governmental organization (NGO) located in Taloja, provides financial support of Rs.1000 each to 25 PLHAs who are widows.

Recreational Activities

The main recreational activities for the residents of the Centres are games like carom, chess, cards and other less strenuous games. Gardening is part of their daily routine. Picnics and outings are organized for the able-bodied residents. Residents expressed the desire for more outings as they feel energised by them.

Both Centres celebrate the main religious festivals like Makara Sankranti (an important Maharashtrian festival that marks the beginning of spring season), Bakri Id, Holi, Easter, Diwali, Ramzan Id and Christmas. The residents and nuns celebrate every patient's birthday with

All the women felt that one of the reasons for desertion is their economic dependence on their family members.

enthusiasm. On birthdays the residents are greeted with flowers and songs, and sweets are distributed. The feast days of the Sisters are also celebrated at the Centres, with the residents organising cultural programmes.

Legal Support

Neither Centre takes up any legal matters of the client, which are mostly left to the clients themselves to deal with. When a client needs any external support, they are referred to Lawyers Collective, an NGO that takes up legal issues of PLHAs. A majority of the clients do not report about their properties and personal belongings. It is sad to note that after their death, even though family members do not come forward to claim their dead bodies, they ask for the death certificates and personal belongings.

JCC - Rehabilitation Centre

Some of the women staying in this Centre take part in JCC's outreach activities such as teaching children and working with Mahila Mandals in the villages around.

JCC plans to introduce training in various skills that would help the women earn a living outside the Centre. At present, JCC is exploring the possibilities of cultivating aromatic plants such as lemon grass, palmarosa and vetiver, and the removal of extracts from them for perfumes and skin lotions, as an income generation activity for women in the Centre.

In the group discussion with the women, they strongly expressed the desire to go back to their families. To quote a resident, "Just like the Sisters take care of us, touch us, eat with us, can somebody go to our families and tell them that HIV is not spread by touching." All the women miss their children, the separation is very painful and their children's well-being is their biggest concern. All the women felt that one of the reasons for desertion is their economic dependence on their family members. They felt that if they had a place to live, together with some kind of employment, they would not only be accepted by their

families, but would also be able to live with their children, like their non-infected counterparts. Hence, they expressed the need for income-generation programmes through which they could gain economic independence.

Strategic Planning and Professional Involvement

JCT initiated the palliative care services based on the mission of the Congregation to reach out to the poor and destitute. However, the programmes at JTCC and JCC are not strategically planned. Services focus on residential care, nutrition and spiritual support. Professional help is mainly in the form of nursing care, medical consultation and counselling. The care team presently does not have the services of professionals like medical specialists, social workers and outreach workers. The Sisters themselves do most of the work.

Both Centres have not explored the scope of home-based/community based care for its clients. The link of continuum of care needs to be established. While providing care and support to PLHAs in the form of food, clothing and shelter are important, a broad range of other care needs like hospital admissions, involvement of family members, children's support and bereavement counselling are equally important. Both Centres have great potential to be complete care providers to PLHAs and their families, but fall short of financial and human resources including more capable staff.

Through monthly or bimonthly meetings with the Sisters, the clients participate in planning, improving and implementing services. The clients themselves plan and decide on routine tasks, and the celebrations of the Centres.

JCT has developed a recording system over a period of time, which include an admission register, case file, nurse's daily report and clinical records. The client's consent is taken prior to admission to the Centres. Monitoring of the activities and clients is done on a day-to-day basis.

Both Centres have great potential to be complete care providers to PLHAs and their families, but fall short of financial and human resources including more capable staff.

All the activities of the Centre are supported by local donations from individuals, charitable trusts and businessmen. Sisters manage to raise donations of food, including oil and milk, through individuals and business people.

Funds and other Resources

Jyothis Care Centre is the best example of attempting to sustain a programme on a day-to-day basis through local fund raising. The Centre survives purely out of people's generosity and compassion for the sick. The monthly requirement for running the Centre is around Rs.1.5 lakhs. JCT has not received any government funding support for JCC. The only foreign grant was for the construction of the building for JCC-Taloja and some of the equipment for JTCC, from the Japanese consulate in Mumbai. All the activities of the Centre are supported by local donations from individuals, charitable trusts and businessmen. Sisters manage to raise donations of food, including oil and milk, through individuals and business people. JCT gets free vegetables and fruit from the wholesale vegetable market (APMC market) at Vashi (Navi Mumbai), on a weekly basis. Other donations in kind include 10

litres of milk daily by the Lions Club of Sanpada, 5 litres of milk by an individual donor from the same club and donations of rice, milk powder, oil, soap, washing powder, wheat powder and toothpaste from individuals.

Support in cash is also provided by Trusts which include Rs.54,000 per month from Dorabji Tata Trust (till November 2004) and Rs.38,000 per month from Ryan International School.

The care team includes the trustees, other Sisters of the Congregation, a medical consultant, peers and volunteers. Jyothis Charitable Trust has five trustees. The core team consists of Sisters. Currently the team at JTCC has four Sisters and JCC has three Sisters. They reside in the same premises and are available twenty-four hours of the day in case of need.

All the Sisters, prior to taking up duty in JTCC/JCC, undergo training in HIV/AIDS work conducted by the Catholic Health Association of India

(CHAI). Besides this, they attend training programmes organized by various organizations in Mumbai. Other staff members and volunteers have no formal training except learning from experience on the job, and guidance from the Sisters.

A qualified doctor visits the Centres three times a week and provides medical support to the patients. The doctor follows-up on each patient. She also monitors the TB drugs administered to the patients.

Patients, who have recovered or are healthy, work as peer staff helping to provide nursing assistance, peer counselling and administrative support. Three female PLHAs work full time in the Centres, providing nursing assistance and care of the sick. They help in preparing the beds, bathing the patients, monitoring intake of medicines, and taking the rounds along with the doctors. Peer volunteers, who are recovered patients lend support in cleaning the rooms, cooking the evening meal, helping the sick and in gardening. All the residents who are able to work also contribute in cleaning the Centres. Tasks for such residents are given on a monthly rotation basis. JCT also has a driver. In the absence of any other trained social workers or counsellors and medical professionals, the entire burden of care and support is in the hands of the present care team.

The Centres from their inception have had problems in getting support staff like ward boys, *ayahs* (female helpers) and security persons, as people were afraid to work in a “Centre for AIDS”.

Trustees of both Centres and staff meet on a monthly basis to discuss matters relating to services and administration. The administrator and the staff supervise the day-to-day running of the Centres.

Role of Volunteers

JCT has demonstrated the effective utilization of services of the volunteers who played

In the absence of any other trained social workers or counsellors and medical professionals, the entire burden of care and support is in the hands of the present care team.

Students from St. Joseph's School-Kalamboli, Pillai's College-Panvel, Ryan International-Kharghar and St. Agnel's School-Vashi frequently visit the Centres.

an important role, in the initial days of the Centres, especially in helping to dispose of dead bodies.

Other activities done by volunteers include: finding donors for the Centres, collecting medicine, organising entertainment programmes for residents, sponsoring food, cutting vegetables, and doing maintenance and electrical work. Volunteers also assist in organising awareness programmes.

The commitment of the volunteers stems from their personal need to do something for people and the commitment to caring for PLHAs demonstrated by the Sisters.

Some of the work done by the volunteers is given below:

- ◆ Mr. X, a tailor by profession, came to know of the Centre through the Keraleeya Malayalee Samajam of Kalamboli. Through his work he meets several customers with whom he shares his experience of the Centre. Then he asks them to make a contribution in kind, like medicines, toothpaste etc. that he gives to the Centre and ensures that Sisters personally thank the donor who has given the aid.
- ◆ Mrs. T lives in Kalamboli. For the last 5 years, she has been coming to the Centre daily between 8.00 a.m.–10.00 a.m and helps the Sisters by cutting the vegetables for the day.
- ◆ Students from St. Joseph's School-Kalamboli, Pillai's College-Panvel, Ryan International-Kharghar and St. Agnel's School-Vashi frequently visit the Centres. They perform entertainment and cultural programmes and organize recreational activities for the clients.

All the volunteers feel that due to a better administrative system, their role at the Centres has been reduced. However, they are eager to learn more about HIV/AIDS, so that they can empower and educate other people about them.

JTCC and JCC follow all the standard precautions during nursing and medical care. The doctor and nurses use aprons, gloves and masks during the examination of patients. Only disposable needles and syringes are used. Disinfectants are used while washing the clothes. Standard precautions are followed in disinfecting clothes or any items with possible contact with blood or body fluids. The Centres have post exposure prophylaxis facilities to deal with accidental needle pricks or blood contacts. JTCC has installed an incinerator for disposal of the waste. All the bio-medical waste is incinerated. Other waste is disposed of according to the City and Industrial Development Corporation regulations.

Jyothis Terminal Care Centre is a model Centre for nursing care. Members of other religious Congregations come to JTCC in order to get their members trained in institutional care. With the current staff and facilities, JCT is willing to offer training and practical work experience to one or two persons at a time.

JTCC and JCC network with NGOs, especially in Mumbai, for the follow up of PLHAs after they are discharged. Children infected with HIV are referred to organizations like St. Catherine's Home, Committed Committees Development Trust (CCDT) and Mukti Jeevan.

In JTCC, volunteers help in disposing of the dead bodies of the residents. They help in cleaning, dressing and carrying the body to the cemeteries for burial or cremation. The bodies are disposed as per the religious practices of the deceased. The relative, NGO or person who referred the deceased to the institution is informed and the body is left in bed for two hours (to be handed over to the relative, should one arrive) before it is given a bath and prepared for burial/cremation. If the person is destitute, undertakers make funeral arrangements (the undertakers charge Rs 2500 for disposal of each body). If the deceased

If the deceased is a Muslim, people from the nearby mosque claim the body and dispose of it as per Islamic rites. It has been observed that in the majority of cases, the relatives do not come forward to claim the dead body.

Apart from giving information on HIV/AIDS and the distribution of Behaviour Change Communication (BCC) materials, the staff and residents of the Centre, share their experiences of working with PLHAs and living with HIV.

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Sensitization and Awareness Building Programmes

Besides the palliative care and rehabilitation programmes for PLHAs, JCT through its two Centres reaches out to different groups of people in sensitising and building awareness on HIV/AIDS. The Centres also conduct sensitization sessions for the visitors, friends and relatives of the patients. Over the years the commitment and the approach of Sisters towards the patients has been a strong moti-

vating force for the relatives, volunteers and the neighbouring communities to come forward and contribute to the Centre.

Apart from giving information on HIV/AIDS and the distribution of Behaviour Change Communication (BCC) materials, the staff and residents of the Centre, share their experiences of working with PLHAs and living with HIV. Target groups of the awareness programmes include school and college students, village women, men and youth, the general public in Kalamboli and Panvel, rickshaw and truck drivers and hotel workers. Various communication methods like talks, video films shows, street plays, rallies, exhibitions and group sessions are used.

Since most of these programmes have been conducted on request, there is no fixed module or definite strategy for implementing the awareness programmes. Nevertheless, the programmes have helped to a large extent in reducing stigma and increasing the acceptance of PLHAs by the neighbouring communities. A significant visible outcome of this initiative is the programmes organized by students from nearby schools for the residents of the Centre on a regular basis, especially during festivals and celebrations. Students and teachers demonstrate a higher level of

awareness and knowledge on HIV/AIDS. Teachers said that “by interacting with PLHAs at the Centre, we want to demonstrate to our students that HIV does not spread by touching.” It was also observed that students interact with the residents freely and without fear.

Information, education, communication (IEC) programmes conducted by JCT are based on Catholic teachings. The emphasis is on abstinence from sex and faithfulness between partners. Condom usage for prevention of STI or for family planning is not discussed in the programmes.

The Centres actively conduct programmes to mobilise the community on various PLHA issues, especially stigma and discrimination. Their community sensitization activities have contributed towards the local residents’ acceptance of both the Centres. JCT is also an active member of the Mumbai & Navi Mumbai Network of NGOs working on HIV/AIDS. JCT has a strong rapport with all the local NGOs, the State Aids Control Society (SACS), hospitals and PLHA organizations in Mumbai and Navi Mumbai.

Though JCT does not have a written policy, it follows a strict code of practice in respecting the rights of clients. No interview with residents is allowed without their prior permission. The Centres do not allow anyone to take photographs of residents and visitors are not allowed to interact with residents without the permission of the management and without any purpose. Orientation is provided to all the volunteers and visitors to make them aware of their duties and responsibilities. JTCC/JCC does not disclose the personal details of the clients to a third party without the consent of the client and the treatment and care plan is organized with the knowledge and consent of the client.

JTCC is the first care home for PLHAs in Mumbai and Navi Mumbai, admitting both male

JTCC/JCC does not disclose the personal details of the clients to a third party without the consent of the client and the treatment and care plan is organized with the knowledge and consent of the client.

Of those admitted to the Centre, nearly forty-nine per cent of the clients were discharged, and the majority of them returned to their homes healthy.

and female clients and providing free services. Clients prefer JTCC and JCC for the love, compassion and care the Sisters provide to the residents. Clients also expressed more trust in a Centre run by Sisters. These opinions were shared by organizations referring PLHAs. The quality of nursing care, personal attention and approach to patients is unmatched when compared to similar care centres in the city. A PLHA organization in Mumbai describes the services of JCT as “the best human care provided in an institution with dignity, respect, love and empathy”. Volunteers call the Sisters of Jyothis Terminal Care Centre as “Kalamboliyile Malahamar” (The Angels of Kalamboli).

Since there is great confidence and trust in institutions such as JTCC and JCC run by religious Sisters, their messages of prevention, care and support are taken seriously. This is evident from the fact that Sisters are able to mobilise local resources for day-to-day functioning, motivate volunteers and increase the acceptance of PLHAs by the community.

Further Learnings from the Experiences of the JTCC and JCC

The “Institutional Care Facility of Jyothis Charitable Trust” is having a significant positive impact on the lives of the men and women infected with HIV/AIDS, especially in the terminal stage of the illness. Experiences clearly indicate the need for institutional care facilities that are PLHA friendly and holistic.

Of those admitted to the Centre, nearly forty-nine per cent of the clients were discharged, and the majority of them returned to their homes healthy. This reiterates the importance of short-term residential facilities for PLHAs especially after hospital discharge or during illnesses when families find it difficult to offer care at home.

Nutritional and spiritual support along with treatment for OIs in a relaxed environment helps PLHAs to regain health and get back to their normal life. Unlike other professionals in the field, Sisters have rarely faced the

issue of burnout as a serious problem. The spiritual strength generated from prayers, helps them to deal with work pressures and they are able to maintain a balance. Flexible admission criteria make the services client friendly and thus accessible.

Maintaining good relationships with NGOs, community-based organizations, volunteers and individuals helps to generate demand for services as well as mobilising the community resources.

Community volunteers could be included in the various activities of the institution, but cannot be the sole caretakers of chronically ill patients. Volunteers need to be trained and monitored in their tasks.

Challenges

One of the major concerns of all the clients is the availability of ART. For this, JCT requires additional financial and technical support. Though JCT has broadened its care and support services for PLHAs by establishing the rehabilitation Centre for women who are in distress, a viable rehabilitation plan that includes reuniting the women with their families and children, teaching them new skills to become economically independent and improving their self-confidence is crucial.

Addressing other special needs of women is a real challenge for JCT. The concerns of women, especially in relation to their inability to provide for their children with emotional support seems to have negative impact on them, often resulting in them feeling isolated and withdrawn, even when the best care is provided. Women were just waiting to go back to their families. While all stated that the Centre was instrumental in their regaining their health, non-acceptance by the family worsened their mental condition. There is the need for more trained counsellors to deal with this situation.

Sensitising and motivating families to accept and take care of PLHAs involves counselling

Sensitising and motivating families to accept and take care of PLHAs involves counselling and training of family members and relatives, and this should be part of institutional services.

and training of family members and relatives, and this should be part of institutional services. This ensures that HIV engenders fewer stigmas at the community level.

The on-going training of staff, peers and volunteers and the sustaining of institutional services requires additional resources.

Additional manpower in the form of professionals such as counsellors, social workers and medical specialists can further enhance the services of both Centres and make them holistic and comprehensive.

Eduljee Framed Allbless Niramay Niketan

Gracy Bibiana Fernandes

The St Vincent de Paul Society traditionally engages in developing services and programmes to meet identified community needs. Registered under the Charity Commissioner, Mumbai, the society operates in Mankhurd - an eastern suburb of Mumbai. Currently one of its projects is a HIV/AIDS hospice, constructed in the mid-nineties, which goes by the name of the Eduljee Framed Allbless Niramay Niketan, as it is located on property donated to the Church by the Allbless family over one hundred years ago.

The intervention of this hospice addresses issues related to the treatment, care and support to people infected with HIV. The service provided is mainly institutional, with some focus on reaching out to the patient's family and community. Most of the clients seeking treatment had been tested for HIV before coming to the hospice and were aware that there was no remedy for their condition. In a city with an excellent networking system, help is usually at hand. The patients were referred to the hospice by non-governmental organizations parishes, church-based organizations through the SVP units, friends, families and social workers.

A look around the hospice confirms what a hospice nurse said, "AIDS is an illness of the young", and of the many complications, "convulsions and meningitis were especially common."

People from different walks of life and family backgrounds come to the hospice. The admission policy of the hospice insists on the patient being accompanied by a family member during the course of treatment. Besides serving as a source of support, this policy, according to the hospice social

People from various different professions, vulnerable groups like eunuchs, commercial sex workers and migrant workers seek treatment in the hospice.

worker, was also born out of the management's negative experience in running the leprosy home (in the same campus). Many of these families had used the leprosy hospital as a "dumping ground" for their loved ones infected by leprosy, never to return back. On the other hand, the admission policy also has its downside, as when the hospice had shown firmness on the issue of the patient being accompanied during treatment, some of the patients had been taken away even before the completion of their treatment.

Additionally, in a city like Mumbai, it is not uncommon to find people living by themselves. One such patient, who arrived at the hospice by himself, was told that he would have to bring someone along. So, "with no family or friends to call my own, I had to go in search of someone to pose as my guardian. I found a man in the street to whom I told my story. He agreed to come with me and pose as my friend." Not surprisingly, the man never came.

The patients in the hospice are charged an admission fee of Rs. 50. However, in case of poor patients the cost is absorbed by the hospice itself. For patients referred by NGO's, the cost of treatment is met by the referring agency.

While patients are asked to buy the medicines from the market, those who have no money are provided the medicines by the hospice. There is no charge for the other healthcare services. One staff member notes, "We have no plans to recover cost, as the service motto of the SVP is to care for the less fortunate."

People from various different professions, vulnerable groups like eunuchs, commercial sex workers and migrant workers seek treatment in the hospice. The number of persons seeking treatment varies.

While most patients came from around Mumbai, there are a few who also came from other parts of India. They were mainly from middle and

lower middle classes and in the age group of 20 to 40 years. According to statistics furnished by the hospice, between May 1996 and July 2003, 400 patients were treated; of this number 344 were men.

The period of stay varies depending upon the treatment and the person's condition. At the time of admission, patients are classified and placed in the wards according to the seriousness of their condition. As Frank Furtado, the Chairperson of Niramay Niketan explained, "We do not put terminal cases together with the less serious ones as this would mortify them [the less serious ones]." Also according to Furtado, there was a ward reserved in the hospice for homosexual men and eunuchs as, "the sexual orientation of these men being different, it could pose a danger to other male patients. We're taking utmost care to prevent any untoward incidents." However, he said so far there has been no segregation of this sort.

Strategic Planning and Monitoring

The Managing Committee of the SVP and the hospice staff meet once a month to discuss and plan for the functioning of the 100-bed hospice. "Monitoring is done by the Chairperson and the Managing Committee of the hospice," said Furtado. As a hospice nurse added, the SVP members show a lot of interest in the functional aspects and are very encouraging to the staff. Ongoing fund-raising for the hospice is done from within the SVP.

Care and Treatment Provision

The hospice's regular nursing staff attends to the patients up to 9 pm. The nurses leave only after making sure that the patients are comfortable and in bed. However, in times of emergencies, the nursing staff works till late hours. Once the nurses leave for their residence (on the campus) the patients are attended to by a nurse on night duty. Through kind words and service, the sisters attempt to create a spirit of

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The significant role played by the People Living with HIV/AIDS (PLHA) volunteers in the hospice has enhanced their self-esteem.

family, “we tell our patients that they are free to return for a check-up, or to the outpatient department (OPD) or simply for a rest,” said the nurse.

The significant role played by the People Living with HIV/AIDS (PLHA) volunteers in the hospice has enhanced their self-esteem. Their work and presence has been especially important, since an HIV/AIDS hospice is not a place where most people (without the virus) would dare to tread, given the fear and misconceptions attached. As Furtado and a hospice nurse stated “it is almost impossible to get workers who are not HIV positive or even nursing staff to work here.” All the three nurses in the hospice (two are trained nurses and the third is a pharmacist) are members of a female religious congregation.

When asked about the care they receive in the hospice, all the patients and their wives have great praise for the way the sisters (nurses) provided treatment to them. Yusuf, a patient being treated in the hospice added that while the sisters worked hard to provide good care, it is also up to the patient to cooperate.

The people seeking treatment in the hospice spend their time helping in the functioning and activities of the hospice. Yusuf stated that “As I can walk about, I help other patients who cannot help themselves; by bringing them their food or helping them to the washroom.”

The hospital accepts the help of patients who are in a position to work and they are paid a monthly stipend. “Five of these [patients] are janitors and six others help patients with the daily activities like bathing, eating, sitting up in bed, etc,” said Furtado. “While the volunteers who performed other tasks are paid a monthly stipend of Rs 1,000, the janitors are paid Rs 500,” he added. The volunteers also being prone to fluctuating energy levels are not pressed when “they feel weak and say they don’t feel like working,” said a hospice nurse.

Patients are served mainly a vegetarian diet; non-vegetarian food (chicken or mutton) is served only twice a month. There are also the frequent treats from donors who wished to celebrate some special event with the patients. "At such times the patients get fruit and some special meal which would be a speciality of the community of the donor," said a nurse. According to Furtado, the hospice had been working with the SNTD University's nutrition department to add value to the diet. According to a nurse, personnel of the Bhabha Atomic Research Centre had offered the hospice some protein supplement. While patients were encouraged to drink plenty of water, this had not been possible based on their difficulties in swallowing.

Medicine Replacement

The hospice pharmacy has been facing difficulty in getting replacements of its drug stocks. Even those patients who can afford to do so fail to replace the stocks which they have used. However, putting patient care first, the hospice went ahead and "administered medication at the time it was needed, without waiting for the replacement to arrive," according to a nurse. "This is despite the fact that some of the medicines are very expensive," she added.

The hospice doctor said, there are simpler drug substitutes, in case the medicine prescribed does not suit a patient's pocket. Or, if a patient can afford to pay for more, "expensive" medicines unavailable in the hospice, could be bought from outside. It should be noted that the hospice does not have a blood bank of its own.

Addictions

An occupational hazard of the hospice staff is narcotic and alcohol addiction among the patients, who manage to smuggle these substances in through relatives or other sources. The neighbourhood, as a nurse said, is full of

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bootleggers which make it easier to procure the substances banned in the hospice. Once within the hospice precincts, liquor bottles were hidden in places like flush toilet tanks. Even when the alcohol is discovered, the staff has to be tactful in reprimanding the guilty because “they could get violent,” said a nurse.

The Changing Scenario

The first signs of HIV in all the patients came in the form of ailments, which at first, do not appear serious and are generally easy to handle. The most common among these symptoms are headaches, fevers, colds, diarrhoea and vomiting, gradually leading to the almost inevitable tuberculosis (TB). While these ailments are taken lightly at first, it is their persistence that indicates something more serious.

One woman described her husband and stated, “He had been healthy and hearty before that. He had never fallen sick.” She said his first signs of HIV began with hiccups and a severe headache, for which he was admitted to a private nursing home. While all the patients have suffered with TB at some point in time some had suffered from meningitis and lost their eyesight.

According to a hospice nurse, a lot of time used to be wasted in some cases with doctors simply treating the patients for opportunistic infections without advising an HIV test. “Nowadays doctors immediately advise an HIV test if they see certain tell tale signs of the virus,” she observed.

The overriding emotion of all the patients when first informed about their HIV positive status is intense fear.

One young man was worried about his future. His mother, who was with him when the news of his being HIV positive was broken, was afraid too. But facing the reality, she consoled him saying, “We must trust God, who will show the way.” In trying to replace hopelessness

with hope, “as there have been cures for other diseases, they will find one for this too,” she added.

“Life with AIDS is something like a roller coaster ride—one day you’re up and then you’re down...the condition of the patients’ changes everyday. They could be in good shape talking to me one moment and five minutes later they could be running a high fever,” said a social worker in the hospice.

Stigma and Discrimination

In a situation where spells of well-being are terribly short lived and medicines cannot be counted on to get the patient back on track, the caring of a loved one makes a remarkable difference. Therefore, when this love is replaced by rejection, as a nurse said, the deep hurt and trauma can even diminish the will to fight the illness. Once this happened there was very little that the staff could do. “Their main pre-occupation becomes death,” said the nurse.

One example of society’s non-acceptance of PLHAs, with which the hospice is familiar, is the occasional phone calls from offices asking for their own staff members, who are PLHAs, to be admitted to the hospice. Firmly adhering to the admission policy of the patient having to be accompanied by an individual or organization willing to take responsibility for the patient, “we tell these people that they would have to come and take care of the patients and not just admit them and go away,” said a nurse.

