The Impact of HIV/AIDS on Women Care Givers in Situations of Poverty: Policy Issues

Aasha Kapur Mehta
Sreoshi Gupta

Indian Institute of
Public Administration

United Nations
Development Fund for Women
UNIFEM

The Impact of HIV/AIDS on Women Care Givers in Situations of Poverty: Policy Issues

Aasha Kapur Mehta and Sreoshi Gupta
Indian Institute of Public Administration
Indraprastha Estate, Ring Road, New Delhi

Supported
by
UNIFEM South Asia Regional Office
223, Jor Bagh, New Delhi 110003

Indian Institute of
Public Administration

United Nations
Development Fund for Women
UNIFEM

UNIFEM is the women's fund at the United Nations. It provides financial and technical assistance to innovative programmes and strategies to foster women's empowerment and gender equality. Placing the advancement of women's human rights at the centre of all of its efforts, UNIFEM focuses its activities on four strategic areas:

- Reducing feminized poverty;
- Ending violence against women;
- Reversing the spread of HIV/AIDS among women and girls;
- Achieving gender equality in democratic governance in times of peace as well as war.

The views expressed in this publication are those of the author, and do not necessarily represent the views of UNIFEM, the United Nations or any of its affiliated organizations.

The Impact of HIV/AIDS on Women Care Givers in Situations of Poverty: Policy Issues

ISBN No. : 1-932827-44-7 - The Impact of HIV/AIDS on Women Care Givers in Situations of Poverty: Policy Issues, New Delhi, India 2005

Designed & Printed by Impression Communications,
Ph.: +91 11 9810096529, E-mail : atulb@impcom.net, www.impcom.net

Foreword

The growing impact of HIV/AIDS on women and girls has alerted us all to looking deeply at ways to confront the poverty and gender inequalities that drive the epidemic. More than any other disease in recent decades, HIV/AIDS has exposed the social inequities that make girls and women vulnerable to infection. Women need to know that they have rights, that they can act in their own self-interest and that they will be supported by their families, communities and nations.

There is lack of information regarding the interdependence between HIV/AIDS and exacerbation of poverty at the micro-level thereby restricting the efficiency of strategies to assist those most affected by the epidemic as well as to prevent its spread. Previous studies, especially those connected with research in Africa show that health-related shocks undermine the already strained coping mechanisms of the most marginalized, especially women, and is one of the significant causes of the deepening feminization of poverty.

HIV/AIDS creates a further distortion of gender inequalities both at the beginning and at the end of a woman's life cycle. Loss of income, additional care-related expenses, and the reduced ability of caregivers to work, mounting medical fees and funeral expenses collectively push affected households deeper into poverty. As the primary care giver, women have to face the impact of the loss of loved ones, as well as invest enormous cost of time, energy and resources to provide this care. Often women have to search for new or additional livelihoods to meet with the new demands within the household.

The imperative to find ways to strengthen the position of affected women and their families in the most marginalized households has resulted in this study. The study is a joint initiative of the Institute of Public Administration and UNIFEM South Asia Regional Office. The findings of the study constitute an important step towards consolidating a knowledge base on the micro-level impact of HIV/AIDS at the household level and the implications for caregivers within the family. Focusing on different dimensions of the issue, it explores the various components of care, which range from the material to the spiritual and the psychological spheres. It also scrutinizes and assesses the ability of the caregiver to earn an income in spite of shouldering the burden of care.

UNIFEM is pleased to further its partnership with the Indian Institute of Public Administration, New Delhi a renowned institution, in exploring a hitherto new area of research. I take this opportunity in extending my sincere appreciation to Dr. Reddy, Director for his leadership in exploring a new area of work, to Prof. Aasha Kapur Mehta for her deep commitment in taking forward such a difficult area of study and to Ms. Sreoshi Gupta for her valuable contributions to the study.

I would also like to place on record my deep appreciation of the partnership of several organisations in the study - Positive Women's Network Chennai, the Railways Women Empowerment and AIDS Society, Vijayawada, Nari, Pune, Mumbai District AIDS Control Society and the many positive women and men care givers who have unhesitatingly shared of their lives and their knowledge. I would also like extend my appreciation to my colleagues - Suneeta Dhar for her technical expertise, Vandana Mahajan and Sarita Jadav for their support.

It is my hope, that the findings of the study shall be widely used by different practitioners, including governments, women's groups, NGOs, national and international organizations working on HIV/AIDS and other stakeholders. It constitutes a crucial stepping-stone in responding to HIV/AIDS in India and indeed, elsewhere, in the most informed and effective manner possible.

Chandni Joshi
Regional Programme Director
UNIFEM South Asia Regional Office

Acknowledgements

We acknowledge with deep gratitude the help provided by a very large number of people and institutions in conducting this study. We are especially grateful to:

- IIPA especially Dr PL Sanjeev Reddy, faculty and staff
- UNIFEM especially Chandni Joshi, Suneeta Dhar, Sarita Jadav and Lisa Miczaika
- PWN+, NMP+, INP+ networks, especially Kousalya, Shabana and Leena
- REAPS team
- Doctors at MSACS, MDACS, Talera and other hospitals, especially Dr Alka Gogate, Dr Borgess, Dr Mehendle, Dr Daksha Shah, Dr Mate, Dr Vaswani, Dr Kulkarni
- Care homes and care givers especially Chelsea and Doe Nair, Sahara NACO and Loon Gangte, the CCDT, CHILD and Roshni care givers and project staff, especially Sara D'mello, Vijayanti, Mugda, Kalyani and their colleagues
- Sarvodaya Hospital especially Dr Meenal Mehta
- Stree Adhar Kendra, especially Neelam Gorhe
- All the positive women and men interviewed, and their caregivers who took the time to talk to us
- NACO
- NARI and the Counsellors at Talera
- All the participants at the Reference Group Meeting on Impact of AIDS on Women's unpaid work within the household and community organised by UNIFEM, YWCA and HelpAge International in Nairobi, November 7-10, 2004 for the Global Coalition on Women and AIDS
- Secretary Health, Shri P.K. Hota for chairing the presentation of an earlier version of this paper, JS Health, Amarjit Sinha, Rama Baru, PSN Rao, and other participants at the CPRC-IIPA Seminar on "Chronic Poverty: Emerging Policy Options and Issues" at IIPA on 29th and 30th September, 2005 for comments and suggestions.
- David Hulme for carefully reviewing the paper and for valuable inputs.

Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ANC	Ante-Natal Clinic
ART	Anti Retroviral Therapy
ARV	Anti-Retroviral
BMC	Bombay Municipal Corporation
CBC	Complete Blood Count
CCDT	Committed Communities Development Trust
CHILD	Children of HIV/AIDS Individuals Living in Dignity
CMV	Cytomegalovirus
DOT	Directly Observed Therapy
ECG	Electrocardiogram
ESR	Erythrocyte Sedimentation Rate
FMP	Free Medical Services for the poor programme
HIV	Human Immunodeficiency Virus
ICRW	International Centre for Research on Women
IDU	Intravenous Drug User
IGP	Income Generating Programme
MDACS	Mumbai District AIDS Control Society
MSACS	Maharashtra State AIDS Control Society
MMR	Maternal Mortality Rate
MSM	Men having Sex with Men
NACO	National AIDS Control Organisation
NCAER	National Council for Applied Economic Research
NGO	Non-government Organisation
NHP	National Health Policy
NMP+	Network of Maharashtra People Living with HIV/AIDS
PCP	Pneumocystis Carinii Pneumonia
PDL	Poverty Datum Line
PEP	Post Exposure Prophylaxis

PLWHA	People Living With HIV/AIDS
PPTCT	Prevention of Parent to Child Transmission of HIV
REAPS	Railway Women's Empowerment and AIDS Prevention Society
RNTCP	Revised National Tuberculosis Control Programme
STD	Sexually Transmitted Disease
TB	Tuberculosis
TBM	Tubular Basement Membrane
UNAIDS	United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNIFEM SARO	United Nations Development Fund for Women South Asia Regional Office
VCTC	Voluntary Counselling and Testing Centre
WHO	World Health Organisation
WLHA	Women Living with HIV/AIDS

Table of Contents

Tables and Boxes

Chapter I

Introduction

What is the impact of HIV/AIDS on women caregivers in situations of extreme poverty in India? What happens when HIV/AIDS enters the home? What are the different dimensions of care needed by positive persons? What interventions can reduce the burden of care and improve the quality of life of those infected and affected by HIV/AIDS? Who should provide that care? How can we best use the funds allocated to the fight against HIV by governments, donors and communities, so that they translate into access to better medical, nutritional, financial, emotional and physical care for positive persons and their carers? These are some of the questions that this paper tries to address.

Shocks, such as those due to the onset of a long and expensive illness, are among the factors that can drive the poor and many who may have initially been better off into chronic or long-term poverty.[1] Analysis of the only national rural panel data set for India shows that there is both substantial persistence and mobility into and out of poverty. More than half (52.61%) of the households that were poor in 1970-71 remained in poverty over a decade later. Further, 25% of households who were not poor in 1970-71 became poor a decade later.[2]

Tuberculosis and HIV/AIDS are amongst the health related shocks that can drive people into poverty. An estimated 5.134 million people are living with HIV in India. Moreover, in many states, the virus has now spread beyond the highly susceptible groups into the general population. It is assumed that about 10% of HIV positive cases will turn into full-blown cases of intractable stage of AIDS.[3] The burden of the disease falls disproportionately on the most vulnerable, including women and scheduled castes,[4] possibly due to lower levels of risk awareness. The fact that the opportunistic illnesses associated with HIV/AIDS require considerable expenditure means that households already below the poverty line suffer extreme hardship because of being infected with HIV. Post-infection longevity depends on awareness about and access to anti retroviral therapy (ART), which is costly and difficult for the poor to access.

---

[1] *Mehta and Shepherd, 2004*
[2] *Bhide and Mehta 2004a and b; Mehta and Bhide 2003*
[3] *Srinivasan undated*
[4] *World Bank 2001*

WHO considers poverty to be the world's most ruthless killer and greatest cause of suffering.[5] Indeed, "poverty is the main reason why babies are not vaccinated, clean water and sanitation are not provided, and curative drugs and other treatments are unavailable, and why mothers die at childbirth…It conspires with the most deadly and painful diseases to bring a wretched existence to all those who suffer it."[6] Crucially, the twin development goals of poverty reduction and economic growth can only be attained through improvement in people's health.[7] Strong links between HIV/AIDS and poverty have been demonstrated, with AIDS deepening poverty and increasing inequalities at every level - household, community, regional and sectoral.[8] Nonetheless, access to public health in India remains grossly inadequate for the vulnerable sections of the society,[9] generating an over-reliance on unregistered private medical practitioners. Mortality and morbidity rates in India remain unacceptably high, with the maternal mortality rate being more than seven times that of China (see Table 1), while Sri Lanka has achieved a reduction of MMR to 46.

Table 1: Selected Health Indicators: India and China

	India	China
Life Expectancy (in years)	63.2	68.9
Male/Female	64.6 (F)	73.3 (F)
Infant Mortality Rate	63	37
Maternal Mortality Rate	407	56
Births per 1000 women (age 15-19)	45	5
Contraceptive prevalence (in %)	48	84

Source: State of World Population, 2004; UNFPA cited in Mid Term Appraisal of the Tenth Plan, 2005

Moreover, India's National Health Policy[10] notes with concern that unsatisfactory health indices are an indication of the limited success of the public health system in meeting the preventive and curative requirements of the general population. In the context of HIV/AIDS it states, "as there is

[5] *World Health Report 1995: 5*
[6] *World Health Report 1995: 1*
[7] *Bajpayee and Goyal 2004*
[8] *Barnett and Whiteside 2002:3*
[9] *Gupta and Datta 2003*
[10] *GOI 2002*

no existing therapeutic cure or vaccine for this infection, the disease constitutes a serious threat, not merely to public health but to economic development in the country." Together with HIV/AIDS, malaria and TB also indicate a high prevalence level. The common water-borne infections – gastroenteritis, cholera, and some forms of hepatitis – additionally contribute to a high level of morbidity in the population, even though the mortality rates may have been somewhat moderated.

