ACCESS TO HIV/AIDS CARE

A STUDY AMONG PEOPLE LIVING WITH HIV/AIDS

A study conducted by

The Maharashtra Association of Anthropological Sciences Centre for Health Research and Development (MAAS-CHRD)

Supported by

Resource Centre for Sexual Health and HIV/AIDS (RCSHA) - New Delhi
&
The Department for International Development (DFID) - UK

This document was produced as part of a research study undertaken by MAAS-CHRD entitled *"Access to HIV/ AIDS Care: A Study Among People Living with HIV/AIDS"*. The study was supported by Resource Centre for Sexual Health and HIV/AIDS (RCSHA) - New Delhi and The Department for International Development (DFID) - UK. The opinions expressed herein are those of the authors and do not necessarily reflect the views of RCSHA and DFID.

Published in September 2006

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SUGGESTED CITATION

MAAS - CHRD. 2006. *Access to HIV/AIDS Care: A Study among People Living with HIV/AIDS, Dissemination Report.* Pune, India.

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ACKNOWLEDGMENTS

This research would not have been possible without the invaluable help and support of many people. We take this opportunity to express our gratitude.

We remain obliged and would like to thank all the study participants for their time and insight.

We would like to thank Ms. Meena Seshu, secretary of SANGRAM, Mr. S.Y Saptasagar, president of Yerala Projects Society, Mr. S. Deshpande, secretary of Yerala Projects Society, Fr. Kuriokose, director of DILASA centre, Dr. Uday Jagdale, trustee of Aamhich Aamache Sanstha, Mr. Ramesh Babu, president of SHIP, Mr. Roshan Kumar, director of SEEDS, Mr. Sambasiva Rao, secretary of AIRTDS, Mr. Loknath Mishra, director of ARUNA, Mr. Brundaban Panda, secretary of GPSS, Mr. Sanjeev Mahapatra, project coordinator of LEPRA Society - Orissa, Ms Anna Downie, country volunteer of VSO, Ms. Bubu Saha, assistant country director of CONCERN - Orissa, for their active support and cooperation in this research.

We appreciate and are grateful to Mr. Shashikant Mane, project coordinator of SANGRAM, Mr. Prashant Bhosale, assistant project coordinator of SANGRAM, all taluka level coordinators and head Mahila Sanghatika's of SANGRAM, Mr. G.A. Joshi, counselor of Yerala Projects Society, Ms. Subhangi Joshi, counselor Yerala Projects Society, Sr. Prakash, in-charge of DILASA centre, all field workers of DILASA centre, Mr. Shaligram Kamble, coordinator of Aamhich Aamache Sanstha, Mr. Wilson Kondapalli, counselor of SHIP, Ms. Sugnana Rani, project coordinator of SEEDS, Mr. John G. Kennedy, administration - In-charge of SEEDS, Mr. Ragupathy, project coordinator of AIRTDS, Mr. Ramesh Das, project coordinator of ARUNA, Ms. Kalyani Biswas, project coordinator of ARUNA for their help and support in managing field logistics.

This study could not have been done without the members of our research team: Ms. Anita Bansode, Ms. Rohini Shinde, Mr. Avinash Shinde, Mr. Virendra Pardeshi, Mr. P.R.D Shoban, Ms. Sudha Rani, Ms. P. Sujata, Ms. Kamala Kumari, Mr. Sheikh Sirajuddin, Mr. Neelmadhava, Ms. Runu Sahu, Ms. Kalyani Biswas, Mr. Ramesh Das and Mr. Markanda Mishra. Our sincere thanks to them.

We would like to acknowledge Ms. Sugnana Rani, project coordinator of SEEDS, Ms. Neela Santhi, field coordinator of SEEDS, Ms. Kalyani Biswas, project coordinator of ARUNA, Mr. Shantanu Ozarkar, research student department of Anthropology, Mr. Prashant Kulkarni, researcher, Mr. Jayaram, project coordinator of LEPRA Society - AP and Mr. Sukanta Mishra, project officer of LEPRA Society - Orissa for their support with translation and back-translation of schedules. Mr. Sheikh Sirajuddin, project coordinator of AIRTDS for his assistance in editing and formatting

schedule. Mr. Akilesh Pillay of RCSHA, Ms. Anisha Dhongade, accounts officer of MAAS and Mr. Vinayak Amle, administration - In charge of MAAS for administrative support.

We would like to thank Dr. Thomas Philip, of RCSHA, Ms. Anupama Appukuttan, consultant with RCSHA, Ms. Geetha Venugopal, Dr. Sangeeta Kaul, senior programme officer (clinical services) of International HIV/AIDS Alliance - India, Dr. J. Subanna, director of SPANDANA HIV division LERPA Society AP, Mr. Vijayakrishnan, director operations of LERPA Society AP & other states, Ms. Rochana Mitra, consultant with RCSHA, Mr. Maulik Chokshi, consultant with RCSHA, Dr. Kabir Sheikh, consultant with RCSHA, for their guidance and support, which enabled us to complete the research. We are grateful to Mr. Maulik Chokshi, consultant with RCSHA for his comments on the first draft of this report. We are also thankful to Mr. Shantanu Ozarkar, research student department of Anthropology, for proof reading this report.

Finally we thank Prof. R. K. Mutatkar, president, MAAS, Dr. John Porter, reader, LSHTM, Dr. Karina Kielmann, lecturer, LSHTM and all the members of MAAS-CHRD unit for their continuous encouragement and support in conducting this study.

This research was supported by funds from RCSHA and DFID TB Knowledge programme at the London School of Hygiene and Tropical Medicine, UK.

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ARV	Anti-retroviral
ART	Anti-retroviral Therapy
CBO	Community Based Organization
HIV	Human Immunodeficiency Virus
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
NGO	Non-governmental Organisation
OI	Opportunistic Infection
PLHA	People Living with HIV / AIDS
PPTCT	Prevention of Parent to Child Transmission
VCCTC	Voluntary Confidential Counseling and Testing Centre

EXECUTIVE SUMMARY

The importance of strengthening care and support for India's 5.2 million people living with HIV/AIDS (PLHA) is increasingly being recognised, and institutional strengthening and capacity building have been adopted as key objectives of the National AIDS Control Programme (NACP). Nationwide hospitals, community care centres and families providing home-based care are working synergistically to provide care and support to PLHA. In order to respond to the full range of care and support needs of PLHA at different stages of the illness, it is necessary to know more about the existing experiences of PLHA in accessing HIV/AIDS services.

In this research study, a survey and in-depth interviews were conducted with PLHA accessing a range of health care facilities (public, NGOs, private) in three different states. This report documents barriers and enabling factors in accessing healthcare and identifies needs from the perspective of PLHA. It also provides insight and information into health services' responsiveness, and sheds light on broader socio-cultural factors at play.

The results of the study can help in improving existing programmes, identifying new focus areas and developing novel approaches for improving access to care. It will also help in the development of measurable indicators for access to services for PLHA.

Key Findings

What is the profile of PLHA who seek care and support from various kinds of providers in the study sites?

- The majority of PLHA are young, belonging to the productive age groups in the population (18-45 years), rural residents (75%), with between one and ten years of education.
- In all the three study sites the PLHA are poor (median per capita income of Rs. 900), with more than half having no stable income, a third (35%) engaged in unskilled labour, living in families where the earner to dependent ratio is 1:3.
- The large proportion of widows (40%) among the PLHA interviewed and the presence of another HIV infected person in the families of 61% of PLHA shows the extent of the epidemic in the study sites.

Where do PLHA get tested for HIV? How do they access various HIV testing facilities? What are their experiences while utilizing HIV testing facilities?

- Relatively more public facilities (56%) are accessed by PLHA for getting tested for HIV for the first time as compared to private sector facilities (44%).
- NGO social workers and private doctors play a key role in referring PLHA for HIV testing.

- While the public sector generally follows national policy guidelines of obtaining consent for testing and pre and post-test counselling, the private sector largely flouts guidelines. Consent is not obtained from two-thirds of PLHA, and pre- and post-test counselling is not offered to 61% and 64% of PLHA, who are seeking help from private sector facilities.

- Key barriers to accessing HIV testing include: direct and in-direct costs for HIV testing irrespective of sectors, the negative attitude of staff in the private sector and inconvenient location of facilities in the public sector.

- Most commonly expressed needs and expectations of PLHA around HIV testing include better behavioural and psychological support from the medical fraternity across private and public sectors.

Where do PLHA seek help for HIV-related illnesses? How do they access various facilities for HIV-related Illnesses? What are their experiences while utilizing facilities for HIV-related Illnesses?

- The private sector is a key provider for the treatment of both major and minor illnesses for 70% of PLHA.

- PLHA who seek care in the public sector face several problems, key among them being non-availability of medicines, staff and diagnostic facilities apart from inconvenient location.

- Across public and private sectors, the costs on medicines and investigations that are incurred by PLHA for availing treatment for HIV-related illnesses, along with the negative attitude of providers act as major barriers in receiving continued and quality health care services.

- Expressed needs of PLHA with regards to treatment of HIV-related illnesses include the availability of patient-friendly and affordable services for HIV-related illnesses located close to their homes.

Where do PLHA access ARVs? How do they access various facilities for ARVs? What are their experiences while utilizing facilities providing ARVs?

- The public sector is a key provider of ART for 88% of the 84 PLHA on ART.

- Half of the 20 PLHA who initiate ARVs in the private sector, subsequently shift to the public sector ARV rollout because of the high cost of treatment.

- NGO workers (27%), referring doctors (20%) and Positive People Networks (10%) are the main enablers facilitating access of PLHA to ARV treatment in either the public or the private health care facilities.

- The cost incurred on receiving ART in the private sector is an important barrier in sustaining treatment and ensuring adherence to ART.

