

**THE EXPERIENCES AND LIVELIHOOD STRATEGIES OF POOR PEOPLE  
LIVING WITH HIV/AIDS IN KOLKATA, INDIA**

**by**

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## **ABSTRACT**

The international literature, policy and action up to now have concentrated predominantly on the prevention and treatment aspects of HIV/AIDS, often neglecting the support and care that poor people living with HIV/AIDS (PLHA) require. Internationally, most studies that have focused on the household livelihood strategies employed by PLHA have been carried out in rural contexts and very few have been carried out in urban contexts, particularly in urban India. The current study addresses this gap by exploring a group of poor PLHAs' own perceptions of their experience of living with and seeking treatment for HIV/AIDS, the adequacy of the health care services they are able to access and the support programmes for PLHA provided by NGOs and other not-for-profit organisations in the context of Kolkata-one of the largest metropolitan cities in India. Semi-structured interviews were carried out with 59 men and women from Kolkata, India, all receiving treatment for HIV/AIDS and some other forms of support.

The study reveals that in the case of HIV/AIDS, it is necessary to divide the post-symptomatic phase into pre and post-diagnosis stages, because it emerged that many PLHA had experienced serious delays in obtaining an accurate diagnosis, resulting in the loss of most, if not all, their existing assets, further impoverishing many at an early stage of the illness trajectory, although by the time of the study most were accessing free antiretroviral therapy. Confirming experiences elsewhere, significant differences were found between the ways men and women experience living with their illness on a daily basis. People's ability to mobilise additional labour assets within their households to 'earn money in new ways' and the characteristics of their 'household relations' emerged as key explanations of how well households fared during the post-diagnosis phase. The PLHA reported that of the NGO programmes, mental support (in the form of counselling and the opportunity to interact with other PLHA), nutritional support and financial assistance were the most useful forms of support, helping them to live with their illness on an everyday basis and avoid becoming more vulnerable and impoverished. These findings have some policy and practice implications, which are identified.

*In memory of my loving parents*

*Mrs. Rita Dam (1947-2005) and Mr. Nepal Chandra Dam (1941-1986)*

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## **ABBREVIATIONS**

ART	Antiretroviral Therapy
ART-LINC	Antiretroviral Therapy in Lower Income Countries
ART-CC	ART Cohort Collaboration
AIIHPH	All India Institute of Hygiene and Public Health
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral drugs
CBHI	Community-Based Health Insurance
CBO	Community Based Organisation
CCC	Community Care Centre
CD4	Cluster of Differentiation 4
CGHS	Central Government Health Scheme
CT	Computed Tomography
CINI	Children in Need India
DIC	Drop In Centre
DOTS	Directly Observed Treatment Short Course
ESIS	Employee State Insurance Scheme
ESRC	Economic and Social Research Council
FAO	Food and Agriculture Organisation of the United Nations
GDP	Gross Domestic Product
GIPA	Greater Involvement of People Living with HIV/AIDS
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human Immunodeficiency Virus
ICTC	Integrated Counselling and Testing Centre
ILO	International Labour Organisation
KNP+	Kolkata Network of Positive People
KMC	Kolkata Municipal Corporation
MSM	Men having Sex with Men
NACP	National AIDS Control Programme phase
NACP-I	National AIDS Control Programme phase I
NACP-II	National AIDS Control Programme phase II
NACP-III	National AIDS Control Programme phase III

NGO	Non Governmental Organisation
NACO	National AIDS Control Organisation
NSP	Non State Provider
NRTI	Nucleoside Reverse Transcriptase Inhibitors
NNRTI	Non Nucleoside Reverse Transcriptase Inhibitor
OPD	Outpatient Department
PI	Protease Inhibitor
PHC	Primary Health Care
PLHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother-To-Child Transmission
QOL	Quality of Life
RNTCP	Revised National Tuberculosis Control Programme
SPARSHA	Society for Positive Atmosphere and Related Support to HIV/AIDS
SE	Social Exclusion
SEWA	The Self-Employed Women's Association
STM	School of Tropical Medicine
STI	Sexually Transmitted Infection
ULS	Urban Livelihoods Study
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNCHS	United Nations Centre for Human Settlements
UNDP	United Nations Development Programme
UNICEF	The United Nations Children's Fund
USSR	Union of Soviet Socialist Republics
TB	Tuberculosis
VCT	Voluntary counselling and testing
WBSAPCS	West Bengal State AIDS Prevention and Control Society
WHO	World Health Organisation

# **CHAPTER I**

## **INTRODUCTION**

### **1.0 INTRODUCTION**

The central concern of this research is to provide an in-depth analysis of the impact that the human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) has on the lives of the poor in Kolkata, India. It will identify the types of illness coping and livelihood strategies utilised by poor people with different social characteristics and their households to mitigate the impact of HIV/AIDS. In doing so, it will also explain the processes by which people living with HIV/AIDS (PLHA) access treatment, preventative, care and support services from different health care providers and local non-governmental organisations (NGOs).

Chapter I introduces the central concern of the research. Section 1.1 sets up the background. In sections 1.2 and 1.3, the research problem and rationale for the study are presented, respectively. Section 1.4 presents the aim and research questions. Section 1.5 describes the overall methodological approach, Section 1.6 presents the main contribution and limitations of the study and the structure of the thesis is outlined in Section 1.7.

## **1.1 BACKGROUND**

According to a recent report produced by UNAIDS, annual new HIV infections fell significantly between 1997 and 2010. However, by the end of 2010, the number of people living with HIV worldwide had reached a total of ~34 million, comprised of ~31 million adults (15-49 years), of whom ~15.5 million were women, and ~3 million children under 15 years (UNAIDS, 2011). The number of people who had been newly infected with HIV in 2010 was ~2.7 million, of whom nearly 85 percent were adults. The number of people who died from AIDS-related causes in 2010 fell to ~1.8 million, down from a peak of ~2.1 million deaths just three years earlier. Sub-Saharan Africa remains the most affected region in the global AIDS (UNAIDS, 2011). In South and South-East Asia, including India, an estimated 4.0 million people were living with HIV in 2010, about 270,000 people became newly infected (although in India, new HIV infections fell by 56 percent) and ~250,000 people died from AIDS-related causes (UNAIDS, 2011).

The majority of HIV infections in this region are estimated to occur among groups at higher risk, such as people who use contaminated injecting equipment or are exposed to unprotected paid sex, leading the virus to spread to other populations (UNAIDS, 2011). According to UNAIDS (2011), overall the HIV/AIDS epidemic is in decline, as the rate of new HIV infections has fallen and the number of AIDS-related deaths has decreased. However, there are still a significant number of people living with the illness who require help to cope with their illness, especially in countries where a significant proportion of the population live in poverty.

Not only do AIDS-related illnesses have an impact on overall life expectancy in the countries that are most affected by the epidemic, due to the numbers of premature deaths they cause, but also HIV/AIDS has an impact on families at all levels of society, governments (as service providers and employers) and societies in general, through their effects on economic growth, social relationships and dependency ratios (Barnett and Whiteside, 2002). HIV/AIDS is an expensive, chronic and long duration illness and so has especially adverse social and economic impacts on people who are already living in poverty (Barnett and Whiteside, 2002; Wagstaff, 2002; Russell, 2004; Mehta and Gupta, 2005). Depending on how many members of a family are taken ill, most of the household's money may go towards the patient(s) for medicines, care and funerals. The rest of the family may have to go without food and medicine and it may not be possible to pay school fees (Bie, 2008). As the virus's debilitating effects may prevent infected individuals from continuing with their work, it usually results in reduced incomes and depletion of already limited assets. Households affected by HIV/AIDS need support in order to cope, i.e. to maintain their assets and consumption rather than become impoverished, and to care for the ill and orphans. It is suggested that both material and social support are needed, including secure access to housing, supportive household relations and social assets (Rakodi and Lloyd-Jones, 2002) and (Mehta and Gupta, 2005). In addition, access to training for less arduous work and support for alternative livelihoods may be desirable so that PLHA can still make a living. Having this kind of support, it is suggested, will increase their capabilities, reduce their vulnerability and prevent them becoming further impoverished (Rakodi and Lloyd-Jones, 2002) and (Mehta and Gupta, 2005).



International literature, policy and action up to now have concentrated predominantly on the prevention and treatment aspects of HIV/AIDS, often neglecting the support and care that PLHA require. Internationally, most studies that have focused on the household livelihood strategies employed by PLHA have been carried out in rural contexts and very few have been carried out in urban contexts, particularly in urban India. This research will therefore consider how people cope with the illness and attempt to mitigate its effects, although this cannot be considered in isolation from prevention and treatment, especially, when prevention will be considered in the context of the support PLHA receive to prevent further transmission, and with regard to treatment, it will focus mainly on whether and how poor PLHA have access to antiretroviral therapy (ART) and drugs to treat opportunistic infections.

The state has a responsibility to support households affected by the disease, or to back non-government organisations to do so, not only through prevention of new infections and treatment, but also through support to their livelihood strategies. However, its capacity is limited, and so emphasis needs to be placed on using resources effectively to support households' own efforts. Better understanding of the ways in which households prevent further transmission, obtain treatment and adapt their livelihood strategies to cope are crucial to improving policy and identifying appropriate support programmes, so this research will focus on the ways in which PLHA cope with their illness, adapt their livelihood strategies and manage their assets. The study was undertaken in India, introductory information about which will be provided in section 1.2. Contemporary international understanding and practice influences policy and programmes also needs to be understood - research findings, policies and

recommended practices with respect to mitigating the impact of HIV/AIDS will be reviewed later in Chapter VIII.

## **1.2 THE RESEARCH PROBLEM**

India, which is the second most populous country in the world (overall population over 1.21 billion), accounts for half of Asia's HIV epidemic, with an estimated 2.4 million people living with HIV at the end of 2010 (UNAIDS 2011). India has multiple epidemics of HIV in different geographical settings and among people with different types of risk; also the epidemic has been experienced in numerous stages (Hawkes and Santhya, 2002). In part as a result, the official figure of the incidence and prevalence rates of HIV/AIDS in India remains approximate. In 1986 the first cases of HIV were found among female sex workers in the cities of Mumbai and Chennai, in Southern India. In subsequent years, the government of India did very little to acknowledge and address the emerging burden of infection within the country due to complacency and also due to the conservative nature of Indian society where open public debate on HIV was taboo. As a result, no or very limited prevention and control efforts were undertaken during the early days of the epidemic (Hawkes and Santhya, 2002; Kielmann et al., 2005). Today, most HIV infections have been reported in six of the country's 28 states – mainly in the industrialised south and west and in the north-eastern tip, i.e. Maharashtra, Tamil Nadu, Andhra Pradesh, Karnataka, Manipur and Nagaland (NACO, 2005; Mehta and Gupta, 2005). However, pockets of high prevalence among population groups at high risk of exposure to HIV have been identified in states where overall prevalence is generally low (UNAIDS, 2007). Overall, most HIV infections (more than 80 percent of reported AIDS cases in

India) occur due to unprotected heterosexual intercourse (NACO, 2005). The HIV/AIDS situation in India will be further discussed in sub-section 4.2.1.

India also has the largest concentration of poverty anywhere in the world, accounting for around 40 percent of the world's poor, with more than a quarter of the population not being able to attain their basic needs as defined in the context of the country (UNDP, 2007/2008). Despite the rapid economic growth in India, averaging 8.0 percent annually between 2003 and 2009 (Singh and Dahiya, 2010), investment that provides work opportunities, and in infrastructure and services, especially for the poor, have all been neglected, resulting in a Gini index of 36.8 percent in 2004 (where 0 corresponds to absolute equality and 100 percent to absolute inequality) (UNDP, 2007/2008). In addition, economic and social disparities between the fast-growing states in the South and West and the lagging states in the North are widening.

According to the 2005 World Urbanisation Prospects report, the global proportion of people living in urban areas increased from 29 percent in 1950 to 49 percent in 2005. The developed world is already urbanised, but the proportion of people living in urban areas in the developing world continues to grow, so this study is concerned with the urban context, especially as most research on the impacts of the HIV/AIDS epidemic globally has focused on rural areas. Like all the countries that have undergone rapid urbanisation in the last 50 years, India faces the major challenges that come with rapid urbanisation, including housing shortages, pressure on the roads, pollution, water shortages and unemployment (Pernia, 1994). According to the recent Indian census, around a third of the urban population reside in slum or slum-like areas (Office of the Registrar General & Census Commissioner, 2011). Data from the 2001 census

showed that men and women living in this type of accommodation were mainly unemployed, informal manual sector labourers, hawkers, or domestic servants (Kundu 2003). With minimal incomes and a lack of education preventing them from obtaining better employment, the likely outcome of one or more members of their households falling ill with a chronic illness such as HIV/AIDS is further impoverishment. This research investigates the effects of HIV/AIDS on poor people living in slums or slum-like areas, particularly how they cope with their illness on an everyday basis, access health care and adapt their livelihood strategies.

### **1.3 RATIONALE FOR THE STUDY**

Poverty and ill-health are intertwined and the association between these concepts “...reflects causality running in both directions...” (Wagstaff, 2002). Consequently, good health has been placed at the centre of development agencies’ poverty reduction targets and strategies (DFID, 1999 and World Bank, 2000). However, as stated in section 1.1, HIV/AIDS-related research and government policies have focused mainly on the prevention and treatment aspects of the illness, often neglecting the support and care that PLHA require, and rarely focusing on the urban poor. As a result, policies that aim to mitigate the effects of HIV/AIDS tend to be neglected or ill informed. In this study, it is assumed that access to treatment and mitigation are linked, with the former affecting the disability or employability of the infected person, the burden they pose on their immediate family, the extent to which transmission to others is prevented, and the ability of PLHA and their household members to provide for children and other dependents.

In India, prevention is concerned with people who are HIV-seronegative, while treatment focuses on the provision of antiretroviral therapy (ART). Although entitlement to ART was established in 2005 by the National AIDS Control Organisation (NACO) via the National AIDS Control Programme phase III (NACP-III) for everybody in India irrespective of class, caste, creed and gender, in reality, provision has lagged behind need, as revealed by a recent country specific study from UNAIDS. By the end of 2009, out of an estimated four million PLHA, only 320,000 were on ART (UNAIDS 2011). Government policies and programmes to mitigate the effects of HIV/AIDS are very limited. As a result, many poor PLHA may fall through the net of government treatment and care programmes, and non-government organisations may lack the resources to fill the gaps.

In order to devise a balanced set of policies and interventions capable of meeting the needs of poor PLHA, in-depth analysis of their lives in the context of a developing country, which seeks to understand their illness-related coping strategies and their livelihood strategies, is needed.

Internationally, most studies that have focused on the household livelihood strategies employed by PLHA have been carried out in rural contexts and are predominantly based on household surveys. As half of the world's population now live in urban areas, and most of the reported cases of HIV/AIDS are in urban areas, it is imperative to document the household livelihood strategies of poor PLHA from their own perspectives and in an urban context. This study was undertaken in Kolkata- one of the largest metropolitan cities in India.

The international literature shows that when people in poverty fall ill, most of their income and effort goes towards paying their medical bills, resulting in further impoverishment. The illness poses a threat to household livelihoods by affecting the capacity to work and earn a living of household members engaged in the labour market. Poor people may lose their homes due to their inability to pay rent and relationships within their households and neighbourhoods can be affected due to the stigmatising nature of illness.

In addition, the international literature reveals that poor people with particular social characteristics, related to gender, age, caste, culture, disability, ethnicity, race, religion and socio-economic background, may be even more socially marginalised, for example, being “treated differently” when they attempt to access help for their illness. Research therefore needs to consider social differences amongst poor people, rather than assuming that they are all equally affected and equally able to cope.

Health care services need to respond to the full range of needs of PLHA at different stages of their illness, so there is a need to understand how they are affected, in addition to the factors that influence and constrain policy and implementation, through examining the processes through which people seek help for their illness (their treatment-seeking behaviour), including their choice of health care providers. A comprehensive review of health care provision and treatment for HIV/AIDS and related opportunistic infections is beyond the scope of this research, but the characteristics of relevant health care will be briefly discussed to provide a context for understanding the choices made by the research participants. Key to understanding both the livelihoods of poor people prior to becoming ill and the effects of illness on

them is their access to assets, with the international literature suggesting that those with adequate assets are more resilient to shocks and stresses. In addition to livelihood support, the international literature suggests that access to supplementary food and counselling are important to PLHA and their families, so the availability of such services to the research participants and the value that they place on them will also be investigated.

The study is located in one urban area – Kolkata. This city was selected because of the author’s familiarity with the setting, as a small part of her childhood was spent there and, in addition, she gained some work experience related to HIV/AIDS within a community based organisation in one part of the city for six months between 2005-2006. As a result, the author became aware of the issues faced by poor PLHA in Kolkata and how some not-for-profit organisations operated. Finally, the native language of the author is spoken in Kolkata, which was a huge advantage, as it enabled her to carry out in-depth interviews with PLHA without the need for an interpreter.

#### **1.4 AIM AND RESEARCH QUESTIONS**

The overall aim of the study is to identify the ways in which HIV/AIDS affects poor people living with HIV/AIDS (PLHA) and their households and to identify the social characteristics that enable or constrain them to maintain their wellbeing and livelihoods, access healthcare for their illness from different health care providers and obtain adequate support for their livelihood strategies.

In order to achieve this aim, the study addresses five central research questions and a set of sub-questions:

- 1) How do PLHA with different social characteristics experience living with their illness on a daily basis? The rationale for this question is to understand how PLHA view their illness, how they cope with it on a daily basis, whether they seek help for their illness and if not, why not. The ways in which people seek help for an illness depends on what understanding they have of their illness, what resources they possess and external factors.
  - (i) What are the experiences of people concerning the symptoms and diagnosis of their illness?
  - (ii) On what aspects of people's everyday lives has HIV/AIDS had an effect and how has the illness affected them?
  - (iii) How do PLHA cope with the illness?
  
- 2) How do PLHA with different social characteristics access and assess the adequacy of health care services for HIV/AIDS? The rationale for this question is to investigate the main factors that enable or constrain PLHA to access health care services and the reasons for choosing one or more health care providers over others.
  - (i) What preventative (in the form of condoms and voluntary counselling and testing), care (in the form of nutrition and counselling) and treatment (in the form of ART and medication for opportunistic infections) services are available?



- (ii) How do people choose health care providers for HIV/AIDS? What factors influence their decision-making processes in accessing these health care services?
  - (iii) How do they assess these services? On what aspects of people's everyday lives has access to health care services for HIV/AIDS had an effect and why? In what ways has access to these services changed their lives?
- 3) How do PLHA with different social characteristics pursue their livelihoods on a daily basis? This question seeks to identify the livelihood strategies that poor PLHA employ when one or more family members fall ill with HIV/AIDS and to analyse whether and how, upon taking up these strategies, their lives changed, in order to deepen understanding of the ways in which poor PLHA manage their assets in the face of shocks and stresses and the actions that they take to avoid being further impoverished.
- (i) What are the perceptions of people concerning the nature and effects of poverty in their lives before and since diagnosis?
  - (ii) What are the everyday livelihood strategies of PLHA and their households?
  - (iii) What factors influence their livelihood decisions?
- 4) Have PLHA received appropriate and adequate support for their livelihood strategies? In order to mitigate the impact of HIV/AIDS, poverty reduction strategies need to consider the particular needs of poor PLHA, so the kinds of livelihoods support PLHA have had access to, and whether the support they have received has helped them cope and is sufficient, is relevant to future policy and practice.

- (i) What support to their livelihood strategies has been available to PLHA?
- (ii) Have those services provided sufficient appropriate support to enable them to sustain their livelihoods since their diagnosis?

5) What are the policy implications of the findings?

## **1.5 OVERALL METHODOLOGICAL APPROACH**

This thesis sought to understand not only how poor PLHA with different social characteristics live with their illness on an everyday basis but also the livelihood strategies employed when one or more people within a household fall ill with HIV/AIDS, in addition to assessing how poor PLHA with different social characteristics access help from health care providers and NGOs. It thus creates a detailed in-depth study in order to build up a rich empirical picture of the experiences and livelihood strategies of poor PLHA with different social characteristics. In order to achieve this, it adopts a flexible, single-method research design and an interpretivist approach, the distinctiveness of which is that it sees people's experiences, interpretations, perceptions, meanings and understandings as primary sources (Mason 2002).

The study therefore adopted a predominantly qualitative methodological approach to data collection, making use of one particular research technique - semi-structured interviews in the context of one urban area. To select poor PLHA with different social characteristics, the study adopted a stratified purposeful sampling (Patton, 1990). To analyse the data obtained, it adopted a combination of approaches as

formulated by Miles and Huberman (1994) and Barbour (2008), which will be further discussed in section 3.2.

## **1.6 MAIN CONTRIBUTION AND LIMITATIONS OF STUDY**

The study's main contribution is an in-depth exploration of poor PLHAs' own perceptions of the experience of being diagnosed and living with HIV/AIDS and of adequacy of the health care services and support programmes for PLHA provided by NGOs and/or other not-for-profit organisations in Kolkata. Amongst the key findings with respect to the latter are that the PLHA found that mental support (in the form of counselling and the opportunity to interact with other PLHA), nutritional support and financial assistance to be the most appropriate types of support that enable them to live with their illness on an everyday basis, preventing them from becoming even more vulnerable and impoverished than they were prior to diagnosis. In addition, as shown in the international and Indian literature, for the majority of PLHA in this study, the stigma associated with the illness was significant, having a negative effect on participants' relationships within their own households (especially for women, due to their culturally defined roles and expectations) and also, for many, outside their households (affecting both men and women, again due to cultural expectations).

This study adds to the understanding of chronic illness amongst poor people in the cities of developing countries, with a specific focus on HIV/AIDS. Another significant contribution it makes is to demonstrate that, in the case of HIV/AIDS, it is necessary to divide the post-symptomatic phase into pre- and post-diagnosis stages, because delays in and the costs of obtaining an accurate diagnosis, even before

securing appropriate treatment, have an early and sometimes severe impact on people's mental state and economic circumstances, triggering a process of impoverishment due to the loss of some or all their assets.

However it is also important to note the study's limitations.

First, the study investigates the ways in which poor people with different social characteristics cope with living with their illness, employ livelihood strategies and access help in the form of health care and livelihood support, from their own perspectives. It was unable to systematically review and evaluate the prevention, treatment, care and mitigation programmes on offer, identifying and explaining their strengths and weaknesses. Therefore, the study does not present a complete picture, which would incorporate the views of the healthcare and livelihood support providers on the ways in which they deliver services to the PLHA in the study context.

Second, the study takes the form of an illustrative case study in a particular city. Because of the limited time and financial resources available, as well as difficulties in accessing willing informants when researching a stigmatised illness, it concentrated on in-depth interviews with PLHA, and it was not possible in a city the size of Kolkata to track down and review all the available secondary data and official household surveys (including those of slum populations), which means that care must be taken in generalising from this study's findings, even to all poor PLHA in Kolkata. In addition, the study is useful in gaining an in-depth understanding of the ways in which poor PLHA cope, employ their livelihood strategies and access help for their health and livelihoods, because of the need to gain access to willing participants, it

focuses on those who have sought health care and other support, and does not include poor PLHA (possibly with different social characteristics) who have not sought any help from health care sources, even after becoming aware of their HIV positive status.

## **1.7 STRUCTURE OF THE THESIS**

This chapter has presented a background to the research, the research problem, a rationale for the study, its aim and research questions, the overall methodological approach adopted and, the main contribution and limitations of the study. Chapter two reviews the international literature on HIV treatment, care and support programmes, along with the livelihood strategies employed by poor urban people, exploring how understanding of these has evolved over time and indicating any gaps in the current literature. In addition, chapter two identifies and assesses the key concepts and analytical approaches used by previous research. Chapter three presents the conceptual framework and a detailed account of the research methods used to carry out this research. The conceptual framework includes operational definitions adapted from the discussions in chapter two, an analytical framework for the research, and some preliminary theoretical explanations, which will be assessed in the light of the study's empirical findings. Chapter four presents a detailed picture of the national HIV/AIDS programme in India and the socio-economic context of the slums of Kolkata in which poor people reside. Chapters five and six present the study's empirical findings, with the former focusing on the research participants' experiences of living with HIV/AIDS before and immediately after formal diagnosis and the actions they took to cope with the illness on an everyday basis (addressing research questions one and two) and the latter focussing on the longer-term effects of the

illness on their livelihoods, investigating specifically the loss and/or gain of livelihood and whether the nature and outcomes of any actions taken to relieve these effects (addressing research questions three and four). Chapter seven draws together the discussions in the two previous chapters, in order to answer the main research question – what are the ways in which poor people with different social characteristics live with HIV/AIDS on a daily basis and access healthcare and livelihood support? In doing so, it also ties together the findings from the review of international literature and the conceptual framework developed in chapters two and three respectively. Chapter eight is the concluding chapter and therefore presents summaries of the research proposition, questions and findings, as well as briefly exploring the implications of the latter (addressing research question five). This concluding chapter outlines the contribution made by the study, in addition to identify areas for future research.

## **CHAPTER II**

### **HOW DO POOR PEOPLE EXPERIENCE HIV/AIDS AND ACCESS CARE, TREATMENT AND LIVELIHOOD SUPPORT? - A LITERATURE REVIEW**

#### **2.0 INTRODUCTION**

One of the main purposes of a literature review is to identify and define relevant concepts and examine whether and how previous studies have analysed the issues to be addressed in a new research study. This review aims to define concepts such as poverty and livelihoods and to analyse how previous studies have understood how people cope with chronic illness, specifically HIV/AIDS; their treatment seeking behaviour, including how they access various health care providers for care and treatment; and the different ways in which people access support for their households' livelihoods. The purpose of the review is to assess whether there are any gaps in current understanding of the issues. It will also assess analytical approaches used by previous research, to identify and define the key concepts with which the researcher will be working, in order to contribute to the development of an analytical framework that will be presented in chapter III.

The initial literature search focused on relevant themes and questions, including how poor people live and cope with chronic illnesses; how poor people live and cope with HIV/AIDS; the characteristics of poor people living with chronic illnesses and HIV/AIDS; the issues of stigma and discrimination, particularly with respect to PLHA; the types of health care services available to PLHA and whether and how they are accessed; PLHAs' views on access to healthcare and their views on the kinds of

care and support available and their suitability. The initial aim was to identify empirical studies in order to learn from their methodological approach, identify findings for comparative purposes and identify empirical gaps. Particular attention was also paid to the conceptual frameworks adopted by different studies, in order to identify a suitable conceptual and analytical framework for this study, and additional sources focusing on the analytical approaches that appeared to be most promising were also reviewed. During this time, a small number of meta-reviews were found. Relevant papers cited in both reports on individual studies and the meta-reviews were followed up. For the most part, the search was confined to research related to urban areas in the developing world, although some studies rural parts of the developing world were also included because the majority of previous studies related to the impact of HIV/AIDS on people's livelihoods had been carried out in the rural context, and their use of a livelihoods framework, which was deemed to be equally applicable in the urban context, made them relevant to this research. In addition, if no studies in developing countries were found on an issue of interest, the search was widened to include the developed world. For example, no studies of the everyday coping strategies of people living with a chronic illness were found in the context of the developing world, but some relevant studies carried out in the United States were found and used to identify findings for comparative purposes. Since this study was concerned with the perspectives of the poor PLHA themselves as to how they live and cope with their illness on an everyday basis, material dealing with the clinical aspects of HIV and its treatment was excluded from the search criteria.

The search was, therefore, mostly confined to the social sciences, including both quantitative and qualitative studies. The types of material used included peer-



reviewed published academic sources, and policy documents from the WHO, World Bank, UNAIDS, UNDP and DFID. Additionally, information from the National AIDS Control Organisation (NACO) and the Census of India was accessed online. Material published by NGOs and/or advocacy organisations was not used, as most of this is not peer-reviewed.

The first stage of the review involved writing a short summary of each article, including the purpose and type of the study, the study setting, key definitions, the data collection method used, major findings, conclusions. The strengths and weaknesses of each publication were identified and a record kept of the researcher's thoughts and comments. The sources were grouped according to the theme or issue with which they were concerned, and reviewed in order to identify empirical gaps, record the findings of relevant studies to assist in analysis of the findings of the Kolkata study and identify possible analytical frameworks.

It emerged from the literature review that how poor people's normal livelihood strategies change due to the onset of HIV/AIDS, what their coping strategies are, and the factors that influence their access to livelihoods support have received only limited research attention, and that many of the available studies focus on rural areas, especially in Africa. In addition, relatively little is known about how people cope with living with HIV/AIDS, their treatment-seeking behaviour and the factors that influence their access to health care. For example, some medical literature on health care services for the prevention, care and treatment of HIV/AIDS argues that the reason that prevention, care and treatment does not work for poor people is because they do not *adhere* to the advice given to them by health care providers. In order to

comprehend these issues, especially the complexity of patient treatment seeking behaviour, an understanding from the perspectives of the people themselves is essential.

In Section 2.1, what is known about perceptions of and responses to ill health in general and evidence on how living with a chronic and stigmatised illness affects people's everyday lives in both developed and developing countries is reviewed, emphasising issues regarding people's treatment seeking behaviour.

Section 2.2 begins with a definition of the term '*poverty*', then the concept of a livelihood is examined, presenting the idea of a livelihoods framework and analysing its use. This section then briefly discusses the characteristics of specific groups of poor people that could possibly affect their access to the resources required to maintain adequate livelihoods, followed by an explanation of the process of social exclusion and its impact on people. This section concludes by examining international evidence on the types of support that have been made available for poor people with different social characteristics.

Section 2.3 provides an overview of the health care systems and services that determine the choices available to poor people with different social characteristics in the context of the developing world.

Section 2.4 provides a discussion and explanation of the evolution of international practices and experiences with respect to the provision of care and treatment services for HIV/AIDS. It examines the ways in which it is suggested that services should be

managed and made available, according to the current international literature, in order to ensure comprehensive and co-ordinated care to meet the needs of different types of patients with the illness.

## **2.1 EXPERIENCING CHRONIC ILLNESS**

This section focuses on the experience of illness and the health seeking approaches adopted by patients, which are influenced by how the services on offer are perceived, in order to reveal the complexity of the processes that are involved on the demand side of accessing health care. Thus this section reviews the evidence available on how people see themselves and what they understand by chronic illness (Sub-section 2.1.1); how they respond to their illness and make a decision to seek help (Sub-section 2.1.2); and their experience of accessing care and treatment from various providers (Sub-section 2.1.3). The section then discusses the available models of the determinants and factors influencing health-seeking behaviour, which are considered to be important in understanding how individuals seek care and why some people seek care earlier than others. The review will focus particularly on HIV/AIDS, in order to reveal what makes HIV/AIDS a stigmatised illness.

### **2.1.1 Perception of chronic illness**

In order to gain a better understanding of why individuals approach their illness in a particular way, there is a need to explore how they perceive it and to identify resulting the blocks and enablers that influence an individual's strategy for coping with their illness.

It is suggested that identifying the meaning of an illness is important because the understanding of health and illness can vary across different contexts, environments and cultures (Heijnders 2004): “...two individuals from different cultures or social backgrounds and in different contexts may interpret the same ‘disease’ (such as tuberculosis) or symptom (such as pain) completely differently. Moreover, this will affect their subsequent behaviour and the sorts of treatment they will seek out...” (Heijnders 2004: 327). Heijnders (2004) explored the ways people interpret leprosy and its treatment, revealing different categories of meanings, each of which influenced the ways people coped with leprosy and its treatment and their help-seeking behaviour. According to Heijnders (2004), one of the relevant categories of meaning was the way people interpreted their symptoms and the influence these interpretations had on their health-seeking behaviour. Most people interviewed had not recognised the signs of leprosy or had not regarded their symptoms as severe and so had not sought treatment for the disease.

Similarly, a study carried out by Thiede (2005) showed that preferences and choice sets for health care differ with individual, household or group characteristics, both between and within cultures, and that choices also vary with socio-economic background. Thiede (2005) suggests that the three factors that explain the differences in people’s actual choices are: their perceptions of illness and of the health system, the subjective choice set and individual preferences, and that these are known to vary between cultures. As a result, an illness causing serious distress amongst people of one society may be regarded as a minor problem in another society.

Due to the complexity of trying to understand how people see, understand and give meaning to their illness, Kleinman (1980) developed a set of explanatory models that seek to explain people's perceptions of what constitutes illness, the meaning of a specific illness and how illness is experienced, suggesting that their experiences and the effects of these on their coping strategies are dependent on their culture.

It is proposed that five major aspects can be distinguished: “...*etiology, time and mode of onset of symptoms, pathophysiology, course of sickness (including both degree of severity and type of sick role – acute, chronic, impaired, etc) and treatment...*” (Kleinman 1980:105).

Using this structure, the author suggests that when a number of open-ended questions are asked to patients, the details of their explanatory models are revealed: “...*what do you call your problem? What name does it have? What do you think has caused your problem? Why do you think it started when it did? What does your sickness do to you? How does it work? How severe is it? Will it have a short or long course? What do you fear most about your sickness? What are the chief problems your sickness has caused for you?...*” (Kleinman 1980:106).

The importance of recognising that an illness has a trajectory over time is revealed by this approach. Corbin and Strauss in Woog (1992:17) identify eight possible phases: the period before the illness begins; the diagnostic period; crisis or a life-threatening situation; acute illness, in which the illness or associated complications require hospitalisation; a stable phase, during which the illness is controlled; an unstable phase, during which the illness is not controlled by a regimen; a progressive or

deterioration phase; and death. Not all phases occur, and illness does not necessarily end in death or result in a downward spiral. Management of the disease during any given phase begins with the identification of problems associated with that phase. Once these are identified, goal setting and intervention can occur. The current study focuses on the physical, psychological and social wellbeing of people suffering from early or later stages of HIV/AIDS and full-blown AIDS during the first seven of Corbin and Strauss' eight phases. Frost et al. (2000) further divide the acute phase into "within 30 days of diagnosis" and "adjuvant treatment".

Wellbeing can be defined as the level of function related to the physical, psychological and social domains of health. According to Hoffman (1988) in Frost et al. (2000:222), distress peaks have been reported after diagnosis and when disease is declared terminal. However, other studies have found that psychosocial wellbeing is reported to have improved with time since diagnosis (Vinokur et al., 1989; Lowery et al., 1993; Hoskins, 1995), whilst others found that psychological distress remains stable over time (Northhouse, 1989; Lewis and Hammond, 1992).

Pierret (2003) points out that when people come down with any type of chronic illness (stigmatised or non-stigmatised), they are usually in search of the meaning/significance of their illness. They start to ask questions such as: why me? Why now? What have I done to deserve this? The result is a shift in their perceptions of self and identity, as highlighted by a study carried out by Kelly (1992), in which people suffering from ulcerative colitis had been cured by having radical surgery in the form of total colectomy and ileostomy that had left them with permanent faecal incontinence.

For younger patients especially, maintaining meaning or finding a new meaning for their disrupted lives involves learning to cope with the illness by redefining the self or renegotiating their identity (Mathieson and Stam 1995).

People's perceptions of their illness and its anticipated effects are intensified by uncertainty: "*...an uncertain diagnosis, itself related to the state of medical knowledge, causes, once it has been made, uncertainty for the patient. How long will things remain uncertain? How will the illness evolve? Do treatments exist? Do they work? What will life be like from now on? Uncertainty about the medical diagnosis can plunge patients into 'existential uncertainty' ...*" (Adamson 1997:134-135)

### **2.1.2 Response to chronic illness**

In addition to individuals' perceptions of their illness and its likely trajectory, the ways in which they respond are influenced by many factors, including the choices previously made by others within their circle of acquaintance, especially those that were seen to 'work'. In the context of developing countries, such factors include whether people can afford both the direct costs of health care and the indirect costs of ill health, especially income foregone if it is necessary to take time off from paid employment to seek treatment. It is assumed that, due to the lack of help available with household and childcare responsibilities, women may find it particularly difficult to seek help. This sub-section therefore aims to identify from the literature what aspects of people's lives chronic illness affects and how; how people cope with living with illness, whether and why they need to make changes in their lives to

accommodate the illness and if so, the outcomes of such changes. The review will also identify what is known about how people make the initial decision to seek care, and what they consider when assessing alternative sources, choosing between them and assessing the care and treatment they receive. In particular, it will consider what is known about why and how people decide to seek treatment for HIV/AIDS and other opportunistic infections.

- **People's everyday coping strategies**

Along with a number of studies reviewed to identify potential coping strategies, this sub-section provides definitions of relevant terms, such as coping.

When people are anxious and stressed as a result of an illness, this may cause additional physiological damage, motivating the individual to try to reduce the stress level by taking action, a process known as coping. Lazarus and Folkman (1984) suggest that coping is not considered a style or personality trait that remains stable across a variety of situations; rather, it is a set of strategies that are available to be implemented to match specific situations. Lazarus and Folkman (1984) distinguish between emotion-focused coping, involving attempts to reduce the negative emotions that often accompany stress, and problem-focused coping, involving an attempt to reduce a stressful situation by trying to understand better its causes and find possible courses of action. By investigating how people cope with particular disease-related and social-related *stressors*, potentially including, in the case of HIV, fatality, specific symptoms, treatment, side-effects, lifestyle stigma and impoverishment, it is argued that it is necessary to understand the coping processes of a patient, rather than treating



coping as a stable personality trait. Stress and coping theory thus posits that the appraisal and coping processes adopted have a significant role in the maintenance of wellbeing under conditions of stress.

A study carried out by Ragsdale et al. (1994) in the United States shows that people living with chronic illnesses such as HIV/AIDS in both hospital and home settings require many adjustments in their lives and lifestyles, in order to accommodate the changes that result from their disease, due to the immune system becoming gradually ineffective. The study shows that the strategies used to make sense of and respond to problems generated by HIV/AIDS differ. They may include human connectedness, focussing on the self, negotiating health care and/or dealing with stigma. In addition, the study found that some people reflected upon their lives spiritually and turned to religion and God.

Barosso and Powell-Cope (2000) took the findings from Ragsdale et al. (1994) further in a study of their own. Based on a meta-synthesis of 21 articles published between 1990 and 1995 in the United States of America, which in total reported on the experiences of 279 men and 28 women living with HIV infection, they found that responses could be categorised into six metaphors: (a) Finding meaning in HIV/AIDS, (b) Shattered meaning, (c) Human connectedness, (d) Focussing on the self, (e) Negotiating health care, and (f) Dealing with stigma.

They found that some PLHA 'found meaning in HIV/AIDS', viewing their illness in a positive light, identifying ways of incorporating it into their daily lives and finding a new meaning in life, as part of a coping mechanism designed to reduce uncertainty,

cope with loss and face death, thus preventing them from falling into depression. Others, however, were unable to cope with their illness, seeing their lives in a different light because they felt that, no matter what they did and how they changed their lives, their future death from illnesses caused by AIDS was inevitable. For those suffering from 'shattered meaning', religion and/or spirituality offered little comfort, as the people concerned often felt cut-off from mainstream religion or were shocked, bitter and depressed at the prospect of their bleak futures. Barroso and Powell-Cope (2000) described 'human connectedness' as people diagnosed with HIV/AIDS making extra efforts to maintain close ties with friends and families, because they felt that this would provide them with emotional support when needed. The study also found that it was important for PLHA to construct new social networks in order to feel a sense of belonging. The fourth possible response, 'focussing on self', was identified as a set of actions that PLHA take in order to seize control of their physical and emotional health and in so doing reduce uncertainty about their future. Barroso and Powell-Cope (2000) found that such people viewed themselves as responsible for their own health and in addition, took an active role in seeking treatment, including initiating discussions about alternative treatments from a variety of health care providers. They found that PLHA who had faced one or more negative experiences within a health care setting were more likely to take control of their health, including negotiating which health care provider to attend in order to receive treatment appropriate for their requirements. With respect to the final response, 'dealing with stigma', Barroso and Powell-Cope (2000) found that PLHA had to face reactions to their HIV infection at the personal, familial, and societal levels. Some felt that being HIV positive was all that they were and that they did not have their own identities, while others felt overwhelmed by a sense of isolation and abandonment, confirming

previous studies which had shown that in a highly discriminatory environment, many PLHA withdraw and isolate themselves for self-preservation, sometimes resulting in their deaths through suicide or euthanasia (Gilmore and Somerville, 1994; Hasan et al., 1994). In addition, according to a study carried out by McGrath et al. (1993), people who know their diagnosis often devise ways of hiding their seropositive status due to fear and shame.

According to a study carried out by Jenkins and Guarnaccia (2003) in the United States, which included 270 anonymous homosexual, bisexual and heterosexual men and women, coping strategies specific to HIV/AIDS are important, such as self-isolation, spirituality, negative rumination, distancing, optimistic planning, social networking with other members of the HIV community, social-emotional support, the use of escape fantasies and anger. These nine strategies were classed into two second-order coping strategies: Negative Internal Coping (containing: Escape Fantasies, Self-Isolation, Negative Rumination, Anger, Distancing) and Positive External Coping (containing: Optimistic Planning, HIV Community, Social-Emotional Support, Spirituality). Jenkins & Guarnaccia's study, carried out in 2003, found that the most significant HIV-related stressor for PLHA was the anticipation and receiving of HIV-positive results, which were reported to have had an impact on both the mood and the immune system of PLHA, confirming the findings from a study carried out by Ragsdale et al., (1994). Because these stressors differ from those experienced by people with other illnesses, the coping strategies appropriate for PLHA may also differ from those of people with other chronic illnesses.

Thomas (2006), who explored the impacts of HIV/AIDS on patient and carer well-being in the Caprivi Region, Namibia, also found that people reported that they had chosen to keep their HIV status secret, due to a fear that they and their families would be stigmatised, which was perceived to be a threat to receiving care, a finding confirmed by a study carried out by Greeff et al. (2008), in which the experiences and perceptions of disclosure of HIV status by PLHA and nurses involved in their care in Africa were ascertained through thirty-nine focus groups in five countries in both urban and rural settings.

Thomas (2006) also found that, due to the nature of the illness, in which people who are ill are often dependent on someone else's help, usually their families, especially in Africa, the result can often be “...*disempowerment and lowered self-esteem, decreasing well-being amongst ill people...*” (Thomas 2006:3184). In addition, according to Thomas (2006), households may become isolated not only because of stigma but also through lack of time and resources for maintaining support networks.

In contrast, a possible positive external coping strategy involves interaction with other HIV positive people. For example, a recent study by Logie et al., (2011) in Ontario, Canada, revealed that a diverse selection of HIV-positive women preferred to interact with other HIV positive women within social support groups to avoid isolation and cope with the intrapersonal stress related to living with HIV.

### **2.1.3 Treatment-seeking behaviour for chronic illness**

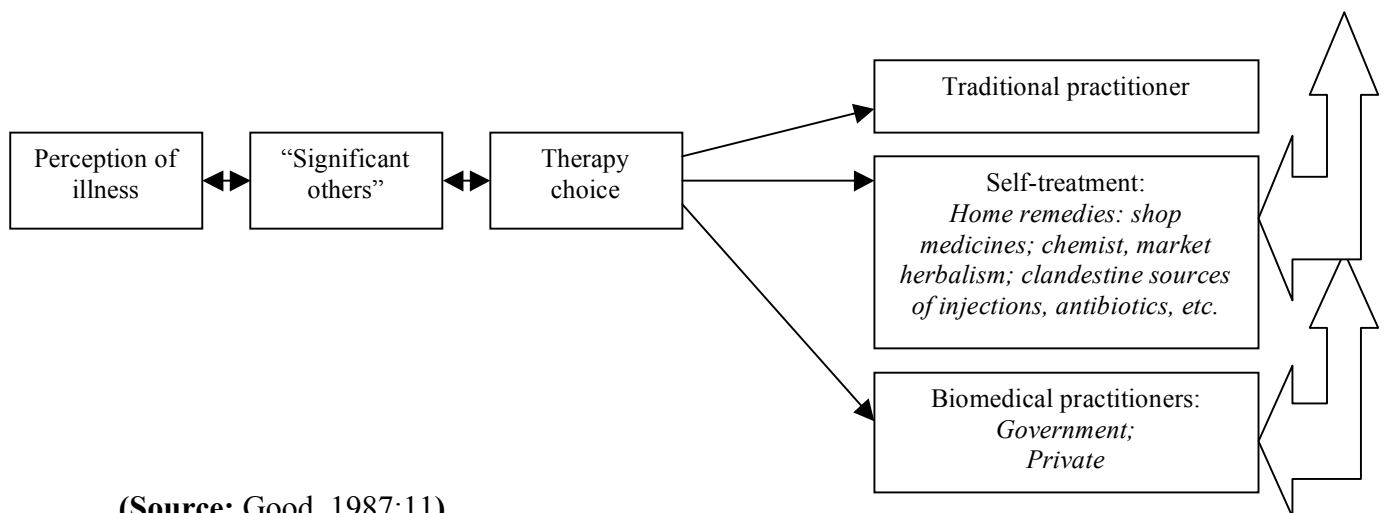
There is a lot of interest in what facilitates the use of health services and what influences people to behave differently with respect to their health in both the developed and the developing world. According to Mackain et al. (2004), there are two dominant approaches found in the literature to understand and explain variations in illness management in different settings and amongst people with different characteristics: the ‘pathways models’ of health-seeking behaviour, which typically describe the series of steps an individual takes; and studies of the ‘determinants’ of behaviour, highlighting the factors that influence individual journeys (Bedri 2001 cited in MacKain et al., 2004:137). These models are briefly reviewed below.

- **Pathways models**

Pathways models were first used to describe illness behaviour as a logical sequence of steps starting with definition and perception of symptoms up to the use of different health care providers (Suchman, 1965). A theoretical model of illness behaviour was developed by Fabrega (1974) that concentrated on the information an individual might be expected to process during an illness episode. This model assumes that people use the principle of cost-benefit in evaluating the best course of action and does not consider other influencing factors that could play a part. Dingwall (1976) then developed a model based on individual choice, which assumes that individuals are autonomous in making decisions and underplays the social context in which they act. Igun (1979)’s model details the process of health-seeking behaviour, moving from one stage to another, but does not describe the factors that influence this movement. Young (1981) describes the pathways individuals undertake during the

process of decision-making around seeking help and the factors that may influence initial choice of care. In pathway models people are usually said to begin with a recognition of their symptoms and the models emphasise the path that people follow until they use various health services. Good (1987) stresses the importance of ‘significant others’ in the ‘decision-making process’, suggesting that sufferers do not make decisions alone, but have support groups, friends and families who are also involved in their health care seeking behaviour (see Figure 1). He suggests that people choose between alternative providers, and may also move from one health care sector to another (illustrated by the block arrows).

**Figure 1: Good’s Model – Structure of health care options and decision-making in rural Kenya.**



(Source: Good, 1987:11)

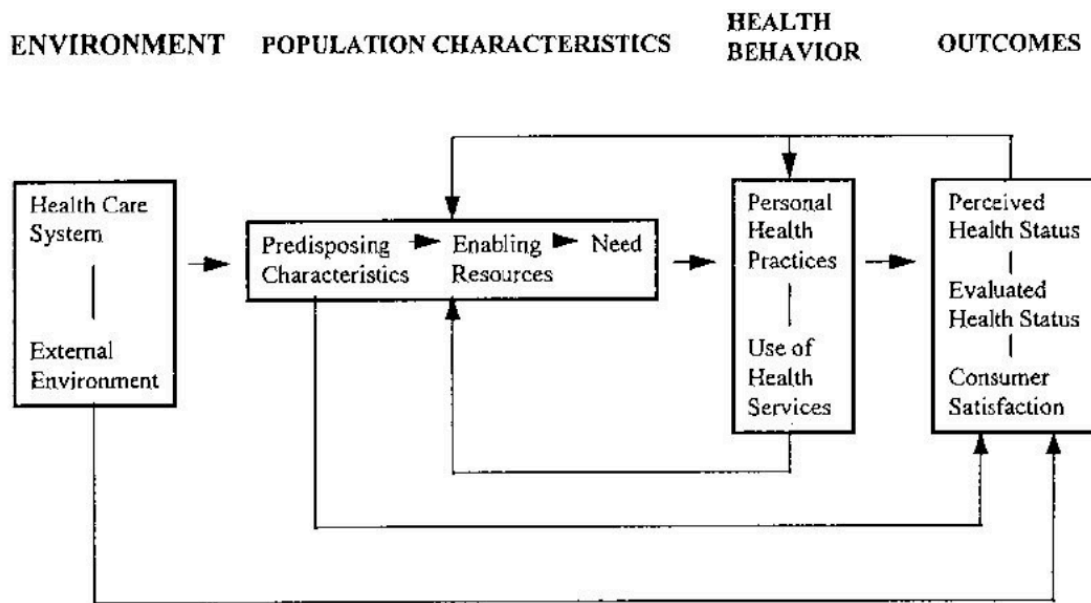
Pathway models depict health seeking as a dynamic process with decisions usually organised in sequences, as in Figure 1: people recognise their symptoms, choose a health care provider depending on their circumstances and on the information they have access to, use a health care provider, evaluate the outcomes of the treatment obtained, re-interpret their illness in the light of these outcomes, and either stay with

the same provider or move to a different provider or sector. Previous studies that conceptualise treatment-seeking behaviour as a pathway, however, consider either that individuals make autonomous decisions or that social processes determine an individual's health care seeking behaviour. No studies appeared to have attempted to combine the aspects until Rogers and Elliot (1997) developed the 'Network-Episode Model', which focuses both on how and when care is accessed and received, and on how the choices and strategies of health seeking are socially organised. Their model, however, does not consider the alternative choice of self-treatment or a decision not to use care (MacKian et al., 2004).

- **Determinant Models**

Models investigating the determinants of health seeking behaviour include Andersen's grouping of factors influencing utilisation into three main categories: external environment, population characteristics and health care systems, incorporating the cultural and social factors, past medical experience and individual orientation found to be important in pathway models. The model is comprehensive in its organisation of possible factors and is widely used by health services research (MacKian et al., 2004).

**Figure 2: Determinant Health Care Model**



(Source: Anderson, 1995:8)

Other determinant health care models focus on individual health behaviour and ignore the impact of social networks on the decision-making process or do not concentrate on how a decision to utilise care is made (Kasl et al., 1966; Zola, 1973). Since 1973, other studies have been carried out that emphasise the major influence on initial decisions to seek care of the direct costs of paying for health care and indirect costs (waiting time, transport and consultation time, and loss of income) in the context of developing countries (Hudelson 1996).

A framework developed by MacKian et al., (2004) categorises the types of barriers or determinants that lie between patients and services, as shown in table 1 below.



**Table 1: A framework of determinants of health-seeking behaviour**

<b>Determinant</b>	<b>Empirical measure</b>	<b>Examples</b>	<b>Sphere</b>
Cultural	Status of women	Elements of patriarchy	‘Cultural propriety’ (informal)
Social	Age and sex		‘Cultural propriety’ (informal)
Socio-economic	Household resources	Education level, maternal occupation, marital status and economic status	‘Cultural propriety’ (informal)
Economic	Costs of care, type and severity of illness	Treatment, travel and time	Physical (infrastructure)
Geographical	Distance and physical access		Physical (infrastructure)
Organisational	Perceived quality	Standards of drugs, standard of equipment, competence and attitudes of staff, and interpersonal process	Technical, staffing and interpersonal (formal)

(Source: Mackian et al., 2004:139)

The models presented so far are based on two assumptions: that health is influenced by behaviour and that behaviour is modifiable (MacKian et al., 2004). However, one of the major disadvantages of these models is that they place the sole responsibility on the individual when it comes to health seeking behaviour. Instead, MacKian et al., (2004) argue, understanding of health seeking behaviour must be located within a framework informed by the concepts of reflexivity and social capital (MacKian et al., 2004). They suggest that a better understanding of health-seeking behaviour is possible if the inter-relationships of individuals within containing social systems, cultural norms and system constraints are explored and the resulting behaviour understood as a product of these inter-relations. Although at the time they suggested

that the term ‘social capital’ was still in its infancy and was poorly understood in the context of health seeking behaviour, they nevertheless suggested that individuals should be seen in the context of the society in which they live (MacKian et al., 2004).

Discussions and arguments with regard to defining the concept of ‘access’ began in the mid-seventies, when it was described as referring to either the potential or the actual entry of a given individual or population group into the health care system: ‘having access’ denoted the potential to utilise a service if required, whereas ‘gaining access’ referred to initiation into the process of utilising a service (Gulliford et al., 2002).

Often, attention has focused on service availability, but it is clear that those in need may have access to services and yet encounter difficulties in utilising them, so that potential access may not be realised. This led Pechansky and Thomas (1981) to argue that access is better described as a ‘degree of fit’ between clients and the health care system, where the ‘degree of fit’ is influenced by the acceptability, affordability and accommodation of services. This extended the concept of access and led Gulliford et al (2002), amongst others, to recognise the importance of considering the personal, financial and organisational barriers to service utilisation:

#### **a) Personal barriers**

Gulliford et al., 2002, assert that people’s recognition of their need for services and their decision to seek medical care are generally the first step in the process of accessing services. They suggest that the probability of utilising services depends on

the balance between individuals' perceptions of their needs and their attitudes, beliefs and previous experiences with health services. Access to health services also implies that the potential users recognise and accept their need for health care services, consent to a role as service user, and acknowledge socially generated resources that they are willing to utilise.

### **b) Financial barriers**

Financial barriers can influence individuals' utilisation of services in countries where people are required to make out-of-pocket payments at both public, and especially private, health care providers due to the systems not being free at the point of use. User charges and other costs affect the poor in different ways. For some, access may not be compromised, whereas for others, costs may be a significant deterrent. The impact depends on the magnitude of the costs and the user's willingness and ability to pay (Gulliford et al., 2002).

### **c) Organisational barriers**

Long waiting lists and waiting times may sometimes be indicative of organisational barriers to access that may result from inefficient use of existing capacity or a failure to design services around the needs of patients. Systematic variations in referral practices, especially referral from primary to secondary care, are also known to act as barriers to accessing care (Gulliford et al., 2002).

In terms of affordability, Mooney (1983) emphasised that, from a health economics perspective, the availability of services may be measured in terms of the costs to

individuals of obtaining care. These may include the costs of travel and other inconveniences incurred in obtaining care or the health benefits foregone by not obtaining care. In addition, if services are geographically distant, such costs will generally be higher, so Mooney (1983) argued that access is a question of supply and utilisation a function of both supply and demand.

Obrist et al., 2007 took the above concepts from MacKian et al., (2004), Pechansky and Thomas (1981), Mooney (1983) and Gulliford et al. (2002), developed them further and came up with a framework that combines both health service and health-seeking approaches for all illnesses, as well as situating access to health care in the broader context of livelihood insecurity - the 'health access livelihood framework'. Similar to what is suggested by Gulliford et al., 2002, Obrist et al., 2007 suggest that once illness is recognised, treatment seeking is initiated and it is at this point that access becomes an issue.

They suggest that five dimensions of access influence the course of the health-seeking process: availability (the existing health services and goods meet clients' needs), accessibility (the location of supply is in line with the location of clients), affordability (the prices of services fit the clients' income and ability to pay), adequacy (the organisation of health care meets clients' expectations) and acceptability (the characteristics of providers match those of clients) (Obrist et al., 2007). According to the framework, the level of access reached along the five dimensions is dependent on two factors: (1) health care services and broader policies, institutions, organisations and processes and (2) the livelihood assets people can mobilise in particular vulnerability contexts (Obrist et al. 2007), as illustrated in

figure 3 below. The provision of health care services that are typically available to PLHA will also be discussed in section 2.3, as it refers to (1) above. Livelihood assets and the vulnerability context will be discussed in sub-section 2.2.2, as it refers to (2) above and which is also part of a general discussion of the livelihoods analytical framework.

**Figure 3: The Health Access Livelihood Framework**



**(Source: Obrist et al., 2007: 1585)**

Because health care seeking behaviour may vary between people with different social characteristics, it may be appropriate to analyse it separately for specific groups within a society. For example, a study of women of Kamwokya origin in Kampala, Uganda by Bantebya-Kyomuhendo showed that money, interpretations and definitions of symptoms and their severity, networks, time use and spouse influence influenced women's choices of the treatment options regarded as appropriate for themselves and their children for specific illness symptoms. The same study also

showed that women delayed seeking treatment from 'outside' even when they had defined their symptoms as 'serious enough' to warrant outside treatment. Instead, when women were ill themselves, they relied on self-treatment, using mainly herbs and over the counter drugs, visiting clinics and hospitals only when in a critical condition and unable to work (Bantebya-Kyomuhendo, 1997). For these women, illness management was not done in isolation from other things happening in the family. They sought treatment in a manner that would ensure minimum disruption to other activities and things happening within the household. The study further found women to be key decision-makers in ensuring the 'well-being' of their families. Increased women's access to income and control had improved their decision-making status, increasing their authority and power within the family. However, it had also come with more responsibilities which traditionally had been men's. In practice, these changes not only increased their burden but also resulted in increased levels of domestic violence (Bantebya-Kyomuhendo, 1997).

Other studies have shown that another important factor that influences people's, especially women's, decisions to seek health care, especially for sexually transmitted infections, is *stigma*.

For example, there is some evidence to suggest that in several African countries schistosomiasis is associated with immoral behaviour in women, but considered a sign of virility in men, which means that women tend to be less inclined to admit that they are suffering from schistosomiasis and as a result may not seek help (Vlassoff et al. 1994). This is consonant with the findings of studies by Hudelson (1996) and Valdiserri (2002), both of which show that, depending on the culture, and where

certain groups in a society are judged based on their social characteristics, it is highly unlikely that members of such groups will seek help for certain diseases that are associated with stigma.

For example, Manhart et al. (2000) showed that seeking care for a sexually transmitted infection is something that is frowned upon in Moroccan society. Fear of the stigma associated with a sexually transmitted infection discouraged the study participants from seeking care, although concern that the disease might transform itself into something more serious provided an incentive to seek care (Manhart et al., 2000). Some respondents did not seek care until it was absolutely necessary, due to their fear that others would learn of their illness. Moreover, when people did seek treatment, the study found that they preferred to seek help from private practitioners specialising in allopathic (Western) medicine, rather than public providers, due to the greater degree of privacy and faster service obtained (Manhart et al., 2000). The issues of social exclusion and stigma will be discussed in further detail in sub-sections 2.2.3 and 2.2.4, respectively.

This section has presented a review of previous studies concerned with the processes in which people suffering from a chronic illness perceive their illness, including whether or not it is stigmatised. It emerges that these perceptions not only enable people to give meaning to an illness, but also influence their illness coping strategies, as extensively discussed in the health care behaviour literature. Insights into the ways in which people suffering from ill health make decisions when it comes to seeking help for their illness and the barriers and/or facilitators that they may face and that

may influence the health outcomes were also revealed by a number of the studies reviewed.