Women suffer doubly when HIV/AIDS enters the home, due to the burden of enduring the infection while also caring for family members who are ill. A woman's vulnerabilities are "further compounded if she is single or widowed; with discriminatory access to inheritance, shelter and other care facilities."[11] In this sense, different dimensions of human development determine the transmission of HIV and its impacts, implying that it is "not simply a function of sexual behaviour."[12] Those with "nutritional deficiencies, with parasitic diseases whose general health is poor, who have little access to health services, or who are otherwise economically disadvantaged have greater susceptibility to infectious diseases, whether they are transmitted sexually, by food, water, air or other means."[13]

1.1 HIV/AIDS in India: Estimates of Prevalence

India accounts for over 10% of the people living with HIV/AIDS (PLWHA) globally, while holding 60% of the 7.4 million PLWHA in the Asia and Pacific region.[14] While those infected with HIV/AIDS constitute less than 1% of the population, India has the second highest number of people living with the virus in the world after South Africa. Given the large population base, a rise of just a few percentage points in HIV prevalence rates increases the number of those living with HIV/AIDS to several million. Considering the present scenario, India is facing one of the biggest public health challenges in its history. This clearly points to the need for improved public health services especially for the poor. Women are especially vulnerable to the disease and there is lack of awareness of HIV/AIDS in the low prevalence states.[15]

According to data collected by NACO in 2004, an estimated 5.134 million persons are infected with HIV. The HIV burden is estimated based on the HIV prevalence observed at designated sentinel surveillance sites for different risk groups. Particularly at risk of infection are men attending STD clinics and intervention centres for men having sex with men (MSM), female sex workers (FSW) and recovering drug addicts.

---

[11] *UNIFEM SARO 2000: 9*
[12] *UNDP 2003: 24*
[13] *Stillwaggon 2002 cited in UNDP 2003: 24*
[14] *WHO 2003*
[15] *Schaffer and Mitra 2004*

Data regarding prevalence of AIDS in India shows that as of June 2005, 1,10,856 cases were reported. The highest prevalence of AIDS is in Tamil Nadu, followed by Maharashtra and Andhra Pradesh. Of the reported cases of AIDS, it is estimated that 85.9 per cent contracted it through sexual transmission, 3.6 per cent from mother to child, 2.01 per cent through blood transfusions and 2.41 per cent through injecting drug use (see Tables 2 and 3)

Table 2: Aids Cases in India (As on 30th June, 2005)

State/UT	AIDS Cases	Percent of total
Tamil Nadu	52036	46.94
Maharashtra	13747	12.40
Andhra Pradesh	12349	11.14
Mumbai Municipal Corporation	7223	6.52
Gujarat	5636	5.08
Karnataka	2896	2.61
Manipur	2866	2.59
West Bengal	2397	2.16
Kerala	1769	1.60
Madhya Pradesh	1396	1.26
Uttar Pradesh	1383	1.25
Chandigarh (UT)	1217	1.10
Rajasthan	1153	1.04
Delhi	950	0.86
Nagaland	736	0.66
Goa	566	0.51
Ahmedabad Municipal Corporation	555	0.50
Haryana	469	0.42
Pondicherry	302	0.27
Punjab	292	0.26
Himachal Pradesh	247	0.22
Assam	225	0.20
Bihar	155	0.14

Orissa	128	0.12
Mizoram	106	0.10
A & N Islands	33	0.03
Meghalaya	8	0.01
Sikkim	8	0.01
Tripura	5	0.00
Jammu & Kashmir	2	0.00
Daman & Diu	1	0.00
Arunachal Pradesh	0	0.00
Chattisgarh	0	0.00
Dadra & Nagar Haveli	0	0.00
Jharkhand	0	0.00
Lakshadweep	0	0.00
Uttaranchal	0	0.00
Chennai Municipal Corporation	0	0.00
Total	110856	100.00

Source: NACO Website

Table 3: Risk/Transmission Categories

	No. of cases	**Percentage**
Sexual	95262	85.93
Perinatal transmission	4016	3.62
Blood and blood products	2223	2.01
Injecting Drug users	2669	2.41
Others (not specified)	6686	6.03
Total	110856	100.00

Source: NACO Website

1.2 HIV/AIDS and Care

The care economy, also referred to as unpaid care work, covers a wide range of tasks and responsibilities generally carried out by women in the household. These include cooking, cleaning, fetching water and many other activities associated with raising the young and caring for the sick and the elderly. The value of time, energy and resources required to perform this unpaid work is largely unrecognised and unaccounted for, despite its vital contribution to sustaining the overall economy and society. When HIV enters the household and community, women and girls pay a high opportunity cost when undertaking unpaid care work for HIV/AIDS-related illnesses, as their ability to participate in income generation, education, and skill-building diminishes sharply.[16] Additionally, care giving involves significant levels of effort within the home. When family members fall ill, women add supporting the infirm to their existing responsibilities in a context where they are already stretched; surviving in conditions of poverty and lack of resources, while often themselves sick. Only when both roles – that of caregiver for the sick and dying and carer of the home and family – are appreciated, the full extent of the impact of AIDS can begin to be assessed. At the same time, the lack of services provided to the family and community by the state becomes glaring.

The vast majority of women and girls who are shouldering the responsibility for HIV/AIDS care in the household, do so with very little material or moral support. They receive no training, support from formal programmes, or hard inputs such as gloves, medication and school support for children. The combined physical and emotional stress resulting from the persisting needs of sick household members, while trying to secure the basic means for survival, inevitably forces women to neglect their own health.[17] These arduous tasks of unpaid care are performed gratis, without national recognition of their importance and value and remain non-monetised and statistically invisible.

Before 2025, AIDS is expected to cause 31 million additional deaths in India.[18] This paper aims to contribute insights on how to respond to this epidemic by examining the impact and burden of HIV/AIDS entering the home, on the lives and livelihoods of women (and men) care givers in situations of poverty. The main challenge is to comprehend the needs of persons living with HIV/AIDS with the purpose of identifying the necessary policy interventions to reduce the burden of care. As part of this study, which builds on the Nairobi Reference Group Meeting on "Impact of AIDS on Women's Unpaid Work within the Household and Community," some of the existing literature on the subject is also reviewed.

---

[16] *Global Coalition on Women and AIDS, Aide Memoire Nairobi 2004*
[17] *ibid.*
[18] *United Nations Department of Economic and Social Affairs, Impact of AIDS: ix and x*

Chapter 2

Methodology

Any chronic illness automatically brings a great deal of suffering with it. Society and health provisioning systems may add to the suffering in ways that worsen the burden of care in families grappling with the illness. Very valuable experience-based information on care needs and ways of reducing the care burden exists with those who are affected by HIV/AIDS, as also care providers. With the objective of using that learning to identify interventions that may make a difference, key informant interviews were held with:

1. A group of seven care givers who have been working with Committed Communities Development Trust (CCDT), Mumbai for several years, providing care and support to families with children on the Children of HIV/AIDS Individuals Living in Dignity (CHILD). After evaluating family needs, they help extremely deprived families through counselling, education of children and a ration bag to ensure that basic nutritional needs are met.
2. The President of PWN+ and several of its representatives in Delhi, Mumbai and Pune.
3. Doctors and counsellors working with HIV positive people in government hospitals, government agencies, drop-in-clinics and private clinics in Mumbai and Pune.
4. An HIV positive nurse in Pune who has suffered discrimination from colleagues in the health care system and now provides support and care to a large group of HIV positive persons.
5. Persons running care homes in Delhi and Mumbai and a community care centre in Mumbai.
6. Focus group discussions with a group of 30 commercial sex workers (through CCDT in Mumbai).

Furthermore, questionnaires were administered to 38 persons (21 women and 17 men) who were either infected or directly affected by HIV/AIDS and were also acting as care givers. 10 respondents were based in Delhi, 5 in Mumbai, 7 in Pune, 10 in Vijaywada and 6 in Chennai.

All positive persons (except those representing the networks) were interviewed in the presence of the NGOs providing support to them. In all cases, the researchers explained that the purpose of the interviews was to write a paper and no benefits would accrue to them from answering the questions. Some NGOs requested that a statement of non-disclosure of identity of the respondents be signed, which was complied with.

Chapter 3

Impact of HIV/AIDS, Coping Strategies and Care: Literature Review

3.1 The Impact of HIV/AIDS

Macroeconomic Factors

Macroeconomic factors affecting susceptibility to HIV include budget allocations to health, health related infrastructure, income distribution and employment.[19] National economies are affected through illness and death of producers, diversion of resources from savings (and eventually investment) to care and a possible reduction in the rate of economic growth.[20] Poorer countries are likely to have worse epidemics than rich nations as their health status is generally worse and income distribution is uneven, rendering the poorest particularly vulnerable to the disease. Indeed, "since the poor are characterised by weak endowments of human and financial resources, few marketable skills and generally poor health, this leads to decreased productivity and increased risk of infection, such as from untreated STDs, which facilitate the transmission of HIV."[21] The ensuing rise in morbidity and mortality levels, which reduce labour productivity at the workplace and generate direct and indirect costs due to medical care, death benefits and replacement costs cause the per capita income of the affected countries to decrease. Bloom and Mahal estimated the correlation between the prevalence of AIDS and the growth of GDP per capita between 1980 and 1992 and found that the growth of income was lower in countries where the epidemic was more prevalent.[22] Therefore, "AIDS has the potential to push economies into decline and then keep them there" due to the reduction in savings and loss of efficiency, associated with the disease, "akin to running Adam Smith in reverse."[23]

---

[19] *Loewenson and Whiteside 1997: 19*
[20] *ibid*
[21] *Desmond et.al. undated: 4*
[22] *Bloom and Mahal 1997a: 31*
[23] *Bureau of Economic Research 2001 cited in Barnett and Whiteside 2002: 7*

Other significant macro level issues that they raise include the strong possibility that governments will have "fewer resources to spend on poverty alleviation and social services at the very point, when demand for those services is most likely to increase."[24]

Microeconomic Factors

At the micro level, though the impact of HIV/AIDS is difficult to quantify and depends on the individual's health, income does decline if the individual is unable to work and the caregiver curtails work outside the home to attend to the needs of sick family members. Expenditure on medical care increases, as do the dietary and nutritional needs of the patient. In Africa, due to the high death toll of the disease, funeral related expenditure is repeatedly mentioned in the literature as draining resources.

The impact of contracting HIV ranges from occasional bouts of illness to being bed-ridden and extremely dependent on caregivers. Studies in Thailand reveal that the opportunity cost of care giving in terms of curtailing of economic activities was very high for low-income groups, indicating that AIDS leads to impoverishment.[25] Poverty resulting from such a situation can be categorised into two types namely 'service poverty', where people are unable to access services such as health and education and 'resource poverty', because of inability to access resources due to poverty with respect to rights and representation or governance.[26]

Research conducted in Africa shows that on an average 30 - 50% of annual household income is spent on health related expenditure, which decreases to 24% if covered by insurance and increases up to 92% for those not covered.[27] The households are mainly affected in three ways:

a) Increased medical care, special diets and transport expenditure;

b) Decreased revenue from loss of labour;

c) Decreased investment in productive activities, education and savings.

While some evidence from Kagera and Cote d' Ivoïre indicates that households somehow manage to cope,[28] Barnett and Whiteside stress that in their experience, no coping takes place, leading to the break up of households. Coping turns out to be another way of saying 'desperate poverty, social

---

[24] *Barnett and Whiteside 2002: 7*
[25] *Knodel and Im-em 2003: 3*
[26] *Barnett and Whiteside 2002:5*
[27] *Loewenson and Whiteside 1997: 31*
[28] *World Bank 1997 and Bechu 1998 cited in Barnett and Whiteside 2002*

exclusion and marginalisation.'[29] Coping mechanisms of households in Sub Saharan countries include:

- Borrowing from friends and relatives.
- Short-term relief through aid organizations.
- Substitution with cheaper commodities.
- Reduction in consumption of food and other expenditure like education.
- Taking children, particularly girls, out of school to care for the sick and help with other household duties.
- Sending away children to live with relatives.
- Marrying for the second time to take care of a large number of grandchildren of varying age groups after children have died.
- Migration in search of new jobs.
- Taking loans, selling assets and using savings.
- Reducing investment.
- Working extra hours in the informal sector or self-employment.
- Selling essential income-generation devices, such as machinery and tools.

