

**EMPOWERMENT OF ANTIRETROVIRAL TREATMENT (ART)  
BENEFICIARIES IN KERALA, INDIA**

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BENEFICIARIES IN KERALA, INDIA**

*Dissertation submitted in partial fulfillment of the requirements for the degree of  
Master of Philosophy in Applied Economics of the Jawaharlal Nehru University*

**Aswathy P R**

M.Phil. Programme in Applied Economics

2008-2010

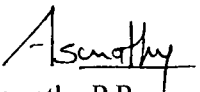
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## Declaration

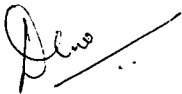
I hereby affirm that the work for the dissertation, **Antiretroviral treatment (ART) beneficiaries in Kerala, India**, being submitted as part of the requirements for the degree of Master of Philosophy in Applied Economics of the Jawaharlal Nehru University, was carried out entirely by myself and has not formed part of any other programme and not submitted to any other institution/university for the award of any Degree or Programme of Study.


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***Dedicated  
To My  
Beloved Parents***

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**Aswathy P R**

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M.Phil Programme in Applied Economics, Jawaharlal Nehru University, 2008-10  
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The need for free access to Antiretroviral Treatment (ART) which consists combinations of antiretroviral (ARV) drugs to maximally suppress the progression of HIV and increases the life expectancy, takes a greater urgency given the economic status of majority of the HIV infected cases in India. Lack of preventive vaccine, absence of curative therapy, and long incubation and morbidity period of HIV infection demands heavy expenditure. In addition to that, the trajectory of HIV infection is accelerated by unaffordable and inaccessible antiretroviral drugs (ARVs). As a way of understanding the context of ART provision in India, this study seeks to examine the scenario of ART across Indian States, especially those with high prevalence; the variations in dropout rates are also tracked. The major research questions of the present study therefore are: (a) Has ART in Kerala made a significant impact in improving the overall well-being of PLHA who have access to it? (b) If ART has had a positive impact, what other institutional factors have contributed to this achievement, and how can it be improved and sustained? (c) If the impact of ART has been negative, what impediments may have contributed to this, given that a great many studies across the world have shown that ART does improve different aspects of the wellbeing of PLAH to a considerable extent?

The present study is an attempt to answer these questions through a field survey based on the survey questionnaire of 120 ART beneficiaries in six districts of Kerala and a case study of six ART beneficiaries. The study aims to provide a more holistic picture of the well-being of ART beneficiaries, and relies upon a notion of empowerment. Thus the experience of wellbeing must necessarily involve not merely the preservation of health or the restoration of incomes, but also social integration. The study finds that the wider impact of free ART availability has been largely positive, which includes better general health status, collective participation within the HIV/AIDS community and recovered economic status. '*Power from within*' is the most attained constituent of empowerment. However failure to overcome stigma and discrimination has negatively affected the attainment of the essentials of empowerment. Around 44% of the ART beneficiaries are unemployed and they are economically vulnerable. The life-long nature of ART treatment makes it essential to rehabilitate the patients by providing them with proper opportunities.

Key Words: Antiretroviral treatment (ART), People living with HIV/AIDS (PLHA), Empowerment.

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## ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARV	Antiretroviral
CSW	Commercial Sex Workers
EMHF	The European Men's Health Forum
GIPA	Greater Involvement of People living with HIV/AIDS
HAART	Highly Active Antiretroviral Treatment
HIV	Human Immune Deficiency Virus
IDU	Injected Drug Users
NACO	National AIDS Control Organization
NGO	Non Governmental Organisation
O I	Opportunistic Infection
PLHA	People Living with HIV/AIDS
KSACS	Kerala State AIDS Control Society
QALY	Quality Adjusted Life Years
SACS	State AIDS Control Society
TES	Treatment Related Empowerment Scale
UNAIDS	Joint United Nations Program on HIV/AIDS
UNDP	United Nations Development Program
USAID	United States Agency for International Development
WHO	World Health Organization
VCTC	Voluntary Counseling and Testing Centre

## Chapter 1

### INTRODUCTION

#### 1.1 The Context

India has a large global burden of Human Immunodeficiency Virus (HIV) infected individuals, who need but do not have access to life-saving drugs (National Aids Control Organization, 2006). Lack of preventive vaccine, absence of curative therapy, and the long incubation and morbidity period of HIV infection demands heavy expenditure. Even though the prognosis for the people living with HIV (PLHA) has improved in developed countries, in developing countries, 95% of the HIV infected people live with limited health provision, nutritionally related diseases, as well as threats of other epidemics that make matters worse (UNAIDS, 2009). In addition to that, the trajectory of HIV infection is accelerated by unaffordable antiretroviral drugs (ARVs) which also difficult to access. The introduction of antiretroviral therapy (ART) is expected to mitigate the alarming effects of HIV infection to a considerable extent and increase the life expectancy of PLHA<sup>1</sup>. Given the economic status of the majority of HIV-infected people in India, the need for free access to ART has become more urgent. In 2004, as a part of World Health Organization's (WHO) programme for universalisation for free access to ART<sup>2</sup>, the Government of India introduced free access to ART for the population in the country that was vulnerable to HIV/AIDS<sup>3</sup>.

#### 1.2 Significance of the Study

Treatment is essential for the 36 million people already infected with HIV/AIDS<sup>4</sup>, failing which a vast majority will die of the disease. In the global debate on free access to ART, it is argued that this programme is for the people living in an

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<sup>1</sup> Antiretroviral therapy is a treatment for HIV-infected people. It is a combination of three or more antiretroviral drugs with the aim of maximal viral suppression for the longest period and minimal adverse effect to reduce mortality and morbidity (Over et al., 2004).

<sup>2</sup> In 2003, the World Health Organisation (WHO) launched the prominent "3 by 4" campaign, with the goal of treating three million people by 2005 (World Health Organisation Document, 2003).

<sup>3</sup> In 2004 India set a goal of putting 100,000 patients on ART within the year and it reached 60,000 people by mid 2007 (NACO, 2005).

<sup>4</sup> With the ability of ART to dramatically decrease viral replication, the chances of transmitting the virus has diminished correspondingly; indeed, antiretroviral drugs administered during labour and delivery have dramatically reduced (by well over 50%) maternal to new born child transmission of HIV; also, after the introduction of ART, AIDS death rates during the past six years have plummeted in the United States and other developed countries (Consensus statement on Antiretroviral Treatment for AIDS in poor countries by the individual members of the faculty of Harvard University, 2002).

advanced state of the disease and that spending a large amount of money on them may not be economically viable, especially when many other public health programmes are struggling to get adequate financial support. Supporters of the government-financed antiretroviral therapy argue that refusal to finance AIDS treatment is like pushing people with HIV out of the lifeboat (Over et al., 2004). According to them, the provision of antiretroviral therapy in developing countries would have positive synergies for the health care system<sup>5</sup>. A number of studies have shown that ARV therapy dramatically reduces morbidity and mortality among HIV-infected individuals, in both industrialized countries and developing countries. The most effective response to the HIV epidemic is the provision of ART (Grubb, Perriens and Schwartlander, 2003).

As far as a developing country like India is concerned, the Indian public sector provides primary to tertiary HIV/AIDS health care largely free of cost. At present, this accounts for a relatively small share of the national health expenditure. However, this may increase in the near future due to the growing role of the government in providing free generic ARVs. To get the real picture of the effectiveness of ART on HIV-infected people it is necessary to ask whether such treatment actually brings sizeable physical, social and economic gains to ART beneficiaries.

This study tries to assess the health, social, and economic empowerment of ART beneficiaries in Kerala<sup>6</sup>. However, as a way of understanding the background of ART provision in Kerala, it attempts to first sketch a picture of the ART coverage in the national context and look at the State-wise estimates. Further, this study tries to reflect on the more specific case of the successes/failures of the ART provisioning through Kerala's public health system, which may be of relevance to health-policy making and provisioning both in regional and national context.

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<sup>5</sup> Some observers believe it is possible to take a position on whether the governments of poor countries should fund AIDS treatment based on ethics alone, without elaborate analysis. The views of advocates and opponents of government financing of AIDS treatment on ethical grounds can be simplistically described in terms of the lifeboat metaphor.

<sup>6</sup> Kerala is believed to show a pattern of low prevalence with regard to HIV infection, but anecdotal evidence reveals that HIV infection in the State is much more than revealed by official estimates, that the treatment of opportunistic infection is unaffordable to many and the case of ART is unimaginable (Timothy, Ajithkumar and Rajan, 2006).

### **1.3 Survey of Existing Literature**

Available studies indicate that greater support for the scale-up of HIV/AIDS treatment programs has been lacking for a number of reasons. These include skepticism that ART may not generate health and economic benefits that are sizable enough to offset its costs and a related debate about how best to allocate scarce health resources in developing countries (Canning, 2006). Once treatment is initiated, it must be taken for the entire duration of a person's life; there has also been concern about the wisdom and sustainability of current expenditures on ART. The people who begin receiving ART today will become tomorrow's 'medical pensioners' whose treatment costs will become the responsibility of countries in which they live and organizations that support these countries (The Economist, 2006). However, the evidence on the various impacts of providing ART has been slow to emerge, until recently, it has been impossible to properly evaluate treatment programs and assess whether the expenditure on such programs may be justified on economic as opposed to humanitarian grounds.

#### **1.3.1 Studies on the Impact of HIV/AIDS on the Lives of the People**

Numerous studies have been conducted to assess the socioeconomic impact of HIV/AIDS. Desmond et al. (2000) argue that because HIV/AIDS causes significant rise in illness and death in prime-age adults, the negative effect is seen in both households and communities. The documented economic impact at the household level includes decreased income, increased costs, decreased productive capacity and changing expenditure patterns. The decrease in income, together with the increase in health care expenditure, leads to a fall in expenditure on other basic needs. This shrinkage and reallocation of the household budget reduces food security, thereby increasing the chances of malnutrition and sickness among the other members of the household. In a longitudinal, controlled study of households affected by HIV in South Africa, (Booyesen et al., 2002) found HIV-affected households poorer, more dependent on non-employment sources of income and spending less money on food. The total cost of morbidity to households was relatively low where unemployment levels were very high. Ill household members were primarily cared by family members, with no direct loss of income reported. A larger number of children in affected households were not attending school and orphans were found to be sheltered

in both affected and non-affected households. Similarly, Bachmann and Booyesen, (2003) found that HIV/AIDS affects the health and wealth of households aggravating pre-existing poverty. Thirty-five per cent of affected households needed someone to accompany an ill member to the health service and the domestic caregivers spent five hours per day with ill members. The study found that, over six months, household expenditure decreased significantly and more rapidly in HIV-affected households than in unaffected households. On the twelve and eighteen month follow-up on the same households, Bachmann and Booyesen (2004) found affected households were less likely to recover from illness, less able to perform the usual tasks and required more care at home. The individuals in the affected households were more likely to need admission to hospital and more likely to lose income while ill.

In Australia, people living with HIV/AIDS were found to be at an economic disadvantage with 26.9% of the sample living below the poverty line and over half the sample listing government benefits as their main source of income (Gierson et al., 2007). The European Men's Health Forum (EMHF, 2005) reported a study of HIV positive adults in Europe where 30% of the respondents in the study had to quit waged employment for HIV-related medical reasons and 34% reported that they need to reduce their working hours due to medical reasons. Fifty-three per cent reported that HIV-related disability lead to unemployment or the need to stop working for six months or more.

### **1.3.2 Studies on the Impact of ART in Developing Countries**

Antiretroviral treatment provides hope for HIV/AIDS-affected persons. For instance, Cleary et al., (2004) conducted an economic evaluation using Markov modeling to establish the cost-effectiveness of ART in a South African township and found that the average life expectancy was 8.33 years for patients on ART and only 2.27 years for patients not on ART. Patients on ART reported higher quality of life as compared to those not on ART. Effectiveness of ART was measured in terms of quality-adjusted life years (QALYs) gained, a common outcome measure, which combines both the quality and quantity of life. The incremental cost per QALY gained on ART indicated that antiretroviral treatment is efficient in economic terms. In addition, the clinical results of this study demonstrated the potential for ART to delay many of the



individual and societal consequences related to early mortality, by extending and improving the quality of life.

A study on the impact of antiretroviral treatment on the labour supply of HIV/AIDS patients (Thirumurthy et al., 2005) which used longitudinal survey data collected in collaboration with a treatment program, estimated the economic impacts of antiretroviral treatment in Africa. The study found that there was a 20 per cent increase in the likelihood of the patients participating in the labour force and 35% increase in hours worked weekly. Since patient health would continue to decline without treatment, these labour supply responses are underestimates of the impact of treatment on the treated. The upper bound of the treatment impact, which is based on plausible assumptions about the counterfactual, is considerably larger and also implies that the wage benefit from treatment is roughly equal to the costs of treatment provision. The responses in the labour supply of patients' household members are heterogeneous.

Another study which explored the short-term socio-economic effect of antiretroviral treatment (ART) in HIV positive patients attending the Perinatal HIV Research Unit clinics in Soweto, South Africa, looks into the overall increase in mean personal and household income following commencement of ART. Mean personal income rose 53% over the baseline income. A decrease in the number of meals missed in households was noted in 10% of the sample. The leading themes regarding income were change in employment status and social grants. Antiretroviral treatment increased the capacity to seek employment and unemployed individuals were actively searching for work. Patients noted an improvement in wellbeing, with fewer to no episodes of illness, and improved quality of life from three months after starting ART. Empirical evidence suggests that individuals gain substantial benefits from being on ART despite the socioeconomic challenges in South Africa, (Varsh, 2008). Another study which analyses the life expectancy of people on ART and the cost effectiveness of the programme of free access to ART in India, found that ART will lead to major survival benefits and is cost-effective by World Health Organisation criteria (Feedberg et al., 2007).

A qualitative study done in the rural wards of North Tanzania investigated the impact of ART availability on perceptions of HIV and its implications for prevention and

showed that people on ART often report feeling increasingly comfortable with their status, reflecting a certain 'normalization' of the disease. This is recognized by the people affected by HIV in regaining their physical health, returning to productive activities and receiving emotional support from health service providers. Overcoming inner feelings of shame facilitated disclosure of HIV status, helped to sustain treatment, and stimulated Voluntary Counseling and Testing uptake. A mix of qualitative methods was used including semi-structured interviews with 53 ART clinic clients and service providers (Roura et al., 2009). In Kenya, free access to ART had a positive effect on PLHA. An analysis of employment, income and health status gave a picture of reducing health spending for PLHAs, improved health status and increased labour force participation from the part of ART beneficiaries (Sarah, 2007). Xu et al., (2007) reported that in rural Eastern China, the treatment costs consume a significant proportion of the family's income. Patients believe they cannot engage in hard labour, give up their existing jobs and also have difficulty in finding other jobs. Ill patients depend on their family members for care, which in turn means that the family members cannot leave the village to get better paid work in the city. This economic impact is not limited to developing countries.

To assess the potential economic benefits of providing treatment to working adults, Larson et al., (2008) investigated the impact of ART for tea-estate workers on days harvesting tea per month in Kenya. They found that the first year of treatment had a large, positive impact on the ability of workers to undertake their primary work activity. However, evidence from Sub-Saharan Africa indicates that providing access to treatment in the absence of other support services (for e.g., food and nutrition, micro-financing and employment assistance, and transportation) prevents the effect of treatment from extending beyond physical health to the social and economic health of individuals, their families, and the community (Wagner et al., 2007). In addition to ART, poor people also require economic support to re-establish their livelihoods. For these reasons, treatment programmes should be combined with economic programmes offering livelihood support and social protection initiatives (Russell et al., 2007).

The experience of programmes in emerging economies like Brazil gives insight to the long-term effects of ART use where the ART medications are always available and also the treatment for opportunistic infections where ART side effects are not

available. The socio-economic and demographic impact of ART on PLHA in Thailand analyzed the consequences of HIV on the family, community and health care system which shows the improved quality of life, social, economic and health status (Coeur, Lelievre and Collins, 2006). In Central and Eastern Europe, Central Asia, Southern Africa and other middle-income countries, ART availability is noted to have enabled successful economic empowerment, improved family health status, social networks and higher labour participation (Maher, 2008). In fact, there are certain barriers which make the free access of ART difficult. Chikaphupha et al., (2009) conducted a study on Access to HIV treatment and care amongst commercial sex workers in Malawi and found that there is a lack of early treatment-seeking practices amongst commercial sex workers (CSW), ill-treatment of CSWs at health facilities by health practitioners, lack of adherence to treatment by most of CSWs.

### **1.3.3 Studies on the Impact of ART in Developed Countries**

The research in the developed world shows the benefits from ART to users more clearly. Patients under treatment in Europe reported that ART had contributed the most for improving their quality of life (EMHF, 2005). In the United States, the impact of ART is very visible in employment of PLHA, according to many studies. An analysis of longitudinal data of ART beneficiaries shows that ART increases the probability of remaining and that the related incremental income is sizable compared to the incremental cost of ART (Goldman and Bao, 1996). This study says that patients who are working like to remain employed because of treatment with ART. In the case of those remaining employed, the employment effect is statistically significant in the less advanced stages of infection and may lead to the greatest gain in employment.

There is also literature that probes the barriers to treatment and other conditions necessary for drug adherence. A study by Kalichman et al., (2006) on African Americans living with HIV/AIDS investigated the association between education literacy and HIV treatment adherence, and the barriers to care among African Americans living with HIV/AIDS. The study found that education and health literacy are important factors in HIV treatment adherence and access to medical care. Interventions are needed for improving treatment adherence among low-income

minorities, and such interventions will need tailoring for individuals with limited reading ability.

### **1.3.4 Literature on Methodology in Research on ART**

Diverse methodologies have been developed for these studies: some are strictly quantitative, seeking to reduce the experience of HIV/AIDS and the impact of ART to manageable and quantifiable indicators. Others have sought to combine quantitative and qualitative methodologies to capture more complex experiences, such as that of empowerment. The latter are particularly relevant for the present study. For example, Webb, Horne and Pinching (1999) present a novel method for assessing patients' perceptions of empowerment in the context of drug therapy or the Treatment-related Empowerment Scale (TES). The 10-item TES was specifically constructed to address components of communication, treatment choice, decision-making and satisfaction. Evaluation of the scale in a cross-sectional anonymous survey of 43 patients with advanced HIV infection revealed acceptable internal reliability and evidence of both criterion and discriminate validity. Patients who perceived a high degree of treatment-related empowerment were less likely to view doctors as overly reliant on prescribing medicines and reported lower rates of intentional noncompliance. TES has scope as a concise measure of patients' degree of control over the selection and use of drug therapy, and may be of particular value for current combination therapy regimens.

### **1.4 The Central Research Question and Methodology of the Present Study**

In India, scholars have investigated mainly employment and other kinds of survival benefits of PLAH on ART. Available study on Kerala focuses on employment status. Ajithkumar et al. (2007) argue that impact of free ART on vocational rehabilitation, particularly the employment status of ART beneficiaries before and after taking ART, will result in significant improvement in the employment status. However, the present study aims at a more holistic picture of the well-being of ART beneficiaries and relies upon a notion of empowerment that contains other significant elements along with employment status that may not be amenable to strict quantification. The latter are extremely relevant when we consider the fact that the stigma around the disease is no less in Kerala, despite its high levels of literacy and other positive indicators of social development (Kerala Human Development Report, 2005). Thus the experience of wellbeing in such a context must necessarily involve not merely the preservation of

health or the restoration of incomes, but also social integration. Studies that may aim narrowly at one of these are likely to miss out on vital though non-quantifiable aspects of wellbeing, which are nonetheless important from a policy perspective.

The major research questions of the present study therefore are: has ART in Kerala made a significant impact in improving the overall wellbeing of PLHA who have access to it? If so, what other institutional factors have contributed to this achievement? How can the wellbeing of PLHA be improved and sustained? If this is not possible, what are the impediments that may have contributed to this – given that a great many studies across the world have shown that ART does improve different aspects of the wellbeing of PLAH to a considerable extent?

Methodologically, this calls for a mix of qualitative and quantitative methodologies. The quantitative analysis of secondary data relevant to understanding the coverage of ART across Indian States and of primary data collected through survey questionnaire forms a part of the study. The major sources of secondary data are the National Aids Control Organization (NACO) and Kerala State Aids Control Society (KSACS) database and publications. Inter-State variations in ART coverage, variations across gender and age, variations in dropout rates, etc., will be tracked. This will form a necessary background for inquiry relevant to the major objective. Special attention will be paid to quantitative information about Kerala, so that we may be able to gain a broad sense of the increase in accessibility of ART in Kerala.

The analysis of qualitative information collected through semi-structured interviews and questionnaire will be vital in gaining an understanding of the degree and kinds of wellbeing achieved by PLHA through ART. Here, the semi-structured interviews try to capture the following aspects of wellbeing, before and after free access to ART was made available. We seek to probe the different aspects of empowerment thus:

- a) health empowerment through a survey that captures ART users' access to general health care, prevalence of nutritional weakness through analysis of daily diet, weight, etc., vulnerability to other epidemics and other illness.
- b) Social empowerment through the assessment of support from family networks, support from/participation in community/local bodies, etc.

c) Economic empowerment through income and employment status, and possible economic gains/losses.

### 1.5 Analytical Framework

Empowerment is regarded as a multidimensional and complex process operating at the level of both the individual and of societal structures (Boulding, 1989). It is a construct that links individual strengths and competencies, natural helping systems, and proactive behaviours to social policy and social change (Rappaport, 1981, 1984)<sup>7</sup>. Naila Kabeer suggests that “empowerment refers to the process by which those who have been denied the ability to make strategic life choices acquire such ability” (Kabeer, 1999). These definitions makes clear that only those previously denied such abilities can be considered to be empowered and also that the choices in question are strategic.

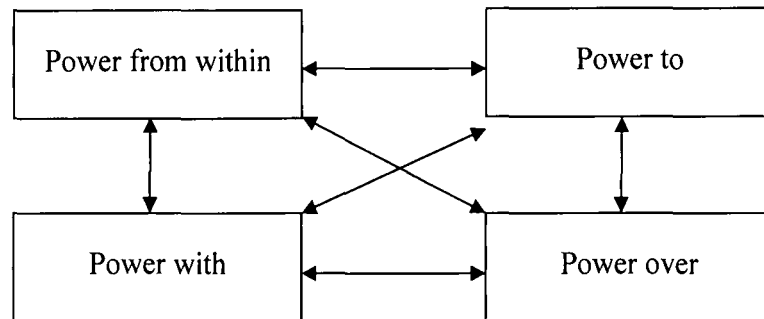
Central to the idea of empowerment is the idea of power (Kabeer, 1999). This is how the notion of empowerment will be used in this study. This study uses the feminist framework of empowerment to assess the health, social and economic empowerment of Antiretroviral Treatment beneficiaries in Kerala. There are different schools of thought within feminist discourse, ranging from moderate to radical thinking, and with diverse ontological and epistemological standpoints (Olsen, 1999). An understanding of the feminist analysis of power may be derived from the works of Rowlands (1997), Townsend et al. (1999) and Allen (1999).

Although there are some differences between them, particularly regarding the significance of the role of *‘power from within’* and the desirability of a male-inclusive approach, the key feature in feminist theorizing about power is the emphasis on power as a relational concept. This particular framework emphasises the multi-dimensional nature of power at different levels: personal, group, regional, national and international. This feminist framework suggests four elements of power: *‘power from within’*, *‘power to’*, *‘power with’* and *‘power over’*.

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<sup>7</sup> Douglas D. Perkins (1995).

**Figure 1.1**  
**Empowerment Framework**



Source: Wong, 2003

This figure explains the interrelatedness of the four components of power. They are mutually interconnected and interdependent. As Shields (1995) remarks: 'These components [of an internal sense of self] include claiming pieces of their identity, the development of self value, the development of self-acceptance, and the development of trust in terms of self-knowledge'. In order to assess the empowerment, this study would like to analyse the problem on the basis of this empowerment framework, understanding each of its components in the following manner:

***'Power from within'***: Otherwise known as personal power, it includes power from both body and mind. ART adherence will have an impact on both body and mind by enhancing their physical health status and encouraging PLHA to lead a better life. Thus in this study ***'power from within'*** will be assessed by looking into the changes in six important aspects such as opportunistic infection, body weight, general health status, food and nutritional security, stigma and discrimination and finally food and nutritional support which constitutes both physical and mental fitness.

***'Power to'***: In the feminist framework of empowerment, this highlights the generative and productive capacity of an individual. There are three interrelated objectives: as a means of liberation (Townsend et al., 1999), as a means of participation (Allen, 1999) and as a means to mobilise for change (Kabeer, 1994). In this study, we will limit ourselves to assessing ***'power to'*** by assessing what the ART beneficiaries are able to do productively whether they are able to actively earn an income.

***'Power with'***: This emphasises collective forces, where people cooperate with each other to solve problems and to attain goals. It is mainly concerned with a sense of

solidarity, capacity building, social networks and organizational strength. '*Power with*' intended to demonstrate the idea of 'I cannot, but we can'. In this particular this study, '*power with*' will be assessed through the participation of ART beneficiaries in different kinds of social and cultural networks, and also in collective action to improve their welfare. This study would like to assess frequency of care centre visits, housing and family support and change in household composition, to understand whether they add to a sense of collectivity among ART users. These are the social spaces in which PLHA can develop an independent sense of worth as opposed to their usual status as inferior citizens.