## **2.2 POVERTY AND AXES OF SOCIAL DIFFERENCE**

One of the purposes of this chapter is to provide definitions of the concepts that are used in this research. Since the study focuses on poor people, it is essential to develop an appropriate conceptualisation of poverty, so definitions of the term poverty are presented and discussed in this section, which also aims to identify and assess analytical approaches used by previous research in understanding the ways in which poor people live on a daily basis within their households, because eradication of poverty can only occur if there is sufficient understanding of the ways in which poor people live and their perceptions of living in poverty. Not all poor people are equally poor or affected by poverty in the same way. The livelihood opportunities to which they may have access and their access to livelihoods support, as well as to health care services, may also differ. This section will therefore also identify the social characteristics that emerge from previous studies as relevant when it comes to excluding the poor from accessing resources, and which need to be taken into account when considering whether processes of social exclusion affect the access of poor PLHA to adequate support.

2.2.1 provides an overview of poverty, 2.2.2 discusses the concept of a livelihood, identifies features of livelihood strategies that people living in poverty employ in times of shock or stress, and reviews some tools used to understand these strategies. Issues of social diversity that can potentially affect people's access to livelihood



opportunities are discussed in 2.2.3, which examines whether and how people with different social characteristics may be excluded from such opportunities. 2.2.4 considers how and why society stigmatises certain types of people, not only on the basis of what social characteristics they possess but also, and especially, if they contract an illness that is historically deemed to be stigmatised by the society in which they live. 2.2.5 identifies the characteristics of various livelihood support programmes that may be suitable for vulnerable people and discusses their strengths and weaknesses.

### **2.2.1 An overview of poverty**

The aim of this sub-section is to understand the different meanings of the term poverty and how these have evolved, to provide an understanding of what it is like for people to live in poverty.

Poverty has been defined in both *absolute* and *relative* terms. The term *absolute* poverty is used when households whose incomes or consumption levels are less than those required to meet certain defined physical needs, such as adequate diet, quality of housing (with basic services), health care, and education. Levels of poverty and official thresholds in a given country are usually measured in monetary terms i.e. a poverty line (Kawachi et al. 2002).

*Relative* poverty is defined in terms of its relation to the standards prevalent in a society (Laderchi et al. 2003). Typically, a relative poverty line is defined as some proportion of a society's average per capita income or expenditure (Kawachi et al.,

2002). Ideas about relative poverty and social exclusion are not new - in the late-seventies, for example, Peter Townsend defined poverty in the following way, “...individuals, families and groups in the population can be said to be in poverty when they lack the resources to obtain the types of diet, participate in the activities and have the living conditions and amenities which are customary, or are at least widely encouraged or approved, in the societies to which they belong. Their resources are so seriously below those commanded by the average individual or family that they are, in effect, excluded from ordinary living patterns, customs and activities...” (Townsend 1979:31). Following Townsend’s definition, the International Labour Organisation (ILO), among others, defined poverty in its broader sense by stressing the importance of lack of access to health, education and other services, in addition to lack of income. However, it was not until the eighties that other non-monetary aspects were included, such as powerlessness and isolation – based on the work of Robert Chambers. There was a new interest in vulnerability and security, which were associated with people being affected by seasonal changes and shocks, notably drought. These pointed to the importance of both assets as buffers and social relations (the moral economy, social capital) (Laderchi et al., 2003).

Also in the eighties, drawing on his work on famines in India, Sen developed the capability approach, in which ‘capabilities’ refers to what a person is able to do or be i.e. the range of choices that are open to him/her and ‘functionings’ to what a person actually manages to do or be, ranging from simple nourishment to participating in the life of the community and the achievement of self-respect. Sen argues that money is used to buy goods and services or ‘commodities’ which help a person achieve their functionings, although the role of money in achieving functionings depends on the

extent to which goods and service are exchanged for money, and therefore varies between societies. In addition, the relationship between money and capabilities/functionings depends in part on how the former are converted into the latter by individuals (Sen 1985). Sen, therefore, described poverty as capability-deprivation, placing the emphasis not only on how people function but also on their capability to function in important ways if they so wish. He has refused to specify the content of capabilities and functionings and critics argue that he has an essentially liberal economic conception of people as individuals with choices. Nevertheless, his thinking has been influential.

Nowadays, absolute poverty lines are widely used, especially within organisations such as the World Health Organisation and the World Bank, because they can be based on indicators that are apparently easy to measure, usually based on income or employment. For example, according to the World Bank, people whose per capita income is below US\$370 per year are considered to be poor, and those with less than US\$275 per year extremely poor (World Bank Report, 2001 cited in Sheuya, 2008:2).

However, there has been increasing criticism of measures of absolute poverty because of their arbitrariness and of monetary measures of poverty more generally, because they “...fail to consider the role of assets; take into account intra-household differences; distinguish between different-sized households; account for non-monetary income sources; and allow for the large variations in living costs within and between nations...” (Sheuya 2008:3). In addition, snapshot views of the incidence of poverty may not reveal the full nature of deprivation or develop understanding of processes of impoverishment. In particular, they fail to recognise that households’

wellbeing varies over time, leading recent studies to distinguish, for example, between the transient poor, defined as people who are in poverty for a short period of time, and persistent poverty, defined as people falling in and out of poverty repeatedly over a prolonged period.

In addition to the above criticisms, estimates of the incidence of poverty in income or consumption terms are criticised for failing to consider the differences in expenditures between rural and urban areas, as urban households incur greater expenditure for transport, housing, access to water for hygiene, health care, energy and child-care than households living in rural areas (Satterthwaite 2004). Monetary and per capita measures may therefore fail to portray the whole picture of poverty within urban households. In order to understand what poverty means and for effective poverty reduction strategies, scholars such as Rakodi (1995, 1999) and Chambers (1995) suggest that it is important for policy makers to understand the nature of poverty from the perspectives of the poor themselves. Studies show that for the urban poor, poverty encompasses not only low incomes, but also relative deprivation and insecurity, and that the ways in which poor households make a living and attempt to address various aspects of poverty demonstrate agency (Rakodi, 1999 cited in Desai and Potter, 2002:255).

This is reflected in the use of 'livelihoods' to denote the multifaceted approaches to achieving wellbeing adopted by households, focusing not on income alone, but also considering whether the poor are able to live a life that encompasses overall wellbeing by having all their basic requirements met (Rakodi and Lloyd-Jones 2002).

Livelihood strategies and the main analytical tool used to analyse them are examined in more depth in the next sub-section.

### **2.2.2 The livelihoods framework**

The aim of this sub-section is to review the concept of a 'livelihood' in depth, in order to understand the ways in which poor people and households make a living, ascertain what actions they are likely to take during periods of stress or shock in order to avoid impoverishment and maintain their wellbeing, and assess whether this concept can be used as part of the analytical framework for this research.

A number of scholars have attempted to define the term 'livelihood' (for example, Ellis 1998) but the definition presented by Carney (1998:2), which captures all the components required in order to understand the concept, has been particularly influential. She described a sustainable livelihood as comprising "*...the capabilities, assets (including both material and social resources) and activities required for a means of living. A livelihood is considered to be sustainable when it can cope with and recover from stresses and shocks and maintain or enhance its capabilities and assets both now and in the future, while not undermining the natural resource base...*"

This definition recognises that in order to maintain wellbeing on a day-day basis, people need to have both capabilities and assets in the form of material and social resources. A livelihood is considered to be secure when people are resilient in the face of shocks and stresses and sustainable when the activities it involves do not permanently deplete the natural resource base on which it depends, an element which is applicable to rural rather than urban livelihoods. The type and number of assets

available to a household, as well as the person(s) who are able to mobilise these assets within a household, may both determine the wellbeing of a household's members. Rakodi and Lloyd-Jones (2002:7) define a household as being: *"...a person or co-resident group of people who contribute to and/or benefit from a joint economy in either cash or domestic labour..."*

The composition of households, particularly in urban areas, is complex, with many consisting of close family, other kin and also unrelated co-residents. A particular member of a household may be regarded as (or regard themselves as) its 'head' because he or she brings in more resources than other household members, and/or has power over the allocation of household resources, especially if the assigned head of the household is a man and the others within the household consist of women and children. Women and men within a household typically have specific duties to perform (Rakodi and Lloyd-Jones, 2002).

Assets not only include those material goods owned or controlled by household members but also publicly owned assets and more intangible assets arising from social and political relations. Scholars argue that household assets are needed to construct a livelihood and access to these assets influences both the livelihood strategy adopted and its outcomes in terms of wellbeing. The types of capital (or accumulated stocks of wealth) typically identified include natural, produced/physical, financial, human, social and political (Moser 1998; Rakodi 1999). As the concept of 'capital' is mainly used in the context of economics and has been criticised by other social scientists, particularly when applied to social resources, it will be replaced in this research with the term 'asset'.

Moser (1998) points out that it is essential to identify what the poor possess, rather than focus on what they do not possess, in order to assess their ability to reduce vulnerability or cope with shocks. The understanding is that being in possession of assets helps in buffering a household when a stress or a shock (such as HIV/AIDS) strikes. Rakodi (1999) defines natural, produced/physical, financial, human, social and political assets as having possession of and/or access to land, water and other environmental resources; basic infrastructure; savings, credit, remittances and pensions; the ability to work, due to knowledge and good health; social relations at household, community and societal levels; and influence on decision-making and politics, respectively.

Moser (1998) argues that labour is the most important asset for the urban poor because they need to generate income either in the formal sector (wages received from employers) or in the informal sector, in particular because urban people must usually pay for their food, shelter, transportation and education, unlike their rural counterparts, who can mostly rely on their own production (Moser, 1998). Housing is also considered to be important to the urban poor, because apart from providing shelter, it can be used for income-generating purposes, such as renting rooms and using the space for home-based production activities (Moser 1998). In addition, Moser (1998) suggests that households living in urban areas are vulnerable to environmental hazards, such as poor sanitation and waste disposal, poor quality housing and inadequate water supplies, which have negative impacts on the health and wellbeing of the poor, and that social and inter-household mechanisms of trust

and collaboration may be weaker in urban than rural areas due to the greater heterogeneity of people and the differences in income earned within communities.

Moser (1998) suggests the use of an ‘asset vulnerability framework’ to categorise the assets available to the urban poor, the ways in which they are able to manage and mobilise their assets to improve their wellbeing, accumulate further assets and avoid or be prepared for any shocks or stresses in the form of illnesses, deaths or natural disasters (known as risks) that could come their way. As vulnerability is considered to be a product of risk, whether and how a household is able to recover from a shock in turn affects whether it becomes vulnerable, secure or highly vulnerable after its members face a shock, depending on how well the assets available to it at the time of the shock are managed.

Moser (1998) argues that use of the ‘asset vulnerability framework’ will help urban poverty reduction strategies to arrive at interventions that enable the poor to get out of poverty by improving opportunities, removing obstacles and ensuring that they can use their assets productively. She also argues that there must be an explicit differentiation between ‘poverty’ and ‘vulnerability’ if the socioeconomic wellbeing of the poor is to be really understood, arguing that unlike ‘poverty’, ‘vulnerability’ is a dynamic concept able to capture the changing processes that affect the poor. In an urban context, she defines ‘vulnerability’ as “...*insecurity and sensitivity in the wellbeing of individuals, households and communities in the face of a changing environment, and implicit in this, their responsiveness and resilience to risks that they face during such negative changes...*” (1998:3). One of aims of this research is to



understand whether and how the poor cope or are ‘resilient’ in the face of danger or hardship, in what ways they try to escape hardship and the outcomes of such attempts.

When livelihoods are exposed to risks that potentially result in shocks, the international literature demonstrates that poor people devise coping strategies in two ways. Households both take precautions to reduce risks (*ex ante*) or devise ways of mitigating shocks (*ex post*) with whatever assets they may possess, in order to prevent themselves from further impoverishment (Rakodi and Lloyd-Jones, 2002:15).

In this research, HIV/AIDS is considered to be a shock. It is known to have a severe impact on poor households, including mortality, morbidity and social marginalisation, and so the focus of the research is on *ex post* coping strategies, specifically looking at how PLHA attempt to mitigate the serious threat that HIV/AIDS poses to household livelihoods. The term ‘*ex post* coping strategies’ with respect to households has been defined by a number of scholars. However, the definition that best seems to capture the broad notion of coping strategies is: “...*all the strategically selected acts that individuals and households in a poor socioeconomic position use to restrict their expense or earn some extra income to enable them to pay for the basic necessities (food, clothing, shelter) and not fall too far below their society’s level of welfare...*” (Snel and Staring, 2001:1).

Other definitions imply or make assumptions that, while acknowledging the limited options available to the poor, they are asset managers with freedom of choice in relation to their actions (Ibid: 11). The term used to describe their actions is typically ‘strategy’, but this has been criticised on the grounds that the poor have few real

choices, having instead to cope with whatever asset they may have available when exposed to risks. They manage these assets within their households, depending on how much of each is available, which members of a household deploy these assets and whether these actors take the needs of their entire households into consideration.

Ill-health or sickness, which this study primarily focuses on, is considered to be a shock to all households, rich or poor, although like most shocks it is likely to have a more devastating impact upon poorer households. First, the findings of two studies that examined the impact of ill-health in general on households in an urban context will be reviewed, and then a number of studies that examined the impact of HIV/AIDS in particular. Even though these were mostly carried out in rural contexts, especially in Africa, it is worth considering them here because many adopted a livelihoods framework.

An early example of a study in an urban context was that by Pryer (1993) in the town of Khulna in Bangladesh. She carried out a study of 208 households grouped into five relatively homogenous livelihood groups within a low-income settlement (*bustee*) over a period of 18 months in 1984 – 1985 and 1986 – 1987. The findings documented the large number of labour days lost by the main income earners within all five livelihood groups owing to illness or accidents. The findings from Pryer's study revealed that the poorest households within the five livelihood groups had lost the most working days and earnings, with the result that most of these households were also heavily in debt. Some of the households contained incapacitated income earners, many with chronic illnesses, which the author suggested could severely limit their future earning potential, leading to further impoverishment. In addition, in

impoverished households with severely incapacitated earners, a much higher proportion of women and children worked, despite the very limited income-earning opportunities open to them. Thus in 1986, labour participation rates among adult women and children were far higher in the households containing a chronically incapacitated member than in the settlement as a whole. In these households, 80 per cent of the women worked, either as domestic servants or petty traders in the informal sector. In addition, 40 per cent of both male and female children aged 5-15 years old contributed to the budget in these households, with boys working as dependent scrap hawkers or shop helpers, whereas girls were either domestic servants or begged and scavenged in the marketplace. The findings also revealed that two of these households had owned either productive or non-productive assets of value in 1984, but reported that they had financed a period of high medical expenditure over the subsequent two-year period by the sale of rural household land and assets solely owned by the households. Once the proceeds from these sales had been spent, the two households had stopped spending further money on costly medical treatment. Households containing chronically ill members that in 1984 did not have any assets to begin with had spent significantly less on medical treatment over the two-year period. However, in all cases, the findings revealed that the estimated value of wages foregone due to incapacity was greater than the estimated cost of medical treatment (Pryer, 1993).

The findings from a study carried out in Dhaka, Bangladesh, gathered through an Urban Livelihoods Study (ULS) and presented by Kabir et al. (2000), confirmed that ill-health is a pervasive factor in the lives of *bustee* dwellers, with respondents identifying illness as an important shock to which any household might succumb,

regardless of its socio-economic standing. The findings reveal that the direct impact of illness on the households of *bustee* dwellers are loss of income, employment insecurity and health expenditure, which in turn may have negative repercussions for intra-household relations and social networks. In addition, the study reveals several examples of husbands leaving their young wives just after they became pregnant, when they became more of a liability in terms of ill-health and were less able to contribute economically to the household. In terms of the negative impact that illness has on social networks, the study found that when members of households fall ill, their social networking may suffer, both because the necessary time cannot be invested and also due to other network members seeking to loosen their ties with the household concerned, mainly because households with a member suffering from chronic illness becomes a net drain on the other members of a network, always taking but contributing little in return (Kabir et al., 2000).

Studies of the impact of HIV/AIDS in particular started to be carried out in the early 1990s in rural Africa and many of these studies confirm that affected households respond to the devastating impacts of HIV/AIDS by adjusting consumption and/or mobilising assets, as predicted by the livelihoods framework (Barnett et al. 1995; White and Robinson, 2000; Harvey, 2003; Loevinsohn and Gillespie, 2003; Russell, 2005; White and Morton, 2005; Crush et al., 2006; Hosegood et al., 2007; Richter et al., 2009 and Abebe and Skovdal, 2010).

Seeley and Pringle (2001), for example, suggested that a livelihoods framework can be used to understand the impact of the HIV/AIDS epidemic, with respect not only to how the illness impacts on people's health but also its impact on social support,

household finances, housing, land use and land tenure. The authors proposed a focus on PLHA and their lives by not only considering their illness (their clinical condition) but also what their lives were like in the past, within their own households, communities and regions, and how they had been affected subsequently. Seeley (2002) suggested that the livelihoods framework can be used to look at the impact of the HIV/AIDS epidemic on a person's livelihood, because in her view it *"...can help us to look at linkages between the impact of the disease on health and human capital..."* (Seeley, 2002:1-2). She suggested that by analysing the five types of asset available to households, the 'asset vulnerability framework' could be used in rural Africa to demonstrate how sickness can be viewed as part of the vulnerability context, which includes shocks, trends and seasonality. She asserted that *"...using the livelihoods framework to assist in analysis, rather than just focusing on the impact of the epidemic on health, enables us to see not only what is being negatively affected, for example finding that land has been left uncultivated because of lack of time or people to plant and financial resources have been used up on treatment costs, but also what strengths may be built upon: what are viable livelihood alternatives, what support mechanisms exist?..."* (Seeley, 2002: 10).

Barnett et al. (1995) investigated the social and economic impact of HIV/AIDS on farming systems and livelihoods in rural parts of Uganda, Tanzania and Zambia. Their findings revealed that as household members become ill and die, not only does this result in labour shortages for both farm and domestic work, but also the family's resources are progressively strained, which in turn can result in a severe fall in its standard of living. The findings further reveal that the combination of a loss of labour, a loss of household members to care for the very young and the elderly, increased

numbers of dependent children and cultivation of a more restricted range of crops, the living standards of households affected by HIV/AIDS continue on a downward spiral. The study identified a number of *ex post* coping strategies employed by rural households in order to cope, for example, reducing the quality of children's diets, providing them with less care, and withdrawing them from school (particularly young women, so that they can fetch water and firewood, and care for the younger children or the sick, as well as work on the farm). The findings also reveal that when married men die of HIV/AIDS-related illnesses, the ownership or cultivation rights to their land may be disputed by the wider family, leaving their widows and children landless, even though the wives may have spent all their married lives carrying the bulk of the farm workload in addition to their domestic activities. The only coping strategies open to such women and children may involve moving away from the area and beginning another life elsewhere, where they may have to resort to sex work to earn a living. While some widows may be allowed to stay on the family farm, tradition and a lack of some types of agricultural knowledge may hinder them from easily taking over their partner's share of the work - it is not only a person who dies, but also the knowledge and skills of that individual which may die with them. In addition, with the death of their husbands, widows are likely to lose access to extension services, credit and marketing facilities, amongst other facilities to which their husbands had easy access (Barnett et al., 1995).

Similarly, White and Robinson (2000) carried out a study investigating the impact of HIV/AIDS on rural livelihoods in sub-Saharan Africa. They noted that most households in rural Africa live with a high degree of risk, in response, whenever possible, diversifying their livelihood strategies to reduce their vulnerability to particular risks. Nevertheless, their findings reveal how households affected by

HIV/AIDS are particularly vulnerable to experiencing a loss of financial assets because labour may be diverted from economically productive activities such as paid employment or cash-crop production to care for sick household members, money needed for medication and treatment and to pay for funeral costs after the death of one or more household members. Like Barnett et al. (1995), White and Robinson (2000) reveal that when HIV strikes a household, the coping strategies adopted usually aim at improving food security, raising and supplementing income in order to maintain household expenditure levels and alleviating the loss of labour, for example by re-allocating labour within the household. According to studies carried out by the Food and Agriculture Organisation of the United Nations (FAO) (White and Robinson, 2000), how well a household is able to generate different sources of cash income depends not only on external opportunities, but also on the assets available to the household and the diversity of its existing livelihood.

Households in the rural parts of Africa may also change the way they access and use land. White and Robinson (2000) note that if a household no longer has sufficient labour to farm all its land, it may hire labour; rent, lend or sell land to other farmers (perhaps on a crop sharing basis); or abandon some of its previously cultivated land. This is confirmed by a recent study carried out in rural China where the findings revealed that households with ill members spent less on farm inputs, so excessive medical expenditure had reduced investment in physical capital, and therefore farming productivity (Wang et al., 2006). Studies carried out by FAO (1995) found large areas of land owned by households affected by HIV/AIDS uncultivated due to a lack of labour or financial resources to pay for workers. While as noted above, land for cultivation or grazing is inaccessible and unimportant to most households living in

urban areas (although some may retain claims to rural land), Moser (1998) considers that housing is an important but unrecognised resource for the urban poor, arguing that if the poor have security of tenure, a house can provide a location for opening up a business, it can be rented out, part of it can be sold, or it can be used to extend personal and social relationships. Many of these functions may be called upon as part of *ex post* coping strategies, but are less available to those who rent rather than own their dwellings.

One of the main assets available to poor households is their human capital, primarily because of the labour household members provide for provisioning and reproductive activities. However, people must have physical strength, be healthy and have knowledge and skills in order for their labour to contribute to wellbeing. The studies identified above have already identified the key role of labour, showing that households affected by HIV/AIDS begin to use their labour more intensively and to earn money in new ways. For example, when men fall ill with HIV/AIDS and can no longer carry out their arduous physical jobs, women usually take on additional tasks and increase their working hours or, in some instances, women may take up commercial sex work in order to replace the lost earnings of their male partners (UNAIDS, 1999). In addition, in households where the main earner has been affected by HIV/AIDS, it is not uncommon for children to leave school early and undertake jobs intended for adults. They may in some instances end up earning for the whole household, especially when both parents are ill with HIV/AIDS (UNAIDS, 1999). For example, a study carried out by Abebe and Skovdal (2010) in rural parts of Ethiopia and Kenya reveals that children under the age of 18 years who had lost at least one parent due to HIV/AIDS-related illnesses carry out domestic, agriculture and



care work, in addition to actively participating in income-generating activities such as; “...selling farm proceeds, carrying out informal labour for cash and [in the case for Ethiopia only] getting paid for coffee picking and processing...” (Abebe and Skovdal, 2010: 572).

Further studies in the context of rural areas show that when household members, especially women and girls, are forced to leave paid jobs and schooling in order to care for their loved ones suffering from the illness, the household loses human assets, as not attending school affects children’s future earning capacity. While many households try hard to keep children in school (Moser, 1998), the main reasons suggested in the international literature for both young boys and girls to be taken out of school when one or more adults are bedridden due to HIV/AIDS are the lack of money to pay for attending school, to help with the housework at home (if girls) or, in the case of boys, to be sent out to work, replacing the main earner of the household (Jacoby and Skoufias 1997; Duryea, 1998; UNAIDS, 1999; Mutangadura, 2000; Skoufias and Parker 2002; Barnett and Whiteside 2002; Ogden et al., 2006; McIntyre et al., 2006).

In both urban and rural areas, migration may also be a response to ill health, either to obtain income to send home, or simply as a way of reducing the number of mouths to feed (Moser 1998). White and Robinson (2000) confirm that in the rural context, migration may be part of households’ coping strategies, permitting individuals to move between areas of limited labour demand and better opportunities in other rural or urban areas, making the allocation of household labour more efficient.

As noted above, a primary need for households is to maintain food security, either by own production, in so far as this was possible prior to the illness and can be maintained given the likely withdrawal of labour, or by purchase, while other goods and services also have to be purchased. Some of the poor may be able to draw on savings from the sales of livestock to pay for food, as well as medical care and funerals, as shown in a study of rural households in Burkina Faso (Sauerborn et al., 1996). Another common strategy is to sell productive assets in order to buy food and pay for funerals (Mutagandura et al., 2000). However, the proceeds of such sales, reduced income and the depletion of savings sooner or later results in households cutting back expenditure on food and health care (Sauerborn et al., 1996; Barnett and Whiteside 2002; Wagstaff 2007).

Moser (1998) considers the relations within households to be important to households' livelihood strategies, especially when they face a shock, describing households as being *"...important adaptive institutions for the poor, providing mechanisms for pooling income and other resources and for sharing consumption. In times of economic difficulty, households act as safety nets, and can be shock absorbers, reducing the vulnerability of those who join them..."* (Moser 1998:8). Nevertheless, she argues that, although households may be important for providing security and redistributing material and other resources, they are also sources of inequality, because entitlement to household resources depends on gender, age and earning capacity. For example, she provides evidence of a link between a declining or zero male income contribution within households and increased levels of domestic violence, which suggests that household relations can both enable and constrain strategies, potentially posing additional challenges for households. Finally, she

suggests that the ability of a household to cope in the face of adversity is dependent on its flexibility, in terms of swapping resources from one activity to another, and re-allocating tasks and responsibility for expenditure. Indeed one of the worst outcomes of shocks and stresses is that a household may break up as a result of its *ex post* coping strategies (Barnett and Whiteside, 2002).

Households are not isolated or self-sufficient units – the opportunities open to them depend not only on wider markets (in labour, housing, food, etc) but also on the relations between them and their wider families and societies, at the neighbourhood or city level, or in rural areas. Within the context of a livelihoods framework, such social relations or networks have been described as ‘social capital’, which has also been linked to important public health variables due to the work carried out by Robert D. Putnam (1993; 2000). As noted by Putnam (2000:18-19); “...*the core idea of social capital theory is that social networks have value...*” although the term has been redefined many times since its first conception. Nevertheless, the term commonly implies trust, reciprocity and cooperation among members of a social network that aims to achieve a common goal (Kreuter and Lezin, 2002 in Holtgrave and Crosby, 2003:62). Access to social capital is generally positively associated with resilience.

The poor use social assets in times of shocks or stresses by calling on close and/or extended families, other households within their communities or wider social networks. Research shows, for example, that many affected households send their children away to live with relatives (UNAIDS, 1999) and in many cases, orphaned children end up being looked after by their elderly grandparents after the death of their parents (Knodel et al., 2000; Knodel and Im-em, 2004). White and Robinson (2000) warn that due to the long duration of HIV/AIDS, and its tendency to affect

many families within a community, social capital may become severely strained over the long term.

In the literature on HIV/AIDS mitigation, livelihood strategies that utilise social assets are often referred to as community responses and so social assets will be used as part of an analytical framework for this thesis, in order to identify the kind of support, help and care poor PLHA are able to draw upon from their families (close and extended), and what social support groups and saving groups are available to them that could help maintain or improve their livelihoods, in addition to the ways in which non-governmental organisations (NGOs) or community-based organisations (CBO) provide support to the livelihoods of poor PLHA.

However, it has already been noted that poverty may be linked to the limited nature of a household's social assets. Thus, the next sub-section will focus on the process of social exclusion and how people may or not be excluded on the basis of their social characteristics, which in turn can affect how they cope with their illness on an everyday basis and determine their access to resources that might enable them to maintain their wellbeing.

### **2.2.3 Exclusion from accessing assets on the basis of people's social characteristics**

The purpose of this sub-section is to briefly discuss which social characteristics can result in people having different assets and experiences of life events and opportunities, providing explanations as to why certain groups within any given

population are excluded from material and social resources, resulting in impoverishment.

Research carried out over the last forty years, as illustrated by the quote from Townsend in the previous sub-section, has shown that there are certain categories of people who tend to be 'left behind' or 'excluded' from living a *normal* life which others in the general population take for granted, resulting in them having different experiences of life events. Such groups often include women, single mothers, the disabled, the elderly, children, and others who are marginalised by the societies they live in due to race (for example in the United States), ethnicity, caste, class or religion. They may be excluded from education, adequate housing, water supply and sanitation, thus are unable to live *normal* lives and gradually become impoverished (Eade, 1996). In addition, there is specific evidence to suggest that some disadvantaged groups, such as women and ethnic minorities, have poorer access to health services. For example, women and people living in economically deprived areas are less likely to be offered cardiac rehabilitation (Melville et al. 1999, Cooper et al. 2002) and members of some ethnic minorities have had reduced access to invasive cardiac procedures (Trevelyan et al. 2001; Ashton et al. 2003).

In India, it appears that exclusion is based on social relations and institutions that exclude, discriminate, isolate and deprive some groups on the basis of identities like caste and ethnicity (Thorat 2007 and Thorat et al., 2009) and in many cases gender and religion, which will be further discussed in section 4.1.

In order to understand social exclusion, it is important to understand the processes by which certain groups are differentiated, the forces that create and reinforce exclusion in different cultural settings, and the mechanisms by which they are then denied access to one or more assets required to maintain their livelihoods, starting with defining 'social exclusion'.

The term 'social exclusion' (SE) was originally developed in France in 1974 to refer to various categories of people who were not protected by social insurance at that time. Still within Western Europe, the concept evolved to reflect wider discussions related to poverty, inequality and justice (Rodgers, Gore and Figueiredo, 1995).

Whether SE should be used as part of an analytical framework or in an operational way with respect to issues of poverty, injustice and inequality in the developing world is still up for debate, as there is scepticism about exporting terms from the North, where the majority of people are rich, to the South, where the majority of people are poor. However, Rodgers, Gore and Figueiredo (1995) argue that SE can be applied in the developing world if the term is used as a way of loosely connecting issues of *"...poverty, deprivation, lack of access to goods, services and assets, [and the] precariousness of social rights..."* (Rodgers, Gore and Figueiredo, 1995:5). The authors assert that the SE approach can be used appropriately in understanding poverty if less emphasis is placed on economic aspects and more attention paid to the political and cultural dimensions of poverty.

They define SE as: *"...a process which restricts the access of certain social groups to valued resources and entitlements, relegating them to the status of social outsiders. It*

*is a multi-dimensional concept, conceived to capture different forms of social disadvantage – economic, social, political and cultural – that persist, in multiple variants and with different intensity, across nations. Consequently, in its widest connotation, the concept encompasses theories of poverty, inequality, racial/ethnic cleavages, long-term unemployment and citizenship...*” (Rodgers, Gore and Figueiredo 1995:237).

Kabeer (2000) suggests that SE is also appropriate when a minority are excluded, resulting in further marginalisation and impoverishment. Laderchi et al., (2003) note that SE is socially defined and is often regarded as a characteristic of groups (the aged, handicapped, racial or ethnic categories) rather than individuals, which differs from the concept of a *poverty line*, which as noted above, is usually used to define the extent of poverty amongst individuals or households.

Desai and Potter (2002:255) state that the urban poor find it difficult to assemble the financial assets needed to access appropriate housing and utilities, with the result that they live in poor housing, their children do not receive adequate education and they do not receive appropriate health care. Accessing these essential resources is made even more difficult when they are excluded on the basis of their social characteristics, such as gender, ethnicity, caste, or religion. Rodgers, Gore and Figueiredo (1995:44) suggest that three types of exclusion are widely found in low-income settings. Firstly, “*levels of living*” are concerned with exclusion from goods and services; secondly, “*means of livelihood*” can involve exclusion from land or house ownership, other productive assets and/or labour markets; and “*social rights*” that may involve exclusion from social protection in work or opportunities to develop skills.

Systematic exclusion on the basis of social characteristics is exacerbated by a positive HIV diagnosis, because of the stigma associated with the illness, and so the following part of this sub-section discusses why and how poor people living with HIV/AIDS (PLHA) in particular are discriminated against and what impact this discrimination has on individuals, their relationships with their partners, their household members, their relations with neighbours, their position within organisations and their roles in wider society. Because of the relevance of stigma to understanding the effects of HIV/AIDS, it starts by examining the concept more generally.

#### **2.2.4 Stigma**

Ever since the recognition of stigma by Goffman, academics have used his ideas in the study of illnesses, beginning initially with mental illness and then later focusing on epilepsy, leprosy, cancer, onchocercal skin disease, tuberculosis (TB), urinary incontinence, and recently, HIV/AIDS (Parker and Aggleton, 2003) and many have developed refinements of his original formulation. According to Malcolm et al., (1998:349), “...stigmatisation can be used as a means of social control through marginalising, excluding and exercising power over people who exhibit particular traits...” McGrath (1992) and Takahashi (1997) assert that by placing blame on certain groups of people for their behaviour, society absolves itself from responsibility, lacks empathy and instead isolates one or more people from a group of those suffering from an illness or at risk of HIV.

Two kinds of stigma have been identified: ‘felt’ or ‘perceived’ stigma and ‘enacted’ stigma (Scambler and Hopkins, 1986; Jacoby, 1994), where ‘felt’ stigma relates to the



perceptions that individuals may have about their condition and the responses they expect it to evoke from others and ‘enacted’ stigma refers to actual experiences of discrimination (Scambler and Hopkins, 1986). Social psychologists utilise social cognitive theories and argue that stigma is an individualistic characteristic. However, authors such as Parker and Aggleton (2003) and Castro and Farmer (2005) argue first, that stigmatisation in the context of HIV/AIDS *should not* be considered highly individualised and second, that stigma is not a static attitude, rather it is a constantly changing (and often resisted) social process, in which people, out of fear of the disease, want to maintain social control and want to get “rid” of people who are “different” to the “normal” population. Parker and Aggleton (2003:17-18) thus conceptualise stigmatisation and discrimination as; “...*social processes that can only be understood in relation to broader notions of power and domination...*” (emphasis in the original). Similarly, Castro and Farmer (2005:53) state: “...*stigma and discrimination are part of complex systems of beliefs about illness and disease that are often grounded in social inequalities...*”

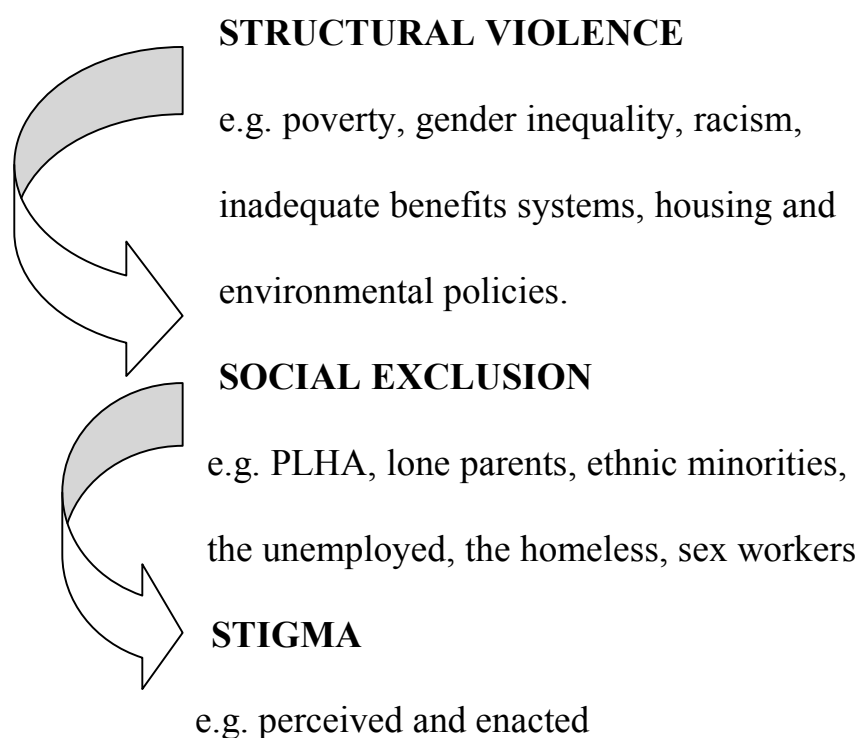
Castro and Farmer (2005) also suggest that PLHA with certain social characteristics, such as being black, a woman and/or in the lowest class within a society, where possessing these characteristics is already frowned upon and discrimination is ingrained within a society, are more likely to be discriminated against. According to them, in essence, social exclusion is part of the social inequality in which stigma is rooted and stigma is both a cause and consequence of social exclusion.

De Bruyn (1999) identified five contributing factors to HIV/AIDS-related stigma: (1) that HIV/AIDS is a life-threatening disease; (2) that people are afraid of contracting

HIV; (3) the disease's association with certain behaviours, e.g. sex between men and injecting drug use; (4) that PLHA are often thought of as being responsible for having contracted the disease; and (5) religious and moral beliefs that lead some people to conclude that having HIV/AIDS is the result of a moral fault in the form of promiscuity or "deviant" sex that deserves punishment. Consequently, HIV/AIDS-related stigma has been known to result in discrimination, which can take many forms and exists at many levels, such as between sexual partners, household members, neighbours and communities, organisations and society in general, in the process violating the affected people's rights to find employment or marry, freedom of movement, and freedom from inhumane and degrading treatment (Maluwa et al., 2002).

Figure 4 below illustrates the complex phenomena in which stigma is considered to be rooted, showing in a diagrammatic format that poverty (considered as an outcome of structural violence) leads to the social exclusion of certain groups in a society. It is assumed that people who are at risk of HIV/AIDS are most likely to be living in poverty in the first place, hence **already** socially excluded, consequently, if these people, who are at risk, contract HIV/AIDS, they are likely to be further discriminated against and socially excluded due to historical, cultural and individual societal factors associated with the disease.

**Figure 4:** Processes of social exclusion



(**Source:** adapted from Purdy and Banks, 1999, Parker and Aggleton, 2003 and Castro and Farmer, 2005)

Not only are PLHA physically weak as a result of the illness, unable to work to their full capacity (especially where hard labour is required), and have few financial resources, they and their household members have to endure the additional burden of being discriminated against for suffering from HIV/AIDS, as shown below by the empirical data at different societal levels.

HIV disclosure to partner, family and friends is a two-sided issue that PLHA have to deal with. Disclosure can be expected to alleviate the stressful burden of concealment and lead to increased material and emotional support (Holt et al., 1998), but it may also lead to PLHA being stigmatised and discriminated against by others, and expose

them to emotional distress (Pettrak et al., 2001; Chandra et al., 2003). For example, Bond et al. (2002) showed that women living with HIV/AIDS in a community in Zambia did not feel that they could disclose their HIV-positive status to their husbands for fear of it leading to divorce or even violence, while men were more willing to share their HIV status with their wives in the expectation of a supportive response. In the context of a household and family setting, Bond et al. (2002) showed that discrimination can take the form of verbal abuse, rejection, eviction and imposed restrictions on a person, while at the community level, people not living with HIV/AIDS may explicitly avoid physical contact, such as shaking hands, and sharing food and drinking utensils, and in general, placing a physical distance between themselves and persons suspected of having HIV/AIDS.

According to McGrath et al. (1993), when PLHA face this kind of derogatory subjugation on a daily basis, they begin to become conscious about themselves, resulting in a fear of revealing their HIV status to others and also avoiding contact with other people. This fear is exacerbated by the symptoms of HIV infection, as PLHA then become worried that others will notice their illness, a fear that appears to increase as it becomes more and more difficult to conceal the evidence of illness. Studies carried out in countries such as Ethiopia, Tanzania and Zambia by Nyblade et al. (2003) confirm that not only PLHA experience discrimination at a community level but also their families and even community volunteers are vilified due to being associated with the person who is suffering from the illness. Another study carried out by McGrath et al. (1993) confirmed that the families of PLHA are shunned by their communities because of their association with a person living with HIV.

White and Morton (2005)'s findings also showed that PLHA and their families were not only experiencing the psychosocial impacts of chronic illness and bereavement, but were also discriminated against by the local community, in turn making these individuals less likely to seek support or to be open about their sero-status to their family and others. Their findings also revealed that fear of discrimination prevented other members of a community from making use of HIV testing services.

Similar findings from a study carried out by Hosegood et al., (2007) confirmed that households experiencing multiple HIV-related illnesses and AIDS deaths face stigma and discrimination, with each new episode of illness or death resulting in respondents feeling increasingly isolated and discriminated against by their relatives and neighbours. When the respondents in this study were asked how their neighbours viewed them, they used words like 'diseased' and 'poor'. Several also felt strongly that their impoverished circumstances deterred people from visiting or helping them out, and that poverty exacerbated the stigma around HIV/AIDS.

At the organisational level, particularly in health services, stigma and discrimination have also been reported. The most extreme forms of stigmatisation are of individuals suspected of suffering from a stigmatised illness such as leprosy or HIV/AIDS; they may result in refusal of treatment and basic care; treatment delay; being neglected and left in corridors; being called names; and breaches of patient confidentiality (Malcolm et al. 1998; Bond et al., 2002; Heijnders, 2004).

Confidentiality is considered to be a major issue in the context of the health care system, according to Malcolm et al., (1998). Informing patients with a positive

diagnosis is mandatory in many countries, although the practice varies. In addition, there have been cases where information about a person infected with HIV has been provided to relatives and family members without the consent of the person concerned. In some cultures, telling relatives and family regarding an individual's status without his/her consent is considered to be acceptable, as group and societal rights are considered to be more important than individuals' rights, so that families and kinship groups are often informed of a person's illness and then share the burden and confidentiality of his/her illness (Malcolm, et al., 1998). This has been termed 'shared confidentiality' by Campbell et al., (1997), where individual needs are balanced with the needs of those at risk and to encourage community and family support for those infected.

With regard to AIDS care issues, fear and AIDS-related stigma and concealment of one's serostatus have been found to cause delays in accessing care (Parker and Aggleton, 2003). In contrast, preliminary data from research in rural Haiti suggested that the introduction of quality HIV care led to a rapid reduction in stigma, with resulting increased uptake of testing. In this instance, the authors suggest that logistical and economic barriers rather than stigma determine who will access such services (Castro and Farmer, 2003, 2005). Piot et al. (2007) also claim that the provision of HIV treatment can help prevent poverty - and indirectly contribute to HIV prevention as well – by helping to break down stigma.

The Indian literature, which will be discussed in section 4.1, suggests that the social characteristics that are most relevant in the Indian context are gender, religion and caste. Because of cultural differences, not all the dimensions of social difference

identified in the international literature are relevant in the urban Indian cultural context, and some aspects mentioned above, such as children and class, will not be discussed further.

The following sub-section will discuss solutions intended to help the poor escape poverty, especially those who are doubly excluded because of their social characteristics and their HIV positive status.

### **2.2.5 Livelihood support programmes**

For poor PLHA to avoid further impoverishment, it is important that support is available for households affected by the illness, including support for their livelihood strategies. This sub-section therefore briefly reviews the characteristics of livelihood support programmes that are currently available, noting their strengths and weaknesses.

While many factors contribute to poverty, its first obvious sign is insufficient household income. Members of poor urban households are typically involved in operating microenterprises, casual work or wage labour, often in the informal sector. Financial services such as micro-credit schemes and other income-generating programmes are necessary to kick-start and then maintain small businesses, enabling households to retain possession of their assets and build them up, as well as enabling them to access other paid work (Rakodi and Lloyd-Jones, 2002; Mehta and Gupta, 2005). In the case of poor PLHA, it is suggested that support may be needed to

enable them to keep existing businesses going, but also access to training for less arduous work may be necessary (Mehta and Gupta, 2005).

Poor households are typically excluded from the formal banking system, hindering them from operating micro-enterprises or investing in other income-generating activities. Access to microfinance, which uses new contractual structures and organisations to reduce the risks and costs of making small and cheap loans without demanding any collateral in return, and is increasingly widely available, can help them manage household and business finances (Morduch 2000).

In particular, microfinance initiatives are frequently claimed to be possible means to empower women by increasing their economic independence (Cheston and Kuhn 2002; UNAIDS, 2008). In one study, 90 percent of women who participated in microfinance initiatives reported significant improvement in their lives, including an improved sense of community solidarity in crisis and reductions in partner violence (Pronyk, 2006). In addition, a randomised controlled trial carried out by Karlan, Ashraf & Yin (2007) on a women's microfinance initiative in the Philippines provided empirical evidence that women with access to a savings product in which the funds in the account were "committed" to a predetermined goal had greater power in household financial decision-making and were more likely to save.

Successful operation of a micro-enterprise requires social and human assets in addition to financial ones (Rakodi and Lloyd-Jones, 2002). Social links provide the networks that support the economic activities of the poor. For example, in South Asia, evidence has shown that local savings clubs and finance groups form an important way to allow accumulation of limited assets (Rutherford, 2000 cited in Rakodi and



Lloyd-Jones, 2002). The Self-Employed Women's Association (SEWA) in Ahmedabad in Gujarat, India is an example of such a local savings group in action (SEWA, 1999).

Micro-enterprises are not necessarily the preferred alternative - they are risky, not least because of harassment from the authorities and/or endemic violence that limits the development of enterprises, as well as community activity and the ability to connect with others interested in forming finance groups (Rakodi and Lloyd-Jones, 2002). Support to microenterprises may range from halting harassment to employing micro-enterprises to deliver urban public services (Harper 2000).

Human assets in the form of education and health are also important for income earning (Rakodi and Lloyd-Jones, 2002). It is asserted that providing education to women is one of the most effective ways of combating gender inequality. Access to health care is also important for maintaining people's earning capacity (Rakodi and Lloyd-Jones, 2002).

Research on the impact of HIV/AIDS in rural areas has shown that as women, often widows and elderly grandmothers, often bear the brunt of caring for PLHA, while also being responsible for securing household food and income, many face critical resource and information needs. For example, as noted above, in addition to a shortage of labour, widows may lack the knowledge and resources needed to sustain the production of cash crops, which had previously provided a vital source of income. In addition, their lack of access to credit, a long-standing constraint, is exacerbated by the loss of male relatives who had wider access to sources of financial support that

had benefited the whole family. While traditionally, extended family and community support networks take in orphans, the increasing number of children left without parents as a result of HIV/AIDS is placing such systems under considerable strain. Orphan-headed households have become increasingly common and are at particular risk of abuse and destitution. Consequently, White and Morton (2005) suggest that attempts to mitigate the impacts of HIV/AIDS on rural households should focus on four main areas: agricultural training; artisanal and vocational training (e.g. teaching, nursing, carpentry, joinery, brick making and laying, commerce and mechanics); the provision of credit and loans; and HIV/AIDS awareness-raising, care and support. Similarly, Richter et al., (2009) suggest that access to health and education need to be made available to children living with their parents, grandmothers or other members of close or extended families, so that their human assets are not neglected (Richter et al., 2009). A study carried out by Schatz et al., 2011 in the context of rural South Africa revealed how younger widows appear to have fewer resources for coping with AIDS-related disruptions and hence are more vulnerable than female-headed households containing older women, especially if their husbands had not yet died due to HIV/AIDS related causes. The authors noted that, although many of both these types of household receive social support through child grants, younger heads often struggle to find sufficient money for basic household needs. The study revealed that most young female heads undertook informal work to supplement the household income, but that most seemed overwhelmed by household demands. The authors suggest that the households of younger widows would benefit from additional grants to help them replace social networks lost to stigma and also the creation of employment opportunities for women (Schatz et al., 2011).

Health insurance schemes offered by CBOs, i.e. community-based health insurance (CBHI) schemes, have been suggested as a means of pooling risks and resources that, in principle, could offer protection against the risk of medical expenses, making health care services that would otherwise be unaffordable accessible to poor people (Ranson et al., 2006). Such schemes are often initiated by a hospital, and then targeted at nearby residents. There is however only limited evidence to assess whether or not CBHI schemes have indeed improved the access of poor people to health care (Ranson et al., 2006). According to some studies, the utilisation of health care services increases with the implementation of insurance (Yip and Berman, 2001) or mandatory prepayment schemes (Diop et al., 1995), but studies also show that if CBHI schemes require a flat premium, they tend to exclude the poorest (Bennett et al., 1998; Preker et al., 2001).

### **2.3 OVERVIEW OF THE HEALTH CARE SERVICES AVAILABLE TO PLHA**

The World Health Organisation (WHO) defines a health system as; “...*all the activities whose primary purpose is to promote, restore, or maintain health...*”

The purposes of this section are to provide a brief overview of a typical health care system in the developing world, to provide a picture of the type of services available to people on an everyday basis, and to make a preliminary identification and assessment of the types of facilities that are typically available to PLHA. This will enable India’s health care system to be compared with health care systems in the developing world more generally and provide an initial basis for comparing whether and how the types of facilities that are available to PLHA in India are in line with the

provisions in other developing countries. Firstly an overview of the idea of a primary health care system will be provided, considering the roles of public (2.4.1), private-for-profit (2.4.2) and private-not-for-profit (2.4.3) organisations and providing a preliminary analysis of international practices on the services typically provided by each for PLHA.

### **2.3.1. Health services provided by the public sector**

This sub-section provides a brief overview of the public health care sector in the developing world and, because the demand side has already been considered in sub-section 2.1.3, an overview of the term ‘access’ from the supply-side (Ensor and Cooper, 2004).

Public health care systems are typically designed to have three levels: primary, secondary and tertiary. It is well known that the lack of or very weak public health care infrastructure, lack of funding, lack of trained personnel and/or low retention levels of staff, and inadequate numbers of and sparsely distributed the health care facilities at all three levels are some of the main reasons why the public health care sector has typically failed to cope with the levels of disease and other public health problems in the developing world. The meagre funding that countries allocate to health care is dictated by the economic and developmental status of a country, in addition to political will (WHO 2004). The HIV/AIDS epidemic has threatened to overwhelm already inadequately funded and over-stretched public health care sectors in many developing countries (Musgrove and Zeramdini 2001). For example, in sub-Saharan Africa, the annual direct medical costs of HIV/AIDS (excluding anti-

retroviral therapy) are estimated at \$30 per person infected, whereas overall health expenditure by the public health sector is less than \$10 per capita in most African countries (UNAIDS, 2002).

It is estimated that half of all health services required in developing countries are for chronic conditions. In response, the WHO (2002) has developed a chronic health care model relevant to the developing world that includes conditions such as diabetes and cardiovascular disease (Epping-Jordan et al., 2004). Increasingly HIV/AIDS is viewed as a chronic condition, which requires comprehensive health services similar to those needed for cancer, diabetes, and cardiovascular care. Although the WHO approach may be useful for delivering comprehensive services to PLHA, who have similar health care needs to others with chronic conditions, the complexities of the medical management of HIV infection and antiretroviral treatment, with regard to drug toxicity, metabolic complications, adherence to treatment and emerging viral resistance, implies that the 'one fit for all' chronic health care model may not be appropriate for the majority of PLHA (Kitahata et al., 2002).

According to Kitahata et al., (2002), the WHO emphasises the importance of defining services to be delivered at each level of health care, from home care, to community level participation, to primary, secondary, and tertiary levels of service delivery, in order to provide comprehensive care to people with chronic diseases. The model proposes primary health care teams trained to carry out clearly defined tasks such as treatment adherence counselling, supporting patient self-management, and providing counselling and testing, prevention services, and palliative care in the community, be established for managing HIV, as well as effective wider communication and referral

systems (Kitahata et al., 2002). Although integration and coordination of services are important elements of the WHO chronic disease model, Epping-Jordan et al., (2004) note often there is poor coordination between local primary health services and more specialised providers based in cities and hospitals.

The WHO chronic disease model also suggests that, as counselling and testing services are key components of HIV care and the prevention of HIV infection, these services can be integrated into existing vertical programmes such as antenatal care, family planning, and maternal and child health programmes, especially to reach women (Kitahata et al., 2002).

There is evidence to show that HIV counselling and testing serves as an entry point into HIV care and referral to other AIDS services, linking care with prevention programmes in countries like Brazil, Thailand, Cambodia and Senegal. Access to government-funded antiretroviral drugs has also encouraged the take up of testing and helped to increase access to antiretroviral treatment in these countries, especially in Brazil and Thailand (Kitahata et al., 2002).

### **2.3.2. Health services provided by the private sector**

The purpose of this sub-section is to give an overview of the functions of private-for-profit provision and the ways in which this sector provides services, especially to the poor. It outlines how private health care systems have developed over the past 20 years in low and middle-income countries, with the result that today non-state

providers (NSPs) in the form of private-for-profit provision are now the main providers of health services in many low-income countries.

The first *real* wave of health care reform in the systems inherited by many newly independent countries was launched in 1978 at the joint WHO-UNICEF conference on Primary Health Care at Alma Ata, USSR, the main message of the declaration being a rights-based one: “...*Health for All...*”(WHO 1978). The declaration focused on prevention, the need to identify the underlying causes of poor health, multi-sectoral collaboration, ‘primary health care’, ‘community participation’ and equitable access to health care at the point of need, irrespective of colour, race, income and gender.

The second wave of health care reform occurred in the late 1980s and early 1990s (and is still occurring). Underlain by neo-liberal principles, it is a ‘market-based’ approach (World Bank, 1993). Responding to economic crisis and poor public sector performance, private provision and ‘decentralisation’ were favoured, in theory making health care services more responsive to user needs. As a result, the growth of private provision, including all providers that are not directly managed and paid by the state, has been a key feature of health systems in many developing countries (Bennett, McPake and Mills 1997). The private sector includes both for-profit and not-for profit formal sector providers, as well as a mass of informal providers such as pharmacists, traditional healers and unqualified drug sellers. The latter are the most numerous and widespread NSPs in most low-income countries (Palmer, 2006).

Empirical evidence obtained over a period of 15-20 years from the developing world reveals a trend towards people preferring privately rather than publicly provided

health care. Data are poor, but for example, in South Africa, estimates are that half or more sexually transmitted infection (STI) care episodes dealt with in the formal health sector are treated by private general practitioners (Schneider et al., 2001). The remainder of this sub-section will discuss private-for-profit provision, while not-for-profit provision will be considered in sub-section 2.4.3.

Studies carried out by Bhat (1999) and the World Bank (1995) showed that private medical facilities are the preferred source of care for many users, irrespective of their socio-economic status or gender, as demonstrated in at least one study examining differences in the use of private provision for early symptoms of TB (Morankar and Deshmukh, 2001). Other studies reveal that people tend to 'shop' for alternative providers, diagnoses and treatment (Uplekar et al., 1998), often, especially in the context of HIV/AIDS and/or other STIs, because the disease is stigmatised (Ward, Mertens & Thomas, (1997); Bharat and Aggleton, (1999); Manhart et al. (2000); Chabikuli, (2002); Schneider et al. (2005).

Overall, studies have found that people choose private providers because of the limited outreach and perceived low quality of government run services; perceived adverse attitudes among staff in public health care facilities; convenient locations and short waiting times in private clinics; the possibility of obtaining credit in private clinics; more privacy; respect for confidentiality; and the availability of family physicians with close social links to patients and their communities (Evans et al. (1997); Kamat et al. (2001); Bhatia et al. (2001); Hong Ha et al. (2002); Sheikh et al. (2005, 2006).



Other studies show that poorer people tend to use the public sector and that people tend to choose the same type of provider as their social peers, for example in Uganda and India (Nuwaha, 2006; Rani and Bonu, 2003). A study carried out by Russell and Gilson (2006) in Sri Lanka revealed that people from the poorest households suffering from chronic illnesses often chose public providers (over private) and that only the ‘better-off’ income group used private providers more often than public ones for their regular treatment. Poor users, especially those with chronic illnesses, sought publicly provided care mainly because it was free, but confidence in the technical competence of doctors in public facilities was also very important. However, uptake of free public health services for acute illnesses was lower, because of their limited opening hours, long waiting times, short consultations and poor inter-personal relations, with a considerable minority, even of the poorest, willing to pay to get quicker care, secure a longer consultation with more of a patient focus, and build a long-term doctor-patient relationship with a ‘family’ doctor. The poorest pawned jewellery and borrowed money to finance private treatment. This study also revealed that providing free publicly provided health care was of a sufficiently good quality to be used by poor people, it offered important protection to livelihoods and for the absolutely poor with no surplus money to pay for health care (even to cover transport costs), free regular treatment of chronic conditions was vital protection against higher borrowing or deeper cuts to food consumption. Nevertheless, the study showed that: “...out of pocket payments add to the other barriers that poor people face when seeking health care, and contribute to their experience of social exclusion. Even relatively small health care payments might push vulnerable households into absolute poverty or deepen their poverty...” (Russell and Gilson 2006:1732), reinforcing the results of an earlier study that found that the estimated cost burden for TB and HIV/AIDS

treatment was more than ten percent of monthly household income, with indirect costs usually being the dominant cost component (Russell 2004). Thus even if official hospital fees are exempted or waived for children under five or for persons temporarily unable to pay, users often had to pay for other items (Obrist et al., 2007).

As a result, serious chronic illnesses that cause high or catastrophic and persistent cost burdens can have a major negative impact on livelihood paths in any given country, requiring broad packages of curative treatment free at the point of delivery (Russell and Gilson, 2006), (Thuan et al., 2006), (Ruger et al., 2007) and Leive and Xu (2008).

### **2.3.3. Health services provided by the not-for-profit sector**

The purpose of this sub-section is to firstly provide a brief overview of the not-for-profit sector and then consider its typical contribution to providing services for chronic illnesses, including services to PLHA.

Initially, private providers were promoted as alternative health care providers to the state, furthering the same goals but less hampered by government inefficiencies and resource constraints. It is assumed that not-for-profit providers' primary motivation is humanitarian, but it is a diverse sector incorporating a variety of different types of organisation. In some cases, for example in Southeast Asia, a not-for-profit status may reflect formal tax status rather than behaviour motivated by charity, with such organisations known to behave essentially in the same manner as for-profit providers, except that they are not allowed to distribute their profits as dividends (Bennett 1992).

Green (1987) identifies six types of not-for-profit organisations involved in the health care sector, including mission or church facilities, international and locally based NGOs, unions and trade and professional associations (interested in the protection and promotion of their members), other non-profit-making organisations (such as occupational health services) and non-profit-making (but pre-paid) health care (such as health maintenance organisations). Mission or church facilities are often the most important in developing countries, as these institutions have a long history of providing a substantial proportion of health care services, particularly to people in rural parts of sub-Saharan Africa (Bennett 1992).

The not-for profit sector has four health care sector functions: service provision, social and welfare activities, support activities, and research and advocacy (Gilson et al., 1994). It plays a critical role in the delivery of health services in numerous countries of the South (Akukwe 1998 and Zaidi 1999). In Bangladesh, for example, it provides health care and social welfare services to almost one-quarter of the population (Rahman, 2003 cited in Zafar Ullah et al., 2006:145). In Mozambique, for example, it provides psychological and medical support to PLHA and their families, home-based care and economic support to PLHA, in addition to being active in the area of advocacy, in order to help grant legal rights to PLHA and in this way, protecting them from discrimination (Bukali de Graça, 2002).

Not-for-profit providers claim to be effective providers of sustainable primary health care (PHC) systems due to their promotion of community participation, close links with the poor, ability to be flexible and committed staff (Mercer et al., 2004; Zafar Ullah et al., 2006). However, critics caution that they have not been adequately

assessed in terms of their efficiency, innovation, quality of services, ability to mobilise resources, contribution to the sustainability of the local health system or coverage of grass-roots communities (Smith 1989; Gilson et al., 1994, Matthias and Green 1994; Stefanini 1995). There is therefore still a need to question the impact and effectiveness of the not-for-profit sector in providing public health care for the least advantaged, particularly women, children and the poor. Mercer et al., 2004 found that in rural Bangladesh, the not-for-profit sector plays an important role in health service delivery, reaching poor women and children whose access to government or profit-making services is restricted. However, Zaidi (1999), also in rural Bangladesh, argues that not-for-profit providers are unable to deliver sufficient services, are dependent on donor funding, adopt donor priorities, are not democratic, participatory, community-oriented, flexible, innovative, cost-effective, replicable or sustainable, and recommends that it would be more appropriate to concentrate on reforming public provision.

