

**A Socio-Demographic Study of  
HIV/AIDS Related Knowledge,  
Attitudes and Sexual Behaviour:  
Patients from south-India**

Ruth Kattumuri

May 2007

Thesis submitted in fulfilment of the requirements for  
the degree of Doctor of Philosophy of the  
University of London

UMI Number: U578614

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



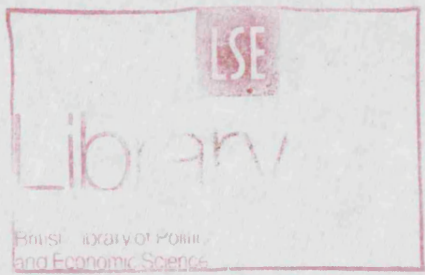
UMI U578614

Published by ProQuest LLC 2014. Copyright in the Dissertation held by the Author.  
Microform Edition © ProQuest LLC.

All rights reserved. This work is protected against  
unauthorized copying under Title 17, United States Code.



ProQuest LLC  
789 East Eisenhower Parkway  
P.O. Box 1346  
Ann Arbor, MI 48106-1346



## *Abstract*

This study investigates HIV/AIDS-related knowledge, attitudes, behaviours and practices among people living with HIV/AIDS (PLWHA). A hospital-based survey of (n=292) PLWHA in Tamil Nadu, using both quantitative and qualitative techniques, was the first of its kind to be conducted in India in 1999. The study represents a contribution to knowledge, being one of very few studies of PLWHA in India.

The main sources of reported HIV knowledge among PLWHA were discussions with peers, community members, other hospital patients, and friends, for both men and women (80% and 79%, respectively). Latent class analysis of correct knowledge showed that 76% of respondents had high knowledge of sex-related transmission and 86% had high knowledge of blood-related transmission. Education was an important predictor of knowledge for women. Contrary to socio-cultural norms, ever-married male respondents reported relatively high levels of premarital sex (80%) and extra marital sex (49%).

This study examined reported behaviour changes post-diagnosis with a positive prevention focus, including condom use. A large majority of PLWHA had heard about condoms (94% men, 81% women) and their use as a prophylaxis for HIV/AIDS. However, only 35% of men (excluding high-risk occupation groups) reported ever-use of condoms. Qualitative evidence revealed that reported consistent condom use did not, in fact, mean every single time they had sex. Culture was intricately interwoven with attitudes and behaviours reported by PLWHA and experiential knowledge influenced attitudes towards possible behaviour change.

This research suggests the need to shift HIV/AIDS prevention models from biomedical to models more closely situated in their socio-economic and cultural

context. In particular, behaviour change communication (BCC) models for positive prevention in India.

## *Acknowledgment*

Ernestina Coast's time and efforts and valuable guidance to submit this thesis have been crucial. Gail Wilson was a Godsend, who un-hesitantly volunteered to supervise at the most critical stage. She, with her great ability to challenge one's intellectual ability, restored my confidence to enable writing this thesis in the first place. John Hobcraft provided valuable guidance during the early stages. Fiona Steele's guidance for analyses and regular support has been very helpful. Jouni Kuha has always responded with prompt and helpful suggestions for the analyses. Hakan Seckinelgin has kindly provided important guidance to develop a broader perspective in terms of policy issues.

The permission to conduct interviews at Government Hospital for Thoracic Medicine and Christian Medical College and Hospital is appreciated. I would like to remember and thank all HIV/AIDS patients who shared their experiences.

I gratefully acknowledge the financial support from Church of Scotland and Cambridge Commonwealth Trust which made it possible to undertake this research in the first place.

God's amazing grace sustained me all through the process of this work. Many friends have provided essential support and encouragement along the way.

# Content

<i>List of Tables</i>	<i>viii</i>
<i>List of Figures</i>	<i>xiii</i>
<i>List of Boxes</i>	<i>xiv</i>
<i>List of Case Studies</i>	<i>xiv</i>
<i>Glossary</i>	<i>xv</i>
<i>Abbreviations</i>	<i>xvii</i>
<b>CHAPTER 1 INTRODUCTION</b>	<b>1</b>
1.1 RATIONALE FOR THE STUDY .....	2
1.2 CONTRIBUTIONS TO KNOWLEDGE .....	5
1.3 THESIS OUTLINE .....	6
<b>CHAPTER 2 LITERATURE REVIEW</b>	<b>8</b>
2.1 KNOWLEDGE, ATTITUDES, BEHAVIOURS AND PRACTICES (KABP): MODEL .....	8
2.2 KNOWLEDGE, ATTITUDES, BEHAVIOURS AND PRACTICES (KABP): SURVEYS .....	10
2.3 LITERATURE REVIEW RELATED TO INDIA .....	19
2.3.1 KABP EVIDENCE FOR INDIA.....	19
2.4 PLWHA AND SEXUAL BEHAVIOUR.....	26
2.5 SUMMARY .....	28
<b>CHAPTER 3 TRENDS IN HIV/AIDS IN INDIA, EVOLUTION OF POLICY RESPONSE AND RESEARCH BACKGROUND</b>	<b>30</b>
3.1 THE IMPACT OF HIV/AIDS IN INDIA .....	30
3.1.1 STATUS AND TRENDS OF HIV/AIDS IN INDIA.....	34
3.1.2 THE EPIDEMIC IN TAMIL NADU AND ANDHRA PRADESH.....	37
3.2 RESPONSE TO COMBATING THE EPIDEMIC AND EVOLUTION OF POLICY .....	43
3.2.1 THE RESPONSE BY INTERNATIONAL ORGANISATIONS .....	43
3.2.2 THE NATIONAL RESPONSE.....	44
3.2.3 STATE RESPONSES .....	47
3.2.4 RESPONSE BY THE INDIAN CORPORATE SECTOR.....	51
3.3 STUDY OF HIV/AIDS PATIENTS AT TWO HOSPITALS.....	52
3.3.1 HISTORY OF HIV/AIDS TREATMENT AT GHTM AND CMC.....	52
3.4 SUMMARY .....	59

<b>CHAPTER 4</b>	<b>METHODOLOGY</b>	<b>61</b>
4.1	GENERAL METHODOLOGICAL ISSUES FOR SOCIAL SCIENCE RESEARCH IN INDIA.....	61
4.2	RESEARCH METHODS.....	65
4.3	FIELDWORK .....	67
4.3.1	SAMPLE .....	69
4.3.2	QUESTIONNAIRE DESIGN .....	71
4.3.3	DATA COLLECTION.....	89
4.3.4	ETHICAL ISSUES.....	96
4.4	ANALYSES .....	97
4.4.1	QUANTITATIVE ANALYSIS.....	97
4.4.2	QUALITATIVE ANALYSIS AND CASE STUDIES.....	103
4.5	SUMMARY .....	105
<b>CHAPTER 5</b>	<b>CHARACTERISTICS OF SAMPLE SURVEYED OF PLWHA</b>	<b>107</b>
5.1	HIV PREVALENCE .....	107
5.2	SOCIO-DEMOGRAPHIC AND ECONOMIC CHARACTERISTICS OF HIV/AIDS PATIENTS SURVEYED .....	110
5.2.1	SEX RATIOS .....	111
5.2.2	RURAL – URBAN DISTRIBUTION.....	113
5.2.3	AGE DISTRIBUTION .....	113
5.2.4	MARITAL STATUS.....	114
5.2.5	EDUCATION LEVELS.....	117
5.2.6	OCCUPATION .....	118
5.2.7	HOUSEHOLD COMPOSITION AND LIVING STANDARD.....	121
5.2.8	RELIGION .....	124
5.2.9	MEDICAL CARE FACILITIES .....	125
5.2.10	THE DISTRIBUTION OF HIV/AIDS PATIENTS SURVEYED BY DISTRICTS.....	126
5.3	COMPARISON BETWEEN GHTM AND CMC.....	127
5.4	COMPARISON OF HIV POSITIVE PATIENTS SURVEYED FROM TN AND AP .....	130
5.5	DISCUSSION AND SUMMARY .....	131
<b>CHAPTER 6</b>	<b>KNOWLEDGE AND ATTITUDES OF PLWHA</b>	<b>135</b>
6.1	AWARENESS AND KNOWLEDGE OF HIV/AIDS .....	135
6.1.1	KNOWLEDGE OF HIV TRANSMISSION .....	136
6.1.2	LATENT CLASS ANALYSIS OF KNOWLEDGE .....	146
6.2	MEDIA AS A SOURCE OF HIV INFORMATION .....	149
6.3	KNOWLEDGE IN THE CONTEXT OF HIV PREVENTION .....	155
6.3.1	CONDOM AWARENESS IN GENERAL POPULATION .....	155



6.3.2	KNOWLEDGE AND ATTITUDES ABOUT CONDOM, PATIENT SURVEY .....	158
6.3.3	EXPERIENTIAL KNOWLEDGE .....	163
6.3.4	KNOWLEDGE OF OTHER PLWHA .....	164
6.3.5	TIME SINCE DIAGNOSIS AND KNOWLEDGE OF, AND ATTITUDES TOWARDS, HIV. ....	166
6.3.6	STIGMA, DISCRIMINATION, COPING AND SUPPORT.....	177
6.4	DISCUSSION AND SUMMARY .....	181
<b>CHAPTER 7</b>	<b>BEHAVIOUR</b>	<b>189</b>
7.1	REPORTED SOURCE OF HIV INFECTION.....	191
7.2	SEXUAL BEHAVIOURS.....	192
7.2.1	SEXUAL DEBUT .....	192
7.2.2	SMOKING, ALCOHOL AND DRUG CONSUMPTION BEHAVIOUR.....	193
7.2.3	FREQUENCY OF SEX.....	193
7.2.4	PREMARITAL SEXUAL BEHAVIOUR.....	195
7.2.5	EXTRAMARITAL SEX (EMS) .....	198
7.2.6	BROTHEL VISITS .....	201
7.2.7	MEN HAVING SEX WITH MEN (MSM).....	202
7.2.8	EVER USE OF CONDOMS .....	204
7.3	ATTITUDES ABOUT CONDOM USE .....	206
7.4	SEXUAL BEHAVIOURS AND PRACTICES IN RELATION TO POSITIVE PREVENTION REPORTED.....	212
7.5	DISCUSSION AND SUMMARY .....	216
<b>CHAPTER 8</b>	<b>HIGH-RISK SUB-GROUPS</b>	<b>226</b>
8.1	LORRY DRIVERS .....	228
8.2	CONSTRUCTION WORKERS.....	238
8.3	HOTEL WORKERS .....	242
8.4	FEMALE SEX WORKERS (FSW) .....	245
8.5	HIJRA.....	252
8.6	DISCUSSION AND SUMMARY .....	260
<b>CHAPTER 9</b>	<b>CONCLUSIONS</b>	<b>269</b>
9.1	LIMITATIONS OF THE RESEARCH.....	270
9.2	RESEARCH FINDINGS.....	273
9.3	CONTRIBUTIONS OF THE STUDY.....	280
9.4	RECOMMENDATIONS FOR FUTURE WORK ON HIV/AIDS PREVENTION.....	283

<b>BIBLIOGRAPHY</b>	<b>289</b>
<b>Appendix A: History of HIV/AIDS in India and Organisations working on related issues</b>	<b>332</b>
<b>Appendix B: Questionnaire</b>	<b>336</b>
<b>Appendix C: HIV/AIDS Mortality trends based on Hospital's records</b>	<b>365</b>

## *List of Tables*

Tab. 3.1	Reported HIV/AIDS cases 1986 – 2006, All India .....	34
Tab. 3.2	HIV prevalence (%) in selected populations in India.....	36
Tab. 3.3	HIV prevalence rates among selected sub-groups, southern Indian states, 2003 .....	38
Tab. 3.4	HIV Estimates of prevalence rates in general population, south India, 1999.....	39
Tab. 3.5	Trends in HIV+ patient treatments and Death Rates at GHTM, 1992 - 2000.....	53
Tab. 3.6	Cummulative number of HIV/AIDS inpatients treated at GHTM, 1993-98 .....	54
Tab. 3.7	Cummulative Number of HIV/AIDS patients treated at CMC, 1990-2000.....	57
Tab. 4.1	Secondary Data Sources .....	63
Tab. 4.2	Interview sample description.....	70
Tab. 4.3	Sections comparable with other surveys .....	73
Tab. 4.4	Knowledge deemed Correct .....	75
Tab. 4.5	Questionnaire Source.....	78
Tab. 5.1	Sex structure of PLWHA, patients survey, compared with TN Census and NFHS.....	111
Tab. 5.2	Place of Residence of PLWHA compared with TN Census and NFHS.....	113
Tab. 5.3	Age distribution of PLWHA compared with TN Census and NFHS .....	114
Tab. 5.4	Marital Status of PLWHA compared with TN Census and NFHS ..	114
Tab. 5.5	Marital Status of PLWHA by Gender, patient survey, 1999.....	115
Tab. 5.6	Education levels of PLWHA compared with TN census and	