A case study from Kenya showed that when the male head of a household fell ill, he disposed off his maize-milling machine to obtain cash for his medical expenses. Since the milling machine bought steady income into the household, its sale meant that the family would soon have no money to hire labour or buy inputs for their sugarcane plots. Cane production fell and so did income from cane crops. Similarly, sale of livestock meant that the households were being cut off from their own access to fresh meat, dairy and eggs.[30]

Consequently, the concentration of HIV infection in the productive age group has significant implications for the productive capacity and income of affected households. In fact, studies in Zambia reveal that 'the economic impact of AIDS in affected families is the rapid transition from relative wealth to relative poverty.'[31] Similar results have been documented in Thailand, where a case

---

[29] *2002:11 and 24 citing Rugalema 2000*
[30] *Desmond et.al. undated: 11*
[31] *Barnett and Whiteside 2002:11*

study was conducted based on a house-to-house survey of only families in which the deceased were of working age.[32] The study was conducted in five districts reporting the highest number of cases and classified their households by the sub-district of origin. To enable comparison and analyse the variation of the impact, an additional 100 households were also selected where a non-HIV related death had taken place. The results show that in terms of direct costs, there was little difference between households with or without deaths due to the infection. Forgone income due to an HIV/AIDS related death and its consequences in terms of economic support required for running the expenditure of the household, depended on the characteristics of the family; whether individual or joint, whether death had taken place at an early stage or later stage. Simple regression analysis was used to determine whether a HIV/AIDS related death causes any particular impact in terms of household income and consumption of the family as compared to a non-HIV death. More than half of the households that had experienced an HIV/AIDS related death had incomes lower than the average of US$ 2,238 per year, a level already considered low by national standards.[33] If the 1988 World Bank poverty line of US$ 275 per person per year for rural areas was adjusted by the rural price index and for the presence of three people in an average household, about one-fourth of the households in the sample studied that had experienced an HIV/AIDS related death would be below the poverty line.

An important policy implication of this study was that education subsidies should be provided to poor families as an incentive to prevent them from withdrawing the girl child from school to work and support the family. Some of the girls withdrawn from school eventually became sex workers. Alternate sources of earning were of primary concern and this could be achieved through short courses in occupational training. It was also realised that access to credit from institutional sources must be expanded, so that the poor are not at the mercy of the exploitative interest rates charged by moneylenders. Farm input subsidies were required for those families who could not labour in the fields and required farm machinery or other equipments. A very important concern was provision of a package for care for the orphans and the older members of the families. It was realised that the Free Medical Services for the poor programme (FMP) and the Health Card programme had not adequately benefited the poor and that there was a ceiling on the number of episodes of illness that would be treated each year. This system had to be strengthened so that it could actually reach the grassroots.[34]

---

[32] *Pitayanon et.al. 1997*
[33] *ibid:64*
[34] *ibid: 94-98*

With regard to studies in India, UNIFEM SARO[35] undertook community-based research on Gender and HIV/AIDS with partners in four regions of India - Pune and Chennai to reflect high prevalence and Delhi, Assam, with low prevalence. They found that most women respondents lacked elementary knowledge of reproduction, health issues, and safe sex practices. There were gender differentials in levels of awareness about HIV/AIDS - low among women and girls compared to boys and men. Positive men were able to get support and care while women, both affected and infected, did not receive the same kind of support and care. In most cases, positive women were dependent on their spouses due to lack of education and insufficient skills. The in-laws denied property after the death of their husbands. The pressures on women were enormous, as they had to support the family, while repaying debts resulting from high medical costs.

Additionally, it was found that women faced high levels of discrimination as they were often blamed for the infection. Lack of access to basic amenities like water was a problem as was loss of jobs when the employer was informed about the seropositive status. Other findings included refusal of treatment, medical care, counselling services, non-functional equipment at hospitals and absence of hospital staff.

Other research conducted in India found that the burden of health care in India is inversely related to economic status of the household, resulting in poorer households becoming victims of an inefficient health care system[36]. Studies conducted in different states of India reveal that the poor had greater problems in accessing treatment, leading to adoption of various coping mechanisms like selling of assets and taking out loans. Many would also resort to home based activities such as vending, to earn extra money to support medical expenditures. Sometimes money would also be demanded from the girl's parents to support the cost of treatment, especially in middle class families. A recurrent coping mechanism was to pull female children out of school to care and maintain the family.[37]

Data on various sources of treatment accessed by patients in urban India for in-patient expenses showed that 37 per cent had utilised their past savings for treatment, while 2.5 per cent sold physical assets and 23 per cent had to borrow money from different sources. It was found that 37% depleted their savings for treatment, 23% borrowed money and 2% resorted to selling their physical assets.[38] Only 6% of the affected families could rely on any financial support from government or

---

[35] *UNIFEM SARO 2000*
[36] *Dilip and Duggal 2002: 2*
[37] *Mukhopadhyay et.al. 2001*
[38] *Dilip and Duggal: 2002*

non-government agencies. An additional survey conducted in Delhi across diverse communities also showed that when the husband falls ill, it is the wife who assumes the role as primary caregiver, while also shouldering the responsibility of acting as main breadwinner.[39] Indeed, women are worse affected by the impact of HIV/AIDS, because they enjoy relatively lower entitlements such as restricted access to land, property and credit.[40]

In 2003, UNIFEM conducted a series of research studies in partnership with the Ministry of Railways, with medical service providers, railway schools, and vulnerable sections of the railways, including TTCs, engine drivers and trolley men and their families which revealed that:

- Men primarily rely on the media for messages about HIV/AIDS, while women also learn about HIV/AIDS from other sources such as friends, relatives, medical staff and teachers.
- HIV/AIDS counsellors are valued in their role as information providers and supporters.
- HIV/AIDS creates severe family budgeting difficulties - 77% of the families reported these. Debts can be as high as Rs 10,000 to 50,000, inspite of most of those surveyed being railway employees with a regular flow of income.
- Myths and misconceptions remained widespread, leading to stigma at the workplace and prevented many from undergoing an HIV test.
- Domestic violence and physical abuse rises when the woman falls ill.
- Boys are better informed about HIV/AIDS than the girls. Over half of the students are aware about the modes of transmission, while 20 to 35% still have certain misconceptions. A majority of the students wanted more information to be provided through the education system.

Sathiamoorthy and Solomon analysed a cohort of 79 men and 46 women across all ages, gender, educational and economic status in the early HIV symptomatic stage of infection to determine the consequences of HIV incidence.[41] They observed that financial assistance was proportional to the employment status, with over a third of those working full time needing financial assistance.

---

[39] *Mukhopadhyay et.al. 2001*
[40] *UNIFEM SARO 2000: 32*
[41] *Sathiamoorthy and Solomon, 1997*

3.2 HIV and Care

Ogden, Esim and Grown note that although few systematic studies have been undertaken to document who provides care at the family level, it is widely acknowledged that women play a central role[42]. Women were the primary caregivers in 86 out of 100 illness episodes, while men were the primary care-giver in only eight of these episodes. In another eight episodes, the husband and wife jointly provide care.[43]

Dimensions of Care[44]

'Care' covers a range of services and activities including physical, clinical, psycho-social, emotional, spiritual, financial and practical care. While many provide care for spouses and family members out of love and compassion, the fact is that their work remains unsupported and unrecognised. Those offering care as volunteers in communities often provide it without any compensation.

Care operates at multiple levels, such as in the health care system, community-based care programmes and within the home. While the burden of care at home falls primarily on women, elderly people, children and men also provide support.

Physical care is only one part of the process. For a bed-ridden family member this may involve bathing, toilet assistance, turning (to avoid bedsores), providing water and nutrition. It may additionally require accompanying the patient to the hospital, bringing food to the hospital and supplementing nursing care. Furthermore, patients are often depressed and stigmatised, requiring the carer to provide counselling and moral support. Marital conflict and relationships may be strained as households grapple with the effects of poverty exacerbated by the disease.

---

[42] *Ogden, Esim and Grown 2004: 7*

[43] *Taylor et al. 1996 cited in Ogden, Esim and Grown 2004: 7*

[44] *This section of the paper is based on discussions at a Reference Group Meeting on Impact of AIDS on Women's unpaid work within the household and community organised by UNIFEM, in partnership with World YWCA and HelpAge International in Nairobi, November 7-10, 2004 for the Global Coalition on Women and AIDS*

Box 1 Additional Care Activities in an AIDS-affected Home

- Bathing and cleaning up after the sick person
- Obtaining and preparing meals in the context of dwindling resources
- Hand-feeding those too sick to feed themselves
- Washing clothes and bed sheets
- Escorting the sick person to and from the lavatory
- Assistance in walking (especially stairs and uneven surfaces)
- House maintenance (particularly where people live in mud-walled homes with thatched roots that demand periodic maintenance and repair)
- Emotional support
- Child care
- Purchasing and administering drugs or remedies
- General household survival needs such as income generation and producing food through subsistence agriculture

Source: Ogden, Esim and Grown, ICRW 2004: 6

Crucially, "all of these problems, and the care required, are significantly compounded by inadequate access to even the most rudimentary of sanitation facilities." The levels of care required ought not to be underestimated - in a survey of 771 AIDS-affected families in South Africa, it was reported:[45]

- 16% of those sick could not control their bowels, with even more lacking bladder control
- 17% could not leave the bed or reach the lavatory on their own
- 19% could not wash without assistance;
- Just under 20% had to be helped to dress[46]
- In one example, a woman carer estimated that due to regular bouts of diarrhoea suffered by a family member who was dying of HIV/AIDS, she was fetching 24 buckets a day, to wash clothes, sheets and the patient.[47]

---

[45] *Steinberg et al (2002) cited in Ogden et al 2004*
[46] *Steinberg et al (2002) cited in Ogden et al 2004*
[47] *UNAIDS, UNFPA and UNIFEM 2004: 32*

Lack of hospital beds may prompt governments to establish home-based care for chronically ill patients, thereby transferring the cost of care to the individual households. This measure has been introduced for instance in Tanzania, where patients suffering from HIV/AIDS related conditions occupy over 60% of hospital beds.[48] Although home-based care is often less expensive than institutional care, the women frequently shoulder the cost, unassisted. In Zambia, home-based care is actually more expensive than treatment in hospital, because of the high transport costs for supplies such as food, nursing aids and drugs.[49] Nonetheless, home-based care may be the only option when marginalized groups are denied care in formal institutions.[50]

Some aspects of care have been reflected in a few studies in India. D'Cruz (2004) investigated the concept and significance of care giving, with respect to HIV/AIDS, based on a survey of nineteen seropositive and seronegative caregivers from different age groups and economic levels in Mumbai. She pointed out that married women had to care for their seropositive husbands despite being positive themselves and in need of care, with the in-law's family providing little or no support. Further, the woman's natal family would ensure that they were not abandoned. Provision of care also depended on the interaction between the perceived source of infection, gender of the infected person and class. From these results, D'Cruz suggests that special programmes of support, including self-help groups, need to be created for infected, care giving wives and elders, who face extraordinary strains.

The level of stigma attached to HIV/AIDS and its impact on the family, especially amongst the poor, has been analysed[51] with the help of data collected through in-depth interviews of nineteen HIV positive men and women in four villages of Maharashtra. When husbands were infected with HIV earlier than wives, the impact on wives included lack of economic resources, stigma and risk of isolation from the deceased husband's family. With resources used up in caring for the husband and mounting debts, women had few economic resources to seek medical care for themselves and their HIV positive children and manage day-to-day expenses. While the husbands had their wives caring for them, there would be nobody to support the wives when they in turn needed care. Many of the surveyed families had sold or mortgaged land to pay for the treatment and other associated expenditures, which varied between Rs. 4,000 to Rs. 50,000. In addition, expenditures on medicines and doctors fees varied from Rs. 400 to Rs. 1000 per month. Consequently, the study found that poverty dominated the lives of the interviewees, either because of their families' pre-existing low economic and caste status or destitution arising out of the disease.

---

[48] *Msobi and Msumi undated:1*
[49] *Loewenson and Whiteside 1997:36*
[50] *Campbell and Foulis 2004*
[51] *Pallikadavath et.al. 2005*

Interviews were conducted by CCDT with 60 women carers in 2003 to ascertain the problems faced by women carers in Mumbai and Thane.[52] Most carers were HIV positive themselves and had undergone an HIV test either during pregnancy or when their spouse tested positive. The difficulties faced by the carers included having to deal with opportunistic infections, preparing for the future, accepting and being accepted as HIV positive, lack of support from family and friends, little or no money and having to search for care systems. Other difficulties included fatigue, emotional exhaustion and depletion of financial resources to meet medical costs. Therefore, policy interventions are needed that offer economic support, reproductive and general health advice, education and employment.