- Non availability of functioning CD4

count testing facility, the high costs of the test in the public sector and the negative attitude of doctors and other staff members are major barriers to accessing ART under the rollout.

- Infra-structural problems like insufficient space result in long waiting hours and queues at the ARV rollout centres.

- Key needs expressed by PLHA with regard to ART are continued availability of drugs and affordable and functional CD4 count testing facility, decentralisation of ART to the level of rural hospitals and taluka level health centres, and nutritional supplements in conjunction with provision of ARVs.

What non-medical needs do PLHA have and who addresses these needs?

1. PLHA have a wide range of non medical needs that range from financial to psycho-social and nutritional needs.

2. Close family members and relatives provide much of the psycho-social as well as financial support needed by PLHA.

3. PLHA also receive support from a range of people outside the family, including NGOs, friends, neighbours and private doctors.

4. The range of services provided by NGOs to support PLHA was enormous from financial, psychological, nutritional, social, legal and medical.

5. Close to a third of the PLHA (32%) report having unpleasant experiences with their family members and relatives as a consequence of their HIV positive status. More women (19%) compared to men (13%) reported facing problems, mostly discriminatory attitude and behaviour, from their family members

Programmatic Recommendations

1. Care, support and treatment-related needs of PLHA

- PLHA in all the three settings seek help from the public, private and NGO sectors for their varied care, support and treatment needs.
- PLHA are burdened with costs, debts, and face stigma and discrimination.
- The burden of high costs is, in large part, due to the regular episodes of HIV-related illnesses, for which PLHA do not have access to free treatment.

> ***Addressing geographical accessibility and bringing care and treatment facilities closer to PLHA in rural areas appears to be a important area for improving access to HIV care and reducing the burden of HIV/AIDS.***

2. Infrastructural, Non-Availability and Supply related issues in public sector settings

- There are several problems in the public sector delivery of HIV care services; these include:
  - Non-availability of testing kits
  - Non-availability of CD4 testing facilities

- Non-availability of essential medicines for OI treatment
- Lack of patient friendly services in the public sector including issues like
    - Staff availability
    - Staff attitudes
    - Space
    - Counselling environments
    - Waiting time
    - Complicated procedures

Infrastructural, non-availability and supply-related issues need immediate attention if the programme is keen to increase access to quality HIV care and thereby reduce the burden of HIV/AIDS.

3. Framework of comprehensive HIV/AIDS care for planning needs of PLHA

- PLHA have varied care, support and treatment needs at different stages of the illness.
- While planning for all these needs, the wider framework of Comprehensive HIV/AIDS Care, as advocated by the UNAIDS, needs to be taken into account.

The programme needs to weave in the different providers to seamlessly address both medical as well as non-medical needs of PLHA, which is the only way to reduce the dual burden of the illness itself as well as the problems in accessing care for HIV/AIDS.

4. Integration, decentralization and rapid scale-up of ART Programme in India

- There are large groups of PLHA with unmet needs and huge expectations regarding ARV treatment across the three sites, indicating the need for decentralization and scale-up of the ART programme in India.
- The present ARV rollout sites are struggling with infrastructural issues with respect to adequate space, counselling environments and staffs. Innovative ways need to be used to address these matters.
- The management of OI is an unmet need even in the case of patients on ARVs. Attempts need to be made to ensure that OI management becomes an integral part of ARV treatment.
- The private sector is a key provider for all phases of being an HIV patient, from initial testing through to being put on ART, apart from playing a facilitating role, along with NGOs, in accessing appropriate treatment.
- Across ARV roll-out sites, PLHA have high expectations from the ARV rollout programmes, that go beyond the provision of treatment and extend to financial and nutritional support.
- NGO partners can be addressed to play this role after assessing their capacities and competence to do so.

NGO and private sector providers can and need to be inducted as formal partners and trained and supported to tackle the issue of decentralising rational OI management and ART.

5. Sensitization of private medical providers (PMP) regarding rights and needs of PLHA

- Although they play a significant role in HIV testing, OI Management and ARV treatment, PMPs do not follow mandatory procedures, particularly with regard to consent and counselling before and after HIV testing and before and after starting ARVs.

Private providers need to be sensitized regarding the rights and needs of PLHA while managing them.

6. **Public-Private Partnerships to ensure continuity of care**
   - PLHA in the study incur both direct and indirect costs while seeking treatment for HIV testing, opportunistic infections and ARV treatment. This additional burden has been identified as one of the barriers to accessing continued and quality HIV care.

Efforts need to be focused on minimising testing and treatment-related costs by ensuring continuum of care in and across public and private sectors through public-private partnerships.

7. **Shift in awareness programmes under the NACP**
   - PLHA have reported the need for access to timely and need-based information about the disease and about the facilities available in the public sector.

HIV/AIDS awareness campaigns need to generate awareness not only about the disease, but provide clear and precise information about services and facilities.

Research Recommendations:

Developing Indicators of Access

In a diverse setting like India where "access" assumes context-specific meanings, there is a need to identify appropriate composite quantitative and qualitative indicators that take into consideration factors such as the presence of different kinds of providers who cater to the PLHA population, the quality of care delivered by them, the burden of disease and the burden of accessing care of varying quality from these different providers. Different kinds of studies might generate data to help develop these indicators, e.g.:

- Studies that delve into help seeking and enablers and barriers to accessing care in different contexts

- Periodically undertaken situation analysis studies using qualitative methods

- Studies on disease burden and coping mechanisms at the individual, family and community level.

Key Recommendations:

- **Improving geographical accessibility of treatment and drugs for PLHA**
- **Ensuring uninterrupted access of PLHA to drugs and investigations**
- **Addressing the unmet need of PLHA for ART**
- **Sensitizing and regulating private sector**
- **Linking different providers to ensure sustained care**
- **Building on the strengths of family and NGO support to PLHA**
- **Orienting PLHA and community in service delivery at public sector**
- **Promoting a better understanding of issues of access to care for PLHA by conducting research studies**

INTRODUCTION

INTRODUCTION

The emergence and pandemic spread of AIDS constitute the greatest challenge to public health in recent times. India faces an accelerating threat from HIV; with some states already experiencing a crossover of the virus from high-risk groups into the general population[1,2]. Poverty, social inequalities and inadequate access to health infrastructure are the factors which increases vulnerability to AIDS epidemic[3].

The importance of strengthening care and support for India's 5.2 million PLHA is increasingly being recognised. Nationwide hospitals, community care centres and families providing home-based care are working synergistically to provide care and support to PLHA[4].

The development of life-saving antiretroviral (ARV) drugs has brought in new hopes and has transformed HIV/AIDS from a fatal disease to a potentially manageable, chronic illness. The new initiative of providing free anti-retroviral drugs to all people living with HIV/AIDS (PLHA) undertaken by the National AIDS Control Programme (NACP) in response to care and support needs of PLHA is a quantum leap in this regard[4]. Presently 54 Antiretroviral therapy (ART) centres across 10 states provide three drug combination therapy and there are plans to further scale up the ARV roll-out programme[5].

Similarly, the government accords high priority for the availability of quality medical care, treatment accessibility for opportunistic infections and support to HIV/AIDS patients and their families, which has been undertaken through collaboration with non-governmental organizations (NGO), community-based organizations (CBO) and positive people's networks. Recently, initiatives have been made to involve private medical providers in care and support of PLHA[4].

With the advent of new initiatives and the development of care and support systems, it is vital to understand more about the existing experiences of PLHA while accessing HIV/AIDS services at various sectors and the factors which act as barriers and enablers to HIV/AIDS care seeking.

Rationale for the study

From the point of view of individuals seeking health care, ***access to care has been broadly defined as the capacity or the ease of individuals in obtaining services they need and want.*** Access does not simply mean geographical proximity to a health care facility[6, 7, 8, 9]. In the context of HIV/AIDS, “access to care” implies that all PLHA should receive a quality standard of care when they need it, throughout their lifetime, which meets their changing needs. At different times of the course of the infection and illness, PLHA have different healthcare requirements:

1. Diagnosis
2. Treatment, including prophylaxis for OIs, adherence to ART regimens and management of OI
3. Referral and follow-up

4. Nursing care
5. Counselling
6. Palliative care
7. Support to meet psychological, spiritual, economic, social and legal needs[10]

Additionally, there is considerable variation in care needs, and in care-seeking behaviour of PLHA according to gender, age, geographical location, and socio-economic status[7, 8]. In order to respond to the full range of care and support needs of PLHA, at different stages of the illness, it is necessary to know more about the existing experiences of PLHA in accessing HIV/AIDS services.

In this research study, a survey and in-depth interviews were conducted with PLHA accessing a range of healthcare facilities (Government, NGO and Private) in three different states. The study provides details of prevalent patterns of health seeking behaviour among PLHA. It documents barriers and enabling factors in accessing healthcare from the standpoint of PLHA, hence providing insight and information into health services' responsiveness, and also sheds light on broader socio-cultural factors at play. The results of the study can help in improving existing programmes, identifying new focus areas and developing novel approaches for improving access to care. It will also help in the development of measurable indicators for access to services for PLHA.

Aim of the study

To understand factors influencing access to HIV/AIDS care from the perspective of PLHA.

Objectives of the study

1. To identify needs of PLHA in accessing continued and quality services
2. To identify barriers and enablers in access of PLHA to continued and quality services

Conceptual Framework of the research

PLHA access a wide range of services to address their needs in care. In addition to the individual characteristics of PLHA, characteristics of the health care services are also important determinants of access[11]. Access to health care occurs in the context of the community as a whole, and community and family environments play an important role in determining access.