	NFHS .....	117
Tab. 5.7	Education levels of PLWHA, patient survey, 1999.....	118
Tab. 5.8	Occupation by Gender of PLWHA compared with TN Census.....	119
Tab. 5.9	Usual occupation of PLWHA before being tested HIV positive, patient survey, 1999.....	120
Tab. 5.10	Current Occupational Status of PLWHA after being tested HIV positive.....	120
Tab. 5.11	Household composition prior to HIV diagnosis, Patients surveyed, 1999.....	121
Tab. 5.12	Household income, by sex, PLWHA.....	122
Tab. 5.13	Household standard of living indicators, by place of residence, PLWHA patient survey data compared with state-level data.....	123
Tab. 5.14	Household Amenities & Possessions, by sex of PLWHA.....	123
Tab. 5.15	Religion of PLWHA compared with TN Census and NFHS .....	124
Tab. 5.16	Health care facilities by place of residence, PLWHA, patient survey, 1999.....	125
Tab. 5.17	Socio-demographic characteristics of survey respondents, by State of origin, PLWHA, 1999 .....	130
Tab. 6.1	Percentage distribution of “Yes” responses to questions on blood-related HIV transmission, PLWHA, 1999 .....	137
Tab. 6.2	Percentage distribution of “Yes” responses to questions on knowledge of sex-related HIV transmission, PLWHA, 1999 .....	139
Tab. 6.3	Percentage distribution, by sex, of “No” responses to question on modes of HIV transmission, PLWHA, 1999 .....	142
Tab. 6.4	Percentage distribution of “Don’t Know” (DK) Responses to HIV transmission knowledge questions, PLWHA .....	145
Tab. 6.5	Latent Class Model for Knowledge of blood and sex related HIV transmission, PLWHA.....	147
Tab. 6.6	Latent Class Model for Knowledge of HIV transmission through	

	other modes of infection, patient survey, PLWHA .....	148
Tab. 6.7	Percentage distribution of ever-married women who had heard of HIV/AIDS by media exposure, secondary data sources, 1998. ....	150
Tab. 6.8	Percentage distribution of sources of HIV/AIDS knowledge among those who had heard about HIV/AIDS .....	150
Tab. 6.9	Exposure to Media: Proportion of PLWHA reporting at least weekly exposure by media type prior to diagnosis, and.....	154
Tab. 6.10	Percentage distribution, by sex and place of residence, of awareness and availability of condoms, secondary data (GBSS).....	156
Tab. 6.11	Percentage distribution, by sex, place of residence and state, of knowledge of condoms for HIV/AIDS prevention, GBSS, 2001.....	156
Tab. 6.12	Percentage distribution, by sex and selected socio-demographic characteristics and Logistic regression by socio-demographic characteristics of “Yes” responses to knowledge and attitudes about Condoms, PLWHA, 1999.....	159
Tab. 6.13	Percentage distribution by sex and socio-demographic characteristics and logistic regression by socio-demographic characteristics of “Yes” responses to attitudes about condom use with partner, PLWHA, 1999.....	162
Tab. 6.14	Percentage distribution, by sex, of ‘Don’t Know’ responses by PLWHA for knowledge and attitudes about condoms .....	163
Tab. 6.15	Percentage distribution of awareness of HIV/AIDS prevalence, PLWHA, patient survey, 1999 .....	165
Tab. 6.16	Logistic regression of Knowledge of HIV positive persons other than oneself, PLWHA, patient survey, 1999.....	166
Tab. 6.17	Percentage distribution of HIV/AIDS knowledge by time since diagnosis, PLWHA, patient survey, 1999. ....	167
Tab. 6.18	Percentage distribution by Gender and socio-demographic characteristics and logistic regression by socio-demographic	

	characteristics of “Yes” responses to attitudes towards HIV Testing, childbearing and disclosure, PLWHA, patient survey, 1999 .....	170
Tab. 6.19	Percentage distribution, by sex and other socio-demographic characteristics and logistic regression by socio-demographic characteristics of attitudes about HIV/AIDS and physical appearance, PLWHA, 1999 .....	174
Tab. 6.20	Distribution of perception that therapy to cure HIV existed, PLWHA.....	176
Tab. 6.21	Percentage distribution, by sex, of Don’t Know responses for questions on some aspects of HIV transmission, PLWHA, patient survey.....	176
Tab. 7.1	Percentage distribution of age at sexual debut, by sex, PLWHA, patient survey, 1999.....	192
Tab. 7.2	Frequency of marital sex per month prior to diagnosis, by sex and age, PLWHA.....	194
Tab. 7.3	Frequency of sex per month prior to HIV diagnosis by time since diagnosis, PLWHA.....	195
Tab. 7.4	Percent distribution and Logistic Regression by socio-demographic characteristics for reported premarital sex, ever-married male PLWHA, patient survey, 1999. ....	196
Tab. 7.5	Report of PMS by length of time between sexual debut and marriage, ever married male PLWHA.....	197
Tab. 7.6	Percent distribution and Logistic Regression by socio-demographic characteristics of Extramarital Sex among ever-married male PLWHA.....	199
Tab. 7.7	Percentage distribution of pre-marital sex, ever-married male PLWHA, patient survey, 1999. ....	200
Tab. 7.8	Percent distribution and Logistic Regression by socio-	

	demographic characteristics of brothel visits by male PLWHA, patient survey, 1999.....	202
Tab. 7.9	Percentgae distribution of ever-use of condoms by respondent characteristics, PLWHA, patient survey, 1999.....	205
Tab. 7.10	Logistic Regression, ever use of condoms, PLWHA, patient survey, 1999.....	205
Tab. 7.11	Percentage distribution of attitudes towards condoms, by gender, PLWHA, patient survey, 1999. ....	212
Tab. 7.12	Percent distribution and Logistic Regression by socio- demographic characteristics of reported post-diagnosis preventive prevention, PLWHA, patient survey, 1999. ....	214
Tab. 7.13	Distribution of reported positive prevention with spouse or regular partner, by sex and partner's serostatus, PLWHA who knew their partner's status, 1999.....	215

## *List of Figures*

Fig. 2.1	KABP Biomedical Model for HIV Prevention.....	9
Fig. 2.2	Conceptual Model for KABP survey of PLWHA .....	17
Fig. 3.1	Map of India .....	33
Fig. 3.2	Modes of HIV Transmission, All India, 2006.....	35
Fig. 3.3	Age distribution of PLWA by sex, All India, 2006.....	37
Fig. 3.4	Map of Tamil Nadu .....	40
Fig. 3.5	Distribution of PLWA by age group, TN, 2003 .....	40
Fig. 3.6	Trends in HIV prevalence TN, 1998-2003 .....	41
Fig. 3.7	Map of Andhra Pradesh.....	42
Fig. 3.8	Age distributions of All Male HIV inpatients, CMC, 1996-1999 .....	58
Fig. 3.9	Age distributions of All Female HIV inpatients, CMC, 1996- 1999 .....	58
Fig. 5.1	Female to Male ratios by District of origin: Patient Survey compared with TNSACS data .....	112
Fig. 6.1	Percentage distribution of reported source of HIV infection, patient survey data compared with secondary data sources .....	136
Fig. 6.2	Percentage distribution, by sex and occupational categories, knowledge that condoms can prevent HIV infection, BSS surveys in TN, 1996-2000. ....	157
Fig. 7.1	Percentage distribution, reported source of HIV infection by Gender: Reports from Patient survey (n=292) .....	191
Fig. 7.2	Frequency of sex per month, prior to diagnosis, by gender, PLWHA. ....	194
Fig. 7.3	Frequency of sex per month, prior to HIV diagnosis by occupation, PLWHA. ....	194
Fig. 7.4	Reported post-diagnosis positive prevention by age group.....	214



## *List of Boxes*

Box 8.1	Lorry Drivers .....	229
Box 8.2	Construction workers.....	239
Box 8.3	Hotel workers .....	243
Box 8.4	Female Sex Workers in Tamil Nadu, GBSS .....	246
Box 8.5	Female sex workers, Patients survey, 1999 .....	248
Box 8.6	<i>Hijra</i> .....	255

## *List of Case Studies*

Case study 8.1	Lorry Driver.....	238
Case study 8.2	Construction workers.....	242
Case study 8.3	Hotel workers .....	245
Case study 8.4	Female sex worker.....	252
Case study 8.5	<i>Hijra</i> .....	259

## *Glossary*

<i>Attitudes</i>	mode of regarding the object of thought, either positive or negative views of an object (person, behaviour or event) (Oxford English dictionary)
<i>Beedi's</i>	Tobacco rolled in a leaf
<i>Chela</i>	companion/student
<i>Chinna veedu</i>	small house, referring to a partner other than wife
<i>Devadasi</i>	temple prostitutes
<i>Donga Gaddi</i>	stolen grass (refers to extra marital sex)
<i>Gaanja</i>	Canabis/smoking drug
<i>Guesstimates</i>	Educated guess at an estimate
<i>Guru</i>	teacher/master
<i>Hijra/Bogams/Thevadiya s/kojja/pottai/ali/onbadu</i>	all these refer to the third gender role in India
<i>Ice Bucket Treatment</i>	a form of treatment for HIV being experimented with at GHTM. The patients are made to sit with their feet immersed in a bucket of broken pieces of solid ice for 30-40 minutes a day
<i>Kachha</i>	temporary/thatch roofed house
<i>Kala-azar</i>	Visceral Leishmaniasis, transmitted by the bite of the infected female phlebotomine sandfly
<i>Knowledge</i>	An acquaintance with ascertained truths, facts or principles or condition of understanding, or information acquired by study (Oxford English dictionary)

<i>Namaste</i>	greeting with folded hands
<i>Nirodh</i>	condom
<i>Pombalai poruki</i>	one who picks up females
<i>Porampoku</i>	poached property
<i>Pucca</i>	concrete roof
<i>Rapid Test</i>	A quick test done by most pathology laboratories for detection of HIV virus and takes about 30 minutes.
<i>Saamy</i>	possession by gods
<i>Siddah</i>	a traditional method of treating illness through mercury based alchemical ideas relating to longevity
<i>Yellamma/Hanuman/ Khandoba</i>	Hindu gods and goddesses

## *Abbreviations*

ABC	Abstain, Be faithful, use Condoms
AIDS	Acquired Immune Deficiency Syndrome
ANC	Ante-natal Clinic
AP	Andhra Pradesh
APAC	AIDS Prevention and Control
APSACS	Andhra Pradesh State AIDS Control Society
ARCON	AIDS Research and Control Centre
AUSAID	Australian Agency for International Development
BSS	Behaviour Surveillance Survey
CHES	Community Health Education Society
CII	Confederation of Indian Industries
CMAI	Christian Medical Association of India
CMC&H	Christian Medical College and Hospital
CSW	Commercial Sex Worker(s)
DFID	Department of International Development
DGHS	Director General of Health Services
DHS	Demographic Health Surveys
DK	Don't Know
DO	Desk Officer
ELISA	Enzyme-Linked Immuno Sorbent Assay
FP	Family Planning
FSW	Female Sex Worker
GBSS	General Population Behavioural Surveillance Survey
GEM	Gender relations, economics and migration
GHTM	Government Hospital for Thoracic Medicine
GO	Government Order
HIV	Human Immuno-deficiency Virus
ICMR	Indian Council of Medical Research

IDF	India Development Forum
IEC	Information, Education & Communication
IHO	Indian Health Organisation
IIPS	Indian Institute of Population Studies
IMR	Infant Mortality Rate
IRFA	Indian Research Fund Association
IVDU/IDU	Intra-Venous Drug Users/ Injecting Drug Users
KABP	Knowledge, Attitudes, Behaviours and Practises
MCH	Maternity and Child Health
MoHFW	Ministry of Health and Family Welfare
MSM	Men having Sex with Men
NACO	National AIDS Control Organisation
NARI	National AIDS Research Institute
NCERT	National Council of Educational Research and Training
NFHS	National Family Health Survey
NGO	Non-Governmental Organisation
NIMHANS	National Institute of Mental Health and Neuro Sciences
ODA	Overseas Development Association
PLWHA	People Living With HIV/AIDS
PVO	Private Voluntary Organisations
SO	Section Officer
SRS	Sample Registration System
STD/I	Sexually Transmitted Disease/ Infection
TB	Tuberculosis
TCI	Trucking Corporation of India
TFR	Total Fertility Rate
TN	Tamil Nadu
TNSACS	Tamil Nadu State AIDS Control Society
TRC	Tuberculosis Research Centre
TRG	Technical Resource Groups
UN	United Nations
UNAIDS	United Nations Program on HIV/AIDS
UNDP	United Nations Development Program

UNESCO	United Nations Educational, Scientific and Cultural Organization
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children's Emergency Fund
USA/US	United States of America
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
VHAI	Voluntary Health Association of India
VHS	Voluntary Health Services
WHO	World Health Organisation

# Chapter 1 INTRODUCTION

Globally there are an estimated 38.6 million (with plausibility bounds estimated at 33.4 to 46 million) people living with HIV/AIDS (PLWHA), 5.7 million of which live in India, making it the country with the highest number of PLWHA (UNAIDS 2006). According to the most recent UNAIDS report, the global adult HIV prevalence rate (calculated by dividing estimated number of PLWHA aged 15 to 49 by the total population aged 15-49) was 1.0 (ranging between 0.9 – 1.2). It is estimated that 4.1 (ranging between 3.4 – 6.2) million people were newly infected with HIV and 2.8 (ranging between 2.4 – 3.3) million died from AIDS-related illnesses in 2005. The adult prevalence rate of 0.9 % (0.5 – 1.5%) in India, the second most populous country in the world, may yet be an underestimate (Walker *et al.* 2003).

Estimates and projections of the scale of the epidemic are important for policy and programme planning. However, they only describe the magnitude of the problem. They tell us little about the context and impacts (social, cultural, political, economic and demographic) of the pandemic. They tell us nothing about the lived realities of PLWHA, a growing and heterogeneous population sub-group. In India, people aged 15-49 account for about 57% of the population, and it is estimated that 3.97 million (0.8%) people in this age group are HIV positive. This study focuses on PLWHA, a group of people in India about which relatively little is known. The aim of this research is to generate new information about the HIV-related knowledge, attitudes

and behaviours of PLWHA. In order to achieve this aim, a series of research questions are addressed:

- What were the levels and sources of HIV/AIDS knowledge among PLWHA?
- What were the prevalent HIV/AIDS-related attitudes among PLWHA?
- What were the socio-economic and cultural factors that correlate with levels and sources of HIV/AIDS knowledge as reported by PLWHA?
- What were the prevalent sexual behaviours that might comprise a risk for acquiring HIV/AIDS in India as reported by PLWHA?
- What were the social, economic, demographic and cultural correlates of sexual behaviour (including condom use) in relation to HIV/AIDS in India as reported by PLWHA?