Gilson et al., (1994) agree that the weaknesses of the not-for-profit sector include its reliance on external funding, a tendency to work in isolation, with little or no attention to the wider health system and with little or no participation in national and district planning, a reluctance to adopt national policy-guidelines where there is a conflict with other concerns (for example the refusal of many Catholic facilities to provide contraception), poor information systems and sometimes weak management capacities.

## **2.4 CARE AND ACCESS TO TREATMENT FOR PEOPLE LIVING WITH HIV/AIDS**

The purpose of this section is to identify from the international literature the trends in approaches to the provision of care and treatment for PLHA, building on the preliminary discussion of provision in the previous section by identifying the strengths and weaknesses of contemporary practices and the lessons that have been learnt and some current suggestions and recommendations for the way forward. It is not possible to assess approaches without an understanding of the characteristics of the epidemic in particular contexts, so relevant information will be provided in each sub-section.

### **2.4.1 Care efforts for PLHA**

The purpose of this sub-section is to provide an overview of the provision of care that is tailored specifically towards the needs of PLHA, which will help when attempts will be made to compare with the types of care packages that are potentially available to PLHA in the Indian context.

HIV infection and the later development of AIDS is manifest in the increasing occurrence and severity of symptoms and opportunistic infections, resulting in PLHAs' increasing need for care as the illness progresses. The burden of care is significant, increases over time, and affects both individuals and their households. It affects the ability of PLHA and their carers to fulfil their other responsibilities, especially earning a living, potentially leading to household asset depletion, strained

intra-household relationships and impoverishment, as discussed in 2.1.2 and shown in a study in the Caprivi region of Namibia (Thomas 2006).

Studies have indicated that up to 90 percent of illness care is provided in the home (WHO 2000, Uys 2003 and UNAIDS 2004). Although according to Ogden et al., 2006, the role of men and boys in providing care for HIV positive or AIDS affected family members is poorly documented, it is generally recognised that women and girls are the main carers within AIDS-affected households.

In a study of family care for those living with HIV in Uganda, the findings showed that women were the primary caregivers in 86 out of 100 illness episodes (Taylor et al., 1996). Steinberg et al., (2002) found that the majority of AIDS caregivers in the home were women and girls (68 percent) and of these, seven percent were less than 18 years of age and 23 percent were over 60 years. The intensity of the care for HIV/AIDS varies on whether the person is mobile or bedridden. For a person who is bedridden, activities that may be needed include bathing the patient, taking them to the toilet, turning bedridden patients to avoid bedsores, feeding the patient, cleaning rooms, and washing the bedclothes, dishes and utensils (Mehta and Gupta, 2005). About 24 buckets of clean water are required every day to care for a PLHA (Columbia University, 2004 in Odgen et al., 2006:336). The continuous and consistent care needed by patients pose a serious challenge to the physical, financial and psychological wellbeing of carers, especially if basic services such as clean water are lacking and the formal healthcare system does not provide support (Thomas 2006; Ogden et al., 2006 and Mehta and Gupta, 2005). In practice, few HIV-infected people living at home may have obtained a diagnosis, with the result that they and their

households are not linked to any formal care programme and have little access to health care facilities. Even if health facilities are available, they may not have the resources of time or money to attend regularly. As a result, PLHA may be obtaining medicines and remedies for their symptoms from other sources (Ogden et al., 2006).

In addition, PLHA may experience hostility, rejection and discrimination after their relatives or communities discover that they are HIV positive, potentially adding self-stigma and depression to the burden of physical illness. For example, a study carried out in South Africa, Steinberg et al., (2002) showed that nearly three quarters of the PLHA interviewed reported such reactions.

Malnutrition is widespread in the developing world, with about a third of the population in the least-developed countries having inadequate nutrition (UNDP, 2007/2008). Poor nutrition compromises people's immune systems; increases their vulnerability to infections and illness, exacerbating the effects of a chronic illness such as HIV and sometimes leading to early death; and threatening PLHA's ability to adhere to ART treatment regimens (Zachariah et al., 2002; Marston and DeCock 2004).

The implications of what is currently understood about the care needs of PLHA are that there is a need for:

- partnerships between public sector and non-governmental actors to provide support for affected families (Ogden et al. 2006)
- the provision or strengthening of home-based care (Ogden et al. 2006)

- budgetary resources for care homes, hospices and peripheral hospitals to help reduce the burden of home-based carers in times of difficulty (Mehta and Gupta, 2005)
- the provision of counselling to enable PLHA to adopt a positive approach to the disease and reduce their susceptibility to stigma and depression (Thomas, 2006; Mehta and Gupta, 2005)
- Nutritional monitoring and the provision of food with a high nutritional content (Mehta and Gupta, 2005; UNAIDS 2008).

However, this review of the international literature reveals few studies that have examined the interactions that occur within households, so relatively little is known about the perceptions and experiences of those who provide or receive care or the impact the need for care has upon the livelihood security and wellbeing of affected households. This gap in the literature is one that this research aims to address.

#### **2.4.2 Access to treatment**

The purpose of this sub-section is to discuss the constraints and enablers that poor PLHA face when they seek to access antiretroviral therapy (ART) and preferably highly active antiretroviral therapy (HAART), which is usually a triple combination of antiretroviral drugs, as well as treatment for opportunistic infections. In addition, it reviews international evidence on whether and how access to ART and treatment for opportunistic infections mitigates the impact of HIV/AIDS on households, so that household members who are engaged in the labour market are able to cope with living



with a chronic illness which is manageable without affecting the capacity to work and earn a living.

In December 2007, an estimated three million people in low-and middle-income countries were receiving antiretroviral drugs (ART), increasing to over six million at the end of 2010. 47 percent of the 14.2 million eligible PLHA were on ART at the end of 2010, compared to 39 percent at the end of 2009 (UNAIDS 2011). Universal access to treatment has been achieved in Namibia (90 percent) and near universal access (70-80 percent) in some other Sub-Saharan African countries (UNAIDS 2011). Despite the steady rise in access to ART, access to prophylactic ART by pregnant women, to prevent the virus being passed on from the mother to the child, has lagged behind, although there have been improvements in recent years (Luo et al., 2007). For example in 2010, 48 percent of pregnant women living with HIV in Sub-Saharan Africa received effective regimens, leading to a reduction in infections among newborn children (UNAIDS 2011). South Africa currently provides an estimated 95 percent of eligible women with ART, up from 57 percent coverage in 2007 (UNAIDS 2011). However, universal access to antiretroviral prophylaxis for pregnant women has still not been achieved in several countries in Africa and in one country in Asia, namely India, mainly due to significant gaps in their basic prevention of mother-to-child transmission programmes (UNAIDS 2011). In addition to prolonging life and reducing morbidity, ART helps to alleviate the epidemic's economic effects on households (UNAIDS, 2008).

ART falls into four drug classes: Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIs), Nucleoside Reverse Transcriptase Inhibitors (NRTIs), Protease Inhibitors

(PIs) and Fusion Inhibitors. Highly Active Anti-retroviral Therapy (HAART) combines three or more medications because reduced viral load resulting from one or two medicines almost always proves temporary, according to Epstein (1998). At the end of 2004, the “hit early and hit hard” approach was replaced by HAART, which advocates monitoring to identify when individuals’ CD4 (these are T-helper cells that are most commonly used as immune markers that monitor HIV progression and the impact of treatment) count falls below 350 (unless viral load is elevated), with ART offered to those with CD4 counts of between 200 and 350 and definitely started for those with CD4 counts below 200 (Panel on Clinical Practices, 2005).

While there is evidence that ART can produce rapid improvements in health and productivity, the drugs often produce side-effects, delaying recovery and their ability to return to work. If no alternative forms of ART are available in PLHA’s local health care centres, they may have to endure the side-effects in the hope that they can adjust to them, or may be forced to stop taking ART altogether, which may have repercussions, such as multi-drug resistance (Larson et al., 2008).

In addition, not all patients who start HAART are able to comply with the regimen. For example, on average participants on ART in one study in Sub-Saharan Africa missed two consecutive clinic visits (Rosen et al. 2007). This ‘loss of follow up’ could, they suggested, have occurred because the limited availability of resources to affected programmes’ ability to retain participants and conduct long-term surveillance of outcomes. Another study showed that mortality rates in the first months on therapy increased, in contrast to those in developed countries, (ART-LINC and ART-CC, 2006). Findings from a study carried out by Brinkhof et al., (2008), indicate that

better ART outcomes, including higher programme retention rates, may be obtained in services with smaller numbers of patients, recommending that rather than a few large programmes, population coverage should be achieved with smaller decentralised facilities that can develop strategies to ensure that patients keep their appointments.

With regards to access to ART/HAART by PLHA, Kitajima et al., (2005) assert that there are few countries in the developing world that have investigated the relationship between socio-demographic status and access to ART. Even where financial barriers are low and providers ready to provide the therapy to patients, services are not equally accessed by all PLHA (Kitajima et al., 2005), suggesting that demand-side barriers are operating, such as distance to facilities and stigma. The factors leading to unequal access are recognised but not discussed in depth in the current HIV/AIDS literature.

## **2.5 CHAPTER CONCLUSION**

In the first part of this chapter, in line with research questions one and two as indicated in section 1.4 (how poor PLHA with different social characteristics experience living with their illness on a daily basis and access and assess the adequacy of health care services for HIV/AIDS), psychosocial aspects of ill-health and their implications for treatment seeking behaviour were discussed. It was found that previous studies show that people suffering from a chronic illness (stigmatised or not) first try to understand their illness. The ways in which they are able to make sense of it can in turn affect their health care seeking behaviour and the ways in which they cope. Two dominant approaches to understanding health-seeking behaviour were identified in the literature. In particular, the health pathways model demonstrates

that, rather than a one-off decision, the search for help and the choice of provider involve sequences of decisions. The importance of understanding decision making and not just exploring correlations between social, health and access to treatment indicators is reinforced by the complexity of chronic conditions such as HIV/AIDS and people's individual and social situations. Once people have decided to seek health care, the research reviewed shows that they may face personal, financial and/or organisational barriers that can influence both their access to appropriate services and the health outcomes. Very little literature is available that explores the ways in which PLHA and their household members (especially their primary care givers) emotionally experience living with the illness and the types of different emotional coping strategies they employ, especially in the context of the developing world, even though this is relevant to understanding their responses to the illness.

The review identified a significant number of studies that explore the ways in which individuals and/or households seek treatment and care when they fall ill, although little of the peer-reviewed literature focuses on health-care seeking behaviour amongst individuals and/or households living with HIV/AIDS, revealing a need for further studies of the health-care seeking behaviour of PLHA in the context of particular health care and social systems, to inform policy and practice.

This research is concerned with poor and disadvantaged people, so the second part of the chapter, section 2.2, in line with research question three (how poor PLHA with different social characteristics pursue their livelihoods on a daily basis), began with a brief overview of how understanding of poverty has evolved over several decades, from being measured in terms of the level of income a household or person receives

to now being seen as a term that encompasses the material and non-material resources needed to maintain wellbeing, with poor households' ability to achieve and maintain wellbeing and avoid impoverishment being linked to their 'vulnerability' and/or 'insecurity'. In addition, the different types of livelihood strategies that the poor employ during periods of ill-health and how well they recover or are resilient during these times have been considered in this review. The factors and processes that emerged from the review as influencing people's resilience during periods of stress or shock will be incorporated into the analytical framework for this research. It emerged that, while previous studies show that poor people living with HIV/AIDS employ the same livelihood strategies as those suffering from general chronic ill-health, for the majority of PLHA, stigma plays a significant part in their lives, in turn having an effect on how and why they employ different livelihood strategies. It is clear that HIV/AIDS is one of the most stigmatised of chronic illnesses in both the developed and developing worlds, and so the review has developed a preliminary understanding of stigma and guidance on how it might be considered in the research.

Although a number of studies, starting in the early 1990s, have documented how HIV/AIDS has had devastating impacts on the livelihoods of the poor, most were undertaken in rural areas and few contain in-depth and systematic pictures of how the urban poor in developing country contexts live with HIV/AIDS on an everyday basis. The small body of literature that has examined the impact of HIV/AIDS on livelihoods and wellbeing among the urban poor refers to the Indian context, and will be discussed in Chapter IV. In particular, the literature review reveals few studies that have examined interactions within households, even though some of the livelihoods literature recognises that households cannot be treated as black boxes because the

roles and statuses of their members are differentiated by gender and age. As a result, relatively little is known about the perceptions and experiences of those who provide or receive care, or the impact the need for care has upon the livelihood security and wellbeing of affected households. This gap in the literature is one that this research aims to address.

As this research intends to find out about the type and quality of services that are available for PLHA to use in the context of Kolkata, in line with research question four (have PLHA received appropriate and adequate support for their livelihood strategies), the review examined the types of services that are generally available for people who are ill, including people who are HIV positive. Its main contribution is to provide some empirical evidence as to why some people (whether they are suffering from HIV or another illness) choose one type of service provider over others. The discussion in this part of the review will help provide a basis for comparing what the PLHA studied in Kolkata have been offered in similar settings and circumstances to those studied elsewhere. The review found only one study that considered the types and quality of services provided for PLHA by not-for-profit organisations, a gap that will be addressed by this study.

The final section of the review provided a brief overview of the pros and cons of contemporary attempts to tackle the HIV epidemic around the world, including care and access to treatment. The main focus was found to be on treatment, with less attention paid to the provision of care and support for PLHA, because there is a tendency to assume that access to treatment will relieve the plight of PLHA. Most

studies fail to consider other aspects of a person's life that are crucial to maintaining wellbeing, providing a justification for the focus of the current study.

This literature review has not only identified and defined concepts relevant to this research and examined whether and how previous studies have analysed the issues of research interest, it has also assessed whether there are any gaps in current understanding of the issues, as shown above. In addition, the literature review assessed the conceptual frameworks adopted by different studies in order to identify a suitable conceptual and analytical framework for this study. The following chapter therefore identifies the concepts discussed in this chapter that are relevant to this research, in order to develop a conceptual and analytical framework for the study, as well as describing the overall methodology adopted. The strengths and weaknesses of the analytical framework employed will be assessed in the light of the findings in Chapter VII.

# **CHAPTER III**

## **CONCEPTUAL FRAMEWORK AND RESEARCH**

### **METHODOLOGY**

#### **3.0 INTRODUCTION**

The previous chapter reviewed a wide range of literature that helped explain how and why poor people living with HIV/AIDS (PLHA) with different social characteristics cope with their illness within their households and access treatment, care and support services from different health care providers and local non-governmental organisations (NGOs) to mitigate the impact of HIV/AIDS. The aim of this chapter is to formulate a conceptual framework and a research methodology for the current study. In section 3.1 the concepts and operational definitions reviewed in the previous chapter are brought together and formulated into a conceptual framework for research into the processes by which PLHA cope with their illness, access health care and obtain livelihood support. In Section 3.2 the overall methodology adopted for the study will be described.



### **3.1 CONCEPTUAL FRAMEWORK**

The purpose of this section is to identify the concepts discussed in the literature review that are most relevant to this research and preliminary theoretical explanations that will be assessed in the light of the findings. The section will primarily focus on Obrist et al. (2007)'s health access livelihood framework and Moser's (1998) asset vulnerability framework, which are considered to be the most appropriate starting points for the conceptual framework for this research. However, it will also be argued that the wider literature points to a number of issues that need to be incorporated when considering HIV/AIDS in an urban setting. The section will, therefore, provide critiques of Obrist et al and Moser's models and identify gaps that appear to be important. Analysis of the findings from this research will take place using an analytical framework that combines and adapts the two frameworks. The combined analytical framework serves to identify the issues with which this research is concerned and demonstrates the possible links between them that were further investigated in the research.

Obrist et al. (2007)'s 'Health Access Livelihood Framework', a diagrammatic representation of which is shown in figure 3 and which was discussed at length in sub-section 2.1.3, combines, usefully for this research, both health service and health-seeking approaches for illness and situates access to health care in the broader context of livelihood insecurity. The authors assert that once illness is recognized, treatment seeking is initiated, influenced by five dimensions of access: availability, accessibility, affordability, adequacy and acceptability (Obrist et al. 2007). According to the framework, the degree of access reached along each of these dimensions depends upon two factors: (1) health care services and the broader policies,

institutions, organizations and processes that influence provision and (2) the livelihood assets people can mobilise in particular vulnerability contexts (Obrist et al. 2007). The model does however have a number of shortcomings, especially when HIV/AIDS is considered as a cause of vulnerability, due to the particular ways in which this illness affects people's livelihoods. In particular, the model does not differentiate between acute and chronic illnesses, and it also fails to consider that some illnesses are stigmatised. Although the model does recognise the vulnerability context within which households seek to develop and maintain their livelihoods and considers a number of livelihood assets that households must have in order for them to avoid further impoverishment following the onset of illness (human, financial, natural, social and physical), it fails to explicitly consider labour assets and household relations, both of which play significant roles in the lives of the poor, as seen in urban households with severely incapacitated earners. The model also fails to consider the importance of illness coping strategies, the significance of individuals' social characteristics, the stigma associated with HIV/AIDS, and the full range of livelihood options, all of which have been shown in other studies to be important. In addition, the model appears to assume that people seek treatment as soon as they recognise illness, which in the context of the developing world may not always be the case. So, a number of additional factors and processes need to be included in the analytical framework to adequately address the areas that this research is concerned with.

One of the central characteristics of poverty is insecurity, which is exacerbated by HIV/AIDS, increasing the risk that people's assets may become depleted, in various ways that will be investigated in the research. HIV/AIDS is also likely to have an

effect on livelihood opportunities, if it affects the ability of individuals and their carers to work.

As with others who adopt a livelihoods analytical framework, Moser (1998) points out the importance of identifying what the poor possess, rather than focusing on what they do not possess, in order to assess their vulnerability or ability to cope with shocks, as already discussed in 2.2.2. Unlike Obrist et al, Moser focuses specifically on the urban context. Like most analysts, she identifies five categories of assets that the poor may possess as being necessary to reduce vulnerability or cope with shocks. However, she emphasises different assets from some other analysts, arguing that labour, housing and social relations are the most important assets for the urban poor when their households face shocks. She also argues that it is necessary to explicitly differentiate between poverty and vulnerability, with the latter being a more dynamic concept able to capture the frequent changes in poor people's circumstances, such as death and illness. Her stress on vulnerability leads to an emphasis on the importance of identifying ways in which people cope or are 'resilient' in the face of danger or hardship and how they recover from hardship. She suggests that increases in stocks of assets can mitigate impoverishment and lead to improved security. Although Moser (1998) does assert that the risk of people becoming more insecure and how resilient they are in the face of danger or hardship are directly correlated with the number of assets they possess. However, she does not suggest how different degrees of vulnerability might be categorised and assessed. Because one of the most important concerns of this research is to gain an in-depth understanding of the ways in which poor PLHA manage their asset (s) in the face of shocks and stresses due to the illness and the type of strategies that they adopt to prevent themselves from becoming more

impoverished, this research will distinguish between degrees of vulnerability. A threefold categorisation into secure, vulnerable or highly vulnerable, prior to and after the onset of the illness can, it is suggested, capture the different illness and livelihood trajectories that the research participants' households had experienced (see also 3.2.4 for a fuller justification).

Moser's (1998) 'asset vulnerability framework' adds some dimensions of particular relevance both to the urban context as well as a concern with the trajectories of households' wellbeing, and so will be combined with Obrist et al. (2007)'s 'health access livelihood framework' to provide the core analytical framework for this research. However, the review of other relevant literature in Chapter II points to a number of other factors that may be important when considering the impact of HIV/AIDS on PLHA and their families, and that therefore need to be incorporated into the analytical framework.

First, it appears from some previous studies (especially in rural settings - see section 2.2.2) that while some households affected by HIV/AIDS can cope with this illness (like any other stress or shock) by adjusting consumption or mobilising assets, some cannot and the household breaks up. Whether and in what circumstances these responses occur amongst the research participants in urban India needs to be considered in this study.

Second, it appears that the nature of HIV/AIDS as a shock differs from many other shocks typically experienced by urban households, because of the particular characteristics of the illness, which develops in distinctive and unpredictable ways

and has, at least in the past, been less susceptible to treatment than many acute and even some chronic illnesses. The research therefore also needs to focus on the trajectory of this particular illness (see also below), to investigate what strategies are adopted at specific points of the illness trajectory, and to assess whether and how these strategies help people both to cope with the shock of learning that they have contracted HIV and to mitigate the effects of the illness on their lives.

Third, both Obrist et al and Moser's models attribute the availability of opportunities and the livelihood assets that an individual or household possesses to the broader policies, institutions, organisations and processes operating in the wider context (the vulnerability context in Moser's terminology). They recognise that such assets include not only those that are owned or controlled by household members, but also publicly owned assets and more intangible assets related to social and political relations. In addition to the evidence that the type and number of assets available to households influences their vulnerability, coping strategies and resilience, various studies in low-income countries, as indicated in 2.2.3, provide evidence to suggest that people's experiences of life events and the opportunities they have in life are dependent on their characteristics. Frequently, people with certain social characteristics are more likely to be poor, and even amongst the poor, the most impoverished and vulnerable may have certain social characteristics. Typically analysed as part of the vulnerability context (institutions, policies, etc), in the context of India, as will be seen in section 4.1, the key dimensions of social difference that appear to determine vulnerability are caste, gender and religion – the extent to which these influence the experiences and strategies of the research participants will, therefore, be assessed in the study. The process by which people with certain social

characteristics become more disadvantaged than others is commonly called 'social exclusion' (see 2.2.3). As in other research, for the purpose of this study, the term social exclusion will be deciphered in relation to PLHAs' ability to access the assets they require to maintain their livelihoods.

However, earlier research shows that a particular dimension of HIV/AIDS is the stigma associated with the illness and so the study will, fourth, examine whether poor PLHA are even more excluded from social and health care resources than other poor people due to stigma. It was noted in 2.2.4 that two kinds of stigma are usually distinguished: 'felt' stigma and 'enacted' stigma. However, it is argued by some that this conception of stigma places the onus on individuals rather than the wider social and cultural context. In response, Parker and Aggleton (2003) and Castro and Farmer (2005) argue that stigma is not a static attitude but a constantly changing social process, which is part of complex systems of beliefs about illnesses and is affected by social inequalities. This research will adopt this perspective and aim to better understand the significance of stigma in the context of HIV/AIDS by examining how it relates to power and domination and concentrating on the concept of discrimination, whereby society is at large is responsible for treating certain types of people unfairly purely on the basis of their belonging or perceived belonging to a particular group. The studies reviewed in 2.2.4 indicate that PLHA are often discriminated against in their families, neighbourhoods and work situations, as well as when they seek care and treatment. Whether and how the PLHA studied have experienced discrimination, with what effects on their everyday lives, their ability to cope with the illness, their livelihood strategies and their ability to access appropriate care and treatment will form a major focus of this research.

Fifth, while Moser's framework prioritises household labour assets in the urban context, Obrist et al do not discuss these in any depth. The income earning opportunities available to the urban poor vary according to their human assets, which in urban labour markets are closely related to the education level of earners, as highlighted in 2.2.5. In assessing PLHAs' and their household members' access to income earning opportunities prior to and after the onset of the illness, this research will need to distinguish between earners with differing education levels.

Sixth, as discussed in 2.2.2 (see, for example, Rakodi and Lloyd-Jones, 2002), internal household dynamics are considered to be important. These include the duties assigned to different household members, cultural factors that influence expectations and power struggles that may arise between household members, all of which will need to be considered in this study. Changing gender dynamics, especially in terms of who is perceived as or is de facto the head of the household before and after individuals within the household are infected and incapacitated, appear from the existing literature to be important and thus form part of the analytical framework for this research.

Seventh, people's livelihood responses influence and are influenced by the ways in which they respond to their illness and their treatment seeking behaviour, as highlighted in 2.1.1 and 2.1.2. Various factors influence their choices and responses. It emerged from the discussion in 2.1.1 that how people interpret their illness is important and so how and why the research participants understand their health and illness forms part of the analysis, drawing on Kleinman's (1980) explanatory models, which help to explain people's perceptions of what constitutes illness, the meaning of

a specific illness and how illness is experienced, each influenced by people's own worldviews and social positions as well as the cultural context in which they live. In particular, although most studies of poor households' livelihood strategies acknowledge that one of the most common and devastating shocks is illness, there is a tendency to assume that illness is usually acute, even though a household or individual may experience more than one illness episode. This does not appear to be an adequate conceptualisation of chronic life-threatening illness, which may have a different pattern of stresses and shocks for households than acute illness. HIV/AIDS is conceived of in this study as having elements of both chronic and acute illness (because infected people may live for many years and may develop chronic illnesses such as TB, but may also experience acute episodes associated with opportunistic infections). This is recognised by Corbin and Strauss in Wood (1992) (see sub-section 2.1.1), who identify eight possible phases that people suffering from a chronic life-threatening illness endure over time and are thought to be relevant to understanding how people manage a disease during any given phase. The research will, therefore, seek to ascertain how and when people recognise their illness, come to some sort of understanding of it by giving the illness or their lives a meaning, identify the problems they face and decide how to respond, taking into account Kelly's (1992) points that people's identity, responses, and search for care and treatment are influenced by the norms of the society in which they live.

Helpful in addressing these issues is the recognition (see the review of literature in 2.1.2) that different types of psychological and practical responses to illnesses occur. These are categorised in different ways by different authors but usefully grouped by Jenkins and Guarnaccia (2003) into 'negative internal coping' and 'positive external



coping' strategies. A study of PLHA specifically found that secrecy over their HIV status is often adopted as part of a coping strategy due to fear that they and their families might be stigmatised, perhaps hindering their access to care (Thomas 2006). In this study, whether and why PLHA in Kolkata have adopted the coping strategies revealed by earlier studies will be investigated.

Eighth, the importance for identifying appropriate policies and services of developing a good understanding of treatment seeking behaviour has been recognised by the model created by Obrist et al. (2007) and has been considered in depth in sub-section 2.1.3. The literature review found two dominant approaches: 'pathways models' of health-seeking behaviour, where an individual usually begins with recognising his/her symptoms and the emphasis is on the path, or series of steps, that he or she follows in seeking treatment and using different health care services; and studies of the 'determinants' of behaviour, which highlight the factors that influence the search for care and treatment. Both have been criticised for being too individualistic and not taking external social factors into consideration, leading to attempts to build on the best features of both, for example Roger and Elliot's (1997) 'Network-Episode Model'. However, as noted in sub-section 2.1.3, this model has also been criticised by MacKian et al., 2004 for focussing on how and when care is accessed and received, and how the choices and strategies of health care seeking are socially organised, but failing to consider the alternative of self-treatment or the decision to not seek treatment. The insights of this earlier research will provide starting points for understanding whether and how treatment is sought by the participants in this study.

Ninth, while Obrist et al's model acknowledges the importance of illness in households' ability to earn income and meet the cost of treatment, it does not adequately unpack the differing effects of acute and chronic illness and the model also does not go into detail on the demands of caring for those who are sick. A variety of challenges for carers of people suffering from HIV/AIDS within their households have been identified in earlier studies, reviewed in sub-section 2.4.1, especially if no help is available from the state. How carers cope physically and mentally, the effects of illness on family members and the additional burden imposed on carers have been shown in earlier studies to have certain common features. Whether and why these have occurred amongst the study participants will be assessed.

Tenth, earlier studies of PLHA point to various types of support that can play positive roles in enabling PLHA and their households to cope with the illness and avoid further impoverishment. In addition to basic infrastructure, such as good water supplies, particularly valuable support seems to include access to nutritional support, home-based care and counselling services (see 2.4.1). In terms of treatment, the literature argues that in addition to prolonging life and reducing morbidity, increased availability of antiretroviral therapy (ART) may result in reduced stigma, increased uptake of testing and may represent a critical means of alleviating the epidemic's economic effects on households (see sub-sections 2.2.4 and 2.4.2). The availability of treatment and support services to the research participants and their perceptions of the provision will therefore be assessed. Access may depend not just on availability but also on whether social or economic barriers hinder uptake. As part of this research, whether or not the PLHA studied have access to free ART, what they consider to be the barriers and enablers to accessing free ART regimens and other treatment for

opportunistic infections, and their perceptions of the services received will be assessed, as well as their attempts to access free ART regimens, nutritional support and other types of support. Finally, advocates of livelihoods and health access frameworks, such as Obrist et al (2007) and Moser (1998) argue that they can help to identify poverty reduction strategies and interventions that can provide opportunities for the urban poor, remove obstacles to their desired livelihood strategies, ensure that they can use their assets productively and enable them to cope with the effects of shocks and stresses, especially illness. The study will therefore, examine whether the policy and practice implications suggested in the international literature are reflected in relevant provisions in the Indian urban context. In addition, assess the extent to which these provisions have been available to and had the anticipated benefits for the study participants, in order to identify the implications of the findings.

To summarise, while both Obrist et al. (2007)'s 'health access livelihood framework' and Moser (1998)'s 'asset vulnerability framework' have analytical strengths, they also have some gaps. Since individually, neither is adequate to serve as an analytical framework for the purposes of this research, key elements of the two models will be combined and supplemented by a number of other components for analysis identified from the literature review, resulting in a combined analytical framework which will be used to analyse the findings presented in Chapters V and VI and further analysed in Chapter VII.

The following section will describe the overall methodology that this study adopted.

## **3.2. METHODOLOGY**

Research is conceptualised as a three-level progression: at the highest level is the research philosophy, followed by the research strategy and finally the research methods or techniques that imply the use of selected data collection instruments. This section describes the methodology adopted for the study, beginning with a discussion of the research philosophy subscribed to 3.2.1 and 3.2.2 presents the research strategy and the study design. 3.2.3 details the primary research technique used, 3.2.4 outlines the approach to data analysis, 3.2.5 outlines the limitations of data collection, while the ethical concerns raised by the research are discussed in 3.2.6.

### **3.2.1 Research Philosophy**

Philosophy is concerned with understanding the kind of things that exist in the world and how we can know them, while social research is concerned with the properties of things that exist in the world. It is therefore useful to set out alternative philosophical worldviews, because these will have a direct impact on the practice of research through the choice of a methodology and specific research methods. The three research philosophies that are considered to be important perspectives in contemporary social research are positivism, interpretivism and, until recently, pragmatism (Williams and May, 1996; Creswell, 1994, 2002, 2009).

- **Positivism**

The underlying principle of positivism is that the experimental methods used in natural science enquiry can also be used in social science research (Henwood and Pidgeon in Hammersley 1993). This approach uses a deductive form wherein theories and hypotheses are tested in a cause-and-effect order, with implications for the nature of research and the methodological approach adopted. First, concepts, variables and hypotheses are chosen before the study begins and remain fixed throughout it. The hypothesis is predetermined and the researcher remains within its boundaries, resulting in context-free research (Creswell 1994). This approach to research is associated with quantitative methods, incorporating a number of different approaches of which the two main ones are the use of true or quasi experiments and social surveys (Creswell, 1994). A well-constructed survey has the capacity to generate quantifiable data on large numbers of people who are known to be representative of a wider population, in order to test a theory or hypothesis (Bryman cited in Brannen, 1992). Surveys include cross-sectional approaches whereby data is collected on a cross-section of people at a single point in time in order to discover the ways and degrees in which variables relate to each other (Bryman cited in Brannen, 1992). In randomised controlled trials, data is collected by means of longitudinal or cohort studies, in which the assigned sample within a population is studied over a period of time. In surveys the perceptions of people are investigated through closed (rather than open-ended) structured questions (Creswell, 1994).

- **Interpretivism (Hermeneutics)**

In contrast to positivism, interpretivists refuse to view the approach adopted in the natural sciences as the only way of obtaining an understanding of reality. Instead, this philosophical worldview holds that individuals seek understanding of the world in which they live and attribute subjective meanings to their experiences. As a result, the main aim of research based on an interpretivist philosophical worldview is to consider the research participants' own points of view with respect to the phenomena and situation being studied (Mason, 2002), implying the adoption of qualitative methods.

Instead of surveys, qualitative researchers tend to take an approach in which theory and empirical investigation are interwoven (Bryman cited in Brannen, 1992). Qualitative methodology uses an inductive logic and categories that emerge from informants, rather than those identified beforehand by the researcher, which in turn provides rich “context-bound” information, leading to the identification of patterns or theories that help explain a phenomenon (Creswell, 1994). The ways in which data are generated are flexible and sensitive to the social context, rather than rigidly standardised or structured (Mason, 2002).

- **Pragmatism**

Following years of disagreements between positivists and interpretivists, pragmatism has been developed into a philosophical worldview, in which the main aim of the research is to understand the research problem and use all available approaches to

understand it (Creswell, 1994, 2002 and 2009). One of the main reasons this approach and the mixed methods it implies has witnessed increasing acceptance is because it emphasises that positivist and interpretivist approaches can be complementary (Creswell, 1994). It is currently common practice to combine qualitative and quantitative methods in a single study of the same phenomenon, with the intent of triangulating the findings (Creswell, 1994). The concept of triangulation is based on the assumption that any bias that occurs as the result of the adoption of one method, data source or researcher, can be eliminated by using a mixed-methods approach, with the intention of providing a detailed and balanced picture of the problem in hand (Creswell, 1994)

### **3.2.2 Research Strategy and Design**

The current study opts for an interpretive, qualitative approach, rather than a positivist one, because of its ability to enter into the worlds of research participants, provide rich “context-bound” information, permit a flexible approach to an under-researched phenomenon and be sensitive to the social context.

- ***Research Strategy***

The distinctive feature of interpretivist approaches is that people, and their interpretations, perceptions, meanings and understandings, are seen as the primary sources (Mason 2002). An interpretive approach not only sees people as a primary data source, but also seeks their perceptions of how they see the world from their

points of view, rather than imposing a view from the outside, it is considered to be ideally suited for the current study, which seeks to understand the experiences of poor PLHA with different social characteristics living with HIV/AIDS and the ways in which they employ certain livelihood strategies to mitigate the impact that the illness has on their lives. While interpretivist approaches have traditionally been associated with ethnography, they do not necessarily have to rely on 'total immersion in a setting', and so can support a study that uses interview methods.

The criticisms of applying this type of approach are that it can be too subjective and is not 'scientific' and so these criticisms have been taken into account during the design of the research. The credibility and validity of data collected using qualitative methods was considered. Credibility involves establishing that the results are believable from the perspective of the participants in research, by ascertaining whether the research achieved familiarity with the setting or topic, determining that the data were sufficient to merit the claims made, and ensuring that systematic comparisons between categories were made. Whether data collected are credible or not can also be determined by assessing whether there are strong logical links between the gathered data and the arguments made in the research and whether enough evidence has been provided for the claims made in the research to allow the reader to form an independent assessment of the findings (Charmaz, 2006). Validity refers to whether or not the researcher is able to demonstrate that the concepts used in the research are authentic, accurate and relevant, and whether they can be identified, observed or 'measured' in the way that the researcher describes in the research (Mason, 2002). To ensure the credibility and validity of the data collected in this study, methodological triangulation - one of four basic types of triangulation



identified by Denzin (2006) - was considered, leading to the identification of complementary methods of gathering data, as further discussed in sub-section 3.2.3.

- ***Research Design***

The current study adopted a flexible research design, which allowed the detail of the research techniques to evolve over the course of the study in two ways. Firstly, it made it possible to adapt the research techniques according to the participants' specific requirements and secondly, as more questions and/or ideas emerged from the research, the author was able to construct new data gathering methods and to revise earlier ones, for example taking notes during interviews when participants were unwilling for interviews to be recorded.

When discussing the importance of reflexivity during any given research process, Finlay and Gough (2003) note that it involves adopting a critical attitude to locating the research context and/or the researcher; recognising that project design, data collection, data analysis, and presentation of findings are all subjective; and acknowledging that the researcher's own characteristics and presence has had effects on the research process. For these reasons, the researcher undertook reflexive practice at the outset of the research design, and continued throughout the research process, including when deciding on the sampling method, during the data collection, analysis and interpretation processes. The ways in which the researcher's identity influenced her perceptions and the reactions of the gatekeepers and research participants towards the researcher will be discussed in depth in sub-section 3.2.3, under the sub-heading 'Reflexivity', and explanations will be provided as to what impact the perceptions and

reactions had on the study design, on the sampling method, on the material collected, on the analysis and interpretation of the collected material.

- ***Sampling method***

As qualitative research usually involves some form of sampling or selection, usually for practical and resource-based reasons rather than for representation purposes, the author identified the type of people to be interviewed early on, using information extracted from the literature review and guided by the conceptual framework. Two kinds of sampling are found in qualitative research: the first based on an idea of who is to be in the sample and the second (theoretical sampling) based on emerging theoretical concepts (Glaser and Strauss, 1967).

A stratified purposeful sampling method was used for the current study. The purpose of this type of sampling method “...is to capture major variations rather than to identify a common core, although the latter may also emerge in the analysis. Each of the strata would constitute a fairly homogenous sample...” (Patton, 1990:174). The aim of the current study is to provide an in-depth analysis of the impact that HIV/AIDS has on the lives of the poor in Kolkata, India. In order to fulfil this aim and in the process build a rich, diverse and in-depth account of the participants’ experiences of living with HIV/AIDS, it was firstly important to make judgements as to which participants were poor and had been tested HIV positive, and this was done mainly with the help of the organisations’ gatekeepers (see below for details). The potential importance of various social characteristics (including caste, gender and religion) in influencing the ways in which poor PLHA experience living with

HIV/AIDS and access support for their health care and livelihoods was to be explored by ensuring that these aspects of social difference were explored with participants during their interviews. In addition, to make it possible to do this and to compare participants with respect to certain key characteristics, it was considered necessary to identify research participants with some of the relevant social characteristics, especially gender, religion and educational level.

Kolkata is the capital and largest city in the State of West Bengal. For practical reasons, this city was the chosen site of study because the researcher is fluent in one of the main local languages spoken there.

Like most cities in India, a significant minority of the population (according to the 2011 Census of India, just over a third) reside in slums or slum-like areas, amounting to around 1.5 million people living without adequate basic amenities in over-crowded and unsanitary settlements (Office of the Registrar General & Census Commissioner, 2011). The term slum can refer to both *bustees* and squatter settlements. Although the former are legally recognised settlements eligible for government improvement programmes, many of the residents in these as well as squatter settlements live in appalling conditions without access to water, latrines, electricity and rubbish removal facilities (see section 4.1).

While not all poor people live in slums and not all slum residents are poor, poverty is closely correlated with slum residence. The study therefore aimed to focus on people living in slums or slum-like areas, in order to investigate not only how the poor live,

but also their experiences when one or more household members fall ill with HIV/AIDS and the type of livelihood strategies that they employ.

Prior to the pilot study, the idea was to select a typical low-income neighbourhood, identify all healthcare and other relevant services available and assess the overall health and social resources package available to PLHA in that particular neighbourhood. However, upon reflections during the pilot study, it became clear that it would not be possible to identify PLHA, even when a good knowledge of a neighbourhood had been developed, because asking people directly about their own HIV status or that of their household members would be unacceptable, because of widespread stigma and lack of privacy. Not only was it impossible to know if somebody was suffering from HIV/AIDS, even if this was known, it would have been unethical to spot-interview PLHA without following the correct ethical procedures. Therefore, for the main field study it was decided that the only way of identifying study participants in an ethical manner (without compromising their anonymity) was by networking with organisations.

Consequently, in order to obtain access to PLHA living in slums or slum-like areas with not many household assets, non-governmental organisations (NGOs) that were known to provide support to PLHA were sought out. First, websites providing information on the HIV/AIDS situation in India and the website of the Ministry of Health and Welfare were searched for non-governmental and governmental organisations providing care, support and treatment to PLHA within the State of West Bengal, further narrowed down to provision of health and support for PLHA within the city of Kolkata. These searches resulted in lists of NGOs in the State and the city

of Kolkata and the names of government-run hospitals treating PLHA for opportunistic infections and with in-patient facilities. Because initial email or telephone contacts with the managers of the NGOs failed, it was decided to divide the fieldwork into two visits. The aim of the first visit was to make contact with relevant NGOs, build trust between them and the interviewer through face-to-face conversations, and ascertain whether they would be willing and able to identify PLHA for interview.

- ***Ethical implications***

The researcher was aware of the ethical implications of the study. First, HIV/AIDS is sensitive, because it is stigmatised, and deals with information that is intimate and possibly incriminating. As Renzetti and Lee (1993) point out, studies of a very sensitive nature may have direct or indirect implications for the participants and for the researchers. For example, research into sensitive topics involves potential costs to those participating in the research including psychic costs, such as guilt, shame or embarrassment, and be seen as threatening because it may intrude into the private sphere or delve into deep personal experience (Renzetti and Lee, 1993). As the current study had the intention of delving into the deep personal experiences of HIV positive participants, the researcher took the advice of Renzetti and Lee (1993) and followed appropriate ethical principles: “...*that not only the research participants should have their rights to privacy, anonymity and confidentiality respected and protected, but it is especially important in maintaining the confidentiality of research data where informants or respondents are being asked to reveal intimate or incriminating information...*” (Renzetti and Lee, 1993:9).

An ethical review took place at the University of Birmingham prior to the first field visit. During this process, the characteristics of the participants that could potentially be the subjects of the current study were revealed, along with a detailed step-by-step account of how the recruitment of the participants was going to be carried out in the field. In addition, issues of consent, participant feedback and participant withdrawal were also discussed. Although compensation to research subjects is generally best avoided, in this case the researcher felt that HIV-positive participants needed to be presented with some form of remuneration, as they were by definition poor and in ill health. For this reason, they were provided with a small amount of money, equivalent to £1.40, towards their transport costs and for one meal of their choice at the end of the interview. Patient confidentiality, anonymity, and the process of storing, accessing and disposing of data were raised as important issues. Finally, the ethical review process also identified potential risks for the individuals involved in the research and the environment and the details of which, will be delved into further in sub-section 3.2.6.

- ***Pilot Study***

The aim of the first visit, the pilot study, which took place in August and September 2008, was to map out relevant organisations within the city using the initial lists of NGOs and government-run hospitals that were actively working in the field of HIV/AIDS and directly providing support for the livelihoods of PLHA, care and treatment for HIV/AIDS in Kolkata (obtained from their official websites). Managers of NGOs interviewed at this stage were asked to identify other organisations involved in similar activities. The purpose of the pilot study was to check the study's

feasibility, refine the aims and objectives and identify their main implications for the detailed design stage.

The study chose to use one-to-one semi-structured interviewing in order to obtain information from the research participants, rather than focus group discussions or unstructured interviews. First, it was felt that one-to-one interviews would be better than group interviews due to the study's sensitive nature. Second, semi-structured interviews were preferred because of the large number of questions to which answers had to be obtained and the restricted time and space available for the respondents to answer the researcher's questions. Unstructured interviews take longer to carry out: typically, the context of an ethnographic study, one interview and related observations can last for several days and in order for the data to be credible and valid, it is suggested that the researcher needs to be given relatively full access to the 'world' in which the participant lives, both within and outside his/her home. As the participants in this research were afraid of being implicated by society due to the widespread HIV-related stigma that is prevalent in Indian society, the researcher was not given access to the majority of the participants' homes, but instead was provided with a specific amount of time and a neutral place where interviews could take place. Further detail of the instrument is given below.

Two separate interview guides were developed in advance of the first field visit - one for governmental and non-governmental organisations and the other for the purpose of interviewing consenting PLHA. The interview guide for NGOs included questions about the types of services they provided (especially livelihood support services), the process of delivery and the ways in which they were organised. The topics in the

interview guide for PLHA were based on the main research questions and focused on people's lives prior to falling ill with HIV, leading up to their diagnosis, then their lives since diagnosis until the present, with the aim of developing an entire picture of how poor PLHA experience living with their illness on a daily basis.

In order to gain the trust of NGO managers who acted as the key informants or gatekeepers, the following items had to be presented to them: a letter each from the principal supervisor and from the researcher's home department, a copy of the ethical review process carried out at the University of Birmingham, a participant information sheet, a copy of the consent form intended for PLHA interviewed to sign, a brief research proposal, and a copy of the researcher's interview guide intended for PLHA. Once satisfied with the submitted documentation, the gatekeepers consulted with HIV positive members of their organisations and together they decided who was willing to be interviewed. In the meantime, a translated version of the consent form was arranged, as the majority of the PLHA only spoke Bengali or Hindi – the two main languages spoken in Kolkata.

During the first field visit, the aim was to interview somewhere between five and ten participants, in order to test the appropriateness of the topics covered in the interview guide with regard to people's lives in the context of the current study. Therefore, in order to select appropriate interviewees, a list of the main criteria of HIV positive research participants was given to each gatekeeper, who chose participants according to the criteria and who were willing to be interviewed. The main criteria were that participants were HIV positive, over the age of 18 years, included both men and



women, were 'poor' in the eyes of the relevant gatekeepers, and were willing to participate in the research.

Out of all the organisations that the author/researcher visited, three were willing to act as gatekeepers and provide access to PLHA willing to be interviewed:

- 1) Kolkata Network of Positive People (KNP+);
- 2) Society for Positive Atmosphere and Related Support to HIV/AIDS (SPARSHA);
- 3) Arunima Hospice.

KNP+ appeared to be the most keen to help the researcher gain access to HIV participants, inviting her to attend one of their monthly meetings. Once she had been introduced to all those attending the meeting, they were able to ask informal questions regarding the implications of being interviewed. Ten PLHA were willing to be interviewed. They, along with the gatekeepers, chose an appropriate room at KNP+ where they felt they could talk with freedom. The researcher informed the participants of the objectives of the investigation, all aspects of the research and responded to further queries that the participants had for her. The participants were told both verbally and in written form that any information that they did provide would be kept in strictest of confidence and their anonymity would be respected, using a participant information sheet that had been prepared prior to the field visit. The participants were also told that remuneration would be in the form of cash. Those who had difficulties understanding the research asked for clarification from the gatekeepers, before deciding whether to stay or leave. They were reassured that if

they did not wish to discuss certain topics with the investigator or wished to leave in the middle of the interview, they were free to do so and would still be provided with the compensation promised. In practice, none of the respondents left during an interview. The counsellor of KNP+ read out the consent forms that had been translated into the participants' native languages to people who were illiterate, who subsequently signed the form using their thumb imprints. Participants who had at least primary school education were able to read and sign the consent forms. Copies of the participant information sheet and consent forms, one in English and two translated into Bengali and Hindi, respectively are provided in Appendix One. There was insufficient time during the pilot study to interview participants associated with the other two organisations, but the ten pilot interviews helped the researcher focus the questions more precisely in interviews during the second field visit, raising some new topics important to PLHA and dropping some topics not considered important by the PLHA (for example, issues of caste). Copies of the interview guides are provided in Appendix Two.

In order to compare the experiences of people who had sought support for their livelihoods before and after being diagnosed with HIV and those who had not sought such support, the researcher decided that it was also necessary to interview people in the latter group in order to ascertain their reasons for not seeking support. Although PLHA may seek treatment from any of the five government-run hospitals in Kolkata, it emerged that only the School of Tropical Medicine (STM) provided access to free first-line and (later second-line) antiretroviral therapy (ART) to PLHA from all over West Bengal. To obtain further information and investigate whether the researcher would be able to gain access to STM's ART centre, contact was made with the West

Bengal State AIDS Prevention and Control Society (WBSAPCS) – a decentralised organisation responsible for the implementation of the objectives set out in the National AIDS Control Programme (NACP) phases I-III. WBSAPCS carries out a number of activities, one of which is the provision of low cost HIV/AIDS care, support and treatment in the public sector (see section 4.2).

After several visits, a face-face meeting was obtained with WBSAPCS's Project Director was obtained and the researcher was informed of the procedure for gaining permission to interview PLHA at STM. Firstly, a letter of permission had to be obtained from the Project Director, which then had to be presented to the Chief Medical Officer of STM and the ART centre. Once this letter had been presented to the relevant person at STM, the researcher was given permission to enter the out-patients department during the main study, provided that she only interview PLHA recommended by the Head counsellor, did not provide remuneration to interviewees and did not interfere with medical consultations.

The initial interviews with the organisations' managers provided the researcher with valuable insights into the ways in which they operate and the types of care and support on offer for PLHA. Prior to the main study, therefore, plans were made to carry out interviews with the key informants or gatekeepers of each organisation to investigate the ways in which they were involved in the provision of care, support and treatment for PLHA.

After completing the initial ten interviews at KNP+, it was noted that the data collected were starting to approach saturation point, so at the end of the pilot study, it

was decided to interview around 15 participants (selected in accordance with the criteria specified above) from each of the four organisations.

- ***Main field study***

The main study took place during the second field visit, between February and April 2009. Similar procedures to those described above were followed for all the participants, except that PLHA from STM and Arunima Hospice were, at the request of the hospital and hospice's gatekeepers, not given any remuneration after the end of the interview. A detailed account of the aims and conduct of the interviews is provided in sub-section 3.2.3. In total, it was possible to interview 59 poor PLHA from the four organisations. An index was prepared (see Appendix Three) which contains a list of the PLHA (anonymised) containing dates of interview and the location of where the interviews took place, where each participant was provided with a letter that represented the organisation in which they were interviewed and an indication of whether they were men or women, along with a number, for ease of identification. In addition to the participant index, a table containing dates of informal meetings with the gatekeepers or key informants are also provided in Appendix Three.

As mentioned earlier, as part of the main study, attempts were made to interview the managers and front-line staff of the NGOs and the Chief Medical Officer of STM – the key informants or gatekeepers - in order to provide the organisations' view of the ways in which HIV/AIDS care, support and treatment are delivered to PLHA. A small number of semi-structured interviews were carried out, where questions

regarding the motivations, funding and structure of the organisations were asked (see Appendix Two). In addition, questions regarding the ways in which these organisations delivered services to PLHA for HIV/AIDS care, support and treatment were also asked. The answers provided were, however, not very detailed, restricting achievement of the relevant research questions, although some of the information provided was useful. Attempts were also made to identify what records the NGOs kept on PLHA and if it would be possible for these to be made available to the researcher. However, due to confidentiality issues, no such documents of any kind were made available to the researcher during either field visits.

The reluctance of many organisational officials to provide assistance meant that the researcher was not able to undertake a systematic review, nor to conduct an evaluation of service providers. Furthermore, her lack of access to official data meant that she could not generalise findings across the city. As a result of officials' initial assumptions about the researcher (for more details see 3.2.3, under the sub-heading 'Reflexivity'), the focus of her research inadvertently shifted. The researcher had not originally intended to conduct predominantly qualitative fieldwork amongst the poor, yet her experience of interacting with people living with HIV/AIDS who, unlike officials, had not pre-judged her on her appearance was a humbling and rewarding experience and a definite highlight of her fieldwork. 3.2.5 provides further details on how the organisational officials' behaviour towards the researcher had an impact on the study design, on the material collected, on the analysis and interpretation of the collected material and the ways in which the researcher had attempted to mitigate these effects.

### 3.2.3 Data collection

Data collection mainly involved using one type of qualitative technique that, as noted above, was considered to be more appropriate than quantitative methods for what the current study was trying to achieve – to understand the social processes and complexities surrounding living with HIV/AIDS and adapting livelihood strategies when necessary, from the perspectives of the poor PLHA themselves. The main method of data collection used was via semi-structured interviewing.

- *Semi-structured interviewing*

There are three main types of interviewing techniques. Structured interviews are usually used in surveys, involving a questionnaire with fixed questions in a pre-decided order and with standardised wording (Robson, 2002). Semi-structured interviewing is when a person is interviewed with much more flexibility of response. Unstructured interviews leave respondents largely free to say whatever they like on the broad topic of the interview with minimal prompting from the researcher. Both semi- and un-structured interviews generally explore the research questions in greater depth than structured interviews (Robson, 2002).

As explained above, the main interview technique applied in the current study was semi-structured interviewing. This type of interviewing technique has predetermined questions, but the order can be modified based upon the researcher's perception of what seems most appropriate, questions added or omitted, the wording of questions changed and explanations given depending on the person who is being interviewed

(Robson, 2002). In addition, emphasis is given to note keeping and perhaps keeping a diary during the period of the fieldwork, to aid with the reflexive process. In the current study, note keeping in a diary was carried out prior to the participant interviews, whilst waiting for interviewees to arrive, usually regarding the environment in which the researcher was located and how she felt prior to the interviews. Notes were also recorded after having completed each interview whilst sitting in the same location, covering the ways in which the participants had spoken to the interviewer, their 'body language', how the researcher felt that the interview had gone and how she felt the participants had interacted with her during the interview – part of the reflexive process which was briefly mentioned in the 'Research Design' sub-section of 3.2.2 and will be further discussed below under the sub-heading 'Reflexivity'. While some participants agreed to have their interviews tape-recorded (and in these cases, additional notes were made), the majority did not want their voices recorded and kept on tape, so their responses were recorded by hand.

Prior to each interview, the main questions asked were whether they were over the age of 18 years, resident in Kolkata, were themselves living with HIV or AIDS and/or had family members living with HIV/AIDS in their households. Once sufficient information had been provided, the research topic was explained again, any questions answered and permission for the interview obtained in writing. Participants were assured that they could still leave the interview if they wished to do so. On a few occasions it was discovered halfway through an interview that the respondent did not meet one or more of the research criteria. At this point, the researcher stopped recording their responses, let the participants finish what they were saying, thanked them for their co-operation and gave them the promised compensation if relevant.

The consent forms, interview notes and/or tape recordings obtained from these interviews were then destroyed safely and not analysed.

In two of the four organisations (SPARSHA and KNP+), the participants usually attended either bi-weekly or monthly meetings, to receive reimbursements for the money they had spent on medicines for opportunistic infections and/or for the purpose of being interviewed as arranged by the organisations' counsellors. The majority of PLHA preferred their interviews to be carried out in the 'safety' of the organisations' premises rather than in their homes due to issues of stigma, confidentiality and privacy. In the case of Arunima Hospice, participants were already present in the hospice, as they were recovering from one or more bouts of serious opportunistic infections or had just arrived at the hospice newly diagnosed with HIV and/or to learn about the use of ART after having been newly prescribed it by the medical doctors at STM.

The limited availability of private spaces in these three organisations proved to be a challenge. Although every effort was made to obtain a room for an hour, there were limitations concerning privacy when other people entered the room without prior warning, causing the flow of individuals' stories to be interrupted. To maximise the flow of people's stories, every effort was made by the researcher to reiterate the final statements made by the PLHA at the time of the interruption. The interviews usually lasted between one and two hours.

In the case of STM, the situation was different due to the circumstances in which the interviews took place and its location. At STM the researcher was given a table at the



back of a large open space, known as the 'out-patients room', which was open on Tuesdays and Fridays of every week (with the exception of holidays) from 11AM-2PM, for the sole purpose of providing treatment and counselling for PLHA. Two doctors were sitting at nearby tables, providing consultations for over one hundred PLHA in each session, ranging from serious conditions (where they had to be then admitted at the in-patients' department) to attending to their six-monthly CD4 count checks and referral to the ART centre adjacent to the STM. A counsellor was also present and after the medical doctors had examined each person, they were sent to the counsellor on the other side of the room to be counselled.

A list of the criteria to be used in selection of PLHA for interview was made available to the counsellor before the start of each day the out-patients' department was open to PLHA. After the counsellor had counselled a person with HIV/AIDS, those satisfying the criteria were asked whether they would be willing to participate in research during which they would be asked to talk about their experiences of living in poverty and of living with the illness. Translated consent forms were also provided to the counsellor, which enabled her to explain to the PLHA the presence of the researcher at the out patients' department. When a participant agreed to be interviewed, whether or not he or she satisfied the criteria was verified, the outline of the research explained and subsequently, consent was obtained using either a signatures or a thumb imprints.

The majority chose not to participate and left the hospital, as they were in a great rush to pick up their antiretroviral drugs from the ART centre (which was located next door to the STM), and which closed at a particular time. Others had to get their blood tests carried out in another department within the hospital. Only those who did not

show signs of serious opportunistic infections, were well enough, were not in a rush to pick up their ART, did not need to get blood tests carried out, understood the purpose of the study and were willing to participate were interviewed. Due to the chaotic circumstances within the out patients' department, limited availability of space and limited privacy, many participants did not feel comfortable in divulging personal information about themselves. The researcher was sensitive to their difficult situations and on many occasions enquired if they would prefer to continue the interview somewhere else where they felt comfortable or reiterated that they had every right to refuse being interviewed. On many occasions, people either refused to be interviewed or were only willing to participate for 15-20 minutes (rather than the hour that typical interviews with the PLHA from the other three organisations). In addition, the researcher was aware of the severe limitations on interviewing PLHA at STM, as she had only just met the respondents and, with the exception of the counsellor, with whom she had built a good rapport, there was no other solid medium through which the researcher was able to gain their trust.

- ***Reflexivity***

As mentioned earlier, because a researcher's own characteristics and presence are known to have effects on the research process, reflexive practice was undertaken at the outset of the research design, and continued throughout the research process, including when deciding on the sampling strategy (see 3.2.2 'Sampling Method'), and during the data collection and analysis processes (see 3.2.3 and 3.2.4, respectively). The researcher did this by keeping a research diary where she recorded reflections on different aspects of doing the research and her role within the context of the research,

including descriptive notes about all the interviews and observations. These notes not only helped the researcher to reflect on the methodological aspects of the research, but also to make sense of the data obtained by bringing several inferences together and then deciphering whether there were any patterns or recurrent themes emerging from the data that were worth considering.

Once I arrived in India for a pilot study, I called these organisations again to request face-to-face meetings. On some occasions I managed to arrange a meeting, but once there, I would be told that they were now unavailable to talk to me either due to prior commitments or because they had forgotten they had scheduled a meeting with me. I would then be told to ‘come back tomorrow’. Sometimes I tried an alternative strategy, which was to arrive at offices without a prior appointment. This was also met with rejection, as I would be told that nobody was available to talk to me and was advised to make an appointment with the relevant person before turning up at the office.

Having repeatedly struggled to gain access to senior staff working within NGOs, public hospitals and other government agencies, I began to suspect that there was something about my research or me that they did not approve or like. When I was eventually granted some interviews, I asked the reason for their negative responses to my previous requests for meetings and interviews.

A typical response was that I was perceived to be ‘one of their own’ because first contact over the telephone or by email had revealed my Indian name (and with the surname, an indication of my caste background). First contact in person had affirmed

my 'native' identity. I was told that because I did not *look* like a 'foreigner' and had spoken to them in Bengali, they had treated my request with less urgency. Cultural sensitivity is one aspect of good ethical behaviour but it transpired that speaking to people in their native language and wearing clothing appropriate to the setting (i.e. salwaar kameez) did not help in this instance.

When I presented my British passport to prove my 'foreigner' status, the agencies became very curious about my background. I also probed them further about what they meant by me not *looking* like a foreigner, to which they responded that I was not a *real* foreigner i.e. a Caucasian. When questioned about why they would treat foreigners differently, their response was that they did not want to appear rude or unwelcoming; they were concerned about making a bad impression and fearful of negative press.