Even educated people are sometimes afraid to take a chance with handling loved ones with HIV/AIDS. A hospice nurse illustrated this through the example of a woman who had come to the hospice to visit her brother, a patient. She said,

“The woman asked me for gloves to touch him. After she took off the gloves, she asked me for Dettol to wash hands, which I refused to give.

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Stigma against HIV/AIDS is found to have a class angle. According to a nurse, stigma seen in the hospice is “most common amongst the middle class.”

She managed to get it from somewhere, though. She then asked me for antiseptic to wash her mouth, explaining that she had been very close to her brother and had been therefore exposed to his breathing. Aghast at all these requests, I refused all of the woman’s requests to maintain her own ‘safety’. All this was after having explained to her the myths and facts around contracting the virus.”

Fear of getting HIV exists not only amongst the misinformed but even amongst healthcare professionals who are aware of the disease. One of the hospice nurses admitted to being “very afraid of handling people infected with HIV,” in the first month of her work in the hospice.

The presence of the HIV infection in a person often caused disequilibria in their family. There are instances of wives refusing to allow their HIV positive husbands to come and sleep in the house with the rest of the family. According to a hospice nurse, while half the patients received support from their caregivers, the other half do not. What is worse for these people is the reproach they face from wives who find it hard to forgive their past actions that led to their present state. Though there is an even worse form of reproach - that of abandonment. The underlying attitude is, “let him (the PLHA) suffer for his sins,” said the nurse.

While some of the patients have been left alone for good, others (at least eight) have had no visitors for about two or three months. Loneliness and depression are the common factors seen in these patients. This loneliness comes from the fact that most of them had little or no company apart from each other and the hospice staff. And when some of them do have the rare visitor like their children, they become so emotionally overwrought, that “they would begin to cry,” said the social worker.

Stigma against HIV/AIDS is found to have a class angle. According to a nurse, stigma seen in the hospice is “most common amongst the middle

class.” She added, “Some of these people would look at a PLHA from far, rather than come close.” In contrast, the tiny percentages of the upper class patients in the hospice are looked after by their families with “much tenderness and care.” Some who could not attend to the patient themselves, had a maid servant look after them. However, having a member who is a PLHA can put the entire family at a disadvantage, particularly in the area of finding a marriage partner.

NGOs, with all good intentions, place the infected person in the hospice but sometimes “*they never return to check on the patient (except to claim the body for cremation).*” By taking the responsibility, the NGO also absolves the family of any care giving responsibility. Therefore, in trying to dissuade the NGOs from intervening, the hospice charges them an additional admission fee of Rs.50 – a total of Rs.100.

Caregiving

A walk around the male and female wards of the hospice reinforces that fact that while male patients had their wives caring for them, there was not a single male caring for any female patient. A majority of the women were commercial sex workers, who had been abandoned by the brothel owners once they were sick; desertion is a common phenomenon amongst female PLHAs. According to the social worker, they were often thrown out of their homes. Widowhood, especially as a result of having contracted HIV from the husband, often brings abandonment to a woman. Males, on the other hand, are typically either divorced or still married.

Child care and family support: Most of the women who stay in the hospice for many weeks caring for their ailing husbands, leave their children to be looked after by their families – typically either their mothers or in-laws.

Most of the wives of the patients are also HIV positive. As the hospice social worker observed,

NGOs, with all good intentions, place the infected person in the hospice but sometimes “*they never return to check on the patient*” (except to claim the body for cremation).

TB is a common opportunistic infection in the PLHAs, especially at the time of admission to the hospice.

quite often entire families or a substantial part of them are infected by HIV.

Treatment

If a patient comes to the hospice and does not require hospitalization, the hospice prescribes medication for the opportunistic infections. The patient is told that he or she can return if the need

arises. This medical advice is given free of charge. The outpatient department (OPD) is functional from 3 p.m. onwards. Most of the patients coming for advice are those who had completed their course of treatment in the hospice.

Tuberculosis Treatment in the Hospice

TB is a common opportunistic infection in the PLHAs, especially at the time of admission to the hospice. Based on experience and symptoms, the nurses are often able to identify the location of the TB bacillus, even before the test is performed. *"While all the patients are put through an X-Ray of the chest, a CT scan is advised in the case of a headache and a stomach X-Ray in the event of diarrhoea,"* said a nurse.

Care in the hospice has resulted in TB patients experiencing a marked improvement, typically in the first month itself. Once the prognosis is encouraging, many patients are discharged. Patients are generally discharged within a fortnight.

One social worker comments that in her experience she finds that patients in an advanced stage of TB move away when approached by others. Besides avoiding contact, they also refrain from offering food to others. While this could be interpreted as a fear of rejection, she rather sees it as an indicator of the patient's awareness of the illness and the possibility of his spreading the infection.

Drug resistance has had an impact on the increase in duration and cost of TB treatment. A normal course of treatment lasts between six to nine

months and can stretch even up to a year due to drug resistance which has become commonplace. The alternate lines of treatment also called for an increase in treatment cost. A single tablet could cost as much as Rs 15 which has to be taken twice a day for at least three months. The total cost of the treatment could go up to Rs 10,000. While the hospice has plans to procure the drugs provided at the TB directly observed treatment (DOT) centres, patients are directed to continue with their treatment at the DOT centres in their locality.

Anti-retroviral Therapy

According to a nurse, while ART is advised by the hospice, it is not provided. Only one patient in the hospice had been on ART so far. The baseline CD4 count for a patient to get started on ART is considered as 250 down. Despite the promise of sending the CD4 count soaring, ART is accompanied by terrible side effects, some of the milder ones being a severe pain in the stomach and the limbs. Among the more serious ones are peripheral neuropathy (numbness), hepatitis, anaemia and kidney failure. The high cost of ART has made it basically unobtainable for the patient. And as a nurse explained, "Even if they do manage to start, they will be forced to stop." Even if patients do manage to raise the resources for ART, the toughest hurdle will be adherence. One nurse describes the stringent schedule, *"It is absolutely imperative to take the treatment at fixed times, in order to break the cycle of the virus. The required adherence to the timing is very stringent. It cannot even be 10 minutes before or after the stipulated time."*

Alternate Therapy

The only alternate therapy practiced is yoga, which the patients practice every morning. A yoga instructor provides guidance and supervision once a week. However, because many of the patients are immobile, not all of them are able to participate in this exercise.

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Sexually Transmitted Infections

The question of the presence of STIs in the hospice drew mixed responses. While one nurse said there had been a couple of cases of STI among the patients, the rest of the staff replied there had been none.

The hospice doctor said he was surprised by the “absence” of STIs as these illnesses are commonly found in PLHAs. One of the reasons for this, he speculated, was that most of the patients who came in the terminal stage would have previously been treated for STIs sometime during their course of previous treatment. Even though STIs are known to be part of the life threatening syndrome, the hospice does not, as a rule, advise an STI test. Instead, “we prescribe the CD4 count test, through which we can also tell the haemoglobin level and advise treatment if it (the haemoglobin) is low. Penicillin and ointments are provided for treating the STIs.

Palliative Care

For patients who have suicidal tendencies or are in severe pain, sedation is a common solution. However, morphine is said to have been used sparingly and only for acute pain.

In terms of medical equipment, the hospice possesses oxygen cylinders, an aspirator, a respirator and intravenous fluids. While oxygen and the aspirator are useful in case of asthmatic patients, IV fluids help revive those dehydrated by diarrhoea, patients of intestinal TB who cannot ingest food or those who are comatose. While the other pieces of equipment are frequently used, the respirator is very rarely used.

The operating theatre and pathological laboratory on the campus need to be restarted. Till the mid-nineties, these were said to have been fully operational, with surgeries being performed on leprosy patients, until the time they had to be shut down “to prevent the entry of dust flying around during the construction of the HIV/AIDS hospice” according to Furtado.

Support

Psychological Support

Death being the major pre-occupation with patients, the nurses have a truly difficult job in consoling them: *“We tell them that one does not have to have HIV to die,”* said one nurse. Through experience, the nurses have also realized that it is best to try and get the patients to a level of acceptance of their condition and fate.

Counselling

While making friends with the patients is not too difficult for the staff, this does not always translate into the winning of confidences. As one nurse said, “Only a very few of the patients share important and intimate details of their lives, especially about how they contracted HIV.” The staff says they do not probe into the patients’ histories and listen with a non-judgmental attitude.

Patients open up based on their comfort level they share with a staff member. While one nurse said that only one male patient had shared with her the story on how he became HIV positive, another nurse said that in the preceding six months, she had three widowed patients confide in her that they had acquired the virus from their partners (not their husbands).

One nurse said she suspected that a strong fear of rejection causes patients to hold back facts during counselling. This, according to her, was understandable, as any rejection from the staff would be the last straw after the stigma they already had to face from society and their loved ones. Rapport building is occurring with the hospice social worker spending about five to ten minutes each with five patients a day.

As part of a structured counselling programme planned by the social worker, two patient histories are recorded in a day; the number gradually being increased as patients show an “increased interest” in opening up and accepting the counsellor. She said she also planned to increase the

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frequency of her counselling sessions to thrice a week. *“Each of these would last not more than 45 minutes, as going beyond this period would make the patient lose interest. Needs assessment of the patient comes before damage control. Patients do not speak unless you ask them questions,”* she said.

Death and Dying

The hospice experiences an average of eight deaths a month. In the absence of the patient’s family to take responsibility for the cremation, either a benefactor or the NGO that referred the patient becomes involved.

Legal Issues

In some cases, relatives have had patients sign legal documents, relinquishing their right to property. These relatives, as a nurse stated, never turn up after getting what they desired. When asked by the nurse, as to why patients let go of their claims to what was rightfully theirs, the common response of patients was, *“Let them take it. I’m just waiting for death.”*

Prevention Programme

The hospice sees little use in informing its patients about safer sex, arguing that the damage has already been done. Nevertheless, the hospice does see sense in discussing issues like avoiding sex to those in the initial stage of AIDS. However, such patients are few and far between, with most of the patients coming in the advanced stage of infection. There is no high risk behaviour analysis and risk reduction strategy implemented in the hospice.

The only awareness literature in the hospice is by the Maharashtra District AIDS Control Society (MDACS). These brochures are given to the relatives of the patients around the time of discharge. Some occasional visitors like members of youth groups are also given these brochures.

There are no audio-visual teaching aids to help impart information on HIV/AIDS. Information about the “do’s and don’ts” of caring for a patient at home is given to the relative, both during the course of the treatment and before being discharged. Plans are being formulated to hold weekly meetings with the wives of patients undergoing treatment to advise them on taking care of their husbands.

The only case of prevention of mother-to-child transmission has been the hospice’s success in convincing one seropositive woman (who had been in the hospice since her fourth month of pregnancy) to avoid breastfeeding her baby, to reduce the chances of passing on the infection to the infant. The baby will be tested for HIV once he turns one-year-old.

All the three nurses said they had not broached the subject of condoms as a preventive measure with the patients.

One of the nurses said that most of the patients endorse the view of the nursing staff that the condom was not a preventive measure. “Besides,” she added, “it is only very rarely that patients want to go out and ‘spread’ the virus. This happens when there has been no acceptance of their condition. Once there is acceptance, there is peace.”

Both, the nursing staff and the hospice doctor agreed that the message to be sent to the patients is that of abstinence or loyalty rather than safer sex. However, one young male doctor did see condoms as a preventive option for single people who are sexually active.

Standard Precaution

The health workers drawn from the patients are given no specific training, whether for jobs which involve cleaning the hospice or for helping the nursing staff with sponging the patients; they all learn on the job. Disposable syringes are used at the hospice and despite

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taking precautions, there have been instances of needle stick pricks after injecting a patient. While two of the nurses said they had not suffered such pricks, one of them said she had pricked herself about two or three times. *“All I’ve done was to squeeze out as much blood as possible and clean the part with Dettol,”* she said. She had not undergone an HIV test, preferring to put the onus for her safety on God. *“If He has called us to do his work, he has to protect us,”* she smiled.

The hospice doctor said he planned to get a post exposure prophylactic (PEP) kit, even though, “the risk of contracting the virus through needle pricks is very low.” According to Furtado, any such eventuality will be handled by administering Nevirapine.

Gloves are used while injecting, dressing wounds or bathing the patients, cleaning the toilets and disposing of used needles in the incinerator. As one nurse said, even the relatives of patients are given gloves when helping to dress wounds. In a place where infections abound, nurses generally go unmasked. One nurse who had worked for over three decades in a TB Hospital in the state, said she had never used masks, despite her regular proximity to TB patients, many of them in the advanced stage. *“Though this continuous exposure,”* she added, *“could prove risky in the long run.”* The hospice social worker does not wear a mask either when dealing with the patients. *“If I did, it would create a bad impression among the patients and they may not open up,”* she said.

Community Outreach

The hospice has plans to start a counselling and diagnostic centre for cases of HIV/AIDS/TB in the vicinity, which is arguably one of Asia’s biggest slums. If the patient diagnosed is in need of hospitalization, he or she will be directed to the hospice.

Pre- and Post-Test Counselling

A majority of the patients coming to the hospice get tested at various clinics, both private and state run. While pre-test counselling is not always available in these institutions, patients in the hospice are always counselled by the social workers in order to give them the correct picture of HIV/AIDS.

As part of partner identification, the hospice insists on the wife of the patient getting tested. There is no partner identification, however, for unmarried patients.

Linkage with Hospitals

There has been a constant give and take between the hospice and other hospitals - both government and private. While the hospice refers patients to these healthcare centres for diagnosis, those centres sometimes send to the hospice patients who are in a state of steady state of deterioration. Of the 400 patients admitted to the hospice between May 1996 to July 2003, 13 were subsequently referred to other hospitals.

Experiences of patients seeking help in government hospitals have often been time consuming and far from positive, despite the treatment being free.

Faith-based Approach

The only form of a faith-based effort in the hospice is the Holy Mass, celebrated in the hospice chapel twice a week. The Mass is attended by patients of different religions, as long as they are mobile. According to a nurse, Mass would be celebrated daily, but it is difficult getting a priest every day. She added that there are plans to have a resident chaplain on the premises. Their agonizing situation has often made it hard for patients to digest assurances like '*Jesus loves you*' said a

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nurse. A common response to this assurance was, *"If Jesus loves us, why did he send us such a dreadful disease?"*

Most of the patients being non-Christian, the nurses said they avoided talking to them about Jesus. Out of respect for the person's faith "we do not compel him or her to have faith in Jesus," said one nurse. While Jesus, as the nurses said, was kept out of conversations during life, he seemed to have figured in comfort sessions at least around the time of death. As an example of this a nurse talked about a commercial sex worker whom she said was heard calling out to Jesus in agony, shortly before her death. As it turned out, a nurse said, *"I had talked about Jesus and his love for her. Maybe she didn't have any other faith."*

A nurse narrates another example she saw of a patient accepting Christ. She saw a 30-year-old male patient who used to be a practicing lawyer looking very happy, poring over a copy of the Bible. She did not know where he got the bible from but the young man told her that he had been assured by Jesus that he loved him and was with him and that he should therefore not be afraid. Three days later the young man died a very happy and peaceful death talking to his family about Jesus. *"We sisters had never spoken to him about Jesus. I'm sure it was God who had spoken to him. After all, God has his ways,"* said the nurse.

Sneha Bhavan

M. Pramod Chand Singh

Sneha Bhavan (Home of Love) is an organization run by the Salesian Sisters of Don Bosco with its provincial headquarters in Guwahati, Assam. The organization is registered under the Registration of Societies Act XXI of 1860. The operational area of the organization covers the state of Manipur, with work in the urban areas of Imphal West and rural areas of Imphal East, and in both rural and urban areas of Chandel district. The services of Sneha Bhavan cater to persons of all religious backgrounds.

Sneha Bhavan is currently undertaking an HIV/AIDS intervention programme in Chandel district and in Ngariyal Hill of Imphal East. The HIV/AIDS programme in Chandel district focuses on empowerment of communities at the village level, so that People Living with HIV/AIDS have access to available services. The main activities of the programme include forming self help groups (SHG) of women affected or/and infected with HIV/AIDS, awareness-building among village people and mobilising community influencers.

Sneha Bhavan runs a Short Stay Home (SSH) for widows infected and/or affected with HIV. It also runs a Drug De-addiction and Rehabilitation Centre for treating chemically dependent women, in which the component of HIV prevention has been incorporated. A dispensary is attached to this Centre which dispenses allopathic and herbal treatment.

Sneha Bhavan provides educational support to children infected and/or affected with HIV/AIDS. It also provides educational support to non-HIV infected orphans who get are in the SSH in the event of the mother's demise.

This project also contributes towards a target of FHI's India country work plan of increased community support for children affected and infected by HIV/AIDS.

Another important activity is providing vocational training to both HIV positive and negative women, to equip them with income-generation skills and to empower them economically.

The Caring Community Manipur Project

The CCM project was initiated by Sneha Bhavan with financial and technical support from Family Health International (FHI)/United States Agency for International Development (USAID) and the Catholic Relief Society (CRS) in August 2003, with the Diocesan Social Service Society (DSSS) Imphal being the legal holder. The project covers people living in six areas of Chandel district namely: Kholian, Machi, Sugnu, Chandel (District Headquarters) and Pallel, and directly addresses the needs of around 100 women and children affected by HIV/AIDS. The project incorporates three cross-cutting themes: 1) greater involvement in society of people living with HIV/AIDS 2) decreasing stigma and addressing discrimination, and 3) gender empowerment. This project also contributes towards a target of FHI's India country work plan of increased community support for children affected and infected by HIV/AIDS.

Programme Implementation Strategies and Activities

Local Resources and Expertise

Local resources and expertise have been mobilized to help engage rural communities, by exposing them to behaviour change communication (BCC) activities that increase their knowledge of HIV/AIDS and address issues related to stigma and discrimination. To this end, project staff, which includes a coordinator, two nurses, and 10 animators, has been selected and trained. A training calendar, based on training needs has been developed, and five different training programmes of two days each are carried out. The staff also attends training programmes organized by FHI.

Project Specific BCC Activities

An assessment was conducted to identify the communities' needs pertaining to the project objectives, and appropriate behaviour change strategies are being developed. All ethical guidelines were followed during the assessment. Appropriate BCC materials will either be collated or adapted as per the strategy. As part of the BCC strategy, 3,100 pieces of material such as posters, flash cards, flipbooks, and pamphlets will be developed and distributed during the project. A key aspect of BCC is providing field animators and peer educators with the skills required to motivate influential persons within the community for promoting attitudinal and behavioural change.

BCC Events

These are held in community gatherings involving youth and elderly people. Special care is taken to ensure female participation during these events which are a part of the communication strategy to reduce stigma and discrimination associated with the disease. BCC tools include a variety of culturally appropriate forms of communication, such as dances, songs and dramas to secure community interest. These also provide an accepted entry point for introducing HIV/AIDS discussions into rural communities. It is envisaged that during the project period, 12 campaigns will be conducted to reach around 6,000 people from the community.

Volunteers

There will be identification of volunteers to be trained as peer educators, change agents, and SHG leaders, whose task will be wider dissemination of information. Seventy-two peer educators and forty-five SHG leaders from the community have been trained on BCC strategies appropriate to the traditions and culture of the concerned communities. The peer educators and leaders include both adults and adolescents.

Participation of Public Systems

In order to secure the active participation of the public health and education systems in the

A key aspect of BCC is providing field animators and peer educators with the skills required to motivate influential persons within the community for promoting attitudinal and behavioural change.

In order to secure the active participation of the public health and education systems in the project activities, staff and authorities of all health clinics and schools in the six project areas are being sensitised on HIV/AIDS issues.

project activities, staff and authorities of all health clinics and schools in the six project areas are being sensitised on HIV/AIDS issues. Planned inputs are given to the health workers, teachers, and students, who in turn play a key role in promoting a stigma-free environment in the health facilities and schools. A total of nine one-day meetings were carried out to sensitise 630 participants. Each event has around 70 participants.

Stakeholder support and participation: This is ensured by involving community leaders such as village headmen, religious leaders, elders and other respected persons whose opinions have influence in the community. This has helped in building acceptability for the project and will help in sustaining the outcomes. These leaders have helped in the selection of peer educators, formation of SHG groups and reaching out to the HIV/AIDS infected and affected families. Apart from numerous one-to-one and group meetings, four one-day long formal orientation and motivation sessions were also conducted for them.

Sustainable Home-based Care for the HIV/AIDS Infected, with Emphasis on Women and Children

Care Manual

A home-based care manual for rural Manipur, which lists common ailments, symptoms and appropriate care procedures related to HIV/AIDS is in the process of development for reference by the community, and for distribution. A core training team, comprised of 10 animators and 2 nurses will be constituted to impart the knowledge in the manual to identified peer educators. Further, the peer educators will be provided on-going support by the core team of trainers in conducting the training sessions for the community. In the six target areas, the project provides training to at least one caregiver from each family of the infected. The caregiver may be male or female but should have the inclination and physical ability to look after the infected family member. A total of 20

one-day trainings will be conducted, each attended by around 30 caregivers. These 600 caregivers will be further provided training on coping with a HIV positive test results, taking care of PLHA and Children Affected by AIDS (CAA), taking PLHA for referral services, handling grief and dealing with death and dying.

Referral System

A referral system was established in the six project areas with the existing government and private clinics, including the church run dispensaries, which provide outdoor and indoor patient care to PLHA. Referrals are made to the government operated voluntary testing and counselling centre (VCTC) for HIV testing. Linkages will also be established with the government supported Prevention of Mother- to-Child-Transmission (PMTCT) programme. The services of the Short Stay Home of Sneha Bhavan in Imphal are used for HIV infected women and children, for handling medical complications or taking care of those who no longer have family or community support. During the project period, about 12 such referrals have been made from the area. The project meets the expenses for temporary institutional care for an average period of four months.

Nursing Care and Counselling

This is provided by two nurses who also refer patients. Based on the needs identified by the peer educators and animators, the nurses provide hands-on nursing training to the caregivers in the households, and also make home visits to provide family counselling. Women and children also come to the project office for counselling and other guidance.

Development of SHG to Economically Empower and Mobilise Women for Social Change

Guidance to SHG

With assistance from the DSSS staff responsible for SHG activities, community members are

The services of the Short Stay Home of Sneha Bhavan in Imphal are used for HIV infected women and children, for handling medical complications or taking care of those who no longer have family or community support.

The women leaders are selected based on their interest, communication skills, acceptability in the community and educational background.

guided in the formation and functioning of SHGs. Subjects such as facilitating group development and promoting savings are included in the guidance meetings. The average size of a self-help group is 20 and each group has a leader. The women leaders are selected based on their interest, communication skills, acceptability in the community and educational background. Presently there are 45 SHGs.

Tapping Government Resources

The existence of SHGs facilitate community access to government resources to meet priority community needs. The project animators provide these groups with information of various government schemes such as the widow scheme, Jawahar Yojna, the procedure for obtaining loans from banks and other welfare schemes. The project also plans to provide the SHG members with information relevant to the community, such as adult literacy, primary education, herbal medicine, improved agricultural practices, and income-generation skills training.

Orientation

The SHG group leaders are provided orientation on various issues related to HIV/AIDS including provision of care and support and addressing stigma and discrimination.

Mobilise Government and Civil Society Networks to Address the Health/Education Needs of CAA

Partners

The CRS supports five partners for health and education intervention in Chandel district. They are St. George School in Moreh; St Mary's Covent in Pallel; Alphonse Covent in Sugnu; Shantal Bhavan in Chandel and St Mary's Health Centre in Kholian. Linkages with these five parish-based partners have been built, which helps in carrying forward the HIV/AIDS agenda through an existing infrastructure that already enjoys very good rapport with the community. Catholic health partners and SHG leaders are enlisted to identify and implement strategies by which district health

clinics can expand outreach services to meet the health needs of CAA. Catholic education partners and SHG leaders are also enlisted to identify and implement outreach programmes to induct out-of school children in the district into formal primary education institutions. Bringing more children and youth into the fold of education helps in reducing their vulnerability to HIV/AIDS and prevents the spread of HIV. The schools would also be encouraged to include “life skill education” in their syllabus.

Youth Leaders

The youth leaders from the project areas are encouraged to conduct regular sports and recreational activities across the district along with disseminating information regarding prevention of HIV/AIDS. Increased sports and recreational activities help keep the community, especially the youth away from drugs.

HIV/AIDS Forum

Initiatives are being undertaken to constitute an HIV/AIDS forum including non-governmental organizations (NGOs), the five existing CRS partners, community-based organizations and Government, to come together to discuss strategies and activities related to HIV/AIDS prevention, and to take initiatives for reducing stigma and improving the quality of home-based care. At the district level, the forum will have around 30 representatives of various social, educational, and religious organizations along with the government bodies and will meet once a quarter.

Seminars

Seminars are conducted to share experiences and lessons learned from home-based care. Community leaders, particularly village headmen, school principals, SHG leaders, and religious leaders, participate in these seminars, not only to provide first-hand input into discussions, but also to return to their communities with tangible action plans for implementation. The project animators support and monitor im-

Catholic health partners and SHG leaders are enlisted to identify and implement strategies by which district health clinics can expand outreach services to meet the health needs of CAA.

The project animators support and monitor implementation of the action plans developed by these village leaders.

plementation of the action plans developed by these village leaders. The project also enlists the participation of the Manipur AIDS Control Society (MACS) in these seminars. This helps to involve MACS in undertaking CAA intervention as a priority in the state.

Drug De-Addiction and Rehabilitation Centre

Sneha Bhavan Drug De-addiction and Rehabilitation Centre was established on Aug. 12, 1994 in Lamphelpat, about 5 km. from Imphal. Its objective is to rehabilitate chemically dependent young women between the ages of 18 to 30 years, most of whom are injecting drug users. The treatment and rehabilitation of these substance abusers is usually of a six month duration, but in some cases can last upto a year. Patients in the terminal stage of their illness are also accepted and provided necessary care and treatment.