## 1.1 Rationale for the study

As the country with the highest number of PLWHA, India is becoming a focus for international efforts to prevent and deal with HIV/AIDS. In India the dominant mode of HIV transmission is sexual, with localised epidemics driven by intravenous drug use (IVDU) in the north eastern region and metropolitan cities. Nationally, there is an increasing political will and commitment for HIV prevention and control efforts, including a recent focus on issues of stigma and discrimination for PLWHA (Godbole and Mehendale 2005). Surveys, both nationally representative and those that focus on sub-populations, have yielded improved prevalence estimates. National sample surveys in resource-constrained settings are needed as evidence for governments to formulate national level policies. However, national sample surveys are limited in their ability to produce knowledge relevant to risk reduction strategies (Lampthey and Gayle 2001).



The major source of information about knowledge and behaviour relating to HIV/AIDS is knowledge, attitudes, behaviour and practices (KABP) surveys. However in recent years, the limitations of the biomedical model of KABP alone to fully understand the dynamics of HIV/AIDS have been recognised (Lugalla *et al.* 2004). There is an increasing recognition that understanding of HIV/AIDS knowledge and behaviours needs to be better situated within their socio-economic, demographic and cultural contexts.

HIV/AIDS has wider implications than health alone and it impacts the socio-demographic and economic fabric of society (Barnett *et al.* 2001; Hunter 2005). Economic underdevelopment exacerbates an already difficult situation. According to Jonathan Mann, the third wave of the AIDS pandemic was an epidemic of economic, social, political, and cultural reaction and response to HIV/AIDS (Earickson 1990). Bulmer and Warwick (1993) describe culture as a concept subject to a broad range of interpretations. In the 1990's there was a change in dominance from earlier biological, technical models to an understanding of the need to place behaviour change in a socio-economic and cultural context that influence knowledge, attitudes, behaviours and practices (Godwin 1998; Roberts *et al.* 2004).

In consequence, greater emphasis is being placed on qualitative or mixed methods approaches in small-scale research in terms of both sample size and geographic coverage, which is more qualitative. The purpose of this shift in emphasis in terms of knowledge production is to better understand the causes of HIV infection and better practices for prevention programs.

Economic evaluation research indicates that interventions to reduce HIV risk behaviours can be highly cost-effective (Pinkerton and Holtgrave 1999). According to Peter Piot, head of UNAIDS, "a delay in prevention of further spread of HIV/AIDS will only aggravate the epidemic and reverse South Asia's expected economic and social progress" (BBC 2003; Piot *et al.* 2002). Successful prevention measures have been hard to implement at the population level and the epidemic

continues to spread. KABP are affected by socio-economic, demographic and cultural conditions (Barnett and Whiteside 2006; Shoveller and Pietersma 2002). MacNeil and Hogle (1998) suggest that it is crucial that effective HIV programme interventions draw on locally relevant research.

In India, although it is understood that information on sexual practices and sexual health is necessary in planning, implementation and evaluation of efficient HIV/AIDS prevention and care programmes, most aspects of sexuality are under-researched (Bansal *et al.* 2001; Chatterjee and Sahgal 2002; Hawkes and Santhya 2001). This thesis adds to the body of evidence by presenting new data on HIV-related knowledge and behaviours of PLWHA in southern India. There are hardly any information about this sizeable population sub-group, mainly because the majority of nationally representative surveys question people who are not HIV positive or do not know their status.

Gaps between knowledge, attitudes, culture and environmental factors in a country like India, constrain general behaviour change. Relatively little is known either of local attitudes or of the ways in which they affect sexual behaviours and practices. When this study began, very little was known about HIV/AIDS in India and hardly any social science research related to HIV/AIDS existed in the country in general.

In particular, PLWHA had rarely been a focus of study in India. Hardly any data exists about an understanding of HIV positive people and their knowledge and behaviour in India, which is the unique nature of our research. The work among PLWHA until the time of our study had been mainly clinical and medical in nature. Our survey of PLWHA included those who were reported to practise high-risk sexual behaviours namely, female sex workers (FSWs), lorry drivers, *hijra* (represents a special inter-sexed category in India), hotel workers and construction workers.

## 1.2 Contributions to Knowledge

At the time of this research, practically nothing was known about PLWHA in India. This research aims to shed light on knowledge, attitudes, behaviours and practices of HIV positive people, and the findings have the potential to inform policy planning and design, in particular policies of positive prevention. In this context we examined knowledge, attitudes and sexual behaviours but aimed to go further in understanding socio-economic, demographic and cultural influences, through quantitative and qualitative analyses of data as reported by PLWHA. This was done with the purpose of understanding best practices for HIV prevention and control in India. The key contribution of this study is to the body of knowledge about HIV/AIDS from the perspective of PLWHA, to understand socio-cultural issues that influence interventions and procedures, in a regional context. In particular, to better understand the context of positive prevention so as to place behaviour change in context in order that behaviour change communication (BCC) might be better designed.

Our study aimed to portray an accurate descriptive profile of a sample of PLWHA in India. This was possible through building on the researcher's previous knowledge, based on earlier research of the situation in the region. These data were supplemented with extensive discussions with policy makers and professionals working with the government health sector, NGOs (national and international) and medical professionals working in the field (see Appendix A2 to A4). PLWHA's own knowledge on topics including transmission and prevention of HIV/AIDS, and the stigma associated with living with the disease has been recorded.

This empirical research was conducted in two hospitals in Tamil Nadu, which had the advantage of PLWHA being more accessible and willing to talk freely in a safe environment and ensured greater reliability of data. It has examined specific questions using quantitative survey data, supplemented by qualitative analysis of answers to open ended questions and spontaneous contributions of patients during the course of their interviews. The sensitive nature of studying HIV/AIDS from the

perspective of people living with the infection required a different approach from a standard quantitative questionnaire. It was necessary to conduct a primary study that combined quantitative and qualitative methods to better understand KABP related to HIV/AIDS in India. Quantitative and qualitative methods were integrated in this study to capture a more complete, holistic and contextual portrayal of the respondents' knowledge, attitudes, behaviours and reported practices.

### 1.3 Thesis Outline

Chapter II reviews the literature with a specific focus on India, introduces the dominant KABP model and sets the study in its wider policy and research contexts. The meanings of knowledge and attitudes in the context of KABP surveys are reviewed.

The context for this research is described in chapter III, and it outlines recent HIV/AIDS trends and policies in India. Chapter III concludes with a description of Government Hospital for Thoracic Medicine (GHTM) and Christian Medical College and Hospital (CMC), our study sites. Chapter IV outlines general methodological issues for social science research in India. It concludes with a description of the research methods and analysis techniques, including a critique of the research instrument.

Chapter V is the first analytic chapter, and presents analyses of background socio-demographic and economic characteristics of the PLWHA sample, including a comparison between the two study sites, GHTM and CMC. The second analytic chapter, Chapter VI, analyses the knowledge of, and attitudes towards, HIV/AIDS and condoms as reported by PLWHA. Chapter VII analyses reported sexual behaviour, particularly in relation to positive prevention with reference to condom use.

Chapter VIII is devoted to analyses of knowledge, attitudes, behaviours and practices of groups identified as likely to practice high risk sexual behaviour (lorry drivers, female sex workers, *hijra*, hotel workers and construction workers). Analyses of data from HIV positive people in chapters VI to VIII have been analysed in ways that link socio-demographic, economic and cultural characteristics to KABP. Chapter IX draws together the findings of this research, and places the contribution to knowledge within the context of the research objectives. It concludes with a discussion of possible avenues for future research.

## Chapter 2 Literature Review

This chapter reviews literature related to KABP in the context of HIV/AIDS. 'KABP' has been referred to in different ways by different studies. It is referred as knowledge, attitudes, beliefs and practices (Camara 2006) as well as knowledge, attitudes, behaviours and practices (Khan 2006; WHO 2006). We have used the latter reference so that KABP in our study means knowledge, attitudes, behaviours and practices.

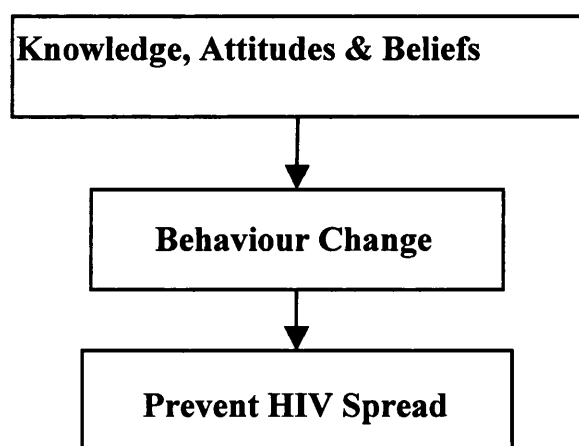
Firstly, the role of KABP studies, both theoretically and methodologically are reviewed, together with their limitations and subsequent modifications, in a global context. Secondly, literature relating to KABP in an Indian setting is reviewed. Thirdly, the body of knowledge relating to KABP of PLWHA is assessed. When this research began (1997), there was a very limited body of evidence relating to HIV/AIDS in India in general and KABP in particular, and virtually no work on PLWHA. This body of evidence has grown considerably over the past three years, and this literature review updates and expands the literature review that was originally done until 2003.

### 2.1 Knowledge, Attitudes, Behaviours and Practices (KABP): Model

The KABP biomedical model of HIV/AIDS prevention was seen in the early 1990s by a wide range of medically influenced researchers as key to strategic planning and implementation of preventive programmes. Thus early HIV research focus and

prevention campaigns used to be KABP centric (Chan R *et al.* 1997; Irwin *et al.* 1991; Maticka-Tyndale *et al.* 1994; Meda *et al.* 1998; Organista *et al.* 1996). The rationale of the original bio-medical KABP model available at that time was that knowledge would influence attitudes, which would enable behaviour change (UNAIDS 1998; WHO 1994). The assumptions behind the model, whether stated or implicit, were that an understanding of how HIV/AIDS was spread, what its consequences were, and how it could be prevented, would lead to modifications in sexual and other unsafe behaviours, and so to control of the epidemic. We represent this relationship diagrammatically in Fig. 2.1.

**Fig. 2.1** KABP Biomedical Model for HIV Prevention



**Source:** (IMPACT/FHI/UNAIDS 1998)

The KABP model used by WHO during the early 1990s was top down in presuming that generic or culture free biomedical knowledge imparted through health education would influence attitudes and result in safe sexual practices (WHO 1994).

Since 1998, UNAIDS has been advocating behavioural research based in sub-populations to help planners design initiatives focused on breaking transmission links. The limitations of a KABP centric focus were realised and since then there has been a shift toward a more holistic approach.

Once developed KABP models had the advantage of being easy to translate to the relevant situation and also cost efficiency. Therefore the convenience of replicating an existing KABP model has retained its popularity for research even in recent times, though with some modification (Morisky *et al.* 2002; Vinh *et al.* 2003).

## 2.2 Knowledge, Attitudes, Behaviours and Practices (KABP): Surveys

KABP surveys are pre-eminent in the body of information relating to HIV/AIDS, and, for example, form part of the knowledge base for evaluation of progress towards Millennium Development Goal #6. If we are to review the recent history and development of KABP surveys, and their contribution to the knowledge base relating to HIV/AIDS, it is important to first outline what is generally understood by the terms “knowledge”, “attitudes” and “practice”. It is interesting to note that few producers and consumers of KABP surveys ever define what is meant by knowledge, attitudes, behaviours and practice.

Knowledge, according to the Oxford English Dictionary, is defined in general as an acquaintance with ascertained truths, facts or principles or condition of understanding, or information acquired by study. It is distinct from belief and opinion, to believe something just means to think that it is true. However, it might be that it might not be true. For something to count as knowledge, it has to be true, for example two people could believe things that are mutually contradictory, but they cannot know (unequivocally) things that are mutually contradictory. Thus knowledge is a subset of that which is both true and believed.

Attitude in the Oxford English Dictionary is defined as a mode of regarding the object of thought, either positive or negative views of an object (person, behaviour or event). Attitudes derive from judgment and are expected to change as a function of experience. Most attitudes are said to be a result of social learning from the environment. It is said that attitudes can be changed through persuasion. The link



between attitude and behaviour exists but depends on attitude specificity, attitude relevance, personality, social constraints and timing of measurement.

Public health education is a complex process (Huber and Schneider 1992), and the simplistic KABP WHO model of the early 1990s was reflected in the use of standardised KABP questionnaires to evaluate programme impact. However, scientific and technical biomedical knowledge that is in the main constituted by 'scientifically' proven facts is not unproblematic. What we know and what research finds out is produced by the social and political context in which we operate (Green and Thorogood 1998). Scientific research then is a product of the economic, social and political interests of the time. Science, seen in this way, according to Green and Thorogood is a cultural product and scientific projects arise from particular 'ways of seeing'. Radley and Billig (1996) also have disputed the traditional clear-cut distinction between scientific or technical biomedical knowledge and other forms of human experience. The former are increasingly seen as the main source of instrumental rationality in modern societies, but other forms of knowledge exist alongside them, and when people are faced with highly sensitive and life threatening topics such as HIV/AIDS, they may become dominant.