Thus during the main field study I wore smart, business-like, western-style clothes and started meetings with senior people from government agencies and NGOs by producing my British passport. I spoke only in English and pretended not to know a single word of Bengali. In practice, the flexibility in my approach to changing my behaviour without causing any harm to the respondents or to myself made the second phase of the fieldwork much more productive.

However, interviewing people living with HIV/AIDS was quite a different story. Having been granted access to respondents, I spoke in Bengali and dressed in Indian clothes. Most of the participants in the semi-structured interviews appeared intrigued by the research topic and often enquired about the reasons why a foreigner had come

all the way from the UK in order to talk to them, as they described themselves as being poor and ill. They were also bemused as to how I was able to speak their native language fluently, albeit with an English accent. Every effort was made to enable the participants to relax and they were also given an opportunity to ask me questions at any point during an interview. However, as other research has shown, there is a limit to the time urban respondents are willing and able to give to a researcher, resulting in a need to restrict the contact with interviewees to a single interview of relatively limited length, limiting the depth of information that could be obtained and preventing later contacts from being used to check information provided during the first interview.

The ways in which women and men spoke to me also varied. With very few exceptions, the majority of the women appeared to be at ease when it came to answering questions regarding various sexually transmitted illnesses they had had. Male participants, however, were more reserved, especially when it came to discussing the ways in which they thought they might have contracted HIV. Many male participants tried vehemently to justify themselves, stating that they had not contracted HIV by sleeping with 'dirty' girls (meaning sex workers), leading me to reassure them that I did not intend to judge them and that the questions were merely important for me to ask in order for me to understand the wider picture. At this point, male participants were given a choice as to whether to continue with the interview, but none left.

Age also played a part, with older men the most reserved of all. Upon realising their discomfort with talking about issues surrounding HIV/AIDS to a visibly single female

researcher who looked younger than her age, every effort was made to make them comfortable, but some were still uncomfortable and appeared to be in a rush to complete the interviews, providing only one-word answers. Although all were reminded that they could choose to leave, nobody chose to leave before the interview was completed.

### **3.2.4 Data analysis**

Miles and Huberman (1994) and Barbour (2008) provide general frameworks for conceptualising qualitative data analysis. Using their frameworks, the researcher initially converted the field-notes and some audio recordings into “write-ups”. Firstly, the 56 interviews that were recorded by hand in written format, general field-notes, any relevant observation recordings and the researcher’s own reflections were all typed up at the end of each day whilst still out on the field, to avoid memory bias on the part of the researcher. Secondly, because it was possible to record only three interviews, it was possible to transcribe all of these recordings word for word.

Prior to starting the analysis process, decisions had to be made regarding the ways in which the first analytic step - qualitative coding - would be carried out, either manually or using Nvivo computer software. As pointed out by Barbour (2008:196); *“...it is the researcher and not the medium of analysis that ensures that analysis is systematic and thorough...”* and so with this in mind, when attempts to categorise the fieldwork data using the Nvivo computer software were felt to restrict the potential for bringing out interesting themes, it was decided to do the analysis manually.

Initially, a provisional coding frame was developed, as discussed in Barbour (2008), after having carried out the initial phase of coding that involved naming each line of data obtained from the field. In this way, early coding categories reflected closely the questions included in the interviews, which in turn reflected the main research questions. With the intention of developing and refining a provisional coding frame, a focused and selective phase that used the most significant or frequent initial codes to sort, synthesise, integrate, and organise large amounts of data, was applied. During initial coding, the goal was to remain open to an array of theoretical directions and subsequently, focused coding was used to pinpoint and develop the most prominent categories in large batches of data, where theoretical integration began and proceeded through all the subsequent analytic steps (Charmaz 2006).

According to (Charmaz 2006), one of the main differences between analyses carried out in qualitative and quantitative research is that the latter applies preconceived categories or codes to the data, whereas, when it comes to qualitative analysis, codes emerge as the data is scrutinised and meanings are then defined within this data. With this in mind, the researcher carried out active coding, interacting with the data over and over again, resulting in different themes and sub-themes emerging, as described by Barbour (2008). Verification of the conclusions was obtained by interrogating the empirical data from the interviews alongside existing literature. From the start of the data collection process to the end of analysis and interpretation of data, the current study drew on material from the international review and the conceptual framework in order to help identify codes around which to build the analysis of the qualitative data.

Relevant information regarding the social characteristics, household composition and the number and type of assets that the 59 participants and their households possessed was obtained during the interviews. All 59 interviews therefore contained useful information relevant to the themes dealt with in Chapter V. However, not all the interviews contained good quality information relevant to the themes of Chapter VI. In practice, 48 of the 59 interviews contained sufficient information on how they had adapted their livelihood strategies to cope with the impact of HIV and the process by which they accessed and utilised livelihood support from NGOs, the hospice and STM (the findings of which are presented in sections 6.2 and 6.3, respectively). Of the 11 participants whose interviews were not included in the detailed analysis, three were PLHA from Arunima Hospice (CM<sub>10</sub>, CW<sub>12</sub> and CM<sub>15</sub>) and eight were from STM (DW<sub>4</sub>, DW<sub>5</sub>, DW<sub>6</sub>, DM<sub>7</sub>, DM<sub>8</sub>, DM<sub>12</sub>, DW<sub>13</sub> and DM<sub>14</sub>).

As already mentioned in section 3.1, for the purpose of investigating how people adapted their livelihood strategies to cope with the impact of HIV when one or more members of their households became ill with HIV, this research distinguishes between people's circumstances before one or more members became ill and after they became ill. The data for each household was divided up into 'before' and 'after' pictures, indicating the type and number of assets the households possessed and how many assets had been used up after someone within the household became ill, to indicate which households fared better than others and attempt to explain why. Using a combination of the factors identified in the analytical framework as being relevant to household wellbeing trajectories, the in-depth information provided by the 48 participants and the researcher's own judgment, each household was allocated into



one of three categories of vulnerability status; secure, vulnerable or highly vulnerable. A detailed account of the household analysis will be presented in section 6.2.

### **3.2.5 Limitations of the data collection**

The limitations of the overall study have been outlined and analysed in section 1.6, however, this section is particularly concerned with the practical restrictions that the researcher faced during the process of data collection.

Although every effort was made to minimise research bias, a number of limitations related to ‘access’ arose during the data collection process, when the researcher had to “think on her feet” and obtain data where access had been provided. As stated in sub-sections 3.2.2 and 3.2.3, prior to the pilot study, the idea was to select a typical low-income neighbourhood, identify all healthcare and other relevant services available and assess the overall health and social resources package available to PLHA in that area. However, as noted above, it was not possible to use this approach. Instead, it was only possible to identify and gain access to suitable respondents by identifying appropriate organisations to act as gatekeepers. Although these four organisations did provide access to a total of 59 PLHA willing to be interviewed, they were unable to provide secondary information or documentation (related to the ways in which they deliver their services to PLHA), resulting in only a partial picture (from the perspectives of the PLHA only) being obtained of the ways in which these organisations deliver their services to PLHA in the context of Kolkata.

Complementary methods of gathering data had been considered during the research strategy and design stage (see 3.2.2). However, when it came to carrying out overt observations, the majority of the PLHA were not comfortable in inviting the researcher into their private lives. Only a few PLHA (4 out of 59) agreed to be interviewed within their households, mostly because they were too ill to leave their homes. In addition, while observations can be a useful source of information, it is also acknowledged that informal, unstructured observations can only give partial impressions. As there are dangers in basing assumptions on such data, this method was not considered an appropriate complementary method of gathering data in the current study.

When it came to using secondary (documentary) data to complement semi-structured interviews, the author/researcher searched for official documents related to the HIV/AIDS situation in India and reports related to the Kolkata context, but was not provided with access to any relevant documents mainly due to the bureaucracy of the city library. This lack of access to official documents led to a reliance on the meagre information provided by the NGOs regarding their organisations, and the websites of the 'Department of Health and Family Welfare in India', the 'National AIDS Control Organisation', the 'Department of Health and Family Welfare in West Bengal' and the 'West Bengal State AIDS Prevention and Control Society'. Again, due to lack of access to relevant secondary documentation, preventing systematic analysis, this method was not considered as one of the complementary methods of gathering data in the current study.

Other limitations during the data collection included a lack of privacy and interruptions. There were also language difficulties during some interviews, as some respondents only spoke and understood the Hindi language (one of the local languages, but not the native language of Kolkata), and the researcher found it challenging to carry out interviews in that language. In these cases, a family member of the respondent had to act as an interpreter, or the interviewer spoke in Bengali (the native language of Kolkata) and the respondent answered the question in Hindi, which the researcher understood.

In addition, as stated in 3.2.4, when all 59 participants were asked to provide details of their livelihoods before they had been formally diagnosed with HIV, not everybody was willing to provide much detail, either because they were very ill or because they did not appear to have the time to go into a lot of detail about their previous lives unless they wanted to talk about some specific details that they felt were important and needed to be told or could remember.

### **3.2.6 Ethical considerations**

As discussed above, attention was paid to ethical considerations throughout the study in line with the UK's Economic and Social Research Council (ESRC) (the main funding body of the current study) framework for research ethics formally published in 2010. In addition, a formal ethical review process was carried out at the University of Birmingham. In line with these two sets of ethical principles, during the two field visits, every effort was made to inform all the participants of the objectives of the investigation and what it was they were being asked to be involved in, how, and why.

The participants were told verbally (especially for those who were illiterate) and in written form that any information they provided would be kept in the strictest confidence and their anonymity would be respected. They were told that they had a choice to not discuss certain topics with the researcher if they did not wish to do so and/or to withdraw from the study at any point without fear of any negative repercussion as far as the researcher was concerned. Four people did withdraw in the middle of interviews, following which their data was destroyed. The participants were encouraged to ask questions throughout the process if there was anything that they had not understood about what the researcher was asking them.

The researcher was aware of the risk that her presence at the hospital and the organisations might give rise to suspicion. So, in order to minimise or to eradicate the risk of PLHA having their confidentiality breached and being stigmatised, as a result of the researcher's presence, where possible, willing participants were taken to a quiet room within the premises of the organisations for the interviews to take place, in order to ensure that participants were able to keep their information confidential from relatives and neighbours if they desired.

Ensuring that the research was ethically sound also involved considering whether to provide any form of remuneration to research participants. As the gatekeepers had been the ones who enabled the researcher to gain access to the PLHA, she considered their thoughts on the matter. The gatekeepers from the two NGOs (KNP+ and SPARSHA) suggested that a small remuneration be made to individual participants towards their transport costs to come to the organisations and also for a healthy meal that could potentially help them. At the gatekeeper's request, individual participants

were provided with Rs. 100.00 (equivalent to £1.40 at the end of 2008-beginning of 2009) at the end of their interviews. However, in the case of STM and Arunima Hospice, at the gatekeepers' request, no form of remuneration was made to the PLHA.

### **3.3 CHAPTER CONCLUSION**

The conceptual framework presented in section 3.1 is a combination of the two most appropriate models identified in the literature review: Obrist et al., (2007)'s 'health access livelihood framework' and Moser (1998)'s 'asset vulnerability framework', with added elements identified as relevant to achieving the research objectives of this study during the international literature (reviewed in chapter two. The new combined framework will be used for analysing the processes by which poor PLHA with certain social characteristics cope with their illness, employ livelihood strategies and access help in the form of health care and livelihood support. The adequacy of the framework will then be assessed at the conclusion of the analysis.

Section 3.2 presented a justification of the overall methodology adopted for this study, which was based on a single method interpretive approach. The section also explained and justified the ways in which data was collected and analysed. The data generated from the semi-structured interviews with PLHA, in particular, generated rich data, despite restrictions on the length of the interviews and the difficulty of ensuring relaxed and quiet settings in which to conduct them. The ways in which limitations on access to data influenced the design of the study and the questions to which answers could be obtained were also explained.

Attention was drawn to the significance of the context in which PLHA live, seek treatment for their illness and attempt to sustain their livelihoods both in the livelihoods and health care seeking behaviour literature and in the analytical framework set out in this chapter. The following chapter therefore describes the broad context in which poor PLHA with different social characteristics live in India and in Kolkata and identifies what is already known about the ways in which they access help for their illness – this information will be drawn upon when analysis of the findings presented in Chapters V and VI takes place in Chapter VII.

## **CHAPTER IV**

### **POOR PLHA LIVING IN INDIA**

#### **4.0 INTRODUCTION**

The previous chapter provided the conceptual framework and the research methodology. The context in which people live is particularly important when it comes to understanding the reasons why they behave in certain ways, in turn helping HIV/AIDS policy makers to formulate policies that are likely to meet the needs of people living in particular contexts. Section 4.1 provides an overview of the physical setting, demographics, poverty levels and social diversity of India, West Bengal and Kolkata. Section 4.2 gives a background to the HIV/AIDS epidemic in India, providing evidence from similar urban settings to Kolkata, and discusses the national and state-level policies for the prevention, treatment, and provision of support and care for HIV/AIDS. Section 4.3 provides overviews first of the national and state-level health care systems, which determine the choices available to poor PLHA, influencing their ability to access the resources they need to cope with their illness and everyday survival, and second of the role of the non-governmental organisation (NGO) sector in providing HIV/AIDS-related care and support in India.

## 4.1 THE INDIAN CONTEXT

The purpose of this section is to locate the case study geographically and administratively within the context of India, so it provides an overview of the physical setting, demographics, levels of poverty and social diversity of India and Kolkata. As this study is concerned with poor people, it also summarises the slum situation and incidence of poverty amongst people who live in the city.

India is divided into twenty-eight states that are further subdivided into districts and seven union territories. According to the country's 2011 census, it is the second most populous country in the world with over 1.28 billion people. 80 per cent of the population are Hindus, 13 percent Muslims, and less than three percent Christians, while other religious groups include Jains, Sikhs and Buddhists, and 0.1 per cent did not state a religion. The average adult literacy rate is 65 percent, with only 25 percent of men never having attended school, compared to 46 percent of women (Office of the Registrar General & Census Commissioner 2011, accessed 14 June 2012).

In India, certain groups are excluded at societal and institutional levels purely on the basis of social characteristics like caste, gender and religion. Historically, the caste system has regulated social and economic life. This system is based on the division of people into social groups (or castes) in which the civil, cultural, and economic rights of each individual are hereditary and therefore pre-determined at birth. In principle, castes are endogamous descent groups, with most people marrying within their own caste and strong social norms against cross-caste marriage. According to the Hindu scriptures, people belonging to each caste are assigned (at birth) to particular duties that they need to fulfil until death and a hierarchy of castes is implied. For example,



*Brahmins* are usually given the right to be scholars and are, therefore, in practice the only group allowed to be priests in Hindu temples; *Kshatriya* are considered warriors, and *Vaisyas* and *Shudras* traders and cultivators, respectively. In addition, below these four castes are a large number of people considered to be spiritually impure. Now generally called *Dalits*, they have been discriminated against by not being allowed to live close to members of the above castes, use the same water supplies or pray in the same temples, resulting in them being systematically excluded from the entitlements of members of the other four castes, leading them to have fewer economic and social rights (Thorat 2007; Thorat et al., 2009).

The majority Hindu religion is closely associated with caste, influencing the religious minorities in various ways, either through the influence of caste institutions on society even amongst Muslims, Christians or Sikhs, or through conversion, especially of Dalits and other disadvantaged groups anxious to escape their perceived social marginalisation. Although the Constitution of India declares the nation to be a secular republic, at the societal level, people tend to live within their own religious communities, inter-religious marriages are not widely practised and inter-religious conflicts have often occurred (Thakur and Pandey 2009). Although poverty is widespread amongst all the religious groups, Muslims in particular are disadvantaged in comparison to most of the others.

In India, like in many other cultures in the world, men and women are led to believe that they have distinct gender-specific roles. Typically, men are seen as being responsible for productive activities outside the home whilst women are expected to be responsible for reproductive and productive activities within the home. Women are

often denied equal access to land and property and they have fewer rights than men. Traditionally women's culturally defined roles have limited them to the four walls of their homes, setting boundaries to whether and where they can work. However, according to Mitra (2004:222), "*...among the poor who are not in a position to enjoy the luxury of female seclusion, women have always entered the labour force when they could find work...*" Findings from a study carried out in the states of Tamil Nadu and Uttar Pradesh reveal that women labourers belonging to the low caste groups have access to the outside world, in ways not possible to middle class women, but are still controlled by their families, including their husbands (Priya and Sathyamala, 2007). Gender is also used to structure the labour market, whereby men are assigned to higher-paid, formal sector and managerial positions and women to lower-paid, casual work, often in various forms of self-employment (Sivard et al. 1995; Buvinic 1995; Kabeer 2002). Therefore women who do go out to work in the "outside" world are not only subjected to restrictions placed upon them by their households and communities, as they are defying social norms, but also face further obstacles in the "outside" world (Mitra, 2004).

Gender within the household also affects sexual behaviour. Not only does a culture of silence surround sex, the balance of power in sexual decision-making usually lies with the man. The prevailing view dictates that "good" women are expected to be ignorant about sex and passive in sexual interactions, which makes it difficult for them to be informed about risk reduction or, even when informed, to be proactive in negotiating safer sex (Carovano 1992 and Mitra 2004). This way of thinking is underlain by the core teachings of Hinduism, in which the specific roles or 'duties' of a wife and husband are laid out. They imply that marriage is a sacred institution devised by the

gods for the welfare of humans, so that the first purpose of a marriage is considered to be procreation and sexual union is seen to be solely for this purpose. The second purpose of marriage is to uphold the social order and the Hindu *dharma* (which means ‘duty’ and ‘morality’, referring to the power which upholds the universe and society), while the ultimate aim of spiritual union with the inner self is only considered to be possible when a married couple perform their obligatory duties and earn a place in Heaven through their good *karma* (which means ‘action’, referring to the belief that every action has an equal reaction, either immediately or at some point in the future in the current or future lifetimes). Married couples are expected to perform their traditional duties by upholding family traditions and fulfilling gender-specific roles - men to provide for their wives and family members and women to care for household members.

The State of West Bengal has a population of just over 91 million, with approximately a third living in urban areas, similar to the national proportion. The adult literacy level of West Bengal is higher than the national average at 77 percent but again a higher percentage of men have received some education than women. Kolkata, the state capital and largest city, is one of the 19 districts in West Bengal. According to the 2011 census, the city had a population of just over 4.5 million, or 14.1 million in the agglomeration as a whole. Reflecting India’s ethnic and religious diversity, the city’s population has a large majority of Hindus, then Muslims and following this, Christians. According to a study of migrants who had been living in Kolkata for a year or more, Kolkata is one of the most common destinations for migrant workers in search of work, especially from poorer neighbouring states such as Bihar (currently, Bihar and Jharkhand), Orissa and Uttar Pradesh, due to the city’s location within the

eastern state of West Bengal (Deb et al., 2009). However, the exact proportion of migrants to Kolkata who have come from these States is unknown, as the available 2011 census data does not provide this information. The languages spoken in the city include Bengali (the main language spoken by Kolkata natives), English (the official language) and Hindi (the national language).

Kolkata city, under the jurisdiction of the Kolkata Municipal Corporation (KMC), has an area of 185 square kilometres. The urban agglomeration is comprised of 72 cities and 527 towns and villages, incorporates part of several other districts and is administered by several local governments, including 38 local municipalities. East-to-west the city is narrow, stretching from the Hooghly River in the west to roughly the Eastern Metropolitan Bypass in the east. From north to south it is roughly divided into North, Central and South Kolkata. North Kolkata is the oldest part of the city, with 19<sup>th</sup> century architecture and narrow alleyways. South Kolkata grew mostly after independence and consists of well-to-do localities (World Association of Major Metropolises, accessed 4 August 2008).

Just over a third of the urban population in Kolkata itself (1.5 out of 4.5 million people) reside in over-crowded and unsanitary settlements without adequate basic amenities (Office of the Registrar General & Census Commissioner 2011). The term slum can refer to both *bustees* and squatter settlements. In Kolkata, *bustees* are legally recognised settlements of permanent structures that are eligible for government improvement programmes. The Kolkata Municipal Corporation (KMC), in theory, does not demolish *bustee* housing and supplies the areas with services such as water, latrines, rubbish removal and occasionally electricity (Schenk 2010).

Squatter settlements, in contrast, are illegal clusters of impermanent houses, predominantly located along canals and railways. The KMC usually does not supply squatters with basic amenities, so residents seek access to water and other resources from the areas surrounding the settlements. However, residents in both *bustees* and squatter settlements are diverse and the distinction between the types of area is not clear-cut. According to Schenk, formative history, migration patterns, ethnic composition, employment opportunities and political history have helped to shape today's slum conditions in ways not explained by the simple *bustee/squatter* settlement distinction (Schenk 2010).

Slums existed during the colonial period, prior to industrialisation, but began to dominate certain parts of the city after Independence in 1947, as industrial growth created a demand for labour. The next major rural-urban influx took place during the 1990s, when India's rapid economic growth led to the renewed movement of population towards centres of economic activity, creating severe strains on the capacity of the major cities (Pernia, 1994).

According to KMC, what makes a house or area 'slum-like' depends on four factors: whether the houses are predominantly made of a permanent material (e.g. concrete), a drinking water source is available, there are latrines within the premises of people's houses and there is a drainage facility (preferably covered). The predominant structure types in the slum areas can be divided into *pucca*, *semi-pucca* and *kutcha* (permanent good quality, semi-permanent, and crude or imperfect respectively). In Kolkata, the majority are *pucca*. Roof materials include grass, thatch, bamboo, wood, mud, tiles, asbestos or, in many cases, concrete. Floors can be made out of stone,

mud, cement, mosaic or floor tiles, and walls are either burnt brick or stone packed with mortar. Most families live in one-room dwellings. According to Kundu, data from the 2001 census showed that most of the men living in these dwellings were unemployed or worked as manual labourers or hawkers in the informal sector, while women worked as domestic servants, in manufacturing, or as beauticians or masseuses in the semi-skilled employment sector (Kundu 2003).

## **4.2 THE HIV/AIDS SITUATION IN INDIA & NATIONAL AND STATE-LEVEL HIV/AIDS POLICIES**

The purpose of this section is to provide a background to the HIV/AIDS situation in India by briefly describing how HIV/AIDS was first discovered and the possible contributing factors that led to its rapid spread across the country. The way it was discovered and the ways in which the government initially tackled it are important, because they still influence how people react to it to this day. This section will, therefore, also investigate what actions the Indian government took initially to prevent the disease from spreading - looking in detail at the progress that it has made since the virus was first discovered, in terms of policy formulation, financial allocations and implementation with respect to the delivery of care, support and treatment for PLHA by the governmental and non-governmental health care sectors.

### **4.2.1 HIV/AIDS in India**

This sub-section discusses the ways in which HIV/AIDS was first discovered in India, the factors that contributed to its spread across the country and how it has affected

certain groups within Indian society, referring mostly to studies in urban contexts similar to Kolkata.

### **a) The spread of HIV in India**

In 1986 the first cases of HIV were discovered amongst sex workers in the cities of Mumbai and Chennai, in Southern India and since then, there has been a “diffusion” of the epidemic from the so-called “high-risk” groups (considered to be female sex workers, men who have sex with men and people who inject drugs with contaminated equipment) to the general population, resulting in a rapid spread of the epidemic in some parts of the country (Hawkes and Santhya, 2002). An epidemiological study conducted in 1992 by the All India Institute of Hygiene and Public Health (AIIHPH) among 450 sex workers in Kolkata’s largest red light area revealed that only 1 percent used condoms on a regular basis and HIV prevalence was around 1 percent, but STDs were confirmed by laboratory diagnosis in 81 percent of women (Evans and Lambert, 1997). Prevalence trends vary greatly between states and regions, with most HIV cases being in the Southern States (Andhra Pradesh, Karnataka, Maharashtra and Tamil Nadu) and in the North East parts of India (Manipur and Nagaland) (UNAIDS, 2007).

Overall, the mode of transmission is mainly through heterosexual transmission (approximately 80 percent) but other modes of transmission have also been reported, including injecting drug use (around 5 percent), via blood or blood products (just under 6 percent) and mother to child transmission (fewer than 1 percent of cases) (Hawkes and Santhya, 2002). Surprisingly, the dominance of transmission via same-

sex contact was not reported in the national surveillance data by the National AIDS Control Organisation (NACO) until 2006, despite studies which reveal that a large proportion of women with HIV appear to have acquired the virus from their regular partners, who were infected during paid unprotected sex (Kumar et al., 2006). Maniar (2000) similarly notes that in most prenatal clinics in India, the HIV-infected woman's risk factor is having had sex with her husband. Moreover, until recently, an increasing number of women attending antenatal clinics were testing positive, thereby increasing the risk of perinatal transmission.

Maniar (2000) discusses the possible contributing factors that could have led to the rapid spread of the epidemic across India, identifying mobility from areas with limited employment opportunities to areas with better job prospects; low literacy levels that lead to low awareness, especially amongst the lower income population; gender disparities in economic power and social status, which limit women's access to paid employment and appropriate health care; and the presence of other sexually transmitted and reproductive tract infections (Maniar 2000; Hawkes and Santhya, 2002; Mitra 2004; D'Cruz and Arora, 2010).

In India as elsewhere (see sub-section 2.2.4), there is considerable social stigma attached to any disease that is transmitted sexually and a 'double stigma' associated with HIV/AIDS because of its moral connotations, due to its previous connection with sex workers and also lack of knowledge amongst the general population about the illness and how it is contracted. There is some evidence from previous research to show in general terms how HIV positive people feel they are treated in the context of their households, in employment and within the health care system. However, the



details vary between people, especially between men and women, between household and work situations, and in people's access to and experience of health care provision. The review below explores these issues in more depth, focusing on similarities and differences between men and women, as a starting point for analysing the data obtained in the current study.

### **b) Interactions between non-PLHA and PLHA in Indian households**

As already stated in section 4.1, women in India are at a disadvantage due to cultural constraints within their homes, communities and society as a whole, so when in addition, they become infected with HIV, social and health studies have shown that it hits them harder than men, both directly and indirectly. Although all those with a socially unacceptable disease such as HIV/AIDS are likely to be stigmatised, women's inferior social status often means that they face a particularly high level of discrimination and social isolation (Bharat and Aggleton, 1999). While, as noted in 4.1, literacy levels amongst men are low, they are even lower amongst women – their limited access to education not only limits their access to knowledge but also increases their economic dependency. As a result, they may feel that they have little choice but to sell sexual favours, engage in unprotected sex and submit to sexual demands from infected partners (Hawkes and Santhya, 2002). The idea of sex workers being both the “vectors” and the “reason” for the spread of HIV into the general population reinforced the social stigma that has been attached to sex workers since the mid-nineteenth century, when the British colonised India. Previously, sex work (workers were known as *devadasis*, with the earliest recorded use of the term in 1113 AD) was an artistic profession for young women, who dedicated themselves to

the Hindu temple deities as their metaphorical “wives” soon after puberty and also provided sexual services to male temple attendants, priests and men who could be considered patrons or clients of the temples, although not in exchange for money or material goods. However, during the British Empire, this profession was labelled prostitution and attempts made to eradicate it. Subsequently, *devadasis* were shunned by their own communities, who had previously revered them as the “wives” of their Hindu deities. With no alternative way of making a living, many eventually resorted to sex work for survival (O’Neil et al 2004).

Historically and culturally in India, women have been seen as caring, self-abnegating, sacrificial and tolerant. Since they hold the majority of caring roles, they bear the most brunt when one or more members of their households fall ill with HIV, whether they themselves are HIV positive or not. One of many examples of empirical evidence of how women put others’ needs before their own is a study that revealed how typical it is for women everywhere in India to neglect their own needs for food and nutrition, rest and medical care (Jejeebhoy and Rao, 1995 in Das Gupta et al., 1995:133; Mitra 2004). In addition, another study carried out in Mumbai showed that for men, household and family responses to HIV/AIDS are generally supportive, with husbands and sons with HIV tending to be cared for by their mothers, wives and other female relatives. Occasionally, too, male relatives (most usually brothers) will help out. However, the study showed that the position of women is very different. Not only do they receive little care and support, when ill, from other household members, but their own health care needs go unmet while they are caring for their husbands and sons (Bharat and Aggleton, 1999). For example, a study of HIV/AIDS positive low

caste women labourers in the states of Tamil Nadu and Uttar Pradesh revealed that their mortality and morbidity rates are higher than men (Priya and Sathyamala, 2007).

Ironically, the unequal power balance in gender relations increases men's vulnerability to HIV infection. While as noted above, in Indian culture, women are supposed to be ignorant about sex, prevailing norms of masculinity mean that men are expected to be more knowledgeable and experienced, even if they may not be, and in addition may be peer pressured into taking sexual risks (UNAIDS 2011).

Although public health and HIV prevention programmes have only recently recognised and acknowledged the potential role of male-male sex in the HIV epidemic in India, Indian scholars have long reported the existence of many gender identities and complex sexual partnerships, including male-male, male-female and male-*hijras* (the closest Western definition is male-to-female transgender) (Hernandez et al. 2006). The western terms 'homosexuality' and 'heterosexuality' are terms that do not apply easily in India, as behaviour is highly varied and sexual identity is not always clear and well defined (Asthana and Oostvogels, 2001). For example, the behaviour of men having sex with men (MSM) does not preclude them from also having sex with women or traditional marriage. Once men reach a certain age, they are encouraged by their families to get married. Generally, their families are involved in choosing their female partner and no exception is made for men who have sex with men. Because of stigma and the fear of being persecuted, such men keep their sexual behaviour secret and marry female partners chosen by their families. However, after marriage, they may continue to have sex with their male partners, ignoring the risk

and thereby increasing their own risk of contracting the virus, as well as the risk of their partners, female or male, doing so (UNAIDS 1999).

Finally, due to the limited economic opportunities in many parts of the country, men relocate to areas with higher earning potential, often leaving their spouses and/or children behind. Again, prevailing notions of masculinity sanction migrant men's indulgence in risky, casual sex with multiple partners. Subsequently, men return to their households and may pass on sexually transmitted infections, including HIV, to their spouses and potentially to their unborn babies (UNAIDS 2011).

A study carried out by Bharat for UNAIDS (2001), in which a total of 44 PLHA were interviewed in Mumbai and Bangalore, revealed that HIV/AIDS evoked a variety of responses, some positive and others less so. At the positive end of the spectrum, although households and families who agreed to provide care and support for affected members were not very common, they were more likely to do so when male rather than female household members were affected. In practice, ostracism and rejection were the most common responses found within the families of PLHA, resulting in the PLHA being afraid, secretive about their HIV status and often withdrawing from all family and social contacts. The study also revealed that in a few cases PLHA appeared to have suicidal tendencies, while in a few other instances PLHA denied their positive status in the hope of not being stigmatised. In a study in Delhi, 100 PLHA wanted to be loved by their families and accepted by the society in which they live, but fewer than a third expressed satisfaction with their family life and a significant proportion had faced discrimination from their neighbours and from society in general (Singh et al., 2009). Similarly, another study carried out in the

context of urban India revealed that stigma plays a big role in the lives of men and women living with HIV/AIDS in Chennai, where married men appeared to have been concerned at the prospect of disclosing their status to members of their households and relatives, and especially to their neighbours, friends and employers for fear that they would lose respect, bring shame upon their families, become socially isolated and lose employment. Many reported that they had become socially isolated and lost employment as a result of their neighbours and employers finding out about their illness (Tarakeshwar et al., 2006). The study also revealed that women who had lost their husbands due to HIV-related illnesses were worse off than men, as they were often blamed for their husbands' deaths, resulting in them being physically and socially isolated by their in-laws. These widowed women did not have any other choice but to return to their natal families. While women infected with HIV by their husbands worried for their husbands' health, they also expressed anger, frustration and resignation because they felt that their lives had changed for the worse since their husbands had contracted the illness. The same study revealed that married women would prefer that they or their husbands contracted any disease other than HIV, as they were afraid of what their relatives and neighbours would say (Tarakeshwar et al., 2006). In contrast to the high levels of secrecy reported elsewhere, most of the 470 PLHA in a study in Andhra Pradesh reported that they had immediately revealed their positive status to their spouses, with fewer than 2 percent of women and 4 per cent of men not doing so, although around 21 per cent of men and 14 per cent of women had not disclosed their status in their wider communities and some of those whose status had become known reported that they had suffered discrimination (Pradhan et al, 2006).

Moreover, in contrast to the sense of shame reported by respondents in some studies, the low caste labourers from Tamil Nadu and Uttar Pradesh studied by Priya and Sathyamala, (2007) did not appear to suffer from shame or guilt due to having contracted HIV/AIDS and nor did they report any forms of discrimination within their households or outside.

The social differences and mores discussed above have implications for people's quality of life. For example, a couple of studies examine the gender differences in Quality of Life (QOL) amongst PLHA in India, showing that HIV positive men generally feel more positively about their future, feel more contented and have more positive experiences than their female counterparts (Wisniewski et al. 2005 and Chandra et al. 2009). Chandra et al. (2009) also found that, even though in their sample men and women had similar education levels, a larger proportion of HIV positive men than their female counterparts appeared to be satisfied and they were less anxious about their financial situation and means of earning a living. A greater proportion of HIV positive women in this study had forgiven or did not blame their husbands for having passed on the virus, with younger married women reporting higher scores on the forgiveness and blame facets than older, leading the authors to suggest that women living with HIV in India tend to be more accepting and forgiving than men (Chandra et al. 2009). This can perhaps be attributed to the patriarchal nature of Indian society, in which preserving a marriage is regarded as a woman's responsibility, so a woman is expected to accept and forgive her spouse no matter what he has done (Krishnan, 2005).

### **c) Access to employment and healthcare services in India by PLHA**

HIV/AIDS-related stigma has been reported in the work place, with some reporting that they had lost their employment after their employers found out about their HIV positive status (Maniar 2000). Although existing studies found no particular differences between how HIV positive women and men are treated, according to UNAIDS, those who keep their HIV status a secret attribute such employer reactions to a combination of the widespread social stigma associated with HIV/AIDS and the lack of legislation and procedures stipulating how PLHA should be treated at work (UNAIDS 2001). In the study in Andhra Pradesh referred to above, about 60 per cent of the PLHA interviewed who were employed at the time of the interview had not disclosed their status to their employers for fear of losing their jobs, but of the 40 percent who had done so, only six per cent reported that they had experienced discrimination (Pradhan et al., 2006).

Maniar's study (2000) showed that some patients had been refused admission to both private and government hospitals and nursing homes. Also, even if they had been admitted, often they were isolated in the wards, generating fear and confusion amongst both them and other patients. However, there is very little other evidence on how people are treated when they attempt to obtain health care, and whether men and women are treated differently. A study carried out by Rajeswari et al. (1999) revealed that it is thought that women are more likely to face obstacles in gaining access to diagnostic facilities, obtaining the necessary investigations and completing treatment for TB due to the lack of time they have as a result of the triple burden of housework, childcare and employment. In addition, as already mentioned, the study carried out

by Bharat on behalf of UNAIDS (2001) revealed that negative responses in the health care setting (or the belief that there will be negative responses) lead people to keep their HIV status a secret in treatment facilities, for fear of being denied care. Individuals who are ill may also delay seeking treatment until the last moment, potentially harming their own health. In the Andhra Pradesh study referred to above, 11 per cent of the male and 13 per cent of the female PLHA reported that they had been denied entry into a government-run and/or private hospital, denied medical assistance and in general treated badly (Pradhan et al., 2006).

#### **4.2.2 HIV/AIDS policies and programmes**

As the above sub-section briefly discussed how HIV/AIDS was introduced to and rapidly spread across India, this sub-section will investigate what actions the Indian government took initially to contain the disease and assess the progress it has made since the virus was first identified.

The National AIDS Control Organisation (NACO) was set up under the Ministry of Health and Family Welfare in 1992, six years after the first cases of HIV were found. Subsequently, NACO was mandated to implement initiatives like establishing HIV testing centres, strengthening blood-safety and controlling hospital infections, in order to contain the disease in the cities with highest prevalence and prevent it from spreading. It prepared an outline - National AIDS Control Programme (NACP) for this purpose (NACP phase I), which was primarily funded by the World Bank and technically supported by WHO (Godbole and Mehendale 2005).



NACP- phase I lasted from 1992 until 1999, during which the NACP co-ordinated a national response and conducted activities such as surveillance, blood screening, and health education. However, as the number of people contracting HIV/AIDS and the absolute number of people living with HIV/AIDS increased every year, NACO introduced a second phase, known as NACP-II, from 2000 to 2006. The aim of this phase was to reduce the spread of HIV through promoting behavioural change, prevention of mother-to-child transmission (PMTCT) and providing free ART (NACO, 2002). During this phase, decentralisation to State level for prevention and control measures was implemented, and collaboration began between governmental and non-governmental organisations at the national, State and local levels (Over et al., 2004).

During NACP-II, many large scale interventions aimed at increasing awareness and preventing transmission were implemented, including the promotion of condom use, provision of HIV testing and counselling, enhanced treatment for STIs, HIV and STI surveillance, harm reduction for injecting drug users, provision of safe blood and blood products, and support for research and development (Over et al., 2004). To provide health care and social support to PLHA, the NACP-II intended that hospitals, community care centres and families would work synergistically to provide care (including home-based care) to PLHA (Hawkes and Santhya, 2002; Over et al., 2004; MAAS-CHRD, 2006). The objectives of the NACP-II also included providing treatment free of charge for HIV/AIDS patients and for the management of opportunistic infections at government health care facilities and providing counselling services for HIV-infected people (Hawkes and Santhya, 2002). However, there were a variety of constraints on implementation.

First, as noted in 4.2.1, various studies have shown that isolation, stigmatisation and other forms of discrimination characterise the experience of the vast majority of PLHA in India and pose severe constraints on people revealing their HIV/AIDS status and getting access to health care and treatment (Bharat and Aggleton, 1999; Hawkes and Santhya, 2002; MAAS-CHRD, 2006).

Second, the ART options available were prohibitively expensive. Until 2000, only three to five percent of HIV-infected individuals were reported to have been able to afford ART, even though pharmaceutical companies in India had started producing generic versions of the drugs, which were being sold to industrialised countries for half the price of those produced in the North (Maniar, 2000). In 2004, during NACP-II, the Indian government began to provide ART free to patients, with the objective of initiating treatment for 100,000 people by 2007. Despite the high incidence of toxicities found in stavudine, this is still the main drug used in India due to its low cost (Kumarasamy et al. 2007).

Following some progress with the national strategic plan phases I and II, NACO began to implement NACP-III in 2007, to build on the experience of implementing NACP I and II by providing integrated programmes for prevention, care, support and treatment over the next five years. The main priorities of NACP-III are:

- Prevention of the transmission of HIV, whilst also looking to integrate prevention with care, support and treatment;
- A strong focus on groups of people who are at the highest risk of exposure to HIV, such as sex workers, men-who-have-sex-with-men, injecting drug users,

long-distance truckers, prisoners, migrants (including refugees) and street children;

- People in the general population with the most need of prevention services are next in the line of priority, to be offered treatment of STIs, voluntary counselling and testing and access to condoms;
- All persons who need treatment will have access to prophylaxis and the management of opportunistic infections. People who need access to ART will also be assured first line ARV drugs;
- The prevention needs of children will be addressed through universal provision of prevention of mother-to-child transmission (PMTCT) services. Children who are infected are also assured access to pediatric ART;
- The needs of persons infected and affected by HIV, especially children, will be met through the sectors and agencies involved in child protection and welfare. In mitigating the impact of HIV, support is also to be drawn from welfare agencies providing nutritional support, opportunities for income generation and other welfare services;
- There will be investment in community care centres to provide psycho-social support, outreach services, referrals and palliative care;
- Coordination will be improved with other agencies involved in vulnerability reduction, such as women's groups, youth groups, and trade unions, to integrate HIV prevention into their activities, because the socio-economic determinants that make people vulnerable also increase their risk of exposure to HIV;
- Mainstreaming and partnerships are intended to be the key approaches to facilitate multi-sectoral responses engaging a wide range of stakeholders.

Private sector and civil society organisations, networks of people living with HIV/AIDS and government departments are all expected to play crucial roles in prevention, care, support, treatment and service delivery.

- It is intended to leverage the technical and financial resources of development partners to achieve the objectives of the programme.
- Technical and managerial capacities for programme implementation are to be built through surveillance, training, monitoring and evaluation, technical resource groups, operational research and programme management (NACO, 2011).

With regard to treatment, the NACP-III guidelines recommend that, depending on the stage of infection, ART is to be initiated. They state that PLHA with less than 200 CD4 (white blood cells/mm<sup>3</sup>) require treatment irrespective of the clinical stage of their illness. For PLHA with 200-350 CD4, ART is to be offered to symptomatic patients. Among those with CD4 of more than 350, treatment is to be deferred for asymptomatic persons (NACO, 2011). The NACP-III plan requires free ART to be provided to all PLHA, irrespective of their socio-economic characteristics. The plan refers to three types of ART that vary in the combinations and doses of drugs used. They are available as a single dose therapy, a two-drug combination therapy or a three-drug therapy<sup>1</sup>.

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<sup>1</sup> A single-dose comes in the form of nevirapine or efavirenz; the two drug combination therapy come in the form of stavudine and lamivudine or zidovudine and lamivudine and the three drug combination therapy come in the form of stavudine, lamivudine and nevirapine or zidovudine, lamivudine and nevirapine (NACO 2011).

The provision of free ART was launched at eight government hospitals in 2004 and some information is available to assess progress with implementing this and other proposals of NACP-III. According to a recent study carried out by the UNAIDS (2011), HIV incidence in the Asia Pacific Region declined by 50 percent between 2000 and 2009 due to programmatic success in six high-prevalence countries. In India, HIV prevalence amongst female sex workers declined to less than five percent, as a result of a significant scale up in coverage of focused programmes among key populations at higher risk, but remained high among men who have sex with men (just over seven percent) and people who inject drugs (just over nine percent). The study also showed that by 2011 320,074 people in India were receiving ART - 20 percent more than the NACP-III target. It noted that HIV-related budgets had increased from US\$ 99.6 million during NACP-I (1992-1999) to US\$ 2.5 billion during NACP-III (2007-2012) and that allocations were balanced between programme components (UNAIDS, 2011).

West Bengal State AIDS Prevention and Control Society (WBSAPCS) is a decentralized government body, which is promoted by the Ministry of Health and Family Welfare, Government of India and Department of Health and Family Welfare, Government of West Bengal. WBSAPCS was first established in mid-1999 (towards the end of strategic plan and related activities for NACP-I) and according to its website, at State level, the NACP objectives regarding prevention and control had “trickled down” to West Bengal in line with the aim of decentralising to facilitate implementation of NACP-I. Since mid-2007, WBSAPCS has been implementing NACP-III, including priority-targeted interventions for the most at-risk population; preventative interventions for the general population; the provision of low cost

HIV/AIDS care, support and treatment; and institutional strengthening. It notes that, as more HIV infected persons are detected at hospitals throughout the State, the demand for care, support and treatment at institutional, community and family levels is increasing (WBSAPCS 2011)

To ensure effective implementation of the Greater Involvement of People Living with HIV (GIPA) principle, it is said that PLHA have been included in decision-making and it is intended to ensure compliance and drug adherence through community participation. Currently, according to the WBSAPCS, about 9,500 PLHA are receiving ART in West Bengal. To increase the number of eligible PLHA on ART, linkages are reported to have been created with a number of programmes, centres and grassroots networks, through the adoption of approaches such as the WHO-recommended Directly Observed Treatment Short Course (DOTS) and establishment of Targeted Intervention groups and Integrated Counselling and Testing Centres (ICTCs) (WBSAPCS 2011).

One of the first places where ART services were provided is located adjacent to the STM in Kolkata. It was established in 2004 and is one of the three ART centres operating in West Bengal. As per the guidelines generated by the NACP-II and III, the objectives of the ART centres are to provide free lifelong ART to PLHA; treatment of opportunistic infections; free CD4 tests; beds for critically ill patients (with the help of adjacent public hospitals); and counselling services to improve education on stigma and discrimination, increase the psychological well being of PLHA and improve adherence to ART. They do not provide any support for people's livelihoods<sup>2</sup> (NACO 2011 and WBSAPCS 2012), even though a quarter of a sample of 100 PLHA interviewed in Delhi said that they would like the government to

provide them with suitable jobs (Singh et al., 2009).

The key features of HIV/AIDS care, support and treatment are listed by the WBSAPCS as including:

- Involvement and participation of PLHA through networks in all the districts of West Bengal through registered community based organisations (CBOs).
- The use of Community Care Centres (CCC) that act as a ‘stop gap’ between the hospital and homes of the PLHA, usually with a maximum capacity of 30 beds.
- Provision of drugs for the treatment of opportunistic infections and post-exposure prophylaxis.
- As TB and HIV overlap, rates of TB recurrence tend to increase due to both endogenous reactivation and exogenous re-infection. In addition, the incidence of TB amongst the general population may increase as a result of the increased number of TB cases amongst those infected with HIV. Thus the prevention and control of these diseases is to be coordinated, through cross-referrals between HIV-VCT centres and TB treatment centres. TB drugs are available in the State through the Revised National Tuberculosis Control Programme (RNTCP), which aims to control TB by detecting at least 70 percent of new sputum positive TB patients and curing at least 85 percent of them (WBSAPCS 2012).

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<sup>2</sup>The availability of these services was confirmed by the Chief Medical Officer (Professor Saha) and the person in charge of STM and the ART centre in Kolkata during an informal meeting in September 2008.

The section above has summarised the priorities identified and main actions taken by the Indian government to contain HIV/AIDS and attempted a preliminary assessment of progress. Many of the initiatives depend on delivery through the health care system, so the following section will provide an overview of the health care system and services available to PLHA in India, and if relevant information is available, in Kolkata.

### **4.3 HEALTH CARE SYSTEM AND SERVICES AVAILABLE TO PLHA IN INDIA**

The purpose of this section is to firstly provide an overview of the existing health care system in India, to provide a picture of the kind of system from which people have to seek healthcare on an everyday basis and then to investigate the types of facilities available to PLHA, in order to understand the availability of facilities and services and identify constraints on accessing them. Sub-sections 4.3.1, 4.3.2 and 4.3.3 provide brief overviews of the public, private and not-for-profit sectors and the types of services they provides for PLHA respectively. This information will be drawn on when analysing the fieldwork findings, enabling comparisons to be made between what is theoretically available to PLHA and the actual experience of the research participants.

#### **4.3.1 Health services provided by the public sector**

This sub-section will discuss the ways in which the public health care sector provides services through the central and State governments, the typical services provided and



how much is spent on health care for the national general and West Bengal population.

Since 1946, health policies and priorities have been outlined in India's Five Year Plans, developed as part of its centralised planning and development strategies. The need for universal comprehensive care was reiterated in the first official National Health Policy in 1983. Shaped by the Alma Ata Declaration, the recommendations emphasised improved primary health care, decentralisation of the health system, improved community participation and expansion of private sector provision to reduce the burden on the public sector (D'Cruz and Bharat 2001). The central, State and local governments provide services in urban areas in the form of health posts, dispensaries, general hospitals and speciality hospitals. The central government runs some public hospitals, provides full financial support to some autonomous institutes of national importance and runs health care services for its own employees and their families through the Central Government Health Scheme (CGHS), with some ministries and departments of the central government managing these services. There are also hospitals that are jointly financed by the centre and the States. State governments operate a hierarchy of agencies including well-equipped hospitals and/or hospitals with medical colleges at State and district levels, civil hospitals at district level and general hospitals. Some of these hospitals cater to the entire population, while others are run by specific departments of the State government for their staff and their families, for example the Employee State Insurance Scheme (ESIS) hospitals (D'Cruz and Bharat 2001).

Overall, India's large public health services delivery infrastructure is characterised by under-funding and low performance, with adverse outcomes for the urban poor: referral, preventive and outreach services are either poor or absent; outpatient departments (OPD) may be opened for only short periods, during which no treatment may be given, especially in the absence of a doctor; overcrowding is common and people are often kept waiting. In addition, poor urban people may find it difficult to access services despite their physical availability, for example because they lack awareness of services that are available and may incur substantial indirect costs, including the time costs of travel and waiting, and income foregone as a result (D'Cruz and Bharat 2001).

Although the public sector provides primary to tertiary care largely free of cost in principle, India spends less than five percent of its gross domestic product (GDP) on healthcare, of which public expenditure on health was estimated to be just over one percent between 2007 and 2009 (Kumarasamy et al. 2007; Balarajan et al., 2011). Expenditure on health differs by a factor of seven between the major states and, in addition to interstate variations, a greater proportion of resources are given to urban-based and curative services, with around 29 percent of public expenditures (both central and State) allocated to urban allopathic services in 2004-2005 (Balarajan et al., 2011). In practice, the majority of curative services are provided by the private sector (Peters and Muraleedharan, 2008). Preventative care, in contrast, is largely provided through the public sector, which carries out about 90 percent of immunisations and 60 percent of antenatal care, with the distribution of both of these services disproportionately favouring the poor (Peters and Muraleedharan, 2008). Overall, therefore, the provision arrangements for health care favour the rich over the poor. In

addition, although there is no regular tracking, the most comprehensive analysis of utilisation and spending of public resources in health demonstrated that nationally, public spending is about three times greater for the wealthiest quintile of Indians than the poorest quintile (Mahal et al., 2001). In 2009, the Government of India drafted a National Health Bill, which recognised the right to health and the right to health care, implying that it would address the social determinants of health and these inequalities. However, implementation of policy commitments to equity in health care remains a challenge because of the lack of institutional and implementation capabilities (Balarajan et al., 2011).

Two thirds of the population of West Bengal reside in the rural parts outside of Kolkata, where most primary health care centres are located. Although only a third of the population live in Kolkata, public provision consists of 48 government hospitals, under the Department of Health and Family Welfare, Government of West Bengal, including five hospitals with medical colleges and a large number of specialised hospitals (Department of Health and Family Welfare, 2012).

In general, when people who do not know their HIV status go to a public hospital for diagnosis and treatment, a routine blood test is usually done to ascertain whether they are HIV positive. If the test results show that they are HIV positive, the hospital concerned refers them to STM, the main ART treatment centre in Kolkata, for further investigation and potential treatment. For confirmation, further tests are carried out and CD4 white blood cells monitored. If a person is confirmed as HIV positive, he or she is counselled in the out patients' department and if necessary, referred to the ART centre for a free of cost first or second-line ART regimen to begin. At the ART

centre, further counselling is provided for new patients, who are told to return to STM after six months for their CD4 levels to be monitored and if necessary, to obtain medication for opportunistic infections. The latter is provided free of charge, though patients incur charges for diagnostic testing (a CD4 count test costs \$10<sup>3</sup>) and in-patient treatment (\$3 per bed per night). However, at the time of fieldwork, STM only had 17 beds for critically ill patients, so the facilities of the Calcutta Medical College and Hospital, a teaching hospital located adjacent to STM, are usually called upon when the facilities of STM reach their maximum capacity (informal meeting with Professor Saha, September 2008).

As per the 2006 guidelines of NACP-III, the WBSAPCS followed a specific protocol for the provision of voluntary counselling and testing (VCT) services for HIV. There were 46 voluntary counselling and testing centres (VCTC) located in various hospitals with medical colleges, district hospitals and sub-divisional hospitals in West Bengal and since 2006, NACO supported nine VCTCs in Kolkata alone, one of which was in STM. West Bengal also has 44 STD clinics supported by NACO, including eight in Kolkata, of which five are in medical colleges that provide testing and treatment for STDs. Other preventive approaches adopted by the hospitals with medical colleges, district hospitals and sub-divisional hospitals in West Bengal and Kolkata and supported by NACO include awareness raising campaigns, the prevention of parent-to-child-transmission (PPTCT) and, blood safety programmes at blood banks that are run by the State, the central government and in some cases, the private sector (WBSAPCS 2012).

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<sup>3</sup> Between December 2008 and April 2009 the exchange rate of one dollar equaled to fifty rupees (\$1=Rs.50).

As already mentioned briefly in sub-section 4.2.2, care and support for PLHA are intended to be provided by the establishment of Community Care Centres (CCC). These are intended to have ‘drop in’ centres for PLHA and in-patient beds for stays of between five and fourteen days. There are seven CCCs in West Bengal, including two in Kolkata. As per WBSAPCS guidelines (supported by NACP-III), the purpose of a CCC is to provide an intermediate care facility between home and hospital and effective referral services to VCTC, ART centres, and providers of treatment for TB, STD, and opportunistic infections. In addition, CCCs are responsible for providing counselling to inpatients; coaching PLHA on the administration of ART, including adherence and treatment of ART-related side-effects; and providing healthy meals with nutritional supplements in the form of multivitamins and multi-minerals to support PLHA. The report by WBSAPCS states that NACP-III is not responsible for providing funding for livelihoods support for PLHA in West Bengal (NACO, 2007 and WBSAPCS, 2012).

### **4.3.2 Health services provided by the private sector**

Although none of the respondents interviewed were attending private clinics at the time of the study, the majority had been to one or more private clinics at some point during their illness trajectories, which is congruent with previous studies carried out in India by WHO (2000) and the World Bank (1995). These studies revealed that private providers are the most common source of outpatient and primary healthcare services in India, and are often health-seeking individuals’ first point of contact within the health system. It was therefore deemed important to consider the range of services potentially available from the private sector before examining research participants’

choice and experience of private providers. The purpose of this sub-section is therefore to provide a brief overview of the operation, provision and organisation of the private health care sector in India in general and, if known, in Kolkata.

The private sector in India primarily consists of individual private clinics run by doctors, often located in residential premises, either individually or with one or more partners. These dominate the private medical sector in most cities (Baru Rama 1998). The doctors include those from both the allopathic and non-allopathic disciplines (Deshpande et al., 2004). This kind of private clinic set-up also exists in Kolkata.

In terms of people's health seeking behaviour, a study carried out by Sudha et al. (2003), which investigated the factors influencing the care-seeking behaviour of people with chest symptoms in South India, found that private health care facilities had been the first and preferred point of contact for over half of the respondents from the urban and rural population studied, due to their proximity to people's places of residence. Similarly, Babu et al. (2010) found in their study of 161 people in an Eastern city that, because there were no government clinics near where their research subjects lived, the majority went to private practitioners. Other similar studies have shown that private health care providers are hugely popular amongst the majority of people in India due to their greater sensitivity to user needs and the assurance of confidentiality (Ogden et al., 1999; Bhatia and Cleland, 2001; Kamat, 2001). Just over 71 percent of health spending in India is paid privately (one of the highest proportions of household out-of-pocket health expenditures in the world), with the result that the financial burden of health care is met primarily by households and

imposes significant demands on their resources. According to Jesani (1996), private providers charge high fees and may deny care to patients who cannot afford to pay.

Nationally, just less than half of all people seeking treatment reported that they had borrowed money or sold assets to pay for hospitalisation (Peters and Muraleedharan, 2008), resulting in more than half the households concerned falling into poverty. Findings from a study carried out in Andhra Pradesh, mentioned above in sub-section 4.2.1, reveal that of the 470 PLHA interviewed, over half stated that they had borrowed money or had had to sell assets in order to raise money for their loved ones to be treated, especially if this involved hospitalisation in a private sector hospital (Pradhan et al., 2006). Similarly, findings from a study in Tamil Nadu, revealed that, in addition to imposing catastrophic burdens on households, private sector health care expenditure led households to use up their savings, borrow from money lenders, friends or relatives, change their consumption patterns and sell physical assets (Vaishnavi and Dash, 2009). Overall, it is estimated that about 39 million Indian people are pushed into poverty every year as a result of health-related expenditure (Balarajan et al., 2011).

As the private sector is the first point of contact for the majority of people in India suffering from any major or minor illness, it is highly likely that many patients are first detected as HIV-infected in a private facility (Kumarasamy et al., 2007). A study carried out by Sheikh et al. (2005) showed that private practitioners are consulted by HIV-infected people and are actively involved in HIV management. They diagnose HIV infection, and treat PLHA with non-allopathic drugs, prophylactic antibiotics and

preventive therapy for TB. Ten percent of the private practitioners interviewed in their study also reported that they prescribed antiretroviral (ARV) drugs.

However, studies have shown that quality of care provided for HIV/AIDS by the private medical sector varies greatly. Examples of inappropriate practices revealed in the studies include unnecessary investigations and inappropriate drug prescribing (Mertens et al. (1998); Uplekar et al. (2001); Yesudian (1994); Kielmann et al., 2005). Sheikh et al's study also found that the regimens of ARV drugs and preventive therapy for TB being prescribed by the private practitioners they studied were not in accordance with standard treatment guidelines and were often inappropriate (Sheikh et al., 2005). In addition, it has been documented that private practitioners may advise patients suffering from HIV/AIDS that they need unnecessary and expensive CD4 investigations (Uplekar et al., 2001). Because of the combination of physicians from private for-profit organisations frequently ordering unnecessary investigations, people 'shopping' for appropriate treatment from different health care providers and CD4 counts alone costing \$25 per test, there is a widespread concern that many patients waste money on inappropriate testing, without necessarily receiving an accurate diagnosis (Kumarasamy et al., 2007; Sheikh et al., 2005).

The general literature shows that patient confidentiality is important to healthcare users, but the same study revealed that, because individual patient welfare is not seen as independent of the welfare of their families, some private practitioners had disclosed the information to patients' close families, sometimes without letting the patients themselves know the diagnosis (Kielmann et al., 2005). Thus the profit motive, which may influence providers to place their interests above those of their



patients, may also result in questionable and exploitative practices (Bhat, 1999; Yesudian, 1994).

### **4.3.3 Services provided by the not-for-profit sector**

The purpose of this sub-section is to give a brief overview of the not-for-profit sector's main functions in India, after which it will discuss the ways in which this sector provides preventative and/or curative health services, care and support to PLHA in the context of India and, if known, in Kolkata.

The not-for-profit sector is comprised of non-governmental organisations (NGOs), often called the third sector or the voluntary or charitable sector, although there is no clear definition of a not-for-profit organisation. One of the criteria is that the organisation concerned should be a legal entity. The Planning Commission considers various societies, associations, trusts or companies registered under the Societies Registration Act, 1860; the Indian Trust Act, 1882 and the Charitable and Religious Trusts Act, 1920 to be NGOs (WHO, 2005). The Charitable and Religious Trusts Act, 1920 governs religious trusts and missionaries. 'Charitable purpose' includes relief for the poor, education, medical relief and the advancement of any other object of general public utility, but does not include a purpose that relates exclusively to religious teaching or worship. The Societies Registration Act, 1860 defines a society as any seven or more persons associated for any literary, scientific or charitable purpose. Both trusts and societies are exempted from income tax. Currently, almost every State has adopted its own Societies and Charitable Trust Acts (WHO 2005). According to proponents, 'third sector' organisations located between the state and

the market share distinct characteristics: they possess an internal organisational structure, are structurally separate from government, and do not generate profits that are distributed to members (Robinson and White 1997). During the 1980s, this sector grew in terms of its size, scope, number of organisations and volume of activity, not only in India but worldwide, in response to the dominant neo-liberal perception that state organisations are inefficient. The term NGO, which began to be used during this period, thus includes a collection of organisations differing in size, form, orientation, resources, target groups and ideological affinity (Valhans 1990).