Sister Teresa Karot, Chief Functionary of the Sneha Bhavan recalled how the Drug De-addiction and Rehabilitation Centre was initiated, ...“Our de-addiction programme started in 1994. Almost all of our patients are from the streets and after 5/6 months’ treatment course, they have no place to go back. But there is no provision for sheltering these women in the Ministry scheme (Ministry of Social Justice and Empowerment, Government of India). As more and more number of patients started dying from AIDS in the centre, people started recognising us as an AIDS Centre. AIDS is a reality for the drug injectors and so we cannot ignore the issue. We are providing medical assistance to such patients. We also provide vocational skills to the patients, so that they can start some income-generation activity to support themselves and their children after they leave the centre...The problem of homelessness and poverty is even worse among widows. So we opened up a short stay home with support from the Indo-Global Social Service Society (IGSSS) in January 2003...During the planning of such a place, CRS came up with a proposal to initiate community-based work. Thus, the process of empowerment of a caring community was initiated in

6 catchments areas of Chandel district from August, 2003. Under the programmes, we provide detoxification, income-generation, education to children (residential), vocational training, awareness-building, providing psycho-emotional support to PLHA and health-care for common illnesses and OIs.”

Regarding the planning process of the programmes, the Sister said, “...We have been working for more than a decade now among the marginalized women, and based on their needs identification and the feedback obtained from them, changes are incorporated into the project”.

Ms. Hatboi, Project In-charge of the Sneha Bhavan Drug De-addiction and Rehabilitation Centre, discussing the Centre said, “Our target is to reach out to women drug users, alcoholics and families of addicts as most of the de-addiction centres are for men only. There is no specific age for admission of a client, and it varies from 17-54 years. At present there are 15 inmates under detoxification and three are under extended care – those who have taken up vocational activity for income generation, 11 of them are in the rehabilitation programme.”

Objectives of the Centre

Providing a home to homeless women and children is the foremost priority of the Centre. Many of the patients do not have anyone to take care of them or are abandoned by everyone. Their partners, husbands, families, and relatives have made them used to drug peddling to earn easy money. Now when they become addicts and cannot earn money for the family they are driven out. They have no place to go back when they complete treatment except to the street.

The second priority is to empower them with vocational skills in order to help them earn a living. They are taught a feasible trade when they are in Sneha Bhavan like tailoring, knitting or weaving.

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The clients availing of treatment and medical attention at the Centre come mostly tribes from various districts of the northeastern states, mainly Mizoram and Nagaland.

Additionally, they are taught poultry, pig and rabbit rearing, farming and mushroom cultivation. At the end of the training, they are provided with some capital to purchase the necessary machine or raw materials.

The third priority is education for the abandoned and homeless children. At present they are staying with their mothers in the Rehabilitation Centre, with other addicts and alcoholics, and are sent to school from there. However, it is necessary to provide them with separate accommoda-

tion so that they grow up in a healthier environment favourable to their normal growth.

The fourth priority is care for the sick. Most of the widows and drug addicts are HIV positive and vulnerable to different kinds of opportunistic diseases before they reach the last stage of AIDS. During this period the continual assistance of a nurse and a doctor is made available and good nutritious food is given to bring up immune system. Most of the patients come from broken families: divorced parents, unfaithful husband, extreme poverty and other such circumstances.

The clients availing of treatment and medical attention at the Centre come mostly tribes from various districts of the north-eastern states, mainly Mizoram and Nagaland. Most of them belong to poor families or have been living on the streets as they have been driven out by their families. They are usually brought by ex-clients or are motivated by or referred by CCM. A few are also brought by their families. On arrival, most of them possess limited knowledge of HIV/AIDS, but in the Centre they are given constant lessons on health, hygiene and risk behaviour associated with drug abuse. The relationship between the clients and staff is more like that of a family, but nevertheless, it is ensured that discipline is maintained while performing day-to-day activities.

A warm and comfortable atmosphere is provided to the patients in the Centre. Since the staff, except for the doctor and the nurse, all the other

staff had been drug users and can empathise with the suffering of the patients, and the patients also look upon them as one of themselves.

Daily Schedule

A normal day for the inmates begins at five a.m. with prayers for half an hour followed by yoga and therapeutic assignment. A reading session for an hour is held after breakfast in which a story is narrated followed by a discussion on it. Re-education or input classes are given to the patients to develop communication and interpersonal skills. The inmates participate in vocational training in post-lunch sessions. Vocational rehabilitation is one of the main components of the programme which provides in-house training in tailoring, weaving, and knitting based on the choice of the clients. In the evening the inmates go for gardening followed by an evening meal. Around six in the evening the inmates share feelings and thoughts experienced during the day. Indoor games are also provided for the clients. A weekly meeting is organised every Friday, and based on the discussions, necessary modifications and correctional measures are instituted.

Detoxification

Detoxification is done based on the physical condition, verified by the doctor or nurse, and the person is kept in a separate room called the 'Detox Room'. Total rest is given and a substitution drug is provided to manage the withdrawal symptoms. Counselling service is also provided to make the inmates conform to the institution's rules.

HIV/STI

The Centre does not provide treatment for sexually transmitted infections (STI) but the infection is highly prevalent amongst the people brought to the Centre. Given the strong linkages with the government hospital and sexually transmitted

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Patients, who realise that they had been at risk of catching HIV infection, volunteer to go for a HIV test at Regional Institute of Medical Sciences (RIMS), where pre- and -post-test counselling are also given.

diseases (STD) clinics, patients with STIs are referred to these places for medical attention and treatment. While suspected cases of STI are taken to the hospital, there is no provision for partner follow-up. However, when they visit the hospital, the staff gives the partners information about STIs and HIV/AIDS.

Patients, who realise that they had been at risk of catching HIV infection, volunteer to go for a HIV test at Regional Institute of Medical Sciences (RIMS), where pre- and post-test counselling are also given. Patients are also referred to the sexually transmitted diseases (STD) clinic, the Directly Observed Treatment (DOT) programme, the Jawaharlal Nehru (JN) Hospital and RIMS.

Handling of pregnant women who are HIV positive becomes difficult as there is no provision for care of children and often it leads to overcrowding in the hospital.

According to a nurse at the Centre, “the clients do not have much idea about STIs. They are very scared of STIs. Generally they have no risk perception of STIs. But those who had received services from other NGO’s have better knowledge of HIV/AIDS/STI. We have no treatment facility for STIs. Our doctor comes thrice a week at the Centre and takes a thorough history of the client and records it. Based on his opinion, the client is taken to RIMS, JN Hospital, and Women Health Clinic run by Meetie Leimarol Sinnai Sang (MLSS). There the clients are tested for STIs and accordingly, medicines are given or purchased by the centre”.

Condoms

Upon discussing the issue of condom promotion, Ms Hatboi, an employee at the Centre, said “We don’t discuss condoms here, as the institute is Catholic based..... we strongly believe that unmarried should not have sex-partners and married should stick to one partner, we don’t talk about it. But for those whose partner or (she) herself has HIV, (they) are

advised to decide accordingly whether to use or not to use condoms. Clients also do not ask about it.....Our slogan of safer sex is 'Stick to one partner and delay sex till marriage'. Input programme is inclusive of BCC. We interact with inmates and try to understand what changes need to be made in their behaviour."

Vocational Training

Vocational training is provided with a view to empower the inmates, increase their self-esteem and enhance their skills for income generation. Many of the people who come to the Centre earned their living by selling drugs. Once they leave the Centre after completion of treatment, earning a living is their most important concern. Therefore, the skills gained at the Centre prepare them for starting life in a new way. Below is a story of a patient of Sneha Bhavan who was able to stop selling drugs and earn a proper living through vocational training:

"One of the first patients of the centre was a young widow living on the street. She did not know how she could earn a living without selling drugs or liquor She left her children in an orphanage after the death of her husband, who was also a drug addict. She came to Sneha Bhavan because she wanted to give up her drug addiction. As long as she was at the centre, it was possible for her to give up drugs. It was difficult to know what she would do when she left the centre because she used to earn her livelihood by selling drugs. If she went back to the same old profession, she would certainly fall back into the same problems. Thus, we felt the need to start vocational training along with the treatment programme. Hence, after her treatment and vocational training for three months, Sneha Bhavan presented her a knitting machine and some wool to begin her life with. Gradually she started earning and then she took her children out of the orphanage and sent them to school with her own hard-earned money. Thus, she was able to give a home for her children. Imparting training also helps the inmates to become independent and helps to rehabilitate them."

Vocational training is provided with a view to empower the inmates, increase their self-esteem and enhance their skills for income generation.

Family counselling is also provided at the Centre.

The families are told about disease concepts before meeting the patients.

After a patient is discharged, based on their skills, a sewing machine, loom or knitting machine is provided to them so that they can generate income. A seed amount of money is also provided to initiate the activity. Constant follow-up is undertaken for a year. In case of relapse, the client and the machine are brought back to the centre.

Counselling

Family counselling is also provided at the Centre. The families are told about disease concepts before meeting the patients. Members of the staff also go out and conduct group discussions with them.

Drug Awareness Initiatives

Apart from the institutional programmes, awareness programmes in schools are organized and drug users are motivated to come for treatment. Classes on the ill effects of substance abuse are also organized in schools. Under the DOT programme anti-TB drugs are made available to patients and cost sharing is based on the financial ability of the families. Presently out of 12 patients, only three of them are paying their mess fees. These three inmates are from well-to-do families and are getting treatment with family support. The other nine families are very poor, and get no support from their families.

Faith-based Approach

The faith-based approach to prevention is taught to the patients as part of the drug de-addiction project. Patients respond to this approach very favourably and it appears to be helping clients considerably. The staff had received some input as part of the Pota Retreat programme at church, as detailed below from Mrs. Hatboi of the centre:

“Prayer gives strength to inmates. Inmates also express happiness that they come to understand the meanings of verses in the Bible and it helps

them in overcoming difficulties. One inmate expressed that since God accepts all types of people, they feel accepted and confident that they can change. Believing in God makes them have a sense of security.”

However, the Sisters felt that there was a need for special training and exposure of the staff to spiritual teaching, to maximise the efficacy of this approach.

Dispensary

The dispensary of Sneha Bhavan provides health services to the drug users who are receiving treatment in the centre and to widows and children under the different projects of the organization. The doctor visits the dispensary three times a week and the nurses look after the patients 24 hours a day.

Treatment

Talking about the treatment facilities in the centre Dr. Chandragupta Singh, Medical Officer at Sneha Bhavan said, “There are STI cases, like vaginal discharge, which can be clinically managed here after taking a thorough history. After we provide medicines including syndromic treatment, 80% to 90% of such cases recover. We provide free treatment to these cases. But we provide in-house treatment to simpler cases like gonorrhoea, fungal infections and wart. Persons with critical diseases are referred to Regional Institute of Medical Sciences, Jawaharlal Nehru Hospital, STD clinic, etc.”

In relation to other illnesses, the doctor said, “Liver disease, pregnancy, jaundice, Hepatitis-B, Hepatitis-C cases can’t be clinically managed in-house. So the better option is to refer them to hospitals. Most of the hospital investigations are incomplete. If diagnostic facility is improved here, better treatment can be given. There should be improvement in terms of diagnostic and management of opportunistic infections (OIs) here. The

Persons with critical diseases are referred to Regional Institute of Medical Sciences, Jawaharlal Nehru Hospital, STD clinic.

The herbal medicines are prepared by me and are used for diarrhoea, cough, fever, loss of appetite, gastric, acne, bronchitis – they are used for general illnesses.

doctors and nurses should be properly trained on management of HIV associated OIs. There should be sufficient manpower and a team who can look after all the cases. But in a place like this, we need dedication and good experience.”

“We do not take up any special programme on Mother-to-Child-Transmission (MTCT) and pregnant women are taken to JN Hospital. There they are provided AZT and Nevirapine,” stated Dr.Singh.

Anti-retroviral Therapy

On the administration of ART to PLHA, Dr. Singh said, “We have never tried ART with our clients. Since they cannot afford the drug, I never advise ART. ART should be given with regular monitoring with tests of CD4 count, and that costs money again. Some doctors advise ART to PLHA without taking into consideration the financial implications. But I feel that the children with HIV should be given ART free of cost, of course for mothers also if possible.”

Herbal Medicine

Sr. Teresa Varkey, Joint Director prepares herbal medicines for the dispensary. She shared her experiences, “Herbal Medicine is curing some of the OIs of HIV/AIDS. Since the OIs medicines are very costly, we grow medical herbs in the compound of the de-addiction centre. The herbal medicines are prepared by me and are used for diarrhoea, cough, fever, loss of appetite, gastric, acne, bronchitis – they are used for general illnesses. The clients are eager to take it, the demand is increasing, and we provide the medicines to all the clients of the three projects. These medicines are very useful for white discharge and menstrual problems. The patients prefer the medicines as they are very effective, freely available and have no side-effects”. Furthermore she states, “We have already planted some [medicinal herbs], but we need more plantation and need to nurse plants. For this we need more space, pots and manpower. The

herbal medicines shall be promoted not only among the clients but in the community as whole. Herbal medicines also help in removing the side-effects of allopathic medicines.”

Training

Regarding training of health workers, the doctor said “I was working with Dr. P. Narendra who was Consultant Physician, National AIDS Control Programme at Jawaharlal Nehru Hospital for two years. Nurses have extensive experience of serving a large number of PLHA and they are aware of safety precautions and first aid. They have sufficient capacity.”

Precautions

According to Dr, Singh, “We follow all the standard precautions to avoid infections from body fluids including blood. Injection safety care taken by us is use of gloves, but we don’t use masks often. We have problem of non-availability of gloves. We take precautions from infection by cleanliness with daily bath, brushing of teeth and tongue, personal hygiene, cleanliness in eating, using clean utensils, flushing of toilets, clean toilets, etc.”

Care for the Children

Currently, the centre provides care to 28 children. Sneha Bhavan has no hesitation in taking children in along with their ill mothers who come for treatment. Sr. Teresa Varkey looks after the children. She commented, “Since our focus is marginalized and abandoned women, we cannot ignore their primary concern - the well being of their children. We give coaching to the children..... and in the month of January we take the children and obtain admission to different schools. We are providing the fees, clothes and text books.....We support them up to tenth standard. After matriculation, what to do, we shall have to decide. Maybe by that time many

Nurses have extensive experience of serving a large number of PLHA and they are aware of safety precautions and first aid.

If orphans are left behind they are sent to the shelter home where good care and treatment is provided to them.

people will take them and (give them) jobs. Fostering these children is a real challenge. We need medicines, clothes and they need books and uniforms. We are having difficulties in managing the programme. Some of these children are very weak in study so we need to arrange special tuitions for them. Spiritual aspect is also taught in the worship service so that they can become responsible citizens.”

Care for the Dying

A 20-year-old dying young woman who had been abandoned by her family was brought by her friend to Sneha Bhavan Drug De-addiction and Rehabilitation Centre. The Centre cared for her until she had a serene and peaceful death. From that incident onwards, the Centre cared for many addicts, young widows and children who are HIV positive and some of them died in the Centre. In the event the families refusing to accept the body, the centre cremates the body. If orphans are left behind they are sent to the shelter home where good care and treatment is provided to them.

Short Stay Home for Widows and their Children

Sneha Bhavan was inaugurated as a Short Stay Home for 15 widows and their children on February 7, 2003, with generous support from Indo-Global Social Service Society (IGSSS). The number of widows seeking shelter in Sneha Bhavan have increased with the years, and so have the number of the homeless girls who are in the Drug De-addiction Centre with nowhere to go after the completion of treatment. Sneha Bhavan also opened a residential school, where recovering addicts are providing primary education to the children.

Motivation to Stay in the SSH

According to employees of the centre, the patient opt for this SSH because they feel that there is a chance of survival if they stay and they know that they are accepted at the centre. They also come to the home

so that their children survive and some come to escape the discrimination from their family.

A Sneha Bhavan employee comments, *“We ensure that their health is routinely checked. But we do not have treatment facilities for STI. The Doctor of the Dispensary at the Sneha Bhavan Drug De-addiction and Rehabilitation Centre comes to the SSH thrice a month. Clients who need special treatment are taken to Imphal for treatment via the Rehabilitation Centre, or taken to Assam Rifles Hospital at Thoubal.”* She also states, *“Our home is faith-based but we have secular approach that Hindus, Christians and anyone can stay at the home. We give assurance that God accepts everybody.”* They usually say, *‘I started believing in God after listening to the spiritual session’, or ‘it gives new meaning to my life’ or ‘my feeling of inferiority and suicide is decreased.’*

The SSH does not have infrastructure for palliative care in the home itself, but when a client is at the terminal stage, she is taken to the Rehabilitation Centre where all the care is given. They also make TB drugs available through the DOT programme at the rehabilitation centre and provide psycho-social support for PLHAs, but no SHG activity is available for them”.

Linkages and Networking

The Centre has good linkages with different government agencies and private practitioners including the Regional Institute of Medical Sciences and Jawaharlal Nehru Hospital for Health Care. Linkages were established with the Manipur Network of Positive People (MNPP+) and the Social Awareness Services Organization (SASO) for providing medicinal and nutritional support to widows and children. Technical support is received through training from the Rehabilitation Research and Training Centre (RRTC) and drug users are referred to Kripa Foundation for treatment. A strong network has been established with the TB Clinic in Imphal, and many of the clients are receiving anti-TB drugs from their DOT programme. Patients

A strong network has been established with the TB Clinic in Imphal, and many of the clients are receiving anti-TB drugs from their DOT programme.

The faith-based approach is helping the programme significantly. The level of commitment among the functionaries is very high.

are also referred to the Hospice, VCTCs at RIMS, J N Hospital and MLSS. The Centre works closely with the Social Welfare Department. Supporting agencies for the programme include Family Health International, Catholic Relief Services, Indo-Global Social Service Society and the Ministry of Social Justice and Empowerment.

Father Varghese Velickakam, Director, shared his experience about the project. He states.

“The uniqueness of this programme is we have a door to door approach in the remotest parts of the state. This way we can disseminate the information at the grassroots level through the SHGs. The biggest problem we are facing is the poor communication infrastructure – it is affecting all the programmes.”

According to him, another problem they face is the need for local people who are committed to work at the grassroots level. He notes, “In the catchments areas, committed people are there but they lack capacity. When we select competent people from places like Imphal, they cannot contribute to the programme wholly, because they have difficulty in dealing with local population who are culturally and ethnically different. So we are taking the available local persons to avoid non-acceptability of *personnel from outside. We simply can't take all staff from (the) valley or one particular area where (suitable) human resources are available.*

The faith-based approach is helping the programme significantly. The level of commitment among the functionaries is very high. People feel comfortable when their problems are understood by church people who are the most influential people at the village level”.

Snehadaan

Bhagwandas Mangalore

The Order of St. Camillus Brothers, whose mission is serving the sick and destitute, had planned to open a destitute centre in Bangalore in 1997. Initially they also admitted a few destitute persons from the streets of Bangalore, and later one among them turned out to be HIV positive. It was at that time the need for a care centre for PLHA was emerging. People were afraid of the illness and of social ostracism, and thus used to throw relatives with AIDS out of their homes. Many of those afflicted were left destitute with no place to go. This situation convinced the Order to take up a programme for the care and support of PLHAs. Br. Luka, who was the head of the mission in Bangalore at that time, was instrumental in initiating this care and support centre. Therefore, at a time when there was nobody to care for PLHA, the Order decided to take up the challenge of doing so, and the centre became the first Care Centre for people living with HIV/AIDS.

At this stage the centre provided more of a rehabilitation facility, as more and more people disowned out by their families needed a hospice to stay. Additionally, there were people from the poorer sections of society who had migrated to the city in search of opportunities, had fallen prey to the virus and thus had no place to go; and also people who were at the last stage of their illness and needed care and support to ensure that they had a peaceful and dignified death. Thus the inmates were almost permanent and lived in the place till their death. Fr. Anthony said, "We

'Heal the sick, Live the Gospel' is the motto and essence of the philosophy of the Order of St. Camillus and it is followed by the Order in every respect.

had no option but to keep them. The anti-retroviral were still at experimental stages. We even tried the possibility of getting ARVs from Italy but the cost was enormous. As people were coming here when they were in the last stages of their life, deaths were occurring on a regular basis. This allowed more new people to be admitted to the Centre"

During this time the Centre also provided occupational therapy to the inmates. They were taught to make dolls, which were even exported to Italy. Fr. Mathew, who has been with the Centre from the beginning, noted, "We wanted the inmates to be participating in some activity which would make them feel that they are still useful to society. Skills in candle making and statue making were being imparted and for a while it continued. We were even exporting these goods abroad. But over a period of time all those who were skilled succumbed to the virus. Moreover, this was the time the people had started going back to the community after a short stay. Thus we did not pursue this activity."

'Heal the sick, Live the Gospel' is the motto and essence of the philosophy of the Order of St. Camillus and it is followed by the Order in every respect. The Order, through its work, continues to inspire workers and the community to take care of PLHA.

The institution is a care and support centre and does not have any other intervention or community awareness programme. The efforts are concentrated on providing the best possible care to PLHAs, and help them to go through the last stage of his /her life peacefully and accept death with dignity. The organization ensures that the person does not feel he/she has sinned in their past life or behaviour and builds confidence in that person to live the present. To date the Centre has cared for more than 660 PLHAs.

A large number of people come from Karnataka, Tamil Nadu and Andhra Pradesh, considered as high prevalence states in the HIV map of

the country. A small number of them also come from Kerala, one of the states where prevalence is below the national average.

Today Snehadaan is a treatment centre where people living with the virus and with the symptoms of developing AIDS, come and seek treatment both as outpatients and inpatients. On an average, between 40 and 50 people come to the centre each month and 30 to 40 get admitted for a week or two and are then discharged. Once admitted they are treated for the opportunistic infections and provided counselling. Good nutrition, adequate rest and a peaceful environment help the patients to recuperate quickly. Terminally ill patients in their final stages are retained and provided with care till their death. These patients require more ambulatory care, psychological therapy and physiotherapy.

The Centre can house 52 people and on an average there are about 40 people in the centre at any given time. Initially people who got admitted were not willing to leave, but recently the trend has changed and the number of people going back to their families has increased through the counselling and education of the family members. During August 2004, 32 inmates returned to their families.

Services Offered in the Institution

The Centre provides care including medical treatment, management of symptoms and nursing services. Additionally, ambulatory, psychiatric and paediatric care and treatment are also provided under the supervision of a full time resident doctor. All patients with admission immediately start getting treatment for their opportunistic infections. Once the symptoms subside, they are sent to the National Institute of Mental Health and Neurological Sciences (NIMHANS) for a blood test to ascertain the viral load and the T4 count. A treatment plan is based on the findings of this test. If the T4 count is below 200 per ml then the patient is put on anti-retroviral

The centre provides care including medical treatment, management of symptoms and nursing services. Additionally, ambulatory, psychiatric and paediatric care and treatment are also provided under the supervision of a full time resident doctor.

Counselling is one of the major components of the programme. Earlier the priests used to provide the counselling and later the management realised that the patients need much more in terms of accepting and coping with the situation.

therapy (ART). If the patient can afford to pay, he/she bears the cost. Otherwise, the centre helps the patient get the treatment at a lower cost as it has an agreement with the drug manufacturer. If neither option is feasible, treatment is provided through local sponsors. Of late all patients hailing from Karnataka are sent to the Bowring Hospital where government has recently set up a centre for ART. Other than this, all patients receive antibiotics regularly to prevent possible infections, receive nutritional care and also get adequate rest. Above all, counselling support is provided regularly. Terminally ill patients are provided all support that is required. The centre also has an intensive care unit (ICU) to provide necessary last minute support. Experienced professionals and trained staff are fully geared to provide such care. One inmate said, "Most of the time, when

a patient goes into the ICU we know that that is the end. We get scared but we know that one day it will be our turn." He added, "even then the efforts from the staff will not stop and they provide the best possible treatment and care and try to save the person."

Family Education, Professional Grief Counselling and other Social Support Through Counselling

Counselling is one of the major components of the programme. Earlier the priests used to provide the counselling and later the management realised that the patients need much more in terms of accepting and coping with the situation. Therefore a professional counsellor is on the staff. The need for family counselling is also considered a key component to ensure continued support to the patient. The counsellor provides continuous counselling as a therapy to build up confidence in the patient. This helps in many ways including treatment compliance in the centre and outside of it, physical care and nutritional care. Moreover, the will to survive is strengthened and the families are motivated to support the patient emotionally and socially.

Assistance With Daily Activities by Professional Care Specialists

When a person is admitted with infections and is undergoing treatment, both personal care and support for daily activities become important. Whether for walking around, eating or having a bath, the patient is dependent on the personal care helpers at the centre. The brothers of the Order provide this support. From giving baths, brushing teeth, feeding and even shifting the patient to a more comfortable position in bed, the personal care persons are always there in attendance. "The devotion is amazing, I cannot think of anybody taking so much of care and trouble to make our life so comfortable" one of the attendants said, with tears brimming in his eyes.

Nutritional Support

The patients get a nutritious diet according to their needs. Individual patients' dietary needs are considered and accordingly modifications are made. "We may not be able to have the same kind of food once we go back to our families but here the food provided to us is very good and well planned" commented one of the patients.

Physiotherapy

Even aside from those who are bed-ridden, many of the patients testing positive indulge in very little movement. To overcome this, physiotherapy facility is provided in the centre. Movement and simple exercises help the patient to feel healthier and more mobile.