Moatti and Souteyrand (2000) argue that while scientific knowledge is seen as the main source of instrumental rationality in modern societies, observed discrepancies exist between biomedical experts and lay people's mental representations of health and illness. There are no direct relationships between an individual's level of knowledge and attitudes toward a disease, and his or her behaviour (Hubert 1990; Turner *et al.* 1989). Information alone is not sufficient to promote meaningful change in risk behaviour, especially when that behaviour is immediately reinforcing and well established, and its negative consequences are temporally distant or uncertain. Ingham (1995) also argues that, while knowledge of HIV/AIDS is a necessary condition for behaviour change, it is not a sufficient condition. According to Bulmer and Warwick (1993), verbal and non-verbal behaviour often are not closely related

and they report the results of studies showing high unreliability of responses to the types of questions asked in KABP-type surveys. They argue that in many KABP studies, quality was compromised in favour of ease of replication. Wellings and Macdowall (2000) argue that KABP surveys have limitations in the extent to which they can monitor changes wrought in the social context, since their focus is on the individual. Thus surveys based on a bio-medical model of KABP alone present problems of validity and reliability and might be susceptible to social desirability responses. The early KABP models using WHO/GPA standard questionnaires were not designed to test any particular socio-cultural constraints on behaviour change (Cleland *et al.* 1995a). It has since been more widely recognised that research on sexual behaviour and the risk of HIV infection requires a focus on the specific social interactions that influence individual behaviour.

Standard KABP questionnaire continue to be the most commonly used tool in describing and explaining the relationship between knowledge and behaviours. However research from early 1990s demonstrates that standardised tools do not adequately capture the apparent dissonance between knowledge/attitudes and behaviours/practices. A number of authors, in a wide range of settings, have found that behaviour change can only occur when knowledge can be related to social, structural and cultural factors in ways that make it seem sensible, possible and worthwhile to change behaviours.

According to Hubert and colleagues (1998), AIDS prevention strategies are unlikely to work if one does not accept the diversity of situations and risk management approaches and consequently, the diversity of strategies of change that individuals construct. Instead there is a need to uncover appropriate specific hypotheses for each situation. They suggest that it is possible that most of the 'levers of change' defined in the literature by the scientific hypotheses may have no relevance for certain categories of people or certain interactions, although they may apply to others, under specific conditions. The next section reviews a range of

literature, drawn from a wide range of geographic settings, on HIV/AIDS knowledge, attitudes, behaviour and practice. The purpose of this review is to highlight how, in a wide range of settings, knowledge does not necessarily translate into a reduction in risky behaviour or practice. This review is not systematic nor is it comprehensive. Rather, it aims to highlight, using examples from a wide range of settings, that the complexity of sexual behaviour cannot be understood simply in terms of individual decisions, or changed through a context-free provision of information.

The first set of studies are drawn from research in the US and Europe, and highlight the importance of socio-economic, demographic and cultural factors in explaining HIV/AIDS knowledge and behaviour. Peruga and Celentano (1993) reviewed eighty US-based studies to explore the correlates of AIDS knowledge, and concluded that high levels of education, younger age groups, and white ethnic groups were more likely to be knowledgeable about AIDS and that strong religious beliefs or conservative political convictions are strongly associated with low AIDS knowledge. Stevens' (1994) study of lesbian and bisexual women in bars and clubs in San Francisco found myriad cultural constraints to enacting safer behaviours, including difficulties related to negotiating safer sex, for example. Schiller and colleagues (1994) examined the cultural construction of high-risk groups in New Jersey. They found that people with AIDS were portrayed as socially deviant, a construction that facilitated distancing and denial of personal risk by persons outside high-risk groups, thus impeding prevention efforts. Goodwin and colleague's (2003) study in central and Eastern Europe suggested that cultural differences were based on examining social representations of HIV/AIDS. Aguilera and Plasencia (2005) examined HIV/AIDS and substance abuse prevention for urban Native youth in California and uncovered a need for culturally relevant and culturally appropriate HIV/AIDS and substance abuse prevention programs that could be creatively integrated into the multidimensional and complex social structures. Lazarus and colleagues (2006) explored knowledge, attitudes and practices among Somali and

Sudanese immigrants in Denmark with regard to HIV/AIDS and condom use, two groups with reported incidence rates higher than the national average and HIV/AIDS knowledge significantly lower than the national average. They concluded that these groups received little information, and indicated a need for targeted, culturally sensitive HIV/AIDS information and advice.

The severity of the pandemic in sub-Saharan Africa has generated a large body of knowledge and research, sometimes contradictory in its findings. Lugalla *et al.* (2004) examined trends in behaviour in Tanzania, and found an increase in condom use, abstinence, mutual faithfulness and uptake of VCT and a decrease in polygamy, widow inheritance, excessive alcohol consumption, and multiple sexual partners. They suggest that these changes were partly a result of the severity of the epidemic itself in the study area and partly as a result of targeted interventions since 1987. Campbell's (2003), work among miners and commercial sex workers in South Africa argues that simply giving people information about health risks is unlikely to change the behaviour of more than one in four people, and those who change behaviours are generally the more affluent and better educated members of a social group. She concludes that health-related behaviours (such as condom use) are determined not only by conscious rational choice by individuals, on the basis of good information, but also by the extent to which broader contextual factors support the performance of such behaviours. Setel (1999) demonstrated the different, and sometimes competing, representations of the HIV epidemic in the Kilimanjaro region of Tanzania, and highlights the paradoxes linked to the cultural, social, economic and demographic context in which AIDS is inscribed. Macdonald (1996) notes the importance of socio-economic and cultural factors influencing the transmission of HIV in Botswana, such as lack of power among women to negotiate sexual relationships, cultural attitudes to fertility and social migration patterns, above and beyond knowledge levels.

Lambert and Woods (2005) conducted a comparative analysis of modes of dialogue, non-verbal communication and embodied action relating to sex and health in India and South Africa, based on material from multiple studies, including ethnographic and other forms of qualitative and multi-disciplinary research. They considered how, and by whom, sex is and is not talked about, in public discourse and private conversation; how sexual intention and desire are communicated through indirect, non-verbal means in everyday life; and how references to sexuality and the sexual body re-enter within a more explicit set of indigenous discourses about health (rather than 'sexual health' per se). For example, this is manifested through concerns about semen loss in India and womb 'dirtiness' in South Africa.

Studies in Asia also emphasise the importance of placing HIV/AIDS in socio-economic and cultural context (for example, Thailand - Ford and Koetsawang (1991); Bangladesh - Rahman et al. (1999); Vietnam - Vinh et al. (2003); China - (Huang *et al.* 2005). Roberts et al. (2004) explored the social and cultural context of sexual health for young people in Mongolia and suggest that recent and rapid political, economic, and cultural changes in Mongolia contributed significantly increased risk of exposure to the risk of HIV infection. Hunter's (2005) book on AIDS in Asia argues that the prevailing economic, social and cultural situation (including unemployment, poverty, economic disparity, low levels of education and poor health care systems including non-existent blood screening procedures) reduce the efficacy of prevention efforts. Taken together, these studies confirm that individual knowledge about AIDS risk is not necessarily simply related to reported frequency of high-risk sexual practices for HIV infection or to observed behavioural change to reduce exposure. Cleland, Ferry and Carael (1995a) argue that behavioural change is important, but has also proved the most intractable aspect of prevention. Research on sexual behaviour and the risk of HIV infection requires focusing on the specific social interactions, including power and negotiation) essential for planning effective interventions (Gausset 2002; Giffin 1998; Hubert 1990; Huygens *et al.* 1996; Macdonald 1996; Rhodes *et al.* 2001; Roberts *et al.* 2004).

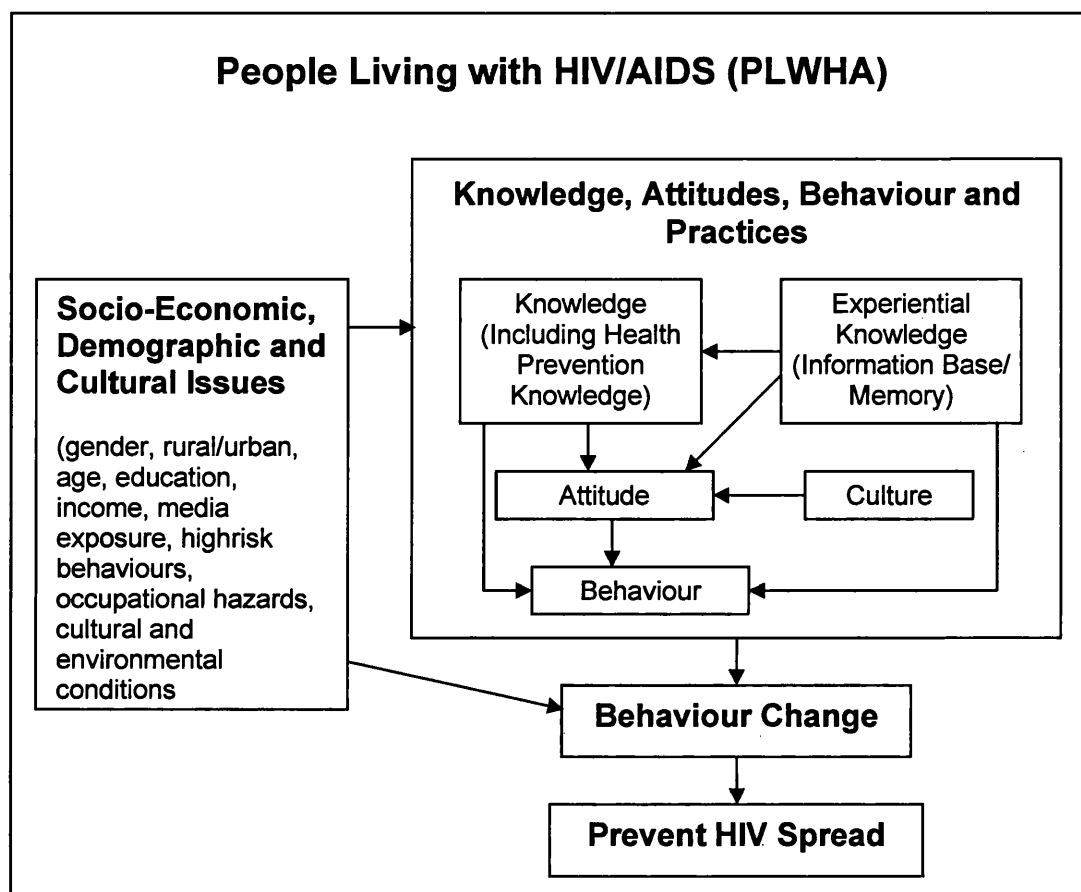
Sexual decision-making involves more than a simple cost and benefit analysis; and the impact of wider social dynamics, including power relations, have to be considered in studying behaviour changes to control the spread of HIV infections (Kraft and Rise 1995; Lie and Biswala 1998; Peruga and Celentano 1993). Auerbach *et al.* (1998) and Fishbein (2000) suggest that individuals and communities, when given appropriate tools, education and comprehensive HIV prevention interventions will modify behaviours that place them at risk of negative consequences.

The concept of ‘indigenous knowledge or experiential knowledge’, building on local knowledge systems and transactions” is increasingly used in HIV/AIDS research, not least because it has been shown to be cost-effective (Pottier *et al.*, 2003). Experiential knowledge, when translated into explicit demands, ideas, or judgements, can contribute to the relevance and quality of biomedical research (Caron-Flinterman *et al.* 2005). For example, a study of the relationships between knowledge, decision-making strategies, and risk assessment about HIV by youths in the US showed that they negotiated their perspectives with the use of justification and elaboration to support alternative opinions and positions (Patel *et al.* 2006). That is, they used their own experiential knowledge in order to understand and make sense of HIV. The utility of experiential knowledge with particular reference to PLWHA is explored in more detail in section 6.3.3.

Following on from these discussions, which emphasise the importance of studying KABP in a socio-economic, demographic and cultural context of HIV/AIDS, we developed the conceptual model for the patient survey (Fig. 2.2). We suggest in this model that knowledge (bio-medical knowledge including health prevention knowledge) could be developed in conjunction with an individual’s existing information base (and memory) developed from experiential knowledge. We suggest that attitudes are not only influenced by knowledge but also experiential knowledge and culture. Thus knowledge and attitudes would need to factor in the influence of experiential knowledge and culture to understand behaviours and practices in a

region. Further it is important to consider the influence of socio-economic, demographic and cultural issues (such as gender, regional differences, age, education, income, media exposure, occupational hazards etc.) on KABP and behaviour change in the context of HIV prevention.

**Fig. 2.2 Conceptual Model for KABP survey of PLWHA**



KABP surveys have therefore been used not only to establish baseline information, but also to evaluate the effectiveness of interventions (Rehle Thomas *et al.* 2006). Measurement of the incidence, nature and circumstances of non-regular partners and high-risk sexual activities continue to constitute a priority for international and national agencies. Nevertheless, compared to other public health areas, the evaluation of HIV/AIDS prevention and care programs is relatively young, and critical questions remain on how best to measure their effectiveness. There are formidable difficulties arising from lack of adequate data on sexual practices, and of

assembling the necessary information (Hubert 1990; Knox *et al.* 1993). According to Knox (1993), models comprising multiple interacting categories of behaviour have proved much more difficult because they demanded inputs of complex data which were simply not available. On the other hand, Anderson (1992) has argued for the importance of the quantification of patterns of sexual behaviour in defined communities, despite the many practical problems that surround data collection and interpretation.

The trend in understanding behaviour change in a socio-cultural context has been accompanied by wider acceptance of cross-fertilisation between different approaches and research methods (Huygens *et al.* 1996; Radley and Billig 1996). This has resulted in researchers from different epistemologies using different methodologies working on similar issues. For example, work by Moatti and Souteyrand (2000) brings together quantitative and qualitative techniques in the modelling of social or sexual networks in order to better understand their influence on risk behaviours. Hence, a combination of reliable quantitative and qualitative methods has become increasingly adopted to study the complicated issues related to HIV/AIDS KABP in a socio-economic and cultural context.