**'Power-over'**: This is a resisting force. It is negative because it forces someone or some groups to do things against their will. However, it can also be positive because it overrules dominance and unequal structures of power. While an assessment of '*power-over*' would ideally involve probing many elements including the control ART beneficiaries have over time, relationships etc., here the element of '*power over*' will be analysed by considering the change in the economic status of the ART beneficiaries. It primarily looks up on the changes that occurred in their assets and savings as a result of the treatment.

There are two things we need to bear in mind about this framework; first, the four aspects of power should not be viewed as separate entities but as components of a web of change. Different types of power are not mutually exclusive and they may coexist in a particular location at a specific period of time. Secondly, this conception of power is not necessarily confined to feminist or gender analysis. Power can and should expand to include different kinds of social relations, so that race, class, ethnicity, age and life-cycle stages may be analysed in parallel with gender.

## **1.6 Chapter Scheme**

The present study is divided in to six chapters including the introduction. The second chapter is deals with the scenario of ART in India. The third chapter deals with the socio demographic profile of ART beneficiaries in Kerala. Fourth chapter examines the empowerment of ART beneficiaries. The fifth chapter assesses the empowerment by taking six cases of ART beneficiaries. Conclusions and policy implications are presented in the sixth chapter.



## Chapter 2

### ANTIRETROVIRAL TREATMENT IN INDIA

#### 2.1 Introduction

HIV/AIDS, unlike most other infectious diseases, strikes working-age adults during their most productive working years. According to the NACO Report 2003, about 89% of the reported cases of HIV/AIDS occur in the sexually active and economically productive age group of 18-49 years (NACO,2003).. The mortality component of this loss is clear: lives lost to AIDS cannot contribute to economic growth (Mathew, 2004). This imposes many responsibilities on the government to take initiatives to mitigate the loss of labour productivity. Regarding public intervention, some observers believe that it is possible to take a position on whether the governments of developing countries should fund AIDS treatment based on ethics alone, without elaborate analysis. The views of the advocates and the opponents of government financing for AIDS treatment on ethical grounds can be simplistically described in terms of the lifeboat metaphor<sup>8</sup>. As far as India is concerned HIV/AIDS emerged as a new and extremely virulent communicable disease in the health scene since the declaration of the National Health Policy of 1983. As there was no existing therapeutic cure or vaccine for this infection, the disease constitutes a serious threat, not merely to public health but to the economic development in the country. This chapter discusses the antiretroviral treatment scenario in India. Firstly, it discusses the epidemiology of the HIV/AIDS scenario both in the global and Indian context which provides a trend in HIV/AIDS epidemic over the years. Secondly, it looks into the antiretroviral treatment scenario in a global context which gives a background picture of ART across the world. Finally, it provides a detailed discussion of the Indian context of the antiretroviral treatment scenario which is the main rationale of this chapter.

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<sup>8</sup> “Supporters of government-financed antiretroviral therapy argue that refusal to finance AIDS treatment is like pushing people with HIV out of the lifeboat. Opponents of government financing argue that the lifeboats in poor countries will have a negative impact, (Over et al., 2004).

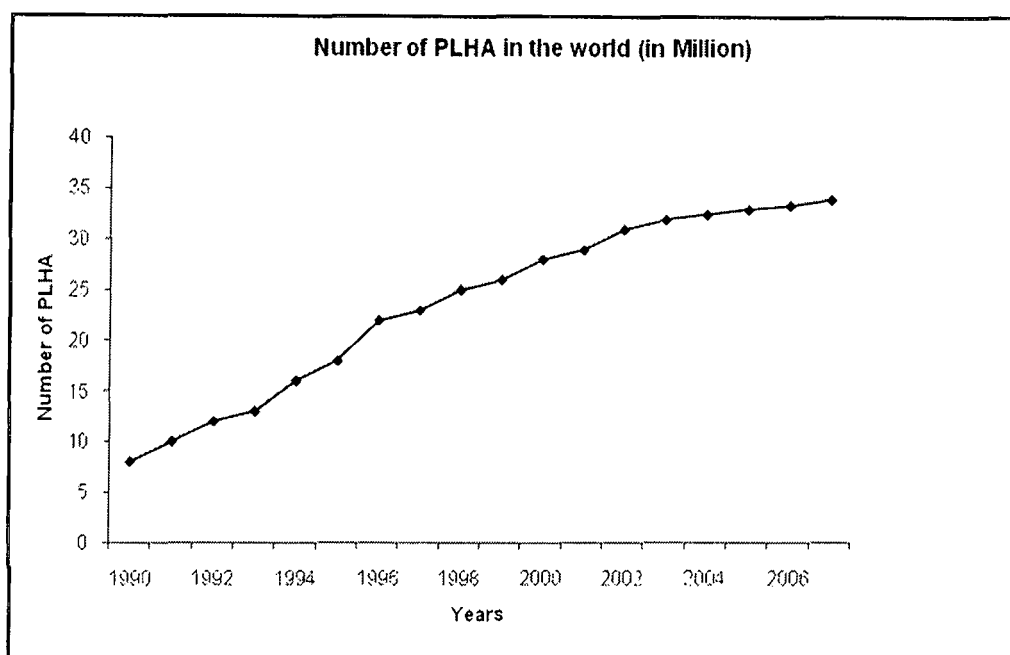
## 2.2 The HIV/AIDS Scenario

### 2.2.1 Global Scenario of HIV/AIDS

The AIDS epidemic is one of the most destructive health crises of modern times, ravaging families and communities around the world. More than 25 million people have died of AIDS worldwide, and another 33 million are currently living with HIV/AIDS<sup>9</sup>. Countries hard hit by the AIDS epidemic have seen mortality surge and life expectancy drop during the last decade. According to the UNAIDS AIDS Epidemic 2009, the epidemic appears to have stabilised in most regions, although prevalence continues to increase in Eastern Europe and Central Asia and in other parts of Asia due to a high rate of new HIV infections. Sub-Saharan Africa remains the most heavily affected region, accounting for 71% of all new HIV infections in 2008. Differences are apparent in all regions, with some national epidemics continuing to expand even as the overall regional HIV incidence stabilises.

Figure 2.1

#### The world Scenario of HIV/AIDS since 1990s



Source: United Nations Programme on HIV/AIDS (UNAIDS, 2007)

<sup>9</sup> UNAIDS/WHO Report on the Global AIDS Epidemic, 2008.

The above figure shows the global HIV prevalence rate over the years. From the beginning of the epidemic it has been increasing over the years till 2006. While cases have been reported in all regions of the world, that large majority with HIV reside in low and middle income countries (96%), particularly in Sub-Saharan Africa<sup>10</sup>. HIV/AIDS has dramatically skewed the natural age distribution in many national populations in sub-Saharan Africa, with potentially perilous consequences for the transfer of knowledge and values from one generation to the next. In Asia, where infection rates are much lower than in Africa, HIV causes a greater loss of productivity than any other disease, and is likely to push an additional 6 million households into poverty by 2015 unless national responses are strengthened (Commission on AIDS in Asia, 2008).

### **2.2.2. Regional Estimates of HIV/AIDS**

Sub-Saharan Africa has the largest HIV/AIDS burden followed by Asia. Sub-Saharan Africa remains the region which is most heavily affected by HIV, accounting for 67% of all people living with HIV and for 75% of AIDS deaths in 2007 (UNAIDS, 2007). Unlike the situation in other regions, the majorities of people with HIV in high-income countries who need antiretroviral therapy have access to it, and so tend to stay healthy and survive longer than infected people elsewhere (Over et al., 2004). Home to 60% of the world's population, Asia is witnessing a rapidly escalating epidemic that has huge implications globally. Indonesia, Nepal, Viet Nam and parts of China have seen sharp increases in the number of infections among injecting drug users. South Asia has some of the fastest growing epidemics in the world, among groups such as injecting drug users, sex workers and their clients and some of the most worrisome increases in infection are now occurring in populous countries in other regions, such as Indonesia, the Russian Federation, and various high-income countries (UNAIDS, 2008).

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<sup>10</sup> UNAIDS/WHO (2008).

**Table 2.1**  
**Regional Estimates of HIV/AIDS, 2008**

<b>Regions</b>	<b>Adults and Children</b>	<b>Adults and Children Newly Infected</b>	<b>Adult Prevalence</b>	<b>Deaths of Adults and Children</b>
Sub-Saharan Africa	22 million	1.9 million	5.00%	1.5 million
North Africa and Middle East	380,000	40,000	0.30%	27,000
Asia	5 million	3,80,000	0.30%	3,80,000
Oceania	74,000	13,000	0.40%	1,000
Latin America	1.7 million	1,40,000	0.50%	63,000
Caribbean	2,30,000	20,000	1.10%	14,000
Eastern Europe and Central Asia	1.5 million	1,10,000	0.80%	58,000
North America, Western and Central Europe	2 million	81,000	0.40%	31,000
<b>Grand Total</b>	<b>33 million</b>	<b>2.7 million</b>	<b>0.80%</b>	<b>2.0 million</b>

Source: UNAIDS Report of the Global AIDS Epidemic, 2008

The above table shows the regional estimates of HIV/AIDS in which it is visible that the epidemic is concentrated in Sub-Saharan Africa (22 million). This has been followed by Asia (5 million) and Latin America (1.7 million).

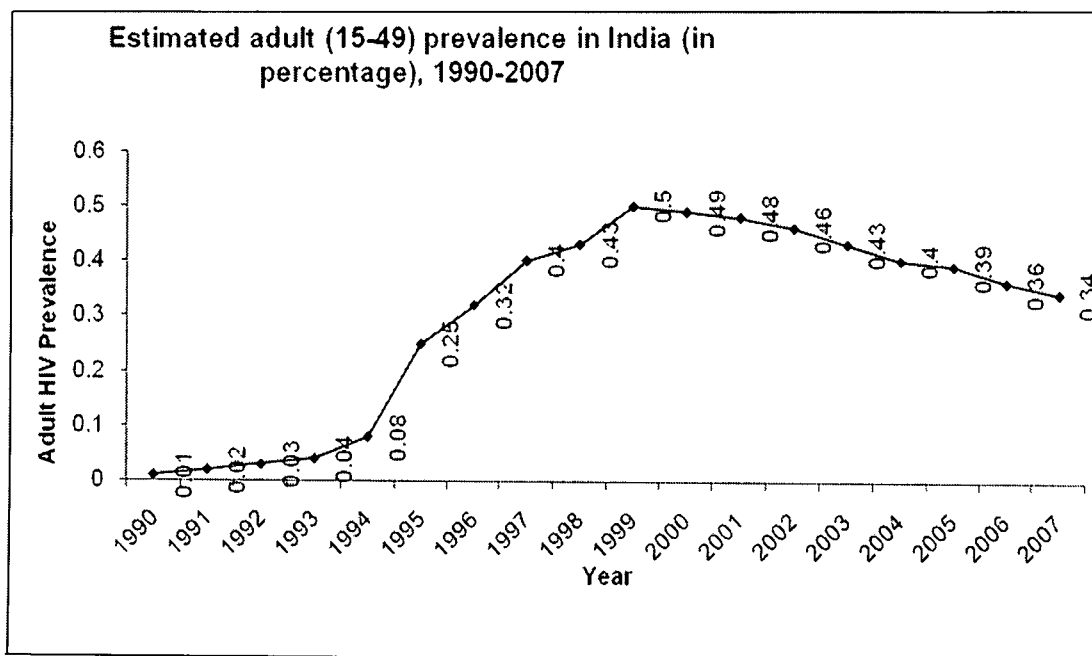
### **2.2.3 Epidemiology of HIV/AIDS in India**

India has the world's third largest population suffering from AIDS, after South Africa and Nigeria (UNAIDS, 2008). However, the estimated number of HIV infections in India has declined drastically in recent years from 5.5 million in 2005 to below 2.5 million in 2007 (NACO, 2009). These new figures are supported by the World Health Organization and UNAIDS. The spread of HIV in India is primarily restricted to the southern and northeastern regions of the country. India initiated sero-surveillance for HIV in 1985, in order to assess the magnitude and dimension of HIV infection even before AIDS cases were reported in the country. Demographically, India is the second largest country in the world and it also has the second largest number of people living with HIV/AIDS. About 26% of the population comprising mostly of agricultural

labour, rural artisans and urban casual household workers live below the poverty line. The number of PLHA in India is estimated to be 5.2 million (0.88%), the second largest in the world. Over the years, the virus has moved from urban to rural and from high risk to general population, disproportionately affecting women and the youth.

**Figure 2.2**

**Estimated adult prevalence of HIV/AIDS in India over the period**



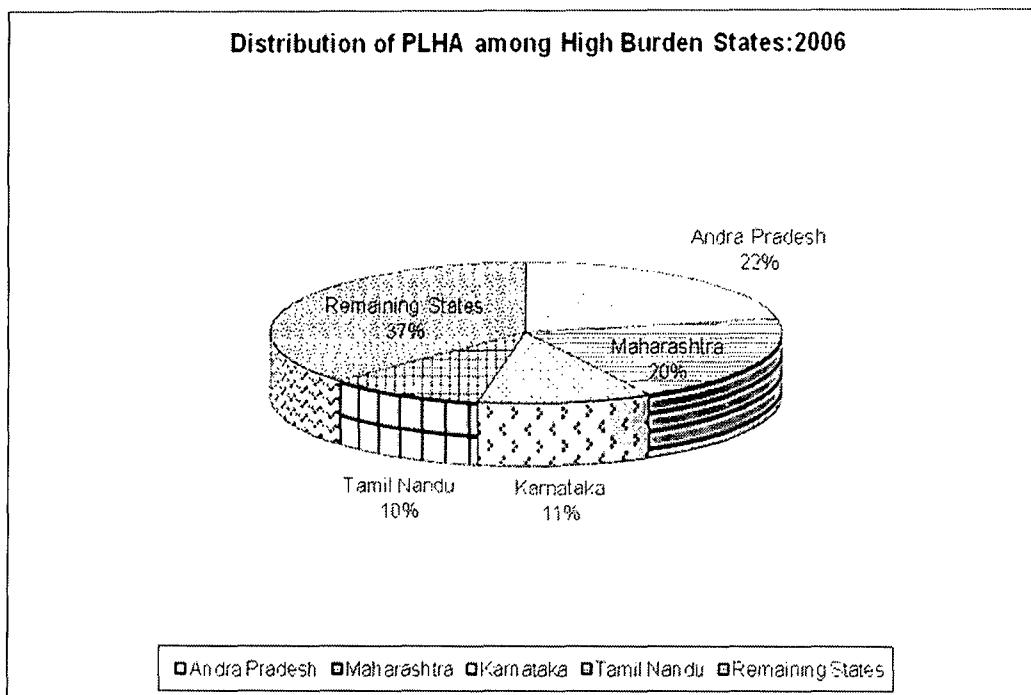
Source: National AIDS Control Organization, 2008

The numbers of people living with HIV/AIDS in India have been steadily increasing in India since 1990, with the trend showing a decline in 2000. In 1994-95, there was a steep increase in the HIV prevalence; in 2007, it was 0.34%. In 1999-2000, the HIV/AIDS prevalence reached its peak. Overall, HIV prevalence was higher among urban than rural populations. However, some states had a slightly higher HIV prevalence among rural populations as compared to urban populations, namely, Punjab, Tamil Nadu and Uttar Pradesh. While the overall HIV epidemic trend is stable in the recent years, there is variation in the trend between the states and population groups. In Tamil Nadu and other southern states with a high HIV burden, where effective interventions have been in place for several years, HIV prevalence has begun to decline or stabilise (WHO, 2007). According to the final report of India's latest and most comprehensive health indicators survey, the prevalence rates (infections per population of 100,000) across India vary between 1.13% in the northeastern state of Manipur and 0.97% in the southern state of Andhra Pradesh.

HIV prevalence continues to be high in Andhra Pradesh, Karnataka, Maharashtra and Nagaland, while it decreased in Tamil Nadu, once among the list of states with a high HIV prevalence.

**Figure 2.3**

**HIV/AIDS in high prevalence states in India**



Source: National AIDS Control Organisation, 2007

The above figure shows distribution of HIV/AIDS prevalence among high prevalence states in India. One hundred and eleven districts have been classified as high prevalence districts with HIV prevalence and/or more than 5% in high-risk behavior groups. Six states (Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur, and Nagaland) are considered as high prevalence states. The total number of People Living with HIV/AIDS in the country is estimated to be 2.47 million, with the highest number in Andhra Pradesh and Maharashtra. Along with Tamil Nadu and Karnataka, the four south Indian states contribute 63% of all the PLHA in the country. Though Manipur and Nagaland have the highest HIV prevalence in the country due to small population size, the estimated number of PLHA in these two states is around 25,000. Overall, the six high prevalence states contribute 65% of all PLA in the country.

#### 2.2.4 HIV Prevalence among Male and Female

Risks and vulnerability to HIV/AIDS are substantially different for men and women. They are most evident in the marked age and sex-differentiated HIV prevalence rates, and in the fact that, even in Asia and the Pacific region, anecdotal evidence suggests that teenage girls and young women increasingly account for the majority of adults living with HIV/AIDS (Asian Development Bank, Gender Network News, 2005). Based on the revised estimates of NACO, it is now believed that the epidemic in India is on the decline. The total number of PLHA in the country is also believed to have declined from 2.73 million in 2002 to 2.47 million in 2006.

**Table 2.2**

#### **Gender distribution of HIV/AIDS prevalence**

<b>Age Group</b>	<b>Male</b>	<b>Female</b>	<b>Total</b>
15-19	0.01	0.07	0.04
20-24	0.19	0.17	0.18
25-29	0.43	0.28	0.35
30-34	0.64	0.45	0.54
35-39	0.53	0.23	0.37
40-44	0.41	0.19	0.3
44-49	0.48	0.17	0.33
<b>Total age</b>	<b>0.36</b>	<b>0.22</b>	<b>0.28</b>

Source: National Family Health Survey, 2005-06

Above table (table 2.2.) shows the male female distribution of HIV prevalence. The HIV prevalence is greater among the males (0.36) than among the females (0.22), irrespective of age groups. The age group of 30 to 34 has the highest rate of prevalence and it seems that this age group is the most vulnerable. In the 15 to 19 age group, it seems that the HIV prevalence among females is higher than that among males. For men aged 15-49, it is 0.36%, and for women in the same age group, it is 0.22%. For every 100 people living with HIV/AIDS (PLHAs), 61 are men and 39, women. Prevalence is also high in the 15-49 age group (88.7% of all infected), indicating that AIDS still threatens the cream of the population, i.e., those in the prime of their working life.

## 2.3 Antiretroviral Treatment Scenario

### 2.3.1. Global Scenario of Antiretroviral Treatment

Globally, many voices have been raised about the necessity of scaling up antiretroviral (ARV) treatment programmes in the developing nations of the world. The reality of a growing commitment to make ARVs available to the world's poor foretells the inevitable development of more and more ARV treatment programs in many nations of the world (Ronald and Valdiserri, 2004). Antiretroviral coverage is defined as the number of patients receiving antiretroviral treatment at a point in time divided by the number needing treatment. Numbers of patients receiving antiretroviral treatment are estimated from public sector data, and data provided by disease management programmes and NGO programmes (Adam and Johnson, 2009). There has been a steady increase in ART coverage over the last decade with a more rapid increase in recent years. Methods for calculating coverage rely on good-quality patient monitoring systems in countries, and well-informed models are needed to estimate the number of people in need of treatment (Mahy et al., 2010).

**Table 2.3**  
**Regional distribution of ART Coverage, 2008**

<b>Geographical region</b>	<b>PLHA receiving ART</b>	<b>PLHA needing ART</b>	<b>ART Coverage</b>
Sub Saharan Africa	2.9 million	6.7 million	44%
Latin America & Caribbean	445 000	820000	54%
East, South & South East Asia	565 000	1.5 million	37%
Europe, Central Asia	85 000	370000	23%
Middle East, North America	10 000	68000	14%
<b>Total</b>	<b>4 million</b>	<b>9.5 million</b>	<b>42%</b>

Source: UNAIDS, 2009

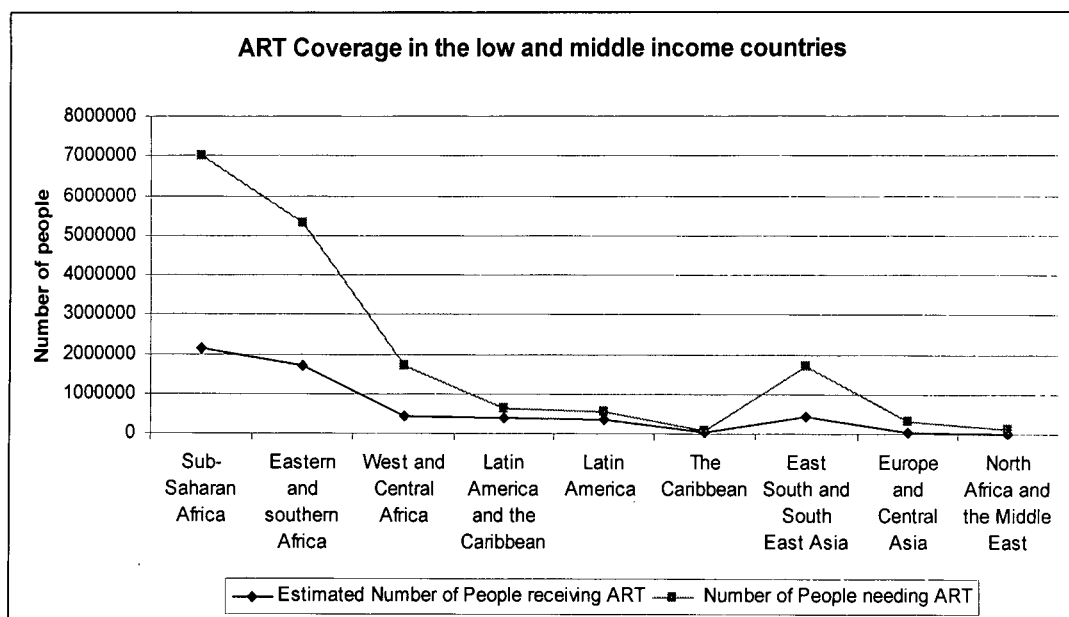
The above table shows coverage of antiretroviral treatment in the world. The Latin American and Caribbean region shows the highest coverage. The Middle Eastern and North American region shows the lowest ART coverage. In developing nations, access to the antiretroviral therapy is growing but still limited. Recent years have seen



an unprecedented momentum to expand access to antiretroviral therapy in low- and middle-income countries and to reduce morbidity and mortality among people living with HIV/AIDS. When the “3 by 5” initiative<sup>11</sup> was launched in 2003, an estimated 400,000 people in low- and middle-income countries were receiving antiretroviral therapy. Since then, increasing political commitments, resource mobilisation and efforts by multiple stakeholders have resulted in a massive increase in the number of people receiving antiretroviral therapy.

**Figure 2.4**

**ART Coverage in the Low and Middle Income Countries**



Source: United Nations Programme on HIV/AIDS (UNAIDS, 2007)

The above figure shows the coverage of antiretroviral treatment in low- and middle-income countries. Since the difference between the total number of people and those who are in need of treatment is very high, the coverage of antiretroviral therapy is comparatively low in the African region, followed by that in East South and South East Asia. Accordingly, the prevalence of HIV/AIDS is very high in this region. On the other hand, the regions which have low HIV prevalence, Latin America and the

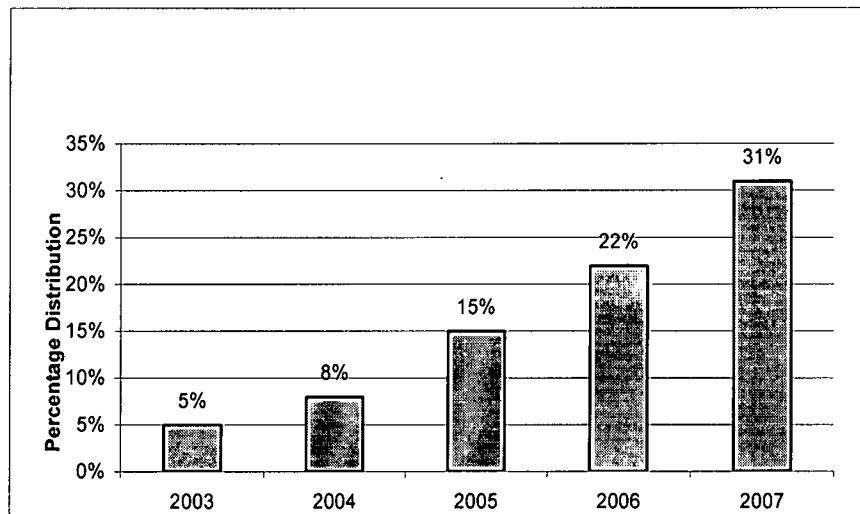
<sup>11</sup> The ‘3 by 5’ initiative launched by the United Nations Joint programme on HIV/AIDS (UNAIDS) and the World Health Organisation (WHO) in 2003 aimed at rapid scale up of antiretroviral treatment (ART) to provide access to antiretroviral drugs for three million people with HIV/AIDS in low- and middle-income countries by the end of 2005 (WHO & UNAIDS 2003). The initiative has been ambitious and groundbreaking and has generated wide-ranging debate on the relationship between ART scale-up and broader health systems in resource-limited settings (McCoy et al., 2005).