Spiritual and Emotional Support for the Residents and Families Help them to Cope with their Issues and Concerns

The Order does not make any special effort to make the residents feel that they are forced to believe in Christ. But evening meetings held on a regular basis help the patients to think of God and bring solace to their lives. Each one is encouraged to pray for his good and the priests also conduct the prayers in which each one is allowed to participate. Although the Chapel is meant for people of the Order and the staff, the inmates are allowed to use it for prayer if they wish. On talking to the inmates it is apparent the priests and sisters have won their hearts

The Order does not make any special effort to make the residents feel that they are forced to believe in Christ.

All training is in-house and the participants are encouraged to participate in all activities of the centre. Thus fear is overcome and the right attitude to working with PLHA imbibed.

and they volunteer to be part of the prayers and services conducted in the centre. Even during the performance of the last rites, patients are allowed to bring in priests from their respective religions and a separate space in the premises is provided for performing these rights. Religious faith does not come from force, but by belief and by realization. "We do our best as servants of God and it is upto them to take a decision" in the words of one of the brothers in the centre.

Besides these Services that are PLHA Centered, the Centre also Provides

Professional training in the area of HIV/AIDS management catering to health care professionals: The centre has a tie up with the Catholic Health Association of India (CHAI) and with St. John's Medical College Hospital, and organises training programmes on demand for the healthcare workers of different congregations who aspire to initiate such programmes for PLHA. Till now the centre has trained more than 1,000 doctors, health care workers and laymen. Most of the congregations who have sent their members for training have initiated a similar kind of work in their areas. All training is in-house and the participants are encouraged to participate in all activities of the centre. Thus fear is overcome and the right attitude to working with PLHA imbibed. A sister who was trained in the centre and decided to work there said, "I had all kinds of fears in my mind when I first came here for training. My first worry was what if I get infected working with them. But after two weeks of training here and watching the people of this institution my fear was gone. I knew how to care for myself and have decided to work with these people. That's why I came back here to join the team as a nurse."

Telephone counselling to the general public: Knowing that Snehadanaan provides services for people with HIV, a lot of people call the institution for more information relating to being positive, on counselling, treatment and care. On any day there are at least two persons calling for such information. Support through telephone counselling

is extended and people are referred to the nearby services for care and support.

Placement Assistance to the Resident and Family

A lot of people who improve after the treatment have no place to go as the family members have shunned them. The centre extends a helping hand in such situations. The patients and their families are helped through placement support and to find houses in the locality. There are many people who have received such support.

Administrative Aspects of the Intervention Programme

Day-to-day Management

Snehadaan is a programme of the Order of St. Camillus and was started on 14th July 1997. In 2003 a separate trust was formed to look after similar programmes of the Order. Sneha Charitable Trust was registered in Bangalore in 2003 under the Indian Trust Act. The main objective of the trust is to provide care to, the most neglected sick of our society.

Sneha Charitable Trust, formed by the Order of St. Camillus, manages the affairs of the centre. The trust composed of members from the Order of St. Camillus and with the experience of managing Snehadaan the trust also has initiated similar care and support centers in Mangalore, Eluru in Andhra Pradesh and Cochin in Kerala. The trust is also planning to start a centre in Maharashtra.

Funding

The major funding of the facility comes from the Karnataka State AIDS Prevention Society (KSAPS). The other financial support is from within the Order. It is said that the brothers of the Order who work in different places including abroad, send their earnings to the trust and support its activities. The project gets support for the care, nutrition and staff for 20 patients from KSAPS, but the Order has the capacity to care for up to 52 patients. The funds received annually for the existing 20 beds is Rs. 22.5 lakhs. From this year the support has been enhanced to 30 beds.

Today the practices adopted in the centre are considered to be of high value and are being adopted by other similar institutions for planning their interventions.

Staff

The staff members that manage the care and support facility include a director who is also from the Order, two resident doctors, 3 nurses , one counsellor, a pharmacist, one personal care manager, one physiotherapist, 2 ward attendants, a receptionist, an accounts officer and a driver. The brothers of the Order of St. Camillus provide support in the maintenance of the wards. This is a continuous learning process for the brothers to carry forward the mission of the Order.

The doctors and nurses belonging to other orders/ congregations are on deputation. All members of the staff are professionally trained and have gone through induction training in the centre.

Planning, Implementation and Monitoring

While there is a Project Director to look after the day-to-day activities, the overall management is done through collective decisions responding to the needs of the patients. Ultimately, the comfort of the patient becomes the key issue and all efforts are made to attain that.

There are no specific processes or guidelines laid down for monitoring the activities of the facility, but as stated earlier, the satisfaction of the patient is considered to be the chief monitoring tool. If the patient complains about the services or is uncomfortable, then the Order takes up the issue and tries to rectify the deficiency in the service. Other than this the KSAPS which supports the project with grants has systems to monitor the fund utilization and service delivery, such as documentation, maintenance of accounts, auditing etc. which are routinely followed. Today the practices adopted in the centre are considered to be of high value and are being adopted by other similar institutions for planning their interventions.

The facility for care and support was not planned for people of any specific geographical area and today the people who need support come from various parts of Karnataka, Kerala, Tamil Nadu, Andhra Pradesh, Mahar-

ashtra and Goa. The Trust has also initiated similar interventions related to HIV/AIDS in Kerala and Andhra. In fact, Fr. Anthony said, “Knowing about the facility, people from different parts came to our centre. We never desisted from admitting them. There were people coming from distant places such as Mumbai and Goa. But a large number of people come from the surrounding areas of Bangalore and from northern Karnataka.”

About 90 per cent patients are from the economically weaker sections of the society and are illiterate or semi-literate. Most of them are daily wage earners and have very little knowledge about HIV/AIDS. About 90 per cent of the people coming to the facility with a positive report have never heard of HIV/AIDS and even if they have, it was when the diagnosis was given to them. Their information is limited to the terms ‘AIDS’ or ‘HIV’ and the implications of being HIV positive is not understood until they go through the initial counselling and speaking to other patients of the facility.

It is interesting to note that many of the patients often had other STIs prior to being tested positive. According to them it is common, and they never knew AIDS existed, otherwise they said they would have been careful.

Patients who have come to the centre have been referred from other institutions such as government hospitals or private hospitals/nursing homes. Recent developments indicate that as the network of positive people is becoming better established, referral by peers who have visited the facility, is also increasing.

Cost Sharing of the Services

The services provided by the organization are largely utilized by the poorer section of society. Often the patient is the only earning member of the family or both the spouses being infected are not in a position to earn a living and thus the centre does not charge for its services.

At the same time, the institution encourages clients or relatives of the patients to contribute to

Patients who have come to the centre have been referred from other institutions such as government hospitals or private hospitals/nursing homes.

The centre admits only patients who have tested positive and thus the team knows the exact treatment requirements.

the specialized services required. Often the contributions received are token contributions, but the spirit and the will to contribute are kept alive. When patients desire to have ART and are able to pay for it, the organization helps them to get the treatment at a subsidized cost.

Components of HIV/AIDS Care

The main motto work and spirituality include: To see the Christ in the sick. To become Christ for the sick. To serve the sick as Christ would have served them.

The daily routine starts with morning prayers followed by breakfast. After breakfast cleaning of the facility is completed by the brothers of the Order and the willing and physically able patients also participate in the activity. The inmates take a bath, and those who are bed-ridden are given a bath by the brothers. Thereafter the inmates are free and those patients requiring special treatment receive it. The institution also has a beautiful garden, developed to provide a cheerful environment for the patients who are encouraged to use it.

The Centre admits only patients who have tested positive and thus the team knows the exact treatment requirements. There are patients who have early symptoms and opportunistic infections such as diarrhoea, fever and tuberculosis and once they feel better they are discharged. Patients are prescribed antibiotics to prevent after treatment infections.

There are also patients who come to the Centre with multiple infections, skin conditions and with varied levels of dementia. Pneumonia, advanced TB and acute skin conditions are common among patients at this level. These people may also have bladder blockage, problems with mobility, considerable weight loss, lack of appetite and psychological disorders such as dementia. The center provides treatment for these conditions, psychological support through counselling DOTS for TB. The majority of patients are bedridden or in wheelchairs and they stay at the Centre for more than three weeks before they start to feel better.

The Order of St. Camillus's mission also takes care of the palliative needs of the patients and every need of the patient is attended to at this stage. The last category of patients who come to the Centre are in the final stages and most of them are the past patients of the Centre. These people require intensive care as they are suffering from serious mental and physical conditions. Because of the severity of the condition and higher levels of viral load and low T4 count, the patient does not survive. The role of personal care is crucial here as the staff tries to make the patient's life as comfortable as possible. The patient at this stage requires help with every activity. The Centre has an ICU with two beds and the best possible effort is made to provide critical care to the patient.

Given that a patient typically comes to the Centre after testing positive and thus the centre does not have the need for a diagnostic facility. When the spouse or the child of the patient needs to be tested, the Centre uses the NIMHANS facility for diagnostic tests. It should be noted that though a large number of patients get admitted as inpatients there are also a large number of patients who visit the facility as outpatients for advice and counselling. The centre provides treatment for STIs as for other opportunistic infections. All inmates who invariably need TB treatment are linked with the DOTS programme of the national TB control programme and the DOTS officers visit the centre periodically and supply the treatment to the inmate.

The institution does not have a lab facility of its own presently but recognises the need for it. The National Aids Control Organization has already agreed to provide support for starting a lab in the facility. This will also help monitor the needs of the patients through diagnostic tests which will make the services more effective. There are also tests such as viral load and Polymerase chain reaction (PCR) that are expensive outside. When the centre is equipped with this facility, it will be a lot more easier to provide better care. The PLHAs from Karnataka are linked with the Government ART programme which has been

The institution does not have a lab facility of its own presently but recognises the need for it. The NACO has already agreed to provide support for starting a lab in the facility.

The center does not have a facility in its premises but has made necessary arrangements with NIMHANS for the post exposure prophylaxis.

launched recently. For others, the Order tries to provide ART either at subsidized rates or through sponsorships.

Adherence to Standard Precautions

The Centre has adopted universal blood safety precautions. All staff of the facility strictly adhere to the prescribed set of precautions. As the facility only deals with the PLHAs and their care, staff members are trained and their practices moni-

tored to ensure that the precautionary measures are adopted. Necessary equipment and support supplies are adequately available in the Centre. The institution uses only disposable needles and syringes and the staff members are trained in handling the needles even during recapping.

Furthermore the facility has a good laundry so that the linen is regularly changed and cleaned. All standard precautions are adopted in handling soiled linen.

The Centre does not have a facility in its premises but has made necessary arrangements with NIMHANS for the post exposure prophylaxis. The routine procedures are followed and the consulting doctor is informed. Based on his advice, the exposed person is asked to take the necessary medication and undergo screening. The KSAPS budget also has allocation for PEP drugs.

All the health workers are already trained medical professionals, but when they join the facility they go through one week training in caring for and managing PLHA. Doctors from the St. John's Medical College and Hospital, CHAI and the experienced staff of the facility provide this training to the new staff.

All patients receive counselling on a regular basis aimed at psycho-social support. The healthcare team regularly meets, discusses and assesses the needs of individual patients and the counsellor provides this support through counselling.

There is an evening meeting of the patients along with prayers. Each patient attends and prays according to their religious faith. This helps them to stay mentally fit and strong. There is no special effort to bring in faith based healing but in each of the services the concept and concern is evident.

Other than evening prayers, the facility does not insist on any religious commitment from the patients. No specific effort is also made to inculcate Christian values or beliefs in them which make them feel comfortable. However, many of the patients feel they have a responsibility to honour the Christian values and beliefs as God has sent these missionaries to care for them. While there is no compulsion, the facility makes it a point to celebrate all major festivals like Deepavali and Christmas.

The Order's philosophy clearly declares that the "patient is the Lord and the members do everything to please the Lord and make him comfortable." Indeed, all staff involved in the care of the patients follow this philosophy in deed and spirit.

One of the patient said *"the staff takes care of the patients the way a mother takes care of her children."*

End of Life Issues

Most of the patients come to the facility at the end of their lives and often die at the facility. There are instances of 5-6 deaths occurring in the facility per month. Most of the time, the relatives take back the body but those remaining are cremated by the institution itself. The facility provides support and encourages the relatives to conduct the last rituals according to their faith. A specific space within the premises is provided for this purpose and rituals such as giving a bath to the body is taken care of by the brothers of the Order. Facility for embalment is not available in-house, when necessary, the body is taken to the St. John's Hospital and

A specific space within the premises is provided for this purpose and rituals such as giving a bath to the body is taken care of by the brothers of the order.

The sexual mode of transmission is explained to the non-infected spouse and they are encouraged to protect themselves.

Medical College for the purpose and then handed over to the family members.

All dead bodies are adequately managed to prevent transmission of virus. The families are provided advice such as not touching the wounds, not giving another bath at home and not open the packed body before cremation.

The organization is not actively engaged in advocacy or raising legal rights issues but plans to initiate community-based work and outreach in order to build an enabling environment purely to build community and family support to PLHA.

It is necessary to note that all the activities of Snehadaan are carried out based on their experience and commitment. There is no written policy to serve as guidelines for action, but commitment to the cause and true belief in the mission which the Order has taken up, guides each individual who works in the facility.

Prevention Programme

The Order has not undertaken any prevention programme or awareness programme. But recently, realising that a lot of the people had no prior information about HIV/AIDS before being infected and knew nothing about prevention, the Centre is planning to initiate such kind of programmes in the surrounding areas. A database maintained at the centre indicates that information dissemination is more important among women, as none of the female patients had any knowledge about HIV/AIDS. In any case, the prevention of the virus from the infected spouse to non-infected spouse is a priority and thus counselling along these lines takes place in the centre. The sexual mode of transmission is explained to the non-infected spouse and they are encouraged to protect themselves. The issue of condoms as a barrier is also discussed with the clients, not as a birth control device but as a life saving device. Condoms are also discussed with couples who both have tested positive as this can stop increased viral load through further cross infection. In fact, Fr. Mathew said, *“we have no hesitation in*

talking about condoms with the couples because we are talking to them about how they can protect themselves or how an infected spouse can protect the non-infected spouse. As a religious order we do not prescribe condoms but we definitely discuss the issue with them. We have two options either to avoid talking about it thus allowing a non-infected spouse to get infected, or, to talk about it and save a life. Though I am a religious person, I prefer the second because I will be saving a life by talking about condoms."

The centre has also decided to educate the local community on HIV/AIDS by speaking about the cause, spread and prevention of HIV. Efforts have been made already with the help of student social workers, with encouraging results, so the organization is planning to appoint a full time social worker. To continue the community education programme, the organization has chosen two panchayat areas in the vicinity. The existing telephone counselling will also contribute to the community awareness programme.

Situated in a care and support centre, the programme specialises only in care and support activities, but not in prevention programmes. The project addresses the needs of the people who are already infected. In the process, the programmes link the family, and while dealing with the spouses, prevention messages are provided if the other partner is not infected.

Counselling and messages for safe sexual behaviour and patient care at home are also provided to the patients and their spouses and relatives so that they will further not infect other general population. The family also goes through counselling so that better care of the person can be taken by the family members. The counselling is successful because of the professional counsellor in the facility.

Enabling Environment

The organization is also planning to network

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The project is one of the first initiatives of its kind in the country. Other than the experiences of similar interventions abroad, there was no place in the country to understand and adapt practices.

with two other programmes in order to provide palliative care to the children. The organization plans to build a linkage with all church-based institutions in Karnataka and other places where the patients come from, to ensure follow-up of the treatment. Presently such a network exists in very few places. Snehadaan is part of the Network for AIDS Prevention (NAP) Karnataka and has a very good link with Karnataka Network of Positive People (KNP+). Each month, network people come to the centre and address the patients in the centre. Fr. Mathew is a consultant to the other similar KSAPS supported care and support initiatives, and thus is in a position to influence the decisions of the Government related to care and support of PLHAs. Furthermore hav-

ing a close relationship with CHAI and St. John's Hospital and Medical College has advantages as a large number of doctors and health care workers can be reached about the care needs of the PLHAs. Fr. Mathew and his team at Snehadaan get many opportunities to address the gatherings on issues related to PLHAs which are used to influence the ethical issues related to testing, care and treatment of PLHAs.

The project is one of the first initiatives of its kind in the country. Other than the experiences of similar interventions abroad, there was no place in the country to understand and adapt practices. Thus as said earlier the entire process was learning while practicing.

The initiative is based on the local need and in response to the local situation. With the afflicted person hoping that death would help him escape disgrace and helplessness, Snehadaan came to the rescue, raised hopes and allowed that person to have the best possible medication, care and a peaceful dignified death.

Even though the infections might have occurred a long time ago and been acquired most likely through sexual contact or some other mode, the present partner/spouse is motivated to go through counselling and

encouraged to undergo diagnostic tests. Most of the time they also turn out to be positive and at times children too test positive.

The facility is unique in many ways:

The programme is the first of its kind in the country

- ◆ The recipient of service is extremely satisfied with the service provided by the centre
- ◆ The people who come there for help do not wish to stay on and become a burden but wish to go back to the community and make space for others to come in, which is unique to the programme
- ◆ The programme is flexible to suit emerging needs and priorities
- ◆ Improved information dissemination and support for self-protection is the most important thing that needs to take place and church-based institutions can play a greater role in this
- ◆ The services of a professionally trained counsellor is part of care and support programmes
- ◆ At this point of time, the organization has a accumulated vast experience in providing care and support to PLHA that can be utilized to initiate similar kinds of programmes by church-based organizations

Snehadaan is a unique, impressive programme and the experiences of the institution in care and support programmes can be drawn upon to initiate similar programmes in other places. Snehadaan is willing to share the knowledge and expertise it has developed over time with people who wish to initiate similar kinds of programmes.

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St. Ann's Snehasadan

Pramod Chand Singh

St. Ann's Society was founded by Fr. William Meyer in 1909 in Switzerland, with the mission to care for mothers with newborn babies in their homes. In 1927, Sister Elizabeth came to India from Switzerland and started working as a nurse in a government hospital in Vijayawada. With the money she earned, she built a small house that was subsequently converted into a dispensary.

This small beginning led to the establishment of St. Ann's Hospital in Vijayawada in 1940, that grew to become a multi-speciality hospital with about 300 beds. A school of nursing was also established to impart excellent nursing education and skills. The missionary zeal and commitment demonstrated by Sr. Elizabeth attracted a lot of young women. The India congregation is divided into three provinces - Central, South and North, with Vijayawada as the headquarters for the Central province. St. Ann's Society has three ministries- education, health and social apostolate.

In health care, the congregation has established small dispensaries, health centres and large multi-speciality hospitals. St. Ann's Health Centre was established around 1975 in a village called Nunna, about 15 km from Vijaywada city, to provide health care to the rural population that had less access to health services.

Around 1995-1996, St. Ann's Hospital in Vijayawada started receiving an increasing number of patients who were HIV positive. Even though the hospital administration wanted to take care of the medical needs of these people, the doctors resisted this move, considering it a serious occupational risk. The resistance that emerged from sister-doctors was high, in particular it was related to deliveries and conducting surgical procedures. In those days, there was limited information and awareness about the standard precautions for exposure to the HIV infection.

The Society of Sisters of St. Ann, Luzerne, in its provincial and general chapters recommended taking care of HIV/AIDS patients as they felt it was a pressing need. The Society organized various sensitization programmes on issues related to HIV/AIDS for the entire staff- including the doctors, nurses, allied staff, Class-IV staff and members of the congregation. Resource persons from CHAI, Osmania Hospital and other NGOs were invited to deliver talks and video cassettes that were screened for the staff and the nursing students. With little knowledge of the type of precautions to be undertaken, the sisters brought bleaching powder and encouraged the use of disinfectants. Instructions were given to use gloves, aprons and masks and there was strict supervision to ensure that all staff followed them. Facilitated by CHAI, doctors were sent on exposure visits to Care and Support centres. Even with these efforts the problems did not cease as the health care providers, while ready to take care of health needs, were unwilling to get involved in surgical procedures and caesarian section and delivery. Therefore, a separate wing for treating infectious diseases and conducting deliveries of HIV positive women was created.

During this period, there was a sharp decrease in the number of patients in the outpatient department. At the same time, the bed-occupancy of people with AIDS was very high, which created a shortage of beds for emergency cases and other illnesses.

Resource persons from CHAI, Osmania Hospital and other NGOs were invited to deliver talks and videocassettes that were screened for the staff and the nursing students.

In 1999, the hospital administration decided to set up a separate unit to take special care of people infected with HIV/AIDS.

In 1999, the hospital administration decided to set up a separate unit to take special care of people infected with HIV/AIDS. This was the beginning of 'Snehasadan'. The health care centre in Nunna was renovated and converted to a Care and Support Centre for People Living with HIV/AIDS [PLHAs], which started functioning in December 2001, but was officially, inaugurated in February 2002, by the District Collector B. R. Meena.

Stepping Stones to a Success Story

The institution faced some teething problems both from within the congregation and without. Sr. Elizabeth, the Provincial Superior mentions that the basic philosophy and the guiding principal for them has been to "render service according to the need of the times". "The pressing need for special attention and care for people living with HIV/AIDS got them into action believing that the need of time is the will of God". "Our response to ethical dilemmas when faced is – to act from our conscience", she said. "One has to use one's own conscience, pray and then make a decision. Issues within the congregation, were not less challenging", she reminisces. Many apprehensions, doubts and fears, including stigma and ethical issues were raised. Some challenged the rationale of taking up a project of this nature. But as it is said "good shall prevail" and the Centre, which has been running for almost two and a half years now, has been able to provide services to many infected patients.

The villagers of Nunna, showed resistance when they got to know that this Centre would be housing and providing treatment for PLHA. It took a lot of convincing and persuasion to gain their approval and support to run the Centre smoothly. After setting up the Centre, the flow of patients was slow due to many reasons - the distance from the city, lack of transport facilities, the lack of public knowledge about the Centre and the lack of proper food and accommodation facilities.

The other major challenge the sisters faced were that of medical-legal issues. Some of the patients admitted to the Centre were abandoned

by their families who did not even come after the death of the patient. In such instances the sisters encountered a number of problems. They had to visit the police station at odd hours of the night, to report the death, file the first information report and get the death certificate. After a number of attempts they finally got help from the municipal staff for cremating the body. Another major challenge was the problem of disposing of dead bodies of unclaimed patients was one of the major challenges faced by them. To find a solution for this, they met the District Magistrate to discuss the issue of abandoned patients. The official suggested that they contact APSACS and network with the nodal officer for the HIV/AIDS programme, the medical superintendent and other influential persons to address such issues more effectively.

Turning Point

A letter about the efforts of the Centre and the challenges it faced was sent to APSACS, seeking its support in addressing the problems. In response to this, a team from APSACS came for inspection and verification of the Centre and its activities. In May 2002 APSACS decided to partially support the Centre's efforts. Initially they were sanctioned financial support for 10 beds with an annual grant of Rs. 4.80 lakhs, and subsequently the funds were increased to support 20 beds. Later the Catholic Relief Services (CRS) contributed support for the nutritional and medical components.

The Daily Schedule

A normal day at the Centre starts with a short prayer participated by the relatives, and those patients who are able to walk. The Centre provides food for the patient and one attendant free of cost (breakfast, lunch, tea and dinner) for which they have to come to the common refectory. Some of the patients are not able to eat or move easily, but once they come together

In May 2002 APSACS decided to partially support the Centre's efforts. Initially they were sanctioned financial support for 10 beds with an annual grant of Rs. 4.80 lakhs, and subsequently the funds were increased to support 20 beds.

All the activities at the Centre are very systematically organized and each of the members perform their duties in an orderly manner.

they experience a kind of joy in sharing and sitting together as a family. For patients who are unable to come to the refectory, the food is served at their bedside. The doctor does his rounds of the inpatient ward twice a day and depending on the patient's condition medication is provided. If a patient shows improvement, he or she is discharged. All the activities at the Centre are very systematically organized and each of the members perform their duties in an orderly manner.

The Staff

The Centre has eight staff members in addition to some maintenance staff. Of the eight staff members four are sisters belonging to the St. Ann's congregation. The others include a medical officer, an administrator, a counsellor, two coordinators- cum-staff nurses, one pharmacist and one lab technician.

The inspiration for working in such a place is different for each of them. The counsellor is a young girl in her 20's. She said, *"My inspiration to work here in this Centre with HIV positive people comes from an incident that occurred in my life ...two years back my parents arranged for a matrimonial match, the boy and girl's families were both related to my family. It so happened that just a day before that couple's first wedding anniversary, the boy passed away. It was at that time that all got to know that the boy was HIV positive and with this revelation all hell broke loose for my family. The girl's family accused us of arranging the marriage, cheating and withholding information regarding the HIV status of the boy".* Later, when she came across an advertisement for a counsellor in the Care and Support Centre at Nunna, she applied, and her father encouraged her to take the job. She was happy to take up a job of this nature because in some way she could get a chance to serve people living with HIV/AIDS. She finds counselling patients with suicidal tendencies challenging. She said, *"All patients who come here are in greater need for psychological/mental support more than medical".*

The Centre has a Residential Medical Officer, who has been working since the inception of this Centre and continues to do so with dedication and interest. He says, "My parents know about the nature of my work in this Centre, about the kind of patients I come across and they have supported my decision". The patients admitted here are mostly in the terminal stage and require constant supervision; sometimes their condition suddenly becomes critical and requires a doctor's attention. He stated that most patients who come to the Centre seeking treatment are males, mostly from the transport field i.e. (lorry drivers and their helpers). Ninety per cent of them come with symptoms of pneumonia and/or T.B. They go to a number of other places seeking treatment for their condition, believing that they will be cured but end up disappointed by false claims. Those who cannot afford to continue spending a lot of money or those who cannot borrow money or take loans even sell their properties and other assets to pay for the treatment, before eventually finding their way to the Nunna Centre.