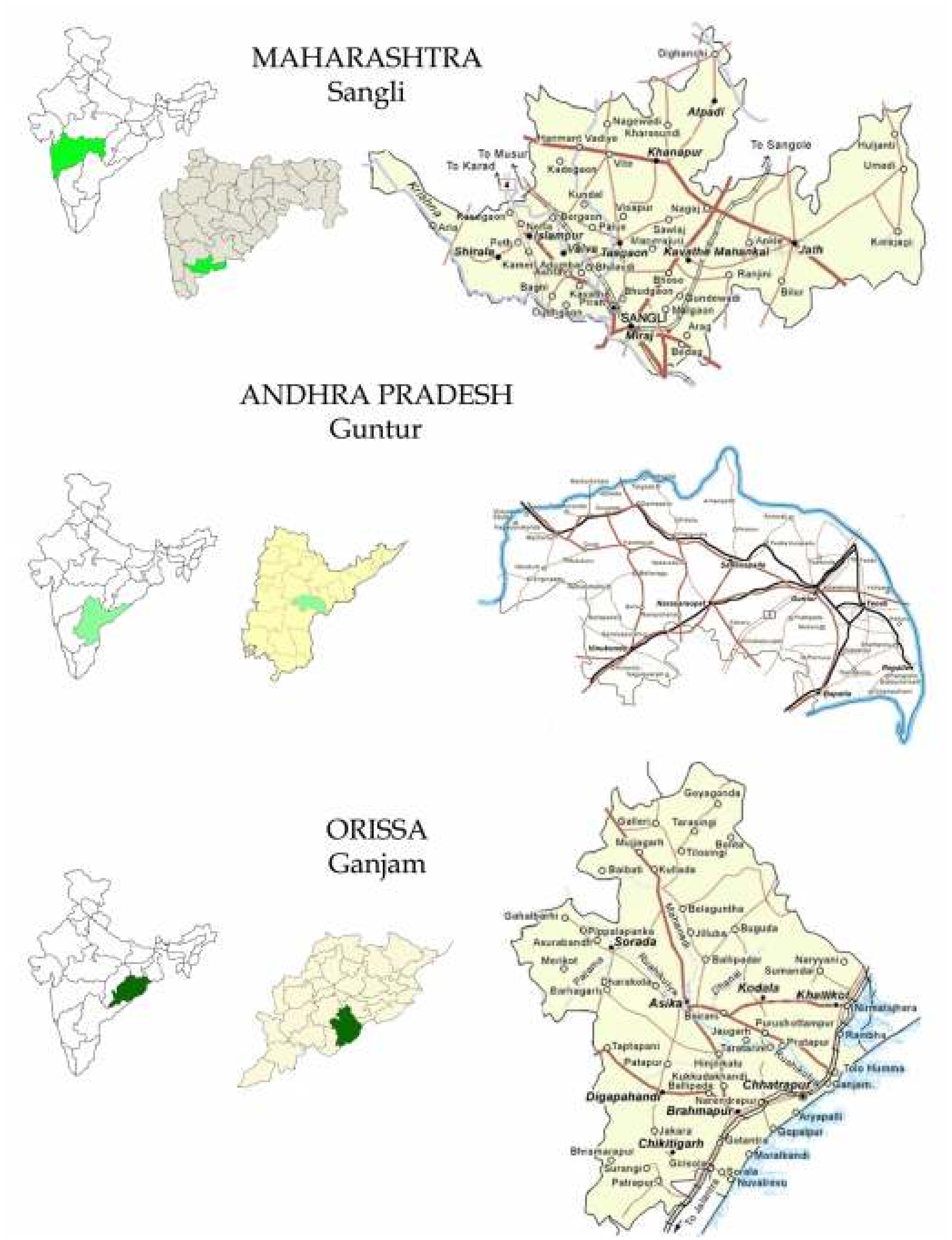
Many PLHA may not be aware of the range of accessible and affordable treatment and care options available to them. As documented in various studies undertaken in India specifically in TB; even if patients are aware, some choose traditional healers or untrained allopathic doctors over formally trained practitioners or government health facilities, for various reasons[12, 13, 14, 15, 16, 17, 18]. A majority of patients frequently shop for diagnosis and treatment[19, 20, 21]. Patients are also known to delay diagnosis and often do not complete lengthy courses of treatment[22, 23].

In view of these documented findings it can be hypothesized that hospitals, clinics, testing centres, care-centres, the community, traditional health care providers and family members all play a crucial part in meeting care, support and treatment needs of PLHA over the course of illness. Provider and service-related factors such as high costs, difficult timings, a hostile environment, lack of confidentiality, poor communication with patients, and unavailability of drugs and investigations can create barriers to the utilisation of services and to uptake of and adherence to treatment. Local NGOs and private practitioners are often preferred providers and serve differing needs of PLHA. Appropriate referrals of PLHA, however, may not always take place when required. In order to improve access to continued quality care, it is important to consider a wide range of service providers, including the private and voluntary sectors, to create an efficient flow of information, resources and services between them.

Prevalent attitudes around gender and social status, stigma around the disease and a supportive (or otherwise) family environment will influence the behaviour of PLHA in seeking care. Community based organizations and positive people's networks can play an important role in facilitating access to care.

STUDY METHODS

Map showing Study sites in the states of Maharashtra, Andhra Pradesh and Orissa



STUDY METHODS

Study setting

The study was undertaken in three states viz; Andhra Pradesh, Maharashtra and Orissa, from which one HIV high prevalence district was selected. Based on sentinel surveillance reports, Andhra Pradesh and Maharashtra were purposively selected due to their high HIV prevalence. Andhra Pradesh has 2.00% and 22.8% prevalence in ANC and STD cases respectively and Maharashtra has a prevalence of about 1.25% and 10.40% in ANC and STD cases respectively. Orissa was purposively selected for its low HIV prevalence of 0.25% and 4.00% in ANC and STD cases respectively.

The selection of districts (Guntur in Andhra Pradesh, Sangli in Maharashtra and Ganjam in Orissa) was also primarily based on sentinel surveillance reports with other socio-demographic characteristics justifying selection of each district.

Study Design

The study was exploratory, cross-sectional and descriptive in nature and was undertaken in three phases. The data collection for the study was undertaken between November 2005 and February 2006 simultaneously in the three study districts. During the first phase of formative research, site visits and talks with key stake-holders provided contextual information. The second phase of exploratory survey helped in obtaining data on the study objectives and in formulating research questions for the next phase. In-depth interviews were conducted in the third phase, to map the pathways of care-seeking of PLHA and to understand the socio-economic context in which care-seeking had been undertaken by PLHA.

Tools

Semi-structured interview schedule for the survey and interview guide for the in-depth interviews.

Sampling

The sampling was purposive in nature. Those NGOs and PLHA networks in the study districts, who agreed to participate in the study constituted the study units. These study units were told to prepare the list of PLHA covering details of five variables viz; age, gender, marital status, occupation and whether undergoing ARV treatment or not.

The first level of PLHA consent was taken by the organization, on the basis of which each study unit gave a list of PLHA who were willing to be interviewed. All PLHA who matched the follow-ing inclusion criteria were considered as the sampling frame for that particular study district:

1. Those who were residents of the study districts and 18 years and above of age at the time of the study
2. Those who were aware of their HIV positive status and

3. Those who were willing to participate in the study by giving the interview on his/her free will.

Table 1 shows sample sizes for the survey as well as in-depth interviews conducted with PLHA. Prior to the actual interview, each PLHA was explained the purpose and objectives of the study. The schedule incorporated a format of written consent which was translated in regional languages requesting participation of PLHA on a voluntary basis. Only those who agreed to participate, were included in the study and were made to give their left thumb impression on the consent form. Each PLHA was paid Rs. 150/- towards their traveling and one time food cost for participating in the study.

Table 1: Sample Sizes across Study sites

District	PLHA Listed	Survey Interviews			In-depth Interviews
		Pilot	Final	Analysis	
Sangli	136	17	115	113	8
Guntur	120	15	105	116	9
Ganjam	119	10	110	118	8
Total	**375**	**42**	**333**	**347**	**25**

A pilot-tested semi-structured interview schedule was administered to the survey respondents (PLHA) in the local regional language, after obtaining their consent. This schedule was used mainly to elicit information on: (i) Socio-economic and household profile of PLHA, (ii) Care seeking for HIV testing, HIV-related illnesses and ART, specifically probing for the first access points (iii) Enquiry into the support received by PLHA for meeting economical, psychological, spiritual, social and legal needs.

The section on care seeking included a list of probe questions eliciting an affirmative ('yes') or a negative ('no') response on the presence or absence of eight to ten different parameters for assessing the quality of services delivered by the public and private health care facilities. The responses of PLHA to these probe questions were useful in assessing, comparing and classifying the role of these quality parameters in access to care for PLHA. In this report, we classified affirmative responses under 'enablers' and negative responses under 'barriers' for HIV testing, and HIV-related illnesses and ARV treatment care seeking.

Towards the end of the sections on care-seeking for HIV testing, HIV-related illnesses and ARV treatment, as well as in the section on support, an open ended question was included that elicited views on what might improve the quality of services at both public and private sector facilities utilized by them as perceived by PLHA. Their responses to these questions are classified in this report under the heading “expressed needs of PLHA”.

Data Analysis

For the purpose of analysis, datasets originating from the three study sites were combined and presented together to provide a broader picture on access issues relating to HIV/AIDS care from the perspective of PLHA.

SPSS Windows-based version was used for quantitative analysis of pre-coded variables. Bivariate analysis with reference to independent variables facilitated the comparison of factors influencing care seeking of PLHA for HIV testing, HIV related illnesses and ART. Further Chi-square test ($\chi 2$) was used to test the significance of associations for cross-tabulated data. Open ended qualitative responses from the survey interview schedules were noted, translated into English and entered into Microsoft Word format. MAXQDA - qualitative data management software (developed by VERBI Software. Consult. Sozialforschung GmbH, Berlin 2001) was used to manage the qualitative data from survey schedules. The quantitative data set from SPSS was imported into MAXQDA software to bring together quantitative and qualitative data sets. In consonance with the frequency distribution of quantitative data set, qualitative narratives were retrieved and analyzed.