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Caribbean, have a high level of ART coverage. The greatest increase is in Sub-Saharan Africa, where the number of people receiving ART surpassed 2 million in 2007. The share of pregnant women receiving ART for the prevention of mother-to-child transmission of HIV increased from 10% in 2004 to 33% in 2007. Access to ART among children has also risen significantly, although they have less access than adults. Despite these successes, more than two-thirds of those in need of ART, have still not received it (UNAIDS, 2008).

**Figure 2.5**

**ART Coverage in Low and Middle Income Countries over the Period**



Source: United Nations Programme on HIV/AIDS (UNAIDS, 2007)

The above figure shows the trends in the coverage of ART in low- and middle-income countries over the years. It has been increasing continuously and the period 2004-05 showed a steep increase. Coverage of antiretroviral therapy in low- and middle-income countries reached 42% [40–47%] of the 9.5 million [8.7 million – 10.0 million] people in need at the end of 2008 (WHO, 2009). More than 4 million [3 700 000–4 360 000] adults and children were receiving antiretroviral therapy in low- and middle-income countries at the end of 2008, over one million more people than at the end of 2007. This represents a 36% increase in one year, and a 10-fold increase in five years. The greatest increase in the number of people receiving treatment in 2008 was in Sub-Saharan Africa, the region with the greatest need (UNAIDS, 2009).

### **2.3.2 Provision of ART in India**

In order to formulate a strategy for the implementation of HIV/AIDS prevention and control programme in India, the Ministry of Health and Family Welfare constituted the National AIDS Committee in 1986, under the chairmanship of the Union Ministry of Health and Family Welfare. The Committee brought together various ministries, non-governmental organisations (NGOs) and private institutions for effective coordination of programme implementation. This Committee is the highest-level body to oversee the performance of the programme, to provide overall policy directions, and to forge multi-sectoral collaboration (NACO, 2005).

On November 30, 2003, the Government of India announced a plan to place 100,000 AIDS cases in India on structured anti-retroviral therapy by the end of 2005 and 15 to 20 per cent additional AIDS cases each year, and thereafter, for a period of five years (Gupta, 2007). Till 2003, the access to ART in India was quite limited; it was estimated that out of 7,50,000 ART eligible individuals, only 13,000 were on ART by the end of 2003; in other words, less than 2% of ART-eligible individuals were on ART in India; the corresponding global figure was around 8% (Gupta et al., 2003). Till then, ART delivery was mainly through the private sector. Antiretroviral drugs were also being provided in the public sector through various government institutions like the Central Government Health Scheme (CGHS), Employees State Insurance Corporation (ESIC), the Armed Forces Medical Services, and the Railways (Gupta et al., 2006).

The supply of antiretroviral drugs to support the first quarter of this initiative, which started in April 2004, was sourced through the World Health Organisation (WHO) procurement mechanism, and it was expected that the government would enter into a pact for the delivery of medicines with the pharmaceutical companies later. Initially, the programme was to be restricted to six high prevalent States of India. NACO, the nodal agency for implementing the HIV/AIDS prevention and control programme in India, drafted the 'Programme Implementation Guidelines for a Phased Scale-up of Access to Antiretroviral Therapy' which dealt in detail with the plan to provide antiretroviral drugs to people living with HIV/AIDS. In June 2004, the Global Fund on AIDS, TB and Malaria awarded a financial grant of US \$ 165 million to provide

ART in the public sector and through public private partnerships for 1,00,000 people living with AIDS over a five- year period (Gupta, 2007).

Consideration of the attributes of the antiretroviral treatment provision is essential to get an understanding of the trends and patterns of its beneficiaries across the country. Over et al., (2004) argues that, for the purpose of policy design, it may be sufficient to focus on three attributes: coverage, the public-private mix, and the transmission-minimizing structure. “Coverage” refers to the percentage of people receiving antiretroviral therapy as a percentage of those whose disease progression makes them eligible for such therapy (UNGASS Country Progress Report, India, 2008). The fact that a person is covered does not necessarily imply that he or she is receiving high-quality care; the person may be on self-medication with antiretroviral therapy drugs purchased from a pharmacy. Coverage refers merely to the consumption of antiretroviral therapy drugs. The ‘public-private mix’ refers to the proportion of public sector spending in total spending. Overall, India’s public sector finances and provides about 10-20 percent of total healthcare spending. “Structure” refers to the set of resource utilisation patterns, decision rules, and counseling practices that guide the service delivery process for people with HIV/AIDS<sup>12</sup>. This particular chapter deals with only one part of the structure, i.e. the distribution of ART centres across the country and the trends and patterns of ART beneficiaries which include distribution of ART beneficiaries across states according to the status of HIV prevalence, dropout rates, and gender difference among ART beneficiaries.

### **2.3.2.1 Antiretroviral treatment Centers in India**

Free access to ART through the government programme for the PLHA is channeled through ART centres set up all over India. The main objective of Anti-retroviral Therapy (ART) is to provide comprehensive services to eligible persons with HIV/AIDS. An operational guideline for ART centres (2008) says that the PLHA should be given holistic care at ART centres. This is possible only if the team is committed and has a comprehensive understanding of the problem and the care involved. For this purpose, the functions of ART centres are categorised as medical,

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<sup>12</sup> Because antiretroviral therapy is a rigorous therapy requiring precise action on the part of both the physician and the patient, the concept of “structured” antiretroviral therapy treatment has been developed to define model clinical practice. The elements of structured treatment vary somewhat from country to country and are in the process of being defined in India (Over et al., 2004)

psychological and social. The medical functions include diagnosing and treating opportunistic infections, screening PLHA for eligibility to initiate ART, monitoring patients on ART and managing side effects, if any, and providing in-patient care as and when required. The psychological functions include the provision of psychological support to PLHA accessing the ART centre, providing counselling for adherence to ARV drugs, educating PLHA on proper nutrition, advice about risk reduction behaviour, including usage of condoms. The social functions include facilitating PLHA to access available resources provided by the Government and NGO agencies, facilitating linkages between other service providers and patients, like educational help for the children and income generation programmes<sup>13</sup>. ART centres are set up on the basis of prevalence of HIV infection in the State, and the availability of existing ART services in the State/region.

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<sup>13</sup> Operational Guidelines for ART Centers (NACO, 2008)

**Table 2.4**  
**Number of ART Centers in India**

<b>States</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>2009</b>
Andhra Pradesh	3	17	28	28
Arunachal Pradesh	1	17	1	1
Assam	1	2	3	3
Bihar	0	2	4	4
Chatisgarh	0	1	1	1
Goa	1	1	1	1
Gujarat	1	2	7	9
Haryana	0	1	1	1
Himachal Pradesh	1	1	1	1
Jammu and Kashmir	0	2	2	2
Jharkhand	0	2	2	2
Karnataka	5	17	27	27
Kerala	2	5	5	6
Madhya Pradesh	1	2	3	4
Maharashtra	9	18	37	37
Manipur	2	5	6	6
Meghalaya	0	1	1	1
Mizoram	0	1	1	1
Nagaland	1	4	4	4
Orissa	0	1	3	2
Punjab	0	2	3	3
Rajasthan	1	2	4	4
Sikkim	0	18	1	1
Tamil Nadu	13	18	27	27
Tripura	0	1	1	1
Uttar Pradesh	3	3	7	7
Uttaranchal	0	1	1	1
West Bengal	1	2	4	4
<b>India</b>	<b>54</b>	<b>164</b>	<b>197</b>	<b>200</b>

Source: National AIDS Control Organization, 2009

Table 2.1 shows that in 2009, a total of 200 ART centres have been functioning in India. Maharashtra and Andhra Pradesh have the highest number of ART centres, followed by Tamil Nadu and Karnataka. The ART centre is equipped with trained

physicians and other health care personnel capable of identifying and treating common HIV-related illnesses and opportunistic infections. These Centres are committed to furnishing information on facilities, services and outcomes in prescribed formats to State AIDS Control Societies (SACS) and NACO at regular intervals (National Guidelines for the Implementation of Antiretroviral Therapy, NACO 2004). The challenge of this programme is to develop systems for the provision of ARVs that follow precautionary practices and minimise risks. Developing systems that institutionalise the moves towards holistic medical care (including optimal use of technological advances) can be long-term achievements of the '3 by 5' initiative of WHO.

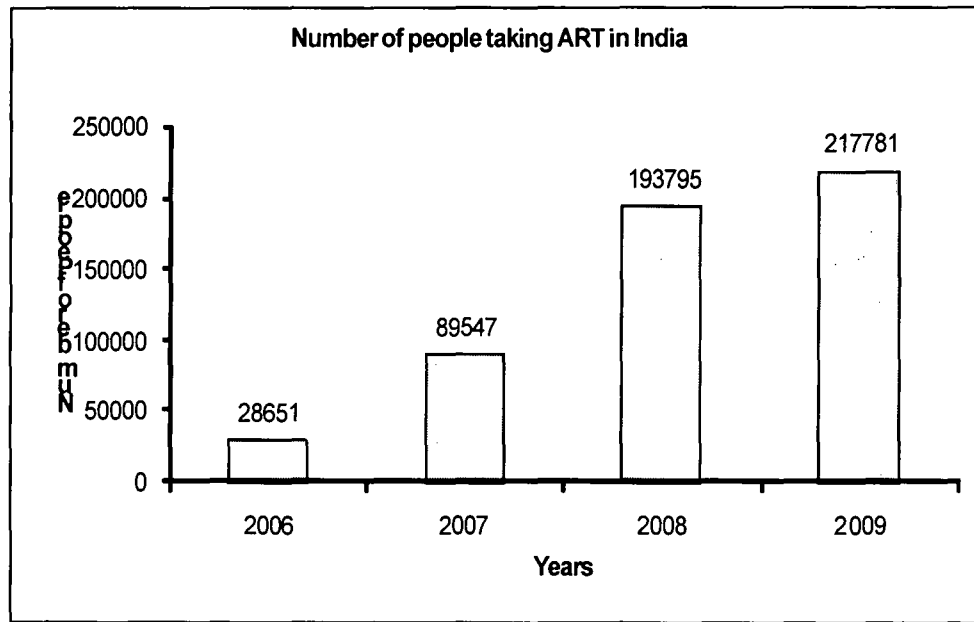
### **2.3.2.2 Trends in ART Beneficiaries in Indian States According to the Status of HIV Prevalence**

Triple-drug combination antiretroviral (ARV) therapy has remarkable effects on the lives of people living with HIV/AIDS. When it is provided on a large scale, people living with HIV/AIDS return to their families and jobs and AIDS-related morbidity and mortality fall dramatically (Egger et al., 2002). Being on ART essentially involves three elements from the patient's perspective: minimum tests to ensure the need as well as the timing of initiation on ART, purchase and use of drugs on a regular basis, and follow-up tests done at regular intervals. In India, all the three elements are given free of cost except the medicines for opportunistic infections<sup>14</sup>. Gupta's (2007) study on willingness to pay for ART for PLHAs in India reveals the fact that individuals generally delay getting tested, and do so only when illness strikes. It is possible that making antiretroviral drugs available and accessible can also be a channel for increased voluntary testing in the country.

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<sup>14</sup> Observation from the field work, October 2009

**Figure 2.6**  
**Number of people taking ART in India over the years**



Source: National AIDS Control Organization, 2009

The figure 2.6 shows that the number of ART beneficiaries in 2006 was 28651 and that the number in 2009 was seven times higher. The fact is that the number of ART beneficiaries shown in the figure is those who have public access and are registered in the public ART centres. The Panos report, (2007) on HIV/AIDS and ART in India reveals the fact that, in the high prevalence states like Tamil Nadu, a large section of the population, specifically the upper middle classes, continues to buy drugs from the private sector. Many people buy drugs from the open market where the prices are coming down as the market expands. The increased public-private partnership has helped to scale up treatment and improve the quality of service. Projects have been launched through the State health machinery to improve the quality of counseling and to provide treatment literacy in Andhra Pradesh, Karnataka, Maharashtra, Manipur and Nagaland (Panos, 2007). In States like Assam, ART rollout is totally managed by a Non-Governmental Organization (NGO), namely, the AIDS Healthcare Foundation (AHF) that works closely with NACO in providing treatment.



### 2.3.2.3 State-wise Distribution of ART Beneficiaries According to the Status of Prevalence

The number of people using antiretroviral treatment is on the rise in each State. As India is a vast country, NACO has classified the States as “high”, “moderate” and “low” HIV prevalence States; more recently, the latter are being called “vulnerable States”<sup>15</sup>. In India, six States are considered as high HIV prevalence States (National Family Health Survey, 2006) and among these, Andhra Pradesh, Maharashtra, Tamil Nadu and Karnataka are considered to have the highest numbers of people taking ART.

#### i. ART in high prevalence states

The high-prevalence States of Maharashtra, Andhra Pradesh, Tamil Nadu and Karnataka have the highest number of ART beneficiaries. In Maharashtra, around 75,000 - 100,000 people need ART; approximately 12,000 people are accessing treatment through the government programme and other agencies<sup>16</sup>. In 2006, Maharashtra’s share of ART beneficiaries was 25.32% and in 2007 and 2008 this became 22% and 24% respectively. In 2006, the total share of ART beneficiaries in Andhra Pradesh was only 7.9%, but in 2009 it was 22.12%. In Karnataka, there were more than 500,000 PLHA and the ART roll-out programme in the State began in 2004. The share of ART beneficiaries was 8.85% and 11.42% in 2006 and 2009 respectively. In Tamil Nadu, HIV prevalence among antenatal clinic attendees was 0.25% (2007). The share of ART beneficiaries in Tamil Nadu State was 24.8% in 2006 and gradually it declined, and stood at 14.76% in 2009. In Andhra Pradesh and Karnataka, the share of ART beneficiaries increased over the years, but there is a decline over this period in the case of Maharashtra and Karnataka. .

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<sup>15</sup>National Family Health Survey Report (2006)

<sup>16</sup> More than 1% of the general population in Maharashtra is believed to be HIV positive, as are more than 5% of groups at high risk, such as injecting drug users, men who have sex with men (MSM) and sex workers. HIV prevalence in the general population, as extrapolated from antenatal clinic samples, is 1.25%, (Panos, 2007)

## ii. ART in medium prevalence states

In India, Gujarat, Haryana, and Punjab are considered as the medium prevalence states<sup>17</sup>. According to the 2007 NACO estimation, Gujarat has antenatal clinic HIV prevalence of 0.25% and STD HIV prevalence of 2.40%. The share of ART beneficiaries was 3.54% in 2006 and was 4.19% in 2009. This shows that Gujarat experienced an increase in the total share of ART beneficiaries over the period. Haryana has more or less the same share over the period. The proportion of ART beneficiaries in Haryana, was 0.60% share in 2006 and 0.51% in 2009. The percentage share of ART beneficiaries over the years in the state of Punjab has also remained more or less same, i.e., 1.12% and 1.55% in 2006 and 2009 respectively. HIV prevalence among injecting drug users in Punjab is 13.79% which is 1.6% of STD clinic ART prevalence (NACO, 2007).

## iii. ART in low prevalence states

According to the NFHS classification 2006, the low prevalence states include Assam, Orissa, Bihar, Kerala, Uttar Pradesh and Rajasthan. The percentage of ART beneficiaries in the state of Orissa was 0.26% in 2007 and 0.56% in 2009. Among the low prevalence states, Rajasthan and Uttar Pradesh have a comparatively higher percentage share of ART beneficiaries, i.e., the proportions for Rajasthan were 2.74% and 2.13% in 2006 and 2009 respectively and for Uttar Pradesh, 4.44% and 3.47% in 2006 and 2009 respectively. .

## iv. ART in the Northeastern states

In the Northeastern region Manipur, Mizoram and Nagaland are considered as the high prevalence states. Manipur is a small state of some 2.4 million people. According to the NACO report, a state-wise HIV prevalence of 17.9% among IDUs, and the studies from different areas of the state find that the prevalence to be as high as 32% (Mahanta, et al., 2008). The share of ART coverage in Manipur was 5.31% and 2.24% in 2006 and 2009 respectively. For Mizoram, it was 0.1% in 2006 and 0.18 in 2009 and there is not that much change over the period. The total share of ART beneficiaries in Nagaland was 0.5% and 0.4% in 2006 and 2009 respectively. The

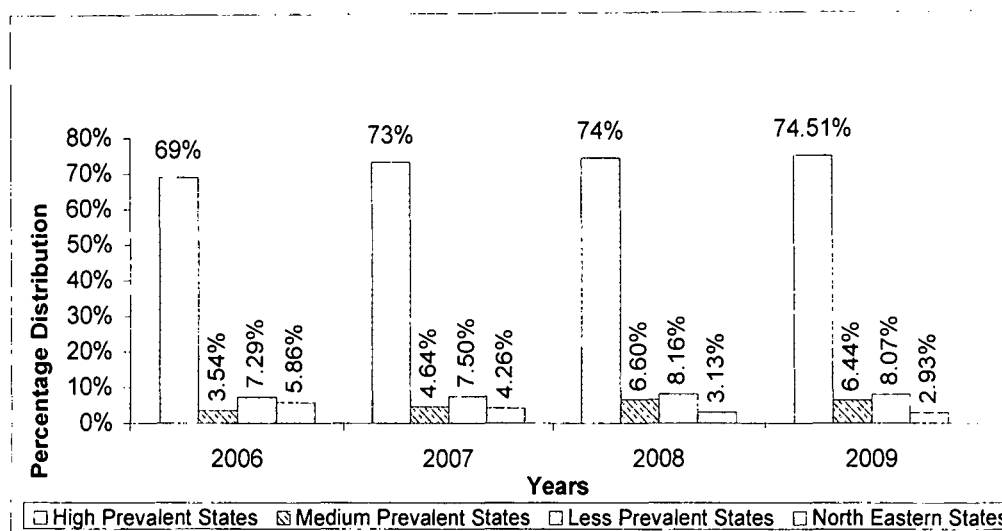
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<sup>17</sup> National Family Health Survey (NFHS), 2005-06

total share of ART beneficiaries in the Northeastern states has been decreased over the years from 5.86% in 2006 and 2.93% in 2009.

**Figure 2.7**

**Percentage distribution of ART beneficiaries among Indian states**



Source: National AIDS Control Organization, 2009

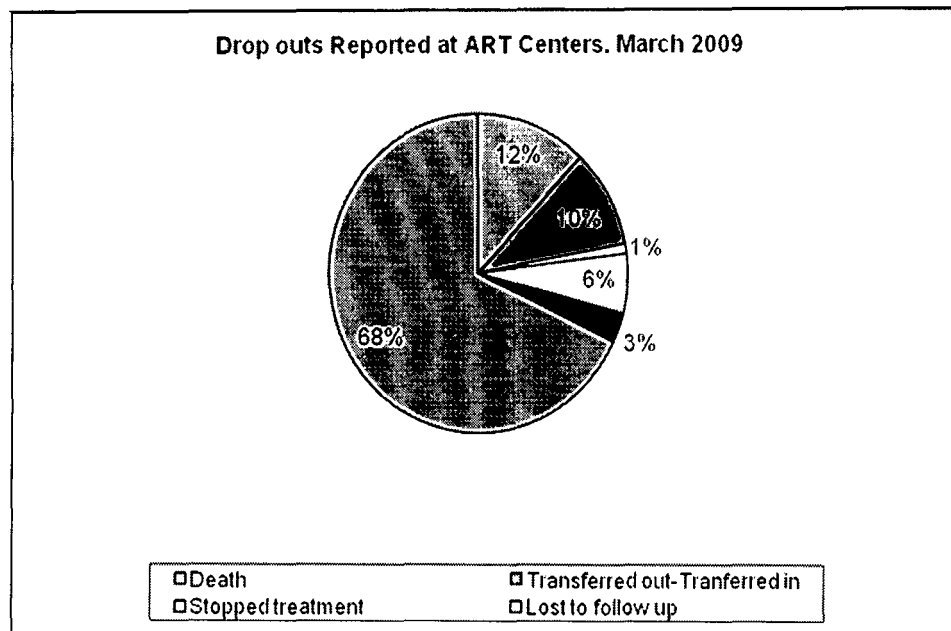
Figure 2.7 shows the overall percentage share of ART beneficiaries among Indian states over the period. Over the years, the share of ART beneficiaries among the high prevalence state is increasing, while at the same time, the share of the Northeastern states is decreasing. The share of ART beneficiaries in the medium prevalence states and less prevalence states continued to increase till 2008, but showed a slight decline in 2009. As a whole, the share has been continuously decreasing over the year in the case of the northeastern states.

**2.3.2.4 Details of patients on ART in India**

This section deals with the details of ART patients, i.e., the dropout rates, transferred out, transferred in, male female distribution among ART beneficiaries, etc., both at the national and state level. Dropout means the number of patients who stopped the treatment due to various reasons, lost to follow up, transferred out, transferred in and died. ‘Transferred out’ means the number of people shifted into another facility and ‘transferred in’ refers to the number of people came for ART from other facilities (Kwong et al., 2008). Transferred in implies the number of patients who entered public access from other facilities. There are a number of studies across the world which actually shows the problem of high rate of dropouts. A study on Malwai

(Kwong et al., 2008) says that the patients who are transferred out to another facility are about 9% and that there is no published information about what happens to the patients who transfer out. But this is important because if they transfer-in and stay alive in these other facilities, then national retention figures will be better than previously reported.

**Figure 2.8**  
**Drop outs rates of ART beneficiaries in India, March 2009**



Source: National AIDS Control Organization, 2009

The figure 2.8 shows the dropout rates of ART beneficiaries in India till 2009 March. After starting the treatment, 12% of the ART beneficiaries died; 10% of them were either transferred in or out and only a minimal number of people (1%) stopped the treatment. Antiretroviral treatment needs a strong and strict adherence transferred out and transferred in (Hope et al., 2007), but 6% of people failed to follow up the treatment due to various reasons. Out of those who started ART, 68% are on treatment. A huge number of transferred out-in, defaulters and those who stopped treatment indicates the inefficiency of the programme. Good documentation of transfer-outs and transfer-ins is needed to keep track of national outcomes. Furthermore, the current practice of regarding transfer-outs as being double-counted in national cohorts and subtracting this number from the total national registrations to get the number of new patients started on ART is correct (Kwong et al., 2008).

#### **2.3.2.5 State-wise Details of ART Beneficiaries**

As already mentioned, the dropout rate of ART beneficiaries indicates the number of people, who missed or stopped the treatment because of several reasons like death, transferred out-in or became unable to continue the treatment etc. It is therefore necessary to understand the details on ART beneficiaries.

**Table 2.5**  
**State-wise details of ART beneficiaries**

	<b>Ever Started on ART</b>	<b>Cumulative List of follow up (%)</b>	<b>No. of missed treatment (%)</b>	<b>Cumulative Deaths (%)</b>	<b>Total Reported Transferred out</b>
Andhra Pradesh(28)	71,829	7,184 (10)	4,169 (5.8)	9,052 (12.6)	5,431 (7.56)
Maharashtra(37)	70,094	3,376 (4.8)	1,276 (1.82)	6,510 (9.29)	7,213 (10.29)
Tamil Nadu(27)	45,373	2,894 (6.4)	742 (1.64)	4,968 (10.95)	5,087 (11.21)
Karnataka(27)	34,549	1,205 (3.5)	719 (2.08)	5,824 (16.86)	3,209 (9.29)
Gujarat(9)	13,156	828 (6.3)	235 (1.79)	1,347 (10.24)	2,235 (16.99)
Uttar Pradesh(7)	11,241	1,126 (10)	219 (1.95)	1,274 (11.33)	1,216 (10.82)
Rajasthan(4)	7,506	518 (6.9)	187 (2.49)	1,325 (17.65)	1,062 (14.15)
West Bengal(4)	5,303	326 (6.1)	86 (1.62)	654 (12.33)	628 (11.84)
Manipur(6)	6,440	273 (4.2)	169 (2.62)	647 (10.05)	537 (8.34)
Madhya Pradesh(4)	4,109	432 (10.5)	197 (4.79)	703 (17.11)	251 (6.11)
Kerala(6)	4,794	252 (5.3)	48 (1)	784 (16.35)	292 (6.09)
Bihar(4)	4,615	209 (4.5)	123 (2.67)	452 (9.79)	448 (9.71)
Orissa(2)	2,204	295 (13.4)	96 (4.36)	259 (11.75)	393 (17.83)
Punjab(3)	4,317	125 (2.9)	90 (2.08)	561 (13)	234 (5.42)
Chhatisgarh(1)	1,686	287 (17)	241 (14.29)	140 (8.3)	26 (15.4)
Haryana(1)	1,765	96 (5.4)	23 (1.3)	490 (27.76)	16 (0.91)
Jharkhand(2)	1,368	30 (2.2)	27 (1.97)	285 (20.83)	84 (6.14)
Goa(1)	1,028	60 (5.8)	9 (0.88)	217 (21.11)	27 (2.63)
Assam(3)	877	38 (4.3)	34 (3.88)	107 (12.2)	127 (14.48)
Jammu & Kashmir(2)	707	57 (8.1)	14 (1.98)	87 (12.31)	85 (12.02)
Nagaland(4)	1,249	13 (1)	3 (0.24)	150 (12.01)	75 (6)
Himachal Pradesh(1)	768	55 (7.2)	9 (1.17)	142 (18.49)	17 (2.21)
Uttarakhand(1)	520	34 (6.5)	13 (2.5)	77 (14.81)	26 (5)
Mizoram(1)	423	9 (2.1)	12 (2.84)	59 (13.95)	3 (0.71)
Tripura(1)	98	18 (18.4)	5 (5.10)	9 (9.18)	19 (19.39)
Sikkim(1)	43	6 (14)	0 (0)	16 (37.21)	0 (0)
Arunachal Pradesh(1)	37	3 (8.1)	1 (2.70)	5 (13.51)	5 (13.51)
Meghalaya(1)	50	4 (8)	0 (0)	3 (6)	2 (4)
<b>Total</b>	<b>307,713</b>	<b>20,616 (6.7)</b>	<b>9,023 (2.93)</b>	<b>37,491 (12.18)</b>	<b>30,438 (9.89)</b>

Source: National AIDS Control Organisation, 2009

This table (Table 2.5) shows the State-wise variations in the number of people who started ART, died after taking ART, transferred out, transferred in and those who failed to follow up the programme. The State-wise percentage of dropout is high in Andhra Pradesh (25836), Maharashtra (18375), Tamil Nadu (13691), Karnataka (10957), Gujarat (4645), Uttar Pradesh (3835), and Rajasthan (3092). The total number of people transferred out is high in Tripura (19%), Orissa (17%) and Gujarat (16%). The large numbers of drop-out cases may be attributed to death and transferring out.