[52] *CCDT Unpublished Mimeo 2004*

Chapter 4

Mapping the Dimensions of Care

4.1 What Happens when HIV/AIDS enters the Home?

Based on a Focus Group Discussion held with caregivers working closely with families that are HIV positive, and with representatives of Positive Networks, many of whom have first hand experience of care giving, the impact of HIV/AIDS entering the home was identified as the following:

- Shock on discovering HIV status, fear regarding the future and uncertainty about the spread of the disease.
- Anger, since the HIV-positive husband often does not share the information with the family. Only when the husband is admitted to hospital frequently does the wife learn of his status.
- Fear of stigma. Due to this the family generally does not share the information with others and becomes more isolated or closed. If treatment is started relatively early, there are fewer opportunistic infections. If help is not sought for fear of stigma, the suffering increases.
- Children drop out of school due to financial problems.
- Mounting financial burden due to expenditures on medicines and medical costs.
- Decrease in income, leading to dropping food intake.
- Early marriage of children out of fear that no one will marry the child once the status is known.
- The wife becomes responsible for supporting the whole family.
- Blaming the wife, regardless of the circumstances. If the husband is detected HIV positive, the wife provides support. However, if the wife is tested HIV positive before the husband, she is abandoned in a government hospital and held responsible for bringing HIV into the house. Even if she is HIV negative, she is accused of not looking after her husband, pushing him to seek comfort outside the home.
- In case of inter religious marriage the woman is affected the worst.

4.2 The Dimensions of Care and Possible Interventions to Reduce the Burden of Care

Care needs specified included emotional care, medical care, physical care, financial care, nutritional care, spiritual care and more. All the respondents felt that each component is important in itself, while also being interdependent with the other spheres of care. Detailed responses to each of the care needs are specified below.

i. Emotional care

Usually provided by family members, counsellors, friends, networks of HIV positive persons, community, health and social workers. Awareness and information must be offered with a positive perspective to prevent stigma and increase social acceptance. Discrimination creates distress for the positive person. Family backing and psychological support are very important - medicine alone does not work. People may only learn about HIV/AIDS once it enters the home. The impact hinges upon how information is conveyed to the person and his/her family. Since this information is extremely difficult to accept, leading to shock and denial, a very sensitive and positive approach is needed. Counsellors, for instance from the VCTC, should provide follow up counselling and ensure that family members who are HIV-negative know how to remain so.

ii. Physical care

This may be provided by the positive person himself or herself, family and friends, doctors and health care providers. The intensity of care required varies, depending on whether the person is mobile or bedridden. If the HIV positive person is at home and bed ridden, the care giver(s) may need to be available 24 hours a day. Children may look after the person when the mother needs to go to work, thereby affecting their studies. Sometimes siblings are very young, adding stress to their future. If the person is mobile and can walk, then limited care is needed. Young, HIV positive children increase the burden of care. However, those not terminally ill should be encouraged to look after themselves as far as possible.

iii. Medical Care

A very important component of care, but many interventions are needed to bring about change. The attitude of health care providers at all levels must be transformed to reduce their fear of contracting HIV from the patient. This can be done through training workshops and follow-ups. Even though NACO and other agencies have been working towards reducing the stigma and fear

associated with HIV/AIDS for many years, the attitude of doctors, nurses and lower level functionaries remains harsh and uncaring. Indeed, professional social workers mentioned that when directions to the HIV/AIDS OPD were sought, people looked at them strangely and asked why they needed to go there. Behavioural change and greater sensitivity towards positive persons are therefore required. Beds are often not available, requiring HIV/AIDS patients to sleep on hospital floors. Some caregivers felt that HIV/AIDS patients were being treated like 'animals' and reported that the attitude of the doctors affects the attitude of the other staff as well as of the other patients. The language used is often very rough and offensive. Frequently, when a patient is discovered to be HIV positive upon admission, the hospital refuses costly medical procedures such as operations for other illnesses.

iv. Care in Hospitals and the Need for Change

Recognizing the need to move beyond documenting the problem of discrimination, Population Council, Horizons (2000) and SHARAN studied three hospitals in Delhi to understand hospital based stigma and discrimination against people living with HIV/AIDS. Pre- and post evaluation design was used to assess the outcomes of the pilot programme using a random sample of 884 health workers representative of doctors, nurses and ward staff from four departments. The researchers found that manifestations of stigma and discrimination in hospitals ranged from condescending attitudes to delay and denial of treatment. Both individual and institutional factors contributed to AIDS related stigma and discrimination in health care settings. The pilot programme made a difference as health workers at the managerial level were now involved in using the PLHA-friendly checklist to guide them in developing hospital guidelines on HIV care and management as well as staff safety, strengthening and mainstreaming HIV counselling and disseminating information on infection control procedures and the availability of post exposure treatment. Follow-up survey showed that overall health workers understanding of HIV transmission had increased but some misconceptions still persist. Changes in stigmatizing and discriminatory attitudes were measured by the 21-item Stigma Index. Health workers made significant improvement in their attitudes towards PLHA following the intervention. Health workers' also reported improvement in their practices in caring for PLHA in their hospitals. For example, more doctors not only acknowledged the importance of informed consent and pre-and post-test counselling but also mentioned offering these services to their patients. All staff, including nurses and ward staff showed marked improvement in use of universal precautions with patients for at-risk procedures.

The results of this study have enabled the widening of this program to all hospital departments. NACO has endorsed the use of the PLHA-friendly checklist to be disseminated to all the State AIDS Control Societies in the country.

Significant improvements remain to be made, however, especially regarding the availability of sufficient staff, funding to carry out the necessary treatment and access to cheap drugs.

A survey conducted amongst 930 doctors in 60 towns and cities showed that 362 doctors were managing 90,000 positive persons, 11,700 of whom were on ARV therapy, most of which was unstructured.[53] More than half the patients were not adhering to the regimen by the end of the first year mainly because of the high cost of drugs and tests. The reasons for poor adherence included the high cost of drugs and monitoring tests, poor counselling and inadequate understanding on the part of patients of proper dosage and continued therapy, stigma and discrimination associated with ARV therapy and intolerance to drugs. Srinivasan (undated) surveyed 269 people in four Indian cities to find that 94% of those not receiving ARV wanted to be on it. Projections indicate that 'by 2033, the number of people in unstructured programmes would reach 5.3 million, 3.9 million of whom would be infected with resistant strains.[54] Cheaper drugs entering the market would enable the poorest of classes to have access to generic drugs for HIV. However, TRIPS regime has seen that most of the Indian pharmaceutical companies manufacturing cheap ARV drugs have had to withdraw their names from the WHO list because they did not match the world standard in equivalence, though UNAIDS does not consider them of poor quality. In the absence of increased state expenditure on health, access to ART will remain outside the reach of most of those who need it. Issues of access to treatment or affordability of drugs and the rural-urban divide with respect to health facilities in India draw attention to the urgent need for support for this sector.

In view of the pressure of time on doctors and long waiting lists, one solution in the context of counselling would be to involve representatives of Positive Peoples Networks as they can take the time to patiently explain the importance of regularity and adherence in taking ART medicines and provide information regarding other health precautions. This should be done at all ART dispensing points.

Further, the HIV positive person should be provided medical care with dignity. In a large metro like Mumbai, ART is available only in JJ Hospital and is dispensed only on two days (Monday and Friday) per week. Patients have to stand in long queues for five or six hours, which adds to their burden. New patients are only admitted on one day in the week, so patients stand in line at 7 a.m. and stay in line until 5 p.m. to be registered. If the number of ART dispensing centres is increased, the time spent by PLWHA and their caregivers in getting the prescription and medication will decrease.

After a person is started on ART, CD-4 counts change and adherence must be monitored. In some Government hospitals, CD-4 machines do not even work and the second line of the drug regimen is not available, meaning that only the basic course is given. Special medicines that may be more expensive, such as Efavarin, are also not dispensed in government hospitals.

---

[53] *Over et.al. 2004:12*
[54] *Over et.al. 2004:73*

It was pointed out that even two days before the death of a person a long list of tests and medicines are prescribed. *"Koi matlab nahi hai phir bhi'* (Quoted by a caregiver). This unnecessarily pushes the family deeper into debt and poverty. In this sense, doctors should be aware of the latest developments in medical science and not purposefully prescribe wrong medicines or experiment on patients. Since the patients are very poor, they are utterly dependent on government hospitals, as doctors' fees at private clinics are often out of reach. Even at government hospitals, expensive investigative tests such as CT Scan and X-ray are required. In view of the extremely limited financial resources of patients, it is important that they are given adequate information about the disease, treatment of opportunistic illnesses and non-availability of full cure, so that they use their money wisely. It was stressed that the cost of drugs and tests should be subsidised for those unable to afford them. The compulsory provision of ARV drugs and CD4 tests in all Government hospitals (including in rural areas), as well as the operation of VCTC centres at the taluka and district levels would improve access to treatment immensely.

Greater support for caregivers has also been voiced as pivotal, so that their health does not suffer because of caring for the family member suffering from the illness. Efforts are necessary to ensure that the atmosphere in the hospitals is patient-friendly, for instance by rendering systems and procedures more patient-sensitive and responsive. HIV/AIDS patients should not be isolated in the ward or kept on the veranda, on the floor or near the toilet, as is sometimes the case. Moreover, hospitals should not mark patients' beds or write the HIV-positive status on the adjacent wall- the right to privacy must be respected. A trained counsellor must always be available, to enable the patient to voice his or her concerns. Healthcare providers must have greater information on post-exposure prophylaxis, so that they are fully aware of the need to take this if they are exposed to HIV infected blood. Post Exposure Prophylaxis (PEP) should also be made available in rural areas.

v. Financial Care

In the context of financial needs of HIV positive individuals, the Network of Positive People reports that all too frequently employers fire their employees if they discover that they are HIV positive. This is especially problematic, because when HIV/AIDS enters the home, financial responsibilities and burdens also increase. Widows, who have never worked outside their homes throughout their lives, have to enter the work force for the first time and are in a disadvantaged position. It is therefore important to implement programmes and policies to strengthen their economic condition, for instance by providing information and training regarding income generation.

Greater legal awareness and literacy should be in place to protect the HIV positive person if the job is terminated because of the person's HIV serostatus, as also stronger legislation protecting the rights of those affected at the workplace.

vi. Nutritional Care

Nutritional care is extremely important for an HIV positive person. A person may be HIV positive, but if appropriate nutritional and other care is provided, he or she will remain productive and survive for many years. Households that are below the poverty line cannot afford good nutrition and yet often try to provide the very best food possible. For instance, scarce funds may be spent on Kashmiri apples on the assumption that since they are expensive, they must be more nutritious. Thus, more information on health and nutrition is required, so that families with HIV-positive members know which options (such as bananas) are both cost-effective and nutritious. Informational booklets with information on nutrition could be distributed and nutritional counselling provided through partners, such as India Network for People with HIV (INP+) and PWN+.

vii. Information and Awareness

Many interviews voiced the need for greater knowledge, education and information, regarding the HIV/AIDS epidemic and health in general. Amongst those affected by the virus, stronger awareness regarding existing networks is crucial. Involvement of positive persons in organizations such as MDACS or MSACS must be encouraged at all levels, so that their concerns can influence policy. Information should be made more accessible to HIV positive persons regarding VCTC and PPTCT, treatment and advanced medication (ARV/HAART) available in the local clinics/PHC/Government hospitals/private hospitals. There should be increased awareness about HIV and sex education in schools and colleges. Information about HIV/AIDS should be printed on calendars and diaries for greater accessibility, and effective advertisements to prevent HIV/AIDS, can be developed.

4.3 Focus Group Discussion with Commercial Sex Workers in Mumbai

A focus group discussion with about 30 commercial sex workers (CSWs), who are part of the CCDT Roshni Project in Mumbai, made it clear that CSWs are among the worst affected. Once they are known to be HIV-positive, they get thrown out of the brothel. With death staring them in the face, and many of their 'sakhis' getting admitted to crisis centers and hospices at the terminal stage, there is no hope for the future. The biggest problem faced by the CSWs is that they have no place to live, rest, bathe, use the toilet and wash clothes. During the day, they may be at the Roshni project premises, but the office closes in the evening and then they are on the road. However, the police do not allow them to stay on the road and take them into custody, where they have to either pay Rs. 1,250 or stay confined for 15 to 20 days. If they sit outside a shop they get driven away. Finding a place to sit until the shops close is problematic.

The most frequent opportunistic infections suffered by CSWs are tuberculosis and diarrhoea. Fever is also frequent. They worry for their own future and that of their children, which causes tension that worsens the problem. If work is available and they are able to get customers, they work. If the work pays decently, they may eat, but on other days, they go to sleep hungry. On an average, they are admitted to the crisis centre once or twice in two or three years. When they reach the terminal stages, they are admitted to a hospice, where there is no charge for either stay or cremation. A major source of worry is the future of their children. Long term rehabilitation options that can enable a safe future for their children are vital sources of support.