Researchers have increasingly converged to support the use of combined quantitative and qualitative methods for the evaluation of HIV interventions (Bajos and Marquet 2000; Booysen and Arntz 2003). In the field of HIV/AIDS, qualitative research, including ethnographic and anthropologic methods, has been demonstrated to be more effective at capturing behaviours which are viewed as “deviant” in general and illegal or socially stigmatised in particular. Quantitative methods, through appropriate questionnaire design, have retained their ability to contribute to our understanding of the social interaction processes involved at various levels in the diffusion of the HIV/AIDS epidemic. In addition, quantitative methods are helpful to avoid the risk of generalising anecdotal reports from qualitative findings by assessing the inter-individual regularities and variance in the behaviours and social phenomena



under study (Booyesen and Arntz 2003). Their review of studies on the socio-economic impact of HIV/ AIDS shows that diversity in methodological design is the norm, and more likely to be the result of practical considerations and resource constraints rather than deliberate design, and that this limits the comparability of research findings. While larger studies have more statistical power, smaller, in-depth studies are recommended for obtaining valuable in-depth information using qualitative methods to complement the current reliance on survey-based methods of data collection.

## 2.3 Literature Review related to India

Research related to HIV/AIDS in India is limited and the documentation that exists are optimistic reports at best, which are easy to write about but far from existing ground realities (Miller 2002). Miller further suggests that Indian national response must learn from the experiences of other countries if that response is to meaningfully connect with and reverse current epidemic trends in the country. In this section, we review literature related to HIV/AIDS knowledge, behaviours and prevention in India separately.

### 2.3.1 *KABP evidence for India*

Previous sections have demonstrated the need for context-specific information in order to best design HIV-prevention strategies. India includes massive diversity (economically, politically, socially and culturally), with implications for strategy design (Singh and Malaviya 1994). This section reviews current knowledge on KABP and HIV/AIDS in India. It is important to note that this review includes information up to and including 2006, although the data collected for and analysed in this study relate to 1999.

Married women in India are at high risk of acquiring HIV infection (Chatterjee 1999). A retrospective study of 134 HIV-infected women reported that single-

partner heterosexual sex with their husband was the only HIV risk factor for the majority of women (Newman *et al.* 2000).

A series of KABP studies have been carried out in a range of sub-populations in India, generally using standardised questionnaires (Balk and Lahiri 1997; Mawar 1997; NFHSAP-1998 2000; NFHSTN-1998 2001; Ponnuraj and Sankarapandian 1994; Rangaiyan 1998; Sambamoorthi *et al.* 2001; Sehgal 1994; Taghizade 2005). Lal *et al.* (1994) assessed HIV/AIDS knowledge and attitudes among 322 students from two colleges, one urban and one rural, and noted that while a majority of respondents were aware of HIV/AIDS, they also had extensive misconceptions particularly regarding disease transmission. Tibdewel and Wadhva (2001) conducted a cross sectional study to assess the basic HIV/AIDS knowledge and attitudes of 250 hospital employees regarding HIV/AIDS. Most of them (93%) had heard or read about AIDS, but again misconceptions were found, together with biased and negative attitudes towards PLWHA. Mukherjee and Sikdar's (2005) study of HIV/AIDS awareness and attitudes (n=400 respondents) in West Bengal found that people in general were not aware of HIV/AIDS and reported negative attitudes towards PLWHA.

Sudha *et al.*'s (2005) study assessed the awareness and attitudes of the general public toward HIV/AIDS in Hyderabad. They reported that 81% of the study population were somewhat aware of HIV/AIDS, but had incorrect perceptions about the mode of transmission or prevention. The majority reported several misconceptions about HIV or about PLWHA, although there were variations by level of education.

A study of the relationships of health beliefs and HIV/AIDS knowledge with frequency of condom use among women of childbearing age in four major Indian cities noted rare or no use of condoms during intercourse (Ananth and Koopman 2003). They also found the levels of misconceptions about HIV/AIDS to be high. Another study investigating HIV/AIDS-related knowledge, perceptions, and

behaviour change among married women in Mumbai found that only two (41%) in five women perceived HIV as a threat to the community; one (12%) in eight perceived personal risk of getting infected as high; and only 7.2% (17) reported behaviour change to avoid infection (Chatterjee and Hosain 2006). The reasons given for not changing behaviour were that they were not commercial sex workers and were not at risk of HIV since their personal behaviour was monogamous and that they trusted their husbands.

KABP-style questionnaires have been used extensively in India to evaluate the effectiveness of HIV interventions. Singh (2003) analysed the effect of an intervention on a group of 200 female college/university students in India, and reported low levels of information on issues related to HIV transmission and prevention. Further, the respondents were neither motivated nor possessed appropriate behavioural skills to engage in HIV preventive behaviours. As a result, half (n=110) of the respondents were assigned to the experimental group (three-session intervention programme) and the remaining 100 to the control group. Post-testing showed a significant increase in the level of information, motivation and behavioural skills of the experimental group compared with the control group. A pre-intervention survey of 2,919 students reported that only 50% of school students knew that HIV/AIDS is transmitted sexually and 24% reported that HIV is transmitted by mosquitoes (Sankaranarayan *et al.* 1996). Following a school-based HIV/AIDS education program, 95% of the students knew that HIV/AIDS is transmitted sexually, 92% knew that there is no HIV/AIDS cure and 76% knew that HIV/AIDS is not transmitted by mosquitoes.

Many studies highlight the need to address not just the biomedical aspects of HIV/AIDS, but also its socio-cultural dimensions, including religion (Bery 2006; Bharat and Aggleton 2002; Gupta and Panda 2002; O'Neil *et al.* 2004; Poddar 1995; Sharma 2006). The ramifications of the need to address the socio-cultural context of HIV/AIDS for successful IEC interventions has been widely noted in India (NACO

2004; Verma and Roy 2002). Because the epidemic in India is one that is largely driven by heterosexual sex, it is important to outline the evidence relating to the socio-cultural setting of sexual behaviour in India.

### ***Research on sexual behaviour in India***

Generally in India there is a widely held perception that it is not appropriate to discuss or research sexual behaviour, and as a result relatively few empirical studies have been conducted (Hawkes and Santhya 2001; Khan 1993; Nag 1996) and there are still gaps in the basic understanding of sexual practices in India (UNAIDS 2000). Data on sexual behaviours are priorities in order to predict the spread of the epidemic, target appropriate interventions, and monitor progress in changing behaviour (Cleland 1995; Nag 1995). The primary mode of HIV transmission in India is heterosexual behaviour, necessitating research into heterosexual sex, and there is evidence of increasing rates of infection among married women in India as a result of sex with their husband (Chatterjee and Hosain 2006). It is vital to understand sexual practices and safe sexual behaviours in a socio-cultural context for a better understanding of what could comprise effective HIV prevention strategies in an Indian setting (Collumbien and Das 2004; Narain *et al.* 1994; Sherman *et al.* 2003). The advent of the HIV/AIDS epidemic in India has stimulated research into sexual behaviour in recent years and the topic in general is also regularly featured by the media (Bhattacharjee, J *et al.* 2000; Kumar *et al.* 1997; Prabha *et al.* 2003; Selvan *et al.* 2001).

There are many widely held misperceptions about sexual behaviour in India in general. For example, a widely held misconception is that the majority of people in India have their first sexual experience within marriage (Pelto *et al.* 2000), a misperception due in large part to paucity of research (Jejeebhoy 1998). Similarly, there is a perception that multiple sexual partnerships do not exist (Sethi (2002). These perceptions are rooted in an assumption of an Indian family system which condones only monogamous marital sex, a traditional ideal of a woman who was a

virgin at marriage and monogamy by married women, combined with norms that tacitly permit men to have premarital and extramarital sex. The result of these perceptions was a situation where the existence of sex outside marriage was camouflaged so well as to be virtually invisible (Knodel *et al.* 1996). Ideals of premarital chastity and marital fidelity are more strictly enforced on women, who pay a higher penalty for violation (Gangakhedkar *et al.* 1997; Hawkes and Santhya 2001; Kaushalendra *et al.* 1998; Nag 1996). Three per cent of Indians use condoms for contraception, with the majority of women having sterilisation or using oral contraception (Agoramoorthy and Hsu 2006). These authors report that over 70 per cent of the men who regularly had sex with prostitutes continued to have sex with their spouses without condoms even when they had an active STDs.

There is a recent and growing body of evidence relating to premarital and extramarital sex among men and women in India (Jejeebhoy 1998; Ramasubban 1990, 1995; Shaikh 2004; Sharma 2001a). Studies, mainly among urban students, are beginning to show that premarital sex is common (Hawkes and Santhya 2001; Rangaiyan and Verma 2001; Selvan *et al.* 2001). Research among high-risk subgroups such as long distance lorry drivers and people attending STD clinics reports levels of pre-marital sex in the range of 81-98% of the men (Hawkes and Santhya 2001; Nag 1996; Rao *et al.* 1994). Work by Pelto *et al.* (2000) shows how Indian men often go in peer groups to visit CSWs. The pre-marital sexual partners of men are often older, married, women (Jejeebhoy 1998; Nag 1996), along with CSWs, friends, relatives and future spouses (Abraham *et al.* 2000). Studies relating to pre- and extra-marital sex among women are much less common, and authors agree that levels of extra-marital sex for women are probably underreported because of the sensitivity of the topic (and the associated social sanctions) (Hawkes and Santhya 2001; Srikanth *et al.* 1997). Current attitudes to sex outside marriage appear to be more permissive in certain sectors of society (for example among secondary school students (Selvan *et al.* 2001). Bhattacharjee and colleagues (2000) report that heterosexual acts with person other than the legal spouse to be 15% among an urban

community of secondary school teachers in India. Some authors argue that increased exposure to global sexual behaviour patterns through media and sexually explicit Indian films and TV programs could also be resulting in higher levels of pre-marital sex (Nag 1996; SifyNews 2002).

In-depth interviews and focus groups among men and women in two Chennai slums examine how gender-based violence reduces women's ability to protect themselves from HIV/AIDS (Vivian *et al.* 2003). Community gender norms sanction domestic violence that interferes with adopting HIV prevention behaviours. Given the choice between the immediate threat of violence and the relatively hypothetical spectre of HIV, women often resign themselves to sexual demands that may increase their risk of HIV. The authors conclude that AIDS-prevention interventions must incorporate gender-related social contexts in settings where husbands strictly enforce their locus of control.

Homosexual activities are still publicly unacceptable in India, making it a difficult topic to study. Data on sexual behaviour among men who have sex with men are not readily available in India (Dandona, L *et al.* 2006), and very few men in India openly express an identity based on their sexual preference and call themselves 'gay' (Pradeep 2002). This does not mean there are not many (Safren *et al.* 2006), and it has been hypothesised that social restrictions on interaction between men and women are associated with homosexuality (Hawkes and Santhya 2001; Nag 1996). *Hijra* in India are another group representing homosexual practices. Hernandez and colleagues (2006) describe the sexual behaviours of men attending STD clinics in Mumbai, where 13% also reported having sex with other men and 13% reported sex with *Hijras*.

Studies have shown that CSW's and truck drivers represent high-risk groups for HIV transmission in India (Jana *et al.* 2002; Jana *et al.* 1994; Rao *et al.* 1993; Rao *et al.* 1994; Shanmuganandan *et al.* 1996). Jana and colleagues (2002) highlight CSW's lack of power to gain control over their sexual practices. O'Neil and colleagues

(2004) conducted two ethnographic studies with CSWs in rural areas of Karnataka and Rajasthan, and argue that in the context of an expanding HIV/AIDS epidemic in rural areas of India, understanding the socio-economic, cultural, historical and structural factors that operate to perpetuate female sex work as a culturally "sanctioned" occupation is critical if interventions intended to reduce the risk of HIV transmission are to succeed.

Systematic data on HIV prevention programmes for female sex workers (FSWs) in India are not readily available to understand program functioning and guide efficient use of resources (Dandona *et al.* 2004). A study of non-brothel based sex workers (the majority of CSWs in southern India) in Andhra Pradesh reports low levels of consistent condom use and extensive discrimination against CSWs, not least because of an unfavourable legal environment (Dandona *et al.* (2005b), and because participation in CSW is strongly associated with low levels of literacy, social status and economic opportunities (Dandona, R. *et al.* 2006). There have been very recent initiatives to target CSWs and reduce the risk of infection, for example, the India AIDS Initiative (Avahan) prevention programme funded by the Bill and Melinda Gates Foundation (Williams *et al.* 2006). Their evaluation of FSW-targeted STD management and treatment, including periodic presumptive treatment (PPT), and condom use in Karnataka concluded that if all components of the intervention reach target coverage of CSWs it could prevent 22-35% of all new HIV infections over 5 years in low prevalence settings, and half as effective in high prevalence settings.

It is extremely important to understand the sexual behaviours of PLWHA but it has been under researched. For a long time, the sexual behaviour of PLWHA did not receive any serious attention for a variety of reasons. The following section reviews literature specific to PLWHA.

## 2.4 PLWHA and sexual behaviour

Schiltz and Sandfort (2000) suggest that diagnosis of HIV-infection implies a death sentence, meaning that the sex life of those infected seemed a secondary issue, and making prevention focused on sexual behaviour hard to imagine. Furthermore, the avoidance of stigmatisation precluded an interest in the sexual behaviour of PLWHA. There are PLWHA (including those with unknown sero-status) who engage in unprotected sex, just as there are HIV-negative people who engage in unprotected sex. For sero-positive people, sex also involves dilemmas over disclosing their sero-status to potential sex partners, and their motivation to protect their partners as well as themselves against sur-infection and STDs. Research shows that infection with HIV has a range of impacts on an individual's sexuality. Schiltz and Sandfort (2000) suggest that having to cope with a serious disease induces negative mood states (particularly depression) and may compromise sexual functioning. Comprehensive prevention aimed at HIV infected persons should address these various issues and should be an integrated part of general HIV-prevention, and the reduction of high-risk sexual behaviour among HIV-infected individuals is a growing aspect of prevention strategies. Rawlings *et al.* (2006) conducted a qualitative study of 279 HIV-positive adults receiving services at a community health centre in Texas, and showed a need for clinicians to more precisely ascertain sexual perceptions and risks. A study of PLWHA in care in the US examined the relative importance and interactive effects of partnership characteristics in unprotected intercourse (Niccolai *et al.* 2006). Of all the demographic, health status, risk history and behaviours and partnership covariates explored, only partnership covariates were significantly associated with unprotected intercourse. The greatest likelihood of unprotected intercourse was identified in two groups of individuals: those in steady relationships with HIV-positive partners; and, MSM in relationships with partners of unknown *sero*-status. Niccolai and colleagues therefore recommend that prevention interventions for PLWHA should focus on partnership characteristics.