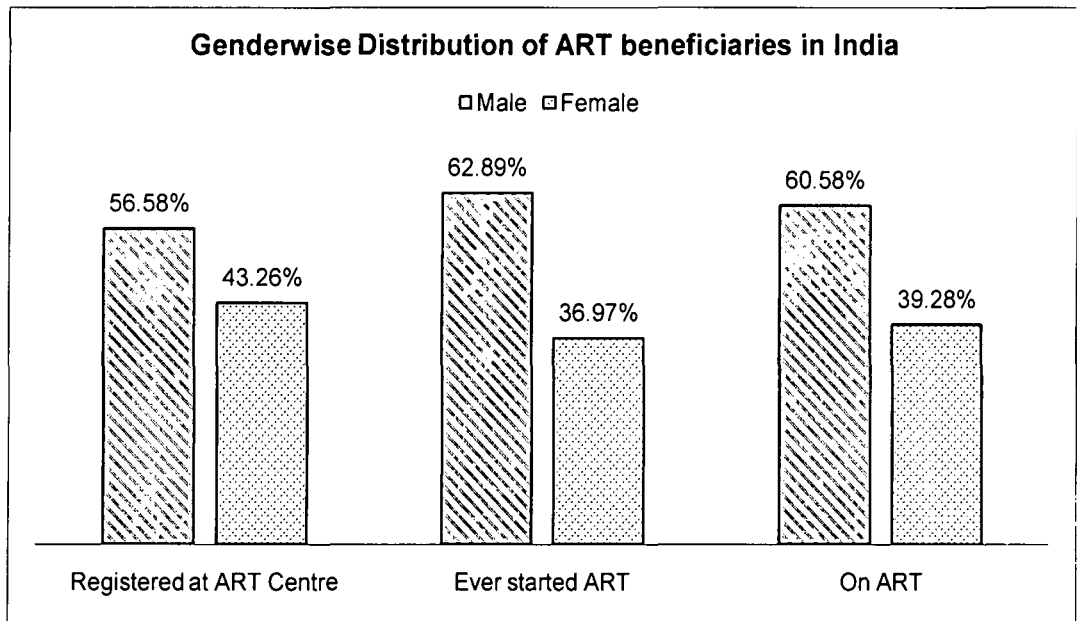
#### **2.3.2.6 Gender and ART Coverage in India**

The HIV pandemic is being viewed as a strongly gendered health, development and human rights issue. The trajectory of the AIDS epidemic clearly demonstrates a shift towards women and young people, with 25% of all HIV infections occurring in women<sup>18</sup>. The United Nations Development Fund for Women (UNIFEM) reports that men tend to enjoy better access to HIV/AIDS care and treatment in the private sector and through drug trials. Men are more likely to be able to afford treatment and to have access to medical insurance, while researchers are reluctant to enroll women in drug trials because of the potential side effects should they become pregnant (Panos, 2007). In Andhra Pradesh, the HIV prevalence rates among wives of truck drivers and agricultural workers are very high. Yet, very few women seem to have come forward for ART and about 65% of the population on ART is men. In the Northeastern States of Manipur and Nagaland, many women do not know about ART and even if they did, many may not have the negotiating power to get access to it. One possible reason for this is that only few women know about their HIV status. Women have been thrown out of their homes and are worried about who will look after their children when they fall ill. They have to fulfill the dual responsibilities of earning as well as looking after the household. Nutrition for infected and affected women and their children, reduction in stigma and discrimination as spouses or widows of Injected Drug Users (IDU), property rights issues such as these remain totally unaddressed (UNAIDS, 2005).

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<sup>18</sup> "HIV/AIDS Prevention in Vulnerable Indian States: Lessons from the Chayan project", 2009.

**Figure 2.9**  
**Gender wise Distribution of access to ART**



Source: National AIDS Control Organization (NACO, 2009)

The above figure shows the male-female distribution of ART beneficiaries in India. The patients are classified as those who registered in ART centers, ever started ART and on treatment. When we look in the gender-wise distribution of HIV/AIDS prevalence, it was 61% of male and 39% of female in 2006. This proportion of gender distribution in HIV/AIDS prevalence remains the same in the case gender distribution of ART beneficiaries also. The gender distribution of those who ever started ART is 62.89% of men and 36.97% of women respectively. In the case of the percentage of people registered for treatment, the gender disparity is comparatively lower. According to the study of Kumarasamy et al. (2002), in South India, there is a significant amount of psychological, immunological and clinical differences as between men and women. Ruderman (2005) argues that the existing socio-economic and cultural conditions make women more vulnerable and hinders their ability to access the treatment. Given the increasing number of HIV-positive women in India, extra attention will have to be paid to the reluctance as well as the ability of women in general to pay for their health; this is especially going to be valid in households with multiple patients, where the woman may be the last or the only person who does not receive treatment (Gupta, 2007). Thorough understanding these critical issues needs to be raised to develop a strong and relevant strategy to prevent the gender imbalances in HIV/AIDS treatment.



## 2.4 Conclusion

HIV/AIDS in India showed a rising trend till 1999. Since then, it began to show a decline. In order to mitigate the negative impact of the disease, ART started in 2004 through eight hospitals in the six high-prevalence States of Maharashtra, Tamil Nadu, Karnataka, Manipur, Andhra Pradesh and Nagaland, and two in Delhi. Later, ART treatment was extended through 25 hospitals in Tamil Nadu, Manipur, Karnataka, and Andhra Pradesh and in the low (or moderate) prevalence States of Gujarat, Goa, Punjab, West Bengal, Rajasthan, Uttar Pradesh and in the Union Territory of Chandigarh. In 2006, it was further extended to a total of 91 centres in high, moderate and low prevalence States. Paediatric ART was also initiated at all ART centres. The majority of the HIV positive people learned about ART from NGOs and passed the word on. Information dissemination on ART plays a vital role in expanding the coverage. Researchers have argued that even at very low prevailing prices for generic antiretroviral therapy medications in India, government financing of antiretroviral therapy is very expensive and reduces the burden of the AIDS epidemic only marginally (Over et al., 2005). Therefore the question of free ART provision by the state needs careful evidence-based consideration. Public policymakers need to consider both the direct and indirect effects of antiretroviral therapy policy. Direct effects are those that improve health and increase lifespan for the patients receiving the therapy. Indirect effects are those that affect the transmission of HIV, that is, the infection of new people. The existence of these direct and indirect effects provides one of the strongest rationales for government intervention. For this, it is essential to know more about the positive effects of the treatment on PLAH and whether it has contributed significantly to their overall wellbeing.

## Chapter 3

### THE SOCIO DEMOGRAPHIC PROFILE OF ART BENEFICIARIES IN KERALA

#### 3.1 The Context

Kerala has made remarkable advances in the basic indicators of the health status of its population. This distinguishes Kerala not only from the rest of India but even from a large number of developing countries. In terms of achievement of high levels of health status, Kerala finds her place along with geographically and socio-politically developed countries (Kannan et.al., 1991). The access to health services and its effective utilisation results in better health outcomes. The utilisation rate in Kerala is high compared to other States. The people of Kerala exhibit a high health-seeking behaviour and as a result, their utilisation of the health services in the State is comparatively high (National Human Development Report, 2001). Kerala is categorised as a low prevalence state for HIV, although it is sometimes described as having pockets that may represent localised or concentrated epidemics (Priya, 2003). Antenatal prevalence, representing adult prevalence in the community, has increased from 0.1% 1998 to 0.33% in 2004 (in comparison, the national adult prevalence is 0.91%). Prevalence in samples from sexually transmitted disease (STD) clinics has hovered at between 2% and 3%. According to the 2006 National Family Health Survey (NFHS), the HIV/AIDS prevalence in Kerala is 0.36%. The first HIV positive person in Kerala was identified in 1987. Since then there has been a gradually growing epidemic in the State. According to the Kerala State AIDS Control Society (KSACS, 2010) estimates, Kerala has over 55, 000 HIV/AIDS patients. Approximately 86% of HIV transmission is reported to be through heterosexual sex. The HIV epidemic in Kerala is distinctly related to migration<sup>19</sup> and presents unique features which differ from other neighbouring states (Kumar, 2004). This chapter presents the socio-demographic profile of ART beneficiaries in Kerala, including their general profile and personal history of HIV/AIDS status.

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<sup>19</sup> A survey was conducted of people with HIV from 75 Kerala households in districts with high rates of infection and high rates of migration. Of those interviewed, 66.7% had a migration history (Timothy 2003).

### 3.2 Antiretroviral Treatment in Kerala

As observed earlier, in many other situations, it has been noted that providing anti-retroviral treatment (ART) would go a long way in reducing the stigma and discrimination experienced by HIV-infected patients. Kerala is the first state in India to start ART for HIV positive people in 2004, by meeting funds from its exchequer (Kerala State AIDS Control Society, 2009). ARV treatment and the CD4 testing are all provided free of cost to HIV positives<sup>20</sup>. Since 2006, the ART centres have been supported by National AIDS Control Organization. All HIV positive persons can register at ART Centres for HIV care. These centres also provide prophylaxis and treatment for opportunistic infections. Counselling is given for ART preparedness and adherence. The CD4 cell count<sup>21</sup> estimation, which is to be done once in six months for all HIV positive persons is facilitated through ART centres and done free of cost. Ushus centres are linked to Community Care Centres, where PLAH requiring nutritional support, counseling, and treatment of minor opportunistic infections are referred to. There are six ART centers in Kerala attached to each medical college. The first centre started in Thrissur Medical College.

**Table 3.1**  
**Details of PLHA on treatment**

Name of ART Center	Patients on Pre ART (HIV Care)				Patients ever started on ART	Patients currently on ART			
	Male	Female	Children	Total		Male	Female	Children	Total
Trivandrum	1285	857	126	2268	1126	452	204	42	698
Alleppy	272	178	24	474	327	124	84	9	217
Kottayam	662	496	72	1230	756	263	177	24	464
Trissur	1957	1252	205	3414	1636	636	363	61	1060
Kozhikode	1339	874	150	2363	1287	581	284	38	903
Palakkad	157	149	25	331	226	115	90	15	220
<b>Total</b>	<b>5672</b>	<b>3806</b>	<b>602</b>	<b>10080</b>	<b>5358</b>	<b>2171</b>	<b>1202</b>	<b>189</b>	<b>3562</b>

Source: Kerala State AIDS Control Society, 2009

<sup>20</sup> Kerala State AIDS Control Organization (KSAC, 2009).

<sup>21</sup> CD4 cells are a type of lymphocyte (white blood cell). They are an important part of the immune system. When HIV infects humans, the cells it infects most often are CD4 cells. The genetic code of the virus becomes part of the cells. When CD4 cells multiply to fight an infection, they also make more copies of HIV

The above table shows the number of PLHA that is under the treatment in the six government medical colleges in Kerala. The number of males is higher both among the patients on Pre-ART Care and patients currently on ART. The Thrissur ART centre has the largest number of treatment-seeking PLHA, both on Pre ART Care and currently on ART. This is probably because this the first ART centre in Kerala and PLHA might have started getting treatment from here.

The services for ART eligible people are provided by 'Ushus' which are the Anti Retroviral Treatment (ART) centers set up in all the Government Medical Colleges in Kerala, functioning under the Department of Medicine, and later in a phased manner in at least one centre in each of the 14 districts.

**Table 3.2**  
**Details of Registration and Treatment at Ushus (ART) Centers**

<b>Details of Registration and Treatment at Ushus (ART) Centres</b>				
<b>Description</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>Progressive total from the beginning</b>
No. of persons Registered for HIV care	1,818	2,580	2,109	8,891
No. of patients started on ART	896	1,069	1,134	4,579
No. of death reported	135	225	254	1,300
No. of Patients alive and on ART	1,604	2,340	3,091	3,091

Sources: Kerala State AIDS Control Society (KSAC), 2009

The table 3.2 sets out the details of registration and treatment at 'Ushus' (ART) centers in Kerala. An HIV patient can register at the 'Ushus' centre even though he/she has not started treatment. The time of ART initiation may differ from patient to patient. From the field study, it is evident that almost all of them started ART only after some other treatments for opportunistic infections; it is only later that they come to know about their HIV status.

### **3.3 Study Population and Sampling**

For this study, a field survey was conducted and 120 ART beneficiaries from six districts of Kerala State in which the ART centers are situated were interviewed. The

samples were collected from the Prathyasa centers<sup>22</sup> and patients below 20 years were excluded. From each district, twenty samples were collected. They were surveyed and interviewed at the 'Prathyasa' centres. Simple random sampling method has been used in selecting the samples for the study and everybody had an equal chance of being selected from the population. Female respondents are more than male respondents this is mainly because the females were more willing to be interviewed. They have been randomly selected. This study has documented their demographic details, change in health status which includes opportunistic infection, general health status, disease history, duration and type of treatment and body weight, change in their social status which includes community participation, household composition, job status, change in economic status includes income, employment, savings and debt, barriers to the treatment, etc. (the questionnaire is appended).

### **3.4 General Profile of the Respondents**

When we consider the community-wise distribution, 74% of the patients are Hindus and among them 65% are Nair and Ezhavas<sup>23</sup>. The rest of them (26%) are Christian and Muslim. The general profile of the ART beneficiaries includes age sex composition, educational status, marital status, and occupation.

#### **3.4.1 Age and Sex Composition of the Respondents**

It is necessary to understand the age structure of the respondents. HI V/AIDS affects people during their most productive age. AIDS-related deaths in economically active age groups will lead to loss of human-power (Nair, 2004).

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<sup>22</sup> The 'Prathyasa' centres started in all districts in Kerala under the auspices of the Kerala State AIDS Control Society is a group movement, which imparts a message of hope to all HIV positive persons in the state. The 'Prathyasa' centres offer opportunities for HIV infected persons to be given counseling and to give direction to their life. The 'Prathyasa' centres also act as forums where HIV patients can air their problems and to obtain solutions to their problems (Kerala State AIDS Control Society, 2010)

<sup>23</sup> The Ezhavas are the largest Hindu community (22.91%, 2001 census) in Kerala and also one of the major progressive communities of the state. Nairs are the another social class in Kerala, (12.88%, Census 2001).

**Table 3.3**  
**Age Sex Composition of the Respondents**

Sex	Age sex composition (%)					
	Less than /equal to 30	31 to 40	41 to 50	51 to 60	More than 60	Total
Male	2 (3.8)	19 (36.5)	23 (44.2)	7 (13.5)	1 (1.9)	52 (100)
Female	2 (2.9)	47 (69.1)	18 (26.5)	1(1.5)	0	68 (100)
<b>Total</b>	<b>4 (3.3)</b>	<b>66 (55)</b>	<b>41 (34.2)</b>	<b>8 (6.7)</b>	<b>1 (0.8)</b>	<b>120 (100)</b>

Source: Primary Survey, October 2009

Table 3.3 plains the age sex composition of the respondents. For this study, 120 ART beneficiaries were studied, (43% male and 57% female). Among the respondents 89% of them are in the age range of 30 to 50, which is the most productive age. In the age group of 31 to 40, the number of females is higher than that of males and in the age group of 41 to 50, it is the other way. The majority of females were in the age group of 30 to 41 and the majority of the males were in the age group of 41 to 50. This implies the fact that when compared to males, females come to know about their HIV status in the early stage of the infection. There is one person (male) who is more than sixty years of old.

### 3.4.2 Educational Status

Educational qualification does matter when we consider the occupational status as it is the deciding factor of occupation and income. To a certain extent, educational qualification gives a hint about socio-economic status.

**Table 3.4**  
**Sex and Educational Status**

Sex	Educational Qualification (%)						Total
	Illiterate	Basic literacy	Primary School	Secondary school	Higher secondary school	Graduate and above	
Male	0 (0)	1 (1.9)	8 (15.4)	35 (67.3)	8 (15.4)	0 (0)	52 (100)
Female	2 (2.9)	6 (8.8)	10 (14.7)	37 (54.4)	12 (17.6)	1 (1.5)	68 (100)
<b>Total</b>	<b>2 (1.7)</b>	<b>7 (5.8)</b>	<b>18 (15.0)</b>	<b>72 (60.0)</b>	<b>20 (16.7)</b>	<b>1 (0.8)</b>	<b>120 (100)</b>

Source: Primary Survey, October, 2009

There were 1.7% respondents who were illiterate. There were no male illiterates, but in the category of 'graduate and above', there was only female (0.8%). Among the males, the majority (67/3%), have secondary school education and this is so for the majority of females (54.4%) also. 1.5% of the females have education up to the level of graduation and above. The female population has both the extremes, i.e., illiterates and graduates.

### 3.4.3 Marital Status

The marital status of the respondents has been separated into 5 groups, married and living with spouse, single, single parent (having children), separated or divorced (without children) and widow or widower (without children).

**Table 3.5**  
**Sex and Marital Status**

Sex	Marital status (%)					Total
	Married	Single	Single parent	Separated/divorced	Widow/widower	
Male	46 (88.5)	1 (1.9)	2 (3.8)	2 (3.8)	1 (1.9)	52 (100)
Female	21 (30.9)	1 (1.5)	43 (63.2)	2 (2.9)	1 (1.5)	68 (100)
<b>Total</b>	<b>67 (55.8)</b>	<b>2 (1.7)</b>	<b>45 (37.5)</b>	<b>4 (3.3)</b>	<b>2 (1.7)</b>	<b>120 (100)</b>

Source: Primary Survey, October 2009

The above table explains the marital status of the respondents. When we look at marital status, it is found that while 88.5% of men are married, only 30.9% of the women are married. Only 3.8% of the male are single parents, but among women, this proportion is 63.2%, which is a very huge difference. This is mainly because most of the female respondents have lost their husbands to the disease. This situation makes the plight of single female parents really pitiable, since they have no earnings and have to bear the heavy burden of responsibilities. They are mostly dependent and economically vulnerable. The number of ART beneficiaries who obtained a divorce after coming to know about the HIV status (it can be either theirs or their partners') is comparatively low and the same among men and women. The numbers of widows/widowers are also few. Among them, the men are most likely to have lost a spouse due to some other reason and not HIV/AIDS, but for women, the loss is usually due to HIV/AIDS. Thus, women seem to be in a more pathetic condition.

### 3.4.4 Sex and Occupation

Occupational status has been divided into working in formal sector, informal sector, self employed, unemployed because of disease and unemployed.

**Table 3.6**  
**Sex and Occupation**

Sex	Sex and Occupation (%)					Total
	Informal sector	Formal sector	Unemployed	Unemployed because of disease	Self employed	
Male	37 (70.3)	2 (3.8)	7 (13.5)	2 (3.8)	4 (7.7)	52 (100)
Female	17 (25.1)	0	46 (67.6)	4 (5.9)	1 (1.5)	68 (100)
<b>Total</b>	<b>54 (45)</b>	<b>2 (1.7)</b>	<b>53 (44.2)</b>	<b>6 (5)</b>	<b>5 (4.2)</b>	<b>120 (100)</b>

Source: Primary Survey, October 2009

Around 95.4% of the respondents are working in the informal sector. Among the men, the percentage is 70.3% and among the women, it is only 25.1%. From this sample, it appears that a few men seem to be in formal sector employment, but no women. Another important factor is that 44.2% of the respondents are unemployed. Around 67.7% of women and 13.5% of the men are unemployed. The unemployment rate among female respondents is very high compared to that among male respondents. When we consider occupational status and marital status together, it seems that females are more in number in the categories of 'single parents' and 'unemployed'. This implies more responsibilities with no occupation/income and makes the situation more precarious for females compared to males.

### 3.5 Personal history of HIV/AIDS status

The personal history of HIV/AIDS status includes reason to check HIV status, duration of treatment, the time in which the subjects came to know about their HIV status, knowledge about ART, and the type of ART medicine they are taking.

#### 3.5.1 Time of HIV test

From the field observations, it was understandable that most people come to know about their HIV status only when he/she becomes ill or when they come to know about their partner's HIV status. Some of the respondents said that they were instructed by the doctor to start ART before getting the free access of ART but they



were unable to purchase the drugs due to the high cost, even though they knew about their status.

**Table 3.7**  
**Time of HIV test**

Sex	Time of HIV test (%)				Total
	within last 2 years	within last 2 to 5 years	within last 5 to 10 years	Before 10 years	
Male	3 (5.8)	28 (53.8)	16 (30.8)	5 (9.6)	52 (100)
Female	9 (13.2)	31 (45.6)	21 (30.9)	7 (10.3)	68 (100)
<b>Total</b>	<b>12 (10)</b>	<b>59 (49.2)</b>	<b>37 (30.8)</b>	<b>12 (10)</b>	<b>120 (100)</b>

Sources: Primary Survey, October 2009

The above table shows the time in which ART beneficiaries came to know about their HIV status. Among the males, the majority (53.8%) came to know about their HIV status within the last two to five years. Among the females, 45.6% of them came to know about their HIV status in the same time period only. For these patients, free access to ART was available right from the time they came to know of their HIV positive status. In total, around 10% of the respondents had come to know about their HIV status 10 years ago. The doctor may have instructed such persons to start ART before getting the free access of that.

### **3.5.2 Reason to check HIV/AIDS Status**

There are a number of reasons for a person to go in for an HIV test. This study considers four major factors: self doubt, illness or doctor's advice, partner's HIV status, and other reasons. Sometimes a person can deliberately go for an HIV test just because he or she wants to. In other cases, a particular situation may arise which makes them to go for test, which is, doctors advise them to go in for the test because of opportunistic infections. In some other cases, a person goes in for the HIV test if his/her partner is HIV positive. In that case the person tests negative, it is possible to prevent the disease from occurring.

**Table 3.8**  
**Reason to check HIV status**

<b>Sex</b>	<b>self doubt</b>	<b>Illness or Doctor's advice</b>	<b>Partner has HIV</b>	<b>Other reasons</b>	<b>Total</b>
Male	3	44	3	2	52
% within sex	5.8	84.6	5.8	3.8	100
% within the reason	75	80	5.7	25.0	43.3
Female	1	11	50	6	68
% within sex	1.5	16.2	73.5	8.8	100
% within the reason	25	20	94.3	75	56.7
Total	4	55	53	8	120
% within sex	3.3	45.8	44.2	6.7	100
% within the reason	100	100	100	100	100

Source: Primary Survey, October 2009

The above table shows the various reasons to check the HIV status. Illness or doctor's advice and partner's HIV status are the two major reasons to go for an HIV test. Around 45.8% of the respondents went for the HIV test because of illness or doctor's advice; 80% of them are male and only 20% are female. From the personal interviews of the ART beneficiaries, it seems that most of the male patients were hospitalised due to opportunistic infections before coming to know about their HIV status and were in an exceedingly poor state of health. The detection of HIV in a man usually prompts his wife to undergo the test. Thus the majority of women generally come to know about their disease from their partner's HIV status and this is evident from the table. In total, 44.2% of the respondents went in for the HIV test because their partners are HIV positive and within that, females constitute 94.3% and males, just 5.7%. Only 3.3% of the total respondents went to check out of self-doubt and among them males (75%) are more compared to females (25%). Only 6.7% of the respondents checked their HIV status due to certain other reasons which they did not want to reveal, and among them females were more (75%) compared to males (25%).

### **3.5.3 Knowledge about ART**

It is important to have an understanding of the knowledge of ART beneficiaries about this particular treatment. A lay person may be unfamiliar with the new treatment, but usually has a number of sources from which information may be obtained. A person

can come to know about ART through many sources like the various awareness campaigns held in the State and through the National AIDS Control Organizations and Non Governmental Organizations, by reading about it from other sources, or from friends of colleagues, and from the doctor.