The Pharmacist is a sister belonging to St. Ann's congregation. She decided to volunteer and joined the team at Nunna. She said, "Besides medical support, treating patients with love and care is a unique feature at this Centre". Other than giving out the medicines, she spends time with all the patients, talks to them, cheers them up a little, and prays for them when they ask for it. She is a favourite especially among the children at the Centre.

When the Centre was started, an option was given to the sisters of the congregation to work there but very few opted to do so. However, Sr. Tessy and Sr. Sujitha joined the team and they function as the coordinators-cum-staff nurses at the Centre. The small number of staff/volunteers leaves them with a lot of multi-tasking to do but as Sr. Sujitha states "God gives us the necessary strength of mind and body to take up the challenges we may have to face during each day. The joy and satisfaction that we get from serving, the sick and those who

The patients admitted here are mostly in the terminal stage and require constant supervision; sometimes their condition suddenly becomes critical and requires a doctor's attention.

The institution caters to any person who is HIV positive and depending on their health condition, provides necessary outpatient or inpatient services.

have lost hope is beyond measure and is enough to keep us going". Sr. Tessy who has been there since the inception has received good practical and theoretical training in caring for the PLHAs, and also went for learning and exposure visits to other similar care & support centres in India.

The role of the Administrator in the smooth functioning of the Centre is truly visible and her efforts are appreciable. She is the Superior of the congregation working in the Centre and is broad minded, futuristic, open to innovation, enterprising and disciplined. It takes a talented person such as her to run the institution in such a wonderful and organized manner.

Except one or two of the staff members, the rest have all been working in the Centre without formal training or specific capacity building programmes. The counsellor however would definitely benefit from formal training in counselling. The doctor mentioned that he received four-day training on syndromic case management of STIs and that he would benefit from training in anti-retroviral therapies [ART] and also in the treatment of recurrent infections.

The institution caters to any person who is HIV positive and depending on their health condition, provides necessary outpatient or inpatient services. The services are not restricted to any particular group or section of the society. As the Centre's Administrator points out, almost 90 percent of patients are from an economically poor background. There are also patients who come from financially stable backgrounds but go bankrupt spending money on treatment from different places. Some of them fall prey to unscrupulous practitioners who take advantage of their ignorance and drain their resources. As for the rich and the more financially secure, they are more conscious of their social status and of what people would think of them if their HIV status was known. To avoid stigma, they generally avoid coming to Centres such as these. However, the poor people due to their poverty cannot hide their sickness and seek help from the Centre. Initially, most of the cases were referred to the Centre by St. Ann's

hospital but today, as Sr. Elizabeth indicates, 'our patients are our media - our publicity. Some of the reasons mentioned by patients/family members/relatives for them to opt for this Centre has been provision of good care and services which are free of charge. Others said that they had been to many such places and this was just another one for them. Today there is rapid increase in the number of patients coming to the Centre for medical aid, food, and nutritional and psycho-social support. At any given time there are at least 30 inpatients.

The Centre has patients coming from different districts of Andhra Pradesh but most come from places in and around Krishna district. Accessibility could be one of the major influencing factors as the centre can be reached by bus/ auto rickshaw /shared autos.

While most of the patients were in the age group of 26-35 years, the Centre has treated outpatients of a range of ages – the youngest being 2-years old and the oldest being 75 years. Male patients outnumbered the females. Most of the adults who sought treatment from the Centre were married for an average period of 11 years. More than 55 percent of the married partners are positive. Of the remaining 45 percent, less than 35 percent have been tested and 10 percent of them tested negative.

Around 75 percent of the patients have availed of treatment from the Centre within 6 months of their diagnosis, which is an indicator that people are probably more aware of this Centre now, and are probably seeking treatment from proper sources as soon as they are faced with an opportunistic infection.

A majority of the outpatients are porters, while 18.5 percent of them are housewives and 10.5 percent of them truckers. If the data is some indicator of the universal population, then it can be said that the HIV is no more limited to the high risk behaviour groups such as sex workers and truckers, but has moved into the general population as well.

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Talking to some of the patients and attendants revealed that they have come to terms with their HIV status and are learning to cope with it after enduring spells of pain, agony, guilt, shame and embarrassment.

On an average an inpatient's duration of stay is 5 days. Talking to some of the patients and attendants revealed that they have come to terms with their HIV status and are learning to cope with it after enduring spells of pain, agony, guilt, shame and embarrassment. The institute has been a great source of hope for all of them. With the efforts of the staff, especially the counsellor, the families have grown to understand more about the disease, accept the patient's status irrespective of how he/she has contracted the HIV and are prepared to take care of the patient without hesitation.

Stigma and Discrimination

"Ms. X is an attendant, the mother of a patient admitted at the Centre. She said that her son had got "this" disease due to "his bad ways/habits". Her son is married with a five-year-old son. When her daughter-in-laws' parents came to know of the HIV status of her son, they took their daughter and the grandson home. She stated, "every unmarried boy/girl should insist on getting HIV status of the partner they plan to marry because marriage is a commitment for life".

On the other hand Ms. Y, the elder sister of one of the patients, comes to see her brother every day. The brother is married with two kids and his wife, who tested negative, is now at the Centre taking care of her husband as attendant. Ms. Y brings food and snacks for her brother and his wife. She stated that on getting to know her brother's HIV status the entire family was devastated but they were never ill-treated, stigmatized or discriminated against. Both her brother's children are being taken care of in her house. She said, "I know my brother made a mistake, he is already bearing the consequences of it and so are his wife and children. But if family members do not support, we cannot expect others to do it".

Another couple who tested positive was diagnosed four years ago. They have two children, being looked after by the members of their family.

On knowing his HIV status and later his wife's, the man's family did not cast them away but supported them. His wife complains saying that he never stays in the house, always goes out and meets all his friends and neighbours but all of them do not know of his HIV status, they think he has been suffering from TB for a long time. They said that today people are much more aware than before, but still continue to discriminate and ill-treat people living with HIV/AIDS and their families. Speaking of his experience in the Centre he said, "I am a firm believer in Jesus Christ but did not see him any time but when... (there are)...these sisters going about helping people like us, I know I have seen God".

Sexually Transmitted Infections

There are quite a few outpatients who come to the Centre with STI problem. They are provided with treatment following syndromic case management. Most of the patients who come for treatment are generally suffering with the problem for a long time. Some of them have also sought treatment from quacks or resorted to home remedies. When they realise that the problem is persisting they finally come to the hospital. Most of the STI patients, who are referred for HIV testing, typically test positive. This is a very alarming situation given the fact that they have contracted the STI from multiple partners or from their spouse who has multiple partners. Knowledge/awareness on the STIs among the patients is very little in comparison to that on HIV/AIDS. There is a lot of stigma and shame attached to STIs because it is a disease that is contracted sexually and often through multiple partners. And so most of the people who have the problem keep it under wraps for long periods of time until probably the situation gets unbearable or difficult to manage with informal cures. Partner treatment is an area which is a challenge still. Most of the patients in spite of counselling do not bring in their partners for a check-up or even for counselling. Sometimes it takes a lot of persuasion by the counsellor and the doctor, for some of them bring their partners.

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The influence of the faith-based approach is clearly reflected in the messages given to the patients who come for counselling and the outreach programmes.

Prevention

The prevention activities which are being carried out with support from CRS were initiated in July 2004. The programme has taken off and the outreach team has so far been involved in rapport building with the community. They occasionally perform cultural programmes related to HIV/AIDS to build awareness on prevention, inform others about testing Centres and caution the public with “prevention is better because there is no cure” kind of messages, conduct group meetings and make home visits. Some of

the HIV positive patients’ wards are also being covered through the Family Health International project. The team has also formed two groups of PLHAs and conducts regular meetings with them at the Centre. In addition it has established good linkages with other Government and non-governmental agencies. The influence of the faith-based approach is clearly reflected in the messages given to the patients who come for counselling and the outreach programmes. The focus of the messages is more on abstinence and being faithful to single partner as methods of preventing HIV, rather than the use of condoms as a means of prevention. The messages also highlight the risk factors involved in high risk behaviours. The outreach staff excepting the counsellor has not received any specific training related to the programmes they are currently implementing. So far no specific study has been undertaken to analyse and understand the influence of socio-economic conditions, behaviour patterns, occupations and risk factors on getting the HIV infection.

If any new cases are identified, they are referred to the VCTC or to the Centre. The team also follows-up on the patients undergoing treatment from the areas being covered under the FHI project. Most of the patients who reported going to the VCTC, go either because a doctor has asked them to, or because they have been referred by an NGO. After talking to some of the relatives of the patients and/or the patients themselves, it seems that quite a few of them have been to other diagnostic centres and they end up spending a large amount of money and quite often fall into a debt trap.

Extending pre- and post-test counselling services to all the cases that come to the Centre is difficult at times because of the number of patients and only one person to cater to the counselling needs. The outreach team has established good linkages with the Government hospital and the VCTC.

Healthcare

Inpatient Facilities

The Centre is being supported by APSACS for a 20-bedded hospice. However, the number of patients that are being cared for exceed that number, and the administration, recognising the demand, has put in 10-20 extra beds as a contribution from the congregation. Nutritious food, medical consultations, diagnostic services, medicines, regular counselling and accommodation are some of the services extended to the inpatients absolutely free of cost. Except for the medicines and diagnostic services, all the rest of the facilities are also extended to the patient's attendants without charge. An attendant for each patient is compulsory at the time of admission. This policy was introduced due to the administrations past experiences of complications arising in the absence of an attendant if the patient passes away, such as property and other legal and medical issues. To a great extent, this attendant system brought down the workload of the staff who are few in number and also made more individualized and personal care possible.

Outpatient Facilities

Free medical consultation, diagnostic services, counselling and medicines are made available for the outpatients. The outpatient ward is open six days a week and for eight hours a day. Expectant mothers who are HIV positive are referred to the Government antenatal clinics for regular check-ups and delivery.

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The patients and/or their family members can walk into the counsellor's room if they want to talk, discuss issues and worries, clarify doubts, seek advice and consolation.

is no provision in the Centre for ART. For those patients who can afford it, the doctor prescribes the necessary anti-retroviral drugs, which can be purchased from outside. The Centre has established good linkages with other Governmental and non-governmental agencies such as the TB Centre, Lion's Club and the Rotary Club.

Other Services/Facilities

The Centre has a lab facility and one lab technician who performs simple diagnostic procedures. They do blood and urine tests and they have a facility to conduct a Tri-dot HIV test. For people who come with multiple health problems but no report on their HIV status, the counsellor assesses the patient's history, and if necessary refers them to the nearby VCTC.

Universal Precautions

Universal precautions are followed, such as safe disposal of used syringes/needles for example syringes are burnt, the needles are cut - and together with the used cotton and dressing material, it is all incinerated. The centre uses disposable gloves, facemasks, and aprons. One of the auxiliary nurse midwives working at the Centre got a needle prick and she was immediately put on post exposure prophylaxis. The exposure is high but the staff states that they take the necessary precautions and care to avoid such accidents.

Care and Support

The patients and/or their family members can walk into the counsellor's room if they want to talk, discuss issues and worries, clarify doubts, seek advice and consolation. The counsellor mentions that handling all this requires a lot of patience. They want somebody to listen to them, give them a word of encouragement and guidance. The patient has to be helped to deal with his health status, the emotional and mental turmoil such as rejection and non-acceptance by self and family, fear, suicidal tendency, guilt, and a gamut of other feelings. There are additional issues related to the patient's spouse (if married), children, and family members, which have to be dealt with as well. Either the counselor or

the doctor discussed condoms with patients and/or their spouse whenever they felt the need to do so. "However, most of the patients who come here are in a terminally ill-stage. As far as the outpatients are concerned there is a definite need to focus on prevention methods especially to avoid increasing the viral load and to ensure protection of at least one partner in the case of a discordant couple." According to her, the administration of the institution also feels that the doctor and the counselor can deal with these issues appropriately as they have no faith-based restrictions.

As part of the psycho-social support initiative, besides regular counselling, the Centre organises get-togethers and meetings of PLHAs. They are provided with a platform to come together to, share their experiences on how they have coped with difficult, challenging situations, and also to provide emotional support and encouragement to each other. The staff of the Centre, some of whom are sister-nurses, also extend spiritual guidance and support to those patients who request it, by praying and sharing the word of God with them and spend time talking to family members and offering moral and psychological support to build up their courage.

All of them said that they found great solace in the service they received from this Centre. They appreciated the work of the staff who tirelessly served them night and day. Irrespective of their job responsibilities, each staff member can be found interacting with the patients and their families. Those who have sought treatment before from other places mention that these sisters provide much better service. "They not only cure us of our illnesses but also provide us with spiritual and mental strength. Every one tells us that we have very little life to live but here we are told that irrespective of the time we live, we must live happily."

Disposing of unclaimed bodies involves a lot of procedures and permissions from the Municipal Corporation, the police and some other government departments. A sister nurse recounted that a full-blown AIDS case patient died last summer.

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The sisters tried to contact the patient's family relatives to inform them about the death but no one came to claim the body. The sisters, after informing the local police and other Government officials performed the burial. Two days after the incident some of the relatives came to the Centre and started questioning the sisters about the patient's will and details of the property he owned. With the help of the police the problem was sorted out and things were clarified. This prompted the administration to make the decision not to entertain admissions unless the patient is accompanied by a family member.

Creating an Enabling Environment

The outreach team also plays an important role in conducting advocacy meetings with different stakeholders such as community leaders, religious leaders, youth, government officials and non-governmental agencies. The objective is to gain their support and cooperation in creating a better environment for carrying out the prevention programmes and in reaching out to the general population in addition to directing some of the agencies' and organizations' services to the deserving. For instance, the Lion's Club conducted a free eye-camp for the patients at the Centre; also some of the children (infected and/or affected by HIV/AIDS) are being given free education and hostel facilities in institutions run by the same congregation.

Linkages

The centre has established linkages with FHI, which has a programme for orphaned/infected and affected children, and with other agencies to mobilise contributions for school fees, rice for the Centre, books and other necessities. Snehasadan today receives a large number of clients through referrals, not only from NGOs working in the field of targeted interventions but also from other private practitioners and nursing homes.

Observations and Suggestions

- ◆ The institution's major strengths are its good support from within the congregation, committed staff, good infrastructure, and the pragmatic approach towards the programme in all aspects. The institute is managed effectively and all the activities being carried out in a disciplined and orderly way.
- ◆ Keeping risk factors in mind, HIV patients affected with T.B are kept in a separate wing, and patients who are in the terminal stage of AIDS are put in a separate room.
- ◆ The management is open to mobilising support from different agencies to strengthen the Care and Support programme, and open to learning and innovation.
- ◆ The institute's large campus provides an opportunity for patients to move around and exercise. Some of the patients who stay at the Centre also help with the gardening.
- ◆ The areas which require strengthening are the prevention programme, counselling services, building the knowledge and awareness levels of the patients and their family members on STIs/ HIV/ AIDS, and the use of good BCC and IEC materials during outreach and counselling.
- ◆ There is need to address the myths and misconceptions related to HIV/AIDS and the person infected by it.
- ◆ Counselling for both the outpatients and inpatients is an area which needs much focus as most of the patients are in need of good psycho-social support.
- ◆ There is a definite need for all the staff to undergo training and capacity building specific to the work they are doing, and also for building a good attitude and knowledge base required to work with such clientele. This will help the staff in performing their duties more effectively and carefully.
- ◆ The institution, instead of providing all the services free of cost can charge the patients a nominal fee to create a sense of responsibility in them, and also to ensure sustainability of services in the long run.

The congregation feels that the Church has a major role to play in prevention and control, and in caring for the people infected and affected

The current HIV/AIDS scenario invites the Church's leadership to take some initiative. Quoting Mother Teresa, Sr. Elizabeth mentions, "our service is only a drop in the ocean".

by HIV/AIDS. There is the need and the scope for a major intervention from the Church and it is its moral duty to extend help to these people. The current HIV/AIDS scenario invites the Church's leadership to take some initiative. Quoting Mother Teresa, Sr. Elizabeth mentions, "our service is only a drop in the ocean". A greater number of programmes need to be initiated without further delay. The Church at every level has to shoulder more responsibility for this problem. Each one in the hierarchy should be able to contribute and make a difference to the situation.

Ways to do this are to sensitise all the clergy during the retreats and seminars and discuss how they can collectively respond to the epidemic, and to introduce compulsory sensitization and awareness programmes on HIV/AIDS in all the Catholic educational institutions. As Sr. Elizabeth beautifully puts it, "preserving life is the priority" for each one of us. Each one of us is called to act to enhance the living. As Jesus said "I have come that you may love life, life in it's fullness".

St. Francis Hospital

Tomy Philip

Founded by Little Sisters of St Francis of Assisi, St. Francis Hospital, Ajmer, has more than a century's health work to its credit. On 25th November 1970 the hospital was registered under the name 'Society of St. Francis Hospital and Nursing Home, Ajmer', as a charitable society under the Rajasthan Society Registration Act, 1958. Located on Beawar Road in district headquarters, St. Francis Hospital is one of three major health care institutions in the area, the other two being the government run Jawaharlal Nehru Hospital and Kamala Nehru Hospital.

Since 1951, the hospital has been owned and run by Mission Sisters of Ajmer, a religious order in existence since 1911. Mission Sisters of Ajmer are involved in education, health care and social work apostolate in 45 different mission stations in different parts of the country. The stated vision of the congregation, 'to be prophetic witnesses of God's kingdom, to the people of other faiths, to the poor and the marginalised especially women and girl children', underlines their commitment in health care activities.

St. Francis Hospital is considered the nucleus of health care work of the Mission Sisters of Ajmer. It is a multi-speciality hospital with departments like General Medicine, Surgery, Paediatrics, Obstetrics and Gynaecology, Orthopaedics, Ear, Nose and Throat (ENT) and Pathology. The staff strength of the hospital is 155 with 42 doctors (full and part time), 43 nurses, 10 paramedical staff and 60 other staff. The major thrust of the hospital is curative care. Most of the services of St. Francis Hospital are urban-based except for those undertaken in rural areas of Kanakheri, Hathikhera and Gajwana.

While the prevention programmes are primarily community based, treatment, care and support programmes are primarily institution based.

The hospital also has a Community Health Department. This department is actively involved in health related work in three nearby villages and a slum. The thrust of the extension activity in these places includes implementation of the DOTS strategy for prevention and treatment of tuberculosis, awareness on immunization, health education and HIV awareness. Trainee community health workers of the hospital are involved in these activities under the guidance of the community health nurse. Most of the people

targeted by the health extension initiative belong to a low socio-economic status.

Rajasthan is not a high HIV prevalence state. However, cities like Ajmer are susceptible to a high rate of HIV transmission because of the large number of tourists visiting the Dargah-e-Shariff, the presence of national and state highways and the large number of truck drivers living in the Srinagar block of the district. The HIV/AIDS intervention programme implemented by St. Francis Hospital includes the components of prevention, treatment, care and support of PLHA. The programme is being implemented by three specific but inter-related delivery systems - Asha Niketan, St. Francis Hospital and Jiwan Dayini Project. The HIV/AIDS intervention of St. Francis Hospital got a boost after the initiation of Asha Niketan, a care and support centre and, subsequently, prevention programmes were strengthened through the Jiwan Dayini Project. While the prevention programmes are primarily community-based, treatment, care and support programmes are primarily institution-based.

Asha Niketan

In 1998 the congregation decided to engage actively in the field of HIV/AIDS. The hospital had started receiving HIV positive cases and there were no services available for the care and support of PLHA in the area. It was decided to start a care and support centre for PLHA in one of the satellite centres of the hospital called Kanakheri, located about 40 kilometers away from the district headquarters. It is a predominantly

rural area inhabited mostly by people belonging to socially backward classes. Kanakheri was selected as the location for the proposed HIV/AIDS care and support centre, taking into consideration the presence of a convent, experience of health care work in the area, availability of land and infrastructure and favourable geographical features.

Asha Niketan was opened in Kanakheri in August 2002 as an extension centre of the hospital. The centre was started with eight HIV/AIDS infected persons referred by the Missionaries of Charity and Kamala Nehru Hospital, Ajmer. The new building of Asha Niketan was constructed in the same premises in January 2004.

Asha Niketan has a capacity to accommodate 20 people (12 men and eight women) with separate dormitories for men and women. Each person is provided a bed, mattress, linen and pillows. There are two toilets and bathrooms attached to each dormitory. People admitted to the centre are also provided with a locker to keep their personal belongings. Furthermore these, provisions for recreation like television and carom boards are also made available.

Asha Niketan provides free stay, food and medicines for all residents. Clothing is also provided to those who cannot afford it. Inmates of Asha Niketan are allowed to manage their daily activities independently. However, in the terminal stage they are provided with adequate care such as for bathing, changing clothes and feeding. Other patients in the centre who are relatively healthy also extend a helping hand to the nuns in looking after the terminally ill. Residents of Asha Niketan are motivated to keep themselves engaged in meaningful activities like gardening and assisting the children of HIV infected people with studies.

Healthy meals are provided and sufficient nutritional support is made available to the clients in the hospital. In order to take care of additional

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nutritional requirements the inmates are provided with vitamin supplements, iron folic acid tablets, osteocalcium tablets, and tonics like Liv-52.

From the founding of Asha Niketan in August 2002 through August 2004, 71 people had utilised its services. The Missionaries of Charity, Kamala Nehru Hospital, Jawaharlal Nehru Hospital and the TB clinic of St. Francis Hospital referred most of the cases. At the time of the study, there were 16 PLHA (13 adults and three children)

staying in Asha Niketan. People from different parts of the country, especially from Rajasthan, Maharashtra, Madhya Pradesh, Bihar and Karnataka have sought its services. Most of the patients belong to lower socio-economic status and were either truck drivers or migrant workers.

A large majority of the affected persons received information about Asha Niketan either from the Missionaries of Charity or from the hospitals where they were tested. A few cases also got to know about it from their social networks and from people who had availed of the services of the centre. This is especially true of people from Ajmer and adjoining districts. Most of the people in the centre were not aware of other facilities offering care and support for PLHA in the area.

The majority of the patients were young adults, ranging in age from 18 to 45 years. The majority were men, hailing from rural areas, and most were married. Most of the patients belonged to lower socio-economic status and were either truck drivers or migrant workers. More than half the inmates in Asha Niketan were illiterate and one-third of the literate inmates had education only upto the primary level.

People living with HIV/AIDS seek admission to Asha Niketan at an advanced stage of the syndrome, with failing health, acute tuberculosis and pneumonia. Most of them appeared to have come to know of their HIV status only during the full blown AIDS stage. The majority are treated for opportunistic infections and are encouraged to return to their communities once they are better. The duration of stay in the institution varies greatly, from as little as five days to two years.

Staff

The team providing care at Asha Niketan consists of five full-time staff members comprised of one graduate nurse, one auxiliary nurse midwife, one sweeper, one cook and one driver. Six part-time staff members include three doctors, one part-time nurse, one sister to look after spiritual needs and one priest for pastoral care. Doctors from St. Francis Hospital visit Asha Niketan once in a fortnight and supervise the treatment of the people in the centre. The nurses administer the treatment regimen prescribed by the doctors. If the cases require greater specialised care, they are transferred to St. Francis Hospital.

The sister-in-charge of Asha Niketan has undergone a one month training in care and counselling at Bangalore. Another sister, working part time, had attended three-day training in St. Francis Hospital, along with the field workers of Jiwan Dayini project.

Treatment

Antibiotics, painkillers, antispasmodics, antipyretics, anti-tubercular drugs, anti-fungal drugs, vitamins, iron tablets, and protein and calcium supplements are provided to the people admitted to Asha Niketan. No person currently admitted to Asha Niketan receives Anti-Retroviral Treatment (ART).

As part of palliative care, PLHA are given voveran injections as painkillers, if required. If they face significant difficulty in sleeping they are administered minor tranquilizers. Caregivers ensure their physical presence by the bedside of such patients at the time of intense pain and suffering especially as they approach death. An oxygen cylinder is also made available in the care centre for use in emergencies.

The hospital has linkages and networking with other hospitals and organizations operating in the area and thus HIV positive people are referred to Asha Niketan for treatment and care.

As part of palliative care, PLHA are given Voveran injections as painkillers, if required. If they face significant difficulty in sleeping they are administered minor tranquilizers.

The spouses identified as HIV positive are also admitted to Asha Niketan. At the time of this study, there were three females in Asha Niketan, all admitted with their husbands.

Counselling

At the time of admission PLHA are educated about the causes, nature, clinical manifestations and treatment of HIV/AIDS. They are also told about the importance of healthy life style for a prolonged life. If the patients are married with children, they are counselled on the need to get their spouses test and children tested as well. To elicit family support, the Sisters also interact with family members and educate them about the disease. This helps the family members in developing positive attitudes towards their kin. Family members are also encouraged to constantly visit the centre and maintain a good relationship with their kin.

Most of the people seeking care from Asha Niketan are married men in the full blown AIDS phase of the disease who have, in all likelihood, already transmitted the virus to their spouses. Thus the majority of the female cases admitted to Asha Niketan contracted the virus from their spouses. After counselling, very few male patients refuse to get their spouses tested. When this refusal does occur, the institution does not force its clients to get their partners tested, although the implications of not testing the spouse are stated in no uncertain terms. The facilities of the hospital or the nearby Voluntary Counselling and Testing Centre (VCTC) are used for getting the spouses tested. The spouses identified as HIV positive are also admitted to Asha Niketan. At the time of this study, there were three females in Asha Niketan, all admitted with their husbands.