Local voluntary efforts long predate the recent growth of the third sector in India. They include the charitable and philanthropic institutions associated with various religious traditions, including health facilities, although during the colonial period, additional welfare and developmental organisations and activities emerged. Until the mid-1960s, the not-for-profit health sector was hospital-based, but it later expanded to include community health, sometimes as part of development projects. The not-for-profit organisations that are presently delivering curative health services range from faith-based to CBOs working at the primary and secondary levels and also a few at the tertiary level. In addition, big business groups have also established hospitals as trusts or societies, which qualify them for tax exemptions. Due to the heterogeneity and plurality of providers, the nature of services also varies. At one extreme, there are CBOs in rural areas that provide health services at the primary level. At the other end of the spectrum, there are trust hospitals, located mostly in urban centres, providing secondary or tertiary care. Allopathic medicine is dominant in most not-for-profit hospitals (WHO 2005).

Today, NGOs work on varied issues, such as poverty alleviation and livelihoods support, women's empowerment, health awareness and education, and improving water supply and sanitation, in addition to the provision of medical care. For example, in health, NGOs are involved in the delivery of interventions in the field of reproductive health in general, while HIV/AIDS support and rehabilitation are almost exclusively the domain of the voluntary sector. However, due to the high numbers of PLHA requiring this support and the NGOs' lack of capacity to meet the demand, the needs of many PLHA go unmet (Hawkes and Santhya, 2002; Mitra 2004; D'Cruz and Arora, 2010).

The programmes initiated by NGOs are heterogeneous, with varying objectives, scales of operation and areas to which they cater. They vary from small grass roots organisations that work in defined locations to large institutions working in multiple sites and with many target populations, and many appear to be more flexible than public sector organisations (Hawkes and Santhya, 2002). In particular, NGOs take on responsibilities for information dissemination among the general population about HIV/AIDS, including de-sensitizing the issues, in addition to being involved in advocacy to protect the human rights of PLHA. The financial sources that not-for-profit organisations draw upon include donations, government funding as grants-in-aid, government support through tax deductions, funding from foreign donors, corporate funding and user fees. In the case of the national programme for HIV/AIDS, the central government of India releases grants-in-aid to NGOs across the States and some funds from foreign funding agencies are also channelled through the government (World Bank, 2006).

There is a lack of evidence related to the quality of health care services provided by NGOs in Kolkata, both in general and particularly for HIV/AIDS, so it is not possible to describe their typical characteristics or assess people's experiences of using them. However, one study carried out in New Delhi of 100 PLHA who had been staying at care homes run by NGOs for a significant period of time, revealed that the majority were satisfied with the medical treatment and overall care provided by these homes (Singh et al. 2009). The lack of previous research means that it will not be possible to compare the responses of the participants in the current study with the findings of previous research with respect to accessing help from NGOs and/or other not-for-profit sectors.

#### **4.4 CHAPTER CONCLUSION**

This chapter has examined the nature of the social context in India, the origins and nature of the HIV/AIDS epidemic, some empirical work that has examined the implications of HIV/AIDS for livelihoods and wellbeing among the poor in India, and the structure and characteristics of health care provision at the national, State and Kolkata levels, with particular reference to the HIV/AIDS prevention, treatment and care services available from a variety of providers. Its intention was to provide information about the context within which the empirical findings presented in chapters five and six and discussed in chapter seven needs to be understood and a starting point for assessing the similarities and differences between the situation studied in Kolkata and the findings of other studies in India. This conclusion will be confined to identifying some of key findings that have emerged from previous studies

and to identifying some of the gaps in existing Indian research, to supplement the conclusions already drawn from the international literature review.

Regardless of whether they are HIV positive or not, women in general have always been treated worse than their male counterparts; be it within the society in which they live and/or by their own household members. As expected, the material reviewed in this chapter reveals that in patriarchal Indian society, women's activities are restricted by both their households and wider social norms, although some women (with certain social characteristics) are 'allowed' to seek employment outside the household. Women are very dependent on the economic and social support they receive first from their natal families, and later from their husbands and their husband's families, and on which they depend for social respectability and emotional wellbeing. Failing to fulfil social and family expectations can make life very difficult not only for women but also for men, and these pressures are exacerbated when HIV/AIDS enters the picture. All the studies reviewed, with one exception, revealed that PLHA were subjected to discrimination and rejection by their family members after disclosure and many reported that they had felt ashamed of themselves, guilty, unloved, alone and often suicidal due to their positive status. Findings from three studies in the Indian context also revealed that most PLHA were afraid to reveal their HIV status to their employers for fear of losing their jobs. The same studies revealed that PLHA have also been subjected to isolation, treated badly, and denied medical assistance and entry to government-run and/or private hospitals. Findings from Bharat's study for UNAIDS (2001) revealed that one of the ways in which PLHA cope with living with their illness is to keep their HIV status a secret (secrecy is considered to be a negative internal coping strategy, see 2.1.2) in treatment facilities, for fear of being denied

care. The need for PLHA to make significant payments for private sector treatment is a final important finding that emerged from this chapter, which correlates with findings that emerged from the international literature (see 2.2.2 and 2.3.2).

It is clear that the Indian literature on a number of issues relevant to the research questions is quite limited – some of the gaps provide a further rationale for the study reported on here. First, there is some research related to Indian PLHAs' own perspectives on living with HIV/AIDS, but none in the context of Kolkata. The respondents in most studies report a sense of shame and experiences of discrimination, although the low caste labourers from Tamil Nadu and Uttar Pradesh studied by Priya and Sathyamala, (2007) did not appear to suffer from shame or guilt due to having contracted HIV/AIDS and nor did they report any forms of discrimination within their households or outside. This study in Kolkata may throw some light on whether the findings from this and other studies are more widely applicable. As reported in 2.1.2, very little evidence is available on the illness coping strategies of PLHA and so it will not be possible to compare the responses of the participants in the current study with the findings of previous research, with the exception of the study by Bharat for UNAIDS (2001) in Mumbai and Bangalore, which found that PLHA used secrecy in treatment facilities for fear of being denied care.

Second, there has been little evaluation of the quality of health care services provided for PLHA in India, especially those provided by NGOs, both in general and particularly for HIV, with the exception of one study in New Delhi (Singh et al., 2009), as discussed above. In addition, very little research has been carried out to

evaluate how and why some HIV/AIDS programmes and policies work or do not work for poor PLHA in either urban or rural India (and whether lessons have been learned as a result) and no research of this kind has been carried out in Kolkata. As noted in 4.2.2 and 4.3, this study will attempt to partially fill these gaps by exploring PLHAs' own perceptions of the adequacy of the health care services and support programmes for PLHA provided by NGOs and/or other not-for-profit organisations, although a systematic assessment of the quality and outcomes of health care provision and support programmes and policies is beyond its scope. As with some other aspects, the lack of previous research means that in several respects this study will be groundbreaking but it will not be possible to compare the responses of the participants in the current study with the findings of previous research.

## **CHAPTER V**

### **EXPERIENCES OF LIVING WITH HIV/AIDS AND THE EFFECTS OF THE ILLNESS ON HEALTH**

#### **5.0 INTRODUCTION**

This chapter will examine experiences of living with HIV/AIDS before and after formal diagnosis reported by the participants in this research and then explore their attempts to cope with the illness on an everyday basis. Part of coping with the illness is the need to access a variety of services dealing with prevention of further transmission, treatment, care and support. In this chapter, the analysis will focus on the types of health care services the respondents sought in order to obtain a diagnosis and subsequently ongoing treatment and care for their illness. The final section of the chapter will focus on the respondents' assessments of the services that they accessed. The chapter thus addresses the following research questions: first, how do PLHA with different social characteristics experience living with their illness on a daily basis and second, how do they access and assess the adequacy of health care services for HIV/AIDS? First, an overview of the social characteristics of the research participants, including their differing levels of education, is provided in Tables 2 and 3 below.



- **Overview of the participants' social characteristics**

This study is concerned with the effects of HIV/AIDS on poor people and their families, and the participants in the study were selected by purposive sampling to reflect the typical characteristics of the poor in Kolkata. As explained in 3.2.2, participants in the study were selected to include representatives with what were considered to be the most relevant social characteristics: HIV positive, both men and women, poor, but with a variety of educational levels, and from different religious groups. The characteristics of the participants are shown in Tables 2 and 3.

**Table 2: The gender and religious composition of the participants**

NGOs	WOMEN	MEN	HINDU (Women and Men)	MUSLIM (Women and Men)	CHRISTIAN (Women and Men)
KNP+	9	6	11	4	0
SPARSHA	9	6	13	2	0
ARUNIMA HOSPICE	7	8	10	4	1
STM	5	9	13	1	0
<b>TOTAL</b>	<b>30</b>	<b>29</b>	<b>47</b>	<b>11</b>	<b>1</b>

Table 2 shows that as intended, half the participants were men and half women, and 80 per cent of the participants were Hindus, 19 percent Muslims and 1 was a Christian, reflecting the religious composition of India as a whole.

**Table 3: The education levels of participants**

EDUCATION LEVELS	NONE	PRIMARY (Years 1-6)	SECONDARY (Years 7-10)	HIGHER (11 or higher)	TOTAL
WOMEN	10	11	8	1	30
MEN	8	11	9	1	29
<b>TOTAL</b>	<b>18</b>	<b>22</b>	<b>17</b>	<b>2</b>	<b>59</b>

While the study set out to focus on poor people, it also recognised (see section 3.1) that one important influence on people's ability to earn a living is their educational level and so participants with a variety of educational levels were selected. As shown by Table 3 above, 31 percent had no education, 37 percent had primary level education, 29 percent had secondary level education, and 3 percent had further education. Reflecting the general situation in India, the men were slightly more educated than the women.

The types of dwellings the participants lived in, mostly gleaned from the interviews, were mainly pucca bungalows and flats with walls of burnt brick or stone packed with mortar, floors of stone or cement and roofs that were concrete or asbestos sheets. As in many Kolkata slums, their dwellings were mostly rented, with one or two rooms, and the areas in which they lived had open drainage.

At the time of the study, the participants had all been diagnosed with HIV. The median year in which they had been diagnosed was 2007, so most were in the early stages of their illness. Their approximate mean age was 36 years.

The participants had lived in Kolkata, other villages within West Bengal, Mumbai, Orissa or Bihar for most or part of their lives, but at the time of interview, most had been living in Kolkata for five years or more.

The organisations of which the participants were members are located in North (SPARSHA and KNP+), Central (STM) and South Kolkata (Arunima Hospice) and those interviewed lived in the areas surrounding the relevant organisation, with the exception of the STM, which has a citywide catchment area. Please see map 1.



**Map 1: The City of Kolkata**

## **5.1 LIVING WITH HIV BEFORE AND AFTER FORMAL DIAGNOSIS AND THE TYPES OF COPING STRATEGIES USED**

This section is concerned with the first stages of the illness, namely the symptoms experienced by people prior to a formal diagnosis, the process of obtaining a diagnosis and people's immediate reactions to their diagnoses. It will begin with an account of people's perceptions of their HIV-related symptoms prior to formal diagnosis, present their accounts of the process of obtaining a formal diagnosis, and identify the effects of their diagnoses on the individuals themselves, their partners, household members, close and extended families, friends and neighbours. Finally, this section will conclude by examining people's immediate coping strategies when they are diagnosed with HIV/AIDS.

### **5.1.1 LIVING WITH HIV BEFORE FORMAL DIAGNOSIS**

The participants reported that they had initially begun to feel very ill and show the symptoms of HIV between one and six years prior to a formal diagnosis. The symptoms they reported included fever, chest pains, flu-like symptoms, vomiting, sexually transmitted infections, rapid weight loss, insomnia, itching, rashes, malaria, a general feeling of weakness and diarrhea. Nearly all had been living with their symptoms on an everyday basis for a significant period of time before they were formally diagnosed. For example, participant AW<sub>1</sub> (see 3.2.2 and appendix three for index of all participants), a 30-year old outreach worker based at an NGO, with primary school level education, had been formally diagnosed with HIV in 2003, five years after she showed HIV-related symptoms:

*“...I was completely broken down; I had TB and herpes. I didn’t know what to do so I just stayed at home. I didn’t do anything after my husband died apart from go and get treatment from private clinics, but I was not recovering and I had fever all the time and herpes, and the pain was unbearable...”*

Her description shows that initially she had no idea what was happening to her, even when the symptoms worsened after the death of her husband in 1998. Participant BW<sub>2</sub>, a 42-year old Hindu woman with no education, whose husband had abandoned her, her son and her grandson, described a similar experience of longstanding HIV-related symptoms before her formal diagnosis in 2006.

Initially, most participants reported that they had sought medication from pharmacies, but when their symptoms persisted, the majority had sought professional help from private clinicians, who as noted in the previous chapter, are found in abundance in India. Participants typically reported multiple visits to health care practitioners before they were able to obtain a correct diagnosis of their symptoms, often leading to depletion of their savings. AW<sub>2</sub>, a 32-year old Muslim woman with secondary school education, who was formally diagnosed with HIV in 1998 and whose husband died a year later, provided a description of the experiences that she and her husband had to go through in order to get a correct diagnosis:

*“...my husband had started to fall ill from 1997 onwards and he went to private clinics to get himself tested but he didn’t go to one private clinic, he went to many private clinics and he spent all the savings on doctor’s visits and on tests. HIV tests were very costly at that time. Eventually, in one of the private clinics, they finally told him that [he] was HIV positive and he was then referred to STM. I went along with him and had my blood test done too*

*at STM. My husband died within few months of being tested... he didn't know where else to go and nobody told him to go to STM until it was too late...*

This participant and others refer to the cost of the consultations, an issue that will be considered in more detail in section 5.2. Similarly, participant BM<sub>10</sub>, a 35-year old unmarried Hindu man with secondary school education, who lived on his own and was diagnosed in 2008, stated:

*"...I was feeling very ill for a long time after I had an operation. My glands were always aching and I was falling ill and had to take time off from work. I kept going to private clinics and one of these private clinics diagnosed me with gland TB. At the same time, he [the doctor] asked me to go to STM. I didn't understand what was happening to me..."*

As a result of their own failure to suspect the root cause of their symptoms and the failure of clinicians, especially an array of private clinicians, to provide a correct diagnosis, the above informant, like many others, began to feel afraid and helpless.

Women in general found out about their HIV status after their husbands became critically ill and were taken into hospital or died, although some found out during antenatal check-ups. For example, participant BW<sub>5</sub>, a 24 year old woman with primary school level education, described how:

*"...my husband and I were diagnosed with HIV two years ago, whilst I was pregnant with my second child...I initially went to a government hospital for a routine antenatal check-up when I was seven months pregnant and after they had done a blood test, they found out that I was HIV positive...I then asked my husband to get himself tested too..."*

As will be discussed below, for a woman to learn about her HIV status when pregnant raises the spectre that the child will be HIV positive when born.

No significant differences were found in the responses of participants with different religions and education levels.

The process by which people sought professional help will be discussed further in section 5.2. In the next sub-section, their reactions to the diagnosis are explored.

### **5.1.2 IMPACT OF HIV AFTER FORMAL DIAGNOSIS**

As discussed in 2.1.3, a study carried out by Jenkins & Guarnaccia (2003) found that for people living with HIV or AIDS, the most significant HIV-related stressor was the anticipation and receipt of HIV-positive results, which had an effect on both their mood and their immune system. This research did not have access to clinical tests to determine the impact of diagnosis on participants' immune systems but it did examine the effects the diagnosis had on their mood and extended the analysis by examining its impact on their lives in terms of (1) how they thought partners, household members, neighbours and people within the society would see them and (2) the effects of partner notification and disclosure of HIV status to their immediate households, wider families, neighbours and others.

What emerged most clearly was the issue of stigma, both perceived and enacted.

A few respondents explained how they had felt prior to disclosing their HIV positive status to their partners. Some felt that it would be futile to disclose their positive status

to their immediate households or families, as members of their households or wider families were neither financially nor emotionally secure enough to be in a position to help them. For example, an uneducated 32-year old married woman with two children, who had been diagnosed at the same time as her husband in 2005 (AW<sub>10</sub>), explained that:

*“...I feel that there is no point in telling my own family or my in-laws, because they won’t be able to help us out, as they themselves don’t have anything...”*

Similarly, DM<sub>11</sub>, a 45-year old Hindu widower, with a secondary school level education, who had initially been diagnosed with HIV at a private hospital three weeks prior to his formal diagnosis at the STM on the day of his interview reported that:

*“...I haven’t told my sons about my illness...I don’t want to tell them because they would be worried. I keep my problems inside me...”*

The participants were also asked what they thought would happen if they disclosed their positive status to their extended families. Several responded that they had been hesitant to do so for fear of being judged adversely. For example, participant CM<sub>11</sub>, a 57-year old unmarried man, with secondary level education, who lived with his mother and brothers and had been diagnosed three months prior to the interview, revealed that: *“...my uncle, aunty and cousins do not know about my illness but my own family knows...”* A woman respondent (participant AW<sub>2</sub>, formally diagnosed with HIV in 1998, who was mentioned in 5.1.1) revealed that she had been reluctant to disclose her status to her sister-in-law for fear of being thrown out of the house.



Several participants showed concern about what might happen to them and their families if their neighbours found out about their positive status, as they were generally aware of the stigma attached to the disease. For example, participant CW<sub>5</sub>, a 60-year old Hindu widow with no education, who had been diagnosed with HIV one and a half years prior to the interview, affirmed: *“...nobody in the neighbourhood knows about my illness. I heard that it’s a bad illness. I am afraid of what other people might say ...”*

On occasion the fear of stigma had been fuelled by professionals, hindering some people from disclosing or talking openly about their status in their neighbourhoods. For example, participant AW<sub>10</sub> related how a doctor from a private clinic had advised her against disclosing her status to her neighbours because not only will she be stigmatised but her family will be ostracised too.

Others (for example participants AM<sub>4</sub> and AM<sub>8</sub>) were apprehensive about telling their neighbours in case their landlords would find out and evict them from their rented accommodation, or their employers would do so, causing them to lose their employment. Thus participant AM<sub>8</sub>, a 45-year old married Muslim man with three children, who had secondary school education, claimed that his livelihood as a religious figure performing rituals and prayers in the homes of neighbours would come to an end if the neighbourhood found out about his positive status, and another participant (AM<sub>14</sub>), a 41-year old Hindu widower with a secondary school level education who had been diagnosed in February 2007, reported that he had left his job for fear that his HIV status would be discovered by his employers

However, for others, disclosing their status to their neighbours did not seem so daunting. For example, participant AW<sub>5</sub> (an uneducated 37-year old Hindu woman separated from her second husband, who had been formally diagnosed with HIV in 2007) stated: *“...My neighbourhood knows about my status. Many are also HIV positive in the area where I live and they come to KNP+ also...”*, and AW<sub>12</sub> (a 42-year old Hindu widow with a 16-year old son, who had studied up to year 8 of secondary school and had been formally diagnosed with HIV in 2005) asserted: *“...I am not scared! Of course, I won't shout it out from the rooftops but I won't be scared of telling someone if they ask me. My old neighbourhood knew about my illness. I wasn't scared then...”*

Finally, the participants were asked what they had thought would happen if they made their positive status public. The majority responded that they were aware of the stigma attached to the illness and so if the wider society found out about their positive status, they expected to be looked down upon. For example, participant CW<sub>12</sub> (a 25-year old Hindu married woman with very little education who had been diagnosed with HIV a few weeks prior to the interview) stated:

*“...people say bad things about this illness but nobody says anything about cancer, even though this is also an incurable illness...”*

Participant AW<sub>3</sub> (a 31-year old Hindu married woman, with a completed secondary school level education, who had two children and had been diagnosed with HIV in 2004) shared this view:

*“...People always see the bad side of things. That's why I don't tell people about my status, because people would be disgusted by me. In Kolkata and in*

*India in general, people don't know much about HIV and so they treat PLHA very badly, treat them with disgust..."*

For some men, the issue of "morality" surfaced: they were concerned about how their neighbours and others would perceive them. Participant DM<sub>12</sub> (a 50-year old Hindu man with a completed primary school education who had been formally diagnosed with HIV at STM less than two months prior to the interview), for example, explained:

*"...I haven't told the neighbourhood because I was and still am a very good boy...if the neighbourhood knows that I have this disease then they would behave very badly and think badly of me..."*

Participant BM<sub>10</sub> (mentioned in 5.1.1) appeared puzzled and scared, asserting:

*"...I haven't slept with a bad girl...I just felt why [did] this happen to me when I didn't do anything wrong to deserve this illness? I was and still am really very scared about people finding out about my illness...people won't understand, they will think that I have been to bad places and treat me very badly..."*

Occasionally, respondents like participant DM<sub>8</sub> - a 37-year old married man with primary school level education who had been formally diagnosed with HIV a few days prior to the interview, expressed remorse for the way they had contracted the virus, making them hesitant to tell their families and/or wives.

The participants were asked what reactions they had experienced once they had decided to disclose their status to their partners, and subsequently other household members, members of their extended families, neighbours, employers and/or people within the wider society. In response, four of the 59 participants explained how they had disclosed their HIV status to their partners, with only one of the four stating that he had felt supported by his partner, while the others felt unsupported or reported that being HIV positive had led to a breakdown of their marriages and their families being torn apart. The first of these, participant BM<sub>6</sub>, a 41-year old married Hindu man, who had two grown up children and had been diagnosed with HIV in May 2007, talked about his guilt when he received his test results and found out about his positive status. He contemplated taking his own life, as he felt that his life would be over if his wife left him. However, he was relieved when his wife (a nurse) did not leave him, and indeed had supported him ever since.

In contrast, CM<sub>6</sub>, a 47-year old Hindu man living with his mother and six brothers and their wives in rented accommodation, who had been diagnosed with HIV in October 2008, five months before the interview, reported receiving an entirely negative reaction: “...*my wife left me when she found out that I was HIV positive and she now lives with her own parents and she doesn't come to see me, nor does she let me see my son...*” He reported finding his wife's refusal to allow him to see his son particularly upsetting.

Similarly, when women told their husbands about their positive status, it appeared quite common for them to be thrown out from their marital homes. For example, CW<sub>1</sub>, a 35-year old Muslim woman (who had been diagnosed a year and a half prior

to the interview), appeared to be in a state of confusion, having been recently thrown out of their home by her husband after she disclosed her positive status:

*“...When he [her husband] found out that I was positive, he had me removed from the house where I shared with my in-laws and made me return to my parents’ home in Kolkata. I try to call him now and again, but he doesn’t answer the phone and the times that he does answer, he threatens to kill me if I ever step foot at his house...I don’t know why my husband is treating me so badly, since he found out that we both are positive...”*

Two women reported that their families and in-laws had been supportive when informed, but these were exceptions. In most cases, members of respondents’ households (their in-laws or parents) were not able to accept the news that their daughter-in-law or daughter was HIV positive. The majority of HIV-positive married women who were later widowed were in a particularly difficult position, finding themselves unable to fit in any households, whether those of their in-laws, extended families or parents, as shown by the examples below.

AW<sub>1</sub>, a Muslim woman with primary school level education, who had become a widow in 1999 after her HIV positive husband died in an accident, described how she had lived with HIV-related symptoms until 2003, when she was diagnosed. Although she had then been able to obtain treatment, care and support, she had only recently been able to start working for one of the NGOs that assisted in this study as a peer worker. She described her situation retrospectively:

*“...My in-laws treated me badly after the death of my husband...they used to tell me to go away if I asked them for money and they blamed me for my husband’s death. I felt so alone at that time...”*

In other cases, women who had been thrown out of their marital homes had been treated badly when they returned to their paternal homes. For example, participant DW<sub>5</sub>, a 20-year old Hindu woman, who had been diagnosed with HIV only a couple of weeks prior to the interview, described what had happened to her when she became a widow at the age of 16:

*“...I had to hear “words” for the fact that I returned home from my in-laws’ place and also because I have the illness...at home we eat separately, they are scared that they might contract the virus by coming in contact with me...”*

Participant DW<sub>5</sub> not only had to tolerate the shame of becoming a widow and returning to her paternal home from her in-laws, she also had to endure discrimination within the household, so was understandably very distressed when describing her experience to the interviewer.

In several similar cases, women participants described how their families, both those of their in-laws and their parents, refused to make any physical contact with them for fear of “catching” the virus. Participant CW<sub>8</sub>, a 25-year old Muslim woman who had contracted the virus from her first husband and had been formally diagnosed in 2003, described how her first husband’s parents treated her when they first heard about her positive status:

*“...They [the in-laws] separated me from the rest of the family, didn’t let me touch my own children, made me use different bathrooms, didn’t let me touch the dishes that I was using and made me eat separately...”*

Participant CW<sub>1</sub>, mentioned above, who had been thrown out by her husband from their marital home and as a result had had to return to her paternal home, described how she was treated by her mother:

*“...Since I have been back in Kolkata, my mum has been horrible to me and makes me sleep in the balcony outside the bedrooms. I don't have a choice but to live there, as I have no money, no accommodation to go back to. I feel low all the time and cry all the time. Nobody at home wants to know me, as they are disgusted by me. My own mum doesn't want to know me, nor does my youngest sister. My elder sister, who is also at this hospice, is the only person who is nice to me and she doesn't feel disgusted by me. They don't like to eat with me, they remove my plate and make me sit separately to them...”*

However, in the view of CW<sub>1</sub>'s sister, it is possible that she was being punished by her Hindu mother for having eloped with and married a Muslim man and converted to Islam, as well as for being HIV positive.

Many participants described how disclosing their status to their neighbours was sometimes taken out of their hands and how their neighbours had sometimes caused problems for them and their families. For example, participant AM<sub>14</sub>, a 41-year old widower (with secondary school education) who had been formally diagnosed with HIV in 2007 after the death of his wife, described how distraught he was when his in-laws told his neighbours about his positive status. Similarly, a 30-year old Hindu married man (BM<sub>1</sub>) with two young children, who had been diagnosed in November 2007, affirmed that he had not had a choice about disclosing his positive status

because his neighbours had found out from his uncle, who had not kept his status confidential.

In most cases, participants believed that disclosing one's HIV positive status to neighbours might be detrimental to a person's employment, accommodation and safety. Their own experiences bore out this belief, so it is not surprising that they feared to disclose their status to anybody outside their immediate families. For example, a 42-year old married Hindu economics graduate (BM<sub>15</sub>), who had been diagnosed in 2002, described what had happened:

*“...There was a huge uproar at my neighbourhood when they found out that we were HIV positive...the opportunities for teaching students at my neighbourhood were gone once they found out about my status...people were trying to get us out of the house we were living in and trying to throw us out from our neighbourhood...”*

This participant was not unusual in experiencing loss or denial of employment. For example, when participant BW<sub>14</sub> (a 28-year old Muslim woman with no education) was made a widow in 2004, she went to ask for a job at her late husband's workplace in order to support her daughter and herself. There, according to her, she was made to do a blood test to prove that she was not HIV positive. When the blood test came out positive, she was not only denied employment, but the result was not treated in confidence and everybody in her neighbourhood had found out about her positive status.



Participant AM<sub>8</sub> (mentioned above) had had a similar experience. He described how he “...used to work in a big clothes shop in a busy shopping area of Kolkata but one day my manager looked into my bag and found my prescription and saw that I was HIV positive. This is how I got sacked from my job...” As a result, at the time of the interview, the only way that he was able to earn a living was to work as a *Mollah* (a Muslim religious teacher trained in the doctrine and law of Islam), and only because his neighbours were not aware of his positive status.

In contrast, a couple of participants described how their neighbours had accepted them, sometimes despite an initial hostile reaction. For example, one of the participants and his family, a 32-year old Hindu married man with two young children who are HIV positive, whose wife is also HIV positive, described how: “...My neighbourhood knows about our status and there has been some behaviour change...I was called out some terrible names but these days they don't call me bad names anymore...everything has calmed down at the neighbourhood...”

In addition to the reactions of others when learning of a participant's HIV status, participants' own feelings when they were first diagnosed were explored. It became apparent that many men and women, from both religions, who had contracted HIV via sexual transmission described feeling “dirty”, “disgusted”, “ashamed”, “angry” and/or “worried” about having contracted the illness. Four out of the 59 participants, of whom three were women, expressed anger either with their partners for having “given” them the virus or with the situation that they had found themselves in. AW<sub>13</sub> appeared to be especially angry about the fact that her youngest son had turned out to be HIV positive. Fearing for her child's future, with no education and without

financial help from her husband, she explained that she did not know what to do, although at the time of interview she was being given temporary accommodation with her cousin and his family.

Those who had been recently diagnosed were particularly likely to express strong feelings about themselves: participants BW<sub>4</sub>, CW<sub>2</sub> and CW<sub>12</sub>, who had been diagnosed with HIV three months, one month and two days respectively prior to their interview; talked about feeling “disgusted”, “dirty”, “scared” and “ashamed” of themselves. One or two people also talked about wanting to take their own lives after their initial diagnosis, for example CW<sub>2</sub>, who explained how she had felt when she had been diagnosed with HIV a month prior to her interview: “...*I felt very low. I still feel extremely low and think about committing suicide often.* ”

Finally, several participants, mostly women, explained that the first thoughts that had come to their minds when they were diagnosed concerned their children’s future. For example, participant BW<sub>5</sub>, referred to above, who had two children at the time of interview, had been pregnant with the second child at the time of her diagnosis, and was waiting for her to turn 18 months before she could have an HIV blood test. Similarly, AW<sub>2</sub>, a Muslim widow who had been diagnosed with HIV in 1998 and was living in her paternal family, expressed her concerns for her own and her daughter’s future.

The strong incentive to deal with the illness provided by responsibilities towards children seems to be particularly strongly felt by women. For example, participant

AW<sub>12</sub> explained how, even when she was depressed after her initial diagnosis in 2005 and the subsequent death of her husband, the thought of her son kept her going.

No matter when they were diagnosed with HIV, be it three months or ten years before the interview, their anecdotes reveal the extent of their fear of disclosing their status to their immediate and extended families, friends, neighbours and others - for fear of being judged adversely or worse, that they would be evicted from rented accommodation or lose their employment, or that their children would be forced to stop attending their schools. In contrast, a couple of people reported that they were not afraid of their status being known by their neighbours. There were no apparent differences between the men and women respondents with regard to how they felt they would be perceived by their neighbours and the wider society if people were to find out about their positive status, and both men and women were afraid of the consequences. However, only some men reported concerns that others would make moral judgments about their behaviour if their HIV status became known.

Most participants described their negative reactions to their own diagnosis and also how, for some people, their worst fears had come true when they disclosed their status to their spouses or immediate families. Only one person said that he had felt supported by his wife, with most feeling unsupported and in some cases, HIV positive status leading to the breakdown of marriages and families being torn apart. One of the main differences between men and women concerned the way they had been treated by their families following disclosure, with it appearing quite common for women to be thrown out of their marital or in-laws' homes. Married women with HIV positive status who later became widows were in an even worse situation, unable to fit

in any household, whether that of their in-laws, parents or other extended family members.

Many participants also described how disclosure was sometimes taken out of their hands when someone aware of their status had passed the news on to family members and neighbours. Respondents reported that stigma had been enacted in various ways, including verbal abuse, segregation, pressure to leave a neighbourhood and loss of employment.

### **5.1.3 COPING STRATEGIES EMPLOYED BY PLHA**

Participants' responses to questions about how they coped with the early stages of the illness concentrated on the period following formal diagnosis, rather than the earlier period during which many started to experience symptoms.

As indicated in 2.1.2, coping strategies related to chronic illness can be broadly classed into two groups, namely 'Positive External Coping', which includes dealing with stigma, optimistic planning and social networking with members of the HIV community, and 'Negative Internal Coping', which includes secrecy, negative rumination and self-isolation (Jenkins and Guarnaccia, 2003). This sub-section will explore how common each strategy was amongst PLHA who participated in this study, examining why people selected particular strategies.

Dealing with stigma is classed as a 'Positive External Coping' strategy, but participants in this study appeared to find it difficult to respond positively to the

stigma they experienced. Only one of the 59 participants referred specifically to attempting to do so. When asked how she had coped with living with her illness on an everyday basis, AW<sub>3</sub>, a 31-year old married Hindu woman who had been diagnosed with HIV in 2004, stated how she ignored people at the hospital or in her neighbourhood who made unpleasant comments regarding her illness, asserting “...*I don't feel low anymore when people say nasty things to me, especially at Calcutta Medical College...I listen with one ear and let it go with the other...I felt bad at first when it used to happen but now I feel OK about it...*” In sub-section 5.1.2, it was noted that when asked about the impact of receiving a formal diagnosis, this participant responded as expected that if people came to know about, she would be judged adversely. It was not clear from the response given above whether living with her illness for over four years had helped her to come to terms with it, enabled her to find ways of preventing people finding out, or enabled her to ignore critical remarks.

In contrast, optimistic planning, also classed as a ‘Positive External Coping’ strategy, was found to be more common, adopted by over 15 percent of the study participants. Some reported hope of recovery, so that they could start providing for their families again, as illustrated by participant CM<sub>3</sub>, a 32-year old married Muslim man who had been diagnosed with HIV two months prior to the interview and who stated his intention to get better so that he could provide for his family

Another, BM<sub>15</sub>, the married economics graduate referred to above, reported that in order to resist eviction he had filed a successful court case and stated his determination to continue doing so if necessary. Others were primarily concerned with the welfare of their children. For example, BW<sub>11</sub>, an illiterate 20-year old Muslim

woman who had been diagnosed with HIV five months prior to the interview, was five months pregnant and had recently been thrown out from her marital home. She stated: *“...I want to get on ART, be well and be concerned about the wellbeing of my baby. I want my baby to be well and not to have this illness, hopefully. I want to raise this baby with my mother and I could even go to work after I gave birth...”* This participant had the support of a strong willed and positive mother who said during the interview: *“...I would look after and protect my daughter as long as I am alive. My daughter doesn't have much contact with her husband. Once he came to Kolkata to try to take her baby away, when the baby hadn't even been born but I protected her and threatened to kill him if he ever came to our house again...”*

However, ‘optimistic planning’ in general was more common amongst men than women, with the former seeing their futures in a brighter light.

Social networking with members of the HIV community is another strategy that a significant minority of participants reported utilising. Eleven of the 59 participants asserted that they enjoyed being part of such a network, claiming that this helped them live with the illness on an everyday basis. Nine of these 11 were women, which could mean that women felt a greater need to be part of such a network than men, or that they felt more able to forge such links. It is possible that this response is not typical of all PLHA, as the interviewer obtained access to most respondents via the NGOs that were providing them with support. The 14 people interviewed at STM, where they had been recently diagnosed, did not have any knowledge of communities with members living with HIV and had not yet had time to make such links.

The types of negative internal coping strategies encountered in this study include ‘secrecy’, ‘negative rumination’ and ‘self-isolation’, confirming the value of Jenkins and Guarnaccia’s (2003) classification.

While some participants reported that they had been able to disclose their status to family members, friends and neighbours without fear, many had kept their positive status hidden from their spouses, mostly for fear that it would be discovered by neighbours or others. For example, participant AW<sub>2</sub> who was mentioned a couple of times in section 5.1, stated that she did not want to receive support from anybody outside her chosen NGO, as she was afraid of people in the wider society finding out about her positive status, which might be detrimental to her daughter’s future.

In another case, a husband had kept his HIV positive status secret from his wife, as she noted while describing how she had initially coped with her own illness:

*“...my husband got caught with HIV before but he didn’t tell me about it. He told his own mother but didn’t tell me about his status and the possibility that I could also be HIV positive...”* (BW<sub>13</sub>, a 20-year old Hindu married woman diagnosed with HIV in 2005).

As asserted by Thomas (2006) and emphasised by Greeff et al. (2008) (see subsection 2.1.2), people generally choose secrecy about their HIV status as a coping strategy if they are afraid that they and their families might be stigmatised, which is perceived to be a threat to receiving care. The findings from this study are consonant with these assertions, as participants reported that they not only expected to be looked down upon but also feared that HIV-positive status might be detrimental to their

employment, accommodation and safety, fears that were realised when they faced discrimination in the form of abuse, eviction and in one case, termination of employment.

Some engaged in the coping strategy, ‘negative rumination’, describing their fear and feelings of helplessness. For example participant BW<sub>12</sub>, a 21-year old illiterate, married Hindu woman, who had been diagnosed in 2009 asserted: “...*I don’t feel that I have anybody behind me to support me and I just want to die...*” Another participant, CM<sub>11</sub>, a 57-year old unmarried man, who had been diagnosed three months prior to the interview and has been mentioned in sub-section 5.1.2, commented on how he had intentionally isolated himself from his friends and neighbours in an attempt to keep his illness hidden: “*Financially, my family helps me, but mentally, I feel very alone.. I, intentionally, detached myself from everyday friends and from the workplace. I don’t want anyone to know. But I want to hang [out] with people who understand and share what I am going through...*”

It is clear from people’s accounts of their experiences before they were formally diagnosed (see 5.1.1) that their lack of knowledge had been very confusing for them. Their confusion and uncertainty was exacerbated by the lack of knowledge displayed and incorrect diagnoses made by the private clinicians from whom they attempted to seek help. These findings are consonant with Adamson’s (1997) concept of ‘existential uncertainty’, which he originally coined in the context of a study in which the participants, including the author himself, were suffering from inflammatory bowel disease and avascular necrosis. Such uncertainty about ‘becoming ill and ‘being ill’ is demonstrated, he suggested, when patients ask themselves the following



questions: “...*How long will things remain uncertain? How will the illness evolve? Do treatments exist? Do they work? What will life be like from now on? Uncertainty about the medical diagnosis can plunge patients into ‘existential uncertainty’...*”

The participants in this research reported that they had asked themselves similar questions both before and immediately after formal diagnosis, because they did not have much understanding of what their illness would mean for them.

It is not entirely clear from the responses whether the participants’ considered that their wellbeing had improved as time passed, but it appears that the majority learned to live with their illness, typically with the support of household members. Regardless of when they had been diagnosed: a few weeks prior to the interview, as for participant CW<sub>12</sub>, or five years before, as for AW<sub>3</sub>, the participants in general appeared to be reluctant to let their status be known in their neighbourhoods or the wider society due to fear of being stigmatised. These findings are consonant with Kelly’s (1992) view that people suffering from a chronic illness are acutely aware of the negative stereotypes held about people suffering from chronic illness, leading them to avoid telling others about their ‘abnormality’ for fear of being judged adversely. The passage of time had not made them any more inclined to divulge their status, although one or two participants reported that after an initial bad reaction, their neighbours had become used to their illness.

With regard to the participants’ ability to cope with living with HIV, the findings reveal that those with a higher education level (completed secondary schooling and/or

a graduate degree) and/or stronger household support coped better than those with very little education and weak or no household support.

## **5.2 ACCESS TO HEALTH CARE**

This section will investigate the process by which people accessed health care services, specifying any enablers and/or obstacles that they faced in the process. It will address the research question: ‘How do people access and utilise health services?’

The analysis is informed by the five dimensions of access discussed in 2.1.3 and 3.1, which influence the course of the health-seeking process, Good’s pathway model and the ‘Health Access Livelihood Framework’ (see figure 3 in sub-section 2.1.3).

### **5.2.1 Availability, Accessibility and Affordability**

In Obrist et al.’s (2007) framework (as noted in 2.1.3), ‘availability’ is defined as ‘the existing health services and goods meet clients’ needs’ and ‘accessibility’ as whether the physical locations of the health care services are convenient, while ‘affordability’ implies that ‘the prices of services fit the clients’ income and ability to pay’. This sub-section will focus on whether in practice diagnostic tests, counselling and treatment services were available to the participants at pharmacies, private clinics, and public hospitals, including a specialist research hospital, STM, specifically reporting participants’ accounts of their use of providers before and after they had been formally diagnosed with HIV. As noted in sub-section 2.1.3, the Indian literature suggests that people attend certain health care facilities because of their convenient

location, so accessibility will be considered in terms of physical proximity. In order to analyse whether and how people were able to afford the health care services available, costs will be subdivided into the direct costs of services and the indirect costs of accessing them, including costs of travel, time and income foregone.

Most participants reported that initially they had treated themselves with medication bought from pharmacies, but when their symptoms persisted, the majority sought professional help from private clinicians. One of the participants was an extreme example: she reported that she had visited a multitude of pharmacies and private clinics to find out why she had been falling ill, until she could not afford any more out-of-pocket expenditure and decided to seek help from a public hospital at a fraction of the cost. From this hospital, she was referred to STM where she was eventually formally diagnosed with HIV. Two thirds of the participants (39 out of 59, of whom 22 were men and 17 women) reported that they had been to both private clinics and public hospitals in search of diagnostic and treatment services, before being formally diagnosed with HIV at a public hospital. A third of the participants (19 out of 59) reported that they had only visited public hospitals, including STM, in search of their symptoms, avoiding incurring the expense of professional help from pharmacies or private clinics. Of these 19, 12 were women, four of whom received a formal HIV diagnosis while attending a public hospital for an antenatal check-up. The participants were asked the reasons for their choice of provider, both before and after formal diagnosis, firstly with respect to private clinics and then public hospitals.

- **Experiences of accessing health care services provided by private clinics – before formal diagnosis**

Those participants who had initially attended private clinics (before being formally diagnosed by a public hospital) were asked their reasons for having chosen private clinics as a first point of contact. One person stated that somebody from his workplace had suggested that he go to a private clinic. Three respondents stated that they had been to well-known private clinics in Chennai (1600 km from Kolkata), because they had not been diagnosed correctly by the health care providers in Kolkata, as shown by an example below:

*“...between August-November 2008, I went to government and private hospitals in Kolkata to find out about my diagnosis and I spent Rs.18,000-Rs.20,000 on this investigation. Then I went to Vellore (Chennai) for diagnosis, at a private nursing home, and was diagnosed with HIV. I started being on ART from there and then got referred to STM in Kolkata...”* (DM<sub>1</sub>, a 42-year old Hindu man, diagnosed with HIV in December 2008).

This man, who had primary school level education and no income, had been so disheartened when he could not find out what was wrong with him that he had spent over \$400 (which was mostly borrowed from relatives), in order to travel a thousand miles to another city in search of a diagnosis, only to be referred to STM in Kolkata in the end.

When asked why they had chosen to go to STM after they had attended private clinics, 18 stated that they had been referred to STM by these clinics or nursing homes. BM<sub>6</sub> (a 42-year old Hindu man with secondary education, diagnosed in May

2007) reported as follows: “... for one year I kept going to private doctors in order to find out what was wrong with me and spent around Rs.1.5 lakhs [approximately \$3000] on trying to find a diagnosis. Finally, a private doctor referred me to a government hospital where I was told to do a blood test again and there I found out that I was HIV positive...”

Three respondents explained that they had been recommended to go to STM by acquaintances after failing to get a diagnosis from the private clinics they attended, as confirmed by a statement from AM<sub>4</sub> (a 42 year old Hindu man with primary level education, working on the pavement as a tea hawker, diagnosed in 2001), who stated: “...I kept going to the private clinics and in 2 years, I spent Rs.10, 000 [over \$200] on private doctors, doing tests, and trying to self-medicate...then somebody recommended that I go to STM and I was finally diagnosed with HIV in 2001 at STM...”

In addition to obtaining a diagnosis by attending private clinics, and paying for consultations, blood, urine and stool tests, some participants reported that they had bought medicines prescribed by private clinicians. One participant (BW<sub>8</sub>) reported that after her diagnosis in 2002, she had bought first-line ART drugs prescribed by private practitioners in Mumbai (where she had been living at that time), although at the time of the interview in March 2009, she was receiving ART free of charge from STM. This 37-year old Hindu woman, who was originally from Kolkata but had moved to Mumbai after her marriage, had been separated from her husband since her diagnosis and described how she had had to sell a sari business she and her husband owned to pay for her first-line ART in Mumbai. She estimated that she had spent over

\$3000 on first-line ART over a period of three years, until she could no longer afford to buy the medicines and had therefore stopped taking them altogether. Eventually, three years prior to the interview, she had moved back to Kolkata with her three children, to live with her parents and had then sought help from STM, where she was tested and advised to start on a standard free-of-charge second-line ART regime.

- **Experiences of health care services provided by public hospitals – after formal diagnosis**

The participants in the current study described their experiences of seeking help from public facilities. For the majority, the services that are in principle supposed to be provided by the public sector (see 4.3.1) were, on most occasions, consonant with what happened in reality. However, a small number of people were unaware of the counselling services available at STM, which are theoretically part of the VCTC service and are available to new patients suspected of being HIV-positive. The experiences of two typical participants are described below.

AM9, a 36-year old widower with no education, who earned a livelihood as a cobbler, described his experience of accessing healthcare from public facilities:

*“...when I was first diagnosed with HIV in 2004 at a government hospital, I was told to go to STM in order to get an official blood test report done ... which cost me Rs.10...since then I have been going to STM to have my CD4 count checked every six months and I pick up my ART from the ART centre every month. I have a card/book, in which the doctor writes down a reminder*

*date for the next 'ART pick-up', and on these dates I go to STM to get my CD4 counted and also to get my next lot of ART..."*

Another participant, AW<sub>10</sub>, who had been diagnosed in 2005, claimed that although she had not received counselling when she first went to STM to seek help, she had received medicines for opportunistic infections and also that she and her husband go to STM every six months to have their CD4 counts monitored and to pick up her husband's ART, expressing satisfaction with the way they are treated at STM.

Private clinics, especially those that trade out of a practitioner's home, are found in almost all neighbourhoods in Kolkata and stay open till later than normal office hours (past 6pm). The majority of the participants reported that, consonant with the literature, their main reason for initially attending a private clinic was its convenient location, although, as mentioned previously, three had attended clinics as far away as Chennai because the health care providers in Kolkata (both in the private and public sectors) had not diagnosed their illness correctly.

STM was less accessible to participants. Several who were on ART complained about having to collect their medicines from the ART centre every month and several, including participants BM<sub>1</sub> and BM<sub>10</sub>, described the difficulty of finding someone to stand in for them at work to enable them to travel to STM, although none mentioned using any other public hospital for these purposes after receiving a diagnosis at STM. However, participant BM<sub>1</sub> described how difficult it had been for him to attend STM to obtain free medicines for opportunistic infections, leading his NGO peer worker to arrange for him to collect them from a nearby government hospital. Like all the other

participants, however, BM<sub>1</sub> still needed to attend STM every month to collect his ART and every six months for a CD4 count.

- **Experiences of using health care services provided by public hospitals**

The participants explained how initially the public hospitals, including STM, charged them for diagnostic testing and in-patient treatment if required. The charges for a CD4 count test and for a bed at any public hospital were reported to be \$10 and \$3 (per night), respectively. For example, participant AW<sub>12</sub>, a 42-year old widower who had been diagnosed with HIV in 2005, complained that: *“...my HIV [CD4 test] at a government hospital in Orissa cost me Rs.500 and an additional Rs.10 for a report. When I came to Kolkata and went to STM, I had to do another HIV [CD4 test], costing me again Rs.500...”*

One woman complained about the direct cost of treatment received from STM after initial diagnosis. BW<sub>14</sub>, a 28-year old Muslim widow with no education, who had been diagnosed with HIV in 2004 and was living with her aunt at the time of the interview, complained about having to pay the equivalent of \$15 at STM for treatment for herpes, one of the many opportunistic infections that HIV patients contract during the course of their illness. Although she understood that the same medication would probably have cost her more if she had bought it from a pharmacy, she still claimed that it was too expensive, especially as she had not been working at that time, due to an infection in her hands.



The Hindu man, BM<sub>15</sub> referred to above, who had been diagnosed in 2002, expressed dissatisfaction with the government for not providing the STM with alternative forms of first-line ART, because since 2005, both he and his wife had been suffering from recurrent side-effects as a result of taking one of the possible three ART drug regimens. He claimed that he had to spend \$135 every month buying two alternative first-line ART drugs, which had been prescribed by the doctor in charge at STM, one for his wife and one for himself. This respondent appeared to be very disheartened, claiming that as the main earner in his family, he could no longer afford to keep buying these drugs at a monthly cost of \$135 when his income was only \$167.

A woman who needed a further investigation and another who had experienced an accidental injury wanted both tests and treatment for injuries to be available free of charge at STM because they had limited incomes, but as HIV positive people, did not feel sufficiently safe to go anywhere else than STM.

In addition to costs directly related to treatment for opportunistic infections and injuries, the research showed that participants incurred indirect costs, such as travel costs, loss of time and income for men, and loss of time at home with their children and, for some women, income, arising from attending STM for ART and/or treatment for opportunistic infections, or treatment for opportunistic infections from other public hospitals.

For the majority of the participants in this research, the cost of travelling to and from STM was between \$1 and \$3 depending on where they resided. Most claimed that they needed to take two or three buses. Nevertheless, for most, it appeared that

receiving what they regarded as the best free care (including both first and second line ART) outweighed the cost and time of travel to STM, feeling that they had no choice but to take a day off work in order to do so. For example, participant DM<sub>3</sub>, a 40-year old married Hindu man who had been diagnosed with HIV a week before the interview, claimed that: *“...today, it cost me a lot of money to come to STM but I would keep coming here with my wife, to get my family and myself treated for free. Here the doctors told me that in a private clinic, it would cost between Rs.10, 000 and Rs.12, 000 to get drugs for HIV, but I don’t have this much money. I prefer coming here, where everything is for free...”*

- **Experiences using health care services provided by private clinics**

Direct costs were more relevant when accessing health care from private clinics. As noted above, most (except for pregnant women and those who had been advised to go elsewhere by friends or family) attended private clinics as their first point of contact, regardless of their type of livelihood. The close proximity of these facilities to where they lived meant that the indirect costs of attending private clinics were limited, so the following will focus mainly on the direct costs.

It appears that the expenditure of 38 out of the 39 participants who accessed private health care exceeded their monthly incomes. On average, participants reported that they had spent the equivalent of approximately \$1000 on private health care (ranging from \$10 to \$3000), incurred over a period ranging from one month to five years prior to receiving a formal diagnosis from a public hospital. The average monthly earnings of these participants ranged from nil to \$208, clearly insufficient to make such

payments, so that, in most cases, they had to sell household items and/or borrow money from various sources. Some had had to pay high interest on these loans, whilst others did not have to pay any interest at all. For example, a Hindu man in a household headed by his son reported that he had borrowed the equivalent of \$833 from relatives and had spent a total of approximately \$2,500 on private health care, including treatment at a private nursing home in Chennai. Others had to rely on assistance from relatives if they needed to purchase medication, for example DM<sub>11</sub>, a 45-year old Hindu widower, who complained that he had to buy the drugs he needed for an opportunistic infection from an outside pharmacy because STM had not provided them, for which he would have to ask his two grown-up sons for financial assistance.

### **5.2.2 Adequacy and Acceptability**

Although the findings reported above show that services provided at private health centres were available and accessible and at most public health facilities were affordable, they did not necessarily meet the specific needs of the PLHA, especially those provided by private clinics. This sub-section will further explore the participants' perceptions of how adequate and acceptable the care and treatment provided by private clinics and public hospitals had been.

- **Experiences of using health care services provided by private clinics – before formal diagnosis**

As described above, most participants sought initial treatment from private clinics.

They were asked whether the services provided by the private health care centres had met their needs. Some responded that they did not know where else to go or that nobody had told them about STM until they had run out of money to pay for consultations, investigations and prescriptions at private clinics. Almost universally, they complained of incompetence, with private providers requiring them to undergo unnecessary tests, failing to provide accurate diagnoses and not referring them appropriately

The participants' main concern was with the clinical adequacy of the service provided, with few commenting on how the private practitioners had behaved towards them. However, participant AW<sub>10</sub>, (diagnosed in 2005 along with her husband) talked about how one private practitioner had asked her to not mention her illness to anybody outside her own household as HIV was a very shameful illness and people would judge her adversely (see 5.1.2 for more detail). None of the other participants mentioned anything with regard to the cleanliness of facilities, privacy or waiting times in private clinics compared to public hospitals, along with attitudes, all aspects of satisfaction highlighted in the literature.

- **Experiences of using health care services provided by public hospitals – before formal diagnosis**

A number of participants complained about the level of care that they had received from public hospitals prior to receiving a formal diagnosis. One example was BM<sub>1</sub>, a 30-year old married Hindu man with some primary education, who had been diagnosed in November 2007, and who talked about how a public sector hospital, although noting that he had TB (one of many opportunistic infections that PLHA suffer from), they failed to perform a routine HIV blood test, leaving him to be diagnosed two years later at another public hospital.

- **Experiences of using health care services provided by public hospitals – after formal diagnosis**

Participants were asked about the counselling and treatment received from STM. Eight participants diagnosed between 1998 and 2003 claimed to have no recollection of receiving any counselling at STM at the time of diagnosis, with only those diagnosed between 2004 and the beginning of 2009 remembering such sessions, although it is not known whether counselling was available before 2004.

One or two people talked about how nice the doctors were at STM, which was one of many motivations for them to return to STM for treatment. In contrast, as noted above, a couple of participants did not consider that the treatment service by STM was adequate. Participant BM<sub>15</sub>'s dissatisfaction with the lack of availability of appropriate antiretroviral therapy for himself and his wife has already been reported,

leading him to express disapproval of the STM and of the government in general for not making free alternative forms of first-line antiretroviral therapy available.

This dimension of access asks whether the characteristics of the providers matched the expectations of the participants and whether they felt welcome and cared for at the facilities used. None mentioned this dimension when describing their use of either private or public providers before they were formally diagnosed, or, with respect to their use of private health care, afterwards. As noted in 2.3.2 and 4.3.2, studies carried out in the international and Indian contexts reveal that people in general have a positive perception of the quality of private services compared to those run by government, including perceived positive attitudes among staff in private health care facilities; the convenient location and short waiting times in private clinics; the possibility of credit payments in private clinics; a higher degree of privacy; greater confidentiality and family physicians with close social links to patients and their communities. Only some of these were borne out by the results reported above. Studies carried out by the World Bank (1995) and Bhat (1999) showed that private medical facilities are the preferred source of care, irrespective of a care-seeker's socio-economic status or gender. Also, studies carried out by other authors have shown that people 'shop' around for HIV/AIDS health care services due to issues of stigmatisation, with private providers being more popular than public health care services for people with STIs. The current study found that people 'shopped around' in the search for a correct diagnosis and subsequently, appropriate care, support and treatment, rather than to avoid stigma.

Several participants acknowledged that the behaviour of staff at STM was generally good.

However, a small number of participants asserted that in previous years, for example in 2004, the attitude of staff at STM had been bad and the nurses unfriendly and rude when participants were first diagnosed with HIV. These participants felt that the staffs' attitudes had improved over time. However, they added that when staff at STM have to work under pressure, especially when they need to see a lot of patients in a short period, the doctors and the main counsellor had a tendency to become irritable during consultations, although the participants felt that their irritability was understandable in these circumstances. In addition, several people who had been diagnosed with HIV between December 2008 and the end of April 2009 (the interviews for the main fieldwork took place between 1 February 2009 and the end of April 2009) complained about the bad behaviour of the counsellors and some staff, inferring that sometimes the behaviour of the doctors was just as bad.

In addition, some people did not like the fact that their confidentiality had been breached by a doctor when, at the time of diagnosis, the participant's HIV status had been disclosed to other members of his or her family before it was disclosed to the participant him or herself. For example, CW<sub>5</sub>, a 60-year old widow with no education, who had been diagnosed a year and a half ago prior to the interview, related how: *"...at the time of my diagnosis at STM, the doctors told my son about my status. The doctors at STM didn't speak with me. My son just signed the documents"* Similarly, participant CM<sub>7</sub>, an unmarried 38-year old Muslim man, who had also been diagnosed

a year and a half prior to the interview, reported that; “...*nobody talked to me about HIV. They spoke to my brother when I was first diagnosed...*”

Most of the participants in the current study complained about the care that they had received from the Calcutta Medical College and Hospital, a teaching hospital located adjacent to STM whose facilities are called upon when the facilities at STM reach maximum capacity. For example, AW<sub>1</sub>, a 30-year old Muslim widow, who had just started working for one of the NGOs as a peer worker, described the way she and others had been treated by the teaching hospital. Normally, one of the tasks she carries out is to pay the small fee (an equivalent of \$3) for a bed in the STM inpatient department for very sick newly diagnosed HIV patients. As an outreach worker, she is given permission to take patients to the Calcutta Medical College and Hospital when a bed is not available at STM. However, she talked about how, on many occasions, in spite of being referred by STM, the families of PLHA are told to remove them from the hospital and also how they are generally treated badly, especially by the front-line staff (not the doctors), who always ask for money before the patient is given a bed. She described how critically ill PLHA are made to wait for a bed and then left to their own devices, with nobody to show them around the ward. While praising the behaviour of the staff at STM, she was concerned about the lack of beds at STM. Several other participants who had accessed help from Calcutta Medical College and Hospital stated how unhappy they had been with the behaviour of the staff there, including doctors, compared with STM.

When the participants talked about their experiences with regards to accessing health care services from private clinics, as reported above, their main concern was cost.



The costs incurred by many had strained their household finances, depleted their savings and required them to sell household goods. When they were then asked to pay for elements of supposedly free treatment at public hospitals, they were, not surprisingly, indignant. In general, the participants were not entirely satisfied with the services and goods provided by the STM and/or the Calcutta Medical College and Hospital, but felt that because of the lack of accessible and/or affordable options, they had no choice but to make do with the services on offer.

### **5.3. CHAPTER CONCLUSION**

The main experiences of PLHA before they were formally diagnosed with HIV, as revealed by participants in this study and presented in section 5.1, were a lack of knowledge when HIV-related symptoms were first experienced and feelings of fear and helplessness. The only difference found between the experiences of men and women during this period was that most women found out about their own HIV status after their husbands became critically ill and were taken into hospital or died, although some women found out about their positive status during antenatal check-ups. Participants described how both perceived and enacted stigma had frequently been experienced and for most, both forms of stigma had led to social exclusion, which had had a negative impact on their well-being. Ways of coping with living with HIV reported by the PLHA studied included various negative internal coping strategies (secrecy, negative rumination and self-isolation) but also positive strategies to deal with stigma, optimistic planning and social networking with members of the HIV community - findings that confirm those of previous studies, and help to answer

research question one as stated in section 1.4: how PLHA with different social characteristics experience living with their illness on a daily basis.

As revealed in 2.1.3, there has been a lot of discussion in the international literature with regard to the process of decision-making that takes place once people with different kinds of illness (in this case chronic illness) decide to seek help. According to Mackain et al. (2004), two dominant approaches have been identified: ‘pathway models’ of health seeking behaviour, which describe the series of steps an individual or most people take, initially until the first contact is made with a health facility and then in further choices of treatment provider; and studies of the ‘determinants’ of behaviour, which aim to identify the factors that explain individual or typical journeys. The findings from this research showed that the health care seeking behaviour of PLHA in Kolkata can best be understood by combining these two approaches, and by examining the five dimensions of access.