4.4 Issues raised by the Medical Care Community

Issues raised by health care providers[55] regarding the stigma and desertion suffered by positive persons, the frequency of opportunistic infections and medical care needed and the minimum cost of medicines if appropriately prescribed are presented below.

i. Stigma and lack of Support

A serious problem confronting care providers is that stigma results in PLWHAs being thrown out of homes or taken to a hospital or community care centre and deserted by their families. Sometimes relatives do not come to take them back and even the last rites are performed by institutions and not by the family. Women are especially vulnerable, as are children. Since the patient is psychologically upset, it is difficult to discuss issues of financial support or employment.

Most children are cared for by the extended family, but where the grandparents are involved in caring for the children, they worry about what will happen to them when they die. Some children are infected, others affected and many end up in orphanages. Several NGOs extend help, but their staff works only during office hours, i.e., 9 am to 4 pm.

ii. The Importance of Nutrition and Hygiene

The major burden on the family occurs when the positive person falls ill. If the HIV positive person is provided nutritive food and clean water and care, he or she is more likely to stay healthy. However, most patients are ill-fed when they come to hospital. They spend their limited resources on eating items like pav-wada, which are less nutritive instead of buying foods rich in proteins and nutrients. Most do not take enough water or milk. If they have trouble in swallowing, they are prescribed more

---

[55] *Health care providers in this study include doctors, counsellors, nurses and administrators of care shelters and community care facilities*

liquid food such as dal. If they are alcoholics, they cannot be given ART, as the liver is already damaged.

Doctors stressed that HIV implies immune-deficiency. Therefore, the person cannot tolerate diarrhoea-causing pathogens. Food, hygiene and clean water are very crucial. They are told to boil water and not keep pets, because they may spread infection.

The experience of a trained nurse who was interviewed for this study was that in slum areas, tuberculosis is the most frequent disease, followed by diarrhoea and other stomach related problems. This is because in slum areas water is either not available or unsafe. Slum inhabitants may also not know about the importance of boiling water and keeping common bathroom facilities clean. If water is boiled and the PLWHA eats nutritive food, the person is able to lead a normal and productive life. It is therefore important that linkages be established with organizations that have nutrition related information. Guidelines for the management of opportunistic infections must be disseminated and strictly followed. Diarrhoea can be treated at a cost of only Rs.50 with oral rehydration.

iii. Opportunistic Infections and Treatment

The most common opportunistic infections[56] faced by HIV positive persons are:

1. TB and TBM - over 50%
2. HIV related diarrhoea – 30%
3. Candidiasis – oral and oesophagel – over 20%
4. Herpes zoster and simplex – less than 10%
5. PCP - less than 10%
6. Bacterial infection – around 5%
7. Toxoplasma - around 5%
8. Cryptococcal - less than 5%
9. Fungal Meningitis, Kaposis, Sarcoma etc, which need confirmation based on specific tests.

[56] *This is based on discussions with doctors*

iv. Medical Costs

All too frequently, even very poor patients spend substantially higher amounts on a large number of tests and on medicines that are not needed. The cost of a CBC and x-ray amounts to Rs.500. In government hospitals, the services are provided free. Since around 5.134 million people have HIV, so if we assume that 10% of them need ART, the treatment needs to be provided to 5 lakh people. However, not even 5% of those needing ART currently have access to the treatment. In the early 1990s, the treatment cost Rs 20,000 per month and was outside the reach of most people. Now, the triple drug combination based on generic drugs costs between Rs 850 to Rs 1,100, depending on the combination of drugs used. 80 to 90% of patients do well on ART, provided it is taken regularly and there are no acute reactions.

An HIV-positive nurse interviewed for this study, who looks after a home-based care project and provides support to a large number of patients, reported that in her experience, PLWHA generally have already spent Rs. 50,000 or 80,000 before they come to the NGO for help. The private clinics charge Rs. 40,000 for one admission. ARV treatment is often started without even explaining the importance of adherence and discussing the issue of affordability. Most people are admitted only for a few days for treatment of opportunistic infections and then sent home for care. Once HIV/AIDS sets in, more than Rs. 2,000 per month needs to be spent on food and medicines. If infection occurs, the expenditure increases further.

v. Taking the Necessary Precautions in Families

Precautions for other family members are not taken, because HIV status is often discovered several years later. For instance, only if the woman is hospitalised at the time of delivery "or" child birth her status is known. Delivery then becomes more expensive, as private doctors charge Rs. 40,000 or 50,000 and government hospitals do not welcome pregnant HIV positive women. Therefore, many deliver the baby at home. However, caregivers urgently require more training and skills regarding:[57]

- How to actually provide care and deliver babies more safely.
- How to handle anxiety and tantrums.
- The importance of a medication regimen, correct dosage and regular check-ups.
- Using ORS and other methods of treating simple infections.
- Teaching pregnant and lactating women to eat regularly - if the WLHA can digest it, then a wholesome breakfast with egg, seasonal fruit; lunch and dinner with chapati, rice, grain, sprouted dals and leafy vegetables is recommended.

---

[57] *The Administrator of Sarvodaya Community Care Centre and the Counsellors at Talera Hospital are gratefully acknowledged for many of these suggestions*

- The necessity of clean drinking water and adequate nutrition even in case of diarrhoea.
- Making soups by mashing vegetables, porridge, sprouting and mixing dals, roasting and making a powder and then cooking a few spoonfuls in water, using ragi and nachni.
- In case of bedridden patients, how to dispose of stools, use of bleaching powder or sodium hypochlorite, use of plastic sheets and home made diapers.
- Avoiding direct contact with blood.
- Cleanliness, hygiene and bathing.
- 'Good Bye Counselling' and accepting death.
- Skill development and employment opportunities for young widows to enable them to live in dignity and not fall prey to commercial sex work for survival.
- Budgeting and negotiating skills.
- Counselling women who feel victimized and exploited by their husbands.
- Access to condoms and microbicides for women who often do not even have money to buy food.

4.5 Responses to Questionnaires: Interviews in Delhi, Mumbai, Pune, Vijaywada and Chennai

The following section profiles the positive persons and caregivers who were administered a detailed questionnaire in each of the 5 cities, and then analyses their responses. Thirty-eight questionnaires were administered; 76% of the respondents were female and 24% male. The information gathered through the survey has been compiled to explain various situations in each of these cities.

Delhi

Six women and four men were surveyed in two care homes in Delhi. Four of the women and all four men are HIV positive. The women have learning skills that enable them to get work, as either they had lost their husbands to AIDS or the husbands were too ill to earn money. A common phenomena across those interviewed was that the women contracted HIV through their husbands. The men are between the ages of 25 and 40 years. The women are between 26 and 32 years of age. Four children from two families are also positive and their ages vary from 2 years to 13 years. The education of caregivers is given in Table 4.1 below.

Table 4.1: Education of Caregivers (Delhi)					
Sex of the Care giver	No education	Primary School	Middle School	High School	**Total**
Females	3	1	1	1	6
Total	3	1	1	1	6

One of the women reported having serious problems after detection of HIV/AIDS of her husband, requiring the family to migrate to Delhi for treatment. She left two out of her four children, one son and one daughter, in the village to be looked after by her relatives. Another woman said that after her husband died of HIV/AIDS, she found it extremely difficult to make both ends meet, because her in-laws extended no support and her brother-in-law took away the income she earned from her husband's shop. She has no education and is in dire need of a job. A further respondent reported migrating from Azamgarh to Delhi to seek treatment for an infection at a Delhi hospital, which was later diagnosed as HIV. Her husband works as a guard at the care home, while she works at the stitching centre in the care home to cope with household expenditures. Yet another caregiver's husband was admitted to hospital for a routine surgery, where he discovered he was HIV positive and subsequently stigmatised. His wife is now his sole caregiver.

One of the HIV-positive men interviewed at another care home, previously worked as a cook in Mumbai. He migrated to Delhi in search of anonymity and a new job after his employer fired him due to his health status. However, he has been struggling in Delhi, while receiving no support from his family. Health permitting, he now takes any casual work that is available and stays at the care home when he falls too ill to cope. The second male respondent was a young boy who did embroidery work in Mumbai and fell into what he called 'bad company'. Since his illness persisted, he returned to his village. His brother brought him to Delhi for treatment. Out of those interviewed, he is the only one with an extended supportive family that is financially well placed.

The third male has been living in the care home since detection of HIV in his hometown, Jaipur. He did not want to live with his family. He provides basic services to the care home, and is looked after by caregivers there. The fourth male is a professional caregiver and himself HIV-positive, but lives alone near the care home. The care home pays for all his expenses.

Most of the respondents suffer from opportunistic infections like tuberculosis, and diarrhoea. Fortunately, malaria, meningitis and pneumonia accounted for only 3 to 4% of the total responses in Delhi. The care and treatment for these infections is sought mainly from hospitals, care homes and at home.

Some respondents have sold assets to meet the expenditures for treatment. Money is frequently borrowed, especially from the wife's parents. Some of the caregivers have no significant source of income. Since they belong to relatively better off families they are not usually expected to work. However, with their husbands increasingly unwell and with no inflow of income, they are willing to even clean and swab floors to survive.

Those who had migrated to Delhi for treatment, described the serious implications of medical costs on the family's budget. The expenditures incurred by the families can be categorised into hospital treatment, care home and home-based. The mean expenditure rises once illness recurs more than once a month, varying between Rs 300 to Rs 10,000 for mere hospitalisation and doctors' fees. The cost of drugs, however, increases abruptly to up to Rs 35,000 for some households over a period of four months. Almost all of the families depend on government hospitals for treatment and access to ARV drugs. When illness episodes are extended or severe, the HIV positive persons surveyed through care homes said they came there for treatment for a few days, as private doctors were too expensive. The care homes arranged to take them to the hospital for tests if needed. Payment to the care home depended on whether or not the person had the means to pay. Care of children of HIV positive women, was mostly home-based.

All the respondents interviewed in Delhi said they have toilets within their homes and access to water supply through individual taps. However, the care homes sometimes face tremendous water crisis. The use of antiseptics is common, but gloves are not used at home, though they are used in care homes. In all the households in Delhi, a common precaution taken by the positive women is to refrain from having more children. The HIV positive men decided they would not marry.

Mumbai

Five women were interviewed in Mumbai. Four out of the five are HIV positive and three of them widows. Their ages vary from 27 to 40 years.

One of the women, a widow, has two daughters and had lived at the care home when she was very unwell. She works as a domestic help to support the education of her children. Another has lost her daughter, but still has a 9-year-old son and works as helper in an NGO. She tested positive six years ago. All her income, Rs 1800 per month, is spent on medicines, food and her son's requirements. The third is a graduate and representative of an NGO network, belongs to a middle class family and has no children of her own. She is the most empowered of those interviewed in Maharashtra. The fourth is working from home, earning Rs 700 per month. Since her in-laws mistreated her, she lives with her mother. The fifth respondent is not positive, but is the most deprived of all. She sweeps and swabs floors, struggling to survive without any education, while also supporting her six children. None of the women had any work experience prior to their husbands falling ill and all are struggling to survive. The education levels of the women are given in Table 4.2 below.

Table 4.2: Education of Caregivers (Mumbai)				
Sex of the care giver	No education	Middle School	Others	**Total**
Female	2	2	1	5
Total	2	2	1	5

In Mumbai, twenty per cent of the respondents reported suffering from tuberculosis, followed by fever. Just over half said that the positive member of the family also often had diarrhoea. Other infections include skin problems, such as herpes and sores, which were reported by 60 and 20% of the respondents respectively. Treatment is sought from hospitals and care provided at home.

Pune

Questionnaires were administered to seven women, all of whom are caregivers to people with HIV/AIDS. Six out of the seven are HIV-positive themselves and between 30 to 34 years of age. Three of the women are young widows. One lives with her mother, another works with NMP+ as a counsellor and a third survives by washing clothes, to provide treatment for her HIV positive daughter. Yet another was deserted by her HIV positive husband, after she also tested positive. She had been his caregiver when he was unwell, but when she fell ill herself, she was sent to her natal home. Shocked by the callousness of her in-laws, she suffered severe weight loss and her parents are attempting to help her out of depression.

The Pune based respondents reported short periods of hospitalisation, which cost up to Rs. 14,500. Education of caregivers is in Table 4.3.