The in-depth interviews were transcribed, translated, typed in Microsoft word and then coded in MAXQDA. Qualitative narratives were analyzed in a number of ways viz; code-wise extraction of descriptive data; cluster analysis of similar categories of interviews (all men PLHA, all women PLHA); comparative analysis of respondent PLHA across study sites. Data analysis involved several close readings of the textual data, grouping and classification of the data in relation to the study objectives in order to answer research questions of the study.

Limitations of the Study

In order to obtain a complete understanding of help seeking behaviour, the pathways used and the costs incurred, a longitudinal study design is necessary. However, given resource constraints, a cross sectional study design had to be used. Sensitive issues around ensuring confidentiality and anonymity of PLHA and ethical procedures to be followed made it a challenge to use systematic or statistical sampling in all the study sites. Purposive sampling was, hence, used in the study, which limits the ability to generalize the study findings to larger populations. The findings originating from such an exploratory study, however, have helped in providing important insights regarding the issues around access to HIV/AIDS care, which can be tested and triangulated by undertaking studies among larger populations. Another limitation of the study is the inclusion in the study of PLHA drawn only from NGOs and PLHA networks. This was once again done given the time constraint and the delays foreseen in seeking formal permissions from the State AIDS Control Societies, to draw the sample from different public sector health facilities providing the range of HIV care. Also, preliminary explorations revealed that the PLHA registered with NGOs comprised those seeking care from both public and private sectors. It was hence, possible to elicit experiences and problems related to accessing care from all three sectors - public, private and NGO- from these PLHA. The findings on the overwhelming NGO support emerging from the study, however, need to be interpreted with caution. Though, for the purpose of analysis, the datasets originating from the three study sites were combined and presented together, it should be noted that these study sites have inherent differences with regard to geographical location and programme infrastructure. In view of these differences, these findings have to be interpreted with caution.

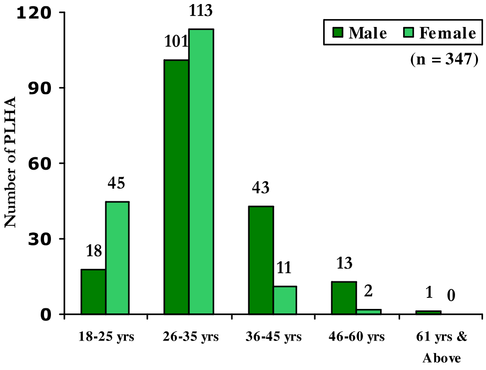
PROFILE OF PLHA

PROFILE OF PLHA

The conceptual framework used in designing this study places issues of access to health care by PLHA in the context of the community as a whole. In addition to individual characteristics of PLHA themselves, socio-economic background factors, community and family environments play important roles in determining access.

- The majority of PLHA are young, belonging to the productive age-groups in the population (Fig 1), rural residents, with between 1 and 10 years of education.

Figure 1: Age-group wise distribution of PLHA

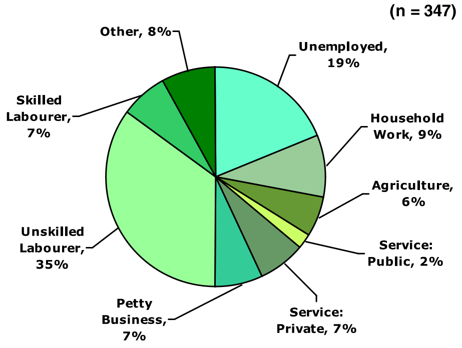


- In all the three study sites the PLHA are poor, with more than half having no stable income, a third engaged in unskilled labour (Fig 3), living in families where the earner to dependent ratio is 1:3, and having a median per capita income of Rs. 900. However, this poverty is much more marked in Ganjam with 44% of the PLHA being unemployed, 86% not having a stable income and a median per capita income of Rs. 225.

- The large proportion of widows among the PLHA interviewed (Fig 2) and the presence of another HIV infected person in the families of 61% of PLHA shows the extent of the epidemic in the study sites.

Figure 2: Sex & Marital Status wise Distribution of PLHA

Figure 3: Occupation wise distribution of PLHA



- PLHA and HIV affected families are in a very vulnerable position. In a third of the cases, the families are bearing the social, economic and psychological burden of providing and facilitating access to care and support for more than one PLHA simultaneously.

HIV TESTING

Table 2: Study-Site Specific Responses to HIV Testing: Government-NGO-Private Sector Interface

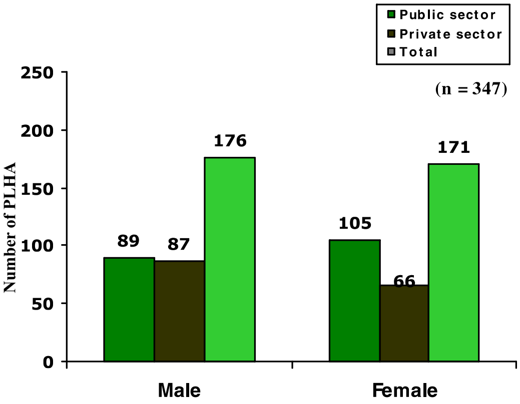
	Public Sector	NGO Sector	Private Sector
Scenario in Sangli	• Runs four VCCTCs, three PPTCTs in ten tehsils • Faces inadequate supply of testing kits • Infrastructure not enough and conducive for counseling	• Gets funds from Avert Society and Maharashtra State AIDS Control Society (MSACS) to encourage voluntary HIV testing • Focus on registering more PLHA so as to garner more funds • Has taken responsibility of running a VCCTC under the NGO involvement scheme, but VCCTC still not functional	• Has been addressing the HIV testing needs of the majority of the population • Undertakes routine HIV testing • Prefers to repeat HIV test for PLHA diagnosed earlier before treating them for minor ailments • Does not follow mandatory guidelines around testing like counseling and consent taking
Scenario in Guntur	• Runs nine VCCTCs, six PPTCTs for 57 mandals • VCCTCs facing excessive work-load • Faces shortage of testing kits • Counselors sometimes fail to address queries from PLHA	• NGO participation encouraged by APSACS • Guides most PLHA to private testing facilities	• Leads in addressing HIV testing needs • Rarely refers patients to the public sector-run testing facilities • Does not follow mandatory guidelines around testing like counseling and consent taking
Scenario in Ganjam	• Runs two VCCTCs (four in the pipe-line), one PPTCT catering to 22 Blocks • Majority of cases for testing facilitated by NGOs	• Refers patients to VCCTCs • Undertakes first level of counselling before referring for testing • Bears the entire cost of HIV testing	• Caters to most of the HIV testing • Charges high fees for testing • Does not follow mandatory guidelines around testing like counseling and consent taking

Note: The information provided in this table is based on factual data from primary and secondary sources, as well as experiential data from patient interviews and information collected through site visits and talks with stakeholders.

HIV TESTING

More than half of the sample of PLHA (n = 194, 56%) had first tested for HIV in a public sector health care facility while the rest utilized the private sector. There was a significant difference (p = 0.04) by gender with regard to the choice of sector whereby more than half of the female PLHA reported going to a public health facility for the first HIV testing (Fig 4).

Figure 4: Gender differences in accessing HIV testing facilities across sectors



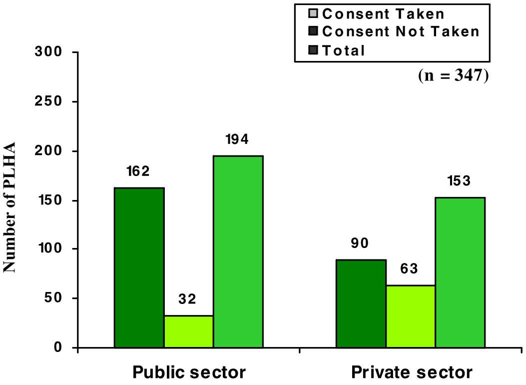
Support during HIV Testing:

More than two thirds of the PLHA (n=225, 71%) reported being supported by someone while accessing health facilities for the first HIV testing. The factors enabling HIV testing were facilitation by social workers, family members, private family doctors, etc. Secondly, being accompanied by someone for HIV testing was also seen to be one of the significant enabling factors, especially for female PLHA.

Consent taking prior to first HIV Testing:

A little less than three-fourths (n=252, 73%) of PLHA reported that consent had been taken prior to getting tested for HIV for the first time (Fig 5), more so in the public sector and this was seen to be consistent over the last five years. Oral consent appeared to be a norm in the private sector compared to the public sector, where written consent was the norm.

Figure 5: Consent taken prior to HIV Testing across sectors



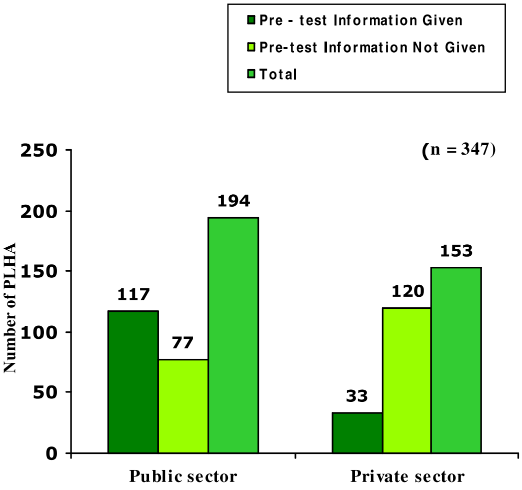
Pre-test Counseling at First HIV Testing:

- Less than half (n=150, 43%) of the PLHA reported having received pre-test counselling.

- While relatively more PLHA reported receiving pre-test counselling from the public sector, there were considerable proportion of PLHA (n = 77, 22%) who reported not being counselled by the public sector (Fig 6).