To summarise, the study found that when participants decided to seek help for their illness, they went directly to a public hospital, a pharmacy, as part of self-treatment, or directly to a private clinic. Many took an independent decision, although on a few occasions, a certain private clinic or going directly to STM was recommended to a participant by someone they knew. If, despite self-treatment, participants' symptoms persisted, they subsequently went to either a private clinic or a public hospital. If their symptoms were misdiagnosed by a private practitioner, participants often visited other clinics for a second or third opinion, until a practitioner recognised their symptoms and referred them to STM. Also, if participants could no longer afford to pay for private treatment, they had no choice but to seek help at a government hospital.

Participants often had to attend a private or public facility more than once before they were referred to STM. Once participants had been referred to STM, they stopped going anywhere else for treatment, unless prescriptions for medicines for opportunistic infections were issued by STM.

One important finding, which has not been revealed in previous studies, is that many people had experienced serious delays in obtaining an accurate diagnosis because when they initially sought help from various health care providers, they were not referred to STM immediately. As a result, many PLHA were not aware of the existence of STM and continued to go to private practitioners with little experience of HIV until, often by chance, they were referred to STM by a medical practitioner or an acquaintance. Already poor, the cost of private consultations during the search for a correct diagnosis had distressed and impoverished many. Although they were not entirely satisfied with the services provided by the STM and/or the Calcutta Medical College and Hospital, they recognised the value of the specialist knowledge and appropriate treatment provided and continued to comply with the requirements for continued access to free ART despite the indirect costs involved. In this way, findings from section 5.2 helped answer research question two: “How do PLHA with different social characteristics access and assess the adequacy of health care services for HIV/AIDS?”

The participants’ description of their experiences revealed the obstacles faced once they had made a decision to seek treatment. Although the perspectives of health care providers were beyond the scope of the research, and so it is not possible to make a full assessment of client-provider fit, the findings do reveal how treatment-seeking

behaviour is influenced not only by the services available but also by the perceived advantages and disadvantages of particular providers and the knowledge, financial resources and social perceptions of PLHA themselves.

To obtain a more rounded picture of the overall wellbeing of PLHA, the following chapter will explore how people coped with the longer-term effects of the illness on their livelihoods, as well as assessing the contribution of sources of wider support to enabling them to cope.

## **CHAPTER VI**

### **HOW DO PEOPLE COPE WITH THE IMPACT OF HIV/AIDS ON THEIR LIVELIHOODS?**

#### **6.0 INTRODUCTION**

This chapter is concerned with the ways poor PLHA live on a daily basis, and specifically with the longer-term effects of their illness on their livelihoods. It investigates the effects of their illness on household composition (section 6.1), and explores the ways in which household members employed livelihood strategies using one or more assets in order to adapt to their situation (section 6.2). Finally, it investigates whether and how PLHA accessed and utilised livelihood support from the organisations with which they had links and what influence this support had on their overall livelihood status (section 6.3).

#### **6.1 THE EFFECT OF ILLNESS ON HOUSEHOLD COMPOSITION**

The purpose of this section is to analyse whether household composition changed after one or more household members fell ill. It compares household composition and the type of assets possessed during two phases: pre- and post-symptomatic. The 'pre-symptomatic' phase refers to a period when all members within a given household are free from ill-health and thus able to function well. The 'post-symptomatic' phase can be divided into two: pre-and post-diagnosis, in each of which one or more members of

a household experienced HIV-related symptoms, although they were not aware of their positive status until diagnosed correctly.

Based on the data from all 59 participants, during the pre-symptomatic phase, 31 lived in nuclear households (one or two parents with children), almost always (29) composed of two adults with one to four children, ranging in age from 7 to 21 years (the latter still in education). Out of these 29 nuclear households, 24 had children under the age of 16 who were dependent on their parents, while the other five contained at least one child aged 16+ who worked part-time (more common for sons) or carried out household chores and acted as carers for their parents (more common for daughters).

Only one person had previously been a single parent, in this instance a widower with grown up sons. Twelve participants, all men, reported that they had lived with their paternal families prior to contracting HIV, of whom five had one or two children under 16. A similar number, mostly women, had lived with their in-laws, and half had one or two children under 12.

A smaller number of participants (one woman and four men) reported that they had lived alone. Two of the men had migrated for work, leaving their families behind (one had a wife and four young children in Bihar, whilst the other had grown-up children); one was unmarried with no dependents; and one was a married man with a child, who had been abandoned by his family and was homeless before contracting HIV. The woman was a widow, who had been living alone since the death of her husband due to heart failure 11 years previously; she had two grown up married sons

living elsewhere. None of the participants reported that they had lived with relatives other than their parents or parents-in-law during this phase.

The participants were specifically asked about the assets that they and their households had had during the pre-symptomatic phase. Of the total sample, 66 per cent had primary or secondary level education and two had Bachelors degrees, while the 31 per cent with very little or no education had some vocational skills. Some of the participants reported that they had had savings accounts; and two that they owned properties. Prior to the development of symptoms, 32 out of the 59 participants interviewed revealed that they had had a job (28 men and 4 women) although 27 of the 59 participants did not (one man and 26 women). Most commonly, those male participants who were working worked for others, as house chauffeurs, security guards, bricklayers, cobblers, electricians, baggage handlers at train stations or sweepers in offices. Some worked as rickshaw and taxi drivers: although people in these occupations are usually referred to as being self-employed, none owned their own rickshaws or taxis and so they had to hire them. Only one person worked for himself, as the owner of a shop selling snacks and tea. Out of the four women who had worked prior to the development of symptoms, two of whom were married, one a widow and the other separated from her husband, one was a private tutor teaching Bengali to children in her neighbourhood, and three worked as housemaids. The 26 women who said that they had not had a job prior to the development of symptoms were housewives and their husbands had jobs instead. However, after their husbands became ill with HIV, two participants reported that they had taken over working in the shop that they co-owned with their husbands (one selling items required for religious events (BW<sub>2</sub>), and the other saris (BW<sub>8</sub>), and others had looked for other

ways to earn a living, for example by sewing clothes in their own homes and selling them door-to-door within their neighbourhoods, or by working as housemaids. Therefore, out of the 26 women who had not worked during the pre-symptomatic phase, 11 went out into the labour market after their husbands fell ill with HIV. The reasons given for not working by the remaining 15 women were their own ill-health, a lack of child care or because their husbands and/or in-laws did not 'allow' them to go out to work. The changing gender dynamics within households brought about by the impact of HIV/AIDS will be further discussed below and in 6.2, and the explanatory factors will be provided in 7.1.2.

Before participants or members of their households fell ill, the total household incomes they reported were the equivalent of between \$6 and \$167 per month, with 38 participants' households having an income of below the absolute poverty line used by the World Bank (\$1.25/day, or \$40/month per capita)<sup>4</sup> and 21 bringing in incomes of over \$40/month. Ten of the 59 participants reported that they had had some savings, in the form of cash, a small shop or land in rural parts of Bihar, Orissa or West Bengal, where they had family connections. The participants who claimed to have both a household income and some savings had at least secondary level education, included both men and women, and those with children reported that all their children attended school, their household members ate at least three nutritiously balanced meals a day and that they had lived without disturbance within their neighbourhoods.

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<sup>4</sup> According to the World Bank (2013), India's poverty line stands at \$1.25 per day



During the post-diagnosis phase (at the time of the interviews), most of those respondents who had previously lived in nuclear households were still doing so (28 out of 31). However, the number of single parent households had increased from one to five, with four women reporting that their husbands had died from HIV/AIDS-related illnesses or that they had separated, leaving them with at least one dependent aged 16 or younger. The composition of the remaining three households had changed as follows: (i) one woman had become a single parent caring for a sick daughter after her husband had left her upon finding out about his positive diagnosis, (ii) a widower, who had been living alone since his wife died of HIV-related illness and had given his young son to his brother and sister-in-law to look after and (iii) a man who had gone to live with his paternal family when his wife left him, taking their son, after finding out about his HIV positive status.

In addition, four female participants who had been living with their in-laws during the pre-symptomatic phase returned to live with their own parents after their husbands had died due to HIV-related illnesses and two had returned to their parents' homes after their husbands and in-laws threw them out. Because the 12 men who had previously been living with their parents continued to live there after they had been diagnosed with HIV, in total 19 participants reported that they lived within their paternal families during the post-diagnosis phase, six women and 13 men.

Of the 12 participants, all women, who were living with their in-laws during the pre-diagnosis phase, four continued to do so, while six went to live with their own families after the death of their husbands or when their in-laws threw them out (see above), and two went to live with their own relatives after the death of their husbands.

During the post-diagnosis phase, six women had been widowed, two had been thrown out by their husbands and in-laws when they found out about their positive status, and four continued to live with their in-laws. All of the five participants who reported that they had been living alone during the pre-symptomatic phase continued to do so. In addition, as noted above, one man became a single person household after his wife died of HIV-related illnesses

As stated in section 3.1, the composition of many households in urban areas is complex and changes over time. It becomes even more complex when the head of a household, usually a man, becomes infected with HIV, falls ill and in many cases dies. This also leads to a shift in the dynamics within households. As discussed in section 3.1, this analysis will focus on the trajectory of individuals and their households and livelihoods and how it changed once one or more household members was diagnosed with HIV. In order to distinguish between different trajectories, households will be categorised as secure, vulnerable or highly vulnerable at each of the key stages of the trajectory. A household's status depends on the resources available to it and how they are mobilised.

The power to mobilise resources usually lies in the hands of the household head. In this research, it was found that the identity of the 'head of household' varied. Participants generally considered themselves to be the heads of their households when they were the sole earners or earned more than any other household member. Some (especially women) had become the head of their household when their husbands abandoned it after being diagnosed with HIV. However, in some cases, a participant

had a dominant presence within a household that led other members to consider them as the head. Examples of each are given below:

Participant BM<sub>6</sub>, a 41-year old Hindu married man diagnosed in 2007, lived with his wife, daughter, elderly mother and younger brother in a house that had been passed on to his mother after his father passed away. His mother and younger brother lived on his father's pension. When asked who he considered to be the head of his household, he replied: *"...my wife works as a nurse and she earns Rs. 3000 [\$60] a month [compared to the estimated poverty line of \$1.25 a day, see footnote 3]. The money I earn, Rs.1200 [\$24] a month is not enough for our household to be run on. My wife is the head of household, as she earns more than me and supports us. ..."* BM<sub>6</sub> thus considered his wife to be head of the household because she was the main earner, even though he earned some money and his mother was receiving a pension.

Participant BW<sub>11</sub> had returned to her parents' house after her husband and in-laws threw her out for being HIV positive. A 20-year old Muslim woman with no education, she had discovered that she was HIV positive during a routine antenatal check-up. She said the following about her mother, who she considered to be the head of her parents' household:

*"...I don't work. I can't work at the moment. My mother, who is getting older, has to do everything for the household and she has to look after me also. She pays for everything. She is the head of the household and earns around Rs. 700 [\$14] per month, working as a housemaid. The rent of the house is Rs. 400 [\$8] per month and the rest of the money has to be spent on the family.*

*She provides for the 6 of us and she will also help me raise the baby when it comes...*

Even though BW<sub>11</sub>'s father was still alive and they all lived together in the same household, because her mother did all the household chores, was the main carer and was also the sole earner, this participant considered her mother the head of the household. Participant BW<sub>11</sub>'s mother expressed a strong familial obligation to provide a place of refuge and support for her daughter.

Participant AW<sub>3</sub> was a 31-year old Hindu married woman with two young children, who had been diagnosed with HIV in 2004 at the same time as her husband. At the time of the interview, she did not work and nor did her husband, due to his bad health. They lived with her in-laws who, she reported, helped them out financially as much as they could. When asked whether she would have been willing to earn an income if well enough to do so, she responded: *"...I was offered a job with KNP+ but my husband is not allowing me to take up this job. My husband caused chaos and disturbance and he even stopped me from coming to KNP+ as a member but I force myself out of my home to come to KNP+..."* When asked how her husband had treated her, she replied: *"...my husband used to drink a lot. He had TB lots of times because he just wouldn't listen to me and did not take his medicines regularly. He used to beat me up regularly but now the beatings have been reduced..."*

Women like AW<sub>3</sub>, who were not allowed by their husbands and/or in-laws to make a living for their households, even when their husbands had become bed-ridden due to HIV-related symptoms, were not uncommon in the sample. All the female participants trapped in such 'power struggles' with their husbands and/or in-laws

stated their frustrations about not being permitted to provide for their children, in spite of being healthy enough to find work (see also sub-section 7.1.2).

The attitudes of men and their parents to wives working to earn an income demonstrates deeply engrained attitudes to gender roles within the family, as illustrated by one male participant's stated reasons for prohibiting his wife from making a living even though he was struggling to cope financially and physically. Participant AM<sub>6</sub> was a 32-year old Hindu man, originally from the Eastern State of Bihar, who had primary school education and had been diagnosed with HIV in 2007. Married with two children, his wife was positive but his children negative at the time of his own diagnosis. AM<sub>6</sub> reported that he earned the equivalent of \$13 a month, which he spent on rent and household goods. When asked whether his wife worked to earn an income, he replied: "*...she doesn't work. In our culture we don't let our women work. Our wives need to stay at home to look after the children. So, she stays at home...*" During the interview, he took for granted that his was the dominant voice within the household and that he could determine what his wife could and could not do.

To summarise, when the participants were asked who had been the head of their household during the pre-symptomatic phase, most responded that in their opinions, men (husbands, fathers, or fathers-in-law) had been the heads of their households, with the exception of one widow who had been living on her own since the death of her husband due to heart failure 11 years prior to the interview.

During the post-diagnosis phase, 11 women stated that they had become the heads of their households, with four becoming single parents, one the head of a household in which her husband was still alive but very ill, two within the households of their in-laws, and one who lived alone. In addition, two women had gone to live in paternal households where their mothers were already the household head and one woman had gone to live with an aunt, who was the head of her household. It appears that for the most part, women became heads of their changed households either because they had been widowed or they had separated from their husbands and had chosen to live alone or only with their children aged 16 years or younger.

Overall, the structure of almost half of all the households in the sample changed following the onset of HIV/AIDS, due to the loss of a male head when he died, separated from his wife and/or abandoned his family, when another male member became the head of household or when the wife of the previous head took on the role. As noted above, the changed dynamics of power within households demonstrated, amongst other things, by changes in the identity of the head, would be expected to influence the mobilisation and use of material and social resources, but little further information is available, because family members other than the research participants were not interviewed. This chapter will therefore base its analysis of the ways in which livelihoods changed on the accounts of the participants interviewed - they were all HIV positive but had different positions in their households.

## **6.2 ADAPTATIONS TO LIVELIHOOD STRATEGIES TO COPE WITH THE IMPACT OF HIV**

This section will firstly describe the ways in which the participants employed the assets they possessed during the pre-symptomatic phase in order to cope with the impact of HIV during the post-diagnosis phase. Subsequently, in order to explain whether and how a participant's livelihood had changed, this section will analyse participants' experiences using the analytical framework as set out in section 3.1. In addition, this section will shed further light on the complex dynamics within participants' households, especially those in which the illness of one member had led to a shift of power.

As set out in section 3.1, the analytical framework suggested a number of categories of assets available to individuals and households, the potential ways in which assets can be managed and mobilised to improve wellbeing, accumulate further assets and avoid or be prepared for any shocks or stresses in the form of illnesses, deaths or natural disasters (known as risks). As vulnerability is considered to be a product of risk, whether and how a household is able to recover from a shock in turn affects whether it becomes secure, vulnerable, or highly vulnerable after its members face a shock, depending on how well the assets available to it at the time of the shock are managed. As described in 3.2.2 and 3.2.3, during the interviews with the 59 PLHA, participants were asked questions designed to ascertain the number and type of assets that their households had possessed during the pre-symptomatic phase and whether or not these had dwindled during the post-symptomatic phase, before households sought help from other sources. In addition, participants were asked how they had coped with the needs arising out of the illness, including which assets they had used

and how, as well as the impact of their strategies on their livelihoods and stocks of assets, during the two phases. Usable responses were received from 48 of the participants.

The analysis will first examine how participants were able to manage and mobilise the assets that they and their households had prior to experiencing the illness.

So, the types of questions dealt with in this section are the following: how did the participants live during the pre-symptomatic phase? Did they have to make any changes to their lives and livelihoods during the post-diagnosis phase? Had they been able to avoid impoverishment? The discussion will be illustrated by providing ‘before’ and ‘after’ pictures of the ways in which people’s assets were used up (or not) during the course of their illness trajectory, differentiating between participants according to their circumstances, education level and gender.

The analytical framework suggests that members of households respond to the impact of shocks and stresses (in this instance HIV/AIDS) by either adjusting consumption or mobilising assets, especially human, labour, financial, and social assets. When poor people are faced with shocks or stresses, they devise coping strategies in order to survive and not become further impoverished, as well as attempting to alleviate the long-term impact of the shock or stress and recover from it. As noted in sub-section 2.2.2, *ex ante* risk mitigation is where households take precautions to reduce risks and *ex post* coping strategies are where households devise ways to mitigate shocks, with whatever assets they possess. In this research, *ex post* coping strategies were found to be the most common response – in addition to seeking medical help, participants and



their households devised ways to mitigate shocks with whatever assets their households possessed. The types of *ex post* coping strategies employed by the participants in the current study included using up their savings, borrowing money, earning money in new ways, selling possessions in order to raise cash, calling upon family members to look after their children, withdrawing children from school and reducing consumption (fewer meals and different types of food). Each of these is described in more detail below.

As already stated in section 6.1, during the pre-symptomatic phase, ten out of the 59 participants had some savings in the form of cash, a small shop or land in the rural parts of Bihar, Orissa or West Bengal, where the participants had family connections. During the post-diagnosis phase, all but one of these described how their savings had diminished and their assets been sold, initially as a result of their attempt to obtain a diagnosis for themselves or a household member. The rest of the participants (50) reported that they had had to borrow money during the pre-diagnosis phase. Half had obtained loans from their close and extended families, who did not charge interest, enabling them to repay these debts, but half, who had been forced to borrow from loan sharks, reported that they had not been able to pay the interest or repay the loan, increasing their anxiety. In order to pay off their loans, some households had utilised their properties to generate income. For example, one woman was using her home as a place of work, sewing clothes for door-to-door sales during religious festivals. In addition, all the participants reported that in order to live on a day-to-day basis, they had sold smaller items that they had been using or keeping as part of their children's inheritance, such as furniture, utensils (some made out of expensive metals) and jewellery.

As discussed in sub-section 5.1.2, many people showed concern regarding the consequences of their neighbours finding out about their status, making it difficult for them to seek help from neighbours (conceptualised as social assets in the livelihoods framework). However, in a few cases, participants were able instead to call upon their close family members to look after their children when they became unable to do so.

Households reported a reduction in the human assets available for livelihood purposes when the main earner became too ill to earn a living. When a man ill with HIV could no longer carry out physically taxing work, women usually took on additional tasks and increased their working hours. Not only did the women (who were very ill themselves) look after their sick husbands, many of them also went out into the labour market in search of jobs. As mentioned in 6.1, of the 26 women who had not worked during the pre-symptomatic phase, 11 went out to earn a living during the post-diagnosis phase (at the time of the interviews). The 15 women who reported that they had not gone out to work attributed this, as noted above, to ill-health, the lack of child care or because their husbands and/or in-laws would not let them go out to work.

In addition, out of 39 households with children under 16, four reported that they had withdrawn their children from school, because of a lack of money to pay for the associated costs. The girls that had been taken out of school had to help care for their loved ones suffering from the illness or with the housework, while the boys had had to start earning, to replace the earnings of the main earner. Three of these households had not taken their sons out of schooling completely, but when times were tough, they reported that they had to take up part-time employment, for example BM<sub>3</sub>, whose son

had just turned 16. Households that could afford to continue to have their children, both boys and girls, educated did so, sometimes choosing government schools because they do not charge fees.

Only a third of the participants interviewed provided information on their household diets. These participants reported that they were, at the time of the interview, unable to eat the same number of meals and type of food as they had during the pre-symptomatic phase, as already mentioned in section 6.1.

The analysis of the effects on households' wellbeing of the illness used a table divided up into 'Pre-symptomatic' and 'Post-symptomatic phases': as mentioned above, the former refers to a period when all members within a given household are free from ill-health and thus able to function well and the latter, which can be divided into two phases: pre-and post-diagnosis, to a phase during which one or more members of a household experience HIV-related symptoms. Subsequently, the assets possessed by each of the 48 households prior to one of its members developing the symptoms of HIV/AIDS and the actions taken following diagnosis were analysed, as well as the effects of those actions on intra-household relations, thus creating 'before' and 'after' pictures for each.

Households that had at least one household member with a secure steady income, no ill-health, no debts, some physical and/or financial assets, and good relationships with friends, neighbours, extended families and their own household members were classed as secure.

Households that had one or more members without a secure and steady income, contained one or members suffering from ill-health, lacked physical or financial assets, were classed as vulnerable, even though they had good relationships with family, friends, neighbours and extended families most of the time.

Finally, households that were regularly unable to meet their basic needs, as nobody within the household had a regular income due to ill-health, one or more household members suffered from ill-health, had to borrow from neighbours and/or their families to survive, had no other forms of social support and instead, were subjected to discrimination by their neighbours, had been cast aside by their spouses, or lived in volatile and unstable households were classed as highly vulnerable.

Six livelihood trajectories were identified. Households were categorised as having an 'unchanged' vulnerability status, if the assets it possessed during the pre-symptomatic phase had not been depleted during the post-symptomatic phase. So, for example, if a given household's vulnerability status had been secure during the pre-symptomatic phase, and it was clear that it had been able to keep most of its assets and its positive interactions with wider family and community members were intact, then that household was considered to have remained secure during the post-symptomatic phase. Similarly, if the circumstances of households with vulnerable or highly vulnerable statuses during the pre-symptomatic phase had not changed for the worse (or better) during the post-symptomatic phase, they were considered to remain vulnerable or highly vulnerable. However, the livelihoods of many households had changed, usually for the worse. Households whose coping strategies had led to the loss of assets and a deterioration in their wellbeing had been impoverished, becoming

vulnerable or highly vulnerable. Data for all 48 households were analysed and each was categorised as secure, vulnerable or highly vulnerable during the pre-symptomatic phase and at the time of the study. The situations of twelve households that typify the trajectories identified are summarised in Table 4.

As noted in section 3.1, it was anticipated that the income earning opportunities available to the urban poor in Kolkata would, as elsewhere, vary according to the education level of earners. The original sample of 59 households was therefore grouped according to the education level of the participants (no education, primary level education (years 1-6), secondary level education (years 7-10) and higher education (year 11 or higher)) (see Table 2). As noted above, 48 of the participants provided sufficient information to be included in the analysis in this section. Of these, 16 had no education, 14 were educated up to primary school level, 16 had secondary level education and two had Bachelor's degrees. The prior and current vulnerability status of these 48 households is presented below.

In the pre-symptomatic phase, eight out of the 16 participants with no formal education lived in vulnerable households, four in highly vulnerable and four in secure households. In the same phase, half of the 14 participants with primary level education lived in secure households and the other half lived in vulnerable households. 14 out of 16 participants with secondary level education lived in secure households and the remaining two lived in vulnerable households. Finally, the two participants with higher-level education lived in households with secure livelihoods prior to the household heads contracting HIV. Although the sample size is small, the analysis shows that while all 48 participants were relatively poor, most of those with

some education had secure livelihoods prior to symptoms developing, with the proportion of those with secure livelihoods increasing with the level of education participants had achieved. In contrast, only a minority of the households containing participants with no education had secure livelihoods, even before their symptoms developed. As stated in section 3.1, it might be expected that the income earning opportunities available to people with education would be greater, enabling them to develop secure livelihoods and build up assets that could cushion the impact of the illness. However, the findings also suggest that having either a higher standard of education or useful vocational skills had not helped most heads of households to accumulate sufficient assets to provide such a safety net and avoid the depletion of existing assets after becoming ill, whether or not they were able to continue to earn a living.

During the pre-symptomatic phase, the majority of the 48 participants who provided the researcher with in-depth interviews and who lived in nuclear households with two adults had secure livelihoods. Of the other households with secure livelihoods, the second most common type was the 'in-laws' household in which married daughters lived with their husbands and parents-in-law, and the third most common was paternal households, in which male participants (married or not) lived in their parents' homes, along with their brothers and their brothers' wives. A small number of people who were living alone also had secure livelihoods.

Many of these households, however, were torn apart when one or more family members contracted HIV. At the time of interview, when all the participants had been diagnosed as HIV-positive, most of the nuclear households had become vulnerable or

highly vulnerable and many had disintegrated as a result of a spouse dying, a husband abandoning his household, or a wife leaving her husband. In addition, during the post-symptomatic phase, some households had taken in additional members, increasing the overall proportion of paternal households. While many retained secure livelihoods, the livelihoods of others were stressed by the need to care for additional people, often in ill health, with the result that their households became more vulnerable.

To examine these trajectories in more depth, twelve households typical of the six most common types are discussed in more detail below. The livelihoods of three of the twelve households remained the same, while those of the others changed, usually for the worse. The findings are summarised in Table 4, followed by a narrative analysis of the twelve households' experiences. The main factors that explain the different household trajectories will be identified and discussed in depth at the end of the 12 narratives.

Participant AW<sub>1</sub> is an example of a household whose livelihood remained secure, while the livelihoods of CM<sub>13</sub> and DM<sub>3</sub> remained vulnerable and highly vulnerable, respectively, in the post-symptomatic phase. In contrast AW<sub>5</sub>'s and AM<sub>14</sub>'s livelihood status changed from vulnerable to highly vulnerable, AW<sub>13</sub>'s, AM<sub>15</sub>'s BM<sub>7</sub>'s and BW<sub>13</sub>'s livelihood status changed from secure to vulnerable, and finally, the livelihoods of BW<sub>8</sub>, BM<sub>15</sub> and CW<sub>1</sub> changed from secure to highly vulnerable. Each of the examples is analysed in turn.

**Table 4: To illustrate how participants' assets changed during the course of their illness trajectories**

Participant	Human Assets	Labour Assets	Financial Assets	Physical Assets	Social Assets	Household Relations	Livelihood Status
AW <sub>1</sub> <b>(Pre-symptomatic phase)</b>	Primary school education. Healthy. Husband alive and healthy.	Husband worked but participant did not work.	Jewellery	A flat she shared with her husband only.	Was friendly with neighbours.	No tension reported.	Secure
AW <sub>1</sub> <b>(Post-symptomatic phase)</b>	Widow and HIV positive.	Has three jobs.	None	Her late husband left the left and any other valuables to his parents - her in-laws.	No support from neighbours. Has good support from local NGO.	Initially discriminated against by in-laws but as time passed, relationships improved.	Secure
CM <sub>13</sub> <b>(Pre-symptomatic phase)</b>	Participant is healthy. His wife suffers from epileptic fits. No education.	House decorator/painter. Work unpredictable but on days he does get paid, he earns \$2 a day.	None reported.	None. Lives with paternal family in a house with a tin roof in a bustee.	He had some friends.	Good relations.	Vulnerable
CM <sub>13</sub> <b>(Post-symptomatic phase)</b>	HIV positive and at the time of interview his wife had still suffered from epileptic fits.	Takes time off work due to ill-health. His elder brother is the main earner and supports the entire household that consists of six people. The brother earns \$50 per month.	None reported.	No change.	He claims to have some good friends who had lent him money that he did not need to pay back. He doesn't go anywhere for support.	Family knows about his HIV positive status. He claims to be treated well.	Vulnerable
DM <sub>3</sub> <b>(Pre-symptomatic phase)</b>	Participant, his wife and his youngest child are healthy. No education	Works as a baggage handler at a train station in Kolkata, earning less than a dollar a day.	Some. Also borrowed money from a neighbourhood money	None. Lives in a small rented place in a slum area.	Not many friends, in spite of living in Kolkata for over	He has family in Bihar but lives in Kolkata with his wife and youngest	Highly vulnerable



Participants	Human Asset	Labour Asset	Financial Asset	Physical Asset	Social Asset	Household Relations	Livelihood Status
			lender.		10 years. He is originally from the State of Bihar.	son.	
DM <sub>3</sub> <b>(Post-symptomatic phase)</b>	Participant and his wife are HIV positive. Status not yet known for their son.	No change. His wife does not work.	No savings. In debt.	No change.	No change.	No change.	Highly vulnerable
AW <sub>5</sub> <b>(Pre-symptomatic phase)</b>	No education. Participant healthy. Younger daughter suffers from epileptic fits.	House servant, earning around \$8 per month.	None	None. Lived with her mother in a one-bedroom rented house.	Yes – friendly with neighbours and has elder married daughter to help her.	Did not get on with her second husband.	Vulnerable
AW <sub>5</sub> <b>(Post-symptomatic phase)</b>	Participant and second husband ill. She often felt ill. Younger daughter still suffering from epileptic fits.	Still working as a house servant earning around \$8 a month, but has to take days off work due to bouts of illness.	None. Has borrowed money from her neighbours.	No change.	Yes. Was able to borrow money from neighbours and her elder married daughter. Has not faced discrimination from neighbours.	Separated from second husband.	Highly vulnerable
AM <sub>14</sub> <b>(Pre-symptomatic phase)</b>	Secondary level education. Healthy. Married with daughter.	Worked for a courier service.	Some. Amount not disclosed to researcher.	None. Lived with his paternal family.	Was an active community member.	Not much. Wasn't close but was left alone by family.	Vulnerable
AM <sub>14</sub> <b>(Post-symptomatic phase)</b>	Widower. Wife died due to HIV-related illnesses. Daughter is HIV	Left his job in the fear of his HIV positive status being discovered.	Spent all his savings and borrowed money. \$240 of the loans.	No change.	None. He has been subjected to discrimination.	A lot of tension.	Highly vulnerable.

Participants	Human Asset	Labour Asset	Financial Asset	Physical Asset	Social Asset	Household Relations	Livelihood Status
	positive.		was still outstanding				
AW <sub>13</sub> (Pre-symptomatic phase)	No education. Whole household healthy.	Husband was the sole breadwinner	Some savings.	Jewellery and furniture.	None.	Not happy with husband due to his drinking problems.	Secure
AW <sub>13</sub> (Post-symptomatic phase)	Separated from husband. Participant and her son are HIV positive.	She was not working. Her cousin, with whom she was living, was the main breadwinner	None.	None.	Received cousin's help.	Some tension between cousin's wife and the participant	Vulnerable
AM <sub>15</sub> (Pre-symptomatic phase)	No education. Participant, wife and daughter were healthy.	House servant, earning \$60 a month.	None.	He lived at his employer's house where food and boarding were part of his employment contract. Wife and child lived in the family home with his mother, brother and sister-in-law.	None.	Good relations.	Secure
AM <sub>15</sub> (Post-symptomatic phase)	Daughter is physically well. But both participant and his wife became unwell after his wife underwent routine surgery and was given contaminated blood.	Lost his previous job and now worked as a security guard earning \$30 a month.	Had no savings and had borrowed money. In debt – owed \$240.	No change. Returned to his family home.	None. His neighbours did not know about his positive status. He did not go anywhere else for support apart from KNP+ and occasionally to a hospice for mental support.	Not good. Claimed that nobody at home took his daughter to school if he was unable to do so due to his odd hours at work or if he was too ill to get out of bed.	Vulnerable

Participants	Human Asset	Labour Asset	Financial Asset	Physical Asset	Social Asset	Household Relations	Livelihood Status
BM <sub>7</sub> <b>(Pre-symptomatic phase)</b>	No education. Participant healthy.	Worked in an office and earned \$30 a month.	No savings.	Has a home in Bihar. In Kolkata lived in a place paid for by his company.	None.	Lived alone in Kolkata but he has a family back in Bihar.	Secure
BM <sub>7</sub> <b>(Post-symptomatic phase)</b>	No education and ill from HIV.	No change	No change.	No change	Felt alone. Appeared to be scared of disclosing his status to anyone.	He was separated from his wife.	Vulnerable
BW <sub>13</sub> <b>(Pre-symptomatic phase)</b>	1 year of education. All family members are healthy.	Husband worked.	None	Household furniture and some gold wedding jewellery.	Some relations with neighbours and in-laws.	No tension reported.	Secure
BW <sub>13</sub> <b>(Post-symptomatic phase)</b>	She and her husband are HIV positive. Their 4.5 year old son is healthy.	Wife has four jobs. Husband continued to work as a labourer but he often had to take sick leave.	Took out a couple of loans worth \$50 and \$18 from her mother-in-law and brother-in-law. Struggling to paying the loans off.	All sold off.	Some help from in-laws. They had been discriminated against by their neighbours.	No tension reported.	Vulnerable
BW <sub>8</sub> <b>(Pre-symptomatic phase)</b>	Completed primary school education. Four children, husband and participant were healthy.	Co-owned a small sari business with her husband in Mumbai. Participant did not work and nor did her children.	Some savings – worth around \$500.	A rented home with three rooms, where her daughter had her own room and her two sons shared a room.	She had many friends in Mumbai but missed her family in Kolkata.	Got on well with her husband and her children.	Secure
BW <sub>8</sub> <b>(Post-symptomatic phase)</b>	She, her husband and her youngest son who was 12 years old	Her 23-year old son was the sole breadwinner. He earned \$25 a month.	None. Had to sell the business, used up her savings and	None – sold all household items and had to move back to Kolkata to stay with h	Moved back to Kolkata – has no friends. Joined an NGO.	Her husband had left her after he found out that he was HIV positive.	Highly vulnerable.

Participants	Human Asset	Labour Asset	Financial Asset	Physical Asset	Social Asset	Household Relations	Livelihood Status
	were HIV positive.		borrowed money from friends in Mumbai that she was unable to pay back at the time of interview	her mum and two sisters in a 3-bedroom house in a slum area		At the time of interview, she reported that she was finding it difficult to get on with her mother.	
BM <sub>15</sub> <b>(Pre-symptomatic phase)</b>	Has a degree. Whole household healthy.	A private tutor. Wife did not work.	Had savings (amount unknown)	Some furniture and wife had some gold jewellery.	No problem with neighbours.	Good relations.	Secure
BM <sub>15</sub> <b>(Post-symptomatic phase)</b>	All three members of family are very ill.	Still works as a private tutor but has to take time off due to the illness. Wife doesn't work.	Dwindling savings and still paying for alternative forms of ART.	Sold all his assets to pay for his and his wife's ART.	Discriminated against by neighbours. He, along with his family, were considering leaving the neighbourhood.	Good relations	Highly vulnerable
CW <sub>1</sub> <b>(Pre-symptomatic phase)</b>	Has secondary level education.	Her husband worked in embroidery.	Furniture and gold jewellery given to her during the wedding.	Her in-laws owned the house.	She was estranged from her mother because she had married outside her religion.	Did not say anything specific with regards to her relationship with her husband and in-laws.	Secure.
CW <sub>1</sub> <b>(Post-symptomatic phase)</b>	Both participant and husband are ill.	None	None	None	Did not say anything about her neighbours.	Her in-laws threw her out of her marital home. Conflict with her mother when she returned home.	Highly vulnerable.

As already mentioned in sub-section 5.1.2, participant AW<sub>1</sub>, a Muslim woman with primary school level education, who had become a widow in 1999 after her HIV positive husband died in an accident, told the interviewer how comfortable her life was before the death of her husband, when he earned a significant amount of money and she did not have to work. However, after the death of her husband she described how she had faced a number of financial and emotional challenges. As the years went on, she reported that she had handled the demands of living with her illness by having two sources of income (one regular and one irregular), eating healthily and accessing social support. She sewed saris and then sold them during religious festivals, earning up to \$40 a month. She lived with her in-laws in a flat owned by her husband but left to his parents, and contributed towards the household by paying a small amount towards the rent, as well as doing the weekly grocery shopping. She considered herself to be the head of the household, after her father-in-law became very ill and no longer had a job driving private cars. She reported that she was able to eat three meals a day and, since she was a vegetarian, she bought plenty of fresh seasonable vegetables, lentils and sometimes fruits, whenever she could afford them. She felt, however, that she did not get much support from anywhere else apart from the NGO in which she worked, although she felt that there was more potential support 'out there' for other PLHA like herself. She did not suffer from malnutrition, as she claimed to have been eating healthily, had no dependants and had a secure place to live, explaining that her in-laws were getting old and they needed her help more than she needed theirs. So, in the post-symptomatic phase, this participant would be classed as having a secure livelihood.

Participant CM<sub>13</sub> is a 44-year old Hindu man with no education, who had lived in Kolkata all his life. He had been diagnosed with HIV 18 days before the interview took place. He had tuberculosis and was on ART. He was married with no children and his wife suffered from frequent epileptic fits. Because of his wife's ill-health, he felt that there would be nobody to look after him now that he was HIV positive and prone to falling ill. At the time of interview he said that he had been working as a painter/decorator for many years but that he did not have a fixed salary. His earnings were unpredictable but when he did get paid, he received the equivalent of \$2 a day for his work. He said that his elder brother was the main earner, earning around \$50 per month, and supporting the entire household, consisting of the participant, the participant's wife, the participant's parents, and his sister-in-law. They all lived together in a house with a tinned tally roof, which was located in a slum area in Kolkata. CM<sub>13</sub> also said that he had a good and supportive family, especially his brother, who let CM<sub>13</sub> take days off if he is too ill to work. He also claimed that, although his family were aware of his positive status, they did not judge him and that he also had some good friends. This household can be considered vulnerable because, even though the participant has good family relations and social assets, he is very unwell, making him unable to carry on earning a living. According to the participant, only one person was supporting the entire household of six people, in which two people were ill (the participant and his wife), making the household vulnerable.

Participant DM<sub>3</sub>, a 40-year old married Hindu man, who has already been mentioned in 5.2.1, had been diagnosed with HIV a week before the interview. He was originally from the State of Bihar and had been living in Kolkata for over ten years. His wife is also HIV positive and he was not sure whether his eight-year old son was

positive or not. He had a 17-year old son living in Bihar, who was married and had a child of his own. DM<sub>3</sub> stated that he worked as a baggage handler in one of the busiest train stations in Kolkata but earned less than a dollar a day. His wife did not work and he did not believe that she should work, despite his ill-health. He receives some help towards his child's education, as his son goes to a school run by the government which is free to attend. He also said that he originally had some savings which he had brought with him from Bihar, but that all this money was gone because of the payments he had had to make to all the private clinics he had attended in order to obtain a diagnosis. He had also borrowed money from a neighbourhood loan shark who was charging him three percent interest, but felt that he had not had much of a choice as he needed to buy essentials in order for him and his family to survive. He stated that he had also borrowed the equivalent of \$120 from another loan shark in Kolkata to help him pay for his medical bills. This household can be considered highly vulnerable because not only are the participant and his family alone in Kolkata with not much social support, nearly all the members of the household are ill, the participant has lost all his savings, he is in debt, he is the only breadwinner in the household and his poorly paid job, from which his earnings are below the poverty line, may be in jeopardy due to his ill-health.

AW<sub>5</sub> is an example of an already vulnerable livelihood that became highly vulnerable during the post-symptomatic phase. A 37-year old woman with no education, AW<sub>5</sub> had been diagnosed in 2007 and at the time of the interview was a single parent separated from her second husband. She had two daughters, one of whom was married and lived in a separate household with her own family. The other suffered from epileptic fits and lived with her mother in a small one-bedroom rented house in a

slum area. AW<sub>5</sub> continued to work as a house servant, sometimes staying overnight in the house of her employers. Her monthly income was around \$8 (as noted above India's poverty line stands at \$1.25 per day) and she said that if someone else asked her to work as a servant, to wash clothes and/or dishes, she carried out these jobs for some extra money. She wanted a better-paid job but because she deemed herself illiterate, did not feel confident that she would be considered for a well-paid job. She also said that, by the time of interview, she often felt very ill, which prevented her from working. AW<sub>5</sub> bought her own food – she said that she had to buy good quality food for her sick daughter but she herself avoided eating this food, as she could not afford to buy expensive food for both of them. She asserted that whatever money she earned, she spent on treating her daughter's illness. When asked whether she had borrowed money, she responded that her neighbourhood knew about her status, as many people were HIV positive in the area where she lived, and that she was able to borrow money from her neighbours. However, she did not have any family from whom she could seek support, except for her married daughter, who provided her with some money whenever possible. AW<sub>5</sub> reported that she did not receive any other support and so felt incredibly alone. She did not appear to have coped well during the post-symptomatic phase, in large part because she did not have many assets in the first place. Her situation was made worse by her responsibility for another sick person requiring more energy and funds than she possessed at the time of interview. AW<sub>5</sub>'s limited income and lack of other support meant that she was facing severe difficulties in managing her household, so had become highly vulnerable.

Participant AM<sub>14</sub> was a 41-year old Hindu widower with secondary level education, who had been diagnosed with HIV in 2007. He had one daughter who was also HIV



positive. He had been on ART for six months at the time of interview but his daughter had not been started on ART, as her CD4 count was still very high. He had worked as an auditor for 12 years, earning \$44 per month, until he was made redundant. Then he had worked at a courier service until he was diagnosed and left the job in the fear of his HIV positive status being discovered. At the time of the interview, he lived in a rented seven-bedroom *kutcha* house (with a tin roof) in a slum area within a paternal household that consisted of his mother, two brothers and their respective wives. While this participant lived within an extended household that supported him with food and accommodation, he informed the interviewer that he felt he had no support. He said that his brothers did not support him even though they lived together, although he had a few friends that he could talk to and they provided him with mental support. When asked whether he had any support in his neighbourhood, he said that in order to socialise, he had become a member of a number of local clubs but after the death of his wife, when neighbours found out that he was HIV positive, everybody viewed him with disgust and since then he had avoided going out. At the time of interview, he said that all he did was watch television all day. Apart from his two brothers and mother, the rest of his family had no knowledge of his illness. He reported that he had spent most of his savings and had also borrowed money to try and obtain a diagnosis for his late wife by attending numerous private clinics. \$240 of the loans was still outstanding. In terms of food consumption, he said that the whole family did not eat very well, as they could not afford to buy meat, fish or eggs. Instead, they consumed rice and lentils on a daily basis, buying vegetables whenever they could afford to do so. Before AM<sub>14</sub> fell ill, his household was already vulnerable and during the post-symptomatic phase, as none of its members earned a decent living, it had become highly vulnerable.

Participant AW<sub>13</sub> was a 32-year old Muslim woman with no education, who was separated from her husband. She was first diagnosed with HIV in 2001, along with her youngest son. She had two children and the youngest son, who was nine years old, was HIV positive and had been on ART since he was 18 months old. She claimed to have spent everything that she had and sold jewellery and furniture in order to find out what was wrong with her youngest son. When asked what she did for a living, she responded; “...*I don’t work. I can’t work because my children are at home and there is nobody to look after them when they get home from school. Before my husband’s illness he used to work in making designs on bangles and worked outside of Kolkata. He earned quite a bit and we lived well. We owned the house. But then, my husband used to drink and smoke a lot and sold the house which left my children and me homeless...*” At the time of the interview, she said that she was living with her cousin and his family and that they supported her and her two children. However, she also said that there was tension between her and her cousin’s pregnant wife, who was not aware of the participant’s positive status, which often made her feel uneasy.

Participant AM<sub>15</sub>’s household livelihood changed from secure to vulnerable after he was diagnosed with HIV. This 45-year old Hindu man with no education had lived in Kolkata all his life. He was diagnosed with HIV in 2005 and recounted the story of how and his wife became infected with the virus: “...*my wife had a major operation a few years prior to 2005 where blood had to be bought from outside. Soon after the operation, my wife started to become ill. We went to the doctors with the help of my employer at that time. There, they said that my wife was HIV positive and I should get myself tested too...*” Before he became ill, he had worked as a house servant,

earning \$60 a month and staying with his employers, where food and boarding had been provided. During this time, he sent most of his money to his wife and his seven-year old daughter who had lived with his mother, brother and sister-in-law in the family home in a slum area in Kolkata. Since he became ill, he not only became a widower but also lost his job because of his inability to meet the demands of what he described to be a gruelling job. He claimed to have fallen ill often while working, which was not appreciated by his employers. When he lost this job, he returned to his family home and took up employment as a security guard, earning \$34 a month. At the time of the interview, he said that he worked 12 hours a day, using whatever he earned to support his daughter and contributing any money left over towards the family home, although he did not have to contribute to the monthly rent. He had exhausted his savings and borrowed a lot of money - \$240, which he was still gradually paying off. He claimed that on the days he felt ill, he was unable to go to work and as a result lost pay. He also talked about how worried he was for his daughter's wellbeing and future, as he felt that if he died, there would be nobody to look after her. He did not get along with his sister-in-law, as he felt that she mistreated his daughter. Participant AM<sub>15</sub> also stated that he had been on ART for six months. He stated that if the drugs worked without any side effects, he hoped to feel stronger and to be able to work more hours to help support his daughter. He is not only a member of KNP+ but also goes to Arunima Hospice sometimes to talk to people for mental support.

AM<sub>15</sub> claimed to have no emotional support and insufficient financial support from his mother, brother and sister-in-law. He and his daughter had a precarious living situation within the household, so he appears to try his best to avoid his daughter

being a financial burden on the household by working as many hours as he could despite being seriously ill. He hoped that his ability to work without taking sick days might improve as the ART took effect. Due to the precariousness of the participant's work and living situation, with him taking sole responsibility for supporting his daughter and with a non-existent social network, this household can be considered vulnerable.

When participant BM<sub>7</sub> fell ill with HIV, the household's livelihood status shifted from secure to vulnerable. BM<sub>7</sub> was a 45-year old Hindu man with no education, who had been diagnosed with HIV and prescribed with ART just over a year prior to his interview. He was separated from his wife and had four children, all of whom lived in the State of Bihar where he was originally from. He said that the company he had worked for prior to diagnosis and still worked for provided him with accommodation, where he lived alone, and he was able send money to his family in Bihar. When asked about the nature of his employment, he said that he worked in an office but that it was hard physical work. He earned around \$30 a month. When asked whether he felt that he had any support, however, he replied, *"...No. I feel that I am completely on my own. Well, my wife knows about my illness and she is very disgusted with me now. None of my other family members know about my illness, nor does the company in which I work..."* He said that he did not have any savings but that he wanted a loan from his employers in order to pay for his daughter's wedding in Bihar. Even though this participant had been able to continue working, and his steady income had enabled him to cope with his illness, he can be considered vulnerable, because he did not have any savings or emotional support, his wife had left him and he was responsible for supporting his children from afar.

Participant BW<sub>13</sub> was a 20-year old married Hindu woman with one-year of education, who had been diagnosed with HIV in 2005. Her husband was also HIV positive but her four and half year-old son was not. They lived as a nuclear household in a stone built one-bedroom house, in which rent and bills came to \$10/ month. Participant BW<sub>13</sub> had not worked during the pre-symptomatic phase. However, when her husband (the only breadwinner) fell ill during the pre-diagnosis phase and was forced to take time off work, she had begun to work as a house servant because otherwise they could not pay the rent. Given a choice, however, she would have stayed at home, as by the time of the interview, she felt very ill. Neither she nor her husband was yet on ART. She reported that she worked in four houses and had not informed any of her employers about her HIV status for fear of being dismissed. Her husband worked as a labourer in a cement warehouse and together they earned the equivalent of \$118 per month, with her husband earning the most. She related how on several occasions her neighbours had caused problems for her family because of her illness, which she had tried to ignore. Although she did not have any initial savings, she had taken out a couple of loans worth \$50 and \$18 from her mother-in-law and brother-in-law respectively, to cover costs when her husband had to take time off work and also for direct and indirect costs of medical treatment, loans that she was struggling to repay. When asked what she and her family ate on a daily basis, she said that she ate vegetables, fruits and whenever they could afford to buy meat or fish, they would do so, especially for the sake of their child who wasn't HIV positive.

The above case demonstrates the degree of adjustment that people had to make during the post-symptomatic phase. This household had made use of its own assets to enable it to live with HIV. The couple had not wasted money seeking a diagnosis from a

private clinic as, upon recommendation by relatives, they had gone directly to STM. Although the participant had very little education and had not worked prior to her husband falling ill, she had found four jobs so that her family could continue to live at the same standard as before. In general, this household had been able to cope with the shock better than many other participants, though it would still be classed as vulnerable as both members are HIV positive, the participant's husband was struggling to keep his job, all their physical assets had been sold off, they were struggling to pay off their loans and they seemed to have lost their social asset after their neighbours found out about their HIV positive status.

Participant BW<sub>8</sub> who has already been mentioned in sub-section 5.2.1, is a 37-year old Hindu woman, separated from her husband for six years, with a primary school education and who at the time of interview, had been living with her three children in her mother's home in Kolkata. She had moved her family from Mumbai three years prior to the interview after she could no longer support herself and her family in Mumbai where, according to her, the cost of living was higher than in Kolkata. After having spent nearly all of their savings on private clinics to find out what was wrong with them, she and her husband were finally diagnosed with HIV at a government-run hospital in 2002, after which her husband abandoned her and their children and was never seen again. In order to survive, BW<sub>8</sub> had sold the business that she co-owned with her husband in order to pay for everyday commodities for her family, but she also had to buy first-line ART from private pharmacies as during that time, ART was not available free of charge. Three years prior to the interview, when she fell ill, her daughter had to leave school to look after her. With her savings dwindling fast, difficulties in finding employment due to her ill-health and lack of child care, and

very few friends from whom she could ask help after she was diagnosed with HIV, she decided to move to Kolkata and live with her mother and two sisters.

At the time of interview, the participant lived in her mother's *pucca* house where she did not pay rent. She was also on second-line ART, as advised by STM, and said that even though she felt weak, she was relieved that she no longer had to pay for her ART. When asked whether she worked, she said that she did not have employment but wanted to find a job as a tailor, working from home. She showed interest in buying a sewing machine for herself in order to open a business from her mother's home and said that she would so, as soon as she could afford to do so. She said that her son was the sole breadwinner of the household, earning around \$25 a month or less, an income that is sometimes sporadic. When asked whether their children were at school, she responded that her son was going to school but that her daughter did not start school when they all moved to Kolkata from Mumbai, as she had been caring for the participant. Her daughter and sometimes her eldest son (when he is able to take time off from work) take her to the hospital appointments. When questioned about how she felt about people becoming aware of her HIV status, she responded that only her household members were aware of her status and that she did not want her relatives or her neighbourhood to know about it because she was afraid that they would "cause problems" for her and her family. She said that she wanted to stand on her feet and work for a living so that she could provide for her family. She was afraid to tell her youngest son's school about his positive status as she felt that he would be thrown out of the school, resulting in everybody becoming aware of their illness. She said that she did not go anywhere for support apart from SPARSHA. In this instance, the participant's livelihood status had been secure prior to her HIV-related symptoms

developing. Her financial and physical assets helped her initially when she was diagnosed with HIV in Mumbai even when the sole earner of the family, her husband, had abandoned the family. However, with a combination of having to buy first line ART, looking after her family and with no income being generated, the participant's livelihood became increasingly vulnerable, until she reached a point when she was left with no assets. After three years of struggling, when she finally moved to Kolkata with her family, although she had a home to go to, due to the loss of all her assets, her livelihood status became highly vulnerable and remained so at the time of interview, three years after she had moved from Mumbai.

Participant BM<sub>15</sub>, who has already been mentioned in chapter five, is a 42-year old married man with a Bachelors degree in Economics, who lived in a nuclear household and earned a living as a private tutor, giving private economics lessons to students at graduate level, as well as teaching maths and physics to children in his neighbourhood. After he, his wife and his son were diagnosed with HIV in 2002, BM<sub>15</sub> was still able to work as a private tutor, in spite of the discrimination he faced from his neighbours due to his positive status. The fact that he and his wife were both suffering from the side effects of one of the combinations of ART did not help matters, in terms of maintaining a healthy livelihood. The medical professionals at STM advised the participant that he buy an alternative form of ART for his wife and himself, which was not available at STM. He had begun to do so in 2005, and was spending \$135 every month at the time of the interview, when his monthly income was \$167. As a result, the livelihood of the participant and his household had become more insecure, meaning that they were unable to eat three nutritious meals a day and were facing difficulties paying for their son's education. In this instance, the



participant's higher level of education had enabled him to work as an educator and buy alternative forms of ART for both his wife and himself, but after three years of spending money on medication, he was having difficulty making ends meet and was becoming increasingly vulnerable.

Participant CW<sub>1</sub> was a 35-year old woman with secondary school level education who had been diagnosed with HIV in 2007. She had been born into a Hindu family but had converted to Islam to marry a man of Muslim origin, which caused friction between her and her mother, who was at the time the head of the household. The participant had been married for five years before her husband and in-laws threw her out from her in-laws' house. Before then, her husband had worked in embroidery, they usually ate well and her in-laws used to help out. After she was thrown out, she had returned to live with her mother, who she alleged treated her very badly. She reported that she had not worked for a living when she was married but said that she would like to find a job when she felt a bit better, as she wanted to move out of her mother's house. She reported that she was on ART and had been trying to get used to being on the medication, by staying in Arunima hospice till she felt better. Other than the hospice, she did not feel she had any support, apart from the little space she had in her mother's house to sleep. She also said that she had no money, nor did she have any savings, with the result that she could not afford to buy even cheap drugs for opportunistic infections when she needed them. Before she had contracted HIV and been thrown out of her in-laws' house, the household that she had lived in was secure, but at the time of the interview, this participant had become highly vulnerable, as she had no assets on which she could rely.

The most common factors that emerged from the experiences of those 11 households who had been able to maintain secure livelihoods even during the post-symptomatic phase, as illustrated by AW<sub>1</sub>, are that the household contained more than one person who had achieved at least primary school level education, explaining why one or more people in the household were still able to find work and earn an income that enabled them to feed their families. In addition, these households had good household relations, despite some tension during the early phase of the illness, and prior to falling ill they had all owned physical assets, such as furniture, gold jewellery and/or their homes. Households such as AW<sub>1</sub>'s were successful in maintaining secure livelihoods during the post-symptomatic phase because they not only had a high number and variety of assets prior to falling ill, which they were able to use to cushion the impact of the illness and mitigate its effects, but in addition, members of the household were able to mobilise and pool their resources or assets, with some family members who had not previously earned taking up work out of necessity (for example, the wives of sick husbands or children taken out of school).

For example, in terms of household relations, participant AW<sub>1</sub> reported that there had been initial tensions in her home, with the participant feeling that she had been treated badly by other household members, but as time passed and with the help of their respective NGOs, family members had come to have a better understanding of the illness and had become supportive of the participant. The most important factor that protected CM<sub>13</sub>'s vulnerable household from becoming highly vulnerable during the post-symptomatic phase was also good household relations. The participant had a good relationship with his paternal family, with whom he and his wife shared a home, and when asked how he thought he would be treated at home and who would support

his family when he was ill, responded immediately (unlike most of the participants interviewed for this study) that his elder brother would look after the entire household, including the participant and his wife, until the participant got back on his feet. Not only was his family providing this man and his equally sick wife with ongoing support, he felt that he had been treated well and provided with emotional support, and that he could anticipate such support being provided in future, enabling him and his wife, unlike many participants interviewed as part of this research, from becoming destitute.

The important factors that explained DM<sub>3</sub>'s highly vulnerable household's inability to improve on his precarious state included his low earnings (less than a dollar a day), his wife not working, the exhaustion of his savings, the need to repay money borrowed from loan sharks at three per cent interest per month, his status as a tenant rather than a home owner, and the absence of relatives living in the city.

The most common factors that explained why some households that had previously been vulnerable had become highly vulnerable during the post-symptomatic phase (AW<sub>5</sub> and AM<sub>14</sub>) were that ill-health had forced them to work fewer days or stop working altogether. Also, while they had responsibility for other household members, they received very little help from family members outside their own households and even though some received support from neighbours, this was limited by the poverty of the neighbourhood in which they lived (e.g. AW<sub>5</sub>), while others experienced discrimination from their neighbours (e.g. AM<sub>14</sub>).

The most common factors that explained the deterioration of some livelihoods from secure to vulnerable during the post-symptomatic phase (AW<sub>13</sub>, AM<sub>15</sub>, BM<sub>7</sub> and BW<sub>13</sub>) were either the loss of a job or that the participant had not been working previously, making them dependent on others. Such dependence was exacerbated by marriage breakdown (e.g. BM<sub>7</sub>) or intra-household tensions. Although it was not always clear whether the tensions pre-dated the onset of the illness or had emerged after a participant became unable to contribute (consistently) to the household income and became reliant on care provided by other household members, the latter appeared to be true for two participants who lived within their extended households: AW<sub>13</sub> and AM<sub>15</sub>.

In addition, specific decisions or events help to explain why the livelihoods of some people changed from secure to highly vulnerable. Participant BW<sub>8</sub>, for example, had co-owned a business with her husband prior to falling ill but her husband had abandoned her when he discovered that he was HIV positive (for reasons that she did not divulge). In addition to becoming ill and unable to work, she had to buy first line ART from private clinics in Mumbai, until she could no longer cope as all her physical assets had been used up and so she had to return to Kolkata to live with her mother and two sisters. Participant CW<sub>1</sub> was also an exceptional case: in addition to becoming ill and unable to work, she was in conflict with both her marital and natal households. BM<sub>15</sub> was also an exceptional case, because of the effects of his efforts to find appropriate medical treatment on his livelihood, despite his high level of education and relatively well paid work.

‘Household relations’ (a type of social asset) thus emerged as a key factor in explaining how well the participants’ households fared. Although some households became vulnerable after one or two members contracted HIV and became dependent on other household members, if a PLHA had a good relationship with other household members, they were able to rely on their emotional and/or financial support. A further example illustrates this: participant CM<sub>7</sub>, who has already been mentioned in sub-section 5.2.2, was a 38-year old Muslim man who had been diagnosed with HIV one and a half months prior to the interview. He lived with his parents and six brothers in a *pucca* house that had eight rooms and where he shared a room with his mother. When asked how his family treated him at home, he said that everyone knew about his illness and had come to visit him at the hospice. Although his father did not work, his brothers did and he felt that they would provide for him financially, enabling him not to worry too much about his imminent future of living with his illness.

In contrast, participant BW<sub>14</sub>, a 28-year old Muslim widow with no education, who has been mentioned in 5.1.2, described how she had to cope with her nine-year old son and work full-time as a house servant after her husband died due to HIV-related illness, even though she was at the time of the interview having difficulty keeping her job due to her illness and had been denied a better-paid job after her husband’s death, due to her positive status. When asked whether she felt that she had any support from her family, she responded that her in-laws had completely abandoned her and her son since the death of her husband and so she was unable to ask them for financial help, although her paternal aunt helped her and treated her well.