Table 4.3: Education of Caregivers (Pune)				
Sex of the caregiver	Middle school	10th standard	12th plus nursing diploma	**Total**
Female	1	5	1	7
Total	1	5	1	7

Vijawada

Ten households were surveyed in Vijayawada. The age of the positive persons in these households varied between 29 and 65 years. Education of caregivers is in Table 4.4.

Table 4.4: Education of Caregivers (Vijayawada)

Sex of the care giver	No education	Middle school	Graduate	**Total**
Males		1		1
Females	3	5	1	9
Total	3	6	1	10

In one joint family surveyed, the HIV positive household member was being taken care of as the wife, an economics graduate, was working as a peer counsellor in the Railway Womens Empowerment and AIDS Prevention Society (REAPS). Four respondents are caregivers and homemakers. In one of the families, the wife provides care, while simultaneously working as a senior attendant at the railway hospital. The caregivers in all the families in Vijaywada are mostly females and are wives of HIV positive husbands. Of them 40% are HIV positive. In one case, the caregiver was the grandson, who lived alone with his HIV positive grandfather. 40% of the households surveyed, do not have toilet facilities within the house, while 20% of respondents have no water supply within the home and access water from a common tap or well. Bringing water from such sources sometimes takes up to 2 hours in a day.

40% of the respondents had suffered from tuberculosis and 50% from diarrhoea and fever. Other opportunistic infections include skin ailments, reported by 30% of the households, fits, E.N.T. problems and swelling, each of which was reported by 10% of the households.

All the respondents reported using the Railway Hospital for testing and further treatment. About 20% of the respondents also receive treatment from care homes, though some families resort to private hospitals. The Railway Hospital provides all services free of cost. In cases where the positive person is a railways employee, the government also covers transport costs. The cost incurred in most of the households relates to home-based treatment and varies between Rs 500 to Rs 3,600. During severe illness episodes stretching over two to three months, medical expenditures rise to Rs 30,000. The cost of medicines, other than ARV available from the hospital, varies from Rs 1,500 to Rs 32,400

in over half of the families interviewed. The charges at the hospital and cost of tests from private hospitals can rise as high as Rs. 30,000, but only 10% of the total households are affected. In Vijawada, noteworthy is the low cost of drugs and doctor's fee, because these are available from the Railway Hospital.

Chennai

Five of the six respondents in Chennai are women and their ages vary between 26 to 31 years. All the respondents are HIV positive. The sole male respondent is 36 years old. Two of the respondents are living separately and alone, while one lives in a joint family. Most of them receive treatment from the Stanley hospital in Chennai, except for one respondent, who relies on a care home that costs him over Rs 55,000 per month. Opportunistic infections are mostly confined to tuberculosis, pneumonia, diarrhoea and fever. Some other infections include herpes and sores, which account for almost 50% of the households surveyed. Treatment of opportunistic illnesses is received from government hospital and the E.S.I. hospital. In four out of six families, food consumption has been reduced to cope with rising expenditures due to the disease.

4.6 Coping Mechanisms

Home versus Institutional Care

The condition of the HIV positive women in all the households surveyed was stable, enabling them to look after themselves without any caregiver. Most also care for their spouse, and said they had to help him to the toilet and also to bathe and this took about one hour. All the households cook a common meal and therefore no extra time is spent on cooking any special meals. About one and a half hours of time are required just to travel to the hospital for getting medicine.

Care homes are equipped with professionally trained caregivers, who are available the whole day. For HIV positive women, caring for all other members and pursuing household chores often poses a tremendous burden, especially because extended family members do not cooperate, even stigmatising and discriminating against them.

Financial Coping Mechanisms

All the respondents experienced financial struggle to cover the increased medical and other costs. The overall expenditure seems to increase the most for families in Delhi, especially for food, rent and education, simply because many migrate to the city from rural areas, where living costs are lower. Generally, families that receive free drugs from the hospital after detection of status are able to

reduce their expenditure on medicines. In Vijawada, overall expenditures seem to rise the most after the detection of the disease, (by over 50%), primarily due to recurring transport charges for visits to the hospital. On the other hand, in Mumbai, budget patterns do not show extreme fluctuations before and after the detection of HIV/AIDS, except for a rise in the expenditure on medicines. The rise in expenses for medicine in Mumbai can be partly attributed to the long waiting lists for ART and many resorting to the purchase of drugs on the open market instead.

The most commonly cited coping mechanism with regard to financial difficulties, is for the caregiver to work longer hours, perhaps even taking up a second job, if possible. Examples include running a small shop or working in a stitching centre at a care home. In 30% of the households in Vijayawada, extra work is undertaken by the caregiver by becoming a member of the Positive Women's Network or REAPS, while in a further 20% of the households, extra work is undertaken by other members of the family. Similar patterns are observed in Mumbai. Some positive persons receive help from Government and non-government organisations to support household and treatment expenditures.

Nonetheless, working longer hours does not seem to be enough, pushing the HIV positive and/ or their families to resort to the sale of valuables, if any. Jewellery was sold by 80% of those surveyed, since it is often the only asset owned by the poor. Furthermore, 10% reported leasing out their lands and selling household equipment.

Not surprisingly, debt is far from uncommon - for example, 80% of the respondents from Delhi have borrowed money and the situation is similar in Vijawada, where 60% are in debt. Approximately one fifth of those surveyed have discontinued medication, due to lack of financial means, for over 6 months. Most drastically, in Vijawada, food consumption has been reduced by 10% of families surveyed. None of the households, however, have resorted to withdrawing children from school to meet household expenditures, except in one case in Chennai.

4.7 Policy Recommendations by Respondents

For most of the individuals interviewed, emotional, physical, medical, financial, nutritional and spiritual support were considered to be of high priority, with many feeling that except for medical and physical aid, other dimensions of care ought to be provided by the family. Nevertheless, most had substantial complaints regarding the medical and physical treatment and care currently available and identified several areas in need of significant improvement.

Respondents in the four cities felt that all medical facilities, including Anti Retro Viral drugs, should be made available at all hospitals, to avoid having to migrate from the rural areas in times of severe illness. Regarding the more basic services offered in hospitals, one-fifth of respondents in Vijayawada

voiced the need for improvements in levels of cleanliness, availability of beds, sanitation and toilets and the provision of mosquito nets. Denial of treatment based on a patient's HIV status was also reported as an issue, with many reporting that NGOs had to complain to higher officials or hospital authorities to facilitate admission. Stigma and discrimination within hospitals were major issues and respondents also wished for greater involvement by NGOs in helping to cope with such situations. Additionally, counselling facilities were considered important and could be provided at hospitals.

Respondents also noted a severe deficit in the availability of information and guidance regarding the prevention and treatment of HIV/AIDS at all levels, especially in Vijawada. Television, print media and door-to-door visits are considered the best medium to disseminate information, as also educational leaflets or awareness campaigns at pharmacies, hospitals and local NGOs.

Concerning financial matters, especially the female respondents expressed the need for vocational and educational training opportunities to improve their employability. In Mumbai, in particular, respondents also felt that specific income generating programmes for HIV positive people were essential. An interesting suggestion made at Vijayawada, was that HIV positive women could be relied upon as resource persons for developing information networks and disseminating awareness. This would provide them jobs, while also benefiting the population in the fight against HIV/AIDS.

Other policy suggestions included subsidising basic food items, special educational funds for children, greater nutritional support and micro-loans to start home businesses.

4.8 Case Studies

On a Footpath of Despair

Parvati and her family live in abject poverty. Her home is a 6-foot by 6-foot space, on a footpath in Kurla, Mumbai. A plastic sheet with holes in it is a makeshift roof. A few planks thrown on the pavement serve as flooring. The family's prized possessions are a few plastic buckets and broken cans of water, a few clothes, a stove and some utensils.

Both Parvati and her husband are migrants from Bihar. Parvati's parents married her off at the age of 12. A few years later, she came to Mumbai and stayed in Kurla with her husband's sister, while her husband worked as a plumber earning Rs 3,000 per month (US$67). As long as her husband was working she did not need to work and they ate well. About four years ago, however, her husband fell ill, testing positive for HIV. The little money they had was spent on doctors and medicines. Once her husband's HIV status became known, they were soon thrown out of her sister-in-law's home, and forced to live on the footpath with their 6 children, all under the age of 12.

With her husband unwell and unable to work, six children to feed and no income, they contemplated suicide. Committed Communities Development Trust (CCDT), a local organisation heard of their plight and was able to provide some help with basic rations, advice about nutrition and medication, and support for education of the children. Parvati was able to start working as a part time cleaner, cleaning floors and washing utensils and clothes, in three houses to earn about Rs 1,500.

Besides working from 9 am to 4 pm everyday to bring in her meagre income, Parvati also has to look after her children and her ailing husband, who suffers from coughs, vomiting, diarrhoea and severe fatigue. There are days when her husband cannot get up, even to take medicine on his own. On these days, she has to take leave from work to care for him. Although he is on anti-retroviral (ARV) treatment, this does not stop the fever, vomiting and diarrhea. To get water, Parvati and her children have to go to the chaul tap that is a 15-minute walk from their makeshift shelter. They must make 10 trips each day to get the water they need. In addition, her husband needs to be helped to the toilet, which is about half a kilometer away.

Parvati and her husband went to the hospital for medication several times each month when he was first diagnosed. Each visit was expensive, even though they went to the public Baba Hospital in Kurla instead of a private hospital. Money was needed for X-rays and CD-4 tests, so Parvati had to borrow money from the people whose houses she cleaned. She sold her jewellery for Rs.10,000 four years ago, when her husband first fell ill. The doctor prescribed medicines for six months, at Rs 800 per month. But they could not afford to pay for medication beyond four months, so it was discontinued. No other help was available in Mumbai.

In recent times, Parvati's health has begun to suffer. Her young children look after her when she is sick. She has had to cut back her cleaning work to just two houses now, earning only Rs 1,200 per month. With no other family or government support available (except for ARV medication from the public hospital), Parvati's sole hope of survival for herself and her family is the CCDT.

Family Support Shines a Light at the End of the Tunnel

In 1994, when she was just 17 and not yet done with her studies, Fatima's family got her married. Despite being fairly assertive in her conservative family and expressing her desire to complete her studies and graduate instead of getting married, family pressure proved too much.

A few years later, her husband began to look ill, and her family asked him to get tested for tuberculosis. He felt insulted and refused to seek any medical attention. Two years after this, her father-in-law had to be operated for cancer and was in need of blood. As the only son, her husband was asked to give blood but he refused. Under pressure from her family members he eventually agreed, whereupon he learnt that he was HIV-positive. He chose not to inform anyone, including

Fatima and both their families, and took no steps, such as using condoms, to protect his wife from infection. Instead, he tried to self-medicate, buying "medicine" from a quack in Kerala.

In 1998, Fatima's husband was tested again, and this time, the doctor told her brother-in-law that her husband had AIDS and that both she and her husband would die within 2 months, and indeed he died 2 months later. Her father took her to get tested. She was tested twice within three weeks, the test positive both times. Incredibly, all this time, Fatima still had not been told that her husband had AIDS and had just died from it. She also had no clue that she was HIV positive. Her husband had chosen not to disclose his status to anyone for fear that Fatima's parents would take her away. Instead, he allowed his family to blame her for his illness. After his death, her mother-in-law, deciding that Fatima too would soon die, said that no share of the property would be given to her.

Fortunately, Fatima's father welcomed her back to his house. One day, she found her test report in her father's bag, and that was how she finally discovered that she was HIV positive. Her initial reaction was outrage at her husband for knowingly exposing and infecting her with the virus, followed by a deep sense of despair about her future.

But Fatima's brother's wife had a friend at the Bombay Municipal Corporation (BMC), and she felt that since science had progressed so much, there had to be hope. So she persuaded Fatima to go to the BMC where she was counselled and told that with treatment she would be able to live out her life, instead of dying in a few months. She met many other HIV positive people, one of whom was setting up a support group and asked if she would work with them. She was hesitant at first but realized that the only difference between her and the person forming the support group was their gender. "If he can live, why not me? I have to die some day. But let me try and do something constructive with my life." Earlier, the doctor had given her just a few months to live but now, with treatment it could be a few years she thought to herself.

So she asked her father if she could work with the support group. Girls typically didn't work in her home, but in view of her circumstances, her father felt that if she worked, it might help her. Less than a year after she was diagnosed, and only 2 months since knowing she was HIV positive, Fatima joined the positive network. She was the only girl, and she was only 20 years old. Slowly, the network helped her to take charge of her life, by arming her with the information, counseling and peer support she needed to deal with her situation.