Kerrigan and colleagues (2006) conducted a qualitative study to explore the influence of HIV treatment optimism on the sexual behaviour of PLWHA receiving highly active anti-retroviral therapy (HAART) at public health clinics in Rio de Janeiro, Brazil. They found that the availability of HAART was conceptualized as a rationale for unsafe sex among a minority of study participants and that this was more common among men than among women. The respondents exhibited fear and/or anxiety regarding behaviours such as disclosure and condom use as a result of the unexplored conflict between implementing these behaviours and continuing with their strategies for social validation within the context of their sexual relationships. These authors conclude that short-term information, education and communication interventions surrounding treatment optimism, disclosure and condom use would be appropriate and necessary; but that they are not sufficient to address the core challenges to unsafe sex among PLWHA. They recommend longer-term individual and group-level opportunities for exploration and critical reflection regarding sense of self and its relationship to social solidarity among PLWHA.

HIV/AIDS researchers in Europe have applied the notion of "social representations" to health beliefs and actions, resulting in research that places PLWHAs' actual subjective experiences of illness the centrepiece of attention for social scientists' investigations (Bajos and Marquet 2000). By focusing on an individual's insider accounts of what it is to be exposed to HIV transmission or to be sick, these lines of research have gone deeper in analysing the effects of social vulnerability, including the major ones associated with illness, identity and people's practical strategies for managing health risks, symptoms or relationships with the health care system (Radley and Billig 1996).

Studies related to PLWHA in India are rare and the few that exist have mainly focused on prevalence and clinical trials (Gupta *et al.* 2006; Gupta and Klasse 2006; Kar *et al.* 2001; Mehendale *et al.* 2006; Mehta *et al.* 2006). For example, Silverman and colleagues (2006) examined prevalence and predictors of HIV infection among

sex-trafficked women and girls rescued from brothels in Mumbai, and reported that 22.9% of trafficked individuals tested positive for HIV, with a positive association between duration in brothels and HIV infection. Rabori *et al.* (2005) found that high-risk sexual behaviour (for example, sex outside marriage without use of condoms) continued among HIV positive people in north India. The majority of studies have tended to focus on issues of discrimination (Sudha *et al.* 2005). Reidpath and colleagues (2005) report on a six-country study of institutionalised forms of HIV/AIDS-related discrimination in the Asia-Pacific region including India, and show that discrimination forms a barrier to disease prevention and treatment. Elamon (2005) uses a combination of legislative policy analysis and key informant interviews to map the forms of structural discrimination that inform the lives of PLWHA in India. His findings indicate that a lack of clearly enunciated and enforced legislation (which is in some instances clearly discriminatory), coupled with an absence of written internal policy, has left room for selective interpretation. This in turn has created opportunities for discriminatory behaviours to be perpetuated against PLWHA.

This section suggests the need for a broader understanding of PLWHA, which would add to the knowledge required for HIV prevention strategies. The studies listed are among the very few that exists about PLWHA. This suggests there are major gaps in knowledge of PLWHA and their behaviours. This thesis based on data from HIV positive people therefore provides valuable resource to understand PLWHA in India.

## 2.5 Summary

The literature examined in this chapter suggests that KABP, when modelled in a way that had relevance to the regional socio-cultural context can impact behaviour change for HIV prevention. There is a dearth of multi-disciplinary research to understand the socio-economic and demographic context of HIV/AIDS in India. Secondary data that

existed from large-scale secondary surveys was limited in scope. Such surveys are constantly improving and more studies are becoming available in recent years. However, data about PLWHA in India is still rare and our research contributes to the body of knowledge in this context.

# Chapter 3      TRENDS IN HIV/AIDS IN INDIA, EVOLUTION OF POLICY RESPONSE AND RESEARCH BACKGROUND

In this chapter we provide the context setting for the study. Firstly, we portray HIV/AIDS trends in India with particular reference to the two south Indian states, Tamil Nadu (TN) and Andhra Pradesh (AP). Secondly, we outline the policy and programme response by national and international organisations involved in combating the epidemic. Thirdly, we introduce the study sites, Government Hospital for Thoracic Medicine (GHTM) and Christian Medical College and Hospital (CMC) and describe the history of HIV/AIDS treatment at these two hospitals.

## 3.1      The Impact of HIV/AIDS in India

The diversity of recorded HIV prevalence in India is in keeping with its heterogeneity. The detection of infection itself was almost a decade behind the rest of the world. The first HIV case detected was that of a female commercial sex worker from Chennai (formerly Madras) in February 1986 who was tested at CMC, Vellore in Tamil Nadu (John *et al.* 1987; Simoes *et al.* 1987; Simoes *et al.* 1993).

The first HIV infection derived from blood transfusion was diagnosed in July 1987 (John *et al.* 1989). The donor reported that his last sexual contact with a CSW had been in 1984, which suggests that HIV might have been present in India by early 1980s (Jain *et al.* 1994a; John and Babu 1995; Nag 1996). A homosexual was identified by Indian Council of Medical Research (ICMR) surveillance system by 1987 and peri-natal transmission of HIV was also documented around that time. HIV-infected intravenous drug users (IVDUs) were found in Manipur State in 1989 (Pavri 1990). In 1990, the first case of HIV-2 infection was identified in Mumbai (Rubsamen-Waigmann *et al.* 1991). Other cases of HIV-2 infection were detected in Chennai and Visakhapatnam (in AP) at around the same time (Babu *et al.* 1993). The first case of clinical AIDS in the country was reported in May 1986. The government of India had received reports of HIV and AIDS infection from all but two of the country's 32 states and union territories by 1994. A Chronology of the epidemic in India is presented in Appendix A1.

Sero-surveillance of HIV prevalence (absolute number of infected people in a population at a given time) and incidence (number of new infections which occur over a period of time) are important to monitor the epidemic and prevent its spread in so far as knowing they are sero-positive may enable people to reduce their risk of transmitting infection to others. However, given the data constraints (see section 4.3.3, 89), the exact size of the epidemic and the reliability of existing estimates in India remain questionable. It is possible that a vast majority of people infected with HIV are not even aware of it (McFarland *et al.* 2002). It is believed that India's socio-economic status, traditional social practices and cultural myths on sex and sexuality make HIV/AIDS one of the most serious public health problems. Due to poor hygiene and nutrition levels people from low socio-economic backgrounds are more susceptible to HIV infection. Poverty and existing levels of wealth inequality imply that some population sub-groups pursue livelihood strategies, which expose them to HIV (Barnett and Whiteside 2002).

The annual cost of HIV/AIDS in economic terms had been estimated at about 1% of the GDP of India (Anand *et al.* 1999). This study was based on an estimate of 4.5 million infected persons and did not include the costs pertaining to: use of Anti-Retroviral Therapy (ART); retraining of new workforce; communication activities; prevention of vertical transmission; and the intangible cost of pain and suffering to the patients and their families and could be an underestimate.

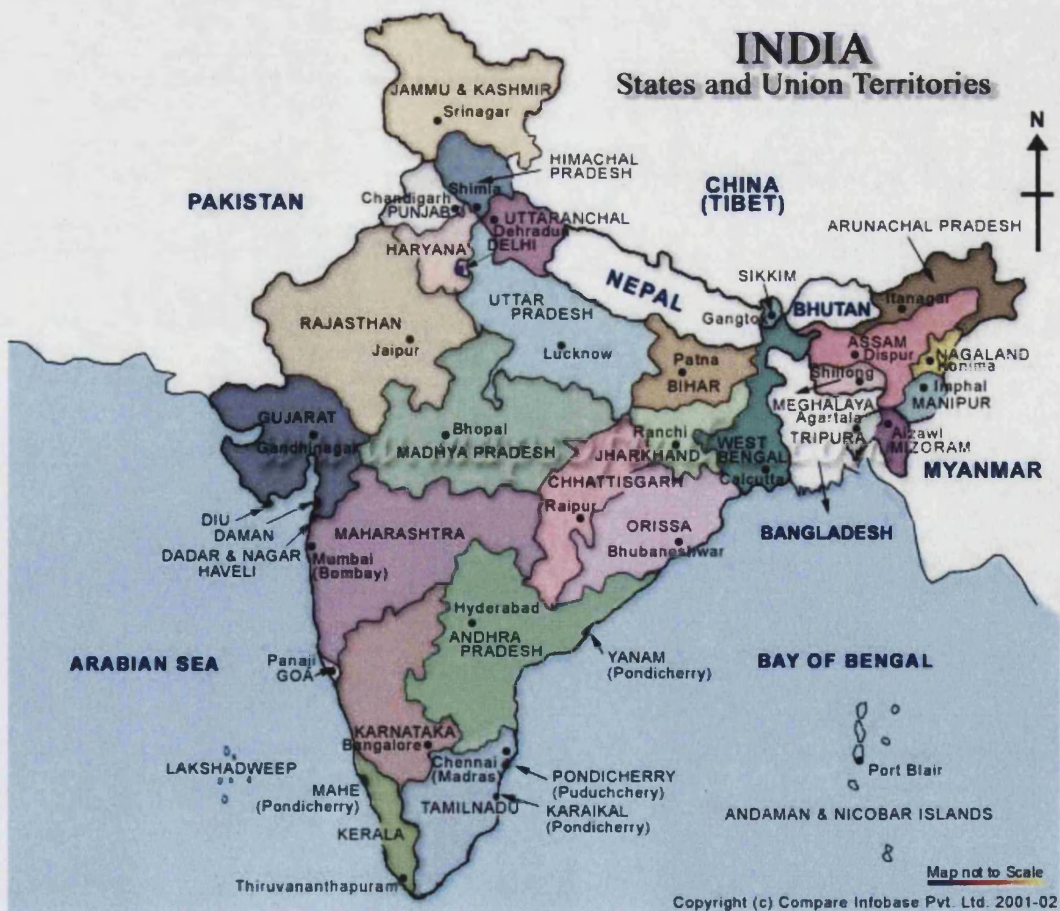
The exact number of years a HIV positive person survives differs according to the country they live in, access to anti-retroviral drugs and also the individual's immunity levels and socio economic status. It is understood that the people in developed countries could be AIDS free for 10-20 years or longer, while in sub-Saharan Africa, the progression is rapid (especially due to lack of access to anti-retroviral drugs) and sero-conversion to AIDS might range from 45 months to the same level as in industrialised countries (Anderson *et al.* 1991; Berer and Ray 1993; Garnett and Anderson 1993; Gregson 1996; Mann 1996; Mulder 1996). The impact of mortality due to HIV/AIDS in India has as yet not been studied adequately. The main handicap to study mortality is the difficulty of obtaining data for India or any state (Muthuswamy 2001). Stover (1999) established that only between 10-20% of deaths are reported in developing countries. Even the data that is obtained after some difficulty suffers from inadequacies and incompleteness. For example the mortality data was being collected at CMC and GHTM but they were incomplete and their statisticians needed training to collect the required information (section 3.3.1). Data available on cause of death does not register HIV/AIDS as a cause.

Primary impacts of AIDS are on demographic factors such as morbidity, mortality, fertility, rate of population growth and age structures. Areas such as sub-Saharan Africa with long-standing HIV epidemics face infertility of HIV positive women, increased under-five mortality, lowering of life expectancy, orphaning of large proportions of child population and severe shortages of labour (UNAIDS 2002, 2002<sup>a</sup>, Stanecki 2002, 2002<sup>a</sup>, Barnett *et. al.* 2001). Some evidence of increase in

mortality due to AIDS in India was presented in a study based on data from the Mumbai Municipality Corporation which showed small but significant increases in mortality between 1986 and 1994 among prime age adults (Elliot 1998) and more research into this will be useful.

The cultural attitudes and traditional social practices in India conflict with the preventive health message. For example, the spread of HIV/AIDS may be increased by the existence of *devadasi*'s (temple prostitutes), similar to that of commercial sex workers (CSWs); lorry drivers believe that they need to have sex with prostitutes to release the body heat caused by sitting at the wheel for long periods (Barnett and Whiteside 2002). Thus India has its own cultural and socio-economic needs, and data collected locally (such as this study) is essential to meet these needs and monitor preventive activities.

Fig. 3.1 Map of India



### 3.1.1 Status and Trends of HIV/AIDS in India

Asia has the second largest number of HIV cases among 60% of the world's population (Burton *et al.* 1995; Kumar 1999; Piot 2000). According to NACO report currently males account for 70% of AIDS cases in India (Tab. 3.1).

**Tab. 3.1 Reported HIV/AIDS cases 1986 – 2006, All India**

AIDS Cases	Cumulative
Males	88245
Females	36750
<b>Total</b>	<b>124995</b>

Source: [http://www.nacoonline.org/facts\\_reportaug.htm](http://www.nacoonline.org/facts_reportaug.htm), 16<sup>th</sup> April 2007

Trends of HIV/AIDS infections in India had also been mapped by the US Bureau of Census between 1986 to 1999 among high-risk groups and pregnant women showed that HIV prevalence had increased from 1% in 1987 to 63% in 1996 among CSWs in Mumbai (USBureauofCensus 2002). Sentinel Surveillance among IV drug users in Manipur state put infection rates at 80% in 1992 and remained at that level through 1997. Fig. 3.1 is a map of India and outlines the states in the country. HIV prevalence among STD patients in Mumbai rose from 1% in 1987 to 56% in 1999. The sero-prevalence of HIV among pregnant women ranged between 1-5% in Maharashtra, Tamil Nadu, AP and Karnataka.