Before people are discharged from Asha Niketan, they are counselled about the possibilities of transmission of the virus and risks increasing the viral load, if the necessary behaviour change is not made. Asha Niketan follows three strategies to deal with the transmission of the virus- advocating abstinence, the need to be faithful to the partner and the use of condoms. Although the Sisters inform the client on the use of condoms as a method to prevent transmission of HIV, they do not supply condoms nor ask people to use them. The ultimate decision to use or not to use

condoms is left to the conscious decision of the individual. The focus of the prevention strategy is more on abstinence.

Counselling services are also provided to people who need it by the Sister-in-charge of the centre. Through individual counselling sessions, cases are given psychological support in an environment of unconditional acceptance. Reassurance and a sense of hope are also provided to people who show signs of depression. Counselling sessions with the cases use a predominantly spiritual healing approach where the focus is on reminding them that God is there with them and that God will protect them in all their difficulties. Through spiritual counselling, patients are encouraged to ask for God's forgiving mercy for all their sins while reminding them that Jesus died on the cross for all their sins and that God will forgive everyone for his/her sins. According to the counsellor, such an approach helps the patients in better coping with the stresses they experience.

Cases admitted to Asha Niketan are encouraged to return to their families and communities once their health has improved. However, at the time of discharge the PLHA are informed that they can return to Asha Niketan anytime if the need arises. Follow-up services are also offered, if the cases are from nearby places where Sisters can make home visits.

The majority of the people admitted to Asha Niketan have a high level of satisfaction with the quality of services they receive. They speak very high about the quality of care, love and affection they receive at the centre. They are also happy with the facilities provided to them as well as with the quality of food in Asha Niketan. PLHA feel that they are accepted very well and the Sisters are sympathetic to their problems and concerns. As one person puts it 'even our parents will not care us like the Sisters here. They make themselves available for us even during night hours. In case of an emergency, we feel free to call the sister-in-charge even at night. The sister will come immediately

Cases admitted to Asha Niketan are encouraged to return to their families and communities once their health has improved.

The frequency and intensity of interaction between the staff and the people admitted in the centre was very high and positive.

to enquire about our well-being. Even one's own mother will not do so'.

The frequency and intensity of interaction between the staff and the people admitted in the centre was very high and positive. The atmosphere in Asha Niketan is very informal and cordial and the people feel free to interact with the staff. People living in the centre have expressed their appreciation for the commitment shown by Sisters in taking

care of them. Sisters are also present during all common activities like food, prayer and recreation. PLHAs staying in the centre, in turn, develop an interest in the welfare of Asha Niketan. For instance, a discharged inmate of Asha Niketan now donates milk for the residents once a month. This is in gratitude for the way the Sisters took care of him while he was a patient there.

The knowledge level of HIV/AIDS among the patients was low. Despite staying in the centre for a considerable period of time, two cases did not have even a basic understanding of HIV/AIDS and another three cases did not have sufficient knowledge. Almost half of the people were ignorant about the seriousness of the condition with which they were living, and believed that they were going to be completely cured and healthy. Others were aware of the modes of transmission but were not very sure about the nature of the disease and its management. This often resulted in PLHA taking the condition very lightly. One PLHA who was interviewed said, 'cure for AIDS is on its way and in a few years from now, medicines will be available world over for curing AIDS'.

Faith-based Approach

There are prayer sessions in Asha Niketan followed by readings of the bible. People interested can attend these sessions voluntarily. The majority of the cases reported that they are happy with the prayer services and the group sessions conducted by the priest-in-charge of pastoral care. Some of the people living in the centre also attend the celebration of Holy Mass on Sundays in the Chapel attached to the convent. The people felt

that prayer gives them strength and courage to face the trauma they are undergoing.

End of Life Issues

Asha Niketan has witnessed 13 deaths (10 men and three women). After death, the body is prepared before it is handed over to the relatives or taken for cremation. The body is laid on a plastic sheet to prevent contact with body fluid. If the relatives want to take the dead body for performing the last rites, it is handed over to them. Otherwise, Asha Niketan makes arrangements for the cremation/burial according to the faith of the person. For cremation of Hindus, the centre has made arrangements with the Jain Trust and in case of Muslims, arrangements for burial is made with the priest of the Dargah. In cases where the centre takes charge of cremation/burial of dead body, consent is taken from patients before their death.

So far Asha Niketan has not come across a situation where the children are orphaned by the death of both parents. One child whose father died of AIDS and whose mother is HIV positive is living in the centre, despite the fact that the child is not HIV positive. Bereaved children are often accepted by grandparents or other relatives. In such cases Sisters encourage the family members to take care of the orphaned child/children. The Sisters in Asha Niketan have already established linkages with an orphanage in Mumbai, which has agreed to accept children orphaned by HIV/AIDS in case they are rejected by their relatives.

Asha Niketan has not encountered any legal issue pertaining to property rights or inheritance disputes yet. One such situation was anticipated in the case of a minor where the uncles intend to take away the property. The Sisters have advised the mother, (also HIV positive) who has inherited the property from her husband, to sell the property and deposit the money in child's name so that uncles cannot cheat the child after her death.

For cremation of Hindus, the centre has made arrangements with the Jain Trust and in case of Muslims arrangements for burial is made with the priest of the Dargah.

The hospital has formed a core group of health care personnel to take care of HIV/AIDS cases that are admitted to the hospital.

St. Francis Hospital

Since 2002, St. Francis Hospital has been receiving HIV positive cases and it has admitted and treated 14 known HIV/AIDS cases. Most of these were either diagnosed as HIV positive during the course of treatment or were referred from Asha Niketan for treatment. The major thrust of HIV/AIDS intervention of the hospital is to provide care and treatment to PLHA especially at the ter-

terminal state of their life.

The hospital has formed a core group of health care personnel to take care of HIV/AIDS cases that are admitted to the hospital. This core group consists of the director, medical superintendent (a sister doctor), a senior surgeon, six nurses, and two laboratory technicians. This team is primarily responsible for the medical care of all those admitted with ARC or those who are eventually diagnosed with AIDS during the course of treatment.

Diagnosis

Diagnostic testing for HIV is available at St. Francis Hospital. During intake interviews at the time of diagnosis, cases with suspected clinical and/or behavioural history are referred for a HIV test. To date, 169 blood samples have been screened, out of which 20 were found to be HIV positive. These twenty cases included eight men, eight women and four children below ten years of age. The hospital uses Tri Dot rapid visual test developed by Biotech Inc. for the differential detection of HIV-1 and HIV-2 antigens. This is a screening test and is for in vitro diagnostic use only. The hospital charges Rs. 200 for a HIV test. However, a concession is given to those who cannot afford to pay. In the case of women attending the antenatal clinic the hospital charges only Rs. 150, because it is a part of the routine investigation. If a case is found to be positive on a Tri Dot test the case is referred to the VCTC in Ajmer for confirmation. Two laboratory technicians in the hospital have been trained to do the screening.

There is no pre-test counselling done in St. Francis Hospital. Post-test counselling is offered wherein they are told about the implications of the test result, about HIV/AIDS and the need to adopt a healthy lifestyle in an environment of acceptance and hope. If the test result is negative, it is given to patients directly. If the result is positive the report is sent back to the referring doctor who communicates the result and its implications. Post- test counselling is most often completed in a single session though follow up sessions are held depending on the merit of the case.

In both situations, the community health nurse discusses information on risks associated with unprotected sex with multiple partners through individual counselling sessions. Both in a clinical setting as well as in the community the issue of safer sex is addressed very cautiously. Since promotion of condoms is not pursued, people practicing high-risk sexual behaviour are advised to make changes in their behaviour. People found to be involved in multi-partner sexual behaviour are informed about the risks associated with it and are motivated to bring about necessary changes in their behaviour. This is done very often in the TB clinic. This issue is raised during awareness generation among the general public as well. Risks associated with multi-partner sexual behaviour are also communicated to the general public in every health education platform.

Treatment

HIV/AIDS cases arriving at St. Francis Hospital are provided treatment and care, both in the outpatient and inpatient departments. A special room has been set aside to admit and treat PLHA, in order to protect their confidentiality and provide better care. If the person requires admission, then they are admitted in private rooms or in general wards depending on patient's ability to pay for the expenses. Cases admitted to the hospital are discharged once the medical condition is treated, or sent to Asha Niketan for further nursing care.

Risks associated with multi-partner sexual behaviour are also communicated to the general public in every health education platform.

HIV positive women are advised about the risks associated with pregnancy so that they can make an informed choice about subsequent pregnancies.

St. Francis Hospital makes all efforts to ensure blood safety. Since St. Francis Hospital does not have a blood bank of its own, blood is obtained from Jawaharlal Nehru Hospital where every unit of blood is routinely screened for HIV. St Francis Hospital encourages relatives to procure blood from Jawaharlal Nehru Hospital on a replacement basis. Since the blood accepted for transfusion is screened for HIV, the hospital does no further screening. Blood of professional donors are discouraged at all costs.

Prevention of Mother-to-Child Transmission

Another important intervention programme put in place in St. Francis Hospital is Prevention of Mother-to-Child Transmission for which the hospital uses a multi-pronged strategy. HIV positive women are advised about the risks associated with pregnancy so that they can make an informed choice about subsequent pregnancies. Every HIV positive pregnant woman is treated with anti-retroviral drugs in the third trimester of pregnancy. The third strategy is to conduct delivery by caesarean section with the objective to reduce chances of mother-to-child transmission. Once the child is born, the recommended single dose of Nevirapine is administered; the mother is advised not to breastfeed and the child is given top-feed to decrease the chances of transmission of the virus. One of the limitations of the strategy adopted by institutions like St. Francis is that this strategy reduces the chances of mother-to-child transmission, but it does not take into account the risks associated with drug resistance and treatment noncompliance with regard to the mother, who may discontinue ART after the delivery.

Precautions

As part of standard precautions in health care settings, the hospital uses only disposable syringes for injection. While performing surgeries or caesarean sections all necessary precautions are taken to reduce chances of exposure and transmission. Masks, clothes and other protective equip-

ment used in surgical proceedings of HIV infected persons are disposed of safely. Health workers are instructed to be cautious with injections/needle pricking and wash hands immediately with soap if there is a contact with body fluids of infected persons. The needles used for injecting a HIV positive person are put in disinfectant solution (bleaching powder) before disposal. If a blood sample taken for a test is found to be positive, the test kit and other equipment used are also discarded. Protocol for the use and provision for post exposure prophylaxis is also made available to protect health care workers, in case of needle prick injury or injuries with other instruments.

Nursing students as well as staff nurses of the hospital are oriented about standard precautions in health care practice. However, no specific training on standard precautions is organised for other health workers including doctors. The hospital has not undertaken any systematic orientation programme for its staff on HIV/AIDS, despite the fact that in the beginning some health care providers had refused to care for people infected with AIDS. However, they have now become more neutral in their attitude towards PLHA.

Prevention Programme

Thus HIV prevention programmes implemented through St. Francis Hospital is done by using only screened blood for transfusion purposes, ART treatment for infected expectant mothers in the last trimester of pregnancy, conducting deliveries of infected women in caesarean sessions, introducing top feed for new born infants, and awareness generation to prevent HIV transmission through sexual routes.

Linkages

The hospital has developed linkages with Jawaharlal Nehru Hospital, Kamala Nehru Hospital and a few private health care providers in the area. Linkages with the above mentioned hospitals help in obtaining screened blood for transfu-

Nursing students as well as staff nurses of the hospital are oriented about standard precautions in health care practice.

Though post-test counselling is offered to all patients detected to be HIV positive, none of them have got their spouses tested for HIV status.

sion and for confirmation of HIV status through the Western Blot test. St. Francis Hospital has also developed close links with its TB programme which was initiated in 1993. Patients suspected of HIV infection (based on history and clinical manifestations) are referred for HIV screening. Out of the ten referrals made till August 2004, five cases were found to be HIV positive. TB patients who have tested positive for HIV are seen in the follow-up clinic on a regular basis. None of the five cases detected in the TB clinic has used services of Asha

Niketan till date. Though post-test counselling is offered to all patients detected to be HIV positive, none of them have got their spouses tested for HIV status.

Jiwan Dayini Project

The Jiwan Dayini project started in March 2004, with support from Catholic Relief Services (CRS), is primarily focused on prevention of HIV/AIDS. Implementation of this project, however, started only in July 2004. Major components of this project include behaviour change communication, training village health committees and members of Panchayati Raj (local government) institutions, networking with agencies involved in health and development work, developing educational material for raising awareness in communities and training of health care personnel. The project purports to undertake awareness generation activities in 75 villages, 50 in Bhinai block and 25 in Srinagar block respectively.

Staff

Recruitment of 20 field staff and their training has been completed. Field workers are currently involved in developing rapport with the community. They are in the process of undertaking house visits, conducting participatory rural appraisals, holding village meetings, conducting street plays and other such activities. HIV/AIDS prevention work in Bhinai block is closely integrated with Samudayik Sawasthya Vikas Kary (SAS-

WIKA), a health programme of the Mission Sisters of Ajmer operating in Bhinai block since 1995.

Strategies

The project has identified 23 tasks/strategies for awareness generation. These include house visits, participatory rural appraisals, village meetings, workshops, seminars, health camps, street plays, film shows, group discussions, posters, slogans, wall writing, debate and poster competition for students in schools, rallies etc.

The project has also identified the vulnerable population in the area. They are truck drivers, mine workers, migrant workers, daily migrant labourers, and women involved in the 'Natha system'- a system practised in some villages in Rajasthan where a man can 'own' a woman irrespective of her marital status by putting a blanket or bangles on her. That woman will be disowned by her husband and family and will be allowed to live with the new man. The man in return will have to pay compensation to the woman's husband or parents, as decided by the caste panchayat. Such women are normally abandoned after few months and find it difficult to re-integrate into the society from which they came. For their survival, they are forced to live with other men for short durations.

Behaviour Change Communication (BCC)

Behaviour change communication (BCC) strategies in the project are designed to cater to the community as a whole though they will be implemented in small groups as well. As part of the prevention project, health education materials have already been printed or developed. Most of these materials are adaptations of posters developed by the National Aids Control Organization (NACO) and the Rajas-

As part of the prevention project, health education materials have already been printed or developed. Most of these materials are adaptations of posters developed by the National Aids Control Organization (NACO) and the Rajasthan State AIDS Control Society.

The faith-based approach to prevention as practised by Jiwan Dayini Project focuses on encouraging abstinence and encouraging moral strength in the vulnerable population.

than State AIDS Control Society. In addition, a few flip charts and flash cards are also used for health education. The content of these materials in Hindi include information on the modes of transmission, nature of the virus and its action in human body, symptoms of AIDS, management of AIDS patients, myths surrounding the syndrome and the need to have positive attitude towards PLHA. To facilitate easy understanding there are illustrations explaining the contents. Field workers of the project have created a street play and prepared a few awareness songs and slogans in Marwari dialect.

In addition, the students of the school of nursing of the hospital also stage a skit for different target groups to spread awareness about HIV/AIDS. This skit covers a wide range of information pertaining to AIDS and its treatment, besides addressing issues pertaining to discrimination of the victims. The skit can be staged with short notice as the nursing students are well rehearsed and are available in the school located near to St. Francis Hospital.

Even though there are a large number of truck drivers in the region there is no specific strategy to address the needs of this vulnerable population. No needs assessment study precedes the planning process, consequently, no strategies to deal with specific target populations have been defined in the project. The prevention programme under the Jiwan Dayini project is, therefore, restricted to conducting awareness programmes for the general public in two blocks of Ajmer district.

Faith-based Approach

The faith-based approach to prevention as practiced by Jiwan Dayini Project focuses on encouraging abstinence and encouraging moral strength in the vulnerable population. Though the use of condoms is discussed in awareness generation programmes, the hospital neither supplies condoms nor advises people to use them. The choice of using condoms is left to people. The project management has explained to the

field workers about the Church's position on use of condoms. However, they are encouraged to provide information to the general public on condoms as a strategy to prevent transmission of HIV. Therefore, even in the educational material prepared by the hospital, the use of condoms has been mentioned as a strategy to prevent transmission of HIV.

Linkages

To make the awareness programme more effective the project has developed linkages with a few organizations i.e. (SASWIKKA and SAVERA) engaged in health and development work in Kanakheri and Srinagar blocks. The project relies heavily on the infrastructure and linkages developed by SASWIKKA in 50 villages in Bhinai block. All the staff members in SASWIKKA are involved in planning and implementation of BCC strategies in Bhinai block.

Enabling Environment

Advocacy is not an integral component of the HIV/AIDS initiatives of the St. Francis Hospital. However, issues like discrimination of people living with HIV/AIDS and their rights are included in the Jiwan Dayini project. As prevention programmes are implemented with support from SASWIKKA it is integrated with the general health interventions and community development activities. Networking with available agencies and disseminating knowledge on HIV/AIDS to these agencies has been envisaged as a part of the strategy. Training village health committees to address issues concerning HIV/ AIDS and linkages with self help groups in villages have also been envisaged as strategies, though work in these directions has not yet been initiated.

St. Francis Hospital has developed effective linkages with a few organizations working in the health and development sectors. These agencies include Jawaharlal Nehru Hospital, Kamala Nehru Hospital, SASWIKKA, SAVERA, the Diocesan Social Service Society, the Health Department of Rajasthan Government, the Missionaries of Charities, the

Advocacy is not an integral component of the HIV/AIDS initiatives of the St. Francis Hospital.

The Health Department of the Rajasthan Government and the Rajasthan State AIDS Control Society have helped the hospital in developing health education materials.

VCTC located in Jawaharlal Nehru Hospital and the Rajasthan State AIDS Control Society. Linkages with Jawaharlal Nehru Hospital and Kamala Nehru Hospital have ensured the widening of St. Francis Hospital service coverage, as these two hospitals refer cases to the care centre. Similarly, linkage with these two hospitals has also been used for free-of-cost confirmation tests and for obtaining screened blood for transfusions. SASWIKA and SAWERA help the hospital in implementing its prevention efforts in Bhinai and Srinagar blocks respectively. These are two grassroots level organizations engaged in health and development work in the region. Linkage with the Diocesan Social Service Society has helped the hospital in obtaining the CRS support for its HIV/AIDS intervention programme. CRS also monitors the progress of the activities undertaken under Jiwan Dayini Project.

The Health Department of the Rajasthan Government and the Rajasthan State AIDS Control Society have helped the hospital in developing health education materials. These agencies/organizations have also been identified as resource agencies for training of field staff and other health workers involved in the HIV/AIDS intervention.

Administrative Aspects of the Initiatives

The project team involved in implementing the HIV intervention programme includes the director of the hospital, the medical superintendent, eight health care personnel (three doctors and five nurses) of the hospital, 20 field workers, two lab technicians, and five full time staff of Asha Niketan. All staff members are paid, except for the Sisters of the congregation. The team members involved in HIV/AIDS interventions are either professionally trained or are specifically trained for the task assigned to them. Field workers and supervisors in the Jiwan Dayini Project were trained for three days before they were inducted into their jobs. The three-day training focused on various aspects associated with HIV/AIDS and strategies of mass communication.

The services offered through the HIV/AIDS intervention are completely free except for the treatment of HIV positive persons. Patients treated in St. Francis Hospital for general medical conditions and opportunistic infections are charged according to their ability to pay. A patient who is capable of paying his medical bill is charged fully on a non-profit basis, while others who cannot pay are provided subsidies according to their need or are fully exempted from payment. The cost of medical expenses in such cases is met from the project assistance.

The primary responsibility for planning and management of the programme lies with the core group, with the director of St. Francis Hospital as the chairperson. The core group consists of the director, medical superintendent, community health nurse, accountant, and two Sisters from the care and support centre. The core group meets once a month to monitor the progress of implementation as planned. Since the Jiwan Dayini Project is assisted by CRS, the Diocesan Social Services Society also monitors the project activities and progress.

The HIV/AIDS initiative of St. Francis Hospital has different sources of funding. A corpus fund of two lakhs was created during the Jubilee year of the Hospital, which was the only source of support when the programme was launched in December 2001. The Jiwan Dayini Project is supported by CRS with a support of Rs. 36 lakhs for a period of three years. Prior to CRS support, donor agencies like Miserior and the congregation supported the programme.

Observations

- ◆ The major thrust of the HIV/AIDS initiative of St. Francis Hospital is on care and support of persons living with HIV/AIDS.
- ◆ There is a need to strengthen the counselling and spiritual/pastoral care components of the intervention. Pastoral counselling should focus more on seeking refuge in God as an effective coping mechanism. During the study, it was observed that pastoral care offered was very infrequent and not very systematic. People should be helped to turn to God for solace and support. They should be given all possible assistance to reconcile themselves with their situation.

Similarly, people belonging to other faiths should also be offered discourses in their respective faiths. This can be made possible by arranging visits by other local faith leaders. It will be wise to appoint a trained counsellor to address emotional and behavioural problems manifested by people infected with HIV/AIDS.

- ◆ Educating people on HIV/AIDS as a group is an idea worth trying. Such a platform can clarify many misconceptions usually not raised in individual sessions. It also gives a platform for discussing issues that can widen the understanding of the individual patients. Besides these educational advantages, a group situation can help universalization of personal distress, which will have a psychotherapeutic effect on individual cases.
- ◆ It will be a good idea to segregate terminal patients as they approach death. As of now such cases are housed in the dormitory along with other cases. Witnessing the death experience of fellow beings can increase the trauma of impending death in other people
- ◆ The hospital needs to work with the vulnerable population in the community, especially truck drivers in Srinagar block. Almost every house in a few selected villages of the block harbours a truck driver who commutes between metropolitan cities. Prevention efforts with such a vulnerable population can bring better results.
- ◆ Cases in Asha Niketan should be encouraged to practice yoga and meditation. Encouragement of these two supportive adjuncts to counselling can not only bolster the mental strength of patients but also increase immunity, as they are effective techniques in handling psycho-social stressors.
- ◆ Promotion of alternative systems of medicine, like herbal medicine, is an idea worth trying. This can also bring down the cost of medical expenses.
- ◆ In order to equip the field workers for effective work, intense training focused on skill development and attitude change rather than enhancement of knowledge should be organized. Field visits to other agencies with successful intervention programmes will also increase the efficiency of the staff.
- ◆ The health education material in Hindi is text-heavy and has few illustrations, while the latter would be more effective for the target audience. Designing material, keeping in mind the socio-cultural and educational background of the target group, can bring about better results.

St. John's National Academy of Health Sciences

Bhagwandas Mangalore

The Catholic Church in India had long felt the need of establishing a medical college to provide health care services for promoting and preserving the health of the community and to provide an example of enlightened training in dedicated service, charismatic of Christian educational and social welfare institution.

The College was accordingly named 'St. John's Medical College', and opened in temporary premises in Bangalore, Karnataka, in July 1963. In June 1968, the College moved to its permanent campus about three miles from the centre of Bangalore. In December 1994, the institution was renamed as St. John's National Academy of Health Sciences and has four Institutes under it: St. John's Medical College, St. John's College of Nursing, St. John's Institute of Health Management and Para-medical Studies and St. John's Research Institute, which was established in 2004, and is the first of its kind in a medical college in India. It is proposed that at a later stage a dental college, a convalescent home, and a rehabilitation centre would be added to the institute. Today the College has a number of specialized departments, operating theatres and state-of-the art facilities.

The Motto of St. John's National Academy of Medical Sciences, Bangalore is "He shall live because of me." The institution is intended primarily for training Catholics and members from religious congregations, who run health care facilities in medically underserved areas and serve underprivileged people; however like other educational institutions it is open to all persons, irrespective of religion, caste or community.

Since its inception, St. John's has adopted the ideal of excellence in academic courses and in service to the society, as a result of which it has become truly holistic in its outlook and in its approach to the problems of community health.

Under the overall policy of the Catholic Bishops' Conference of India' (CBCI) Society for Medical Education, the objectives of the institution are grouped as follows:

- ◆ Excellence in all fields of health care education
 - ◆ Adequate Christian formation of the students
 - ◆ Upholding respect for life, from the moment of conception to its natural end
 - ◆ A special thrust towards community health fostering the dimensions of participatory team work
 - ◆ A genuine feeling of compassion for the patients and their families as persons
 - ◆ Serving the health needs of medically underserved areas of our country and our medically underprivileged brethren
- ◆ Striving towards promoting holistic health.
 - ◆ Acquiring an exemplary steadfastness to principles and moral values so as to live a life of honesty and integrity
 - ◆ Acquiring the ability to research and apply the advances in scientific knowledge to the relevant fields of work

Since its inception, St. John's has adopted the ideal of excellence in academic courses and in service to the society, as a result of which it has become truly holistic in its outlook and in its approach to the problems of community health. The institution envisages building community capacity and participating in health care initiatives in its preventive, promotive and rehabilitative dimensions.

Being a tertiary care unit the hospital has different departments with renowned medical professionals heading them. People from various parts of Karnataka, Andhra Pradesh, Tamil Nadu, Kerala and other parts of the country seek treatment from it. Being a private hospital the services are charged as the expectations for range and quality of services are high. The institute also has designated some amount for charitable use and pa-

tients coming from lower socio-economic backgrounds and those who cannot afford treatment and services are given concession.

HIV/AIDS Initiatives of the Institution

The Hospital does not have a specialized facility for HIV/AIDS care. However, a significant number of people who come to seek treatment for general ailments, when tested for the virus, are found to be positive. Therefore, if the examining doctors feel the symptoms are indicative of HIV/AIDS, they are referred for VCT. On average 40-50 blood samples of suspected cases are tested for the virus daily and three to four test positive. The hospital continues to provide care and treatment to these patients irrespective of their HIV status. In most of the cases, the patients seeking treatment are themselves not aware of their HIV status. While attending to HIV positive patients, strict confidentiality is maintained.