At home, her condition prompted some challenges, but her family has remained supportive throughout. At first, she was not allowed to work in the kitchen because her family was afraid she might cut her hand while working with a knife. But her father's elder brother or "tayaji" said she had to be allowed to do some work – at least knead flour or something else useful in the kitchen. Now, Fatima cooks at home and everyone in her family eats what she cooks. She also looks after

her niece – no one in her family has ever said that the child should not go near her for fear of infection. The only discrimination she has suffered is from her husband's relatives. Children who had grown up with her were kept away from her after her status was known.

Today, Fatima is a confident and healthy 27 year-old woman who is a senior representative of the Positive Women's Network in Maharashtra, a grantee of UNIFEM's Trust Fund to End Violence against Women. She was encouraged to resume her studies, and is now in her final year of college and learning to work with computers. The only opportunistic infection she has had is herpes. She takes good care of her nutrition, has a very positive outlook towards life and rarely falls ill. She saw the worst side of life while caring for her husband after his diagnosis. He suffered through several opportunistic infections – tuberculosis, diarrhoea, fever, weight loss and even memory loss. He had no access to anti-retroviral treatment. While he was bed-ridden she would care for him day and night, bathing, shaving and dressing him, and all without knowing why he was even ill in the first place. But her story has turned out well; she is one of the fortunate few. Because of her family's support, she is pursuing her education, and working through the positive network to improve the HIV/AIDS information and care services of government hospitals in her area. She can negotiate and demand facilities at government hospitals, and many of the suggestions given in the context of care needs draw on her suggestions.

Chapter 5

Conclusions And Policy Recommendations

5.1 The gravity of the problem

In India, the state of healthcare provision in general and in the context of HIV/AIDS in particular is disquieting. The National Health Policy document (2002) provides scathing criticism of the public health infrastructure on grounds of insufficient funds, inadequate medical and paramedical personnel, and inconsistent availability of consumables, obsolete and unusable equipment, dilapidated buildings, over-crowding and low quality of service. This study confirms the general case for more resources for the health sector and improvements in performance.

The spread of HIV/AIDS in India is facilitated by the fact that most Indians do not take the virus test until plagued by recurring opportunistic infections. The number of Indians suffering from HIV/AIDS is therefore likely to be far higher than currently estimated. Crucially, the virus is no longer limited to the so-called 'high-risk population' comprising truck drivers, commercial sex workers, drug users and men having sex with men, but has spread into the general population. While Mumbai was once considered the 'AIDS capital of India'[58], today there are multiple epicentres. Since experiences from countries such as South Africa indicate that once a threshold percentage of AIDS cases among the HIV positive is crossed, the disease mushrooms to cover 25% of the population, "action against HIV/AIDS needs to be taken at war footing"[59].

Critically, in some African countries such as Kenya, there are provinces where the prevalence of HIV/AIDS has reached levels of 50%. In other words, every second person is infected with the virus. Once the infection reaches such massive proportions, there is no longer any room for stigma. However, health systems get paralysed by the sheer number of people that need care, thereby exacerbating the state of emergency. India consequently needs to act quickly on this issue that has the potential to wipe out the development gains made. Accurate information regarding the infection,

[58] *Bharat and Aggleton 2004: 108*
[59] *Chandra 2005*

prevention, treatment and care of HIV/AIDS must be made available as universally and effectively as has been in the case of polio.

Meanwhile, the grassroots reality remains that most PLWHA and their families do their best to enable survival. Many sell their meagre assets and fall into debt to meet the substantial costs inflicted by the disease. Private clinics may charge between Rs. 25,000 and Rs. 40,000 for each admission, with PLWHA and their families often spending as much as Rs 80,000 before they eventually reach an NGO or hospital for help. Indeed, one of the major impacts of HIV/AIDS on almost all the affected and infected women interviewed was financial destitution and debt, due to the loss of employment opportunities for the spouse combined with soaring medical expenditures.

What is the learning from some of the research, that can help reduce the difficulties suffered by those who are poor and are infected and affected by HIV? To mitigate distress and relieve the workload on caregivers the following need attention:

5.2 The Urgent Need for Improved Medical Care and Information

Currently, in all hospitals of India, the demand for services far exceeds supply. Given that 80% of the qualified 40 000 allopathic doctors work in the private sector,[60] it is critical that they be included in strategies for care and obtain greater access to information on the latest medication, HIV/AIDS monitoring and testing, with the aim of reducing incorrect diagnosis and prescriptions. Therefore, to reduce the possibility of ill-treatment of HIV/AIDS patients, while facilitating the work of doctors and caregivers, it is vital to:

- Urgently allocate more funds to pre- and post-test counselling, information on nutrition and medical care, antiretroviral drugs and service quality in hospitals, including hygiene and sanitation.
- Make doctors aware of the latest developments in medicine to minimise the scope for prescribing wrong medicines. Identify and meet the training and infrastructure needs of health care providers at all levels.
- Provide accurate information on HIV/AIDS prevention, opportunistic illnesses and other symptoms, testing facilities, treatment, care and costs to boost longevity and productivity at all levels and reduce exploitation and unnecessary expenditures.
- Widely publicise information regarding the relevant medication and the effects of incorrect medicinal intake; render testing facilities available in the public and private sectors.

[60] *ibid.*

- Ensure that doctors, functional testing equipment and ambulances are available in all PHC and peripheral hospitals, 24 hours a day.
- Include the latest antibiotics in the medicinal stocks of government hospitals. Newer medication may be more expensive, but it should be made available for the most severe cases.
- Improve the coverage of ARV by making it available throughout the country to improve the quality of life of the PLWHA.
- Monitor more closely the HIV/AIDS patient's adherence to drugs, while also discussing the affordability of ART treatment and adequate examination.
- Monitor changing CD-4 counts after ART is commenced.
- Ensure the presence of representatives of the Positive Peoples Networks at hospitals when patients start ARV, so that they may familiarise the patient with key health precautions, such as the importance of taking medicines regularly and drinking boiled or purified water.
- Maintain official standards with respect to ARV drugs.

5.3 Attitude of Health Care Providers

With regard to healthcare providers, it is imperative to:

- promote behavioural and attitudinal sensitivity at all levels and introduce sensitisation workshops.
- publicise openly the availability of beds in hospitals, so that lack of vacancy is not used as an excuse to deny services to HIV positive patients.
- ensure that hospitals do not discriminate and stigmatise HIV positive patients.

5.4 Increased Budgetary Resources for Care Homes, Hospices, Peripheral Hospitals, Water and Sanitation

In the context of chronic ill health, there is a need for adequate budgetary allocations for community care homes and crisis centres for those who do not have access to family support. This may also help to reduce the burden of care on home based caregivers in times of difficulty and opportunistic illnesses. Hospices are needed for terminally ill patients. Provisions must be made for cremating persons who are abandoned and die at community care centres or hospices.

Adequate beds, doctors, functional testing equipment and an ambulance must be available in all PHC and peripheral hospitals if they are to respond to patient needs. There must be enough doctors

and an ambulance at all times so that patients can be rushed to the larger hospitals in case of need. Equipment such as x-ray, sonography, ECG and CD-4 machines must be functional, maintained and available round the clock. In government hospitals the schedules need to be changed to include the latest antibiotics that can be used, depending on the discretion of the doctor, if bacteria do not respond to treatment.

Lack of access to water and sanitation increases the suffering of those who are HIV positive as many of them frequently suffer from diarrhoea and other opportunistic illnesses. In large cities lack of access to water and toilets creates considerable distress especially for those who live in slums or on pavements.

5.5 Access to Knowledge, Skills and Work to Reduce the Burden of Home-based Care

To reduce the physical, emotional and financial burden on those providing care at home, counselling and skills must be made more readily available.[61] Especially important is more knowledge regarding the general provision of care, providing moral support when faced with stigma and discrimination and sustaining the HIV positive patient in times of low self-esteem, anxiety and tantrum. Caregivers at home must also be informed about the importance of regular medication regimens and correct drug dosage, as also regular check ups by qualified physicians. Further, more awareness is needed on the use of ORS and related methods for treating infections and the crucial role of nutrition, hygiene and safe cooking techniques. Such information can go a long way towards preventing the immune system from becoming suppressed. Related techniques that caregivers need to be familiarised with include boiling water for purification, ensuring adequate nutrition even in case of diarrhoea and preparing inexpensive, high protein meals. Simple steps such as providing frequent, yet small meals and making soups and diluted dals with nutritious and inexpensive grains such as ragi and nachni also aid the patient's digestion.

With regard to bedridden patients, caregivers would benefit from learning techniques on cleanliness, including the use of bleaching powder or sodium hypochlorite, plastic sheets and homemade diapers. The risk of transmission between patient and caregiver can be reduced through the use of gloves and plastic bags. At more advanced stages of illness, caregivers should also be provided with 'Good Bye Counselling' and support in accepting death.

---

[61] *Doctors formerly and presently at MDACS, the Administrator of Sarvodaya Community Care Centre and the Doctors and Counsellors at Talera Hospital are gratefully acknowledged for many of these suggestions.*

Furthermore, the need for skills, training and employment is critical, especially when a family or individual is saddled with the financial burden induced by HIV/AIDS. There is an urgent need to provide social safety nets and link the poor with employment generating projects, networks and support groups. Additionally, skill development and employment opportunities for young widows are vital to enable them to live in dignity and not fall prey to commercial sex work. To break the cycle of poverty, gender inequality and vulnerability to HIV transmission, it is imperative to provide women with work-related skills. Affected family members must also be provided information regarding how to handle money and not spend it all on tests and medicines.

5.6 Access to Treatment, Networks and Responding to HIV/AIDS

Women carers who are HIV positive have a right to equal treatment and resources. Networks are of immense support, since they provide counselling for women who have been victimized and exploited by HIV infection through their husband. For women in particular, counselling and improved access to male and female condoms and microbicides is needed to reduce their risk of exposure. Frequently, the most marginalised households do not even have the necessary money to buy food - it is precisely for these women that such facilities must be made more available, since their situation is the most grave. In case of HIV/AIDS infection, counselling and hotlines can be pivotal in encouraging those affected to live well in spite of their HIV/AIDS status. Simple measures such as good nutrition, adequate exercise, progressive relaxation techniques and moral support can prolong the HIV stage, postponing the onset of AIDS.

Crucially, if the spread of the epidemic is to be contained, the issue of spouse notification needs to be addressed, to reduce chances of inter-partner transmission. This is a salient gender issue, since a large proportion of women who test positive have only one partner and feel victimised, because their spouse would often know that he was positive, yet refrain from taking measures to protect his wife.

5.7 Conclusion

A family's response to HIV/AIDS entering the home hinges upon how the test results are conveyed to both the person and the family. The information is extremely difficult to accept, frequently leading to shock and denial, and requires a sensitive and positive approach. If test results are conveyed through the VCTC, counsellors should offer follow-up advice and support. If the test result is not positive, the VCTC should nonetheless familiarise the individual with the key strategies available to minimise exposure to HIV/AIDS.

Chronic ill health creates immense stress, even among the financially secure. However, stress levels escalate sharply when chronic illness is combined with persistent (chronic) poverty or entry into it. The existing health sector needs urgent attention and priority in the allocation of resources. As early as in 1946, the Bhore Committee established that no individual should fail to secure adequate medical care because of inability to pay for it.

The National Rural Health Mission notes that hospital expenses account for one of the main reasons for falling below the poverty line - an estimated 25% of new entrants into poverty do so because of crippling medical expenses. Hospitalised Indians spend a staggering 58% of their total annual expenditure on medical care. Most have no insurance, thus borrowing heavily or selling invaluable assets to cover expenses. The importance of publicly available, good quality healthcare, to enable greater access to health services cannot be overestimated in preventing the non-poor from entering poverty or reducing the suffering of those already below the poverty line.

The carers of those suffering from HIV/AIDS (mainly women) provide an enormous service to Indian society but receive little support and recognition. This paper has identified ways in which diagnosis and treatment of HIV/AIDS might reduce the pressures on carers and provide support for them. Poverty, HIV/AIDS and caring for the PLWHA are deeply interrelated. A key component of India's struggle to eradicate poverty has to be decreasing rates of mortality, morbidity and chronic infections such as HIV and supporting those who provide care.