HIV/AIDS in India had been reported from all states/union territories by 2000 and all of south India except Kerala indicated high prevalence; Gujarat, West Bengal and Nagaland indicated medium prevalence; Kerala and Delhi, which had exhibited low prevalence until 1999, also reported medium prevalence. The geographical variations in HIV prevalence across the country had been classified as follows:

**High Prevalence States:** includes states where infection exceeds 5% among high-risk groups and is between 1 - 3 % among antenatal women. The states are, Maharashtra, TN, Karnataka, AP, Manipur and Nagaland.

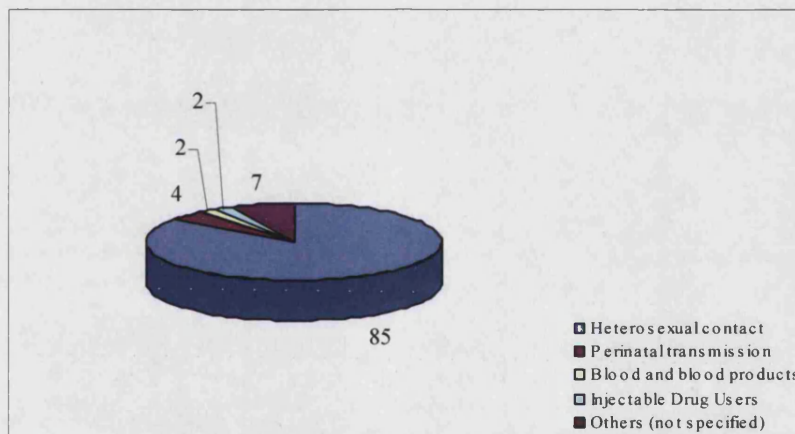


**Moderate prevalence States:** infection exceeds 5% among high-risk groups but is below 1% among antenatal women. These include Gujarat, Goa and Pondicherry.

**Low prevalence States:** includes all other states. In these states infection is reportedly less than 5% among high-risk groups and below 1% among antenatal women.

Existing research indicates that the predominant mode of HIV transmission in India is through heterosexual relations (85%), perinatal transmission accounts for 4%, followed by blood transfusion and blood product infusion (2%); IVDUs (2%); and the remaining 7% was unspecified (NACO 2006)(Fig. 3.2).

**Fig. 3.2 Modes of HIV Transmission, All India, 2006**



**Source: NACO 2006**

Biannual updates on global HIV/AIDS epidemic are produced by UNAIDS and WHO, the US Bureau of Census assimilates HIV/AIDS surveillance data base country wise. The UNAIDS/WHO (2002) estimates among selected sub-groups are given in Tab. 3.2 and is the most up-to-date available in this format. These estimates were indicative of the diversity of prevalence even among high-risk groups. The estimate for injecting drug users was dated back to 1996, which is indicative of problems with up-to-date data assimilation in India.

**Tab. 3.2 HIV prevalence (%) in selected populations in India**

Selected Populations	Median	Minimum	Maximum
Women in antenatal clinics, outside urban, 2000	2.0	0.0	3.3
Women in antenatal clinics, urban, 1999	2.0	1.0	3.9
Male STI patients, urban, 1999	3.6	0.8	64.4
Female sex workers, urban, 1998	5.3	5.3	5.3
Injecting drug users, urban, 1996	3.5	3.5	3.5

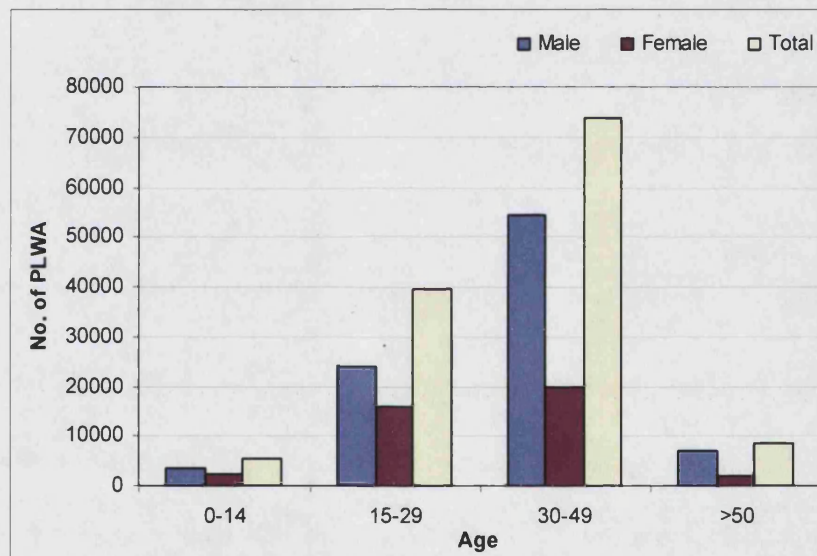
Source: UNAIDS/WHO Table of country-specific HIV/AIDS estimates end 2001

In the second decade of experience with HIV in India the epidemic has reportedly spread from high-risk to bridge population (clients of sex workers, STD patients and partners of drug users) and subsequently to the general population (John and Nisha Bhushan 1993; UNAIDS 2001). This is similar to the early pattern evinced in Africa, where the initial level of infection was high among high-risk groups and subsequently spread to the general population (Pais 1996). Studies in India showed truck drivers to be a high-risk group, with over 80% of them being clients of sex workers and/or having multiple partners. They then transmitted the infection to their wives (Ahmed 1992; IDF 1997; Singh and Malaviya 1994a). Other studies indicated transmission of the infection from husbands to wives of Intravenous Drug Users (IVDUs) (Panda *et al.* 2000).

Men still have higher prevalence compared to women but the epidemic continues to spread increasingly among women resulting in an increase in vertical transmission and paediatric HIV (ICMR 1998; Khanna S.A and D.N Lanjewar 1993; Malhotra and P Seth 2000; NACO 2001a; Sen 1995). Estimates show that for every infected female there were 1.2 males in high prevalent states, 2 males in moderate prevalence states, and 3 males in low prevalence states. Current estimates show higher prevalence in rural areas (59%) compared to urban areas (41%) (NACO 2006). However, data is inadequate to be categorical about this.

HIV prevalence rate in young people (15-24) was estimated to be between 0.46% and 0.96% among females and between 0.22% and 0.46% among males (UNAIDS/WHO 2002a). Some studies reported a sero-prevalence of 13-14% HIV among female STD clinic patients who were not selling sex (Divekar and Gogate 2000; Gangakhedkar *et al.* 1997; Jain *et al.* 1994a; Mehendale and Shepherd 1996; Srikanth *et al.* 1997; Thakur 1998). Epidemiological analysis of full-blown AIDS cases indicates that the disease is mainly affecting people in their prime reproductive years. A majority of them (57%) were aged between 30-49 years and 89% of AIDS persons were 15-49 years old (Fig. 3.3).

**Fig. 3.3** Age distribution of PLWA by sex, All India, 2006



Source: NACO 2006. PLWA- People living with AIDS

### 3.1.2 *The Epidemic in Tamil Nadu and Andhra Pradesh*

Surveillance reports indicate a concentrated epidemic in most of South India. This region is economically dynamic and there is considerable and regular population movement between states. So it is not surprising that the spread of HIV is at broadly similar levels. 75% of all recorded AIDS cases in India were from the southern states (46% were recorded in TN and 21% were recorded in Maharashtra) (NACO 2003).

The data evidences that data recording of the epidemic in Tamil Nadu was most efficient rather than the actual prevalence, since Maharashtra with higher prevalence had recorded only a fifth of the reported cases.

Heterosexual transmission was the predominant mode even in the southern states. Surveillance data have revealed high HIV prevalence (1-2% among antenatal women and 10-30% among STD clinic attendees) (Tab. 3.3). HIV prevalence among IVDUs in south India was reported more recently (2002) in Mumbai (41%) and Chennai (25%) but these were concentrated at one site. High prevalence among IV-drug users was evident only in the north-eastern states of the country in Manipur (56% among IV drug users), Mizoram and Nagaland. HIV prevalence reported by men having sex with men (MSM) was still low in TN. AP had the highest prevalence (27%) based on STD clinics.

**Tab. 3.3 HIV prevalence rates among selected sub-groups, southern Indian states, 2003**

States/UT	STD patients		ANC		IVDU		MSM		CSW	
	n	%	n	%	n	%	n	%	n	%
Andhra Pradesh	4	26.6	9	1.5	n.a.		n.a.		n.a.	
Goa	2	15.0	2	0.5	n.a.		n.a.		1	50.8
Karnataka	7	16.4	10	1.1	1	2.0	n.a.		n.a.	
Kerala	3	6.4	3	0.1	n.a.		n.a.		n.a.	
Maharashtra&Mumbai	9	9.2	14	1.8	1	41.4	1	23.6	1	52.3
Pondicherry	3	2.0	1	0.3	n.a.		n.a.		n.a.	
Tamil Nadu	5	12.6	10	1.1	1	24.6	1	2.4	n.a.	

Source: (NACO 2003);

Note – n represents the number of sites; prevalence in the case of more than 3 sites are median values and with those less than 3 they are mean values

The generalised HIV epidemic in Andhra Pradesh (AP) was detected as late as 1999. It had the highest level of infection as a percentage of the general population (3.1% among urban males and 2.6% among urban females) followed by Maharashtra (2.5% among urban male and 2.1% among urban females), then by Tamil Nadu and Karnataka (Tab. 3.4).

**Tab. 3.4 HIV Estimates of prevalence rates in general population, south India, 1999**

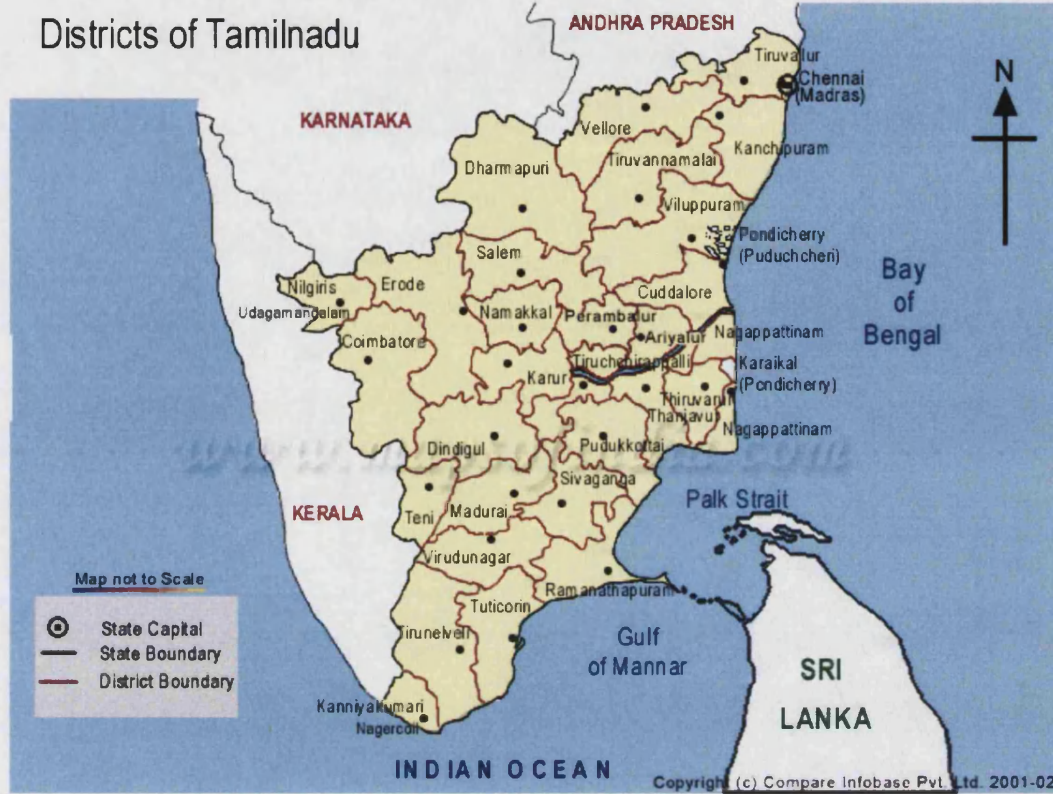
States/ Union Territories	<i>Male</i>				<i>Female</i>				F:M Ratio
	<i>Urban</i>		<i>Rural</i>		<i>Urban</i>		<i>Rural</i>		
	Total (‘000)	%	Total (‘000)	%	Total (‘000)	%	Total (‘000)	%	
Andaman&Nic	0.3	0.9	0.1	0.11	0.1	0.3	0.1	0.04	0.3
Andhra Pradesh	343.6	3.1	118.8	0.39	275.9	2.6	61.0	0.31	0.7
Goa	4.8	1.6	0.8	0.20	2.4	0.8	0.3	0.10	0.5
Karnataka	123.8	1.2	36.5	0.15	96.2	1.0	17.3	0.12	0.7
Kerala	11.9	0.3	5.5	0.04	4.1	0.1	1.2	0.01	0.3
Maharastra	447.1	2.5	88.7	0.32	327.3	2.1	45.9	0.25	0.7
Pondicherry	4.1	1.8	0.2	0.23	2.1	0.9	0.1	0.11	0.5
Tamil Nadu	131.1	1.2	33.8	0.15	107.9	1.0	18.2	0.12	0.8

Source: (NACO 1999)

### *Tamil Nadu*

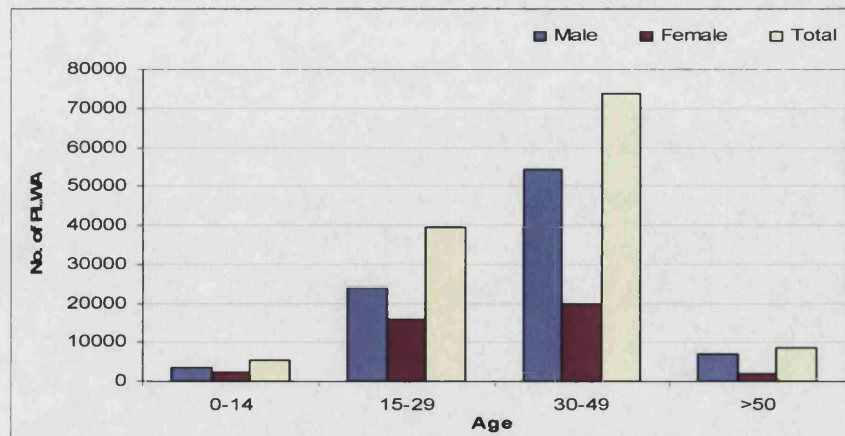
Since 1986 TN has been in the forefront with HIV/AIDS sero-surveillance (see Fig. 3.4 for map of TN). As of February 1999, 22% of total samples screened of HIV in India (3,437,118) were from Tamil Nadu (739,776). And HIV prevalence in Tamil Nadu was 17.8 per thousand (13,196 of those screened). According to NACO (2003), the high prevalence districts in TN were Madurai, Truchirapalli, Salem, Coimbatore, Namakkal, Tirunelveli, and Chennai. As in the case of all India, the predominant mode of transmission was through heterosexual behaviour (95%) (TNSACS 2003).