During the initial days the hospital authorities and doctors were apprehensive about treating HIV positive patients, as there was fear and anxiety surrounding the issue. Dr G. D. Ravindren, recalls, "Since the beginning we have never rejected even one patient who had come to this Hospital for treatment on the grounds that the patient was HIV positive. But there was a lot of uneasiness among the doctors who were conducting delivery and surgery." The institute also has the distinction of training medical personnel from all parts of the world on caring for and working with PLHA. The Hospital's HIV/AIDS intervention can be grouped into three major areas viz. treatment of PLHA; training of the medical professionals on HIV/AIDS and; outreach activities through the community health department.

Treatment

The doctor in the outpatient department provides clients with pre-test counselling before undertaking HIV test. In some departments such as Obstetrics and Gynaecology there are trained coun-

During the initial days the hospital authorities and doctors were apprehensive about treating HIV positive patients, as there was fear and anxiety surrounding the issue.

The doctors handling HIV/AIDS cases are not trained for counselling. Professional counsellors are available only in the OBGYN Department where each person is encouraged to undergo HIV testing.

sellors. In the case of an emergency situation, the confirmed HIV status of the person would alert the staff to undertake necessary precautions. However, the doctors do not wait for the rapid blood test confirmation and start the necessary procedure, as they believe these delays may cost the patient his or her life.

The doctors handling HIV/AIDS cases are not trained for counselling. Professional counsellors are available only in the OBGYN Department where each person is encouraged to undergo HIV testing. In the past year around 2,500 deliveries were conducted and only one patient declined to undergo the test. Expectant mothers attending ante-natal care (ANC) are also encouraged to be screened, so that those who test positive to the

virus can be provided with anti-retroviral treatment (ART) to prevent transmission of the virus to the child. Additionally, this enables doctors to take the required precautions, and the necessary care is provided to the patient.

There is lack of information and awareness among a large section of patients on issues related to HIV/AIDS. Thus most of the patients do not get too concerned when asked to undergo screening and feel that this is just one more test. A large number of patients who come with opportunistic infections are suspected to be in the AIDS Related Complex (ARC) stage and asked to undergo the test. Presuming the test has something to do with the opportunistic infection, mentally they are prepared to undergo any test, which can help them recover. The patients attending the ANC are exceptions to this, as many may not have any other health problems at all.

Persistent efforts are made by the doctors to provide pre-and-post-test counselling. However, the training, skills and the time available for such counselling is inadequate. There is no system to monitor the quality or the kind of counselling provided to the patients by the professional counsellors, who are from the Prevention of Mother-to-Child-Transmis-

sion project, and thus outside the scope of hospital monitoring. However, it is found that nearly all those people who undergo counselling also undergo screening for HIV.

The other issue related to testing is the cost. Being a private hospital, there is a charge for every service provided, but sometimes concessions are provided to the poor patients. Because of the tie-up with the PMTCT programme, the HIV testing done through the OBGYN Department for the women undergoing ANC is free of cost. Once tested and found positive, the mothers are put on ART from the 14th week of pregnancy or from the date of detection. The medication, which costs roughly Rs. 1,200 is free. All ANC mothers testing positive receive AZT (Zidudine or its equivalent). There is no practice of administering Nevirapine prior to delivery, which is otherwise advised world over. As much as possible, caesarean sections are also avoided and further follow-up of treatment, however, is non-existent. Once the patient has delivered, the treatment provided to her is stopped and the child is transferred to the paediatric department. The child receives ART till the age of 18 months.

Standard Precautions: Hospital had laid out a policy in 1997 for guiding its systems on adherence to universal precautions. The policy outlines the practices to be followed by doctors while treating patients and conducting procedures where medical professionals would come into contact with blood and other body fluids. The staffs, including doctors in surgery and gynaecology, need to take utmost precautions as the possibility of blood splash and injury through sharp instruments used for surgery and needles is also high.

Doctors are divided on the issue of taking standard precautions for all patients irrespective of their being tested and found to be HIV positive. Some believe that the cost is too high for the patient to make universal precautions a routine procedure, while others are of the opinion that it is necessary to assume that all patients undergoing an invasive procedure are potentially infectious, and that ap-

Being a private hospital, there is a charge for every service provided, but sometimes concessions are provided to the poor patients.

The blood used in the Hospital for transfusion is normally collected from the voluntary donors or the relatives of the patient, and not a single unit of blood is used without screening.

plying protective measures to all, irrespective of their serological status, avoids HIV transmission.

Some of the doctors were unhappy with the inadequate supply of protective eye glasses, visors and about the use of recyclable gowns and drapes. It was also said that there is an immediate need to have disposable protective gear and needle cutters in each of the wards, so that the routine screening of patients for HIV which is unnecessary can be stopped, and at the same time doctors can feel safer. The blood used in the Hospital for transfusion is normally collected from the voluntary donors or the relatives of the

patient, and not a single unit of blood is used without screening.

Disposal of Bio-waste

The procedures for disposal of hospital waste are clearly stated. There is also a department with a manager responsible for bio-waste disposal. The Hospital generates a huge quantity of bio-waste such as blood, excised tissues, wet mops, gloves, gauze, dressings, drapes, needles, scalpel wastes, IV lines etc. While a small number of patients are screened due to necessity, a large number are not screened for HIV. Thus as a policy the Hospital considers each piece of bio-waste material to be hazardous and its disposal is carried out with adequate care and all bio-wastes are incinerated.

All staff handling waste are advised and trained to use gloves as a preventive procedure but at times the class IV staff, who generally handles the waste, find the procedures very cumbersome and do not follow them. Even if there is a prick or cut while handling the waste they do not report it to the authorities. Information and guidance is provided, but strict adherence is not ensured. There is no monitoring of the handling, which is very necessary. When doctors were asked they said, "We have provided information but we do not know how they manage."

The 1997 HIV/AIDS policy was being revised and a committee was

formed which comprised of the heads of department of Surgery, Medicine, Urology, Social Work, Nursing, Psychology, Microbiology, Representative OBGYN, Psycho-social Work and Waste Management, as well as the head of the Hospital Infection Committee and the Vice Principal of the College of Nursing. Dr. Ravindran stated that the new policy would look into social and ethical issues related to testing procedures, universal precautions, protection of health care workers (HCWs), and the policy related to care. He also said that there are a lot of ethical issues involved with the policy and they need to be respected by the staff and the medical students.

Post Exposure Prophylaxis

During the past year 55 needle stick injuries and cuts were reported by the HCWs which include doctors, interns, postgraduate students and nurses. As a procedure, such injuries are reported to a specific doctor in charge, who provides the first aid instructions and counselling and then the HCW is advised to take ART (Indivan + Lamivudine) for 28 days. The person is also advised to go for screening and repeat the screening after two months. The post exposure prophylaxis is available 24 hours a day, in the hospital. If the exposure has happened not due to the carelessness of the HCW, the prophylaxis is provided free of cost, otherwise the cost is waived only at the discretion of the management.

Concept of Confidentiality

The hospital has a very good practice related to confidentiality, and no patient's HIV status is divulged unless for specific purposes related to providing treatment. Otherwise the HIV status of the patient is known only to the patient concerned and the doctor treating him. Although initially there was a procedure to mark the treatment chart and the records with the bio-hazard sticker, lately this has been discarded. There are times the doctors make independent decisions about disclosing information to the patients' families because of the patient's condition, otherwise, as a principle, the information is divulged only to the patient and the

The hospital has a very good practice related to confidentiality, and no patient's HIV status is divulged unless for specific purposes related to providing treatment.

The hospital advises patients on the basis of their financial capability and progression of the virus to take the highly active anti-retroviral therapy.

patient is left to share the information only with whomsoever he chooses.

The Laboratory Facility

To support the testing there is a well equipped laboratory which is efficiently managed. Usually the laboratory screens 40–50 samples a day and at times even 80–100 samples. It generally takes four hours to get the report, but in the event of an emergency delivery or surgery, spot testing is used where the report is given within 10 minutes.

The blood screening is done with the enzyme-linked immunosorbent assay (ELISA) test. Three different kits are used as a standard procedure. The hospital also has the Western Blot testing facility which is more accurate and more expensive. Depending on the requirement and capability of the patients to pay, this test is undertaken.

Anti-retroviral Therapy

The hospital advises patients on the basis of their financial capability and progression of the virus to take the highly active anti-retroviral therapy (HAART). The doctors treat all opportunistic infections but anti-retroviral therapy is provided only when the CD 4 count goes below 200 cells per mm. At times patients who have heard about ART demand this treatment, but doctors explain the situation to them and start the regimen only after the CD4 count test and viral load test indicate that it is appropriate to start the therapy.

All patients in the OBGYN receive treatment through PMTCT programme during pregnancy and new born babies receive Ziduvodine Suspension, which is free, till they are 18 months old. All other patients have to bear the cost of the ART /HAART therapy. The combinations are different for different patients and cost effectiveness is also taken into consideration. The present regimen generally used is Ziduvodine-Lamivodine + Nevirapine combination.

For patients with tuberculosis (TB), treatment is provided under the Directly Observed Treatment Schedule (DOTS) programme. The Hospital

has a tie-up with the national TB control programme and all patients from Karnataka receive the treatment free.

Counselling Facilities

The Social Work Department has been partially involved in providing counselling to the patients and their families to build confidence and help them cope with the situation. Social workers also help the positive people with job placement and children's education, help rebuild their families if broken, and provide follow up counselling. The physicians who make the decision for a patient to be tested provide the pre-test counselling. In case of need, the psychiatry department is also involved in counselling. In OBGYN, there are two trained counsellors who are part of the PMTCT programme.

Cost of Treatment

There is a charge for all treatment provided in the hospital including nursing care, procedures and materials. The drugs and disposable needles when prescribed, need to be bought by the patients. The Hospital has a policy to give concessions on the basis of the financial ability of the patient, and the Medico Social Work Department plays a major role in deciding the amount of this concession.

The positive people are also referred to Bowring Hospital in Bangalore for ART. Dr. Ravindran explained "The patient's capacity to pay decreases as the illness progresses. This is the stage when families' debts mount and the patient's capacity to earn become low." Thus the support for treatment becomes very crucial. Though there is no special policy for HIV positive people in general, the people who have tested positive do get concessions for care and treatment in the Hospital.

Training to Medical Professionals on HIV/AIDS

Medical students at both graduate and postgraduate level receive training on care and management of HIV-related complications on a regular basis. During their internship they also get to

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Under the leadership of Dr. Sanjeev Lewin of the Paediatric Department, the hospital has initiated a capacity building programme for medical practitioners in Karnataka.

handle patients and deal with them closely. The nursing students also undergo the same kind of theoretical and practical training. Other than this, the hospital conducts a great deal of training and provides exposure for HCWs in its premises. The community health department is not only involved with organising training but also provides technical support to projects like Aids Prevention and Control Project (APAC) in Tamil Nadu and the Karnataka State Aids Prevention Society (KSAPS) in Karnataka. It also conducts a lot of evaluations of HIV related programmes in Karnataka and Tamil Nadu.

Under the leadership of Dr. Sanjeev Lewin of the Paediatric Department, the hospital has initiated a capacity building programme for medical practitioners in Karnataka. The training is basically on ethical issues related to HIV/AIDS (which includes issues like law and HIV, consent for HIV testing, access to ART and adherence to treatment protocols) along with discussions on issues related to the care and treatment of patients. As many doctors involved in care and treatment of PLHA are not clear about the treatment policies and the ethics involved in the treatment, Government, which wants to address this issue, has given the responsibility for this training to the Institution. The Hospital's training wing on medical education and ethics has the responsibility of conducting this training for medical doctors, nursing staff, auxiliary nurse midwives (ANMs) and non-formal health providers from the government as well as private nursing homes and clinics. This training wing will also train the students, faculty of nursing, doctors and paramedical staff. This programme is supported by KSAPS, the Bill and Melinda Gates Foundation (BMGF) and the Indo-Canadian HIV/AIDS project (ICHAP).

The training modules are developed and pre-tested with the help of the Population Council/ Foundation for Research for Health Systems, in four places in Karnataka, and during the year 12 training sessions are planned. The training team includes 38 faculty members from the Academy, including 10 nurses and 28 doctors. The methodology used in the training

is in line with adult learning interactive and participatory methods. The institution also conducts training in association with the Catholic Health Association of India (CHAI) and Snehadanaan, for professionals who want to develop expertise in care and management of PLHA.

The expertise developed over the period of time in treating and caring for PLHA is put to use in these capacity building sessions. Health care workers, including doctors and nurses, are better equipped to take care of people if they are knowledgeable about the ethics involved in their work, as this would help them to deliver services more efficiently. The Academy itself has formulated a committee to look into the ethical issues, and it is important to also train other people in these ethical issues.

Community Health Department

The Department of Community Health works in nearby Anekal Taluk (District) uses the villages in the area for field practice. The department also runs a community health centre in one of the villages. It has been running a Maternal and Child Health (MCH) programme in the area for the past 10-15 years, and sexually transmitted infections/reproductive tract infections (STI/RTI) care is part of this programme. Awareness programmes on HIV/AIDS were also conducted in a few of the villages. The Department also has the responsibility of being the lead non-governmental organization (NGO) for the Reproductive and Child Health (RCH) programme of the Government of India for the southern parts of Karnataka.

Linkages have been formed with the Asha Foundation that introduced the Prevention of Parent-to-Child-Transmission (PPTCT) programme in the area. The services offered include information dissemination, screening of ANC patients with pre-and-post-test counselling, providing links with the main hospital for ART, and paediatric ART support. A trained counsellor has been deputed from the Asha Foundation to be part of the programme being monitored by the Department.

Linkages have been formed with the Asha Foundation that introduced the Prevention of Parent-to-Child-Transmission programme in the area.

The department provides technical support to Government programmes such as APAC and KSAPS, in reviewing and planning their programmes.

Since the beginning of the programme in May 6th 2004, 38 mothers attending ANC care have been counselled and tested, of whom two were detected to be positive. In the community, rapid test kits are used, and if they test positive they are referred to the main Hospital for the ELISA test.

The Department also conducts information, education and communication (IEC) campaigns periodically in the area, which include activities such as group meetings, individual discussions, poster campaigns and street theatres in the community

to educate people on HIV/AIDS.

The department provides technical support to Government programmes such as APAC and KSAPS, in reviewing and planning their programmes. A large number of organizations, both private and governmental, contact the department to conduct evaluations of their programmes as well as provide technical support. In all the activities the department applies an integrated team approach and along with medical doctors, social scientists, social workers and counsellors are involved.

The department also trains all the students and nurses of the St. John's Medical College and Nursing College in community health work. Over a period of time the department has also trained volunteers in the community, and a team to continue the follow-up is in place.

Prevention

The department believes that while generating awareness about the cause and spread of HIV in the community is imperative, talking about prevention is also important. The discussion on prevention largely focuses on sexual transmission of the virus and thus talking about condoms becomes necessary. Dr. Dhara Amar of the department said that the people need to know about how to protect themselves. He said, "We always tell them to be faithful to one partner but there are people who still are at high risk because of their behaviour, thus we must dis-

cuss condoms.” The department categorically states that they would not advise or insist on condom use, but only provide information. Thus the decision of whether or not to use condoms is left to the person who indulges in high risk sexual behaviour.

The department over a period of time has organized womens’ and mens’ groups and the members of these groups actively participate in these awareness programmes. There are also volunteers identified and trained in the community, and these volunteers play a major role in community awareness programmes by taking forward the work which has been initiated, thus maintaining the efficient continuation of the programme.

Faith-based Approach

Once the PLHA are in the Hospital they are visited by chaplains and support is provided through prayers and counselling. If the patients wish, they are allowed visit the hospital chapel.

There is provision for palliative care and the Hospital looks after the patients till the end, if necessary. These patients are not discriminated against but looked after like all other patients. No special support is provided to the grieving relatives of the deceased. In case of necessity, the Hospital has the facility for embalming bodies.

Management of Intervention

St. John’s National Academy of Health Sciences is a huge institution and under the leadership of the present Director, the management is very efficient. It is the Director’s initiative which has led to the HIV policy being revised and revived. Once the revised HIV policy of the Hospital is in place, managing the programmes related to HIV/AIDS will become more effective. The lapses and loopholes have already been identified by the committee and they are working to improve them so that the best practices are in place without compromising on the basic ethics.

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The Hospital is a super speciality health care centre and each department is headed by a doctor who is specialized in the area. Most of these doctors are experienced and have exposure outside the country as well.

Staff

The Hospital is a super speciality health care centre and each department is headed by a doctor who is specialized in the area. Most of these doctors are experienced and have exposure outside the country as well. Each team of specialists has six to eight doctors who also run the outpatient department in smaller teams. In addition, they are part of the teaching team. The students take part in the OPD as observers and also practice in the wards under the supervision of the respective department heads. The nurses are also well trained and knowledgeable. Most of the nurses were students of the St. Johns Nursing College. Overall, the team which manages health care in the Hospital is

highly professional and efficient. That is why St. Johns Hospital is considered to be one of the best health care facilities, not only in Karnataka but also in the country.

Planning Implementation and Monitoring

The individual departments plan their programmes based on the Hospital policy on HIV/AIDS. There are committees constituted to plan, implement and monitor the specific activities. Similarly, the Community Health Department will do its own planning, implementation and monitoring of activities, while the training wing will have its planning, implementation and monitoring done by the head of its programme. All these activities will be within the framework of the hospital policy, and the Director, the CBCI Society for Medical Education and the Hospital management committee will be the final decision-making body.

The Ethical and Policy Development Committee headed by Dr. G. D. Ravindran is developing the new Hospital Policy on HIV/AIDS. Responsibility for monitoring the policy will be borne by that committee in general, but department-wise the department heads will be responsible.

Care and Support Facility

The Hospital does not have a specific care and support unit to provide this service. Since patients cannot be kept in the Hospital for longer than necessary, as that will be expensive for the patient, those who require care are referred to Snehadan, a care and support centre in Bangalore. A large number of inmates in Snehadan are referred by the hospital. For ART the hospital refers poor patients to the Government facility at Bowring Hospital and for patients in the OBGYN and Paediatrics, ART is provided through the Prevention of Parent-to-Child-Transmission (PPTCT) programme of the Government.

Observations

It was felt that a reorientation on counselling policy was needed. Only professional counsellors should be allowed to provide counselling, and this counselling should help clarify to the patient the decision of whether to undergo HIV testing or not. This not only saves the time of the overloaded doctors but also helps the patient to make his decision. Some of the doctors are too concerned about their personal safety and insist on compulsory testing.

Disposal of waste is not monitored and the persons in charge of the departments do not supervise waste management. They know that the procedures are explained to the staff especially to the attendants and ward boys, but no monitoring takes place.

The institution continues to make a qualitative contribution to health care, medical education and research through the training of medical, paramedical, nursing, health management, community health workers, and other personnel who are dedicated to healing in the spirit of Christ.

Some of the doctors are too concerned about their personal safety and insist on compulsory testing.

St. Josephs' Hospital

Jennifer Matthew

Located in Pratipadu, a small town in East Godavari district of Andhra Pradesh, St. Joseph's Hospital, is an institute managed by the Sisters of St. Joseph of An-necy. According to the founder the mission of the Sisters of St. Joseph, is to look after the poor and the most neglected in society, especially widows and orphans. Later the mission was expanded to include care for the sick and the suffering and to provide them education.

At the request of the people a small dispensary was started at Kirlampudi in 1951 for providing basic health services. This dispensary was shifted to Pratipadu a year later and was slowly upgraded to a general hospital with a capacity of 30 beds, which was later converted into a leprosy hospital. Because of its drop-in counselling-cum-care and support centre, St. Joseph's Hospital has been performing a further valuable service, to people infected with and affected by HIV/AIDS.

The infrastructure of the Hospital includes inpatient wards with 75 beds, a laboratory, operation theatre/labour room, X-Ray facilities, a pharmacy, dressing room for leprosy patients, two kitchens and a dining hall-refectory, besides an office and a few guest rooms. The campus has a well-maintained garden, a small chapel, a grotto of Mother Mary, the residence of the Sisters, a small cowshed, a bio-gas plant and a few acres of agricultural land. The institution's major thrust of intervention is health-combining prevention, treatment, care and support aspects.

HIV/AIDS Interventions

St. Joseph's Hospital manages different programmes in the field of

HIV/AIDS prevention, treatment, care and support. One of the major programmes is the drop-in counselling-cum-care and support centre with support from the Andhra Pradesh State AIDS Control Society (APSACS). Additionally, with support from Catholic Relief Services (CRS) and the Catholic Health Association of India (CHAI), a community and home-based care and support programme is being implemented in 40 villages covering a population of 80,000 people. The CHAI supported programme started in February 2004 and the CRS supported programme started in June 2004.

East Godavari is a high prevalence district because of the proximity to Peddapuram, a place well known for sex workers.

In addition, the Hospital has made educational provision for young girl children of PLHA, and other such children are also being trained in tailoring, typing, computers, radio maintenance and as ANMs. A boarding school for the children of leprosy patients and children infected with or affected by HIV/AIDS is under construction with financial assistance from a German Catholic Mission.

From Leprosarium to Care Centre

Since 1952 the hospital has been treating patients with various health problems. In recent years, it was observed that some patients repeatedly visited the hospital with different kinds of infections. In spite of treating them for specific ailments, their health kept deteriorating. It was realised that HIV/AIDS was taking the shape of a major public health problem, affecting people across different sections of society - rich, poor, literate, illiterate, young, and old without any discrimination. Due to the lack of appropriate and adequate information about the disease, people who were HIV positive were being treated only for the specific infections, or being referred to the tuberculosis hospital. Andhra Pradesh has a high prevalence of HIV infection. East Godavari is a high prevalence district because of the proximity to Peddapuram, a place well-known for sex workers.

In January 2001, Mr. Chandra Mouli, former Project Director, APSACS, based on the reference of the District Leprosy Officer, proposed setting

A unique feature of this intervention is that all patients, whether infected with leprosy or with HIV/AIDS live in a common wing, in separate wards.

up a drop-in counselling-cum-care and support centre for PLHA in St. Joseph's Hospital. The Hospital already had experience implementing the leprosy programme, so it was decided that the infrastructure used as the leprosarium be converted into the care centre for PLHA. This care and support centre, which was started in January 2001, is the first of its kind in the state of Andhra Pradesh.

The care centre is 20 km away from the nearest railway station and is 45 km. from the district headquarters, Kakinada. Located a few meters away from the bus stop, the centre is easily accessible by road. Though located in a small town, the centre and its activities are widely known in the area due to publicity via the radio, local newspapers and word of mouth.

The care and support centre provides institutional care and support for chronically ill PLHA. At the time of this study the centre was accommodating 28 PLHA, even though it receives financial support for 10 beds from APSACS. Averages of 10 new cases are admitted per week and the centre makes sure that no person who comes is denied service. At any given point in time, there are about 25 patients in residence in the care centre. Although the centre has the facility to conduct HIV Tri-dot tests, all cases are referred to the nearest Voluntary Counselling and Testing Centre for confirmation.

A unique feature of this intervention is that all patients, whether infected with leprosy or with HIV/AIDS live in a common wing, in separate wards. This was done to ensure that they do not feel isolated, secluded or discriminated by virtue of their infection. This arrangement gives scope for interaction between them. The people infected with leprosy, currently around 30, are cheerleaders for people infected with HIV/AIDS. They interact with each other, join together for prayers, and sing songs together. Some of them also volunteer as physical instructors to conduct exercises in the morning. All these activities give the inmates in the centre a feeling of hope and create a healthy atmosphere for them to recuperate.

The majority of the beneficiaries of the care centre are from the lower economic background, most of them being farmers, labourers, drivers, housewives and sex workers. People in the productive age group of 25-40 years seem to be the most affected by HIV/AIDS. The majority of the beneficiaries are married. On an average a patient is allowed to stay in the centre for six days.

According to the Sisters, the virus is no longer limited to vulnerable groups of people and has affected the general population as well. With the outreach activities extended to 42 villages in the Pratipadu Mandal, people from different parts of Andhra Pradesh including Vizag, Rajamundry, Peddapuram and Kakinada benefit from the centre. Between January 2001 and August 2003, the centre admitted 1,806 PLHA. In August 2003, 288 people attended the outpatient department and there were 59 inpatient admissions to the centre.

Most of the clients are referred by government hospitals, private practitioners, non-governmental organizations (NGOs) or by the outreach team of the hospital. Apart from relatives and friends beneficiaries also learn about this centre from the hospitals where they were tested positive for HIV infection.

The knowledge level of the clients on HIV/AIDS/ STIs is minimal. They are usually aware of just one route of transmission, and there is a definite need for addressing the myths and misconceptions surrounding the issues of prevention, treatment and care. Most of the clients who know a little about HIV/AIDS/STI receive the information from their friends, NGOs or doctors.

The opportunistic infections identified among the clients are pneumonia, diarrhoea, dysentery, continuous vomiting and fever, TB, skin infections and STIs. Dr.-Sr. Arogya observes, "With increased awareness, these days people infected with HIV/AIDS are seeking treatment at the early stages of the infection. The death rate has also come down." She further noted that, "some of

According to the Sisters, the virus is no longer limited to vulnerable groups of people and has affected the general population as well.

Most of the patients mentioned their satisfaction with the services like food, treatment and care provided by the centre.

the beneficiaries prefer to stay in the centre because of the nutritious food they receive as they are not in a position to earn a square meal for themselves.”