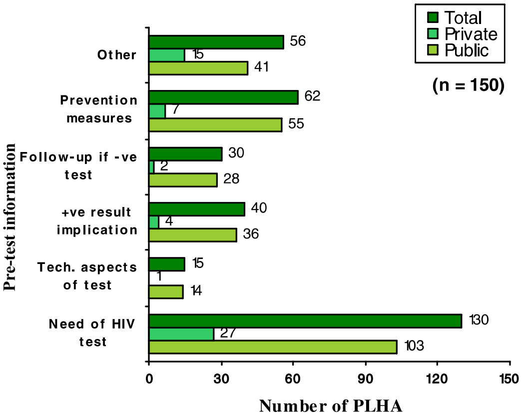
- When the PLHA (43%) who reported being given pre-test information (n=150) were probed regarding the key contents of information provided to them before HIV testing, they reported that they had been given information on the need/necessity to do an HIV test, technical aspects of HIV testing, the implications of positive test result, the need to do follow-up test in case of negative test result and HIV prevention.

Figure 6: Pre-test Information given to PLHA by Private and Public Sectors



- Fig 7 provides details on the range of information given to PLHA across the public and private sector setups. The content of the pre-test counselling, though better in the public sector, was still lacking comprehensiveness.

Figure 7: Key aspects of Pre-test counselling

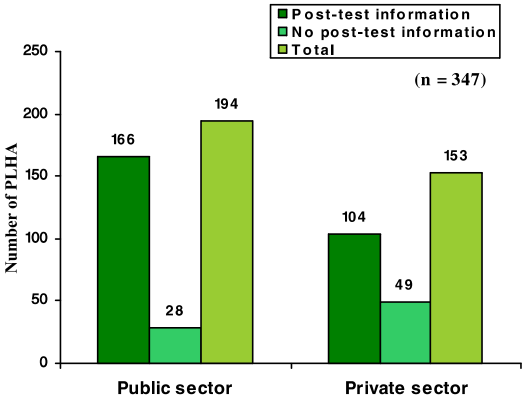


Post-test Counselling at First HIV Testing:

- More than three-fourths of PLHA (n=270, 78%) reported having received post-test information.

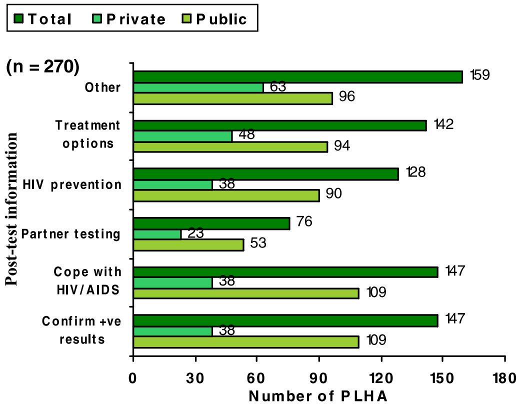
- While a little less than half of the PLHA reported receiving post-test information from the public sector (n=166, 48%), a small segment of PLHA (n= 28, 8%) however, reported not being given post-test information by the public sector (Fig 8).

Figure 8: Post-test Information given to PLHA by Private and Public Sectors



- With regard to coverage of essential contents and comprehensive provision of post-test information, while the public sector had been outperforming the private sector (Fig 9), there was scope for qualitative improvements.

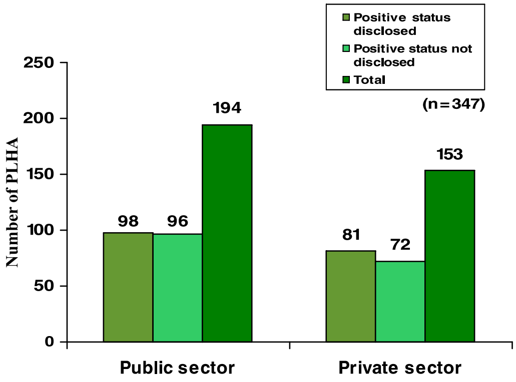
Figure 9: Key aspects of Post-test counselling



Disclosing Positive Status to others:

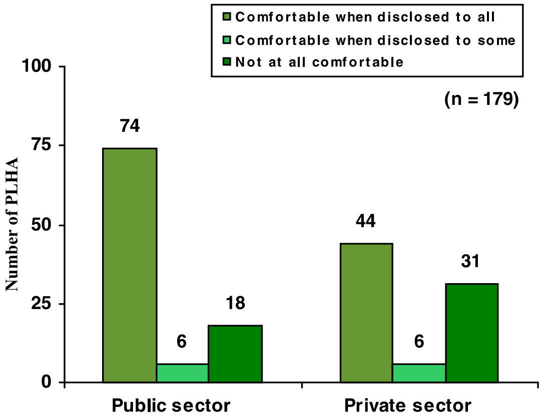
- More than half the PLHA (n=179, 52%) reported that their HIV positive status had been disclosed to others (mostly family or immediate kin) by health providers (Fig 10) with or without assessing their wish to do so.

Figure 10: Disclosure of Positive status by Health Care Providers across sectors



Out of the 179 PLHA who reported their positive status been disclosed to others, little more than a quarter (n=49, 27%) reported that they had felt uncomfortable with this disclosure (Fig 11).

Figure 11: Comfort levels of PLHA regarding positive status disclosure to others



There was highly significant difference (p= 0.008) across sectors with regard to feeling uncomfortable with this disclosure, with more PLHA seeking care from private sector (n=31, 18%) compared to those seeking care from public sector (n=18, 10%) reporting discomfort.

Barriers for HIV Testing:

Unpleasant experiences while accessing HIV testing in the private facilities were one of the significant barriers to getting tested for HIV. These included negative attitude and rude behaviour of counselors and other staff members at public and private sector health facilities towards PLHA in suspicion and anticipation of their positive status prior to and after HIV testing. Further, the costs for HIV testing were also one of the crucial barriers in seeking care, with the median total cost being Rs. 260 (Range: 0 to 36,000) with direct and indirect costs of Rs. 160 and Rs. 100 respectively.

Enablers for HIV Testing:

While utilizing HIV testing services in the public sector, enablers in receiving quality care services were availability of staff and testing kits, convenient timings, cleanliness of the facility and atmosphere of maintaining anonymity and confidentiality regarding HIV status.

The factors hindering the reception of quality care services in both public as well as private sector were negative attitude of staff, direct and in-direct costs of HIV testing and inconvenient location requiring commuting over large distances to reach the facilities.

Expressed Needs of PLHA regarding HIV Testing:

PLHA expressed their expectations of receiving better behavioural and psycholo-gical support from the medical fraternity across private and public sectors.

"That doctor should have given psychological support, then I would have felt better. But he did the exact opposite and did not give me any hopes" *(Female, 29 yrs, Widowed, 8th Standard Fail, Peon in a school)*

HIV RELATED ILLNESSES

Table 3: Study-site Specific Response to HIV Related Illnesses: Government-NGO-Private Sector Interface

	Public Sector	NGO Sector	Private Sector
Scenario in Sangli	• Has facilities for management of OIs • Faces shortage of required medicines • The attitude of staff and doctors towards PLHA is not positive	• Dispenses medicines in weekly clinic at district and tehsil level headquarters	• Manages majority of HIV-related illnesses • Rarely maintains anonymity and confidentiality
Scenario in Guntur	• Has very poor availability of treatment for all OIs • Asks PLHA to buy prescribed medicines from outside	• Facilitates access of PLHA to OI management facilities • Advises PLHA to buy medicines from medical shops instead of traveling long distances to government facilities where medicines are prescribed and not supplied	• Majority of PPs manage HIV-related illnesses • Reported by PLHA to be very expensive for treatment of OIs
Scenario in Ganjam	• Treatment for OIs available but not accessed by many • OSACS has initiated a scheme for OI treatment of PLHA	• Provides medicines under Targeted Intervention programmes to PLHA	• Provides treatment for OIs though it is expensive • Local HIV specialists present in rural and urban areas

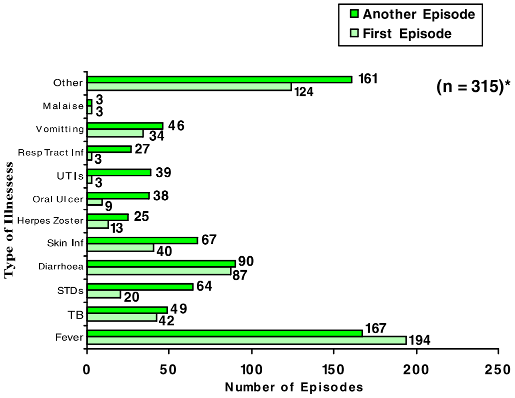
Note: The information provided in this table is based on factual data from primary and secondary sources, as well as experiential data from patient interviews and information collected through site visits and talks with stakeholders.

HIV-RELATED ILLNESSES

HIV-related illnesses are taking a huge toll on PLHA.

- Out of the 347 PLHA in the study, 315 (91%) reported having on an average, two episodes of HIV-related illnesses at the time of seeking treatment for the first time for these illness(s).
- The reported HIV related illnesses ranged from major illnesses such as Tuberculosis, Sexually Transmitted Diseases, Diarrhoea, Herpes Zoster, etc. to minor illnesses and accompanying symptoms such as fever, skin infection, oral ulcer, respiratory tract and urinary tract infections, vomiting, malaise, etc (Fig 12).
- Moreover, more than three-fourths of the PLHA (n=248, 79%) reported having more than one episode of HIV-related illnesses.