Another factor that influenced how well households coped with the illness or death of one or more members was whether or not the women within those households had employment. In all those households that remained secure even in the post-symptomatic phase, either the participants or the wives of participants had previously worked or had found employment when their husbands fell ill or died (e.g. AW<sub>1</sub> and BW<sub>13</sub>). In all the other cases (households that remained vulnerable or highly vulnerable or whose vulnerability increased), the women did not take up any employment or had died, leaving their widower husbands and children behind, often in addition to other stresses or shocks. As already discussed in section 6.1, some women reported that they had been prevented from earning by their husbands and in-laws even when their husbands were bedridden, demonstrating gender attitudes that exacerbate the inequality ingrained within Indian society, as discussed in 4.2.1. The further example of participant CW<sub>2</sub> (who has already been mentioned in 5.1.2), whose livelihood status was already vulnerable, but became highly vulnerable when the head of her household contracted HIV, illustrates these factors. CW<sub>2</sub> was a 45-year old married Hindu woman, originally from Bihar, who had come to Kolkata for her husband's job. They lived in a small house together and had both been diagnosed with HIV in February 2009, a month before the interview. They had four grown up children in Bihar who were all HIV negative, but to whom they sent money. Before her husband was diagnosed with HIV, he had worked as an electrician earning \$32 a month, but he became so ill that he lost his job and at the time of interview, the participant (even though she was also ill) had been looking after him in Arunima hospice for two months. They had debts of over \$4000 because they had borrowed from extended family members and friends before her husband was formally diagnosed with HIV. In the hospice, they had been provided with a bed, four meals a

day and medicines for opportunistic infections, but CW<sub>2</sub> said that she felt she had no other support. However, when she was asked whether she worked, she responded; *“...in our culture, women are not allowed to work outside for a living. It’s a shame because I would have liked to earn some money now, since I am not as ill as my husband. I need to send money home in Bihar for my children. I feel so helpless that now no money is being sent for my children in Bihar...”* This demonstrates CW<sub>2</sub>’s frustration and feelings of hopelessness about having to follow a cultural protocol that prevented her from supporting her children in Bihar, potentially adversely affecting their chances to live good lives.

The findings from sections 6.1 and 6.2 reveal the ways in which the PLHA in the current study had attempted to adapt their livelihood strategies to cope with a positive diagnosis. They show that overall, during the post-symptomatic phase, the situation had changed for many households: fewer had secure livelihoods and the proportion with vulnerable and highly vulnerable livelihoods had risen sharply. The vulnerability status of about a third of the households (16 out of 48) remained the same during both the pre-and post-symptomatic phases, while the vulnerability of 32 households increased during the post-symptomatic phase, regardless of the participants’ education levels. Thus, although some had been able to maintain secure livelihoods or at least not become more vulnerable than they already were, households’ ability to respond to the challenges had varied. There is no evidence to suggest that any of the participants diagnosed with HIV had been able to improve their livelihood status, with the analysis suggesting instead that many had become more vulnerable. More detailed information on the earnings, savings, borrowing and repayments, and consumption of not only participants but also other members of their

households would be needed to develop a sound understanding of these processes, but it is difficult to obtain such data for households whose composition changes over time, that are mostly engaged in irregular or own account work, do not keep records, and are reluctant to divulge financial information to outsiders. The ability to obtain support from outside the family has been briefly mentioned during the analysis so far and is one of the factors that might determine the ability of a PLHA to avoid impoverishment – what was available from organisations and used by participants will be reviewed in the next section.

### **6.3 ACCESS TO AND UTILISATION OF LIVELIHOOD SUPPORT FROM NGOS, THE HOSPICE AND STM**

The support provided to PLHA by their households may or may not be sufficient for them to avoid impoverishment, as discussed in sub-section 2.2.4 and shown in the previous section. There is wide international recognition that other sources of support need to be provided as part of an AIDS policy, to assist households containing HIV-positive members to obtain appropriate treatment, as well as cope with the adverse effects of their illness on their livelihoods. The central concern of this section is to analyse what sources of wider support were available to the participants in the study, which they were able to access, and the nature and extent of the contribution these sources of support were making to their security and wellbeing. It begins with how PLHA came to know about the support available, and then identifies the types of support that were available to them in theory and practice. It concludes by exploring the effects on people's livelihoods of having accessed livelihood support and discussing their expectations of future support that might be provided.



### **6.3.1 Access to livelihood support**

This sub-section will firstly analyse the ways in which the PLHA came to know about the support available, focussing on who offered them advice, who received advice, from whom, how soon they acted, and what they did in response. Secondly, it will examine the main types of support that were available in theory at the hospice and the NGOs for the PLHA and what support they obtained in practice.

The PLHA were asked whether they had known where to seek support for maintaining their livelihoods. Out of the 59 participants interviewed, 48 acknowledged that the doctor who had formally diagnosed them as HIV-positive at STM had recommended that they should seek livelihood support. Eight of the people interviewed at STM were either busy seeing a doctor or counsellor or shocked by their newly diagnosed status and did not respond to this question. In three cases, the participants reported that the doctor concerned had introduced them to the peer workers of one of the NGOs discussed in the current study, who were at STM during opening hours looking for newly diagnosed patients to join their NGO. . Of the six others, none said that they had been advised whether and where to seek support with maintaining their livelihoods.

In contrast, 12 out of the 15 PLHA interviewed at Arunima hospice who were willing to talk in-depth reported that the doctors at STM had recommended that they seek help from the hospice, to which they had been referred for observation after commencing ART. None of these had been made aware of other sources of support.

The participants who were interviewed at KNP+ and SPARSHA confirmed that the peer workers from these organisations had been present at STM or a government hospital when they were first diagnosed and had urged them to become members of the NGO that they represented, promising that they would receive financial, nutritional, mental/social support.

The length of time that participants had taken to seek livelihoods support after formal diagnosis with HIV varied: the majority of people who were advised by a doctor or peer worker to seek help did so immediately but a few, mostly those interviewed at KNP+ and SPARSHA, reported that they had left it for a few months. Six of the people interviewed at STM, as mentioned above, did not at the time of the interview intend to seek help from outside their families, in part because they had not been told where help might be available, but also because they were all afraid that their neighbours, friends and extended families would find out about their positive status if they did so. Participants who had been referred to the hospice attended it immediately. While almost everyone else did eventually seek help, they delayed doing so for between one month and 10 years, depending on a number of factors, including whether he or she wished to seek support, had been introduced to NGO outreach workers at the time of their diagnosis in STM, or simply wanted to see what was available that would be beneficial for themselves and their families. It appeared that more women than men had sought help from the NGOs for their own livelihoods than those of their children or their spouses.

The main types of livelihood support that were available in theory from the two NGOs included professional counselling and learning about how to live with HIV

safely on a daily basis; the provision of dry food to enable recipients to cook a very basic meal for their family, including lentils, rice, oil and sometimes barley flour for making traditional 'chapattis' if rice was unavailable; reimbursement of the cost of medicines for opportunistic infections; reimbursement of travel costs to visit the NGO concerned; 60 percent of the school fees for one child in a household or for two children per household if one turned out to be HIV positive; the provision of condoms at a subsidised cost; short-term project based employment; and social interaction with other PLHA. The hospice provided an in-house bed; four meals a day; medicines for opportunistic infections; professional counselling; and information about how to take ART. Services provided by the ART centre adjacent to the STM, as described in 4.3.2, focused on regular CD4 tests and medical treatment (ART and medicines for opportunistic infections) but also included professional counselling both after diagnosis in STM and when picking up ART drugs at the ART centre.

In practice, one or more of the PLHA interviewed had received almost all of the services that were offered by the NGOs and the hospice. In particular, the majority reported that they had found common ground with fellow PLHA while attending the organisations and that they had benefited from sharing their stories with others. However many complained that they had not received counselling when they were first diagnosed with HIV and some also complained about not being counselled when attending STM for their six-monthly CD4 count tests. A couple of the participants had been diagnosed with HIV at STM in 2002 and both were put on ART, during a time when neither first nor second line ART was available at STM free of charge. PLHA in need of first-line ART had to buy these medicines till the beginning of 2004, when they became available for free, while second-line ART did not become available free

of charge at STM until December 2008. As these participants did not have sufficient money, they reported that they had had no choice but to ‘shop around’ for free ART from different NGOs in and around Kolkata.

The following sub-section will discuss the PLHA’s experiences of accessing livelihood support from the formal institutions and investigate whether their livelihood outcomes had improved as a result of receiving such support.

### **6.3.2 People’s assessments of the livelihood support**

This sub-section will explore whether participants whose household livelihood status was either vulnerable or highly vulnerable during the post-symptomatic phase noticed any improvements in their lives and the lives of their families as a result of accessing livelihoods support. Finally their expectations for future livelihood support are discussed.

Participants reported that their main motivations for seeking livelihood support were to receive free medication, food and part of the cost of education for one or more children. However, some people, especially those living on their own or involved in high-conflict family relationships on a daily basis, stated the importance of visiting their chosen NGO to simply interact with people who were also living with HIV/AIDS and that this sometimes outweighed the other types of support that they received.

For example, participant BW<sub>14</sub>, a 28-year old Muslim widow, formally diagnosed with HIV in 2004 and whose livelihood status had changed from vulnerable to highly vulnerable, explained how her initial motivation was to gain access to low cost ART and medicines for opportunistic infection. However, as the years went by, she said that she continued to attend in part because her association with SPARSHA gave her a sense of belonging.

When the participants were asked whether the support they received from the institutions helped them cope better, people responded that they appreciated the reimbursements for opportunistic infections and people with young children appeared to be satisfied with the 60 percent of school fees paid by the two NGOs for one or two children within their households. For some people, this support meant that they did not become completely destitute. However, almost all the participants complained about the process by which people were reimbursed for their medical bills and also about not having any money to buy medicines to treat opportunistic infections in the first place, so on many occasions people reported that they had gone untreated for opportunistic infections until they had become very ill and had to be taken to STM or the hospice for further treatment and observation.

One participant, BW<sub>2</sub>, who has been mentioned several times in both chapters five and six reported that her respective NGO had helped her to combat discrimination, when peer workers and the NGO's medical doctors visited her household, talked to her son and daughter-in-law and encouraged them to ask questions about living with someone with HIV/AIDS.

When the participants were asked about their overall assessment of the livelihood support that they received from KNP+, SPARSHA and Arunima Hospice, the majority, whether widows, families with young children, nuclear families, or single people living alone, felt that the support they received from KNP+ and SPARSHA had not been enough, so that that they were still struggling. They (for example AW<sub>2</sub>, AW<sub>7</sub>, AW<sub>3</sub>, and BM<sub>7</sub>) mostly complained that the nutritional support provided by KNP+ and SPARSHA was insufficient and too unreliable to enable them to feed their families for an entire month, although they enjoyed being able to interact socially with fellow PLHA at these two NGOs.

Some participants had expectations from the NGOs, for example, participant BM<sub>10</sub> who has been mentioned several times in chapter five, felt that SPARSHA could do more to help him. Because he found his current job working in a bookshop (where he earned around \$31 a month) challenging, as he had to be on his feet all day, he wanted SPARSHA to help him find a less arduous job so that he could continue earning a living.

A couple of participants, for example, participants AW<sub>1</sub> and BM<sub>15</sub>, who have been mentioned several times in chapter five had been concerned about the non-sustainable support and ‘handouts’ that had been provided by the institutions, expressing a preference for being able to work for a living, so that they could sustain themselves into the future. Thus they both felt that the government should be made responsible for providing PLHA with employment.

As already stated, most of the PLHA who had sought help from Arunima hospice had not done so voluntarily. Nevertheless, when asked about the services provided and how they were treated by the staff, 12 out of the 15 PLHA interviewed at the hospice (who were willing to talk in depth), expressed satisfaction with the services provided and the respectful attitudes of the staff. In addition, a few participants talked about other support that they wanted. For example, CW<sub>1</sub>, who was very ill and had nobody to help her get her medicines, wanted an easier way of obtaining them than personally attending the ART centre, and CW<sub>8</sub>, who had worked as an outreach worker for another NGO (CINI) on the outskirts of Kolkata since the death of her first husband, wanted more financial support for her children's education. Finally, CW<sub>9</sub>, a 33-year old married woman with two young children, was first diagnosed with HIV at STM in 2004 and began taking first-line ART in 2006 at the hospice. At the time of her diagnosis and since, her husband had been critically ill and unable to earn a living. Once CW<sub>9</sub> had adjusted to the toxicity of the medicines, the hospice gave her a job as an outreach worker. Though she was able to earn \$62 a month (more than the majority of the participants), and received reimbursements of the cost of medicines for her and her husband's opportunistic infections, she had accumulated debts during the process of obtaining a diagnosis for her husband and so wanted further help from the hospice.

After having sought livelihood support from the NGOs and the hospice, the participants appeared to enjoy being part of a group where they had the freedom to talk about the challenges of living with the illness and also found it useful to learn about self-care and safe sex. A handful of participants, mainly women, found employment as outreach workers after joining their respective NGOs. However, this

employment is insecure, as it is subject to the funding available to the NGO, so all the women who were in such employment had additional jobs.

Although the majority of the participants were not entirely satisfied with the support they received, they continued to attend these organisations because they felt that whatever support they received was better than receiving no support at all and acknowledged the benefits obtained from the mutual support provided by other members. Some people had even ‘shopped around’ other NGOs to obtain appropriate livelihood support.

## **6.4 CHAPTER CONCLUSION**

The households to which the participants in this study belonged had all been affected by their illness (and often that of other household members), with the structure of almost half of all the households changing. As revealed by findings from previous research, the analysis for this study has also shown that the PLHA employed various livelihood strategies to cope with the impacts of the illness, using the assets they possessed before they fell ill. While some had secure livelihoods prior to falling ill and had been able to maintain a similar livelihood status, some were already vulnerable or highly vulnerable and the livelihoods of many became more insecure. Findings from previous studies reveal how loss of income, employment insecurity and health expenditure can potentially have negative repercussions, not only on stocks of labour, human, financial and physical assets, incomes and standard of living but also on intra-household relations and social networks. This has also been found from the findings in this research, with some families breaking up after family members



revealed their positive status, and it was not uncommon for participants to live in households where there was a lot of tension, in many cases due to them having become burdens on their families. As revealed by a number of authors in previous studies, human and labour assets are considered to be the most important assets for the urban poor, who live in monetised economies with few common resources or scope for self-provisioning. The findings from this research reveal that when a man falls ill with HIV/AIDS and can no longer carry out his physically demanding job, some women who had not worked before their husbands fell ill went out to work (often taking on more than one job) (in addition to their existing reproductive tasks) to help support their families, although others were prevented from doing so by their own ill-health, lack of child care or the disapproval of family members. The existence and nature of intra-household and family relations were important variables explaining the different strategies available to participants and their ability to cope with the illness without becoming even more impoverished and vulnerable.

Most participants had sought some type of help or livelihood support from outside their families and, with the exception of recently diagnosed PLHA interviewed at STM, the majority reported that they had obtained the three main types of support on offer from the NGOs and the hospice, although it was not possible to draw a clear conclusion from their responses with respect to whether they felt that the support received from these formal institutions had had a positive overall impact on their livelihoods during the post-diagnosis phase. The following chapter considers possible reasons for the differences, similarities and anomalies between theory and practice identified in chapters five and six and in this way systematically tries to answer the research questions.

## **CHAPTER VII**

### **EXPERIENCES OF LIVING WITH HIV/AIDS, THE EFFECTS OF THE ILLNESS ON HEALTH AND THE LIVELIHOOD STRATEGIES OF PLHA**

#### **7.0 INTRODUCTION**

This chapter will examine the empirical findings about the effects of living with HIV/AIDS on a daily basis before and after formal diagnosis and the longer-term effects of the illness on the livelihoods of PLHA reported in the previous chapters in more depth. It also discusses the study participants' attempts to cope with the illness on an everyday basis, including the ways in which they access a variety of services dealing with prevention of further transmission, treatment, care and support. The findings from the current study will be compared with those of previous research, their implications explored and the adequacy of the conceptual framework assessed.

Firstly, in section 7.1, people's response to early signs of HIV before diagnosis, their responses to living with the illness before and after diagnosis during the post-symptomatic phase will be considered, and explanations of its effects on households and the types of illness coping strategies that result suggested.

Secondly, section 7.2 will explain how and why people seek treatment from alternative sources, with respect to the types of public and private sources of healthcare that they can access.

Thirdly, section 7.3 will examine the livelihood support that the PLHA had received and assess whether or not it had a positive impact on their lives and prevented them from being further socially excluded.

Finally, section 7.4 will conclude the chapter by pulling together the main findings.

## **7.1 PEOPLE'S RESPONSE TO EARLY SIGNS OF HIV AND TO LIVING WITH HIV/AIDS BEFORE AND AFTER DIAGNOSIS**

As stated in section 1.4, the overall aim of this study is to identify the ways in which HIV/AIDS affects individual poor people and their households, identifying the social characteristics that enable or constrain their ability to maintain their wellbeing and livelihoods, access healthcare and obtain adequate support for their livelihood strategies. This section discusses the findings presented in chapters five and six in relation to the theoretical and empirical starting points that emerged from the literature review, the conceptual framework developed and presented in chapter three, and the description of the Indian context, in particular highlighting any differences or similarities according to gender.

### **7.1.1 Response to early signs of HIV before diagnosis**

This sub-section addresses the first part of research question one: 'What are the experiences of people concerning the symptoms and diagnosis of their illness?' including differences between people with different social characteristics, especially gender (see 1.4).

Corbin and Strauss in Woog (1992) (see 2.1.1 and 3.1) identify eight possible phases that people suffering from a chronic life-threatening illness endure over time: the period before the illness; the diagnostic period; crisis or a life-threatening situation; acute illness, during which hospitalisation may be required; a stable phase, during which the illness is controlled; an unstable phase, during which the illness is not controlled by a regimen; a progressive or deterioration phase; and death. Not all phases occur, and illness does not necessarily result in a downward spiral or end in death. The findings presented in 5.1.1 reveal that the participants in this study and/or other members of their households had experienced all the phases, depending on the rate of illness progression for each individual. Management of the disease during any given phase begins with the identification of problems associated with that phase. Although during the pre-diagnosis phase, the HIV-infected participants in the current study had not recognised the symptoms of the virus, did not understand their illness and therefore, had not been able to interpret the meaning of their illness, they had nevertheless begun to manage the disease, mostly by visiting a pharmacy from which they bought over-the-counter drugs for the purpose of self-medication, as a means of saving time and money.

If their symptoms persisted and their health did not improve, they sought further help, mostly from the private health care providers that are found in abundance in urban India, although some did go to public health care providers. For many, misdiagnosis led to further private consultations, until they were referred to STM, which also provided treatment. As a result, for most of the participants significant time elapsed between experiencing the first symptoms and obtaining a correct diagnosis, leaving them feeling fearful and helpless about their health. Such a feeling of ‘existential

uncertainty' when it is proving difficult to obtain a medical diagnosis is also mentioned in a study carried out by Adamson (1997) (see 2.1.1).

Although the participants in the current study had few assets to begin with, they initially sought help from private providers (pharmacies and private clinics), whose incompetence delayed the receipt of a correct diagnosis and was also costly, increasing participants' indebtedness and loss of assets and jeopardising their families' livelihoods. Since people's livelihood strategies both influence and are influenced by the ways in which they respond to their illness and their treatment-seeking behaviour, the ways in which they adapted to their strategies to cope with the impact of HIV will be the focus of discussion in the following sub-section.

### **7.1.2 Responses to living with HIV/AIDS before and after diagnosis**

This sub-section is concerned with how and why changes occurred within the households and livelihoods of PLHA when one or more household members became ill with HIV, specifically focusing on the period of time when they began to show symptoms of HIV before they were officially diagnosed (the pre-diagnosis phase) and the time after they were eventually diagnosed with HIV (the post-diagnosis phase). This sub-section will help answer research question three in 1.4: 'How do poor PLHA with different social characteristics pursue their livelihoods on a daily basis?'

## - **Livelihood strategies**

It was suggested in section 3.1 that the concept of a livelihood based on the mobilisation of assets and resources makes it possible to first, identify the many ways in which HIV morbidity and mortality affect households through their impacts on human, financial, social or political, natural and physical assets, and second, to analyse and explain whether and how the poor are able to ‘manage’ their asset portfolio during the post-diagnosis phase in order to avoid increased vulnerability leading to further impoverishment.

The findings from the current study confirmed previous studies reviewed in 2.2.2, showing that one of the major changes that occurs within households after one or two members contract HIV is a decrease in the availability of assets, as revealed by differences in the number and type of assets possessed between the pre- and post-diagnosis phases. Household members had been unable to prevent their assets from diminishing, so appeared to have had no other choice but to adopt new strategies in order to survive.

Similar to findings from the international literature, as reviewed in 2.2.2, for example Barnett et al. 1995; White and Robinson, 2000; Harvey, 2003; Loevinsohn and Gillespie, 2003; Russell, 2005; White and Morton, 2005; Crush et al., 2006; Hosegood et al., 2007; Richter et al., 2009 and Abebe and Skovdal, 2010, the current study also found that after one or more members of their households became ill with HIV/AIDS, participants had had to devise *ex post* coping strategies that included reducing consumption (fewer meals and different types of food), earning money in

new ways, borrowing money, selling possessions in order to raise cash, withdrawing children from school and sending children away to live with other family members. For example, during the pre-diagnosis phase, out of the ten PLHA who had owned small enterprises or had savings in the form of cash, nine either went out of business or had lost all their savings. The latter reported that their savings had diminished as a direct consequence of the cost of obtaining a correct diagnosis for themselves and/or another household member. In addition, many described how their living standards had declined to a point at which they no longer earned enough to eat three nutritious meals a day.

As the *ex post* coping strategy ‘earning money in new ways’ and the role of ‘household relations’ (a type of social asset) emerged as key factors in explaining how well households fared during the post-diagnosis phase, the focus of the remainder of this sub-section will be on these two factors.

### **- Labour Assets**

The most common *ex post* coping strategy that emerged from this study involves the labour available to a household. Many households affected by HIV/AIDS began to earn money in new ways, which is congruent with the studies mentioned above and in 2.2.2. What emerged was that it is not unusual for women to take on additional tasks when their husbands become too ill with HIV to carry out their physically taxing work (see 6.2). During the pre-symptomatic phase, only four female respondents earned a living and these participants continued to do so even during the post-diagnosis phase (at the time of their interviews) even though they were suffering from ill-health. In

addition, nearly half of the female respondents who had not worked during the pre-symptomatic phase (mostly because their husbands were the sole breadwinners) (11 out of 26) not only cared for their sick husbands (despite often being ill themselves) but also went out to the labour market in search of work during the post-diagnosis phase, irrespective of the level of education and/or vocational skills that they possessed. This finding is congruent with studies carried out by Pryer (1993) in the context of ill-health in general and by UNAIDS (1999) in the context of HIV/AIDS (see 2.2.2). Pryer's study in particular found that when the main earner within a household is incapacitated, more women (and children, which will be discussed later on) go out to work, despite the very limited income-earning opportunities open to them.

Factors that prevented the other 15 women in this study from entering the labour market included ill-health, the lack of child care, and cultural restrictions placed upon the women by their husbands and/or in-laws that forbade them to go out to work. This finding is somewhat in contrast to findings from a previous study carried out by Priya and Sathyamala (2007) in the Indian context (see 4.1), where the authors found that even though women labourers belonging to low caste groups go out to work, they are still controlled by their families, including their husbands. The finding is in complete contrast to Mitra (2004)'s findings which lead her to suggest that women have always entered the labour market when they can find work (also see 4.1). This issue will be discussed further in the context of gender dynamics within households (see below).



Findings from this study also revealed that the human assets of children are affected when one or more parent becomes ill with HIV. Children under the age of 16 had been withdrawn from school because of lack of money to pay for the associated costs, with the girls having to help care for their loved ones suffering from the illness or assist with household chores and boys having to start earning, in order to replace the earnings of the main earner. However this study also found that, congruent with Moser (1998) in 2.2.2, participants had tried hard to keep their children in school, so that three of the four households whose sons had been withdrawn from school had not taken them out of schooling completely. However, when times were tough, the respondents reported that these boys had had to take up part-time employment (see 6.2). These findings are congruent with previous research which reveals that when a main earner and/or carer are incapacitated due to ill-health, a higher proportion of children (as well as women, as mentioned above) enter the labour market (Pryer, 1993), carry out domestic and care work, and/or participate in income-generating activities (Abebe and Skovdal, 2010; Jacoby and Skoufias 1997; Duryea, 1998; UNAIDS, 1999; Mutangadura, 2000; Skoufias and Parker 2002; Barnett and Whiteside 2002; Ogden et al., 2006; McIntyre et al., 2006).

As stated in section 3.1, it might be expected that the income earning opportunities available to people with education are greater, enabling them to develop secure livelihoods and build up assets that could cushion the impact of the illness. However, the findings reported in 6.2 suggest that having either a higher standard of education or useful vocational skills had not helped most of the heads of households to accumulate sufficient assets to provide such a safety net and avoid the depletion of

existing assets after becoming ill, whether or not they were able to continue to earn a living.

These changes in patterns of earning and schooling, as well as new needs, may lead to changes in household composition and dynamics (see 2.2.2). Since the power to mobilise resources usually lies in the hands of the household head, typically acknowledged as the member who brings in the most resources, usually a man, if the 'head' contracts HIV/AIDS, this not only may affect decision-making within a household but may also lead to a change in the dynamics within households. The latter is discussed below.

#### **- Gender dynamics within households**

Due to the stress brought about by HIV/AIDS, changes in household composition and dynamics within households were indeed reported during the post-diagnosis phase (at the time of the interviews). As elsewhere, in this sample, typically, the member of a household who brings in most resources is acknowledged as its 'head', usually a man. However, as shown in section 6.1, the identity of the 'head' of over half of the 48 households in which the participants resided had changed since the pre-diagnosis phase, mainly because of the loss of a male head when he died, separated from his wife and/or abandoned his family, when another male member became the head of household or the wife of the previous head took on the role. Some (especially women) had become the heads of their households when abandoned by their husbands after the latter were diagnosed with HIV. However, in some cases, a participant maintained a dominant presence within a household and continued to be regarded as

its head, even if bed-ridden due to HIV-related symptoms. In such cases, it was not uncommon to find female participants being prevented by their husbands and/or in-laws from making a living for their households even when they might have been able to work. Not only did all the female participants trapped in such ‘power struggles’ with their husbands and/or in-laws state their frustrations about not being permitted to provide for their children, in spite of being healthy enough to find work, many narrated how they had to tolerate domestic violence.

The men in the study talked about how, in their “culture”, they did not “let” their women go out to work, a typical view amongst both men and women in India, who are led to believe that they should have distinctly different roles specific to their gender (see 4.1 and 4.2.1). Typically, men are seen as being responsible for productive activities outside the home whilst women are expected to be responsible for reproductive and productive activities within the home. Although some women do work, for example women labourers from low caste groups, as demonstrated by findings from a study carried out by Priya and Sathyamala (2007), they are still controlled by their families, including their husbands (see 4.1). In addition, in the cultural context of India, power in sexual decision-making also usually lies with the man. Thus, cultural attitudes, in particular the double standards that govern what is regarded as acceptable behaviour for men and women within Indian society, help us to understand the different ways in which men and women contract HIV and experience shame and discrimination due to the stigma attached to the illness.

Nearly all the women in this research had found out about their HIV status after their husbands became critically ill and were taken into hospital or died, although some

found out during antenatal check-ups. Nearly all the 30 women interviewed had contracted HIV after having sexual intercourse with their husbands, while only one of the 29 men interviewed had contracted the virus from his wife, after she had received contaminated blood products during an operation. This pattern is typical in India, as elsewhere, as revealed in 4.2.1, with studies showing that a large proportion of women with HIV acquire the virus from their regular partners, who are infected during unprotected paid sex (Kumar et al., 2006), and that large numbers of married women attending antenatal clinics test positive, thereby increasing the risk of perinatal transmission (Maniar 2000).

#### **- Household relations**

During the post-diagnosis phase (at the time of the interviews), in certain households, it was reported that relations between HIV-positive men and other household members had deteriorated sharply, resulting in these men feeling lonely and isolated. In others, relations between husbands and their wives had worsened, along with those between sons' wives and their parents, with the latter often blaming daughters-in-law for their son's illness and demise, leading to many women returning to their paternal households, increasing the overall proportion of paternal households. This finding is congruent with a study carried out by Tarakeshwar et al. (2006), who found that women who had lost their husbands due to HIV-related illnesses were often blamed for their husbands' deaths, resulting in them being physically and socially isolated by their in-laws, and that these widowed women did not have any other choice but to return to their natal families (see 4.2.1).

Most of the nuclear households in this study had become vulnerable or highly vulnerable and many had disintegrated as a result of a spouse dying, a husband abandoning his household, or a wife leaving her husband. Although many households retained secure livelihoods, the livelihoods of others were stressed by the need to care for additional people, often in ill health, with the result that their households became more vulnerable, either because the participant had lost his/her job or was not working previously, making them dependent on other household members. Such dependence was exacerbated by marriage breakdown (e.g. BM<sub>7</sub>) or intra-household tensions (see 6.2).

For participants AW<sub>5</sub> and AM<sub>14</sub>, not only did their ill-health force them to work fewer days or stop working altogether, they also had responsibility for other household members despite receiving very little help from family members outside their own households. Although some reported that they had received support from neighbours, this was, limited by the poverty of the neighbourhood in which they lived (e.g. AW<sub>5</sub>), and others had experienced discrimination by their neighbours (e.g. AM<sub>14</sub>) (see 6.2).

The above findings are congruent with a study carried out by Kabir et al. (2000). The authors found that the direct impacts of any illness on households are loss of income, employment insecurity and health expenditure, which in turn may have negative repercussions for intra-household relations and social networking. In addition, when a person suffers from HIV/AIDS, White and Robinson's (2000) study reveals that, due to the longevity of HIV/AIDS and its tendency to affect many families within a community, social capital may become severely strained over the long term (also see 2.2.2).

In contrast, household and family relations protected the households of several participants in this study from becoming further impoverished. This was especially true for CM<sub>7</sub>, CM<sub>13</sub> and to a certain extent for AW<sub>1</sub>, although, for the latter, there had been initial tensions in her home with her in-laws, when she had been first diagnosed with HIV after the death of her husband. Some participants were assisted by members of their wider family (see 6.2).

As reported in 4.2.1, historically and culturally in India women are seen as the main carers within households, whether household members are sick or not, so it is not surprising that when it comes to providing care for PLHA, especially when the latter become bed-ridden, the onus of caring falls on women. Although complete and systematic accounts of the types of care that the PLHA receive from their household members were not obtained in this research, and it was not possible to interview other members of the participants' households to ascertain their perceptions and experiences of providing care for affected members, it emerged that most women respondents living with HIV/AIDS continued to carry out their usual reproductive duties by providing care for their husbands, children and/or in-laws in spite of themselves suffering from typical HIV/AIDS symptoms. These women were those who had either lived with their husbands in nuclear households or with both their husbands and in-laws and had not moved to their paternal homes during the post-diagnosis phase. This finding is congruent with the Indian literature (see 4.2.1): women everywhere in India are known to neglect their own needs for food and nutrition, rest and medical care and, when infected with HIV, not only to receive very little care and support from other household members when ill, but also for their own health care needs to go unmet while they are caring for their husbands and sons

(Jejeebhoy and Rao, 1995 in Das Gupta et al., 1995:133; Mitra 2004 and Bharat and Aggleton, 1999).

The findings of this study confirm that PLHAs' *ex post* livelihood strategies (see 6.2) are for the most part no different from those adopted by the poor in the face of any other type of shock. However, with only a couple of exceptions, the majority of participants in this study had felt unable to ask for help from their neighbours during the post-diagnosis phase, when they had already lost other assets, primarily due to the stigma attached to HIV/AIDS, which will be examined further in the following subsection.

### **7.1.3 Stigma and discrimination**

The international literature discussed in 2.2.3 reveals that poor people in general are socially excluded, resulting in a lack of assets, and moreover that people with particular social characteristics may be further marginalised. It was clear also that the research participants felt that the specific characteristics of their illness influenced both the strategies open to them and their wellbeing. With respect to the aspects of people's everyday lives on which HIV/AIDS has an effect and how, it emerged that the key dimension is stigma within households, neighbourhoods, employment and in the health care sector.

## **- Stigma and discrimination in households**

The findings revealed that the participants in this study saw themselves in a negative light, mostly because of the stigma that is attached to the illness, a reaction that is not unusual in the Indian context, as revealed in 4.2.1. Not only is considerable social stigma attached to any disease that is transmitted sexually, HIV/AIDS, however has a 'double stigma' because of its moral connotations, due to its previous connection with sex workers (see Hawkes and Santhya, 2002, sub-section 4.2.1) and also lack of knowledge about the illness and how it is contracted. Because of this, when first diagnosed, most of the participants reported that they had not disclosed their status to anyone, even members of their close families, for fear of being judged adversely or worse, evicted from their rented accommodation, losing their employment or their children not being allowed to stay on in school. This finding contrasts with a study carried out by Pradhan et al., (2006) in Andhra Pradesh (as reported in 4.2.1), where most of the 470 PLHA interviewed revealed that upon discovering their positive status, they had immediately disclosed it to their spouses.

The participants in this study described how they had come across other PLHA who had been humiliated and badly treated, leading them to fear that they would suffer similarly if their own HIV-positive status was discovered, leading some to exclude themselves completely from all societal interactions. In addition, some reported that other household members had initially been reluctant to share food and drinking utensils with them (see sub-section 5.1.2). This finding is congruent with a study carried out by Bharat for UNAIDS (2001) in the Indian context (as reported in 4.2.1), which also found that ostracism and rejection were the most common responses within the families of PLHA, causing the PLHA to be afraid of the effects of



disclosing their status. Similarly, the study by Singh et al. (2009), reported in 4.2.1, revealed that although all 100 PLHA interviewed expressed a desire to be loved by their families and accepted by the society in which they lived, fewer than a third expressed satisfaction with their family life and a significant proportion had faced discrimination from their neighbours and from society in general. Whilst Holt et al., 1998, (see sub-section 2.2.4) suggest that disclosure is known to alleviate the stressful burden of concealment and to increase the availability of material and emotional support, more commonly other studies reported in 2.2.4 revealed that disclosure may lead to PLHA being stigmatised, discriminated against by others, and exposed to emotional distress, as was found in the current study.

As revealed in 5.1.2, there were no apparent differences between the men and women respondents with regard to how they felt they would be perceived by their neighbours and the wider society if people were to find out about their positive status. Both men and women were afraid of the consequences. Occasionally, men expressed remorse for the way they had contracted the virus, which had made them hesitant to tell their families and or/wives, partly because they were aware of the social stigma that is attached not only to the disease but also to sex workers all over India. On many occasions during the interviews, men who had had sexual encounters with sex workers on a daily basis nevertheless referred to them as “dirty girls”. Thus some of the men in the current study, who had contracted HIV after having unsafe sexual intercourse with one or more sex workers over a period of time, especially migrant men who lived away from their wives, and had then had unsafe sexual intercourse with their wives, infecting not only their wives but also possibly their unborn children, had been unable to handle the guilt and broke down whilst reporting their

experiences to the interviewer. They were clearly aware of the implications of being HIV-positive, with both Hindu and Muslim men who had contracted HIV via sexual transmission describing feeling “ashamed”, “dirty” and “worried” about having contracted the illness. Although this finding is consonant with the majority of the findings reported from previous studies, as discussed in 2.2.4 and 4.2.1, it contrasts with those from a study carried out by Priya and Sathyamala (2007), which found that low caste labourers from Tamil Nadu and Uttar Pradesh did not appear to suffer from shame or guilt due to having contracted HIV/AIDS and nor did they report any forms of discrimination within their households or outside.

Five factors that contribute to HIV/AIDS-related stigma were established by De Bruyn (1999, see sub-section 2.2.4), one of which is relevant to this study. In many societies, people do not like to be associated with behaviours that are already stigmatised – in this instance associated with transmission of the virus (such as homosexuality, injecting drug use, sex work and sexual “promiscuity”) – the double stigma referred to above. Thus as suggested above, some of the men in this research, who had contracted HIV after having unsafe sexual intercourse with sex workers, reported that they felt guilty about the way they had contracted the virus.

As revealed in sub-section 5.1.2, four out of the 59 participants (all men) explained that when they had disclosed their HIV status to their partners, only one felt supported, while the others felt unsupported or reported that being HIV positive had led to marriage breakdown and families being torn apart. This finding contrasts those from studies by Bond et al. (2002) in Zambia and Bharat and Aggleton (1999) in India, reported in 2.2.4 and 4.2.1 respectively, which found that men were more

willing to share their HIV status with their wives than vice versa in the expectation of a supportive response.

The study by Tarakeshwar et al. (2006), reported in 4.2.1, revealed that women whose husbands had died due to HIV-related illnesses had often been blamed for their husbands' deaths, resulting in them being physically and socially isolated by their in-laws and leaving them with no choice but to return to their natal families. Widowhood is itself socially and morally stigmatising in Indian society, but if a widow is HIV positive, she suffers a double stigma. As discussed in sub-section 4.2.1, the identity of women in India is solely based on how to be a 'good' daughter, wife, and eventually mother, whilst keeping a high moral profile within the community or society in which she resides. Not only are women seen as part of the 'weaker sex', requiring protection when out of the safety of their homes, but also whether they are considered 'good' or 'deviant' is purely based on their sexual activities. Consequently, when a woman is found to be HIV positive, her behaviour is seen to have been deviant, leading the household and community in which she lives to treat her badly, eventually ostracising her from society. In addition to having no or very little education, limiting their access to paid employment, and the restrictions placed on them because of the reproductive and cultural expectations of their families and society in general, widows from the lower income population who are HIV positive might be expected to be even more excluded than their male counterparts because they are socially ostracised for being 1) HIV positive and 2) a widow.

The study did indeed find that, when women respondents told their husbands about their positive status, it appeared to be quite common for them to be thrown out of their

marital homes – only two reported that their families and in-laws had been supportive towards them when informed. Women who had been thrown out of their marital homes also described how they had been treated badly when they returned to their paternal homes. Those who had later become widows were in a particularly difficult position, finding themselves to no longer fit in any household, whether those of their in-laws, extended families or parents. Thus six women not only had to tolerate the shame of becoming widows and returning to their paternal homes from their in-laws' households, but they also had to endure discrimination within their parents' households.

**- Stigma and discrimination in neighbourhoods, employment and the health care sector**

Some participants also reported that their neighbours had verbally abused them and one that her neighbours had tried to force her to leave the neighbourhood where she was living. One participant also reported that she had been denied employment when her workplace found out about her positive status. Bond et al. (2002), in the context of a Zambian community (see 2.2.4), found that discrimination against PLHA takes many forms, two of which are relevant in this research – verbal abuse and eviction. When PLHA face this kind of derogatory subjugation on a daily basis, they begin to become self-conscious, resulting in a fear of revealing their HIV status to others. Tarakeshwar et al. (2006) (reported in 4.2.1) also revealed that stigma and discrimination played big roles in the lives of both women and men living with HIV/AIDS in Chennai, where people feared to disclose their status to anyone, even household members, in case they lost respect, brought shame upon their families, became socially isolated and lost their employment. Their respondents reported that

these fears were realised, as they became socially isolated and lost employment when their neighbours and employers found out about their positive status. Similarly, the study of 470 PLHA in Andhra Pradesh carried out by Pradhan et al., (2006), that has been mentioned above (and also reported in 4.2.1), found that, although most of the PLHA reported that they had immediately revealed their positive status to their spouses, a much higher proportion (both men and women) had not disclosed their status in their wider communities due to the fear of being ostracised and some of those whose status had become known reported that they had suffered discrimination. The findings from the same study revealed that over half of the PLHA interviewed who were employed at the time of the interview had not disclosed their status to their employers for fear of losing their jobs, although of the 40 percent who had done so, only six per cent reported that they had in practice experienced discrimination.

Discrimination may also occur in health facilities. Empirical evidence provided by Malcolm et al., 1998; Bond et al., 2002 and Heijnders, 2004 (reviewed in 2.2.4) reveals that PLHA may be refused treatment and basic care, suffer treatment delay, be neglected and be called names. Both Maniar (2000) and Pradhan et al., (2006) provided evidence in the Indian context (4.2.1) that some patients had been refused admission in both private and government hospitals and nursing homes, denied medical assistance and in general treated badly. Also, they found that even if admitted, PLHA were often isolated in the wards, generating fear and confusion amongst both them and other patients. In this study, as revealed in 5.2.2, a small number of participants asserted that in previous years, for example in 2004, the attitude of staff at STM had been bad and the nurses unfriendly and rude towards participants when they were first diagnosed with HIV. These participants felt that the

staff's attitude had improved over time. However, several people who had been diagnosed with HIV between December 2008 and the end of April 2009, complained about the bad behaviour of the counsellors and some staff, inferring that sometimes the behaviour of doctors was just as bad. Most of the participants who had received care from the Calcutta Medical College and Hospital, a teaching hospital located adjacent to STM, whose facilities are called upon when the facilities at STM reach maximum capacity, complained about their treatment. It appears, therefore, that even at the time of interviews, three years after Pradhan et al.'s study, PLHA still face discrimination, despite the NACO phase II and III policies that prohibit subjecting people to stigma and discrimination within health care settings (see 4.2.2), although perhaps this is not surprising, given the stigma attached to the illness in wider society in India and beyond.

#### **- Breaches of Confidentiality at STM**

Participants reported with anger and resentment that breaches of confidentiality on the part of medical professionals had caused particular problems. At least six revealed that their HIV diagnosis had been disclosed by a doctor at STM to members of their family and announced in the waiting area before it was disclosed to the participants themselves, even though, according to the Chief Medical Officer, STM supposedly follows all the NACO policies. These breaches of patient confidentiality had devastating consequences for two of the six participants, as the family members concerned had then announced the participants' HIV positive status to their neighbours, causing huge problems. These findings are consonant with those of most studies carried out in the international and Indian contexts (see 2.2.4 and 4.3.1),

although a multi-country review carried out by Malcolm et al., (1998) reveals that in some cultures it is acceptable for a doctor to tell relatives about an individual's status without his/her consent, as group and societal rights are considered to be more important than individuals' rights and it is felt that relatives can then protect the patient's confidentiality and share the burden of the illness.

#### **7.1.4 How do PLHA cope with their illness?**

This sub-section will analyse how the participants coped during the early stages of the illness following formal diagnosis, specifically identifying and explaining the coping strategies that they used to deal with their symptoms (both positive external and negative internal coping).

As noted in 2.1.2 and in the conceptual framework (3.1), different types of psychological and practical responses to illnesses occur. These have been grouped by Jenkins and Guarnaccia (2003) into two groups, namely 'Positive External Coping', which includes dealing with stigma, optimistic planning and social networking with members of the HIV community, and 'Negative Internal Coping', which includes secrecy, negative rumination and self-isolation. The participants in this study reported that they had used all six coping strategies (reported in 5.1.3), confirming the results reported by Jenkins and Guarnaccia (2003).

### - **Positive external coping strategies**

Dealing with stigma is classed as a positive external coping strategy, but all except one of the participants had found it difficult to respond positively to the stigma they experienced. This is perhaps because HIV/AIDS is still a relatively new disease in India (and in the rest of the world), which moreover was first identified amongst sex workers (a stigmatised group of people, as discussed in 7.1.3) and also was seen as a “problem” which the government of India initially tried to avoid, perhaps rather naively hoping that it would go away. Whilst the government was deciding what to do, the disease spread, affecting not only sex workers but also migrant workers, truck drivers, men who have sex with men and injecting drug users, who were all at risk of contracting the virus. By the time the government of India decided to tackle the problem with HIV/AIDS preventative measures, one of which was education, the disease had already spread amongst the general population, leading to confusion and panic because people had not been aware of this new disease and were thus fearful of it. Most of the participants in the current study felt that the wider population still needed to be educated with regard to modes of transmission and how to prevent infection, which would, they hoped, reduce discrimination against PLHA.

Optimistic planning, classed as a positive external coping strategy, had been adopted by over 15 percent of the study participants, some of whom reported hope of recovery, so that they could start providing for their families again, and one of whom reported that he had filed a successful court case to resist eviction and stated his determination to continuing doing so, if necessary (see 5.1.3). In general, ‘optimistic planning’ was more common amongst men than women, with the former seeing their futures in a brighter light, perhaps because of the ways in which women have been



treated historically and currently within patriarchal Indian society. As discussed in 4.2.1, women in India have first hand experiences of patriarchy in the families in which they are born and raised, where the head is a man – her father who, unlike for boys, controls his daughters’ mobility, sexuality, labour and reproduction. Families are an unequal forum for girls to grow up in, resulting in even more inequities between girls and boys as they get older. When women eventually get married, they get passed on like possessions from their fathers to their husbands, where the whole cycle of respecting and obeying the male household head continues, along with an obligation to produce male progeny, in return for a home and being looked after for the rest of their lives. As a result of such ingrained cultural differences with respect to the roles of women and men, first within the families in which they grow up and then in their marital homes (whether nuclear households or living with their in-laws), women are led to believe that in order to live well, they need to be looked after by a man. Consequently, as shown in the current study, when a devastating shock such as HIV/AIDS strikes, resulting in illness or death, more women than men appeared to feel that they had no control over their situations, making them particularly anxious about their own and their children’s futures without a healthy husband to look after them. This is unsurprising given the ways reported above in which women are treated in the households of their parents or in-laws.

Perhaps as a result, it is not surprising that more women than men reported using the coping strategy, social networking with members of the HIV community (see 5.1.3). All 11 participants who adopted this strategy reported that they had not intentionally set out to network with members of the HIV community, but that with time, and after frequent visits to their support NGOs, both men and women began to consider social

networking with other PLHA integral to their survival, with more women than men emphasising the importance of this coping strategy in their lives. These findings are congruent with another study that investigated the lived experiences of diverse HIV-positive women in Ontario, Canada, where the findings showed that in order to avoid isolation and cope with intrapersonal stress related to living with HIV, women preferred to interact with other HIV positive women within social support groups (Logie et al., 2011) (see 2.1.2).

### - **Negative internal coping strategies**

The participants in the current study used all three negative internal coping strategies (secrecy, negative rumination and self-isolation), as reported in sub-section 5.1.3.

As discussed above, while some reported that they had been able to disclose their status to family members, friends and neighbours without fear, many had kept their positive status hidden from their spouses, neighbours and others. These findings are consonant with the assertions made by Bharat for UNAIDS (2001) (see 4.2.1), Thomas (2006) and Greeff et al. (2008) (see 2.1.2), which suggest that people generally choose secrecy about their HIV status as a coping strategy if they are afraid that they and their families might be stigmatised, which is perceived to be a threat to receiving care. In addition, they also avoid contact with other people by withdrawing themselves from all family and social contacts.

Keeping their HIV positive status hidden is an emotional burden. It may also have implications for access to care. Although the majority of participants in this study

reported that they endeavour to keep their status hidden, they have continued to attend STM for six-monthly blood tests to check for CD4 levels, and to pick up medicines for opportunistic infections and monthly antiretroviral drugs from the ART centre (if required). In addition, they attend the NGOs studied for other types of livelihood support.

The types of livelihood and illness coping strategies that the participants in the current study have been shown to use reveal that they are not free agents, as socially excluded individuals who are also chronically ill with a stigmatised illness have few real choices, having instead to rely on whatever assets they may have (see also 2.2.2), and an illness coping strategy that feels appropriate, given the risks to which they are exposed. In addition to not having many options, PLHA are subject to the culture in which they have been brought up and the expectations of their immediate household members, their extended families, neighbours, friends, employers, landlords, and even healthcare providers and NGO staff.

## **7.2 ACCESS TO HEALTH CARE**

This section will explain the treatment seeking behaviour of PLHA and the ways in which the participants in this study accessed and subsequently assessed the private and public health care providers used at different stages during their illness trajectory, to address research question two (see section 1.4) – ‘How do PLHA with different social characteristics access and assess the adequacy of health care services for HIV/AIDS?’

## - **PLHA's treatment-seeking behaviour**

Obrist et al. (2007)'s 'Health Access Livelihood Framework' both combines the two dominant approaches to understanding treatment-seeking behaviour and situates access to health care in the broader context of livelihood insecurity. As discussed in 2.1.3 and 3.1, the authors assert that once illness is recognised, treatment seeking is initiated, influenced by five dimensions of access: availability, accessibility, affordability, adequacy and acceptability. Using this framework, the participants in the current study were asked which health care services and goods were available to them and whether these services had met their needs, in terms of physical proximity; whether the direct and indirect costs, including costs of travel, time and income foregone, had been affordable; and finally, how adequate and acceptable the services received had been.

The findings, as portrayed in 5.2.1, showed that when people first decided to seek help for their HIV/AIDS-related symptoms, access indeed became an issue, which was congruent with the findings reported in 2.1.3. In practice, the health seeking behaviour of participants in the current study followed a pattern that consists of a combination of 'Good's pathway' (figure 1 in 2.1.3) and Obrist et al's (2007) 'health access livelihood framework' (figure 3 in 2.1.3).

When the participants in the current study initially decided to seek help for their illness, they went directly to pharmacies, public hospitals, or private clinics, as revealed in 5.2.1. In some instances, they were recommended to go to certain private clinics or directly to the STM by someone they knew. When those who had taken over-the-counter drugs noticed that their symptoms persisted, they subsequently went

to either a private clinic or a public hospital for a diagnosis. If a private practitioner misdiagnosed a patient's illness, the participants reported that they then attended further private clinics for a second or third opinion until a private practitioner recognised their symptoms and referred them to STM. However, if a participant ran out of funds, he or she had no choice but to seek help at a government hospital. Once referred to STM, they stopped going anywhere else for treatment, unless they were given prescriptions for medicines for opportunistic infections by STM.

The treatment seeking behaviour adopted was dependent on the availability of facilities. Studies reported in 2.3.2 and 4.3.2 show that in many developing countries, private medical facilities are the preferred source of care for many, because they are more plentiful and accessible than government-run services, in addition to having a number of other perceived advantages, including better quality than government-run services; positive staff attitudes; short waiting times; the possibility of obtaining credit; more privacy; respect for confidentiality; and the availability of family physicians with close social links to patients and their communities.

The private sector is the first point of contact for the majority of people in India, including in Kolkata, when they suffer from any kind of illness, major or minor. It is, therefore, not surprising that many of the participants in this study initially sought treatment from pharmacies or private clinics.

It is common knowledge that the government of India lacks the institutional and implementation capability to regulate the private sector, which does not regulate itself, with the result that services are uncoordinated and often poor quality. Private

providers are known to take advantage of the lack of regulation to charge their clients as much as they want, provide inappropriate rather than standardised therapeutic strategies, provide no information to their clients and pay no attention to national programmes. The perceived incompetence of many of the private practitioners consulted by participants in this research and their tendency to overcharge, forcing poor PLHA to sell their possessions and/or borrow money, are congruent with the findings of previous studies (see sub-section 4.3.2).

As revealed in sub-section 4.3.1, India's general public health care system is characterised by under-funding and low performance and, similar to the private health care sector, has no organised referral system. Some public hospitals funded by the Central government provide free treatment for personnel working in certain central government offices through the Central Government Health Scheme (CGHS) and State governments operate Employee State Insurance Schemes that permit factory workers and some government employees whose employers pay for the Employee State Insurance Scheme (ESIS) to obtain subsidised hospital treatment. One participant in the current study had access to ESIS and was referred directly to STM via this type of insurance without having sought treatment elsewhere and incurred unnecessary expenditure. However, none of the other participants had health insurance and, in addition to paying for private treatment, those who had been diagnosed by STM before 2004 and who required ART immediately due to their CD4 count being very low, complained that they had not been provided with the medicines free of charge and instead had had to buy them from pharmacies. Those who had been diagnosed after 2004, in contrast, had been provided with free first-line ART, as part of the Indian government's AIDS programme (see 4.2.2).

As reported in sub-section 4.2.2, an entity (separate from the general Indian public health system) was established to provide HIV/AIDS care, treatment and preventative measures: NACO. NACO started to implement the second phase of its national strategic plan in 2000, involving decentralisation of prevention and control to the State level, and collaboration between governmental and non-governmental organisations at the national, State and local levels. It appears from the interviews that most of the NACO policy guidelines governing case management of patients are being followed (see sub-section 4.2.2). However, many participants complained that they had not received counselling at STM when they were first diagnosed with HIV there and also did not mention that they had received any 'home-based' care, the provision of which is part of the NACO guidelines, even though the Chief Medical Officer at STM reported that his organisation had been following the NACO guidelines on patient case management.

Understanding men and women's treatment seeking behaviour is important when it comes to investigating the ways in which they access health care services, because various studies have revealed that men and women have different requirements and different expectations (see 2.1.3). As stated above, most participants, both women and men, reported that they had initially bought medication from pharmacies but when their symptoms persisted, the majority (both men and women) had sought professional help from private clinicians. It also emerged that the women participants had attempted to manage their illness alongside their other household responsibilities, such as childcare, household chores, taking care of their husbands and sometimes in-laws and, for some, employment during the post-symptomatic phase of their illness trajectory. This is congruent with the findings from previous research in a multi-

country HIV/AIDS context carried out by Ogden et al., (2006) (see 2.4.1) and in the Indian context by Rajeswari et al. (1999) (see 4.2.1). Ogden et al. (2006) assert that women living with HIV/AIDS may not have the resources of time or money to attend regularly, causing them to obtain medicines and remedies for their symptoms from other sources. Rajeswari et al.'s study reveals that it is thought that women are more likely to face obstacles in gaining access to diagnostic facilities, obtaining the necessary investigations and completing treatment for TB due to the lack of time they have as a result of the triple burden of housework, childcare and employment. As already discussed in 7.1.2 with regards to how and why the onus of the caring roles in Indian households always falls upon women even if they are also suffering from HIV/AIDS, findings from this study reveal that women whose husbands were still alive when they found out about their own and their husbands' positive status had a tendency to put the needs of their husbands, children and even in-laws before their own, for example, making sure that their husbands kept appointments, in the process often neglecting to take care of themselves, which may have repercussions for their wellbeing. This is congruent with the findings from previous research in India carried out by Jejeebhoy and Rao, 1995 in Das Gupta et al., (1995:133), Mitra (2004); and Bharat and Aggleton (1999) (see 4.2.1).

#### **- PLHA's assessment of the health care facilities**

The criteria for choosing particular providers can, it has been suggested, be grouped under the headings of availability, affordability, accessibility, adequacy and acceptability (see section 3.1). As described above, the majority of the participants reported that they had chosen private clinics as their first point of contact before



diagnosis due to their convenient location, although, as stated in sub-section 5.2.1, one person had been recommended to go to a private clinic and three had attended nursing centres as far away as Chennai, because the health care providers in Kolkata (both private and public) had not diagnosed their illness correctly. Participants did not, however, mention cleaner facilities, being less busy, having shorter waiting times or flexibility in terms of accepting non-cash payments as reasons for preferring private clinics over public health care providers, as found in other studies reviewed in 2.3.2 and 4.3.2.

Some participants also complained about the difficulties they experienced in obtaining a correct diagnosis from public general hospitals. However, many chose public providers, especially STM, because they were perceived to have the professional competence to provide a correct diagnosis, and above all were able to provide appropriate treatment, often free. However, disadvantages of attending STM and the ART centre were also identified, for example earlier charges for diagnostic testing and in-patient treatment if required and the time and money costs of travel to STM, especially for their six-monthly CD4 tests. As already mentioned in 5.2.2, this finding reveals that most of the PLHA studied went to one health care provider after another in search of a correct diagnosis and subsequently, appropriate care, support and treatment, rather than to avoid stigma, which is contrary to findings from previous studies, the authors of which suggest that people suffering from HIV/AIDS and/or other STIs tend to 'shop' for alternative providers, diagnoses and treatment because the disease is stigmatised (see 2.3.2).

In addition, those on ART complained about having to collect their free drugs from the ART centre every month, because some had to take time off from work, and some were too ill and had to ask their spouses to collect the medicines (typically wives, who had to leave their housework). Failure to collect medicines regularly has both medical and economic implications, because missed dose(s) jeopardise the immune systems of PLHA, may lead to resistance to a particular combination of ART, and then may necessitate the provision of second line ART, which is more expensive and has a higher risk of side-effects, as reported by Larson et al., (2008) in 2.4.2.

In spite of being mistreated by health care staff at STM in the earlier years and the bad behaviour that had been taking place at the Calcutta Medical College at the time of the interviews, as discussed in 7.1.3, the PLHA in this study reported that they continued to access care and treatment for their illness, largely due to the subsidised medicines for opportunistic infections and the free ART they were able to obtain. This finding is in contrast to studies carried out by White and Morton (2005) in sub-Saharan Africa, Parker and Aggleton (2003) (a multi-country review) (see 2.2.4), and Bharat on behalf of UNAIDS (2001) in India (see 4.2.1), who found that it was in fact perceived and enacted stigma that discouraged PLHA from accessing HIV testing services, care and treatment for HIV, jeopardising their health. Whilst Castro and Farmer (2003, 2005) (see 2.2.4) suggest that logistical and economic barriers (rather than stigma) determine who will access such services, this also contrasts with the findings from this research, as the PLHA in this study not only attended STM for their (and their spouses') six-monthly CD4 tests and for medicines for their opportunistic infections, but also, for those who were on ART, attended the ART centre to collect their monthly ART free of charge, as already discussed above.

### **7.3 ACCESS TO LIVELIHOOD SUPPORT FROM NGOS, THE HOSPICE AND STM**

As stated in section 1.4, the fourth research question is to investigate whether the PLHA in the study had received appropriate and adequate support for their livelihood strategies. This is because, in order to mitigate the impact of HIV/AIDS, poverty reduction strategies need to consider the particular needs of poor PLHA, and especially those with certain social characteristics, who as reported in previous studies, are likely to be more disadvantaged than others (see 2.2.3 and 4.1). In the literature on HIV/AIDS mitigation, livelihood strategies that utilise social assets are often referred to as community responses and so social assets have been used as part of the conceptual framework for this thesis (see 3.1), in order to identify the kind of support, help and care poor PLHA are able to draw upon. As discussed in sub-section 2.2.2., this may be available from their families (close and extended), social support and saving groups, NGOs, CBOs or public sector programmes.

The following section aims to investigate the kinds of livelihood support that the participants in the current study had access to in theory and in practice. In addition, it examines whether and why the PLHA whose household livelihood status was either vulnerable or highly vulnerable during the post-symptomatic phase noticed any improvements in their lives and the lives of their families as a result of accessing livelihood support.

## - **Types of livelihood support received**

In India, the guidelines generated by the NACP-II and III (see 4.2.2.) do not require any public health care providers to provide livelihoods support for PLHA, at least in Kolkata. The findings from this study also revealed that the perceived need to keep their status a secret prohibited many from seeking support over and above that already provided by family and neighbours, and in this way losing their social networks due to stigma. This is congruent with the findings from previous research in rural South Africa by Schatz et al. (2011) (see 2.2.5).

NGOs attempt to respond to many issues of concern to the poor, including the provision of vocational training; credit and loans; healthcare and education for children affected (directly or indirectly) by HIV/AIDS living with their parents, grandmothers or other members of close or extended families, so that the children's human assets are not neglected; employment opportunities, especially for women; and support and rehabilitation for PLHA. They also disseminate information about HIV/AIDS among the general population and advocate to protect the rights of PLHA (White and Morton, 2005; Richter et al., 2009 and Schatz et al., 2011 – see 2.2.5) and (Hawkes and Santhya, 2002; Mitra 2004; D'Cruz and Arora, 2010 – see 4.3.3).