Most of the patients mentioned their satisfaction with the services like food, treatment and care provided by the centre. They do not feel any sort of discrimination based on their HIV positive status. Inmates are provided with nutritious and variety of food including non-vegetarian dishes that are served on Sundays. Furthermore they commend personal attention provided by the staff. The frequency and nature of interaction between the staff and the patients is good. As the doctor puts it, “we do not bind them with any formal rules like a school. Here, PLHAs are given their freedom and they learn to respect it. We do not close the gates of the centre, nor do we restrict their movement within the campus. However, we are strict about the cleanliness of the centre.”

Some of the clients, who are Christians, spend time in prayer near the grotto, some join the inmates of the leprosarium during their evening and morning rosary, and some patients ask the Sisters to pray for them. All activities in the centre take place in a very orderly manner. At the same time the inpatients and their attendants (a family member who is required to accompany the patient) are given sufficient freedom to move around the campus and the gates are always kept open as the Hospital also caters to general cases through its outpatient department.

Prevention Programme

Use of condoms as a method of HIV prevention is discussed by the doctor whenever need arises. The centre receives a regular supply of condoms from the DLO. Besides condoms, they also talk about other methods of protecting oneself from getting infected with STIs.

Faith-based Approach

As far as the faith-based approach to prevention is concerned, people are

made aware of the risks involved in having multiple partners and unsafe sex. Abstinence until marriage and being faithful to a single partner, are highlighted as methods of preventing STIs/HIV, even though condom usage is mentioned the hospital does not directly promote condoms or supply condoms in the premises. The outreach workers too are aware of the Church's stand on use of condoms.

Treatment

St. Joseph's Hospital also offers treatment for people infected with STI/ RTI. The medical officer has received specific training on syndromic case management of STIs. According to the medical officer, "STI/ RTI infection is a major challenge, as people still have a lot of myths and misconceptions about them. At the early stage STI, infection is not taken seriously and patients approach health care institutions only when the infection becomes chronic. Many people continue to resort to local cures and remedies (nattu vaidyam) from quacks." The outreach staff takes an active role in referring symptomatic STI cases to the hospital. Those who report to the hospital of complaints like abdominal pain, white discharge, swelling in genital area, boils etc., are always not aware that they are infected with STI/RTI. There are many relapse cases reporting to the hospital due to discontinued treatment. All these indicate low awareness of STI/RTI and their relationship with HIV.

Referrals for Further Treatment

Pregnant women who are HIV/STI positive are referred to the PPTCT clinic in the government hospital. People who come with STIs are told about the risks involved in non-treatment of STIs, and are referred to the VCTCs for a HIV test. The doctor advises these people to change their behaviour by informing them about the risks involved in having multiple partners. If the infected person has a regular partner, the doctors counsel them about partner treatment. If

There are many relapse cases reporting to the hospital due to discontinued treatment. All these indicate low awareness of STI/RTI and their relationship with HIV.

People with chronic and more acute opportunistic infections like TB, diarrhoea, pneumonia and multiple infections are admitted and closely supervised.

the person is single, they are advised to abstain from sex till marriage.

There is a separate wing for outpatient consultation. Outpatient consultation is available six days a week between 9.30 am to 1.00 pm and from 3.30 to 6.30 p.m. On days when the number of patients is high, timings are extended. HIV positive people are given free treatment that includes medical consultation and medicines. The other patients are charged for the medicines. No separate case sheets are maintained for outpatients.

Whenever a new HIV case arrives in the hospital, the doctor records the case history with complete detail. Inpatient facilities of the centre are extended to those people who are in a critical stage of AIDS and need constant medical supervision and treatment. The facilities include; bed, treatment, diagnostic services if required, nutritious food and psycho-social support. There is also a common recreation room with television. These services are provided free of cost along with the provision of food for the attendants. People who can afford a private room can opt for it at a charge.

People with chronic and more acute opportunistic infections like TB, diarrhoea, pneumonia and multiple infections are admitted and closely supervised. Individual case records are maintained by the nurses, which are reviewed by a medical officer during the rounds. Patients infected with TB are put on DOTS. The centre does not provide anti-retroviral therapy nor are alternative/complementary therapies being practiced at the centre.

Psycho-social Support

PLHA admitted to the care and support centre are typically not in a state of good physical and mental health. Their anxiety and tensions aggravate their already poor physical health. Some of them fall into a deep state of depression. The atmosphere in the centre helps in preventing

loneliness and depression and discrimination. Other patients, attendants and people infected with leprosy staying in the same campus, all act as motivators and cheerleaders for each other. They share their worries, sorrows, and difficulties and learn from each others' experiences to cope with similar situations. During group counselling sessions conducted by the doctor-sister, patients are encouraged to talk about their medical history.

The influence of faith is clearly seen in the messages given during the counselling sessions. The sisters ask them to confess their sins to God who will forgive them and bless them. They provide hope to the people and the family members by spending time talking to them and helping them to believe that God loves them and cares for them. The family members are encouraged to come and visit the patients more often.

Adherence to Universal Precautions

Since the Hospital does not have a blood bank, family members of the patients are advised to arrange for blood from the government blood banks as and when required. Blood supplied from the government blood banks are tested and screened for HIV. All medical professionals are trained on standard precautions to be taken while treating or caring for PLHA.

Universal precautions are taken to ensure safety by using and properly disposing of gloves, aprons, facemasks, disposable syringes and needles. In the event of a needle prick or injury, post exposure prophylaxis is administered.

All the cases receive pre- and post-test counselling at the VCTCs. The doctors also provide counselling to the clients at the centre. However, it was observed that counselling inputs are sometimes inappropriate and insufficient.

The influence of faith is clearly seen in the messages given during the counselling sessions. The sisters ask them to confess their sins to God who will forgive them and bless them.

Through the community based intervention programme, families of people living with HIV/AIDS are educated on aspects of home-based care and support and nutrition.

End of Life Issues

Whenever a patient dies, the family members of the deceased are informed. With their assistance, the body is carefully covered before handing over to the family. In a few instances in the past, however, the family members did not come forward to claim the body. In such situations, the Sisters had found it very difficult to get permission from the police station and the municipality to arrange for a decent burial/cremation. Such bitter experiences forced the management to make the attendant system compulsory and now they do not accept people without attendants.

Some children orphaned by the death of a positive patient are placed in the care of immediate family members. At times, due to issues of stigma or poverty, the children of the deceased are left with all alone with no family friend coming forward to care for them. The sisters take responsibility of such children and provide necessary care and support to them. The Sisters also care for some of the patients' children, orphaned by the virus. They are put in schools and provided with boarding facilities.

Intervention Programme

Through the community-based intervention programme, families of people living with HIV/AIDS are educated on aspects of home-based care and support and nutrition. They are also offered counselling, if necessary, and are encouraged to support the afflicted member. The team is attempting to mobilise PLHA from 42 villages to form a network to help each other.

The centre staff team is comprised of one medical officer (who also functions as a counsellor), two nurses, one ANM, one pharmacist, an administrator-cum-accountant and one laboratory. Out of the seven staff

members, four belong to the congregation of St. Josephs. The same team is responsible for running the general hospital as well. In addition there are some maintenance people and two cooks.

The staff members involved in the HIV/AIDS intervention programme of the hospital are both professionally trained and experienced. The community-based programme is carried out by a team consisting of four members who previously worked in the leprosy project. They have good experience in conducting outreach programmes, rapid assessments and door-to-door surveys. One of them, a senior worker, received formal training in counselling and was oriented on HIV/AIDS. In turn, he oriented the rest of the team members. The sister-doctor has also received formal training in counselling. The staff has conceptual clarity and possess the necessary experience and commitment to work in this field. According to the Sisters, they do not need people with degrees but those with the necessary talents, and most importantly, people with dedication and commitment who can work without bias and deliver the necessary results.

The dedication, hard work and compassionate attitude of the staff is reflected in the smiles of the people when they recover and return home. However, given the fact that most of the people coming to the care and support centre need psychological support, there is a need for employing more counsellors.

General patients are charged for the services they receive and for medicines. Medicines for poorer patients are provided either at a subsidized rate or free of cost. All services provided to the inmates are provided free of cost, as per the guidelines of APSACS. Furthermore the attendants are not charged for their stay or food.

The institution's major strength lies in the care and support aspect of the HIV/AIDS intervention. The prevention dimension, however, is yet to gain further ground. Without necessary tech-

The dedication, hard work and compassionate attitude of the staff is reflected in the smiles of the people when they recover and return home.

The institution receives funds from APSACS for 10 beds, medicines and staff salaries, even though the initial commitment was for 20 beds.

nical inputs, the programme may not have the necessary impact in the long-run.

Creating an Enabling Environment

The project staff has invested significant effort in conducting advocacy programmes with different stakeholders including government departments, VCTC, PPTCT Centres, local Public Health Centres, the Lion's Club, village heads, youth groups

and mahila mandalis, to gain their support in making the interventions a success. These organizations help in disseminating information about the care and support centre and its services, and extend their co-operation to the outreach team to take up different mass events and programmes. The project staff has, furthermore, established a good rapport and linkages with the government hospital, local NGOs, and the District Collector. The District Collector, who recently made a visit to the centre, was impressed with the work of the Sisters. He assured them assistance for the purchase of an incinerator and financial support for 10 more beds, in addition to support for the children who are HIV positive.

The institution receives funds from APSACS for 10 beds, medicines and staff salaries, even though the initial commitment was for 20 beds. Besides this, it also receives support from CRS for the community-based care and support programme, which meets the salaries of the outreach workers, medicines and outreach programme costs. CHAI does not provide any kind of medical support; it supports networking and capacity building. In addition to all this, the congregation contributes by providing human resources (sister-doctor nurses and a pharmacist), land for farming, education and boarding facilities for the orphaned, infected and/or affected girl children.

The sister-doctor, who is the administrative head, does internal monitoring reviews the daily work and conduct weekly meetings with the outreach teams. The external monitoring and project review is undertaken by, the DLO who is the nodal officer for HIV/AIDS in the. Officers from the respective funding agencies make visits to assess the work.

Community-based Care and Support Programme

When the care and support centre for PLHA was started, the number of other patients with other health conditions in the hospital started declining. About sixty per cent of the outpatient cases that were suspected to be HIV positive or had already tested positive stopped visiting the hospital. To ensure that these people received regular care and support services, both CRS and CHAI were consulted. This resulted in the initiation of the community-based care and support intervention.

With support from CRS, the prevention efforts began formally in February 2004. By means of this programme, with support from CRS and CHAI, they are able to reach out to 42 villages, covering a population of 80,000 people. There are four outreach workers in this programme. They focus on building awareness and knowledge on HIV/AIDS/STIs through one-to-one and group sessions. Various songs, skits and plays are used for awareness building. The outreach workers also refer symptomatic HIV/STI cases to the VCTCs, help people who already know their HIV status to access treatment and care and also follow-up on these cases. "Today HIV infection is not restricted to high risk populations but has spread to the bridge population too," states the doctor at St. Joseph's Hospital. The project has identified more than 500 cases in the project area through its community-based HIV/AIDS intervention programme. The outreach workers use different information, education and communication (IEC) materials. In addition, regular health camps are conducted in these villages with the help of the medical officer and staff nurse.

To monitor the work of the outreach team the medical officer uses indicators such as number of STI/HIV cases referred, new cases identified and cases followed-up. Initially when people would see the field workers interacting with a particular person they would suspect that person to be HIV positive. In order to avoid such situations different, participatory rapid appraisal techniques were used to get information about people living with HIV/AIDS.

St. Joseph's Hospital has established a good rapport with the government hospitals and other private practitioners in the area, who refers cases to the care and support centre. Besides this, the centre has links with a cultural troupe that performs plays and skits related to HIV/AIDS as part of the community-based prevention programme.

Annexure

Church-related Centers in India for Care and Support of the People Living with HIV/AIDS

SN	State	Name & Address	Chief Functionary	Type of Project	Target	Area of Action	Year of Initiation
1	Andhra Pradesh	St Joseph's Hospital (old) Pratipadu, E. Godavari – 533432, A.P Tel: 08868-246659	Rev. Sr. Bernadette	Community Care Centre	People Living With HIV/AIDS	East Godavari	2001
2		St. Ann's Society Central Province Nunna, Vijayawada, Krishna – 5200 04, A.P Tel; 0866-451686, 450355	Rev. Sr. Marietta Provincial Superior	Community Care Centre	People Living with HIV/AIDS	Krishna	2002
3		Damien Leprosy Centre Vegavararam, W. Godavari –534 450, A.P Tel; 08812-30465	Rev. Sr. Bridget Director	Community Care Centre	People Living with HIV/AIDS	West Godavari	2002

4	Andhra Pradesh	Viswakarruna Dermatological Centre Fatimanagar, Warangal – 506 004, Tel: 08712-2459405	Rev. Fr. A Raja	Community Care Centre	People Living with HIV/AIDS	Warangal	2002
5		Assisi Dermatological Centre Assisi Nagar, Konkepudi Via Pedana, Krishna-621366, A.P Tel: 08674-248335	Rev. Sr. P.R. Prasanth Mary	Community Care Centre	People Living with HIV/AIDS	Krishna	2002
6		Mariyanilayam Service Society Gangeya Puram Kurnool – 518 452, A.P Tel: 08518-38148	Rev. Sr. Leelavathi DSS	Community Care Centre	People Living with HIV/AIDS	Kurnool	2002
7		Asa Niketan Kavali & Thallapalem Nellore, Andhra Pradesh			Drop in & Counselling		
8		Lodi Multipurpose Social Service Society Fatima Nagar Warangal, Andhra Pradesh Tel: 08712-276405			Drop in & Counselling		

9	Andhra Pradesh	Vijay Marie Hospital Saifabad Hyderabad – 500 004 Tel: 0826-220077			PMTCT Program & Counselling		
10		St. Xavier's Hospital Vinukonda – 522 647 Guntur Dt, A.P Tel: 08646-272084(Hosp) Tel: 08646-272032(Res:)	Dr. Sr. Alphonsa, MD, DGO				
11	Bihar	Fakirana Sister's Society C/o Sacred Heart Health Centre Banuchaper, Bettiah West Champaran – 845 438 Tel: 06254-32950	Rev. Sr. Mary Elise (Director)	School AIDS Education Programme	Truck Drivers & Students	W. Champaran, Motihari Bettiah to Raxaul	2002
12		Holy Cross Convent Fair Field Colony P.O Patna – 800 011, Bihar Tel: 0612-266759 E-mail: scsapat@sancharnet.in	Rev. Sr. Mary James Monteiro	School AIDS Education	Students	Darbhanga, Bettiah & Muzaifarpur	2002

13	Bihar	Kurji Holy Family Hospital (Community Health & Rural Development Centre P.O. Sadaquat Ashram, Patna – 800 010, Tel: 0612-262540/ Fax: 268374	Rev. Sr. Julian D'Cunha Administrator	School AIDS Educa- tion	Students	Patna, Bihar	2002
14		Nazareth Hospital Mokama Post Patna Dt., 803 302 Tel; 0613-2232267		Aware- ness Educa- tion & Coun- selling			
15	Gujarat	Social Welfare Centre Mota Devalia, Viachamradi Dt Amreli-365 601, Gujarat	Rev. Fr. Joseph Prakashbai	School AIDS Educa- tion	Students	Amreli	2002
16		Samagra Vikas Trust ASHISH Ramnagar, Amreli – 365 601 Gujarat	Rev. Fr. George Mathew	School AIDS Educa- tion	Students	Amreli	2002

17	Haryana	Asha Niwas K7/44, DLF Phase II Gurgaon – 120 002 Haryana Tel: 91-364140, 91-364565	Rev. Fr. Joshy K Director	Centre for Rescued children of CSWs	People Living with HIV/AIDS	Mangalore	2001
18	Karnataka	Snehasadan St. Camillus Rotary, Rehabilitation Centre P.O. Kinnikamblam Gurupur Mangalore – 574 151	Rev. Fr. Baby Illickal Administrator	Care & Support	People Living with HIV/AIDS	Bangalore	2001
19		Snehadaan St. Camillus Home of Charity, Sarjapura Road, Ambedkar Nagar Carmalaram post Bangalore – 560 035 Tel: 080-28439516		Care & Support	People Living with HIV/AIDS	Bangalore	2001
20		Infant Jesus Childrens Home Kothanore, Bangalore – 560 077			Home for HIV/ AIDS children		

21	Karnataka	Holy Cross Health Centre Jyothinagar. "Anukampa" Chikmagalur Karnataka 577 102 Tel: 08262-220077				Community based, awareness education		
22		SUMANA P B No.5, Siddarthanagar Mysore 570 011				Community based, awareness education		
23	Kerala	Mar Kundukulam Memorial Research & Rehabilitation Complex, P.O. Peringandoor, Trichur – 680 581 Tel: 0487-201732, 200261	Rev. Fr. Var- ghese Palath- ingal Executive Director	Care & Support		People Living with HIV/AIDS	Trichur	1999
24		Amala Cancer & Research Centre Ayurvedic Unit, P.O Amalanagar Trichur Dt, Kerala 680 553 Tel: 0487-2711950/51/240 Fax: 910457/711020 E-mail: amalacan@md3.vsnl. net.in amalacan@eth.net www.amalacancerhospital.org				Alternative Sys- tem of Medicines for HIV/AIDS persons		

25	Kerala	Divine Retreat Centre Muringoor P.O., Chakkudy, Trichur Dt., Kerala – 680 316 Tel:0488-2708097/2706913 E-mail: divine@md2.vsnl.net.in			Hospice for HIV/AIDS people		
26		Infant Jesus AIDS Home For Children Kannur – 670 002, Kerala			Home for HIV/AIDS children		
27		Jeevodaya HIV/AIDS Research & Rehabilitation Centre SEVASHRAM Mele Chovva P.O. Kannur – 670 006, Kerala	Rev. Fr. Joseph Charackal, Ofm Cap		Research & Rehabilitation Centre for HIV/AIDS	Kannur	1997
28		St. Camillus Hospital Chungakunnu P.O., Via Kelkam Cannanore Dt – 670 651, Kerala Tel: 0490-2412056			Care & support		

29	Kerala	Jeevana Samskrithi 1 st Floor, Sri Mahal, Talapp P.O. Kannur – 2, Tel: 0497-707239, 201	Rev. Fr. J.J. Pallath (Project Director)	Targeted Intervention	Commercial Sex Workers, Homosexual	Kannur	1998
30	Madhya Pradesh	Vishwas Care Centre Holy Spirit Sisters Indore- 452 001 Tel: 0731-2702611/ 2700711 E-mail: vishwasps@sancharnet.in	Rev. Sr. Jaisa Antony				
31	Maharashtra	John Paul Slum Development Project Carol Color Studio, S.N. 2 Yerwada, Pune –416 416, Tel: 9520-6690282/ Fax: 6696426	George Swami	Targeted Intervention	Truck Drivers	Pune Ahmednagar Highway	2002
32		Bel Air Hospital Dalkeith, Panchgani – 412 805 Satara Dt, Maharashtra Tel: 02168-40309, 41109 Fax: 02168-40955	Rev. Fr. Tomy K Administrator	Care & Support	People Living with HIV/AIDS	Satara	2000-01

33	Maharashtra	Jagruti Kendra (Extension) Centre C/o St. Jude's Church Jerimeri, Mohil Village M.V. Road, Mumbai – 400 072 Tel: 022-8511369	Rev. Fr. Bar- thol Machado	Targeted Inter- vention	Migrants	Zerimeri area	1999
34		Shelter Don Bosco St. Joseph's High School Wadala (W) Mumbai – 400 031 Tel: 022-24150562, 24316104	Rev. Fr. Xavier	Targeted Inter- vention	Street Children	S. Mumbai, Dadar, Mahim, Andheri	1999
35		Jyothi Terminal Care Centre Sector II, Plot No. 4, Kalamaboli, Navi Mumbai Maharashtra 410 218 Tel: 022-27423399			Hospice for HIV/ AIDS people		
36	.	Snehanilaya 36 St. Catherine's Home Ve3era Desai Road, Andheri (W) Mumbai, Maharashtra – 58 Tel: 022-6232312			Care & support, Counselling of HIV/AIDS (Women & Chil- dren)		

37	Maharashtra	Mukta Jeevan Hospital Vehloli Village, Shahpur Thane Dt – 421 601 Tel: 0252-278251			Hospice for HIV/ AIDS, Children & Women	
38		Naya Jeevan Kalemba Village PO Shahapur, Asangaon Thane Dt Maharashtra 421 601 Tel: 02527-252036			Home for Children with HIV/AIDS	
39		Anugraha Dispensary cum AIDS Counselling Centre Verai, Bhudhwadi, Bharene P.O. Khed, Ratnagiri – 415 709, Tel: 0235-2664493			Counselling Centre	
40		Niramayi Niketahan, SVPS, Archdiocese of Bombay V.N. Purav Marg Dhobi Ghat, Trombay Mumbai –400 088, M.S. Tel: 022/25513314/2558			Care & support	

41	Maharashtra	Nirman College of Social works Nirmala Niketan Institute, 38 New Marine Lines, Mumbai – 400 020 Tel: 022-22002615, 22067345, Fax: 2014880	Dr. Mary Alphonso & Silpa Tel: 022-24144471 E-mail: Isocwl@vsnl.com	Targeted Intervention	Slum Population	Mumbai	2002
42	North East	Social Welfare Society C/o St. Francis of Assisi School Bazar Veng, Mamit – 796 441 Tel: 0389-65317	Rev. Sr. Christina BS President AIDS Program I/C	Targeted Intervention	Injecting Drug Users	Mamit Town	2002
43		Bethany Health Centre Sihphir Vengthaar, Aizawl Dt - 796 031 Tel: 0389-364408 (O) 364407(R)	Rev. Sr. Valsa	Targeted Intervention	Injecting Drug Users	Sihphir, Lungdai	2001
44		N-E Drug HIV/AIDS Training Centre Tuli Town, Mokochung Super Market P.O. No. 174 Tel: 03862-233238 e-mail:nedhiv@yahoo.co.in	Rev. Fr. Joe (Director)	Targeted Intervention	Injecting Drug Users	Tuli (Mokokchung) Dimapur	2001

45	North East	The Director Shalom Rehabilitation Centre Chumukedima Nagaland 797 103 Tel: 03862-240238			Rehabilitation for Drug Addicts & Hospice for HIV/AIDS cases		
46		Catholic Medical Centre Imphal Manipur Tel: 0385-2427372 / 2427365			General Hospital care for HIV/ AIDS cases		
47		Sneha Bhavan Rehabilitation Centre C/o Little Flower School Imphal – 795 001 Manipur Tel: 0385-2220022			Drug Rehabilita- tion & Hospice Centre		
48		Shanti Dan Lonkeswar, W.Jalukbari Guwahati – 781 014, Assam			Care & support		

49	Rajasthan	St. Francis Hospital Beawar Road Ajmer Rajasthan 305 001 Tel: 0145-2431327 / 2422925						
50	Tamil Nadu	Sahai Trust 19 Vaidyaram Street, T.Nagar Chennai – 17, TN. Tel: 044-24322225, 24328979	Rev. Fr. Desmond Daniels	Targeted Intervention	Injecting Drug Users	Chennai, Perambur, Moolakadai, Vyasarpadi, Ottery	2003	
51	Tamil Nadu	Mottukal 32 College Road Nugambakkham, Chennai – 600 006 Tel: 044-28241933	Rev. Sr. Mercy	Targeted Intervention	Street Children	Chennai,	2002	
52		Jeevodaya Hospice 1/86, Kamaraj Road, Mathur, Manali PO Chennai – 600 068			Hospice for HIV/AIDS people			

53	Tamil Nadu	Holy Redeemer Hospital Madurai Theni Dt- 626 531 Tamil Nadu Tel; 04546 – 272502			Training Counselling and Community based intervention, Care & Support	
54		Vimal Jyothi Hospital Saravanampatty Coimbatore Tamil Nadu 641 035 Tel: 0422-2866469			Awareness & Counselling of HIV/AIDS	
55		Nirmala Leprosy Rehabilitation Centre Koviloor, Nallampalli PO Dharmapuri Tamil Nadu 636 807 Tel: 04342-244214			Awareness education & Counselling of HIV/AIDS & Leprosy	
56		Holy Family Hansenorium Fatima Nagar Trichy – 621 316,			Awareness Education & Counselling of HIV/AIDS	

57	Tamil Nadu	St. Mary's Hospital Arisipalayam, Salem-636 009, Tel: 0427-212988 E-mail: Francina@eth.net	Rev. Sr. Sophie (Administrator)	Clinic Inter- vention Project	STD Clinic At- tendees	Arisi- palayam, Salem	1998
58		Shanthy Bhavan St. Josephs Hospital Chinna Kaalaaspattu Pondicherry 605 014 Tel; 0413-2655790			Awareness Education & Counselling of HIV/AIDS		
59		Leonard Hospital Batlagundu PO Dindigul Dt Tamil Nadu 624 202 Tel: 04543-222670 / 340			Awareness Education & Counselling of HIV/AIDS		
60		Reaching the Unreached Genguvarpatti PO G Kallupatti, Periyakulam Tq. Theni Dt, Tamil Nadu 625 203			Community based Support & Care		

61	Tamil Nadu	Care and Support Wards (HIV/AIDS) St. Joseph's Leprosy Hospital, Arokiapuram Tuticorin – 628 002, Tel; 2320372			Community based Support & Care	
62		St. Ann's Hospital P.B. No.8, Thirunagar P.O. Thanakkankulam Madurai, TN 625 006 Tel: 0452-2882335			Awareness Education & Programmes	
63	Uttar Pradesh	Lisieux Shanti Nikethan Dasauli, Basa-ha P.O. Kursi Road, Lucknow-226 007 Tel: 0522-2890750/2890744			Hospice	
64	West Bengal	Jesu Ashram P.O. Matgara Dt. Darjeeling – 734 428, Tel: 0353-2580952			Care & Support	

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