Figure 12: HIV-related Illnesses: Types & Episodes



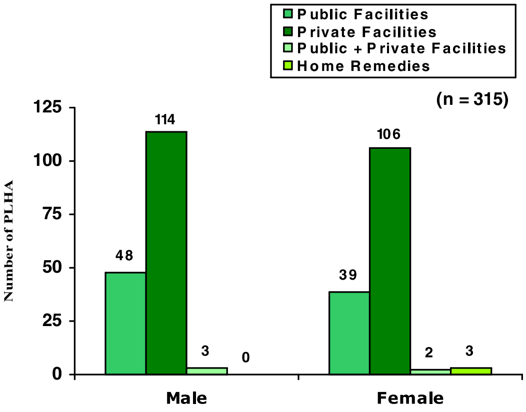
Help Seeking for the First Episode:

Private sector health facilities were utilized by the majority (70%) of PLHA for seeking care for their first episode of HIV-related illnesses (Fig 13).

Reasons for choosing private sector health care facilities (n = 315) were as follows:

- Past experience with the facility (29%)
- Persuasion or suggestion by family members (19%)
- Convenience of commuting and less time and distance to travel (19%)
- Inexpensive (17%)
- Suggestion by NGO worker (14%)
- Reputation of the facility (12%), etc.

Figure 13: First Access points for treatment seeking for HIV-related illnesses



While 28% PLHA do seek care in the public sector, particularly when they find the cost of treatment for recurring or chronic problems in

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* Percentage total exceed 100% because of multiple responses

the private sector unaffordable, they face several problems. Key among them are non-availability of medicines, staff and diagnostic facilities, apart from inconvenient location.

Enablers for Care Seeking: HIV-related Illnesses:

The major factors enabling care seeking for HIV-related illnesses were support and facilitation by family members, social workers and private family doctors. Besides this, always been accompanied by someone, especially in case of female PLHA, was identified as a significant enabler while accessing services for HIV-related illnesses.

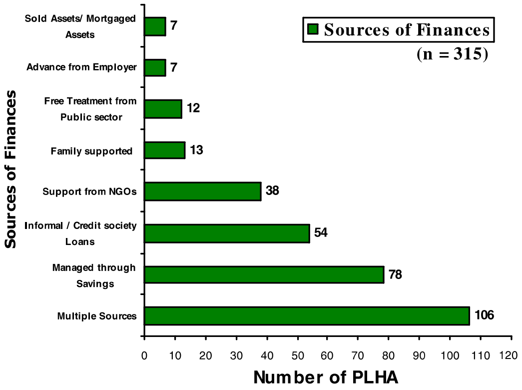
Barriers for Care Seeking: HIV-related Illnesses:

Across public and private sectors, costs of medicines and investigations that were incurred by PLHA for availing treatment for HIV-related illnesses along with the negative attitude of providers acted as major barriers in receiving continued and quality health care services. The median total costs for treating HIV-related illnesses were Rs. 900 (Range: 0 to 1, 30,000), of which the direct and in-direct costs were Rs. 600 and 300 respectively.

Sources of Finances to meet expenditure for treatment of HIV-related Illnesses:

PLHA had to rely on multiple sources of finances to meet the continued demands in expenses for treating their new or repeated episodes of HIV-related illnesses, which ranged from their own savings in addition to informal and formal loans, advances from employers and either selling or mortgaging assets etc. (Fig 14).

Figure 14: Sources of Finances to meet Expenses for treatment of HIV-related illness



Expressed Needs of PLHA Regarding HIV-related Illnesses:

Based on their experiences of seeking treatment from public sector facilities, PLHA expressed four distinct needs:

- Getting information regarding medicines available in the public sector
- Having patient-friendly services
- Having medicines available at closer distance to reduce indirect costs in availing treatment
- Ensuring availability of essential medicines needed to treat HIV-related illnesses.

"Medicines are not available free… sometimes I have to purchase it from the medicine shop…if we go to the medical shop then it is more expensive…above that bus fare, hard work, half a day wage we lose…so all type of medicines should be made available free of cost." *(Male, 32 years, Married, 5th Standard Pass, Skilled Labourer)*

ANTI RETROVIRAL TREATMENT

Table 4: Study-site specific Response to ARV Treatment Needs: Government-NGO-Private Sector Interface

	Public Sector	NGO Sector	Private Sector
Scenario in Sangli	• Pressurised by the government to rush into ARV roll-out without adequate preparation, with the result that several PLHA started on ART without CD4 testing in the initial stages of the programme • Runs a once-weekly ARV OPD, resulting in long queues and waiting hours • Counselors in the ARV OPD are overburdened with excessive workload • Lacks facilities for CD4 count monitoring	• Directs PLHA to the ARV rollout • Guides PLHA and helps in enrolling them on ARV • Few NGOs have clarity about the WHO clinical stage classification for enrolling patients on ARVs	• Does not inform PLHA that they will be started on ARV medicines, which need to be taken life-long
Scenario in Guntur	• Provides free ART and CD4 testing, follow technical guidelines • Poor overall management due to lack of commitment and expertise	• Advocates and pressurizes public sector to ensure access to ARVs for PLHA • Promises ARVs to all PLHA, without understanding the technical guidelines, thereby raising expectations • Treatment Counselling Centre run by NGO consortium under GFATM round IV not very successful in ensuring treatment adherence and tracing defaulters	• Private doctors handle large numbers of PLHA, without adequate training or expertise
Scenario in Ganjam	• Has recently planned to launch the ART programme in the district	• Advocates for better HIV testing and OI management before jumping on to the ARV bandwagon • Provides nutritional support to PLHA	• Prescribes two-drug ART regimen to PLHA • Does not emphasize on CD4 count test due to lack of availability in any of the sectors • Sends blood samples to cities like Mumbai and Hyderabad for CD4 count testing if patient can afford

Note: The information provided in this table is based on factual data from primary and secondary sources, as well as experiential data from patient interviews and information collected through site visits and talks with stakeholders.

ANTI-RETROVIRAL TREATMENT

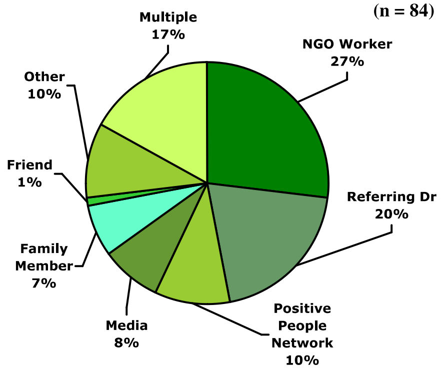
Out of the 347 PLHA in the study, just under a quarter (n = 84, 24%) had started ARV treatment. Out of these, 49 were males and 35 were females. Out of these 84 PLHA, a little more than three-fourths (n= 64) had first started taking ARVs from the public sector and the rest had started in private sector (n=20).

Of the PLHA who had started their ARV treatment in the private sector (n=20) one-fourth (n=5) had stopped taking treatment from the private sector, while half (n=10) had switched over to the public sector-run ARV rollout. The main reasons for stopping the treatment as well as switching the treatment to the public sector were lack of money and non-availability of ARV drugs at subsidized costs in nearby places.

Facilitators Instrumental in PLHA Accessing ARVs

The main enablers in facilitating access of PLHA to ARV treatment were NGO workers, Positive People Networks and referring doctors in either public or private health care facilities (Fig 15).

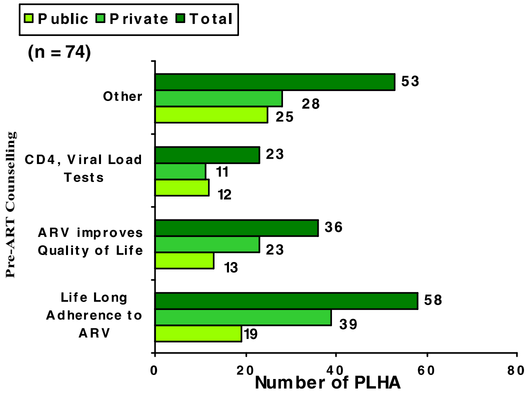
Figure 15: Actors Instrumental in facilitating PLHA Access to ARVs



Pre-ART Counselling across Sectors

Out of the 84 PLHA on ARVs, 74 reported being given some information and or counseling before being started on ARVs.

Figure 16: Key aspects of counselling prior to ART



When probed regarding the key contents of information and/or counseling provided to PLHA before starting ARVs, they reported they had been told about the need for life-long adherence to ARV drugs, that ART does not cure HIV but helps in improving overall quality of life and the importance of regular monitoring of HIV infection by doing CD4 and Viral Load Assay tests.

Fig 16 shows the range of information given on these aspects to PLHA across the public and private sector setups. From the graph it is clear that the public sector facilities totally outshine the private sector with regard to providing the essential information/ counseling on ARVs prior to the start of ART.

Costs borne by PLHA for accessing ARVs: Private Sector

The total median costs borne by PLHA, who had started on ARVs in the private sector, was Rs. 8,845 for those who had been diagnosed up to a year back and Rs. 28,900 for those who had been diagnosed between one and three years back.

Costs borne by PLHA for accessing ARVs: Public Sector

The median total costs borne by PLHA on ART in the public sector was Rs. 1,340 for those who had been diagnosed up to a year ago and Rs. 6,490 for those who had been diagnosed between one and three years ago. Direct costs in public sector include costs of medicines, cost for investigations like CD4 and costs of hospitalization. The main components under indirect costs were loss of wages and commuting costs.

This distribution of costs incurred clearly shows that at least four to eight times more expenses were incurred by PLHA in the private sector compared to PLHA who were taking ARV treatment in the public sector facilities.

Thus, costs incurred for seeking ARVs in the private sector is a prime barrier in sustaining ARV treatment and ensuring adherence to ART.

Enablers in seeking quality ART services

After reaching the public sector health facilities for treatment of ART, the enabling conditions, which facilitated access to quality ARV services were, availability of free ARV drugs and the atmosphere of maintaining anonymity and confidentiality regarding the HIV status.