**Table 3.9**  
**Knowledge about ART**

<b>Sex</b>	<b>Self Knowledge</b>	<b>Doctor's advice</b>	<b>Awareness campaigns</b>	<b>Total</b>
Male	0	45	7	52
% within sex	0	86.5	13.5	100
% within source	0	54.2	19.4	43.3
Female	1	38	29	68
% within sex	1.5	55.9	42.6	100
% within source	100	45.8	80.6	56.7
Total	1	83	36	120
% within sex	0.8	69	30	100
% within source	100	100	100	100

Source: Primary Survey, October 2009

The above table shows the sources of ART knowledge and explains how the ART beneficiaries come to know about the treatment. The majority of the respondents (69%) came to know about the treatment from the doctor's advice. The basic reason behind this is that most of the respondents were hospitalised and unaware of their HIV-positive status. Knowledge of HIV came afterwards. Around 86.5% of the males came to know about ART in this manner; among female the corresponding proportion is 55.9% which comparatively low. The respondents who themselves know about ART (self knowledge) from other sources are very low in number and only around 0.8%, including males and females. From awareness campaigns, around 30% of the respondents came to know about ART. Among them, the proportion of female respondents is high (42.6%) compared to that of male respondents (13.5%). From the observations made during the field, it was evident that most of females went to the care centers regularly before starting the treatment and this makes them aware about ART initiation. However, it was found that most of the males will go to the care centers only after the treatment initiation.

### 3.5.4 Duration of treatment

ART beneficiaries have started ART initiation at different points of time. The time of ART initiation varies from patient to patient and depends on their CD4 count. Some patients have to start ART as soon as they come to know about their HIV status, but for others, the health status may be better and they may be able to cope without ART initiation for some time.

**Table 3.10**  
**Duration of treatment**

Sex	last one year (2008-09)	within 2004 to 2006	within 2006 to 2008	Before 2004	Total
Male	17	22	8	5	52
% within sex	32.7	42.3	15.4	9.6	100
% within duration	41.5	44.9	38.1	55.6	43.3
Female	24	27	13	4	68
% within sex	35.3	39.7	19.1	5.9	100
% within duration	58.5	55.1	61.9	44.4	56.7
Total	41	49	21	9	120
% within sex	34.2	40.8	17.5	7.5	100
% within duration	100	100	100	100	100

Source: Primary Survey, October 2009

The table shows the duration of the treatment among both males and females. Most of the respondents (40.8%) started ART during 2004- 2006. This is the period in which the Government started giving ART free of cost and facilitating free access in every Government medical college in Kerala. There is not much difference between males and females. Around 17.5% of the respondents started ART initiation during the period from 2006 to 2008, i.e., 15.4% of males and 19.1% of the females. Around 7.5% of the total respondents started ART initiation before 2004, i.e., before getting free access to the treatment. They might have spent a lot of money to get the treatment. However, there are people who were asked by the doctor to start ART initiation before getting the free access, but they could not do so due to the high cost involved.

### **3.6 Conclusion**

There are more than 10,000 PLHA who are under pre-ART HIV care. More than 3,000 PLHA are taking the treatment in Kerala (KSAC, 2009). From 2006 onwards, the number of ART beneficiaries has been increasing considerably. Around 89.2% of the respondents were in the age group of 31 to 50. Majority (60%) of the respondents have studied only up to secondary school. When we look into their occupational status, around 45% are employed in the informal sector and 44.2% are unemployed. The high rate of unemployment is not because the incidence of the disease is high among female ART beneficiaries. Very few of the respondents (1.7%) are working in the formal sector. The majority of the males (84.6%) went in for the HIV test due to illness or doctor's advice, and among the females, most of them went for the HIV test because of their partner's HIV status. Most of the ART beneficiaries were unaware of ART till they came to the doctor. Awareness campaigns also have a vital role in making them aware about the HIV treatment. Around 92.5% of ART beneficiaries started taking ART only after getting the free access. The rest of them started taking it before getting free access and then they transferred it to the free access.

## Chapter 4

### EMPOWERMENT OF ANTIRETROVIRAL TREATMENT (ART) BENEFICIAIRES

#### 4.1 Introduction

Health can be empowering if people have greater control over the factors that influence their health and their lives. Public health experts demand that the empowerment factor should be the key consideration when evaluating the long term implications of any health care project (Vathsala, 1996). As ART becomes increasingly available, affordable and accessible, it brings undeniable benefits to those served by programme in many countries<sup>24</sup>. With these benefits come new aspirations in people living with HIV and therefore, different expectations by them of the programmes that support them. Consequently, they look forward to the future and to strategies that will sustain them and their families. This chapter will assess the changes in the lives of ART beneficiaries after the ART initiation, using a feminist framework of empowerment, in which power has been divided into four components, i.e., '*power from within*', '*power with*', '*power to*' and '*power over*'.

#### 4.2 Assessing Empowerment

##### 4.2.1 Power from within

'*Power from within*', otherwise known as personal power, which examines the psychological power and focuses on the sense of self-confidence, self esteem and self-respect of the individuals (Wong, 2003). The need for a psychological improvement in the condition of the PLHA comes from the fact that HIV/AIDS can cause depression, trauma and other kinds of psychosocial adversities<sup>25</sup>. This can be due to several reasons like the fear of social stigma and discrimination, etc. To overcome this

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<sup>24</sup> Access to the drugs means a chance of recovering from illness. The treatment's presence means greater community awareness and discussion of HIV and AIDS, often resulting in dissipating negative attitudes. Much has changed in the context of HIV and AIDS and the rebuilding of lives begins in this new and complex environment, (Maher, 2008).

<sup>25</sup> Mood and anxiety disorders, particularly depression, are the most common psychiatric diagnoses, and are 5–10 times more common in PLWHA than in the general population. In the USA, approximately half of PLWHA have significant depressive symptoms and 20% to 25% meet diagnostic criteria for a depressive disorder. The presence of multiple rather than a single psychiatric diagnosis (e.g., co-morbid depression and substance abuse) is the norm rather than the exception, (Pence, 2009).

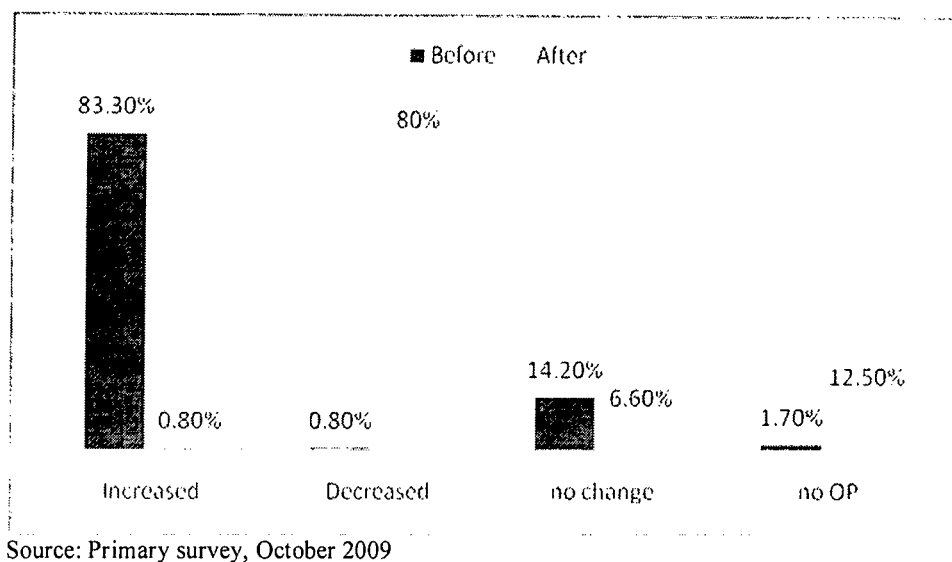
particular situation, ART adherence should have a positive impact on both the body and mind by enhancing physical health status which improves the quality of life. There is one study says that this wider impact of ART is largely positive (Maher, 2008). To assess '*power from within*', this study is tries to probe whether there are any improvements as a result of ART in the case of prevention of opportunistic infection, improvement of body weight, general health status, food and nutritional security and reduction of stigma and discrimination. These elements constitute the mental and physical status through which power from within is attainable.

#### 4.2.1.1 Opportunistic Infection (OIs)

People with advanced HIV infection are vulnerable to infections and malignancies that are called 'opportunistic infections' because they take advantage of the opportunity offered by a weakened immune system. Opportunistic infections (OIs) continue to cause morbidity and mortality in patients with human immunodeficiency virus (HIV) infection throughout the world. Potent combination antiretroviral therapy (ART) has reduced the incidence of OIs for certain patients with access to care (AVERT, 2009)<sup>26</sup>.

Figure 4.1

#### Change in Opportunistic Infection



<sup>26</sup> AVERT is an international HIV and AIDS charity, based in the UK, working to avert HIV and AIDS worldwide, through education, treatment and care.

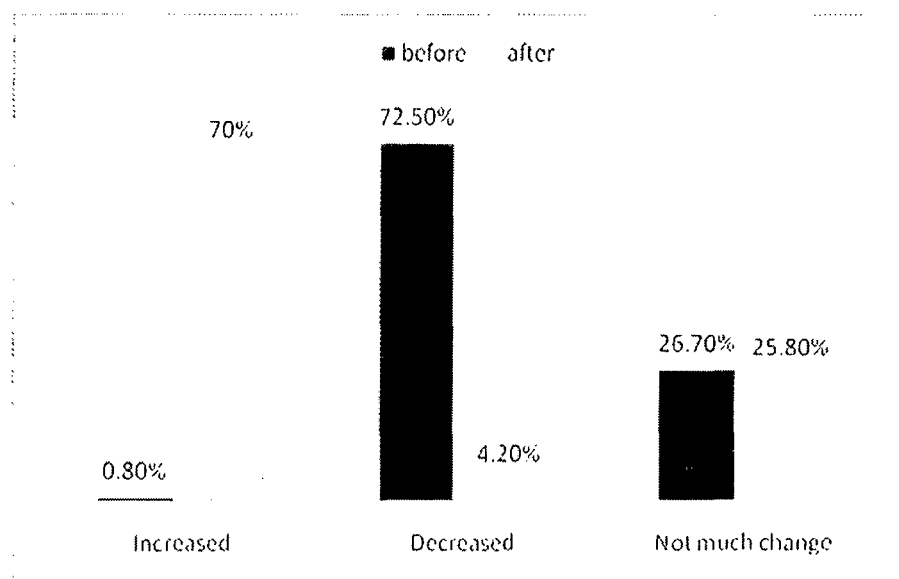
The above figure shows the change in opportunistic infection before and after taking ART. The opportunistic infection of 80% of the respondents has come down after taking ART and 12.5% of them have not faced much opportunistic infection. The rest remained in same status as before taking ART or they did not experience much infection. This figure shows a significant reduction in the case of opportunistic infections after taking ART. Reduction of the opportunistic infection will make the ART beneficiaries healthier than before.

#### 4.2.1.2 Body Weight

Many people diagnosed with AIDS lost weight through chronic ill health. PLHA can quickly become malnourished and start to lose weight. They may have decreased appetite, be unable to eat much because of candidacies in the mouth or esophagus, have poor absorption, or have chronic diarrhea (Israel, 2007). Co-infection with TB is common with HIV infection, and widespread TB infection may also cause weight loss. Weight gain may be rapid for persons commencing ART and after treatment of OIs and TB (Israel, 2007). Some ARVs must be taken with food and recovery may be assisted by a good diet.

**Figure 4.2**

**Change in Body Weight**



Source: Primary survey, October 2009

The above figure shows after became infected 72.5% of the people lost body weight before ART and after taking ART 70% gained body weight. Around 25% of them have not come across any kind of change in body weight. Thus this reveals the fact

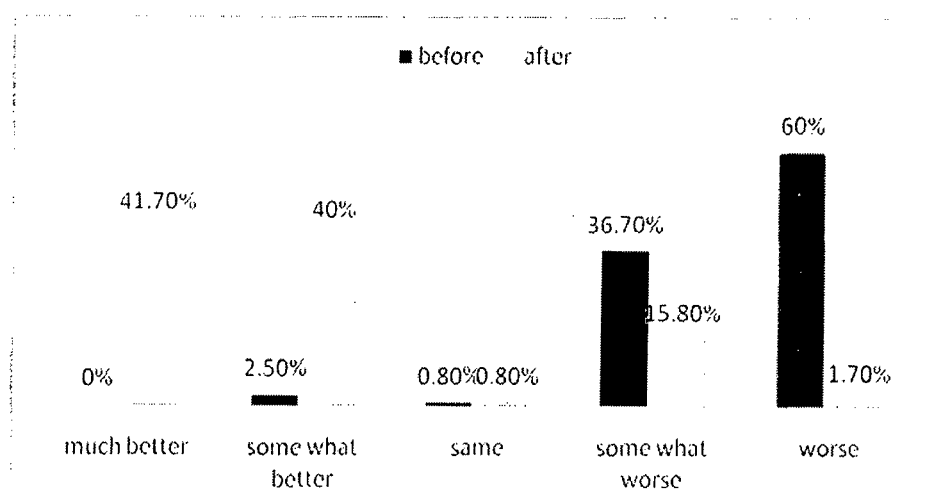


that ART adherence has a positive impact in the case of change in body weight. There are also many factors like food and nutrition supply both from the public and private accesses that helped to increase their body weight.

#### 4.2.1.3 General Health Status

A study done by Estrada (2003) shows that ART patients are in need of not only specialty care for HIV/AIDS, but also that, in most cases, would also benefit from psychosocial stabilization via a critical care team that includes ongoing case management. This kind of care will help to improve their general health status. In this study, PLHA were asked how they felt about their health status in general. We mentioned both physical and psychological conditions.

**Figure 4.3**  
**Change in General Health Status**



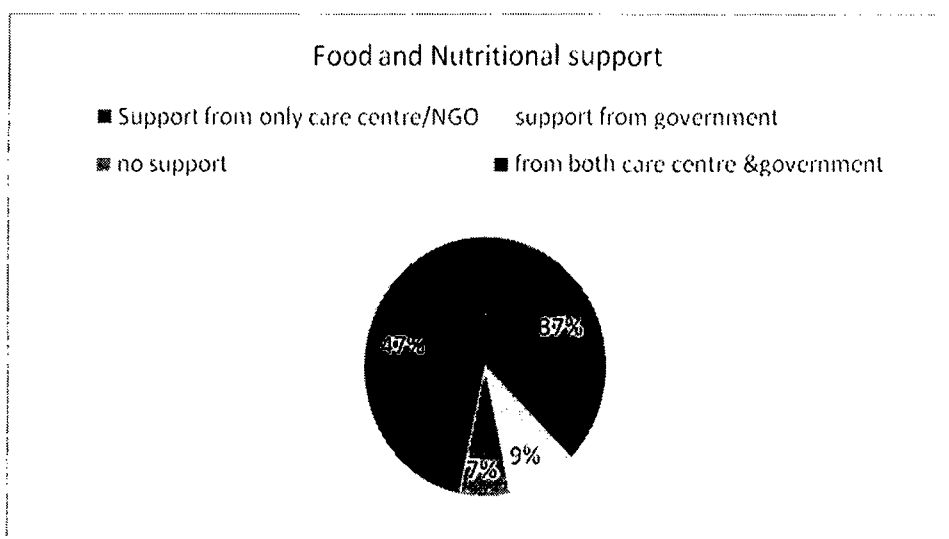
Source: Primary survey, October 2009

The above figure shows that for 95% of the respondents' general health status was either somewhat worse or worse before taking ART. The rest (5%) of the patients' situation were more or less the same before and after taking ART. After starting the ART health status of 85% of respondents was much better or somewhat better and 16% of them remained in a somewhat worse condition than before taking ART. This figure shows an improvement in general health status which implies an enhancement of both mental and physical capacity which will make PLHA confident enough to undertake productive work; if they are not physically or mentally fit, they cannot go for any kind of activity.

#### 4.2.1.4 Food and Nutritional Support

Interactions between ARVs and food and nutrition can significantly influence the success of ART by affecting drug efficacy, adherence to drug regimens, and the nutritional status of PLHA. This will enhance their physical health capabilities. Managing the interactions between ART and food and nutrition is a critical factor in the extent to which the therapy is effective in slowing the progression of HIV/AIDS and improving the quality of life of PLHA (Castleman, 2004). To ensure the greatest benefits ART needs to be taken along with nutritious diet. Proper nutrition helps to strengthen the immune system, manage opportunistic infections, optimise response to medical treatment, and may contribute to slowing the progression of the disease. In Kerala, the PLHAs used to get food and nutrition support from the government, Non Governmental Organization (NGO), food relief groups, etc (Observation from the field, October 2009). The ART beneficiaries are getting the nutritional supports from the care centers called 'Prathyasa' under the Kerala State AIDS Control Society, and also from ART clinics. Considering the financial difficulties of the ART beneficiaries it became very difficult to purchase nutritious food without support.

**Figure 4.4**  
**Food and Nutritional Support**



Source: Primary survey, October 2009

The above figure shows that among the ART beneficiaries, around 47% get support from both the government and care centre/NGO which include 100% of females. Around 37% of the population gets support only from the care centre and they are all males because almost all the female patients are getting nutritional support from

government (Primary Survey, October 2009). Around 9% of the respondents are getting support only from the government, which includes only the female population which is not getting any support from the care centre or NGO. The remaining 7% of the patients are not getting any kind of nutritional support either from Government or from NGO/care centers which include only male population (Primary Survey, October 2009). As a whole, around 93% of the ART beneficiaries (including 100% of females) get some kind of food and nutritional support, which shows a very good support system on the part of both the government and NGOs which helps them to improve their physical health status and also their standard of living.

#### **4.2.1.5 Removal of Stigma and Discrimination**

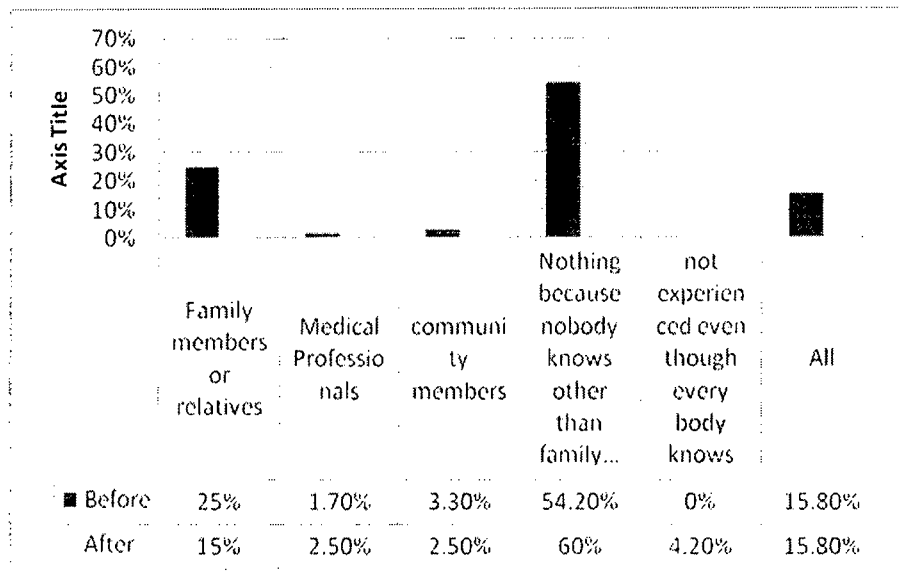
Stigma remains the single most important barrier to seeking treatment. It is the main reason why too many people are afraid to see a doctor to determine their HIV status, or to seek treatment if they are affected. This stigmatization makes AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is the chief reason why the AIDS epidemic continues to devastate societies around the world (Williom et. al, 2007). In healthcare settings people with HIV/AIDS have to experience stigma and discrimination such as being refused access to medicine and other facilities, receiving HIV testing without consent, and lack of confidentiality (Fikremariam, 2004). Such responses are often fuelled by ignorance of HIV transmission routes amongst doctors, midwives, nurses and hospital staff. The discrimination can happen even from the family members or relatives which negatively affects ART beneficiaries' adherence to the treatment<sup>27</sup>. One of the important observations from the field is that PLHA usually do not like to reveal their HIV status even to close family members or relatives because of the fear of stigma and discrimination. This makes attaining power from within very complicated.

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<sup>27</sup> Family responses to infected relatives are heavily influenced by community perceptions of the disease. Families that include an individual with HIV may fear isolation and ostracism within the community. Consequently, they may try to conceal an HIV diagnosis, which in turn may cause considerable stress and depression within the family (Bharat, 2001)

**Figure 4.5**

**Change in Stigma and Discrimination**



Source: Primary survey, October 2009

The above figure shows there is a considerable change in stigma and discrimination after starting the treatment. A significant level of decrease is visible in the case of discrimination experienced from the family and relatives which falls from 25% to 15% close to half. On the other hand, the discrimination from the medical professionals has increased to some extent. This may be because after starting treatment the patients have more contact with the medical professionals than before. Before starting the treatment, 54.2% of the patients did not experience any kind of stigma or discrimination because nobody knew of their HIV status other than family members. This number seems to have not fallen after treatment initiation, but rather risen to 60%. It shows the fact that more relatives came to know about their HIV status after starting the treatment but PLHA do not experience any stigma and discrimination because they still keep their status secret, within the family. That indicates that there is fear of stigma. After starting the treatment, around 4% of the ART beneficiaries say they are not facing any kind of discrimination even though everybody knows that they are. Nevertheless, as a whole, the treatment did not make any difference in the case of stigma and discrimination.

The concept of power from within or personal power has been influenced by the treatment to a certain extent. In the case of physical power, i.e., opportunistic infection, body weight and general health status improved substantially. However,

there was no such improvement in the case of stigma and discrimination and which remains more or less same. The study done by Williom et al. (2007) on the impact of ART in reducing stigma and discrimination says that antiretroviral therapy access may be a factor in reducing HIV stigma. Nevertheless, the persistence of stigmatizing attitudes and significant anticipated stigma suggest that HIV stigma must be a target for ongoing intervention. Thus we can say that on all factors except stigma and discrimination component there is an increase in the '*power from within*'.

#### **4.2.2 'Power with'**

'*Power with*' implies a collective initiative and the ability to do things within the group. Here, this study is trying to assess ART beneficiaries' participation in different kinds of social and cultural networks which have developed or supported by ART initiation. As a part of the national response to HIV/AIDS in India, the Government has introduced the Greater Involvement of People living with HIV/AIDS initiative (GIPA)<sup>28</sup> which promotes the socialisation of PLHA through various collective initiatives. In this particular context, it is necessary to understand whether the improved health status of ART beneficiaries has had any impact on their collective activities. To assess the degree of improvement in '*power with*', this study will consider the changes in the frequency of care centre visit and participation in social, political and cultural organisations. Through these channels, people on treatment can be supported by and continue to be integrated into the community. These are the social spaces and securities in which people can develop an independent sense of worth as opposed to their usual status as inferior citizens.

##### **4.2.2.1 Frequency of Care centre visit**

Before taking ART, people may not be ready to go to the care centers because of the fear of social stigma. After taking ART, each and every patient is advised to visit the care centre<sup>29</sup> to get both mental and physical support. The centers check whether they

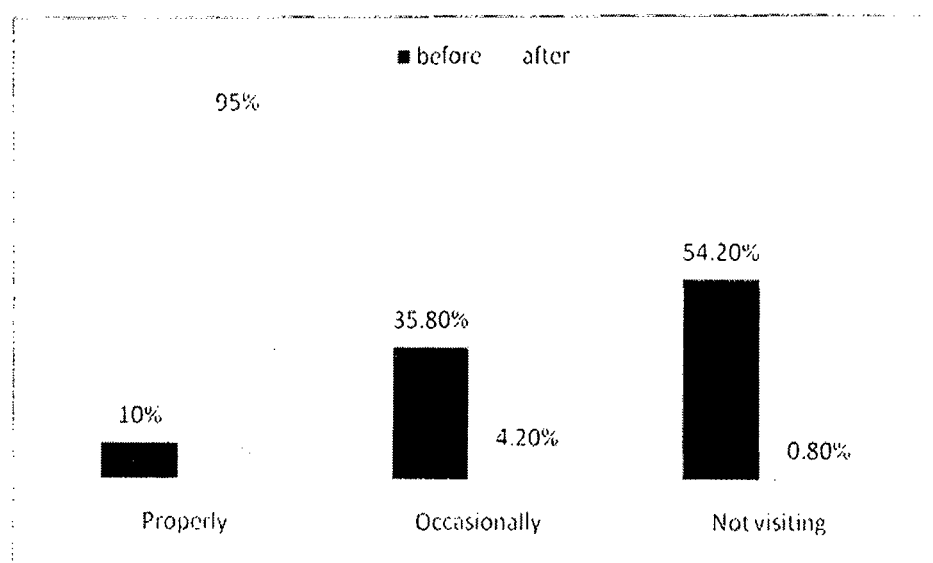
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<sup>28</sup> In 1994, during the Paris AIDS Summit, 42 national governments, including India, through a declaration that has come to be known as the GIPA Declaration collectively recognised the need for the greater involvement of people living with HIV/AIDS (PLHA) in response to the AIDS pandemic. The GIPA Declaration states that the greater involvement of people living with or affected by HIV/AIDS is 'critical to ethical and effective national responses to the epidemic'. Conversely, the declaration clearly implies that the absence of GIPA may adversely affect the national responses to HIV/AIDS. (NACO,2004)

<sup>29</sup> Observation from the field, (October 2009)

are getting the medicine from the ART centre properly. Another important advantage of this care centre visit is that PLHA from different social groups, economic classes, different places can get together, which will make them confident enough to carry out a normal life. The kind of collective power among PLHA often form local organisations that advocate for better access to care and treatment and more resources to be spent on addressing HIV/AIDS. Some form or join existing local support groups and these can be very useful for providing psychosocial support.