Typically, the support provided to PLHA includes nutritional and financial assistance and mental support in the form of counselling and facilitating networking with other PLHA. The main types of livelihood support that the two NGOs on which this study focused claimed to provide, as reported in sub-section 6.3.1, included these typical types, and also the provision of condoms at a subsidised cost and short-term project based employment. The main types of support that the hospice claimed to provide, as

reported in sub-section 6.3.1, predominantly followed the guidelines of WBSAPCS, as supported by NACP-III, as reported in sub-sections 4.2.2 and 4.3.1. In practice, the PLHA interviewed reported that they had received almost all of the services the NGOs and hospice claimed to offer, with the exception in many cases of counselling (as reported in sub-section 6.3.1).

#### **- PLHA's assessment of the livelihood support**

When the PLHA were asked to assess this support, including whether they had noticed any improvements in their lives and the lives of their families as a result of accessing it, the following findings emerged:

Although the principal motivation of the participants in seeking out help from the NGOs was to obtain livelihood support, the majority continued to seek help beyond this initial need, because after they, especially the women respondents, those living on their own or those involved in high-conflict family relationships, had experienced poor treatment by their household members, extended families, neighbours and society in general, they appeared to have felt a need to find a space free from discrimination where they could discuss the challenges of living with HIV/AIDS with others facing similar issues. As reported in 6.3.2, they stated the importance to them of visiting their chosen NGO simply to interact with fellow PLHA, which for them outweighed the other types of support that they received, due to the widespread discrimination present in Indian society.

When the participants were asked about their overall assessment of the livelihood support they had received from KNP+, SPARSHA and Arunima Hospice, the majority felt that the support they received from KNP+ and SPARSHA had not been enough, resulting in them struggling to cope.

A handful of participants, mainly women who found employment as outreach workers for the NGOs, stated how this employment was insecure, as it was subject to the funding available to the NGO, so all those who had been given such employment had additional jobs in order to support their families. In addition, a couple of participants (as reported in 6.3.2) expressed a desire to be able to work for a living, so that they could sustain themselves into the future and felt that the government should be made responsible for providing PLHA with employment. This finding is congruent with the findings from a previous study in New Delhi, where a quarter of a sample of 100 PLHA interviewed also said that they would like the government to provide them with suitable jobs (Singh et al., 2009) (see 4.2.2).

Despite the inadequacy of the support received, the PLHA continued to attend KNP+ and SPARSHA because they felt that whatever support they received was better than none at all. This is contrary to the findings from the study carried out in New Delhi where the majority of the 100 PLHA who had been staying at care homes run by NGOs for a significant period of time revealed that they were satisfied with the medical treatment and overall care provided by these homes (see 4.3.3). The 15 participants interviewed at the hospice had been referred there for treatment and were not attending voluntarily in the same way as members/clients of the NGOs. The

hospice provided only limited help to support livelihoods, although these participants expressed satisfaction with the services provided and the respectful attitudes of the staff, as reported in 6.3.2.

However, as in other studies of NGO support for PLHA, this research found that due to the high numbers of PLHA requiring many different kinds of support to meet their needs, and the limited funds available to NGOs, the latter are unable to meet the demand, resulting in needs going unmet.

It is not possible to draw a clear conclusion from this study with respect to whether the support received from the NGOs and the hospice had had a positive overall impact on the livelihoods of the participants during the post-diagnosis phase of their illness trajectory, protecting them from further social exclusion and/or improving their overall vulnerability status. The most that can be inferred is that the participants reported that accessing support for their livelihoods from the NGOs did have a positive impact on their lives. This is especially true for the women respondents who lived on their own or those involved in high-conflict family relationships, whether or not they had young dependants, as well as for PLHA who had experienced poor treatment by their household members, extended families, neighbours and society in general. However, the lack of funding available to the NGOs in Kolkata, which is a common challenge for almost all NGOs around the developing world, meant that the support provided was often felt to be insufficient to meet their needs and its continued availability is uncertain.

## 7.4 CHAPTER CONCLUSION

Contrary to the findings of some previous research, even though the PLHA in this study did not attribute a meaning to their illness prior to seeking treatment, mainly because they did not recognise their symptoms as being associated with HIV/AIDS, they had still sought treatment immediately they began to feel ill, drawing on the few assets that they possessed before they fell ill to meet the costs. The alleged incompetence of the private providers to whom most went first to seek treatment, delayed the receipt of a correct diagnosis, in addition to their perceived tendency to overcharge, forcing many participants to sell their possessions and/or borrow money, increasing their indebtedness and jeopardising their families' livelihoods.

As shown in previous research, in their attempts to mitigate the impact of HIV on their livelihoods, the participants in this study employed similar livelihood strategies to people suffering from chronic illness more generally, although as predicted, for the majority of PLHA, stigma played a more significant role, having a negative effect on participants' relationships within their own households (especially for women, due to culturally defined roles and expectations) and also, for many, outside their households (affecting both men and women, again due to cultural expectations). While not all the participants reported that they had experienced discrimination, they were all aware of the stigma attached to the illness.

Although the findings from this study revealed that those participants who had lost assets during the pre-diagnosis phase had not been able to recoup them, they also revealed two ways in which some households had been able to fare better than others (meaning that they were not further impoverished): first, when women were able to



mobilise their labour to earn income when their husbands (the breadwinners) became bedridden, and second, when household members were supportive towards one another and household members who were HIV positive were not discriminated against (good household relations).

On a day-to-day basis, the participants had learned to cope in various ways, with whatever options they had available at the time they were formally diagnosed with HIV and thereafter. However, their fear of disclosing their HIV status to anyone outside their household (even years after they had been formally diagnosed) because of the stigma attached to the illness, resulted in many losing access to vital actual and potential social assets. In order to access alternative sources of livelihood support, many of the participants had sought help from the two NGOs studied, from which they obtained various types of support intended to help them maintain their livelihoods. Most reported that the support provided by the NGOs had been insufficient, but because they had nowhere else to go for practical assistance and valued the social and mental support NGO membership provided, they continued to seek support from the NGOs.

In the concluding chapter that follows, the problem and questions that led to the current study, the analytical starting points, the author's expectations with respect to the research findings and the major findings in practice are all brought together. The chapter will also discuss the significance of the work carried out and identify some of its wider theoretical, methodological and conceptual implications in the fields of poverty, livelihoods and chronic ill-health.

# **CHAPTER VIII**

## **CONCLUSIONS**

### **8.0 INTRODUCTION**

The concluding chapter consists of five sections. It begins with a summary of the aims of the research, the research questions and the analytical starting points, developed from chapters two, three and four (section 8.1). Section 8.2 summarises the key findings and some of their implications for mitigating the impact of HIV/AIDS on poor PLHA in Kolkata are discussed in section 8.3. The ways in which the thesis contributes to the current state of knowledge are identified in section 8.4. Finally, section 8.5 provides suggestions for future research.

### **8.1 THE RESEARCH PROPOSITION AND QUESTIONS**

The central aim of the current study was to identify the types of coping strategies used by poor urban households in India to deal with the impact of HIV/AIDS on their lives, including understanding the processes that are involved when poor PLHA attempt to access health care from different providers and assessing whether they are able to access adequate support for their livelihood strategies.

Starting from this aim, the four research questions are:

- 1) How do poor PLHA with different social characteristics experience living with their illness on a daily basis?

- 2) How do PLHA with different social characteristics access and assess the adequacy of health care services for HIV/AIDS?
- 3) How do PLHA with different social characteristics pursue their livelihoods on a daily basis?
- 4) Have PLHA received appropriate and adequate support for their livelihood strategies?

The research aim and questions arise out of and draw from an extensive literature review related to the current state of knowledge in the fields of poverty, livelihoods and chronic ill-health. Four sets of literature were reviewed in chapter two:

The first revealed the importance of understanding the meaning attributed to illness, which can in turn affect health care seeking behaviour. This literature stresses the need to identify the ways in which people make decisions to seek care, what they consider when reviewing alternatives and making decisions, and how they assess their care and treatment. The review revealed that very little literature is available that explores the ways in which PLHA and their household members (especially their primary care givers) emotionally experience living with the illness and the types of different emotional coping strategies that they employ, especially in the context of the developing world, even though this is relevant to understanding their responses to the illness. In contrast, the review identified a significant number of studies that have explored the ways in which individuals and/or households seek treatment and care when they fall ill, although little of the peer-reviewed literature focuses on health-care seeking behaviour amongst individuals and/or households living with HIV/AIDS.

The second set of literature argues that poverty and ill-health are interrelated, so that the ways in which people cope or are resilient in the face of chronic ill-health (such as HIV/AIDS), in order to avoid increased insecurity, depend on the type and quantity of assets their households possess in the first place. It claims that poor people are socially excluded on a daily basis from acquiring resources that the rest of society takes for granted. The nature and severity of their social exclusion depends in part on their social characteristics and is exacerbated when they are HIV positive, due to the stigma attached to the illness, resulting in further impoverishment. The available studies reveal that stigma plays a significant part in PLHA's lives, in turn having an effect on how and why they are able to employ different livelihood strategies. As HIV/AIDS is considered to be one of the most stigmatised of chronic illnesses in both the developed and developing worlds, the review contributed a preliminary understanding of stigma and how important it is to consider it. Amongst the assets crucial to poor people's livelihoods are their labour and social relations, both within and outside their households. However, the review identified few studies that have examined interactions within households and so relatively little is known about the perceptions and experiences of those who provide or receive care or the impact the need for care has upon the livelihood security and wellbeing of affected households.

The third set of literature argues that poor PLHA's wellbeing is partly dependent on the provision of appropriate health care services. The review provided information on the types of health care services available to PLHA, generally and in India and Kolkata in particular, enabling the healthcare seeking behaviour of the participants to be compared with wider groups, although very few studies have considered the types and quality of services provided for PLHA by not-for-profit organisations.

The fourth set of literature reviewed the pros and cons of contemporary attempts to tackle the HIV epidemic around the world, including the provision of care and access to treatment. In practice, the main focus of the literature is on treatment, with less attention paid to the provision of care and support for PLHA. This is because there is a tendency to assume that access to treatment will relieve the plight of PLHA, leading to a failure to adequately consider other aspects of people's lives, which are also crucial to maintaining wellbeing, and which this study has tried to address.

The key findings of the review of the Indian literature, presented in Chapter IV, supplement the findings of and gaps in the international literature review, provide information about the context within which the empirical findings presented in chapters five and six and discussed in chapter seven need to be understood. In addition, the key findings constitute a starting point for assessing the similarities and differences between the Kolkata case study and the findings of other studies in India. In particular, the Indian literature argues that the key dimensions of social difference that appear to determine the nature and extent of disadvantage and vulnerability are caste, gender and religion. It was, therefore, anticipated that these would be significant predictors of difference amongst the sample of poor PLHA studied, influencing their experiences and livelihood strategies. The important role played by private for-profit practitioners in providing diagnosis and treatment, even for poor people and despite the presence in India of extensive public health services, and its implications for the costs incurred by those seeking care, emerge very clearly from the wider Indian literature, and correlates with findings from the international literature (see 2.2.2 and 2.3.2).

However, some significant gaps in the Indian literature were identified. First, although there is some research related to Indian PLHAs' own perspectives on living with HIV/AIDS, none of these studies were conducted in Kolkata. Second, there has been little evaluation of the quality of general or HIV/AIDS-specific health care services provided for PLHA in India, with the exception of one study in New Delhi (4.3.3). Third, very little research has been carried out to evaluate HIV/AIDS programmes and policies intended to provide support for PLHA and mitigate the impacts of the illness on their livelihoods and wellbeing more generally in either urban or rural India (and whether lessons have been learned as a result) and no research of this kind has been carried out in Kolkata.

The aim and objectives of this study were defined in order to address some of the gaps identified, informed by a conceptual framework that brought together those used in previous healthcare seeking behaviour and livelihoods studies, based on a combination of two models: Obrist et al's (2007) 'health access livelihood framework' and Moser's (1998) 'asset vulnerability framework'. A number of other issues revealed as important during the wider literature review (and identified as gaps in the two models) were incorporated in order to consider HIV/AIDS in an urban setting. Thus analysis of the findings from this research (see chapters V and VI) used an analytical framework that combined and adapted the two main frameworks, as elaborated below (see section 3.1).

Obrist et al's (2007) 'Health Access Livelihood Framework' combines both health service and health-seeking approaches to understand treatment-seeking behaviour for all illnesses and situates access to healthcare in the broader context of livelihood

insecurity. As discussed in 2.1.3 and in 3.1, the framework suggests that once illness is recognized, treatment seeking is initiated, influenced by five dimensions of access: availability, accessibility, affordability, adequacy and acceptability, with the degree of access reached along each of these dimensions depending upon two factors: (1) health care service provision and broader policies, institutions, organisations and processes and (2) the livelihood assets people can mobilise in particular vulnerability contexts (Obrist et al., 2007). However, the model has a number of shortcomings.

First, it does not differentiate between acute and chronic illnesses, and also fails to consider whether some illnesses may be stigmatised.

Second, although the model recognises the vulnerability context within which households seek to develop and maintain their livelihoods and considers a number of livelihood assets that households must have in order for them to avoid further impoverishment following the onset of illness (human, financial, natural, social and physical assets), it fails to explicitly consider labour assets and household relations, both of which play significant roles in the lives of the poor.

Third, it also fails to consider the importance of illness coping strategies, the significance of individuals' social characteristics, the stigma associated with HIV/AIDS, and the full range of livelihood options, all of which have been shown in other studies to be important.

Fourth, the model appears to assume that people seek treatment as soon as they recognise illness, which in the context of the developing world may not always be the

case. So, a number of additional factors and processes needed to be included in the analytical framework to adequately address the areas that this research is concerned with.

As with others who adopt a livelihoods analytical framework, Moser (1998) points out the importance of identifying what the poor possess, rather than focusing on what they do not possess, in order to assess their vulnerability or ability to cope with shocks, as already discussed in 2.2.2. Unlike Obrist et al, Moser focuses specifically on the urban context. Like most analysts, she identifies five categories of assets that the poor may possess as being necessary to reduce vulnerability or cope with shocks. However, she emphasises different assets from some other analysts, arguing that labour, housing and social relations are the most important assets for the urban poor when their households face shocks. She also argues that it is necessary to explicitly differentiate between poverty and vulnerability, with the latter being a more dynamic concept able to capture the frequent changes in poor people's circumstances, such as those arising from death and illness. Her stress on vulnerability leads to an emphasis on the importance of identifying ways in which people cope or are 'resilient' in the face of danger or hardship and how they recover from hardship. She suggests that increases in stocks of assets can mitigate impoverishment and lead to improved security.

Moser (1998) does, therefore, assert that the risk of people becoming more insecure and how resilient they are in the face of danger or hardship are directly correlated with the number of assets they possess. However, she does not suggest how different degrees of vulnerability might be categorised and assessed. Because one of the most



important concerns of this research is to gain an in-depth understanding of the ways in which poor PLHA manage their asset (s) in the face of shocks and stresses due to the illness and the type of strategies that they adopt to prevent themselves from becoming more impoverished, this research will distinguish between degrees of vulnerability. A threefold categorisation into secure, vulnerable or highly vulnerable, prior to and after the onset of the illness can, it is suggested, capture the different illness and livelihood trajectories that the research participants' households had experienced.

Since individually, neither Obrist et al. (2007)'s 'health access livelihood framework', nor Moser's (1998) 'asset vulnerability framework' are adequate to serve as an analytical framework for the purposes of this research, key elements of the two models were combined and supplemented by a number of other components for analysis identified from the literature review, resulting in a combined analytical framework, as indicated in 3.1.

The above research questions and propositions have been examined in one location in urban India, using a mainly qualitative research methodology, in which one-to-one semi-structured interviewing featured as the primary data collection method. Focusing on four organisations providing treatment and support to PLHA, 59 poor users of their services were interviewed about specific periods in their lives. As already mentioned in 3.2.4, relevant information regarding the social characteristics, household composition and the number and type of assets that the 59 participants and their households possessed was obtained during the interviews. Although all 59 interviews contained useful information relevant to the themes dealt with in Chapter V, not all the interviews contained good quality information relevant to the themes of

Chapter VI. In practice, 48 interviews contained sufficient information on how the participants had adapted their livelihood strategies to cope with the impact of HIV and the processes by which they had accessed and utilised livelihood support from KNP+, SPARSHA (the two NGOs studied), Arunima hospice and STM.

Guided by the research aim and questions, the propositions outlined in the combined analytical framework, the experiences of a group of poor PLHA living in Kolkata have been described in chapters five (with interviews from 59 participants) and six (with interviews from 48 participants) and further analysed in chapter seven. The findings are summarised below with respect to the four research questions.

## **8.2 SUMMARY OF RESEARCH FINDINGS**

This section deals with the main findings of the research, which sought to investigate the ways in which HIV/AIDS affects poor PLHA and their households and to identify the social characteristics that enable or constrain PLHA to maintain their wellbeing and livelihoods, access healthcare for their illness from different health care providers and obtain adequate support for their livelihood strategies. Sub-sections 8.2.1 to 8.2.4 attempt to answer the four research questions and 8.2.5 offers a critique of the combined analytical framework used for the study.

### **8.2.1 How do PLHA with different social characteristics experience living with their illness on a daily basis?**

One of the main findings of the research was that many PLHA had experienced serious delays in obtaining an accurate diagnosis, incurring significant expenditure in the process. Those with more assets or a higher income when they started to experience symptoms had been more able to afford to pay for the necessary consultations, tests and travel than those without. By the time health professionals had diagnosed their HIV status, many of the participants had ended up losing most, if not all, of their assets, becoming further impoverished as a result.

It appeared from the Indian literature that religion (and, linked to this, caste) and gender have the most influence on urban poor people's social position and access to opportunities and services (see sections 4.1 and 3.1 for the combined analytical framework). However, religion and caste were rarely mentioned by the participants in this study, perhaps because of their sensitivity or perhaps because they are not significant differentiating factors *amongst* the poor. Respondents were not pushed to describe and analyse these aspects of their identity further. Because the research was already dealing with very sensitive and emotional issues, the researcher decided not to probe further to assess the possible influence of caste or religion on participants' experiences. As a result, this research was unable to examine the effects of religion and caste on PLHA's livelihoods and their household vulnerability status.

Significant differences were however, found in the ways in which men and women experienced living with their illness on a daily basis. It emerged that women respondents with a positive status had often been more badly treated than many of the

men, especially those who had lost their husbands due to the illness, many of whom were excluded from their households, shunned by other family members and discriminated against in the neighbourhoods in which they resided.

In response, more of the women respondents had joined the NGOs studied, often after some initial hesitation. Moreover, once a member (or user of the services provided), they continued to return for reasons besides the nutritional and financial support provided. It appears that they returned to their respective NGOs as an indirect or direct consequence of being cast aside by family members and others within the society, because they felt a need to belong somewhere where they did not experience discrimination. In contrast, 'optimistic planning' was a coping strategy that was found to be more common amongst men than women, with male PLHA seeing their futures in a brighter light. This gender difference appears to be related to the ways in which women have been treated historically within patriarchal Indian society, which have led them to believe that they are indeed the 'weaker sex' and thus not capable of looking after their own and their children's futures without a healthy husband to look after them, as discussed in 7.1.3.

### **8.2.2 How do PLHA with different social characteristics access and assess the adequacy of health care services for HIV/AIDS?**

The health seeking behaviour of participants in the current study followed a pattern that consists of a combination of those suggested in 'Good's pathway' (figure 1 in 2.1.3) and Obrist et al's (2007) 'health access livelihood framework' (figure 3 in 2.1.3). Treatment seeking behaviour was clearly dependent on what is available within the health care system in the first place. As discussed in section 7.2, most

people reported that they had initially been misdiagnosed, ill - advised, overcharged and prescribed inappropriate medicines for a long period before being appropriately diagnosed by a government hospital and then referred to the STM for a formal diagnosis and treatment. The participants reported that, in their view, the private health care providers they had consulted not only lacked the expertise to diagnose HIV but also had a tendency to overcharge their patients.

Due to the Indian government's lack of co-ordination of care, support and treatment of HIV, failure to provide good quality accessible information and lack of regulatory control over private practitioners, the participants in this research appeared to have had little idea of where to go for an initial diagnosis and treatment and so the way in which they chose health care support for their illness appeared to be quite erratic. The centralisation of diagnostic expertise and treatment relevant to HIV/AIDS in a single tertiary level institution in Kolkata (STM) seems to have posed barriers to people either accessing adequate information about HIV/AIDS or, once they began to suspect what their symptoms might indicate, knowing where to go for diagnosis and treatment.

As with people's experience of living with HIV/AIDS, treatment-seeking behaviour did not appear to differ between respondents of different religions and castes, but did differ between men and women. The findings from this research are, therefore, congruent with the findings from previous research in India, which found that women manage their illness in the context of the other responsibilities they have within their households, such as childcare, household chores, taking care of their husbands and sometimes in-laws and, for some, employment. As discussed in 7.1.2 and 7.2, this

can be attributed to the social expectations governing what happens within households in India, with a woman's role being first and foremost to look after her husband's and children's needs without making any complaints.

### **8.2.3 How do PLHA with different social characteristics pursue their livelihoods on a daily basis?**

The livelihoods framework was examined in its entirety, using the international literature, but subsequently the research focused on the most relevant elements. The purpose of using the livelihoods framework as part of the combined analytical framework for the research was to understand how poor people make a living, how living with HIV/AIDS affects their ability to do so, and what opportunities or possibilities are available to enable them to avoid impoverishment and maintain their wellbeing.

As discussed in 6.2, typically the participants employed *ex post* coping strategies at different points of their illness trajectory, in order to cope with the shock of contracting HIV/AIDS and to mitigate the effects of the illness on their lives. During the post-symptomatic phase, but prior to receiving a formal diagnosis (the pre-diagnosis phase), in addition to seeking medical help, participants reported that they had reduced consumption (fewer meals and different types of food), used up their savings, borrowed money and sold possessions in order to raise cash, mainly for the purpose of obtaining a correct diagnosis. When they had been formally diagnosed with HIV and had finally found an appropriate place from where they could potentially access treatment free of charge and/or at subsidised cost, they continued to seek this treatment. In addition, they continued to reduce their consumption.

The *ex post* coping strategy ‘earning money in new ways’ and the important role played by ‘household relations’ (a type of social asset) emerged as key factors in explaining how well households fared during the post-diagnosis phase. Some members of households affected by HIV/AIDS began to earn money in new ways, which is congruent with the studies mentioned above and in 2.2.2. The findings from this research reveal that when a man falls ill with HIV/AIDS and can no longer carry out his physically demanding job, the proportion of women who had previously not worked but who started to go out to work increased. To help support their families, such women often took on more than one job) (in addition to their existing reproductive tasks), although others were prevented from doing so due to their own ill-health, lack of child care or the disapproval of family members (see 6.2).

In addition, girls (under the age of 16 years) were taken out of school to help care for their loved ones suffering from the illness or assist with the housework, while boys were taken out of school to start earning (at least part-time), to replace the earnings of the main earner. In a few cases, other family members were asked to look after the children of PLHA when they were unable to cope financially. The existence and nature of intra-household and family relations were important variables explaining the different strategies available to participants and their ability to cope with the illness without becoming even more impoverished and vulnerable. While some PLHA and their households had been able to maintain their incomes and wellbeing at a similar level to that in the pre-symptomatic phase, there is no evidence to suggest that any of the participants diagnosed with HIV had been able to improve their livelihood status using the different types of strategies they employed during the post-symptomatic

phase. Instead, the findings in section 6.2 suggest that many had become more vulnerable.

Two particular characteristics of HIV/AIDS emerged as significant influences on the ability of poor people to pursue their existing or desired strategies. The first, as mentioned above, was the length of time it took them to obtain a diagnosis and the expenses incurred in doing so. Second, given that there are a number of other chronic illnesses that are difficult to diagnose because their symptoms are vague, mild or absent, one of the major differences between other under-diagnosed chronic illnesses and HIV/AIDS is the stigma that is attached to the latter. The additional stigma not only added to the sudden shock experienced by participants when they were first diagnosed but also had an impact on their household situation, work opportunities, health and general wellbeing in the long-term.

#### **8.2.4 Have PLHA received appropriate and adequate support for their livelihood strategies?**

As revealed in sub-section 6.3.1, for some participants the main motivation for seeking livelihood support (after having been recommended to do so by doctors and outreach workers based at STM) was for the sake of their children's health and education, whilst for others it was to obtain services specific to their requirements. With the exception of the people interviewed at STM, who had been diagnosed soon before the research, most of the other participants did, after initial hesitation, eventually seek the support provided free of charge by the NGOs studied or the hospice. As revealed in section 7.3, the main types of support that they had received included nutritional and financial assistance, short-term project-based employment,



counselling and learning about how to live with HIV safely on a daily basis, social networking with other PLHA, and, in the case of the hospice, in-patient beds, especially for those who needed to be coached in how to adhere to ART treatment regimes or who had no families to care for them.

When the participants were asked whether the support they had received had helped them cope and whether it had, in their opinion, been appropriate and sufficient for their specific needs, their responses were mixed. Many responded that they had found it useful to learn about self-care and safe sex, and welcomed the provision of condoms at a subsidised cost. One person also reported that the NGO from which she was receiving support had helped her to combat discrimination, when peer workers and the NGO's medical doctors visited her household, talked to her household members and encouraged them to ask questions about living with someone with HIV/AIDS. Participants who frequently suffered from bouts of opportunistic infections reported that, although they appreciated that the NGOs provided them with reimbursements for the medicines required to treat their infections, their lack of money to buy the drugs in the first place was often a problem. Instead, they suggested that they would much prefer either to be given the money in advance, so that they could buy the drugs from pharmacies, or better still if the drugs were to be available from the NGO itself.

Participants with young children, especially those who were single parents, praised the NGOs for having provided them with a third of the school fees for one or two children within their households. For these people, this support meant that they did not fall into complete destitution. A handful of participants, mainly women, had found employment as outreach workers after having joined their respective NGOs.

However, they noted that this employment was insecure, as it was subject to the funding available to the NGO, so all the women who had been given such employment had additional jobs in order to support their families.

Most of the participants were not entirely satisfied with the nutritional aspects of the livelihood support provided by the NGOs, as they felt that the food provided was never sufficient to feed their entire families, let alone on a permanent basis. Instead, many felt that they should be given the opportunity to work for a living rather than being provided with 'handouts', with nutritional support being confined to single mothers or those too ill to work.

It was obvious from the research findings that some participants who had been diagnosed with HIV many years prior to the research had had to seek livelihood support specific to their and their families' needs from various NGOs around the city. They admitted that they were not entirely satisfied with the support received from their chosen NGOs, but felt that they did not have any other option and were, in any case, better off with whatever support they received than none at all. The participants' search for appropriate livelihood support was not helped by the fact that NGOs insist that people can only be a member or beneficiary of a single NGO at a time.

The only aspect of the support provided by the NGOs on which all the participants involved agreed was the common ground they found with fellow PLHA within an NGO, with all claiming to have benefited from sharing their stories with others. In particular, they especially enjoyed being part of a group where they had the freedom

to voice their concerns about the challenges of living with their illness, and reported that these discussions helped them when they went back to their homes.

This research aimed to develop a comprehensive understanding of how and why poor people with different social characteristics behave in certain ways within Indian urban society. It found that due to the history of stigma attached to HIV/AIDS, expectations associated with certain social characteristics (especially gender), an unregulated private health care sector, an inadequate public health care sector and the limited or non-existent livelihood support for the vulnerable, most had become more insecure and socially excluded. That is not to say that their reactions were entirely passive: most had attempted to devise coping strategies to enable them to live with their illness, obtain treatment and avoid further impoverishment, with those of the female and male respondents differing in important ways because of the opportunities available to and constraints on women and men.

### **8.2.5 Critique of the study's combined analytical framework**

The findings presented above emerged from an analytical framework that is a product of a combination and adaptation of two frameworks. This combined analytical framework was designed to enable a systematic identification and investigation of the ways in which poor urban PLHA in a developing country context experience living with their illness on a daily basis and accessing healthcare for their illness and support for their livelihoods.

The study confirmed that, as anticipated, social exclusion had resulted in PLHA being denied access to healthcare and social resources. The study revealed that both men and women had been subjected to discrimination within their households, by their neighbours, within their workplaces and in some cases in government-run hospitals at some point of their illness trajectories. More women reported discrimination than men, especially within their households, attributable to the cultural expectations that household members have of women in general, especially if they are married, separated or become widows, as within Indian society they are expected to behave in certain ways. Even though some had not personally experienced discrimination, they were all aware of the stigma associated with the illness and the possible negative impact of this on their lives.

In addition, the findings highlighted other important factors that contributed to the understanding of the effects of HIV/AIDS on poor PLHA developed in this study, which were not explicit in the combined analytical framework and could be included in it for future work. For example, one of the main issues that emerged from this study is the importance of identifying a timeline for both the pre and post-diagnosis stages, beginning with the first symptoms, identifying when PLHA begin to lose assets and tracking a period of several years after diagnosis, when PLHA may either become impoverished or develop ways of coping with their illness by maintaining their own health and ability to work and safeguarding the wellbeing of their families. Secondly, the role of health care providers in delivering services, which affects the treatment-seeking behaviour of PLHA, needs to be made more explicit in a future analytical framework, as the ways in which the providers deliver services emerged as important determinants of the impact of the illness on PLHA. Though this research

did not set out to describe and assess health care delivery in a systematic way, it found that users' health-care seeking behaviour was largely dependent on the ways in which health care providers are organised in India and the services they aim to deliver to users, which have an impact on the overall health status, wellbeing and satisfaction of the research participants.

### **8.3 IMPLICATIONS OF THE STUDY FINDINGS**

No attempt is made in this section to develop a comprehensive set of recommendations for providers of treatment and support for PLHA, since as noted above, various other aspects would need to be considered before this could be done. However, some implications of the findings are clear and can be taken into account in future debates about policy and practice.

As discussed in section 7.1, the delay in receiving a correct HIV diagnosis led most of the participants in this research to gradually lose their assets, jeopardising their families' livelihoods, with devastating effects, especially on those lacking many assets in the first place. This finding demonstrates the importance of people being able to get an early and accurate diagnosis in order to avoid spending large sums of money on wasted consultations. In addition, it demonstrates the importance of disseminating not only information on how HIV can be contracted but also on typical symptoms and the steps an individual should take when they suspect that they might have these symptoms. Developing a better understanding of a typical trajectory for the pre and post-diagnosis stages, beginning with the first symptoms and ending with a time several years after diagnosis, as discussed above, could help future policy makers in

knowing when to take precautionary measures to prevent poor PLHA from becoming even more impoverished. Although this study did not assess the level of knowledge of HIV/AIDS symptoms and relevant diagnostic tools amongst health care providers, it appeared from the accounts of participants that the staff of both public and private health care facilities lacked knowledge. If this is the case, it is important to ensure that all primary health care providers (especially private practitioners, since 80 per cent of the population in India go to them as their first point of contact) receive an in-depth training in line with the NACO guidelines for medical practitioners, so that they are aware of symptoms that may be HIV-related and where to refer people presenting with these symptoms for diagnosis, counselling and, if relevant, treatment (currently, in Kolkata, STM).

Information in the international and the Indian literature (see sub-sections 2.3.3 and 4.3.3, respectively) indicates that the NGOs are not only responsible for the provision of psychological and medical support to PLHA and their families, and home-based care and economic support to PLHA, but also that they take on responsibilities for information dissemination among the general population about HIV/AIDS, including de-sensitising the issues, in addition to being involved in advocacy to protect the human rights of PLHA. However, the participants in this study appeared to be unaware that STM is the best place to go for initial diagnosis and subsequent care and treatment services, resulting in them wasting money and risking the depletion of their assets seeking for a diagnosis from private clinics. It would seem, therefore, that the NGO programmes on offer at the time of the study were insufficient to ensure that all those at potential risk of infection were aware of this and the need for other strategies for HIV/AIDS education and awareness raising at neighbourhood level need to be

considered. HIV/AIDS awareness and education programmes not only need to educate people in the risk factors of contracting HIV, the types of symptoms that are likely to arise if infected, and which health care providers provide appropriate care, support and treatment for HIV/AIDS, but also they need to tackle the issue of stigma. These might be more effectively achieved through the delivery of HIV/AIDS awareness programmes at neighbourhood level.

As noted in 5.2.2, users of some health care facilities complained of discrimination and bad behaviour. The participants in this research were typical, but not necessarily a representative sample, and the study did not seek to systematically document the attitudes of staff in all medical facilities. However, one of the problem facilities mentioned by participants was the Calcutta Medical College and Hospital, to which PLHA are referred when the facilities at STM reach maximum capacity. Following further investigation of the nature and extent of staff knowledge and attitudes, changes to management attitudes and staff training may be necessary to ensure that staff at all levels have received appropriate HIV/AIDS education. In general, in all health care centres, the human rights principles of informed consent and confidentiality need to be more widely adhered to in medical practice, so that health care staff and professionals do not violate patients' rights to informed choice, privacy and counselling. The value placed by PLHA on counselling services indicates that the need for them to be made available in all health facilities, to provide for the psychological needs of PLHA, should be assessed. In addition, efforts are probably needed to ensure that private health care providers do not carry out HIV testing without the informed consent of the patient and pre-and post-test counselling.

The research showed that the initial reluctance of the Indian government to openly discuss, acknowledge and address HIV/AIDS had hindered the timely development of adequate services. Although the study did not conduct a general evaluation of relevant policies, arrangements for implementation, effectiveness and outcomes, it appeared that the lack of a well-informed public debate and an over-emphasis on prevention had failed to address the issue of stigma. This indicates that, in general, more open discussions should take place within the government (and also the media, especially if the government does not take action) to change attitudes to HIV/AIDS and enable people to live without fear.

In healthcare studies and policy, it is often asserted that access to treatment is better in urban than rural areas, because most secondary and tertiary level facilities are located in urban areas, and primary facilities are easily accessible to all urban residents. However, for many of the poor participants in this study, the distance that they had to travel to reach STM and the ART centre attached to the STM in order to receive care and treatment for their illness was an issue, with many reporting that they sometimes had to spend an entire day travelling to and from (and waiting at) the STM and/or the ART centre. While this study did not review the spatial distribution of ART provision, the need for a more decentralised system should be investigated.

Women in India have always been burdened with the responsibilities of caring for their households, including being the sole carers for their husbands, children and in-laws. Within the context of HIV/AIDS, the findings from this study showed that when a man falls ill with HIV/AIDS and can no longer carry out his physically demanding job, some women (who may also be HIV positive, and who had not



worked before their husbands fell ill) had started to go out to work (often taking on more than one job), although others were prevented from doing so by their own ill-health, lack of child care or the disapproval of family members, confirming most other studies of urban household livelihoods in India and elsewhere. Both men and women reported that they had faced discrimination outside their homes and some men reported that they had faced discrimination within their own households. However, a higher proportion of women reported that they had faced not only discrimination, but also violence, within their households, confirming other Indian household studies carried out in the context of HIV/AIDS. The existence and nature of intra-household and family relations were, therefore, found to be important variables explaining the different strategies available to participants and their ability to cope with the illness without becoming even more impoverished and vulnerable. In this context, PLHA living in households that lack supportive household relations and social assets are potentially vulnerable and in particular need of help. Households consisting of widows or widowers and particularly those with dependents, women ejected from their marital households, households whose income earner has become bedridden and unable to work but which lack other adults or older boys, households that are about to withdraw children from school are indicators of potential vulnerability that might be useful as a kind of screening device and a way of directing NGOs' efforts towards those who are more likely to struggle to cope with the disease.

## **8.4 CONTRIBUTION MADE BY THE CURRENT RESEARCH**

The international literature highlights the need for good health to be placed at the centre of development agencies' poverty reduction targets and strategies (DFID, 1999 and World Bank, 2000), however, HIV/AIDS-related research and government policies have focused mainly on the prevention and treatment aspects of the illness, often neglecting the support and care that PLHA require. Internationally, most studies that have focused on the household livelihood strategies employed by PLHA have been carried out in rural contexts and very few have been carried out in urban contexts, particularly in urban India. Furthermore, government policies and programmes to mitigate the effects of HIV/AIDS are very limited in India, with most not even considering PLHAs' everyday lives beyond their treatment programmes. As a result, with the exception of providing six monthly routine tests for CD4 levels, in addition to professional counselling at this point, for the rest of the time PLHA are potentially left to their own devices, with no other care and support from the government. As a result, many poor PLHA fall through the net of government treatment and care programmes, and are forced to rely on under-resourced non-government organisations.

This study has attempted to fill the gaps in knowledge about the impact of HIV/AIDS on the daily lives of poor people and the strategies they employ to cope with the illness and prevent themselves from further impoverishment, by investigating the perspectives of 59 poor men and women living with HIV/AIDS in Kolkata in depth. Most previous studies that have focused on the household livelihood strategies employed by PLHA have been carried out in rural contexts and are predominantly based on household surveys. As half of the world's population now live in urban

areas, and most of the reported cases of HIV/AIDS are in urban areas, the current study attempts to fill this gap by investigating the household livelihood strategies of poor PLHA from their own perspectives within Indian urban society.

For the purposes of analysing the processes by which poor PLHA with certain social characteristics cope with their illness, employ livelihood strategies and access help in the form of health care and livelihood support, the current study developed a new analytical framework in which key elements of two existing frameworks were combined and supplemented by a number of other components for analysis identified from the literature review.

The current study goes beyond biomedical definitions of health and considers the overall wellbeing of PLHA, exploring the physical, mental and social aspects of health, and, to obtain a rounded picture of people's physical, mental and social wellbeing, analysing how people cope with the longer-term effects of the illness on their livelihoods, including the contribution of alternative sources of support. In doing so, three particular findings can be highlighted, two that make contributions in the context of Kolkata, and the third that fills a gap in our understanding of chronic ill health.

The international literature has provided plenty of evidence to show that HIV-related stigma and discrimination play a significant role in PLHAs' lives, with disastrous results, as discussed in 2.2.4. Not only do stigma and discrimination have negative effects on PLHAs' relationships within their own households, they also, for many, affect social relationships with people outside their households, in the neighbourhoods

in which people live and in their work situations, as well as when they seek care and treatment. Information analysed in sub-section 4.2.1 confirmed the findings of previous studies which indicate that women are more adversely affected by HIV-related stigma and discrimination than men, both within and outside their households, due to their culturally defined roles and expectations. While not all the participants reported that they had experienced discrimination, they were all aware of the stigma attached to the illness. Although a number of studies related to the effects of HIV-related stigma and discrimination have been carried out in other Indian contexts, this was the first such study to be carried out in Kolkata.

In terms of the support that is provided by NGOs, the international literature reports that they typically provide mental support (in the form of counselling and the opportunity to interact with other PLHA), nutritional support and financial assistance. In the Indian context, available information analysed in 4.3.3 indicated that NGOs are involved in providing different kinds of support to poor people with various medical conditions, including HIV/AIDS. In addition, they have taken on responsibilities for information dissemination among the general population about the illness and advocacy to protect the human rights of PLHA. With the exception of one study in New Delhi by Singh et al., 2009, as indicated in 4.3.3, the other available studies are quite general and often do not distinguish between the services NGOs claim to provide and what they actually provide, let alone assess the appropriateness and adequacy of the services provided. No research of this kind has been carried out in the context of Kolkata, so this study's in-depth analysis of the services available in practice to some poor PLHA in Kolkata and their assessment of the appropriateness

and adequacy of the support provided is the first to do so, to the best of the author's knowledge.

Previous studies in the international and the Indian health literature had demonstrated that chronic ill health, especially HIV/AIDS, hits the poor hardest due to the out of pocket cost of treatment, while other treatment-seeking behaviour studies have revealed the ways in which people seek treatment. This study confirms much that is already known but also fills a gap in understanding of chronic ill health, by demonstrating the importance of analysing treatment seeking behaviour during the entire illness trajectory, including both the pre-symptomatic and the post-symptomatic phases. The pre-symptomatic phase denotes the period before an illness begins or the healthy phase of a person's life. In the case of HIV/AIDS, the study reveals that it is necessary to divide the post-symptomatic phase into pre- and post-diagnosis stages, because delays in and the costs of obtaining an accurate diagnosis, even before securing appropriate treatment, have an early and sometimes severe impact on people's mental state and economic circumstances, triggering a process of impoverishment due to the loss of some or all their assets.

## **8.5 AREAS FOR FURTHER RESEARCH**

This study highlights a need for further research in order to further improve understanding of the illness coping and livelihood strategies of PLHA, for the purpose of devising a balanced set of policies and interventions capable of meeting the needs of poor PLHA. The current study set out to develop an in-depth understanding of the ways in which poor PLHA developed illness coping and livelihood strategies,

including accessing help from health care providers and NGOs. It therefore paid attention to a wide range of elements. There is, however, a need to investigate specific aspects of people's treatment-seeking behaviour and the ways in which they pursue their livelihoods in more depth. This study highlights, for example, the need for in-depth investigations with regard to:

- The participants in the current study were all PLHA who had sought help during the post-symptomatic phase. It revealed that, unlike the claims made in much of the literature that deals with treatment seeking behaviour, the existing health services are not necessarily available, accessible and affordable to everyone seeking help. However, because of the way in which respondents were identified, it was not possible to assess whether some people with HIV/AIDS symptoms choose not to seek treatment and help, what social characteristics they have and why they choose not to do so.
- The primary respondents in this study were individuals living with HIV/AIDS and although it was recognised from the outset that they were members of households, they did not all have the same position in the households in which they lived and the analysis of those households was based on the viewpoints of the individual participants. As a result, it was not possible to analyse intra-household power relations and dynamics in as much depth as desired. For example, a future study could investigate how the 'head' of household exerts power over the allocation of household resources in practice, throwing further light on how intra-household relationships influence illness coping and livelihood strategies and enabling a comparison of the strategies adopted by and overall vulnerability status of households with different characteristics,

including one, two and three generation households; nuclear and extended households; and male and female headed households.

- The ways in which the participants' livelihoods varied during the post-symptomatic phase were based on the accounts of the research participants only, and were not supplemented with the accounts from their family members, as the participants were identified through their use of treatment services or NGO programmes and preferred not to be interviewed at home lest others become aware of their positive status. Even so, there is no evidence to suggest that any of the participants diagnosed with HIV had been able to improve their livelihood status, with the analysis suggesting instead that many had become more vulnerable. More detailed information on the earnings, savings, borrowing and repayments, and consumption of not only participants but also other members of their households would be needed to develop a sound understanding of these processes.
- As already mentioned above, the primary respondents in this study were individuals living with HIV/AIDS. This study explored the ways in which PLHA emotionally experienced living with the illness and the types of different emotional-based coping strategies that they employed. However, for the reasons given above, it was not possible to explore the illness coping strategies of other household members, especially the primary care givers of PLHA unless they were also living with HIV/AIDS.

A systematic documentation of healthcare and other support programmes provided to PLHA by public and not-for-profit organisations in Kolkata was beyond the resources of this study. In addition, because it was necessary to rely on specific organisations to

provide access to informants, the study focuses on a limited number of providers of treatment and support. In the absence of a comprehensive review of provision or any previous studies of user perspectives on such programmes, it is not possible to assess whether the services accessed by the research participants reflect the full range of services available to PLHA in Kolkata, whether the treatment and support they received did have a measurable impact on their livelihoods and wellbeing, or whether it is possible to generalise more widely from the participants' assessment. Future studies could investigate a wider range of healthcare and support providers, including analysing supplier perspectives on which services are provided and why, and examine the actual impact of assistance received on the livelihoods and wellbeing of PLHA (and possibly other illnesses).



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## **APPENDICES**

### **APPENDIX ONE: PARTICIPANT INFORMATION SHEET AND CONSENT FORMS – IN ENGLISH, BENGALI, AND HINDI**

#### **Participant Information Sheet**

##### **Research Summary**

The research will seek to understand the different coping strategies that poor HIV/AIDS-affected households with different social characteristics employ in order to deal with the impacts of HIV/AIDS, their decision-making processes in seeking help for HIV/AIDS, and whether and how they have access to care, prevention and treatment services from NGOs, public hospitals or private clinics as well as when they seek appropriate support for their livelihood strategies in urban India. It is hoped that this research will provide information that will help health service providers to make services more accessible for low-income people living with HIV/AIDS.

The chosen city for carrying out the fieldwork for this research is Kolkata, since over a third of the population live in slums or slum areas. Kolkata, also consists of people from diverse backgrounds and there are also high levels of migration from neighbouring north-eastern states and from countries such as Nepal and Bangladesh. The prevalence of HIV/AIDS is not high in Kolkata, like in other cities, such as Delhi, Mumbai or Chennai, however, no research of this type has been carried out before, especially within a general population, instead of targeting specific groups such as sex workers and truck drivers who are known to be at much higher risk of contracting HIV/AIDS.

So, the main of the field visit is to understand the main issues concerning people living with HIV/AIDS (PLHA), that would require interviewing willing PLHA regarding their experiences of living with HIV/AIDS and to identify relevant secondary data from different organisations, such as non-governmental organisations, community-based organisations and hospitals.

## **PARTICIPATION AND ANONYMITY**

Please note that:

Your participation is voluntary. Should you choose to participate, you do not have to answer all the questions. The interview will last for approximately 60 minutes. You may choose to withdraw from the study at any time. Some of the content may be regarded as sensitive, but I would like to assure you that: your answers will remain anonymous and the data cannot be linked to individuals.

**Your knowledge, opinions and experience are valuable to my research. Thank you, in advance, for participating in this interview.**

**Participant Identification Number:**

**CONSENT FORM FOR RESEARCH STUDY (IN ENGLISH)**

**Funded by:** Economic and Social Research Council, UK

**Affiliation:** International Development Department, University of Birmingham, UK

**Title of Research:** Analysing the impact of HIV/AIDS on the lives of the poor in Kolkata, India.

**Name of Researcher:** Rinita Dam

- I confirm that I have read and understood the information sheet dated..... for the above study Yes  No
- I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily Yes  No
- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected Yes  No
- I understand that the data collected during the study will only be looked at by the investigator, where it is relevant to my taking part in this research. I give permission for the investigator to have access to my records Yes  No
- I agree to my organisation/ART centre at School of Tropical Medicine, Kolkata to being informed of my participation in the study Yes  No
- I agree to take part in the above research study Yes  No

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Researcher                      Date                      Signature

When complete, 1 copy for Participant: original copy for researcher site file





## CONSENT FORM FOR RESEARCH STUDY (IN HINDI)

प्रतिभागी पहचान संख्या:

शोध अध्ययन के लिए सहमति फॉर्म

आर्थिक और सामाजिक अनुसंधान परिषद, ब्रिटेन द्वारा वित्त पोषित है:

सम्बंधता: इंटरनेशनल डेवलपमेंट विभाग, बर्किंगम, ब्रिटेन के विश्वविद्यालय

अनुसंधान का शीर्षक: कोलकाता, भारत में गरीबों के जीवन पर एचआईवी / एड्स के प्रभाव का विश्लेषण.

शोधकर्ता के नाम: Rinika Dani

- मैं इस बात की पुष्टि करता हूँ कि मैं पढ़ और समझ लिया किनांक जानकारी प्रदाता ...  
अपनी अध्ययन हां  नहीं
- मैं जानकारी पर विचार करने का अवसर मिला है, सवाल पूछना और  
है इन ही संतोषजनक ढंग से जवाब नहीं था हां  नहीं
- मैं समझता हूँ कि मेरी भागीदारी स्वैच्छिक है और मैं किसी भी समय वापस लेने के लिए स्वतंत्र हूँ, बिना कोई कारण बताए  
अपने चिकित्सा देखभाल के बिना, कि या कानूनी अधिकार प्रभावित किया जा रहा है  
हां  नहीं
- मैं समझता हूँ कि केवल आवेपक, जहां यह मेरे इस शोध में भाग लेने के लिए प्राथमिक है के द्वारा अध्ययन के दौरान एकत्र  
किए गए आंकड़ों पर देखा जा. मैं आवेपक के लिए अनुमति देने के लिए अपने रिस्क के लिए उपयोग नहीं हां  नहीं
- मैं ट्रांस्क्रिप्ट रिकॉर्डिंग के रफ़ल से मेरे संगठन : एआरटी सेंटर के लिए सहमत हूँ, कोलकाता के अध्ययन में किया जा रहा है  
मेरी भागीदारी के बारे में बताया हां  नहीं
- मैं ऊपर शोध अध्ययन में भाग लेने के हां नहीं करने के लिए सहमत हां  नहीं

प्रतिभागी के नाम	तिथि	हस्ताक्षर
शोधकर्ता	तिथि	हस्ताक्षर

जब पूरा, प्रतिभागी के लिए 1 प्रतिलिपि: शोधकर्ता साइट फाइल के लिए मूल प्रति

## **APPENDIX TWO: INTERVIEW GUIDES**

### **INTERVIEWS WITH 59 PLHA FROM KNP+, SPARSHA, ARUNIMA HOSPICE AND STM**

#### **Categories of people that needed to be interviewed during both visits in the field, if applicable:**

- Women with HIV Vs. Women with AIDS Status (PRIORITY)
- Men with HIV Vs. Men with AIDS Status (PRIORITY)
- People of a *dalit* caste Vs. People of a ‘higher’ caste (PRIORITY)
- Muslim Vs. Hindu (PRIORITY)
- Informal wage earners Vs. Employed by public an/or private companies, (PRIORITY)
- People who sought support for their livelihoods Vs. People who have not sought this support, (PRIORITY)
- People who have sought treatment Vs. People who have not sought treatment, (PRIORITY)
- People who have the support from within families and neighbours Vs. People who do not have the support from within families and neighbours,
- People who own their properties Vs. People who do not own their properties.

#### **FOLLOW-UP QUESTIONS RELATED TO RQ 1: How do PLHA with different social characteristics experience living with their illness on a daily basis?**

1. How did you feel when you were first diagnosed with HIV?
2. Did you know what the disease was, what their symptoms were and how it was going to affect you? What did you think about it? Who told you about your diagnosis?
3. What do you think of your illness? How do you see yourself with this illness?
4. How do you think having HIV has changed your lives from before?

5. Can you give me examples on what aspects of your life and the lives of people within the household has the illness had an effect? What are the things that you did before diagnosis that you cannot do since your diagnosis?
6. Do you have friends within the community? If not, why?
7. If so, do they know about your or your family's HIV status? If not, what do you think they would say if they knew and why?
8. How do you cope with HIV? What do you do on a daily basis?
9. Have you sought treatment for the illness? If so, why? What made you seek treatment for it?
10. If not, why not? What are the reasons for you in not seeking treatment?
11. Have you ever sought treatment from anywhere, since diagnosis?

**FOLLOW-UP QUESTIONS RELATED TO RQ 2: How do PLHA with different social characteristics access and assess the adequacy of health care services for HIV/AIDS?**

12. When you went for help for HIV/AIDS in the health care services, do you remember what programs were available to you?
13. How did you choose the health care providers for HIV/AIDS?
14. What factors influenced you in accessing the appropriate health care services in your opinion?
15. How did these decisions fit in with your day-day basis of living? i.e. do people have time in general to go to seek help from different health care providers? Do people take time off from formal or informal jobs or from their household activities?
16. What benefits have you noticed because you accessed help from health care services for HIV/AIDS and what are the reasons for them, in your opinion?
17. In what ways has the access to these services changed their lives?
18. What did you think of the care, treatment and preventative services that you received from the different health care providers that you visited? Were the services that you received adequate and appropriate to your needs? How were they delivered to you?

**FOLLOW-UP QUESTIONS RELATED TO RQ 3: How do PLHA with different social characteristics pursue their livelihoods on a daily basis?**

19. How many occupants do you have in your household? How many dependents are under 5 years and over 65 years of age?
20. What is the age and gender of the family head?
21. Does the family head work? If so, what kind of work does she/he do? E.g. informal or wage work?
22. Does she/he have any other jobs?
23. Is there anybody else within the households who is in full-time occupation also, either formal or informal work and how many jobs does she/he have?
24. How many people within the household are infected with HIV?
25. Is the family head infected with HIV?
26. Have members of the family taken up employment due to the family head falling ill with HIV or AIDS?
27. How do you receive support from family members and do you share out your tasks between yourselves within the household?
28. Do your children go to school? If not, why?
29. Are there any reasons why they are not sent to school?
30. If so, are you able to pay school fees for children?
31. Have you reduced your expenditure on food and health care?
32. Have you had to sell things within the house and also sell your assets to raise money for your survival?
33. How long is it since you were diagnosed with HIV?
34. Have you had any other recent stresses? E.g. deaths within your family, maintenance of your house, floods due to the monsoon.
35. If so, how did you cope with this stress?
36. Have you received support from extended families, neighbours and friends?
37. Do you have any knowledge regarding any support that you can receive from other sources, such as NGOs, CBOs, religious groups or any other groups for families like yourself?
38. If so, have you or your family received support to help you manage within the household at any point of your lives? Before and especially since, diagnosis?

39. What made you decide in going to seek support for your livelihoods in the first place?
40. If not, why not? Have you ever been anywhere to seek support for your livelihoods before diagnosis and what makes you decide to not go for help?
41. Have you borrowed money from individuals or organisations?
42. Have you withdrawn money to cope?
43. Are there any other ways that you coped with living with HIV or AIDS?

**FOLLOW-UP QUESTIONS RELATED TO RQ 4: Have PLHA received appropriate and adequate support for their livelihood strategies?**

44. (For families who did seek help for their livelihoods) – Where did you go and what support did you and/or your family receive? What did you think was available to you?
45. How did you feel about the support that was provided to you?
46. How did you feel about the way you were treated by people at those services?

**CLOSE OF INTERVIEWS, ANSWER ANY QUESTIONS THEY HAD, REITERATE POINTS ABOUT CONFIDENTIALITY TO ALL PLHA BUT OFFER REMUNERATIONS IN THE FORM OF CASH TO PLHA FROM KNP+ AND SPARSHA ONLY**

## **INFORMAL MEETINGS WITH GATEKEEPERS FROM THE ORGANISATIONS**

1. Who seeks help from these NGOs/hospitals? What are the social and economic characteristics of the people who use their services and are these the people you want to reach?
2. What is the aim/motivations of the organisation, where does the funding come from and what is the structure of the organisation?
3. What prevention services for HIV/AIDS are available for PLHA? Do you provide condoms (free or subsidised), voluntary counselling and testing services and anti-HIV drugs for pregnant women?
4. What care services for HIV/AIDS are available for PLHA? Do you provide home-based care, nutrition, counselling?
5. Do you provide anti-retroviral drugs and drugs against opportunistic infections for PLHA?
6. What livelihood support programs are available for poor PLHA and their families?
7. How do you deliver the (above mentioned) services to PLHA? And why do you deliver some services in certain ways?
8. Are you satisfied with the range and quality of services that you offer? What are the opportunities and constraints that you face when providing these services?
9. In your opinion, are people satisfied with the services that they receive from here?

10. Have your policies changed over time? If so, what are the reasons for these changes and over what time have your policies changed? What policies have changed?
11. Are you aware of any other places the PLHA go to seek help for their illness? If so, why do you think they go there?
12. What records do you keep on PLHA and in what form are they kept? Do they do counts or have reporting statistics?
13. What is their opinion of the current HIV/AIDS situation, the statistics within the general population on the ground level in the city, including recent figures on the incidence of HIV, it's socio-economic and geographical distribution within the city?
14. Are there any other NGOs or other networks that you are aware of that also provide prevention, treatment, care services and support for the livelihoods strategies for PLHA?



**APPENDIX THREE: INDEX OF ALL PARTICIPANTS AND DATES OF FORMAL INTERVIEWS WITH ALL PARTICIPANTS AND INFORMAL MEETINGS WITH GATEKEEPERS**

**FORMAL INTERVIEWS WITH ALL 59 PARTICIPANTS**

Participants	Organisations							
	KNP+ (A)	Dates of interviews	SPARSHA (B)	Dates of interviews	Arunima Hospice (C)	Dates of interviews	STM (D)	Dates of interviews
1	AW <sub>1</sub>	18 February 2009	BM <sub>1</sub>	21 February 2009	CW <sub>1</sub>	20 February 2009	DM <sub>1</sub>	17 March 2009
2	AW <sub>2</sub>	18 February 2009	BW <sub>2</sub>	24 February 2009	CW <sub>2</sub>	20 February 2009	DW <sub>2</sub>	17 March 2009
3	AW <sub>3</sub>	18 February 2009	BM <sub>3</sub>	24 February 2009	CM <sub>3</sub>	20 February 2009	DM <sub>3</sub>	17 March 2009
4	AM <sub>4</sub>	18 February 2009	BW <sub>4</sub>	12 March 2009	CW <sub>4</sub>	25 February 2009	DW <sub>4</sub>	20 March 2009
5	AW <sub>5</sub>	18 February 2009	BW <sub>5</sub>	21 March 2009	CW <sub>5</sub>	25 February 2009	DW <sub>5</sub>	20 March 2009
6	AM <sub>6</sub>	18 February 2009	BM <sub>6</sub>	21 March 2009	CM <sub>6</sub>	25 February 2009	DW <sub>6</sub>	20 March 2009
7	AW <sub>7</sub>	18 February 2009	BM <sub>7</sub>	21 March 2009	CM <sub>7</sub>	26 February 2009	DM <sub>7</sub>	24 March 2009
8	AM <sub>8</sub>	19 February 2009	BW <sub>8</sub>	21 March 2009	CW <sub>8</sub>	26 February 2009	DM <sub>8</sub>	24 March 2009
9	AM <sub>9</sub>	19 February 2009	BW <sub>9</sub>	31 March 2009	CW <sub>9</sub>	26 February 2009	DM <sub>9</sub>	27 March 2009
10	AW <sub>10</sub>	19 February 2009	BM <sub>10</sub>	31 March 2009	CM <sub>10</sub>	26 February 2009	DM <sub>10</sub>	27 March 2009
11	AW <sub>11</sub>	19 February 2009	BW <sub>11</sub>	28 March 2009	CM <sub>11</sub>	3 March 2009	DM <sub>11</sub>	3 April 2009
12	AW <sub>12</sub>	19 February 2009	BW <sub>12</sub>	4 April 2009	CW <sub>12</sub>	3 March 2009	DM <sub>12</sub>	3 April 2009
13	AW <sub>13</sub>	19 February 2009	BW <sub>13</sub>	8 April 2009	CM <sub>13</sub>	3 March 2009	DW <sub>13</sub>	3 April 2009
14	AM <sub>14</sub>	19 February 2009	BW <sub>14</sub>	8 April 2009	CM <sub>14</sub>	5 March 2009	DM <sub>14</sub>	3 April 2009
15	AM <sub>15</sub>	19 February 2009	BM <sub>15</sub>	8 April 2009	CM <sub>15</sub>	5 March 2009	X	X

**Note:** Organisations are used for ease of identification only, where W denotes women, M denotes men, A denotes KNP+, B denotes SPARSHA, C denotes Arunima Hospice and D denotes STM. Comparisons of participants between these organisations have not been made.

### INFORMAL MEETINGS WITH THE GATEKEEPERS

Dates of meetings	KNP+ (A)	SPARSHA (B)	Arunima Hospice (C)	STM (D)
9 February 2009		Manager		
6 March 2009			Manager	
16 March 2009	Manager			
18 September 2008				Chief Medical Officer