References

Amis, Phil 2002. 'Thinking about Chronic Urban Poverty', Working Paper 12, Chronic Urban Poverty Inception Report, January, CPRC, UK. (available online http://www.chronicpoverty. org/ pdfs/12A mis.pdf)

Bajpai, Nirupam and Goyal, Sangeeta 2004. 'Primary Health Care in India: Coverage and Quality Issues', CGSD Working Paper 15, June. (available online www.earthinstitute.columbia. edu/cgsd/ documents/bajpai_primaryhealth.pdf).

Barnett, Tony and Whiteside, Alan 2002. 'Poverty and HIV/AIDS: Impact, Coping and Mitigation Policy', in Giovanni Andrea Cornia (ed.), AIDS, Public Policy and Child Well-Being. (available online http://www.unicef-icdc.org/research/ESP/aids/chapter11.pdf).

Barnett, Tony and Whiteside, Alan 2000. Guidelines for Studies of the Social and Economic Impact of HIV/AIDS, UNAIDS. (available online http://www.iaen.org/ files.cgi/156_JC326-Guideliens.pdf).

Barnett Tony, and Whiteside, Alan 1999. HIV/AIDS and Development: Case Studies and a Conceptual Framework. (available online http:// www.ukzn.ac.za/heard/research/Research Reports/1999/ Ejdr.pdf).

Bharat, S. and Aggleton, P. 2002. 'Community Response to HIV/AIDS in Mumbai City', in Samiran Panda (ed.), Living with AIDS virus: The Epidemic and the Responses in India.

Bhide, Shashanka and Mehta, Aasha Kapur (forthcoming). 'Tracking Poverty through Panel Data: Rural Poverty in India 1970-1998', Paper presented at the Seminar on 'Chronic Poverty: Emerging Policy Options and Issues', September 29-30, 2005.

Bhide, Shashanka and Mehta, Aasha Kapur 2004a. 'Correlates of Incidence and Exit from Chronic Poverty in Rural India: Evidence from Panel Data', Working Paper 15, CPRC-IIPA, New Delhi.

Bhide, Shashanka and Mehta, Aasha Kapur 2004b. 'Chronic Poverty in Rural India: Issues and Findings from Panel Data', Journal of Human Development, 5(2), July, 195-209.

BIDPA 2000. Impacts of HIV/AIDS on Poverty and Income Inequality in Botswana. (available online www.iaen.org/files.cgi/208_31Greener.pdf).

Bloom, David E. and Godwin, Peter (ed.) 1997. The Economics of HIV and AIDS: The Case of South and South East Asia. Delhi: Oxford University Press.

Bloom, David E. and Mahal, S. Ajay 1997a. 'The AIDS Epidemic and Economic Policy Analysis', in David E. Bloom and Peter Godwin (ed.), The Economics of HIV and AIDS: The Case of South and South East Asia. Delhi: Oxford University Press.

Bloom, David E. and Mahal, S. Ajay 1997b. 'AIDS, Flu and the Black Death: Impacts on Economic Growth and Well-being', in David E. Bloom and Peter Godwin (ed.), The Economics of HIV and AIDS: The Case of South and South East Asia. Delhi: Oxford University Press.

Bonnel, Rene 2000. Economic Analysis of HIV/AIDS. Background Paper, The World Bank AIDS Campaign Team for Africa, September. (available online www.iaen.org/files.cgi/435_HIVEconAnalysisADF.pdf).

Campbell, C. and Foulis, C. 2004. 'Creating contexts for effective homebased care of people living with HIV/AIDS'. (available online http://eprints.lse.ac.uk/archive/ 00000340/01/Item_3_-_Campbell.pdf).

Chandra, Shailaja 2005. 'There's no time to lose; action against HIV/AIDS needs to be taken at war footing', Pioneer, June 7.

D'cruz, Premilla 2004. 'The Family Context of Care in HIV/AIDS: A Study from Mumbai, India', The Qualitative Report, 9(3), September, 413-434. (available online www.nova.edu/ssss/ QR/QR9-3/dcruz.pdf).

Desmond, C. et. al. (undated). 'The Hidden Battle: HIV/AIDS in the Family and Community', Health Economics and HIV/AIDS Research Division, University of Natal, Durban. (available online www.icross-international.net/Documents/PDF/karen _chris_jeff.pdf).

Dilip, T. R. and Duggal, Ravi 2002. 'Incidence of Non-Fatal Health Outcomes and Debt in Urban India', Draft Paper prepared for Urban Research Symposium, December 9-11, The World Bank, Washington DC. (available online www.ucl.ac.uk/.../drivers_urb_change/urb_society/pdf _health_educ/CEHAT_Ravi_Non_Fatal _Health_india.pdf).

Donahue, Jill 1998. 'Community Based Economic Support for Households Affected by HIV/AIDS', Discussion Paper 6, Health Technical Services Project, USAID. (available online www.synergyaids.com/documents/409_care6.pdf-Supplemental Result).

Duraiswamy, P. (undated). 'The Economic Impact of HIV/AIDS on Patients and Households in South India', IAEN Annual Conference: Current Issues in the Economics of HIV/AIDS. (available online http://www.iaen.org/conferences/ f2f2003/).

Government of India 2002. National Health Policy. (available online http://mohfw.nic.in/np 2002.htm).

Gupta, Indrani and Datta, Arindam 2003. 'Inequities in Health and Health Care in India: Can the Poor Hope for a Respite?', Institute of Economic Growth, Delhi, December. (available online ieg .nic.in/dis_ind_80.pdf).

Knodel, John and Im-em, Wassana 2003. The Economic Consequences for Parents of Losing an Adult Child to AIDS: Evidence from Thailand, Population Studies Centre Research Report, University of Michigan. (available online www.psc.isr.umich.edu/ pubs/papers/rr02-504.pdf).

Loewenson, Rene and Whiteside, Alan 1997. 'Social and economic issues of HIV/AIDS in Southern Africa', SAFAIDS Occasional Paper Series 2. (available online http://www.iaen.org/ impact/sfaids1.pdf).

Loewenson, Rene and Whiteside, Alan 2001. 'HIV/AIDS : Implications for Poverty reduction', Background Paper prepared for the United Nations Development Programme. (available online http://www.iaen.org/files.cgi/389_PovertyReduction. PDF).

Mahal, Ajay and Rao, Bhargavi 2003. 'HIV/AIDS epidemic in India: An economic perspective', Indian Journal of Medical Research, 121, April, 582-600. (available online www.icmr.nic.in/ ijmr/ 2005/April/0428. pdf).

Mehta, Aasha Kapur and Shepherd, Andrew 2004. 'Chronic Poverty In India: Overview of Key Emerging Issues', Working Paper 24, CRPC-IIPA, New Delhi.

Mehta, Aasha Kapur and Bhide, Shashanka 2003. 'Issues in Chronic Poverty: Panel Data based Analysis', in Mehta, Aasha Kapur et. al. Chronic Poverty in India. Delhi: Indian Institute of Public Administration

Mutangadura, Bindura Gladys 2000. 'Household Welfare Impacts of mortality of adult females in Zimbabwe: Implications for policy and Programme Development', Paper presented at AIDS and Economic Symposium, organized by IAEN Network held in Durban. (available online www.iaen.org/ files.cgi/194_03mutangadura.pdf).

Msobi N. and Msumi Z. (undated). 'HIV/AIDS and other chronic conditions: Home based care cost study, Bagamoyo district-Tanzania', Paper presented at AIDS and Economic Symposium, Durban. (available online http://www.iaen.org/conferences/ durbansym/papers/42Msobi.pdf).

Mukhopadhyay, Swapna et. al. 2001. Living Under a Shadow: Gender and HIV/AIDS in Delhi. Delhi: ISST.

Nimla, Bindiya and Shinde, Madhavi 2004. To Assess the Needs of Women Carers of Those Affected by HIV/AIDS, CCDT, Mimeo, (unpublished).

Ogden, Jessica et. al. 2004. Expanding the Care Continuum for HIV/AIDS: Bringing Carers into Focus, Horizons Report, Population Council and International Centre for Research on Women, Washington DC.

Over, Mead et. al. 2004. HIV/AIDS Treatment and Prevention in India: Modelling the Cost and Consequences, Human Development Network: Health, Nutrition, and Population Series. (available online www.siteresources.worldbank.org/INTINDIA/Resources/IndiaARTReport1. pdf).

Pallikadavath, Saseendran et. al. (undated). 'HIV/AIDS in rural India: context and health care needs'. (available online www.socstats.soton.ac.uk/choices/HIV%20AIDS%20in%20rural%20India%20WP13.pdf).

Pitayanon, Sumalee 1997. 'The Economic Impact of HIV/AIDS Mortality on Households in Thailand', in David E. Bloom and Peter Godwin (ed.), The Economics of HIV and AIDS: The Case of South and South East Asia. Delhi: Oxford University Press.

Schaffer, Teresita C. and Mitra, Pramit 2004. India at the Crossroads: Confronting the HIV/AIDS Challenge, Report of the CSIS HIV/AIDS Delegation to India, January 3-10. (available online www.csis.org/saprog/0401_hivindia.pdf).

Sathiamoorthy, K. and Solomon, Suniti 1997. 'Socio-economic Realities of Living with HIV', in Peter Godwin and Charles Gilks (ed.), Socio-Economic Implications of the Epidemic, UNDP Regional Project on HIV& Development, 71 -101. Delhi: Oxford University Press.

Srinivisan, R. (undated). 'Health Care in India - Vision 2020: Issues and Prospects'. (available online www.planningcommission.nic.in/reports/genrep/bkpap2020/26_bg 2020.pdf).

Solomon, Suniti, and Ganesh, Aylur Kailasam 2002. 'HIV in India', HIV Insite, Special Contribution, 10(3), July/August. (available online http://hivinsite.ucsf.edu/ pdf/md-04-01-46. pdf).

UNAIDS and ILO Report 2003. Socio-economic Impact of HIV/AIDS on People Living with HIV/AIDS and their Families, Study conducted by Delhi Network of Positive People, Manipur Network of PLWHA, Network of Maharashtra by PLWHA and Positive Women Network of South India. (available online http://www.ilo.org/public/english/region/asro/newdelhi/aids/ download/socioec.pdf).

UNAIDS, UNFPA and UNIFEM 2004. Women and HIV/AIDS-Confronting the Crisis. (available online http://www.unfpa.org/hiv/women/docs/women_aids.pdf).

UNAIDS and WHO 2001. Improving Access to care in developing countries: lessons from practice, research, resources and partnerships. Report from a meeting on 'Advocating for access to care and sharing experiences'. (available online http:// www.who.int/hiv/pub/ prev_care/care/en/).

UNAIDS 1999. A Review of Household and Community Responses to the HIV/AIDS epidemic in the Rural Areas of Sub-Saharan Africa. (available online www.iaen.Org/files.cgi/ 241_una99e39 .pdf).

UNAIDS South Asia and UNIFEM SARO 2004. The Gender Dimensions of HIV/AIDS: Challenges for South Asia.

UNDP 2003. 'HIV/AIDS and Development in South Asia', Regional Human Development Report, New Delhi.

UNIFEM SARO 2000. Community based studies on Gender and HIV/AIDS, New Delhi.

UNIFEM-REAPS 2003. Equalizing Gender Relationships in the Context of the HIV/AIDS epidemic.

United Nations Department of Economic and Social Affairs: Population Division (undated). 'Impact on the Health Sector', in Impact of AIDS. (available online http://www.un.org/esa/ population/ publications/AIDSimpact/90_CHAP_VII.pdf).

World Bank 2001. India Raising the Sights: Better Health Systems for India's Poor Overview, Health, Nutrition, Population Sector Unit, India, South Asia Region, November 3. (available online lnweb18.worldbank.org/sar/sa.nsf/Attachments/rprt/ $File/INhlth.pdf).

WHO 2002. 'Integrating Gender into HIV/AIDS Programmes', A Review paper, Department of Gender and Women's Health, Family and Community Health and World Health Organization. (available online www.peacewomen.org/resources/HIV-AIDS/WHO2002.pdf).

World Health Policy Report 2002. (available online www.who.int/entity/whr/2002/en/ whr02_en .pdf).

World Health Report 1995. (available online www.who.int/entity/whr/1995/en/whr95_full_ report_fr.pdf).

Indian Institute of Public Administration
Indraprastha Estate, Ring Road
New Delhi - 110 002

United Nations
Development Fund for Women
UNIFEM

United Nations Development Fund for Women
223, Jor Bagh, New Delhi - 110003
Tel: 91-11-24698297, 24604351
Email: chandnijoshi@undp.org
Website: http://www.unifem.org.in