**Figure 4.6**  
**Change in Care Centre visit**



Source: Primary survey, October 2009

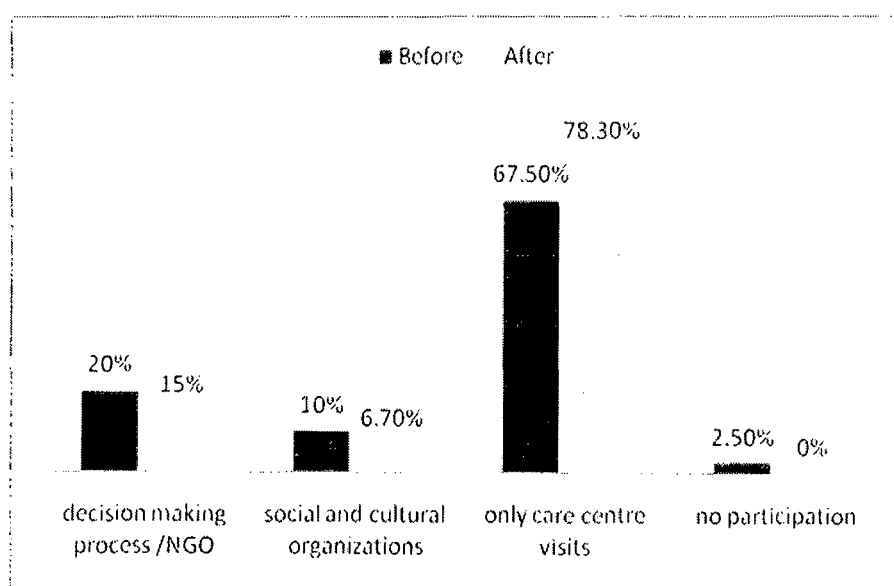
After taking ART, people are supposed to go to the care centers especially when they need any kind of help and support from others. Only 10% of them were used to visiting the care center regularly before taking ART, while 54% of them did not visit the centre. However, after taking ART, 95% of them are seen to be visiting the centre regularly and rest of them, either occasionally or not visiting it at all. This shows that there is an improvement in the collective participation of ART beneficiaries and it imparts the '*power with*' to them. This kind of support group can accommodate those who want their status to remain private. Their fellow beings with HIV/AIDS provide personal support and encourage the person living with AIDS to take the ARVs as prescribed. This can be particularly important if the person suffers side effects from the ARVs. In some models, for ART delivery, the treatment companion receives special advice and counseling to help them in the role.

#### 4.2.2.2 Participation in social, political and cultural organization

Here, we consider the change in the collective participation and activities before and after taking ART. We examine whether the resultant improvements in physical and mental health status as a result of ART enables PLHA to participate in various social, political and cultural organizations or if they are remaining in the same situation as before taking ART. There are studies (Maher, 2008) that show that after coming to know about the HIV status, PLHA are reluctant to participate in social activities, but after starting ART, there is a renewed ability in most to become active members of society.

Figure 4.7

#### Participation in social political and cultural organizations



Source: Primary survey, October 2009

Participation in the decision-making process, especially in local self-government, was 20% prior to starting treatment and 15% after starting treatment. Around 10% of the respondents participated in social and cultural organisations before treatment, but after starting treatment, only 6.7% of them participated. In both the cases, it shows a negative impact. This can be because of the fear of stigma and discrimination. There are large numbers PLHA who have no social participation other than the care centre visit and it was 67.5% prior to the treatment, 78.3% after commencing treatment. Instead of having a positive impact because of the treatment, a negative impact is seen here in the case of participation in social and cultural organisations and in the local political institutions. This kind of participation plays a vital role in making the ART beneficiaries take collective initiatives which enhance '*power with*'. It is perhaps the

strength of the stigma that is evident here: either society does not seem to be open towards ART beneficiaries, or their fear of stigma has deepened after seeking ART. This point makes sense in the light of the weakness noted earlier in their '*power from within*'.

Within the context of the '*power with*', there is a positive change in the case of visiting the care centre, but when it comes to public participation there is a negative result after taking the treatment. '*Power from within*' may work to make possible more active participation in collective spaces and the articulation of a sense of collective by ART beneficiaries, but it appears that the ART beneficiaries are ghettoized in certain spaces. '*Power from within*' and '*power with*' are interrelated, which works together for the ART beneficiaries' wellbeing, but in this case, while the former has increased, the latter has improved only in a limited way.

#### 4.2.3 'Power to'

'*Power to*' refers to the unique potential of every person to shape his or her life and the world. When based on mutual support, it opens up the possibilities of joint action, or the '*power with*' (Klasen, 2002). In '*power to*', this study will be looking at what ART beneficiaries are able to do productively, i.e., whether they are working and whether they actively earn an income which is central to their economic wellbeing. It examines whether the resulting effectiveness of ART is enabling the ART beneficiaries to earn income and to what extent the ART beneficiaries are able to take active decisions or roles in the family.

##### 4.2.3.1 Monthly Income

AIDS related ill health will affect the earning capacity both by increasing health expenses and decreasing working capacity<sup>30</sup>. Most households have no reserves to pay for a sudden increase in health care expenditures or to weather a sudden loss in income, (observation from the field, October 2009). A study by Ajithkumar et. al. (2007) on the impact of antiretroviral treatment on vocational rehabilitation found that

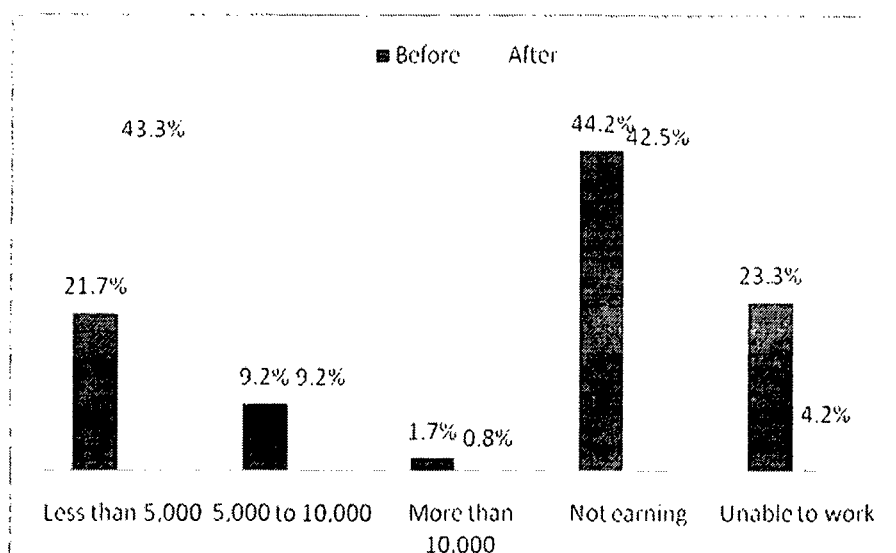
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<sup>30</sup> One of the most frequently observed ways in which HIV/AIDS affects households and individuals is through the sudden and tragic loss of income and economic security as household earnings decline and medical expenses increase. Household resources erode quickly while exposure to economic risk is exacerbated by the stress of illness as, first, adults and, then, children become caregivers for sick family members, ("The Socioeconomic Impact of Viet Nam", Prepared by the Policy Project in collaboration with the Community of Concerned Partners, Viet Nam, June 2003).



96.4% of those previously employed are at present employed, while 65.8% of those previously unemployed are employed at present.

**Figure 4.8**  
**Change in monthly income**



Source: Primary survey, October 2009

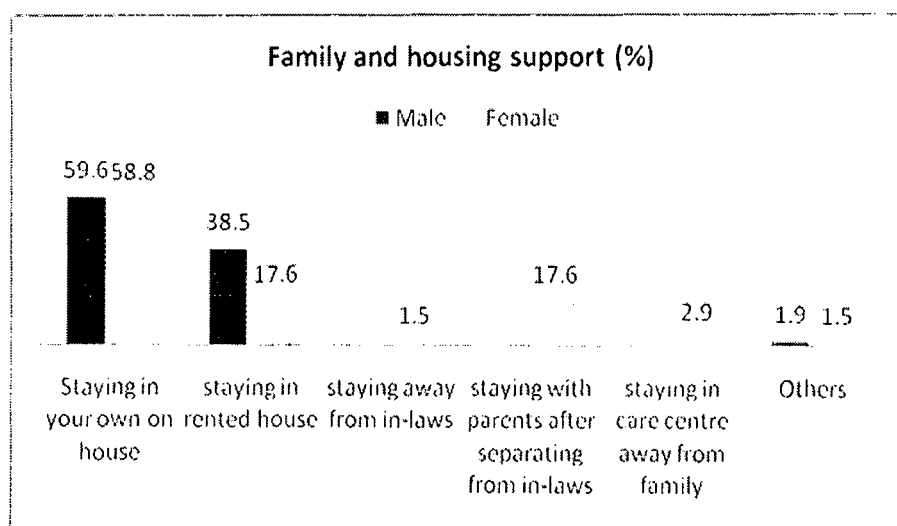
The above figure shows the change in monthly income after taking the treatment. It shows that the number of people earning less than 5,000 has increased after taking ART, the number of patients who were not able to work because of the disease has decreased. These both implies a positive impact of the treatment on the lives of the ART patients. However, when it comes to the case of the patients who were not earning, this has decreased only a bit, i.e., there is not much reduction in the number of unemployed after taking ART. The numbers of those who were earning more than 10,000 has come down.

#### **4.2.3.2 Housing and Family Support**

Human Immunodeficiency Virus (HIV) has a large psychological, physical and social impact on infected individuals and their families. Without strong support from their family, it is difficult to initiate the treatment. High levels of treatment adherence are crucial for the success of expanding ART treatment programmes and this mostly depends on support from the family. A study done by Knodel et al (2010) regarding the role of family and parents in ART treatment examines the extent to which family members, especially parents, assist adherence. Results indicate that most adult ART

patients live with family members and over half live with or in the same locality as a parent. Moreover, parents often remind patients to replenish supplies of food and medicine and sometimes accompany them to appointments. Clearly close family members, including parents, should be explicitly incorporated into adherence augmentation programmes and provide adequate information to facilitate their role as long-term adherence partners. ART recipients are closely linked to family members through living and care-giving arrangements (Knodel et al, 2010).

**Figure 4.9**  
**Family and Housing Support**



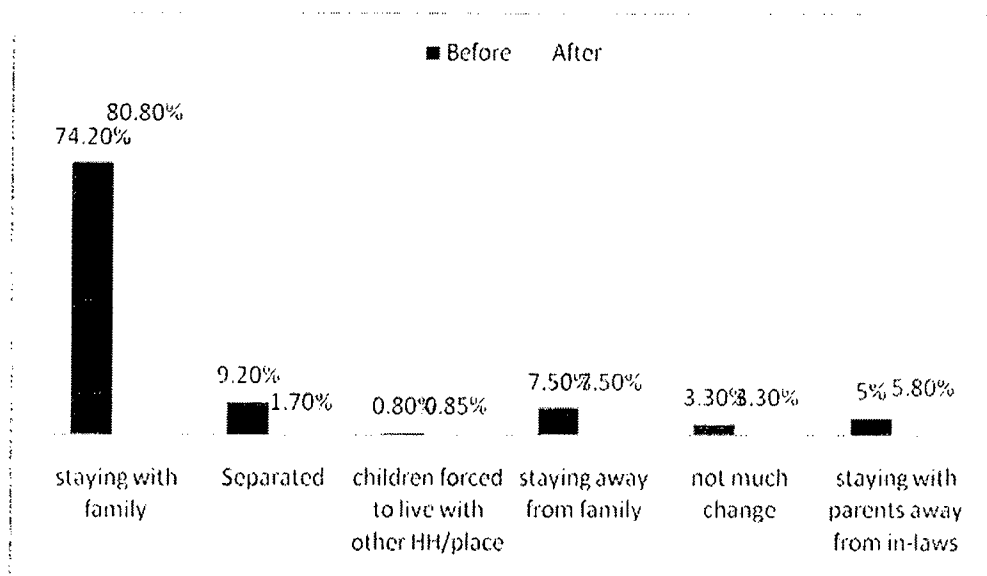
Source: Primary survey, October 2009

The above figure shows the housing and family support of the patients. Around 59.2% are staying in their own houses and 26.7% are staying in rented houses. Also around 12% of them are staying with parents after moving out from their in-laws' place and this includes only the female population, because it is extremely difficult for them to stay with their in-laws following the husband's ill health and death. Most of the respondents had children and 1.5% of them were not staying with either their parents or in laws. A small percentage of the patients (2.9%) are in care centers away from family, which includes only female PLHA. These are the most vulnerable sections among the patients and those who left their family because of several social and economic reasons. This kind of a weak position at home will not enhance the '*power to*' take any decisions or any initiatives. If the ART beneficiaries live in their own houses, it gives them a sense of freedom in which they can take their own decisions.

### 4.2.3.3 Change in Household Composition

The social stigma that surrounds HIV may have adverse repercussions not only for the individual, but also for their family. Sometimes, this drives patients to leave the family and even the native place. Some of the PLHA prefer to leave their family and community due to several reasons and try to make a new beginning where they are not known (observation from the field, October 2009). It shows their inability to face the problems by living as they did before being affected by the disease.

**Figure 4.10**  
**Change in Household composition**



Source: Primary survey, October 2009

The above figure shows that there is a significant increase in the number of people who are staying with family members after the initiation of the programme. Before the treatment, the proportion who stayed with their families was 74.2%, and after starting treatment, it rose to 80.8%. This shows the positive impact of the treatment. Those who are separated also shows a very good improvement and the number of people living separately from their spouse have decreased from 9.2% to 1.7% after starting the treatment. These findings seem to imply that if PLHA were living separately before taking treatment, after the initiation of the treatment, they are more likely to be living together and it seems a substantial improvement due to the result of the ART initiation. However, there is no change in the case of those who started staying away from home and those who stayed with parents and away from in-laws

(mostly widows) even before taking treatment. In addition to that, their profile reveals the fact that most of them are unemployed and this will make them dependent on their old parents. That causes them live under somebody else's control. Thus, from the above figure we can concur that the treatment does not make any significant improvement in the case of change in household composition for those who were away from home and from their in-laws. The case of widows is especially important and reveals a very serious disadvantage.

Klasen and Miller (2002) shows that when '*power to*' is based on mutual support, it opens up the possibilities of joint action. The improved health status enabled ART beneficiaries to have collective initiatives with other PLHA and also that helped them to go back to their work and became able to earn income. Thus '*power-to*' here reveals a positive picture, overall. On the one hand, there is improvement in the ability to earn, and it also appears that those who were separated from their families have been able to rejoin them. Nevertheless, those who left their families for good did not rejoin them; nor did the break with the in-laws heal; the latter cases, it may be surmised, are also likely to be unemployed.

#### **4.2.4 Power Over**

'*Power over*' implies capacity to hold, have control over certain resources which influences their lives and this has many negative connotations<sup>31</sup>. The '*power over*' resources depend upon various factors. '*Power from within*' and '*power with*' should be the basis to obtain any sort of dominant capability to fulfill their requirements. In other words, if the ART beneficiaries are physically and psychologically miserable they cannot make any further progress to improve their lives. Here, the element of power over has been analyzed by considering the change in the economic status of the ART beneficiaries. It primarily looks upon the control over economic resources.

##### **4.2.4.1 Fixed assets**

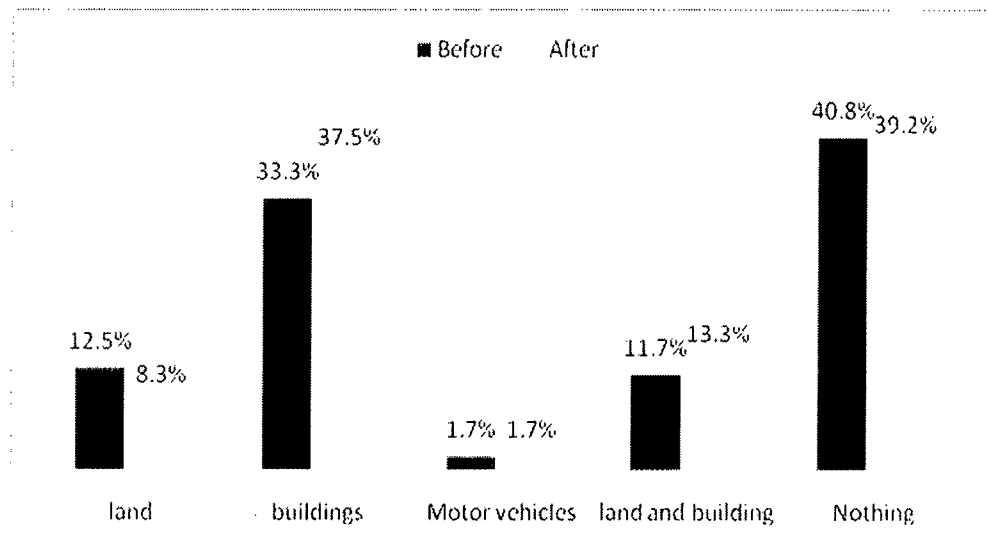
Fixed assets include land, building and motor vehicles. There is a heightened possibility of losing assets because of the financial burden of the disease. At the same time, PLHA can regain assets due to their improved physical and mental status which

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<sup>31</sup> Having power over involves taking it from someone else, and then, using it to dominate and prevent others from gaining it, (Wong, 2003).

is supposed to get back as a result of the treatment. This makes it necessary to see whether this change has happened or not. If they are regaining the assets it will reduce their dependence on others.

**Figure 4.11**  
**Change in Fixed assets**



Source: Primary survey, October 2009

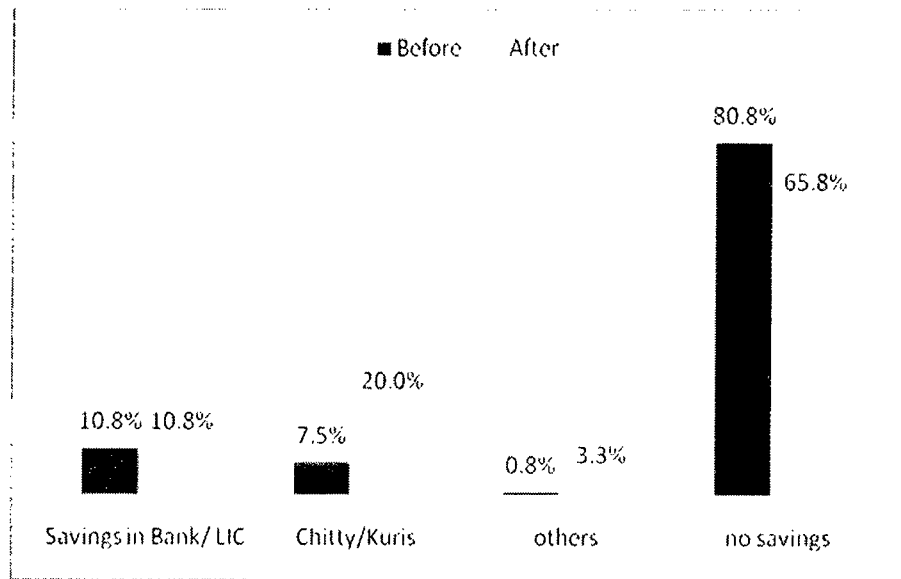
The status of fixed assets which consists of land, building, and motor vehicle also does not show much change. Before taking ART, 12.5% of the respondents possessed land as an asset, but after taking the treatment this proportion has come down. After taking ART, the estimate of the respondents who were possessed buildings has increased slightly. The respondents who had properties said that because of their ill health, most of them sold their properties to meet the medical expenses. After taking treatment, the number of respondents without any assets decreased which means there is an increase among those who possess assets.

#### 4.2.4.2 Savings

As consequences of the loss of income and increased expenditure for medical care, savings are used, assets are sold and money may be borrowed (observation from the field, October 2009). In many cases, the health costs associated with HIV/AIDS consume all the savings of a family, leaving no reserves to cope with the shocks such as actual loss of the person like breadwinner, business owner, etc. (International

Labour Organisation 2000). In this context, it is important to know the ART has any impact on the saving habit of the ART beneficiaries.

**Figure 4.12**  
**Change in savings**



Source: Primary survey, October 2009

The above figure shows the changes in the saving habit of the respondents. After taking ART, savings in the form of *chitty* and *kuri* have increased. Another important fact is that after taking ART, the percentage of the respondents who did not have any sort of savings has decreased which implies the savings among the respondents has improved. According to the figures, 80.8% did not have any savings before, and 65.8% have no savings after. So the number of people without savings had fallen. Even after starting the treatment, savings in the bank and insurance companies remained the same. Monthly income and savings improved, but not significantly.

Here the power to earn income has a positive effect on the power over assets and savings to a limited extent, mostly in the form of ‘chitty’ and ‘kuri’. Thus the increase in the ‘*power over*’ certain resources will increase the well-being of ART beneficiaries, and it can further enhance their individual and social life. As a whole, there is a slight positive change in the case of ‘*power over*’ resources.

### 4.3 Conclusion

When we analyse the empowering effects of ART through the changes in the lives of the PLHA after taking ART, it is observed that the individual sense of self-worth

connecting to the value they attach to their own health (*'power from within'*) improved considerably. The collective empowerment (*'power with'*) through participation in HIV/AIDS-related care centres has improved after the ART initiation. In addition, this collective empowerment helped them to practice proper adherence to the treatment and also enhanced their self confidence (*'power from within'*). Even though *'power with'* does not extend to the full public participation of the PLAH. The fear of stigma remains quite strong. Instead of having a positive impact, the treatment here shows a negative impact in the case of participation in decision-making process. This kind of participation is vital to the PLHA to be able to claim full citizenship in public institutions. It is perhaps the strength of the stigma that is evident here: either society does not seem to be open towards ART beneficiaries, or their fear of stigma has deepened after seeking ART. This point makes sense in the light of the weakness noted earlier in their *'power from within'*. Thus *'power within'* and *'power with'* are mutually reliant. As for *'power to'*, we have noted a rise in incomes and the capacity to earn in the post-ART phase; however, it is also evident that even a rise in income or earning some income will not guarantee the other aspect of *'power to'*, vital for ART beneficiaries', i.e., public participation (*'power to'*). Because of the fear of social stigma and discrimination, ART beneficiaries' participation in social, cultural and political organisations (*'power to'*) has come down. Unless and until the ART beneficiaries have not achieved *'power from within'* completely by resolving the problem of stigma and discrimination and by attaining psychological wellbeing, full attainment of *'power to'* is unfeasible. Attainment of *'power to'* will create a space for ART beneficiaries to be involved in the decision-making process (Oxaal, 1997). From the analysis, it is evident that power over resources has increased in the form of savings. In addition to that, the ART beneficiaries' ability to earn after starting treatment has also improved. Nevertheless, the plight of especially disadvantaged groups, who have not gained much *'power-to'*, is worth noting. As a result of the treatment *'Power over'* resources has increased slightly by making them able to possess some kind of resources like savings or assets. However, it is noticeable from the study that *'power from within'* is the most attained constituent of empowerment, save for the freedom from fear of stigma.

## Chapter 5

### CASE STUDIES

#### 5.1 The Cases

Analysis of the primary data indicated that the lives of the ART beneficiaries has improved considerably especially physical health status, collective initiatives related to HIV/AIDS, and also their economic status. However it shows that they are lacking the essentials of 'power to' and '*power over*'. It may be interesting to consider a few case studies which may provide deeper insight than may be generated through a survey questionnaire. Presented here are six different cases of three male respondents and three female respondents from different districts of Kerala. They are from different social groups and having different life situations. This chapter tries primarily to understand the effects of ART on the lives of ART beneficiaries from the angle of their experiences. The names and the place names that may appear in these narratives are not of the interviewees. They have been changed to assure complete anonymity.

#### **Lekha**

I got married at age of 22 and am now 35 years old. My husband was a driver in Mumbai and ours was a typical arranged marriage. He went to Mumbai at the age of 15 and used to come to Kerala only rarely. I have two boys; one is 17 and the other, 14 years old. Basically, I am a tailor by profession and I used to get a lot of orders before being affected by the disease. Now I am not able to work because of the ill health due to the disease.

From 2006 onwards, I was suffering from many health problems like tuberculosis, weight loss, hair loss, etc. My husband kept saying that all these health problems were due to my lack of faith in God; he compelled me to perform many religious rituals to cure my health problems. After one year, due to the severe ill-health, I went to a private physician and underwent a detailed check-up. The doctor asked me about my private family matters, my husband's whereabouts, etc. Then I was told the shocking news that my husband also used to visit the same doctor without my knowledge whenever he came to Kerala. The doctor told me that he had asked my husband to bring me in for a test. He then gave me a letter and he asked me to go to Trivandrum



Medical College to meet a particular doctor. He told me not to open and read the letter and I was unaware of the things which were happening to me. When I went to the medical college and had the check-up as advised by doctor who gave me the letter, I came to know that I was a HIV patient and that my husband had also been infected. He had been consulting this doctor since then.