Barriers in seeking quality ART services

On the other hand, non-availability of diagnostic tests such as CD4 count, the negative attitude of public sector doctors/ staff, inconvenient distance for commuting and unaffordable diagnostic costs in the public sector acted as barriers for PLHA in accessing continued and quality ART services.

Problems Reported by PLHA while accessing ARV treatment services

More than a third (n = 31) of the PLHA reported experiencing problems while accessing ARV treatment services. These problems ranged from side effects due to ARV drugs to problems of long waiting hours and queues and the attitude of health care providers and financial problems such as loss of wages/job and unaffordable costs of commuting and accessing treatment at ARV treatment services.

One female PLHA elaborating her account of side-effects due to ARV drugs mentioned that,

"Initially I took ARV treatment for one month. After I started taking medicines I suffered from acidity, vomiting, developed boils on my face and head, for which I consulted a doctor in Civil Hospital and stopped taking ARV medicines. After stopping these medicines I have no problems". *(Female, 32 years, Widowed, SY BA, Household work)*

PLHA, who were accessing private medical care, faced several problems related to expenditure incurred on medicines and travel. The following narrative elaborates these problems:

"It was too expensive. I was advised to come to the clinic frequently and every time the doctor prescribed medicines, which were too costly, and every time he also used to take consulting fee". *(Male, 36 Years, Married, Secondary School education, Unemployed)*

PLHA experienced several problems at the public sector facilities while reporting for drug collections. Because of the demands of the system, PLHA had to spend long hours in queues feeling exhausted and hungry, and due to the fear of losing their turn in the queue, they did not get time to even drink a cup of tea.

"The whole day is spent standing in a queue. If I come in the morning at 8 a.m. then I have to stand in a queue for making pass, case papers. So three times I have to stand in the queue so entire day time is spent in that." *(Male, 57 years, Widower, Diploma holder, Unemployed)*

Further, there were also problems with regard to the attitude of health care providers in the public sector facilities.

"They (providers) make us sit far away, do not touch us the way they (providers) used to do earlier (when we are not HIV positive). They tell us sarcastically, don't spread your disease to others". *(Female, 30 years, Widowed, 6th Standard Pass, Unskilled labourer)*

PLHA found the regular visits to the ARV treatment centres problematic. A male patient explained how the clinic visits negatively affected the interaction with his employer,

"I have to go for service. I have to wake up early in the morning and the whole day is spent at work. If I ask for half-day leave on Tuesday (ARV OPD day) they do not agree. They say that if this keeps happening you will need to resign". *(Female, 35 years, Widowed, 9th Standard Pass, Private sector service)*

Key Problems Experienced at Public sector-run ARV Roll out programmes

- Non availability of functioning CD4 count testing facility and the high costs of the test in the public sector
- The negative attitude of doctors and other staff members
- Structural problems resulting in long waiting hours and queues at the ART centres
- The quality of counselling and information provided regarding ART

Expressed Needs of PLHA regarding ART services

When asked what could have been done to improve the quality of ARV treatment, PLHA suggested that ART services could be improved by spreading awareness among the general public and providing information about the availability of ARV drugs in public sector facilities to PLHA.

"HIV positive patients should get the medicines earlier. At many places people don't know that ARVs are available. They should know it through the media". *(Male, 31 years, Married, 12th Standard Fail, Agriculture)*

PLHA expressed the need for decentralizing ARV delivery sites to the rural hospital level in order to reduce travel costs and travel time.

The need to establish a separate HIV unit with specialized doctors at ARV rollout sites was also expressed:

"(In Government Hospital) ...Separate department and doctors should be there for such patients. Doctors should have limited patients so that they can pay proper attention towards them." *(Male, 31 years, Married, 10th Standard Fail, Agriculture)*

Beyond ARV drugs, some PLHA also felt the need for getting nutritional supplements from the public and or NGO sectors in order to improve their physical condition.

"If somebody cannot afford the diet expenses during the treatment then government or NGOs should help them. Government should adopt some NGOs to provide proper medicines and diet to people like us". *(Male, 31 years, Married, 10th Standard Fail, Agriculture)*

Finally, they were concerned about the unavailability of CD4 count testing facilities in the ARV rollout centres and wanted these facilities to be functional as early as possible. Also in view of the future availability of CD4 count test, the estimated costs of the proposed CD4 as projected by the public sector really disappointed them and they demanded revision of these costs considering the regularity with which these monitoring tests need to be undertaken by them in the future.

"CD4 test should be made free of cost. We have to pay Rs. 1000-1200 for this in other hospitals…" *(Male 49 years, Divorced, Literate, Unemployed)*

Key Needs Expressed by PLHA Regarding ART

- Continued availability of ARV drugs
- Affordable and functional CD4 count testing facility
- Decentralisation of ART to the level of rural hospitals and taluka level health centres, and
- Nutritional supplements

SUPPORT TO MEET NON-MEDICAL NEEDS

SUPPORT TO MEET NON-MEDICAL NEEDS

Extent of support / lack of support from family

A little less than three-fourths of the PLHA (n = 251, 72%) reported receiving support from their close family members and relatives. Wives were the main supporters other than parents for male PLHA, whereas for most female PLHA who were widowed, parents were the main supporters followed by their brothers and in-laws. Fig 17 gives a detailed account of the various types of support which PLHA are getting from their family.

Figure 17: Different Facets of Family Support received by PLHA

Less than a third of PLHA (n = 111, 32%) reported experiencing problems from their family members after knowing their HIV positive status. Significantly more female PLHA as compared to males reported having problems (p = 0.01). For female PLHA these were mostly problems from their in-laws and other relatives.

"They have stamped me that I have AIDS and I am a "sex worker"! Further they said that it's your fate you have to suffer. They keep even my children at a distance, your mother is having AIDS is the way they tell. They talk in a sarcastic way." *(Female, 27 years, Widowed, 4th Standard Pass, Unskilled labourer)*

The main problems reported by both male and female PLHA revolved around the discriminatory attitude and behaviour shown by their close family members towards them.

"When family members came to know (about HIV positive status) they kept clothes, food utensils as well as water utensils separately. They did not allow us to enter the home. They removed me and my husband from home. We stayed in a stable for 15 days. When my husband died, he was so well wrapped up in a cloth such that nobody could even see his nail. People came closing their mouth with their hand. Some people did not come. I was removed from the home for 1 year. At present I stay here but nobody comes here. The other members in the home say that you can eat or drink what you want but don't come in contact with children. You just stay away." *(Female, 35 years, Widowed, 6th Pass, Semi-skilled worker)*

Expectations of PLHA from their family

- A range of expectations by female PLHA from the parental family from getting continued support from family members to support in fighting legal battles to claim and/or regain their land and property rights from their in-laws.

- Need for family members to behave with them as normal human beings and expect non-discriminatory behaviour from them.
- Worry regarding the future of their children and expectations from family members to take care of children after their death.
- Expectations around help in earning livelihoods and economic rehabilitation from family members by male PLHA

Extent of support / lack of support from people other than their family

More than 90% of PLHA reported getting support from people other than their family members including NGOs, friends and neighbours. Fig 18 gives a detailed account of the various types of support which PLHA are receiving from NGOs.

Less than a fifth (n = 69, 19%) reported having unpleasant experiences from their neighbours, friends and villagers and in few cases from doctors and NGO workers. Types of unpleasant experiences include:

- Stigmatizing and discriminatory behaviour shown by others.

Figure 18: Different Facets of NGO Support received by PLHA

"They are treating me as a different human being - as though I had done some mistake. They kept my utensils cloths, separately. They have labelled our family as 'AIDS family' *(Female, 25years, Married, Illiterate, Household work)*

- Discrimination of children of PLHA by neighbours.

"Our children were discriminated at school by telling them your parents are HIV/AIDS so we won't talk to you, or play with you." *(Female, 29 years, Married, 5th class, Agriculture work)*

- Prevented from utilizing common public amenities in the villages.

"Nobody talks in front of me. Everybody talks behind me like; her husband has that disease so she would also have the same disease so she should not be allowed to fetch water from here". *(Female, 25 years, Widowed, 5th Pass, Laborer-Unskilled)*

Change in attitudes and behaviour in recent times were reported and attributed to the efforts made by NGOs in carrying out HIV/AIDS awareness programmes in the community.

Expectations of PLHA from people other than family

- Lots of expectations - mostly from NGOs
- Expectations restricted not only to just psychological, financial, treatment related and/or legal support but also support regarding economic rehabilitation, facilitating and providing nutritional supplements and even for dispensing ARV drugs.

Table 5: Summary Sheet Elaborating on Barriers and Enablers in Accessing Continued and Quality Services for PLHA

ENABLERS	BARRIERS
1. Availability-related Factors: • Availability of doctors / staff in public and private sectors • Availability of medicines for OI management and ARV drugs • Availability of testing kits, diagnostic facilities • Availability of NGOs and Positive People Networks • Clean health care facilities • Conducive atmosphere for maintaining anonymity and confidentiality regarding HIV status at health care facilities **2. Affordability-related Factors:** • Affordable cost of investigations and treatment **3. Accessibility-related Factors:** • Convenient distance for commuting • Convenient timings **4. Acceptability-related Factors:** • Support and facilitation by family member(s) • Accompaniment by somebody in accessing health care facilities	**1. Provider-related Factors:** • Negative attitude of doctors / staff in public and private sectors • Rude behaviour of doctors / staff in public and private sectors • Poor quality of counseling and information provided regarding HIV testing, OI management and ART **2. Geographical distance or location related-Factors:** • Inconvenient location of facilities for testing, OI management and ART delivery in the public sector • Inconvenient distance for commuting over distances to reach the facilities **3. Facility/ Infrastructure-related Factors:** • Non-availability of diagnostic tests like CD4 count • Structural problems resulting in long waiting hours and queues for drug collections **4. Medicine-related Factors:** • Side-effects due to ARV drugs **5. Cost-related Factors:** • Cost of investigations • Cost of medicines • Costs incurred for availing treatment for HIV-related illnesses • Cost of treatment for recurring or chronic illness(s) • Costs incurred for seeking ARVs in the private sector • Expenditure of medicine and travel –direct and indirect costs

IMPLICATIONS OF THE STUDY FINDINGS FOR NACP

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- Most of the PLHA needing care and support are young, rural residents who have less than 10 years of education. They belong to the poorer sections of the community, with more than half of them having no stable income. Hence the poor, particularly the rural poor, need to be targeted as a special group needing attention.