My husband and his family kept this information very secret for many years. My husband was in Mumbai at that time, but I started taking ART from Trivandrum Medical College. My health condition was really pathetic and I never thought that I could be like this and in the condition that I am in now. Because of the severe drugs, I had some problems like vomiting in the beginning of the treatment, and after that gradually became normal and recovered to a certain extent. After two months of ART initiation, my physical health status improved, I gained weight and I was able to do domestic work. But by that time my family was in debt because in the absence of my husband's support and because I had to borrow money for the many kinds of treatment I tried before I came to know about my HIV status. Even after beginning the treatment, I was not able to work and earn. After one year my husband came back from Mumbai. He was severely ill due to HIV infection and I took him to the Medical College. At that time my older son left home in secret, not able to bear the stigma and discrimination, both of relatives and neighbours. I was not an earning member and I sank more and more into debt. My husband was not ready to go in for the treatment because of the fear of social stigma, but somehow everybody had come to know about our situation. I forced him to come to the Medical College, with me, helped our younger son.

He has also recovered physically now and will find work after some time. I am taking care of my family with the help of my brothers. When we became healthier, our elder son came back and that was a great relief for me. I am getting food and nutritional support from the Government. Even though I am experiencing financial difficulties, ART helped me to recover physically and I can now live with my family. Since I have only boys I don't have to worry about them because after some years, they will be able to take care of themselves. Even now my husband does not allow me to go out for social or cultural programmes because of his fear of social stigma. He never comes to the care center and he will not allow me to go but, sometimes I used to go

there without his permission. But I used to go for Kudumbasree<sup>32</sup> meetings regularly and two or three time 'Kudumbasree' members became willing conduct meetings in my home and I felt very happy with them. Both financially and socially, 'Kudumbasree' is a great support for me.

I am back to life because of ART initiation even though I have so many problems like economic instability and stigma. Gradually I am coping up with the current situation and I have to have a life for my children. Since I am getting free ART and emotional support from my brothers I think I can live for some more years to make my children bold enough to lead a life in the absence of their parents.

### **Indu**

I am 30 years old, married and have two children. Currently I am working in a care centre and earning Rs.4000 per month. My family and husband's brother's family is staying together. My husband is a driver and we were in Kerala only. I came to know about my HIV status from my husband's status. Both my children tested negative.

Before getting free access to ART my husband started taking ART by paying more than Rs.6000 per month. After some days, the doctor instructed me also to start ART and if possible, to continue lifelong. But financially we became so weak because of the disease that we stopped taking ART. I then started going to do cleaning jobs in several houses. When I got tuberculosis, I stopped going for the work and became bedridden. Since the cost of treatment was very high, my husband and I were not able to afford it and this made the situation more pathetic. I never thought that I will be able to come back to normal life and consider this is my second birth.

In the year 2006, when the government started giving free access to ART, I started taking the treatment. After getting free ART, we started taking it regularly and I used to come to the care centre for the job. For me and my family ART initiation was the only way to get back to our life. Now we are able to look after our children and their education is going well. When my husband started working, we moved to my husband's family home from our rented house. There I faced stigma and discrimination from the family members which made our life miserable. When my

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<sup>32</sup> It is the state-wide network of below-poverty-line women set up by the State Poverty Eradication Mission which conducts micro-finance and micro-enterprise and is also closely involved in the implementation of state welfare at the local-level.

husband's family came to know about our disease they were not ready to give us our share of the family property, but somehow we managed to live in the part of the property which was his share. Now we cannot rent a good house in the nearby town because of the high rents and even if we manage to get a house in a remote area at a low rent, it will be difficult for us to get medical access. Even though we are living with my husband's brother's family, due to their fear of the disease, we have separate kitchens. My in-laws informed the neighbours, friends and relatives about our HIV status. Earlier I used to think about it and suffered a lot but now things have changed. My mother-in-law told our neighbours that her son got infected with HIV as I had given him contaminated water. Since she is an old lady she does not have a proper understanding of HIV/AIDS and its ways of transmission. However her understanding was that HIV/AIDS is 'bad disease' which affects only 'bad people' and that is what she tells everybody.

After facing situations like this, I decided to work, and then I got a job in a HIV/AIDS care centre. After getting the job I am not much concerned about the society or social stigma and now I am earning Rs. 4000 a month. At the same time, I am a positive speaker<sup>33</sup>. I used to go to Kudumbasree meetings for positive speaking where I found so many people who don't have an understanding about HIV/AIDS. The Kudumbasree members could not believe that I am a HIV/AIDS patient who is leading an active life. According to their understanding, a HIV/AIDS patient is bedridden and sick. I think I was able to make them understanding about the life of PLHA.

I don't have any kinds of barriers for taking treatment as I had it before commencing free access for ART. Since my husband is also taking ART, we are able to run the family very well. We take all the decisions together and we have my husband's share of the family property. I am getting sufficient emotional support from my colleagues which is the prime inspiration. If I stay at home and not go for work, this will cause depression. Even though I have some debts, my husband and I are able to work and

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<sup>33</sup> HIV Positive speakers are those PLHA who are trained to share their personal story and the reality of living with HIV/AIDS, to provide relevant information where appropriate and requested, to convey challenging myths and preconceptions about HIV/AIDS to reduce stigma and discrimination (Arnold, W., 1990)

we are economically better off than before taking treatment. I don't have any kind of savings. My only one concern is about our children. If anything should happen to my husband or to me, who will look after them? There is still a lot of uncertainty regarding our health and life; we are not sure about how long we can live like this. If there was no free ART access, we will not be able to go for private treatment and we might have died. Now when I come to the care centre and when we go for positive speaking, I forget all my sorrows and all these positive factors give me courage and happiness to live for our children.

### **Hari**

I am 40 years old and working as an outreach worker in the HIV/AIDS care centre. My native place is Kannur but I am now staying at a care centre in Trivandram due to my disease. My father, mother, wife and son are at home in Kannur. I studied only up to 10<sup>th</sup> standard. Before becoming ill, I was doing lottery business in Kannur. In November 2003, I got sick and was admitted to Pariyaram Medical Collage (Kannur district). I got pneumonia and spent around Rs.300 a day for the treatment. Even though my CD4 count was very low when I came to know about my HIV status, I couldn't take medicine due to pneumonia. Then I took my wife and son for the HIV test without any delay and they were negative. I don't know how I got infected with HIV.

Before I came to know about my HIV status, I had a good business and that income was enough for my family to live without any difficulties. After became ill, I was not able to work. I was staying with my family in my wife's house with her mother and I was the only earning member. I had a good relationship with all the family members, relatives and neighbours. When I was hospitalised my family and relatives came to know about my HIV status. I became very weak both financially and emotionally. My wife's mother did not allow me to stay in her house and she was not ready to send my wife and son to stay with me. Then I thought of staying with my parents and brothers because I had a share of the family property.. But they were ready to accommodate only my wife and son and not me. Anyway, my mother in law took my wife and son to her house. At that time I really wanted to stay with my mother for some days, but my brothers were not ready to look after my mother if I stayed with her. It was this situation which forced me to leave my place and come to Trivandram. My health

condition was very weak, I was almost dead. Somehow, I tried to get ART in the private sector, but due to the high cost, I was not able to afford it. When reached in a care centre at Trivandram I got accommodated there and I got food and proper rest. In that way, I somehow survived till 2006 without taking ART.

In the year of 2006 December, I started getting free access to ART. After that, my health status improved little bit. My body weight has increased considerably and opportunistic infection has decreased. Since I am in the care centre, there is no difficulty for food and am getting nutritional support from the care centre. After the initiation of the treatment, I started working as an outreach worker in the care centre and getting Rs. 4000 as monthly income. I cannot go for work which needs high physical ability. So I can't earn as much as I did before getting the disease. I am still suffering from opportunistic infections. But I can only serve PLHA who are suffering from the disease.

I have experienced lots of discrimination even after starting the treatment both from family and relatives and also from medical professionals. When my HIV status was revealed, my family members refused to accommodate me. Now I can't go to my house and my wife and son is staying with her mother. Even if I want to see my son they won't allow me to go to home. Whenever I want meet my son, I ask my wife to bring him to the town and we will spend some hours together. We go together and I buy some toys, snacks and clothes for them. I come back to Trivandrum on the same day. If there is a function in the family, nobody informs me. I am almost excluded from the family and even if I earn some money and give to them they won't accept me. In the hospitals too, I faced many bad experiences. Once when I went to a private hospital, the doctors asked me to purchase costly gloves; otherwise, they were not ready to examine me. There was delay in treatment when the doctors and nurses came to know about my HIV status.

I don't have any other social or cultural activities and my life is devoted to the service of HIV/AIDS patients. The treatment improved my physical health status and there are now no barriers for treatment. Other than this, ART has not made any changes in my family life. Because of stigma and discrimination, I suffered a lot in my life. Other things are not a problem. I don't feel like working and earning. Whom am I earning money for? I don't have any savings. I get enough money for my own

expenses. Since I am working within the PLHA community, I don't have many problems. I cannot go to my place, nobody will accept me. I don't have any other place to go and live and my health is bad sometimes. This care centre has given me shelter and I will be here till my death. I have lost my family; I have lost my native place. The treatment can improve our physical health status but, mentally still we face many problems. The support system we are getting from the care centers is really worthwhile. But in our society, our life cannot be normal as it used to be before being affected by the disease.

### **Jose**

I am 30 years old, working in a welding workshop and earning nearly Rs. 5000 as monthly income. At the age of 15, I left my native place and went to Hyderabad and at the age of 25, I came back to my place. I have four siblings and now I am married and have a son. I am staying with my father, mother, wife and son. My wife is working in a care centre and earning Rs. 4000 a month.

In 2007, when I was in Hyderabad I became sick. After a lot of treatment and tests I came to know about my HIV status. I was a bachelor. I was admitted in a hospital due to tuberculosis for three months, but nobody was there to look after me, so I came back home. Then my family, relatives and neighbours came to know about my HIV status. Again, I was admitted in the Medical College for one month. The condition of my health condition was very poor. I never thought that I would survive and have a life like this. I lost weight and got so many other infections. Free ART was available at the time, but due to my bad health, I was not able to take the drugs. At that time I was almost like dead and my siblings started telling everybody about my condition, wanting to usurp my share of the family property if I died of HIV/AIDS. I lost my job in Hyderabad and I was sure that I could not work anymore. I did have some savings with me but when I became ill I spent all my savings. Very bad physical health condition, loss of job and savings, etc. made my life pathetic. I didn't get much moral support from my family; due to all these troubles I became weaker.

When the tuberculosis came down, the doctor instructed me to start taking ART. It took some more days to cope up with the treatment. After starting the treatment, my physical health improved considerably. I gained weight and started going for work which made my life quite normal. I used to visit care centers frequently and got

support and relief from there. Even though my family was not ready to accept me I started thinking about a new life. However I realised that for an HIV patient, leading a normal life is not possible. It was clear in my mind that I cannot go back to Hyderabad due to the need for frequent medical checkups and the medication. Financially, my condition was very pathetic at that time due to the medical expenses. I started looking for a new job here in my place itself and I started going for work. I never had a barrier to take the treatment. My siblings thought that since I have HIV/AIDS, I cannot get married and I will not have a family and so that they can get my share of family property. Since my physical health status improved significantly, I tried to make them believe that I am not an HIV patient, so that I could get my share of property and build up a life.

Fortunately, I met a HIV positive widow with a kid in the care centre. We both liked each other and decided to get married and she was HIV positive. I told my family that I am not an HIV patient; I got married (she is HIV negative) when I was in Hyderabad. I lied to my family because I wanted to have a good life. When I started living like a normal person with my wife and son my family, relatives started believing that I am not an HIV patient. My wife's family knows all the stories but they won't reveal it to anybody. Now I also have a family and am leading a peaceful life. My siblings and relatives are not creating any problems now because I make them believe that we are not HIV positive. Sometimes relatives and neighbours used to ask to my wife whether you people have 'matte asukham',<sup>34</sup> but she handles this situation very cleverly. However, one day they will come to know the truth and we still don't know how to face the situation.

Because of the ART initiation, my health has improved and I am now leading a peaceful family life. If there was no free access to ART, I would have been dead. Apart from care centre visits, I don't have any social or cultural activity. Sometimes, we are scared to go to the care centers because others will come to know about the real situation. We have a little bit of debt, but it is possible to repay it soon. My life has changed a lot because of the ART initiation. I can now go for work and earn money. Since I am living like a normal person without any opportunistic infection,

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<sup>34</sup> This is a Malayalam colloquial usage which means bad disease. The word 'matte' indicates 'the other' and in this context this word means nobody should speak about because it is something very bad. The word 'asukham' indicates disease.

others are also accommodating me. Now our only concern is our son. If anything happens to us, who will take care of him?

### **Ramani**

I am 29 year old widow, not working, and have a daughter. I studied till 10<sup>th</sup> standard. I was staying in my brother's house. My parents were with him but they are no more. I was a housewife, but after husband's death I don't have any source of income. My husband died because of AIDS and after that husband's family didn't allow me to stay there. They are saying that he got the disease because of me and I didn't get my husband's share of the family property. I am not well enough to go to court.

It was when my husband died that I came to know about my HIV status. It was a big shock for me to know that my child and I are positive. We became the victims of stigma and discrimination from my husband's family after his death. They didn't even think that my daughter and I couldn't go anywhere without any source of income. They didn't even give us my husband's share of the family property and started telling relatives and neighbours about our health status. At last, we thought of leaving the place and going to a place where people don't know anything about us. After that the condition of my health condition became very pathetic. Since I was not working financially, I was weak. When I became ill, I borrowed money to meet the medical expenses. After that, I and my daughter were admitted into a rehabilitation centre. Around one year we both were there only and after that I came to my brother's house with my girl. Then I started doing some jobs and that was the only source of income. After a few months, I became sick and was admitted to hospital. My daughter was staying with me in the hospital. My brother helped me to meet the medical expenses. I felt very bad when I thought that I was becoming a burden for my brother and I was sure that after a point, he could not help me. My health condition was becoming worse and nobody was there to look after my daughter. After some days, she too became very ill. Our CD4 count became very low and the doctor instructed us to take ART. But that time free access to ART was not available and doctor suggested second line medicine for my daughter which was more expensive. Since our financial condition was weak, I decided not to go for private access of ART. Both us lost weight and I contracted tuberculosis. At that time, I was reluctant to go to the care



centers because of the fear of social stigma. Somehow, my daughter and I managed to live for some more time until we got free access to ART.

In 2006, we got access to free ART. Even though we have to travel a long distance for getting the medicine it was a great relief for me and my daughter. In the initial stage I had some kind of side effects due to the use of highly active antiretroviral drugs. After ART initiation, I started going to the care center with my daughter. When I interact with PLHA, I feel a kind of relief and strength to live. Gradually my physical health status improved and my daughter also became better. After that I took up a job as 'anganvadi' teacher and rented a small house.. My daughter and I shifted out of my brother's house. But our rented house is far away from the hospital and it is difficult to travel. After the ART initiation, my daughter has started going to school.

When my condition improved, I started going for 'Kudumubsree meetings' which is a strong financial support. Later, I thought of constructing a house in the share of land which has given my father. For that, I took financial loan from the 'panchayat'. I am now staying in my own house with my daughter and have taken up a job. So I can meet my basic needs, but I don't have any savings. I have contact with all my neighbours and they don't know about my disease. I am entitled to my husband's share of the family property, but I am really scared to go and ask for it. If I go to court, everybody will come to know about my HIV status. Then our life will become more miserable than before. I don't have any contact with my husband's family now. I don't know how I survived. I have some debts -- more than fifty thousand rupees. Now my concerns are my daughter's education and how to repay my debts. I don't when our lives will end, but we have to live till then.

ART has changed my life a lot. If the free access for ART was not there I would have died. Because of my improved health status, I became able to go to work and the care centre visits also helps me to get enough confidence to live alone with my girl. However I realized that it is difficult for a woman with a daughter to live alone in this society. I have to answer so many questions; it is hurting my personal life. There were many times when I thought of committing suicide, but now I feel that I also can have a life like everybody has because now I am both physically and mentally capable of doing things on my own. Primarily, it is because of the initiation of the treatment

which improved the health status and secondly, the emotional support that we are getting from the care centers.

### **Dasan**

I am 60 years old and an astrologist. I have a wife and two sons and both of them are working. I studied ITI and got a job in Bombay at the age of 26. After three years, I got married. I used to come home once in six months.

I came to know about my HIV status at the age of 53 and my wife and sons are HIV negative. Before coming to know about my HIV status I was suffering from tuberculosis and fever. I was hospitalised in Bombay for some time. When my health became very weak, my friends helped me to reach my native place. After that, I was hospitalised again for some months, and during that time I spent all my savings. My sons were studying. That was really a tough time for my family. Without knowing about the real disease, I went through many check-ups and treatments. Later, the doctor asked me to do the HIV test, and it was then that I came to know about my HIV status. I informed my wife and asked her to go for the same test. She did the test and it was negative. Since my CD4 count was very low, the doctor suggested that I take ART. But free access to ART was not available. Even though the cost of ART was very high I somehow managed to get it from the private sector. To meet the treatment expenses, I even started selling my property. Soon all my savings were finished and I fell into heavy debt for lakhs of rupees. I never had gone to any care center before getting free access to ART. I was not able to work and left my job in Bombay. I remember it was a good job. Only my wife and I know about my HIV status, so that I never experience any kind of stigma and discrimination. My wife gives me all the support I need and that is a great relief.

In 2006, I started getting free access to ART which was a great assistance for me and my family. After starting ART, my opportunistic infection got reduced and my body weight increased considerably. My house is near the Medical College so there are no physical barriers to access to the treatment. After two or three months of ART, I became able enough to work in my native place. We had a huge debt and my elder son alone and not able to repay it. Though I was not physically fit enough to work, I started practicing as an astrologist and I am getting enough money from that job. My elder son has also started earning. My younger son stopped his studies and went to

work because of our financial problems. However, after one year we insisted that he continue his studies.

Socially, I belong to an orthodox Hindu Brahmin community, so if other comes to know about my disease, anything can happen. Since I don't have any daughters, the social consequences will be less. When my physical health status improved, I became an active member in the Panchayat and this helped me be active in my life. I have not faced any stigma or discrimination because nobody knows this other than my wife. Our monthly income has increased considerably since I started working. I am now serving the PLHA, and sometimes offer financial assistance also. I start my day at 4'o clock in the morning and go for work at 6'o clock. I go the care centre around eleven in the morning and am there till the afternoon.

Now I feel that I am perfectly alright and we are paying off the huge debt caused by my disease caused. The emotional support that my wife and the care centre members give me has become an inspiration for me to go on living. Since I am the head of the family I don't face problems to take decisions. In addition to that, nobody knows about my HIV status except my wife. So no one will question my identity and role as a father and as head of the family. All of us in the family have always led a disciplined life. I don't know how I got this disease; however, I am now able to face all the challenges of life. When I see the lives of other PLHA I feel that I should serve fellow sufferers in some way or the other.. Even if others come to know about my HIV status, I think I can face it now.

## **5.2 Assessing the cases**

When we assess the cases through an empowerment framework it is necessary to look at the various four aspect of the framework i.e. '*power from within*', '*power with*', '*power to*' and '*power over*'. The cases are consisted of three males and three females and each of them are from different backgrounds which strongly influenced their lives. Among them one female is unemployed due to the disease and all others are currently working. The age of the cases varies from 30 to 60 years. Except one widow and one male all are staying with their families.

### 5.2.1 Power from within

All of them have said that their general health condition was poor before they started the treatment and that after the initiation of treatment, there was a considerable improvement in their physical health status. However, the mental health status does not show equal improvement in all the cases. Half the interviewees reveal the fear of social stigma and discrimination and the extent to which they have experienced the stigma has not reduced even after the initiation of the treatment. As much as they interact with their family members, relatives and neighbours, they are becoming the victims of stigma and discrimination. The words of Mrs. Indu that “I don’t have time to think about stigma and discrimination”, shows that as she is very involved in activities like positive speaking and actively participates in the decision-making, self-help groups (*‘power with’*), she became able to overcome the HIV stigma and discrimination even though she is a victim. Mr. Dasan says that, except my wife, nobody knows about my disease and I consider this is an advantage for not being a victim of stigma, even if others come to know about my disease, I think I can face it now. Here Dasan is an economically well off person, but Indu is still facing a social and economic dilemma. Indu has attained ‘power from within’ to a certain extent because of her improved physical health status which made her socially active (*‘power with’*), even though she is not economically well off (*‘power over’*). The vital factor behind their success stories is the improved physical and mental health status, though they have other limitations. Mrs. Ramani who has a HIV positive girl child says “I feel that I also can have a life like everybody else now because I am both physically and mentally capable of doing things” which implies the attainment of *‘power from within’*. The experience of Mr. Hari shows a depressed mindset even after taking ART. Even though he is able to work and earn, it is not possible for him to return to his family and native place, because of stigma and discrimination he would have to face. In Jose’s life, there were changes regarding stigma and discrimination. Since he is leading a normal life, others believe that he is not an HIV patient, which is exclusively because of the ART initiation. However he lives in the fear of stigma and always thinks that one day, others will come to know about his HIV status. Mrs. Lekha’s words also prove that she cannot get rid of stigma and discrimination even after improving their physical health status. She still has many financial instabilities and debts which shake her life. These three ART beneficiaries

partially attained the '*power from within*' and being victims of stigma and discrimination, this became the root cause of why they could not attain '*power with*'.

### 5.2.2 Power with

From the above discussion it shows that the people who attained '*power from within*' without being a mere victim of stigma and discrimination are very active in the collective initiatives ('*power with*'). Lekha's experience shows that even though there are barriers to go to 'Kudumbasree' meetings, she somehow managed to participate, and this is essential for her to get financial support. Other than this, she is unable to go for any kind of public gathering mainly due to the troubles from the family. The experiences of Indu demonstrate that she is an active member in their 'Kudumbasree meetings' and that she is attending several other public talks on HIV/AIDS with the full support of her husband, though not from the other family members. Ramani is also an active member in the Self Help Group (SHG) which lends her financial support in the absence of husband, and she also gets relief when she interacts with others. But the fact is that, in some of these cases, the neighbours who also probably from the Kudumbasree unit there, do not know of their condition and this reveals the vulnerability of these individuals. Dasan says he is an active member in the 'Panchayat' and interacts with everybody in any public meetings. This gives him confidence that he can also have a life as a normal person. Among these cases, women are comparatively willing to go and participate in the social spectrum and this is not only for financial assistance, but also to get relief by interacting with others, which makes their life lively. From their experiences, it is evident that attainment of '*power from within*' became the fundamental ground for helping them to accomplish '*power with*'. Nevertheless, '*power with*' is not often attained through the successful efforts to remove stigma and integrate these individuals fully into the local community. Hari does not have any kind of social life other than care centre visits as there are no barriers for that. His basic problem seems to be that he does not have anyone 'to live and earn for', and as a result, he is mentally depressed. Jose says that "other than care centre visits, I don't attend any public gatherings, and sometimes even I am scared to go to the care center because others may come to know about the real situation". There is fear even though he has support from his wife. Here, '*power with*' makes them emotionally capable, i.e., helps them to make use of '*power from within*'. Sometimes it serves the purpose of '*power over*' by helping them financially

so that they can buy assets. At the same time, in a basic sense, and even counting the fact that '*power for within*' has not been achieved to the fullest (the fear of stigma has not lessened and continues to limit access to '*power with*'). Unless and until a person is physically well and feels confident about her/his health status, she/he cannot even aspire to take part in collective activities.

### 5.2.3 Power to

Almost all the individuals in these case studies have productive work. '*Power to*' would consider whether they are able to carry on any income generating activities because of the treatment initiation. It also will look to what extent the ART beneficiaries are able to take any active decisions or roles in the family. In Lekha's case, she is not earning an income. Even after the treatment initiation, she is not able to do her work in order to earn income. However, after the treatment initiation, her son who left home came back. But at the same time, because of her husband's restrictions, she is sometimes not able to go to the care centre or to the "Kudumbasree" meetings. Hari's case is little different even though he is earning income. He is unable to convince his family and stays away from them. He does not have housing or family support. Even though Ramani is working, earning and staying in her own house with her HIV positive child, there is nobody to support her family. When it comes to Indu's case, she is very active and able to work because of the ART initiation. Her husband is her great support, so it is not difficult to convince him to take any decision. Dasan's case is also similar to hers; he started earning after became physically well due to the treatment and also gets enough support from his wife, which helps him to be active. Jose's experience is also similar. After the initiation of the treatment, he started working and earning money. He is getting enough support from his wife and is staying with his family. Here, we find that these three cases attained '*power to*' to work and earn income and also have enough power to take decisions affecting their domestic domain. This is mainly because of their improved physical and mental health status. Thus the attainment of '*power to*' depends on the fact that the attainment of '*power from within*' is a necessary condition. Unless and until the individual is both physically and mentally fit, it is not possible to achieve '*power to*'.

#### 5.2.4 Power over

*'Power over'* has been analysed by looking at the ART beneficiaries' ability to control resources. When we take Dasan's case, it is seen that as the head of the family, he does not experience any stigma or discrimination and has the control and power over all the family properties, including the house and related assets. In addition, he is earning around Rs. 500 per day. When it comes to Indu's case, even though she is not the head of the family, she has equal control over the properties which they own. But since she is staying in a joint family in which everybody knows about her and her husband's HIV status, it is very difficult for her to get her husband's share in the family property. She does not have any savings like chitty, kurries, etc. Ramani's case is little different: she has a plot of land, but she has to get her husband's share from his family. Since she is a HIV patient, she says that they are not ready to give it to her. However, she is self-reliant. Jose's experiences say that he fought a lot to get his share of property from his family and his siblings were not ready to give him his legal share. To get the property, he made them believe that he is not an HIV patient since he has a wife and child. He has now got his legal share of the assets. He does not have any savings or debts. When we look in to Hari's case, since he is staying away from home due to stigma and discrimination, he does not have any property. He is working and earning. He says "since nobody is accepting me, how can I get my legal share of property and even if I do, what purpose will it serve?" In Lekha's case, she was earning money before became ill, is not working now and her husband is also not earning. She says "we somehow manage to live". She is staying her own house and does not have much land. She is not working; she does not have much property, except for the house. We find that except in Dasan's case, all the others face a barrier to get their family properties and their family members are negatively inclined in the matter. Except for Dasan, nobody has any kind of savings or assets. Almost all the cases except one are economically vulnerable, having no *'power over'* resources, and are, at the same time, suffering from their relatives' control over the family properties. Even though they are working, the money they earn is just enough for their survival; there is hardly any saving or enough money to afford assets.

### 5.3 Conclusion

The physical health status of all the individuals in this case study has improved after they started taking treatment. However, the mental health status does not show much progress in all the cases. As much as they interact with their family members, relatives and neighbours, they are victims of stigma and discrimination. Except for two individuals, the rest live with family. Of the two who are not living with their families, one is widow and the other actually has a family, but is living apart. Of those who are living with the family, all except one have a peaceful life with their spouse, though not with other family members. Among the three cases, the females are comparatively willing to go out and participate in public forums and this is not only for financial assistance, but also to get some relief from the interaction with others, which makes their life an active one. Except for one, all the cases are economically vulnerable and have no '*power over*' resources; at the same time, they experience difficulties because of their relatives' control over the family property. Even though they are working, their earnings are enough just to make ends meet and are not enough to save and afford assets. From the analysis, it is clear that there are two major concerns, i.e., stigma and discrimination, and economic instability.



## Chapter 6

### SUMMARY AND CONCLUSIONS

Globally, many voices have been raised about the necessity of scaling up antiretroviral (ARV) treatment programs in the developing nations of the world. In India, free access to ART started in the year of 2004 in six high prevalence states and later expanded to all the states in 2006. The Government of Kerala started giving free access to ART in the year of 2004 without the Central Government fund allocation and since 2006, the ART centres are supported by the National AIDS Control Organization. The Kerala State AIDS Control Society (KSACS, 2010) estimates shows that Kerala has over 55,000 HIV/AIDS patients. There are more than 10,000 PLHA who are under pre-ART HIV care and more than 3,000 PLHA are under treatment in Kerala (KSAC, 2009).

#### **6.1 Improved Outcomes of the Treatment**

##### **6.1.1 Better Physical Health Status**

When we examine the impact of the treatment through an analytical perspective, it is confirmed that 'power from within' has improved distinctly after starting the treatment which consisting of both physical and psychological aspects. After the initiation of the treatment, the intensity of opportunistic infection (80%) has declined drastically. After taking ART, the body weight of 72.5% of the respondents increased considerably. Food and nutritional support also has increased considerably after taking the treatment. Thus after beginning the treatment, the physical status of the PLHA has improved substantially. The physical improvement also has a positive effect on the psychological characteristics of the patients, especially stigma and discrimination. When it comes to their general health status, more than 80% of the PLHA showed improvement after taking the treatment. In the case of food and nutritional support, around 93% of the ART beneficiaries (including 100% females) benefited through nutritional support. This contributed greatly to the status of their physical health. Thus, the patients attained 'power from within' which is the basis of all other personal enhancements. The ART programme has to also take care of the psychological problems of the patients so as to make their life peaceful or trouble-free. There are other studies which support the hypothesis that the societal level

stigma around HIV and AIDS is reduced because people living with HIV are no longer seen as condemned to death because of the treatment (Maher, 2008). Mrs. Indu, one of the subjects of the case study, says that “I don’t have time to think about stigma and discrimination”; she is engaged in activities which clearly indicate the attainment of better physical health status due to ART initiation which makes them lead a socially active life just as normal persons not affected by HIV do. In the present study it is seen that discrimination by the family members has come down because the income effect and substitution effect caused by the diminished productivity of the PLHA mitigated by the treatment. A study by Zivin (2006) also shows the same result. However, this does not mean that the stigma against the disease has decreased in equal measure. The improvement of their health helps PLAH to conceal their condition better.

### **6.1.2 Improved Collective Initiatives Related to HIV/AIDS Care**

Around 95% of the ART beneficiaries used to visit care centres regularly after starting ART and the basic reason behind this was the treatment. But the fact is that collective initiatives other than the care centre visit have not improved; instead, it has been decreasing. They attained the aspects of ‘power through care centre visits’<sup>35</sup>. It makes them able to enjoy a renewed social life and also benefit from community involvement. The collective participation within the HIV/AIDS related care centers can change perceptions as well as impart experience and knowledge related to the treatment adherence.

### **6.1.3 Recovered Economic Status**

The ART beneficiaries gained only certain aspects of ‘power over’ when considering the respondents’ ability to earn a monthly income, accumulate savings and acquire fixed assets. There has been an increase in the number of ART beneficiaries who earn a monthly income, especially the category of people earning less than Rs. 5000. This implies that the income of the PLHA has not only improved, but also that the number of PLHA who are able to earn has increased significantly. The key factor behind this improvement is their better health status which enabled them to go back to their jobs. Before taking ART, 23.3% of the ART beneficiaries were not able to work; after

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<sup>35</sup> Around 95% of the ART beneficiaries used to visit care centers properly after starting the treatment (Primary survey, October 2009)

starting the treatment, this proportion fell to 4.2%. Economic resources, fixed assets in the form of buildings (houses), and savings in the form of chitty/kurri have all increased.

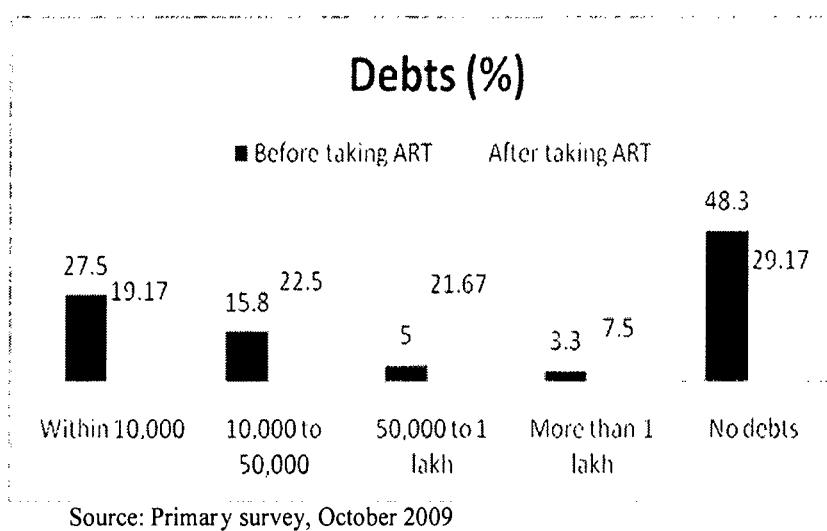
## **6.2 Barriers to the Treatment**

Barrier to access of the treatment is anything that prevents a person from getting the treatment they need. People living with HIV/AIDS can face many such barriers. Even though the treatment is completely free of cost, there are barriers to access that are social, cultural, economic and physical, and is seen across countries (Boyer et al., 2007). Increasing the accessibility of HIV/AIDS treatment services to the patients requires overcoming many obstacles. In this section, this study particularly looks into three kinds of barriers which can be classified as economic and physical, social and cultural and service quality related obstacles. Economic and physical barriers include lack of financial or material resources, social and cultural barriers include lack of mobility, fear of social stigma, fear of loss of family affection and the fear of being subject to physical violence by society, and lastly, service quality related barriers include lack of faith in treatment and lack of therapeutic drugs, etc.

### **6.2.1 Economic and Physical barriers**

Economic and physical barriers imply lack of financial or material resources to access the treatment and the distant location of the treatment centre which implies high travel cost. According to the primary survey, around 50% of the ART beneficiaries have both economic and physical barriers in terms of the lack of financial or material resources and the distant location of the treatment centre. About 40% lack financial and material resources. Around 6% have no physical or economic barriers. According to the field survey report, around 30% of the respondents are earning below Rs. 3000 a month and this condition makes them economically more vulnerable. There are several reasons for their financial barriers. Most of the patients go in for several kinds of check-ups and tests before they get their HIV status finally identified. This is the major reason for their financial problems, including their debt burden.

**Figure 6.1**  
**Change in debts**



The above figure shows the debt status of the respondents before and after taking ART. Before taking ART, around 48.3% of the respondents had no debt, but after the treatment, the figure has fallen to 19.17%. This means that the number of respondents who are in debt has increased. Earlier, most of them were in debt for the amount of below Rs. 10,000, but after starting ART, a large number of them became indebted for between Rs. 50,000 to Rs. 1 lakh. This implies that the financial burden of most of them has increased due to various reasons.

Another fact is that the financial instability of male and female respondents differ in nature. From the personal interviews of the ART beneficiaries, it was evident that among the females, 63.2% were widow and single parents and that most of them are unemployed<sup>36</sup>. This unemployment status combined with family responsibilities in the absence of their husbands (usually the only earning member in the family) on whom they were economically dependent makes them more economically vulnerable. For males, the most important reason is their inability to continue in their job because of the disease. Many of them leave their jobs<sup>37</sup> when they come to know about their HIV status and are in the vulnerable stage of the infection. During this period, many become indebted because of their medical expenses; unless and until they become

<sup>36</sup> According to the primary survey among females, 67.6%, consisting of housewives, widows, single parents and those separated from spouse, are unemployed, (Primary Survey data, October 2009)

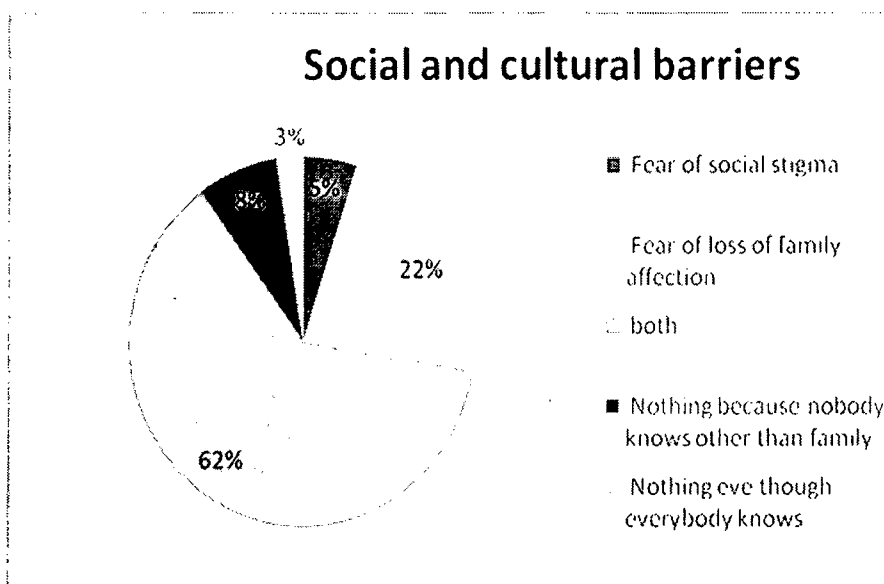
<sup>37</sup> Especially those who have migrated to states will quit their job and come back to Kerala because of ill health due to the disease, (Observation from the field, Field work October 2009)

able to go back to their job and are as healthy as before, they cannot pay off their debts. A number of studies in other countries establish the fact that in addition to the cost of ART, other economic constraints include additional medical expenses, lack of food, and lack of money for clothes (Weiser et. al, 2003). Another study (Riyarto, 2009) on Indonesia confirms previous findings that providing subsidised ART drugs alone does not ensure financial accessibility to HIV care. When we look into the physical barriers among ART beneficiaries in 14 districts of Kerala, it is seen that there are only six ART centres across the state, and so to get free access to the treatment, they need to travel long distances which results in high travel expenses. Many of the women respondents, especially housewives, have less mobility and said that their regular visit to the ART centres makes the family members and neighbours aware about their disease (Observation from the field, October 2009).

### **6.2.2 Social and Cultural barriers**

Social and cultural barriers denote the obstacles occurring due to fear deriving from social and moral concerns. Usually PLHA do not want others or the society to know about their HIV status, and they are afraid of the fact that if they go for the treatment in a public place, that will reveal their HIV status to others. The UNAIDS report on “HIV and AIDS-related Discrimination, Stigmatization and Denial” (Bharat, 2001) discusses the incidence of various kinds of stigma and discrimination in India. This can be in the form of severed relationships, desertion, separation, denial of share of property or access to finance, blocked access to spouse, children, or other relatives, physical isolation at home, blocked entry to common areas or facilities, blocked entry to common places like village or a neighborhood area (Bharat, 2001). The stigma associated with HIV in many communities translates into PLHA being accused for immorality. For this reason, many of them will not seek voluntary counseling and testing, will try to keep their HIV status a secret, and are unlikely to seek care, treatment and support.

**Figure 6.2**  
**Social and Cultural barriers**



Source: Primary survey, October 2009

According to the above figure, 62% of the respondents of the respondents fear both social stigma and loss of family affection. The respondents think that if they regularly attend clinics for ART, others will come to know about their status and that will result in more dilemmas. Some respondents only reported the fear of losing family affection; they are less concerned about society. Around 5% of the respondents reported that they have only fear of stigma and discrimination including prejudice; negative attitudes, abuse and maltreatment, to get the treatment. Around 22% of the respondents have only fear of loss of family affection and they are not concerned about social stigma and discrimination. Most of the respondents' family members do not know their HIV status, and in majority of the cases only partners were informed<sup>38</sup>. There are a small number of patients (8%) who say that there are no barriers of discrimination because nobody knows about their condition other than family members. At the same time, a few (3%) say that they do not experience any social or cultural barriers even though everybody knows their HIV status. Fear of stigma and discrimination is the major barrier to going in for treatment and this prevents them from taking vital decisions in their lives.

<sup>38</sup> Observation from the field (Field work, October 2009)

### 6.2.3 Service quality Related barriers

Counseling and proper supply of medicines are the two important services provided in the ART Centre which influence the efficiency of and adherence to the treatment. When PLHA start treatment, they are unaware of the usage and other side effects of the drugs, and so they need to be guided through proper counseling. In addition to that, it provides support and strength to individuals, couples, families or groups by competent persons, to help them cope with the knowledge that they are infected or affected by HIV. Among the total respondents, 4% have difficulties regarding counseling which they are getting in ART centres. Some of the respondents say that on each visit to the ART centre, they have to undergo counseling for a long time and that the repetitive nature of the counseling makes it inefficient. Another problem is drug shortage. The provision of free ART is only for first line medicine, while some of the patients are badly need of second line medicine which is more expensive. About 7% report the problem of inadequate drugs. The data shows that 89% of the patients are satisfied with the services which are provided through ART centers. When Kerala shows a positive sign in the case of HIV/AIDS related treatment services, in other rural settings in India, the condition is very pathetic. All the problems associated with a public institution are evident: doctors would change, sometimes they were absent, and the tests were not freely available so that patients sometimes got them done at private clinics for a fee. However, the scenario has changed as now there are many hidden costs. Further, patients co-diseased with TB have to endure side effects of combination therapy<sup>39</sup>.

### 6.3 Conclusions

The study found that '*power from within*' is the most attained constituent of empowerment and after the treatment initiation, the individual sense of self-worth connecting to the value they attach to their own health, improved considerably. More than 80% of the respondents show an improved general health status. The empowerment ('*power with*') through collective participation in HIV/AIDS related care centres has improved after ART initiation. Around 95% of the ART beneficiaries used to visit care centres regularly after starting ART and the basic reason behind this was the treatment. The '*power over*' resource has increased in the

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<sup>39</sup> Info change News and Features, March 2009

form of savings. In addition to that, ART beneficiaries' ability to earn income after starting treatment has also improved (*'power to'*). Around 89% of the patients are satisfied with the services which are provided through ART centres. The sense of self-worth of the ART beneficiaries, however, is still challenged because stigma and discrimination as not lessened. Because of the fear of social stigma and discrimination, the participation of the ART beneficiaries in social, cultural and political organisations has come down. The case study analysis reveals the fact that due to the fear of stigma, they are reluctant to go in for any judicial assistance to get their legal properties from their family, especially widows. Unless and until the ART beneficiaries have not achieved full *'power from within'* completely by resolving the problem of stigma and discrimination and become psychologically well-built, full attainment of *'power to'* is impossible. Around 90% of the ART beneficiaries have either both economic and physical barriers in terms of lack of financial or material resources or have barrier of distant location of treatment. This implies the financial burden of most of them has increased after the treatment initiation. Stigma and discrimination is the major barrier to getting the treatment. Around 7% of the respondents face the problem of inadequate drugs.

#### **6.4 Policy Implications**

The analysis of the impact of ART on PLHA by using the Empowerment Framework substantiates the thesis that ART improves the lives of PLHA considerably. However, the fear of stigma and discrimination stands as a major barrier for the treatment and also it prevents them from being an active member in the public sphere. Thus, adequate measures need to be taken to mitigate this dilemma.

Even though ART first line medicine is completely free of cost there are PLHA who urgently need second line medicine for which free public access is very limited; it is also very expensive. When we consider the economic status of the PLHA, policies should aim either to subsidise the prices of second line medicine or facilitate the free access to it.

The number of ART beneficiaries who are becoming indebted is increasing even after the treatment initiation. In addition to that, 44% of them are unemployed. The unemployment rate is 67.7% among the female respondents,. Some of the respondents say that they are not able to do hard work due to their weak physical condition, even



though they are taking ART. When we consider their weak economic conditions, it is essential to rehabilitate them by providing them with appropriate job opportunities.

The case study analysis shows that since the life of the ART beneficiaries is clouded in uncertainty, they are really worried about the future of their children. They fear that in the event of their death, there will be nobody to look after their children, and that if they too are HIV positive, their future will be even more uncertain. Given the weak economic condition and the existing stigma and discrimination, it is essential to make possible an efficient support system for the children of ART beneficiaries.

The physical barriers to ART treatment in Kerala arises because there are only six ART centres in 14 districts across the state .To get free access to the treatment the patients need to travel long distances and this is very difficult especially for those in remote areas; this also leads to high travel expenses. Many of the female respondents, especially housewives, have less mobility. So the free ART access needs to be expanded a little more, which will reduce their travel expenses and ensure regular visits to the centre.

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*Appendix 1.1*

**Centre for Development Studies**

M.Phil Programme in Applied Economics, 2008-2010

Questionnaire for Field Survey

**Confidential**

*(For Research Purpose only, your name or identity will not be revealed under any circumstances)*

**Survey Questionnaire of the Empowerment of Antiretroviral Treatment in Kerala**

FSU Number \_\_\_\_\_

**1. General Information**

1.1 Age \_\_\_\_\_, 1.2 Place of origin (town/ village, state, country) \_\_\_\_\_,

1.2 Sex \_\_\_\_\_, 1.3 Religion \_\_\_\_\_ 1.Hindu, 2. Christian, 3.Muslim, 4. Others

1.4 Caste \_\_\_\_\_ 1. Scheduled cast/tribe, 2.Nair, 3.Ezhava, 4. Brahmins, 5.other  
Hindus

1.3 1.6 marital status: \_\_\_\_\_

a: Single, b: Single Mother/father, c: Separated or Divorced, d: Widowed, e: Married,  
f: steady/ long term relationship, g: other, h. widow.

1.7 Monthly income \_\_\_\_\_

1. less than 3,000, 2. between 3,000 to 05,000, 3. between 5,000 to 10,000, 4. more  
than 10,000, 5. not earning

1.8 Occupation \_\_\_\_\_ 1. agricultural work, 2. employed in informal sector, 3.  
employed in formal sector, 4. unemployed

1.9 Educational qualification \_\_\_\_\_ 1: illiterate, 2: basic literacy, 3: primary  
school, 4: secondary school, 5. higher secondary, 6: graduate or above

**2. History of HIV status**

2.1 When did you come to know about your HIV status? \_\_\_\_\_

1. at the time of infection, 2.within last 2 years, 3. within last 2-5 years, 4. within 5 to  
10 years, 5.within more than last10 years

2.2 What made you to check your status? \_\_\_\_\_

1. Self doubt, 2. illness/doctors advice, 3. awareness campaigns/advertisement, 4. partner has HIV, 5. other reasons (specify)

**3. Details of Treatment**

3.1 First line medicine/Second line medicine \_\_\_\_\_

3.2 Duration of treatment (in months) \_\_\_\_\_

3.3 Do you receive routine physical examinations or health check-ups? Yes/No \_\_\_  
If it's no reasons \_\_\_\_\_

3.4 How did you come to know about ART? \_\_\_\_\_

1. Self knowledge, 2. illness/doctors advice, 3. awareness campaign/advertisement, 4. others (specify)

**4. Barriers to the Treatment**

4.1 Economic and physical barriers \_\_\_\_\_ 1. lack of financial/material resources, 2. distant location of treatment

4.2 Socio Cultural barriers \_\_\_\_\_ 1. lack of mobility, 2. fear of social stigma, 3. fear of loss of family affection, 4. fear of physical violence from community, 5. all, 6. nothing because nobody knows other than family members

4.3 service quality related barriers \_\_\_\_\_ 1. lack of faith in treatment, 2. lack of proper counseling, 3. drug shortage and delay in getting treatment, 4. All, 5. nothing

**5. Health Status**

		Before taking ART	After taking ART
5.1	Opportunistic infection		
5.2	Body weight		
5.3	Frequency of visit		
5.4	In general how would you state your physical health		

5.1) 1. increased, 2. decreased, 3. same as before taking ART

5.2) 1. increased, 2. decreased, 3. same as before taking ART

5.3) 1. properly visiting, 2. occasionally

5.4) 1. much better, 2. some what better, 3. same, 4. some what worse, 5. worse

5.5) The obstacle you face for access to health care \_\_\_\_\_

1. attitude of the family, 2. lack of instructions for medication, 3. side effects other than Opportunistic infection

### 6. Factors affecting health status

6.1) 1. Do you have any kind of Food and nutritional security \_\_\_\_\_?

1 Food supplements from organization, 2. faith based food-relief groups, 3. nutritional support provided by the government, 4. no special diet

6.2) Housing and family support \_\_\_\_\_

1. staying in and support from your own house, 2. staying with and support of in-laws

6.3) Daily working hours \_\_\_\_\_

6.4) Daily travels to work place and back (in km) \_\_\_\_\_

### 7. Social empowerment

Support from family Network and community

		Before taking ART	After taking ART
7.1	Change in household composition		
7.2	Community Participation		
7.3	Job Status		
7.4	Discrimination from		

7.1) 1. staying with all the family members, 2. seperated from your spouse, 3. got divorced, 4. children forced to live with other HH/places, 5. staying away from family but giving rational support, 6. visits and interaction to extended family, 7. attendance at marriages and other family functions, 8. recreation and going out with family, 9. Same as after getting disease

7.2) 1. participation in decision-making process of local bodies or NGOs, 2. withdrawal from the position, 3. dismissed from the position, 4. membership in social and cultural organizations (church/temple committees and festivals), 5. nothing other than care center visit

7.3) 1. Expulsion/suspension from the job, 2. rejoining the job/work, 3. remaining the same, 4) different or new job/work, 5. same as before, 6. unemployed because of disease

7.4) 1. Family members/relatives, 2. other relatives, 3. work place, 4. friends and colleagues, 5. medical professionals, 6. community members, 7. church, 8. temple, 9. nothing because nobody knows other than family members, 10. not experienced even though everybody knows

7.5) Have you/your partner ever migrated yes/no \_\_\_\_\_

1. Internal, 2. International

**8. Economic Empowerment**

Income, employment and assets

		Before taking ART	After taking ART
8.1	Monthly Income		
8.2	Employment		
8.3	Fixed assets		
8.4	Savings		
8.5	Source of financial support		
8.6	Debts		

8.1) 1. less than 5,000, 2. 5,000 to 10,000, 3. more than 10,000, 4. not earning

8.2) 1. agriculture, 2. formal sector, 3. informal sector, 4. self-employment, 5. unemployed, 6. not able to work because of disease

8.3) 1. land, 2. buildings, 3. motor vehicles

8.4) 1. savings in Bank/LIC, 2. chitty/Kuris, 3. others, 4. nothing

8.5) 1. family (specify), 2. friends, 3. colleagues, 4. bank, 5. self reliant

8.6) 1. within 10,000, 2. between 10,000 & 50,000, 3. more than 50,000, 4. no debts

**9. Expenditure occurred related to Treatment during the last one month**

9.1	Expenditure in the absence of free ART	Rs.
9.2	For Opportunistic infection	Rs.
9.3	For special diet	Rs.
9.4	For monitoring various tests	Rs.

Observations \_\_\_\_\_  
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