- The high number of widows among the PLHA interviewed and the number of PLHA with another infected person in the family shows the extent of the problem in rural India.

- In poorer contexts, where there are limited job opportunities, the vulnerability of HIV affected families is doubly increased due to higher levels of unemployment and lower household incomes combined with poor access to HIV services in the public sector with resultant increase in expenditure in the private sector. Hence there is an urgent need for the programme to focus attention on poorer states and districts and in coordination with the NRHM, strengthen the public health care sector so as to deliver the entire range of services from HIV testing to management of opportunistic infections (OI) and ART.

- The family and close kin of PLHA are found to play a variety of supportive roles, key among which is facilitating access to HIV testing and treatment of OIs. While there are instances where PLHA have complained of stigmatizing and discriminatory behaviour by their families, there is overwhelming evidence of their support to PLHA. Hence there is a clear mandate for involving them in care and support activities including ensuring adherence to ART.

- Private providers, apart from their role in provision of medical care, are also seen to facilitate access of PLHA to appropriate services and provide advice and support. However, they fall short with regard to following programme norms for taking consent, providing pre and post-test counseling, and counseling for ART. Also, in contexts where the public sector ARV roll out is yet to be implemented, it is the private sector which fills this gap. Hence, the programme needs to take the lead to sensitize, train and involve them in providing rational HIV care, so that PLHA who seek care in the private sector do not have to bear excessive costs on unnecessary investigations and wrong medications.

- NGOs in all the sites are seen to be playing the most supportive role for PLHA. The range of services provided by them help PLHA and their families cope with HIV as well as accessing care for HIV. It is imperative for the NACP to make them equal partners without making them lose their sensitivity to the needs of PLHA, since it is with their help and support that PLHA are able to meet both their medical and non medical needs, both of which have emerged as equally important for PLHA.

- While the NACP has been increasingly making access to HIV care a reality for PLHA, particularly over the last three years, there are several areas for qualitative improvements:
  - Attending to infrastructural problems such as non-availability of staff, testing kits and medicines at VCCTCs and ART centres
  - Ensuring the entire range of care and support services are provided in a patient friendly environment
  - Ensuring quality of pre- and post-test counseling
  - Ensuring availability of medicines for treatment of OIs, which has emerged as a key need of PLHA
  - Decentralising OI management so as to facilitate ease of access for PLHA, a majority of whom, are currently seeking care in the private sector and consequently bearing more cost.
  - Making OI management an integral part of ARV treatment, since management of OI seems to be an unmet need even in the case of patients on ARVs.
  - Sensitizing staff, including doctors, at all levels so as to bring about a change in their negative attitude, which is currently a barrier to accessing quality and sustained HIV care.
  - Decentralising ART delivery through involvement of family and NGOs so as to reduce the indirect costs of accessing ART.
  - Ensuring availability and affordability of functioning CD4 count testing facility in ART centres so as to reduce the burden of undergoing CD4 count in the private sector.
  - PLHA have expressed a need for access to timely and need-based information about the disease and about the facilities available in the public sector. This indicates a need for shifting the focus of HIV/AIDS awareness campaigns, from merely generating awareness about HIV/AIDS to providing clear and precise information about services and facilities.

- Considering the varied nature of care, support and treatment needs of PLHA at different stages of the illness, while planning for all these needs, the wider framework of Comprehensive HIV/AIDS care, as advocated by the UNAIDS, needs to be taken into account.

- The programme needs to weave in the different providers to seamlessly address both medical as well as non-medical needs of PLHA, which is the only way to reduce the burden of HIV/AIDS. Such public-private partnerships would also help in ensuring continuum of care in and across public and private sectors thereby minimizing testing and treatment related costs for PLHA.

RESEARCH RECOMMENDATIONS

Developing indicators of access

In a diverse setting like India where “access” assumes context-specific meanings, there is a need to identify appropriate composite quantitative and qualitative indicators, which take into consideration factors such as the presence of different kinds of providers who cater to the PLHA population, the quality of care delivered by them, the burden of disease and the burden of accessing care of varying quality from these different providers. There is, hence, a need for different kinds of studies to generate data to help develop these indicators.

- Studies, which delve into help seeking and enablers and barriers to accessing care in different contexts
- Periodically undertaken situation analysis studies using qualitative methods
- Studies on disease burden and coping mechanisms at the individual, family and community levels
- Studies to document the ever changing and varied needs of PLHA at different stages of the illness
- Studies to determine the response of public, private & NGO sectors to the needs of PLHA

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ANNEXURE

ANNEXURE

CONSENT FORM

We work with an organization named The Maharashtra Association of Anthropological Sciences (MAAS), which is a non-government organization (NGO), based in Pune district of Maharashtra state, India. We have been involved in research activities in the areas of health and development for the last 28 years. We have been conducting research studies on various aspects of TB, HIV and AIDS. We have now been provided support by the Resource Centre for Sexual Health and HIV/AIDS a Delhi-based organization that works closely with the National AIDS Control Organization (NACO), New Delhi, to understand the experiences and problems faced by people like you while accessing care and support at various institutions and providers for their illness.

The interviews we are conducting in Sangli/Guntur/Ganjam with people like you are part of a larger study, being conducted simultaneously in other states of India as well. We wish to understand how you became aware about different providers and services available for HIV/AIDS, your perceptions/experiences about these services, various individuals and institutions which have helped you in availing these services and problems / barriers which you might have faced while accessing these services and the money you have spent in availing these services, etc. The information you provide us would help the government in planning effective programmes for people living with HIV/AIDS. Please be aware that this interview is not part of any national programme, nor does it guarantee you any special benefits with regard to the treatment or care services from any of the sectors or providers. This is simply an attempt we are making to document and communicate the ground level situation around HIV/AIDS care to programme officials.

We would like this interview to be two-way process, and would like you to feel free to express your views and opinions while answering these questions. We give you our assurance that your identity, including the name and the address of this organization where we are conducting the interview, would not be documented and or reported or communicated anywhere, anytime. This interview will take approximately 40 45 minutes to complete. During the interview, if you feel that some questions are difficult for you to understand, please let us know and we will try to explain them better. Likewise if you feel that some of these questions are making you feel uncomfortable or are hurting you in any manner, you can let us know and we could move to the next question. Also, if at any time you would like to discontinue the interview, you are free to do so. We assure you that the information provided by you would be used only for the study purpose.

We are aware about your sufferings and our sympathies will remain with you always. As a token of appreciation of your participation in this interview, we would like to offer you a small amount of 150 Rs to cover your costs of one time travel and meal. We are well aware that this amount is highly insufficient and would not be of much help to you, but this is the amount that is available in the study budget.

This information we have given you so far is to inform you about the study and also to make you aware about your rights regarding the participation in the study. It is entirely upto you to decide whether you would like to participate in the study. Please be assured that even if you refuse to participate in the study, you will continue to receive the care and support you have been receiving from this or any other health facility and you will not be subjected to any harassment.

In case you do decide to participate in the study, we would like you to sign or provide your thumb impression, to confirm that you have been told about the study and the purpose of the study and that you are agreeing to be interviewed of your own free will without any coercion from anybody. We will start the interview once you have signed this form. We thank you for your patience hearing.

Thumb impression (Participant) Date:

Sign (Interviewer): Time:

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ABOUT MAAS-CHRD

Maharashtra Association of Anthropological Sciences (MAAS) is an academic non-governmental organization based at Pune, Maharashtra in Western India. Since 1976, it has functioned through three arms, Centre for Health Research and Development (CHRD), Centre for Tribal and Rural Development (CTRD) and a quarterly popular publication Hakara (Clarion Call). MAAS is involved in training in research methodology, health and development through course work, seminars, symposia and workshops. It undertakes basic and intervention research in the areas of public health and development through holistic perspective. MAAS has organic links with the University of Pune and other academic and research institutions in India

Centre for Health Research & Development (CHRD) is a unit of MAAS, with a focus on health-related research issues. The main areas of research in CHRD are HIV/AIDS, Tuberculosis, Leprosy, Malaria and Reproductive and Child health. The researchers at CHRD have training and expertise in different disciplines like medical anthropology, health and social sciences, public health and epidemiology. CHRD is a partner in a research consortium led by the London School of Hygiene and Tropical Medicine, London, UK, called TARGETS (Team for Applied Research to Generate Effective Tools and Strategies for Communicable Disease Control), a five-year programme (2005-2010) funded by the UK Department for International Development (DFID).

Studies on Tuberculosis and HIV at CHRD: CHRD initiated studies on TB and HIV/AIDS under the Tuberculosis Knowledge Programme, a five-year programme (2001-2006) undertaken in collaboration with London School of Hygiene & Tropical Medicine, and funded by the UK Department for International Development (DFID). The studies under this programme, which are now being continued under TARGETS, broadly aim to identify and study the gaps between policy and practice, using a mix of qualitative and quantitative research methods. In the last five years, CHRD has been able to establish itself as an organization committed to working on policy and programme at local, national and international levels. The outputs under these programmes have been in the form of research reports and publications, papers in peer-reviewed journals, participation and presentations in conferences and invitations to research and policy meetings, both at the national and international levels.