Fig. 3.4 Map of Tamil Nadu



Cumulative record of HIV/AIDS infections in TN as of end 2003 (NACO) showed a majority of women (46%) to be infected at younger ages (15-29) compared to men (65% were infected between 30-49 years) (Fig. 3.5).

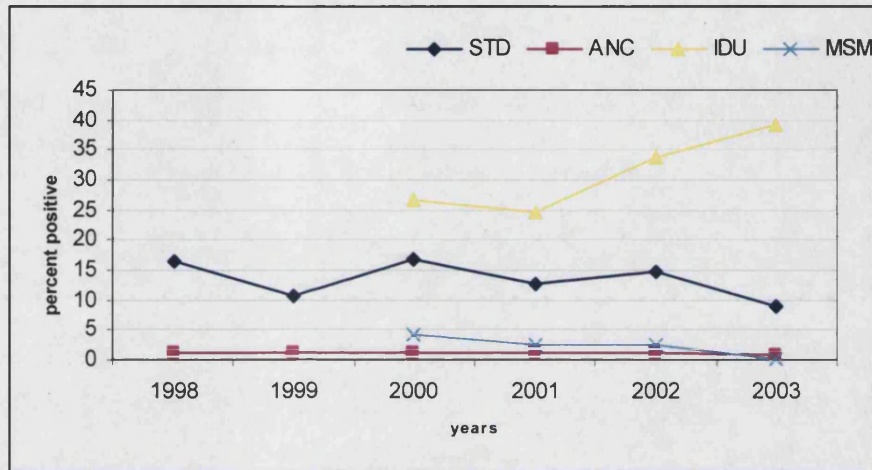
Fig. 3.5 Distribution of PLWA by age group, TN, 2003



Source: NACO 2003. PLWA – People living with AIDS

Fig. 3.6, from NACO report, and other studies suggest that HIV cases have been declining in Tamil Nadu in recent years (Kumar *et al.* 2006).

**Fig. 3.6 Trends in HIV prevalence TN, 1998-2003**

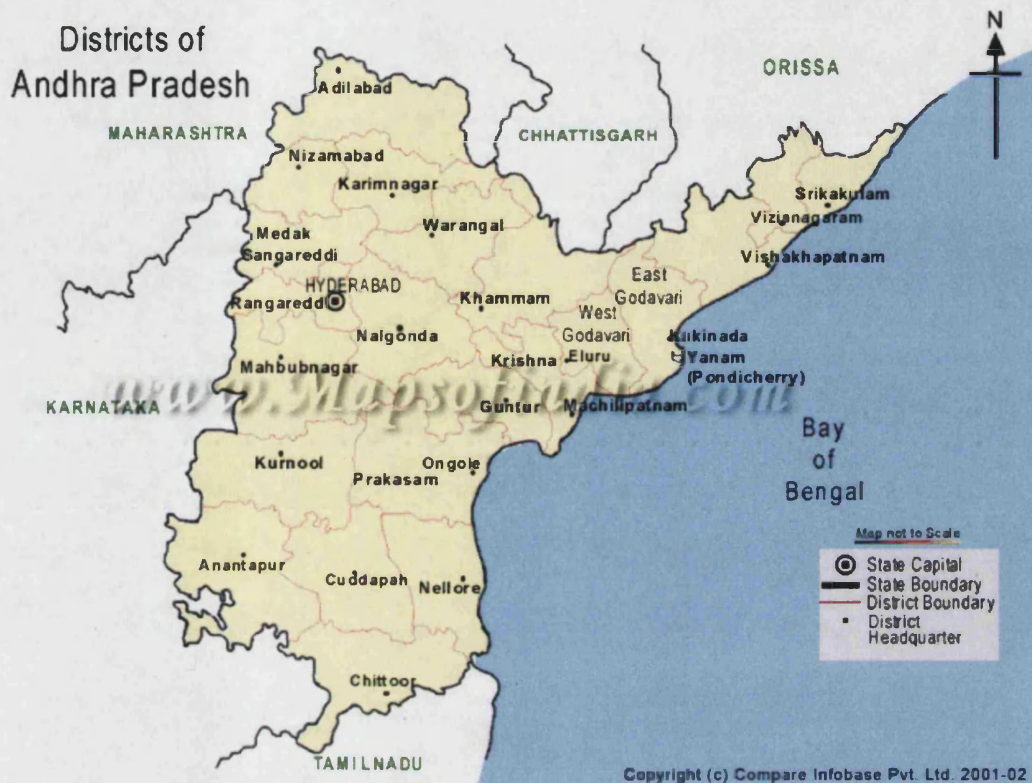


Source: [http://www.nacoonline.org/facts\\_overview.htm](http://www.nacoonline.org/facts_overview.htm), April 2006

STD- Sexually Transmitted Diseases, ANC- antenatal clinics, IDU-injecting drug users, MSM-men having sex with men

The social and cultural issues surrounding HIV/AIDS and associated stigma and discrimination are complex in India, so that it might be premature to engage

Fig. 3.7 Map of Andhra Pradesh



The generalised epidemic measured by HIV prevalence among women attending antenatal clinics in AP (1.5%) was lower than only two other states in the country; Maharashtra and Manipur (each with 1.8%) (Tab. 3.3). HIV prevalence among persons attending STD clinics in AP (26.6%) was the highest recorded among all states. In the absence of interventions, HIV prevalence was estimated to go up to 50% among persons attending STD clinics and 4% among women attending antenatal clinics in AP by 2004 (APAC 2001). However these are constrained by limitation of data and the reliability of these results is debatable.



## 3.2 Response to combating the epidemic and Evolution of Policy

### 3.2.1 *The response by International Organisations*

By the late 1980s, the hazard of HIV/AIDS in India was realised globally and this initiated the interest and support of international organisations such as World Health Organisation (WHO) and World Bank in developing HIV/AIDS prevention and control programs (NACO 2000; UNAIDS-India 2000). The joint United Nations Programme on HIV/AIDS (UNAIDS) and its seven UN co-sponsor agencies UNICEF, UNDP, UNFPA, UNESCO, WHO and the World Bank concentrated efforts to combat the epidemic and to prevent its escalation in India. Their input and support has contributed greatly toward making the national HIV/AIDS control programs to be judged the best among health programs implemented in the country (Lal and Thakur 1993). UNAIDS made important contributions to prevention and care in India through development, reinforcement and strengthening of national, state, and local capabilities to fund, design, plan, implement, co-ordinate, and monitor HIV/AIDS and STDs (Brenny 1998; UNAIDS 2002b).

Besides the UN system, DFID, the European Community, Canadian International Development Agency (CIDA), Swedish International Development Agency (SIDA), AusAIDS and Norwegian Agency for Development Cooperation (NORAD) have also been providing support (DFID-India 2004; NACO 2000). Several non-government organisations (NGOs) such as the Ford Foundation, Population Services International, the World Council of Churches and others have supported community-based initiatives for HIV and STD education, prevention, and care. Universities and research institutions, such as, John Hopkins University, London School of Hygiene and Tropical Medicine, and a number of others have provided extensive support to both development and training of personnel for HIV and STD related research and prevention. The combined external inputs to HIV and STD prevention and control efforts in India from these organizations since 1990 have surpassed US\$200 million

(NACO 2000). Bill and Melinda Gates foundation is increasingly investing in HIV/AIDS prevention programs in India (Sharma 2003). Also Bill Clinton through Clinton Foundation HIV/AIDS Initiative signed a memorandum with three Indian drug companies - CIPLA, Ranbaxy and Matrix Laboratories - on bringing down the cost of anti-retroviral (ARV) drugs (Bhushan 2003).

Multinational corporations and industrial concerns such as Levi Strauss, Aetna Insurance, United Distillers, and other international business concerns have also been interested in sharing their experiences in the development of workplace-based HIV and STD prevention programs, along with integrating such programs in the joint-venture activities being developed in India; and Private benevolent institutions and charitable trusts have provided support and encouragement for community-based projects which focus primarily on sensitive issues, ethical education and training of organisations and groups to help them respond to the HIV epidemic.

The well-meaning international organisations in supporting HIV/AIDS preventions programs in developing countries, such as India, do not always get it right from the beginning. They continuously have to go through a learning curve as new experiences provide new lessons in what works and what does not.

### *3.2.2 The National Response*

In 1986 the Indian Council of Medical Research (ICMR), in collaboration with CMC, began investigating HIV in south India. In the same year, the National AIDS Committee was established. This committee formulated a four-year National AIDS Control Program of increased surveillance together with health education messages. By early 1990's, the initial phase of denial had to give way to programs to control HIV/AIDS and the government had set up surveillance centres in 23 states and union territories by 1990. These centres were equipped with enzyme-linked immunosorbent assay (ELISA) testing equipment. Four referral centres were set up for Western blot

testing. About 128 blood banks were established in 68 cities and towns with facilities for HIV screening of blood donors (NACO 2000).

The first Five-Year Strategic Plan (Phase I – 1992-1997) was implemented when the National AIDS Control Organisation (NACO) was formed in 1992 under the Ministry of Health and Family Welfare, Government of India, to oversee AIDS prevention and control efforts and the National AIDS Research Institute (NARI), based in Pune, was created for conducting research on HIV/AIDS (NACO 1995).

Phase II (1999 – 2004) of the National AIDS Control Programme was effective from November 1999. The key objectives of phase II were to reduce the spread of infection and strengthen its capacity to respond to HIV/AIDS on a long-term basis (NACO 2000; Sharma 1999). A practical approach to the epidemic followed with projects comprising program management; IEC with awareness targets of not less than 90% among selected sub-populations; social mobilisation, surveillance, increased blood safety, condom promotion (achieve condom use of not less than 90% among high risk groups), clinical management, treatment, care and support. NACO (2002) also focused on the prevention of mother-to-child transmission and prevention of infection in health care workers, training of medical and health care professionals, and Voluntary Counselling and Testing (VCT).

The third round of a five year National AIDS Control program (NACP- III) was launched in India in April 2007 with a budget of \$2.6 billion with more than 80% of the funding coming from international donors including World Bank, UNAIDS and Gates Foundation. Two thirds of this budget has been allocated for prevention, one sixth for treatment and the remainder for management (Steinbrook 2007). The HIV/AIDS control strategy in India is focused on prevention efforts targeting high-risk groups such as commercial sex workers and 'bridge populations', for example lorry drivers. These central government efforts for tackling HIV face opposition from some state policies. For example, several states (example, Maharashtra, Gujarat and

Madhya Pradesh) have banned the introduction of sex education in schools following protests from legislators (Chadha 2007).

However prevention and control programs mainly focused on metropolitan cities and known epicentres of HIV infection, and resources were allocated according to the prioritisation of program areas. Although the programs included health education and information, they mostly consisted of developing, printing and distributing AIDS prevention material and related information (Dasgupta *et al.* 1994). The message to encounter least resistance, abstain (A) and be faithful (B) to one partner was delivered. Only intervention programs targeting commercial sex workers and lorry drivers attempted to promote the use of condoms (C). Thus the scope of 'abstain, be faithful, if indulging in unsafe sex use condoms' (ABC) efforts was limited (UNAIDS 2002). Although the reports seem optimistic, the reality of the situation is that the services are not only inadequate but also suffer from a lack of political will and socio-cultural structural barriers such as resistance to condom promotion and stigma toward commercial sex worker.

The development of anti-retroviral drugs is prolonging thousands of lives in wealthy countries, as well as among the wealthy minority in the less affluent world. However, in India the great majority of those who suspect that they might be HIV positive have little access to health services and are unlikely to be diagnosed or treated (NACO 2004). A majority of HIV positive people have no access to antiretroviral treatment and even drugs for opportunistic infections are inaccessible and unaffordable by a majority before they die of AIDS (McFarland *et al.* 2002). India had until recently resisted pressure from international bodies to provide AZT to PLWHA. It was as late as World AIDS Day 2003 when the Indian government announced the provision of free AZT through hospitals and antenatal clinics to HIV positive children, women and men who suffered from full-blown AIDS in the six most prevalent states (AIDS-INDIA 2003a, 2003b). The government is having difficulties in sustaining its commitment to provide antiretroviral therapies for HIV

to children and patients even in high prevalence states (AIDS-INDIA 2004b, 2004d). Low-cost combination therapies supplied by Indian companies for distribution to resource poor countries through Medicins Sans Frontiers, are not affordable by the Indian government itself for provision to its own PLWHA. We quote a reported situation by a doctor in Tamil Nadu, 'in 1997, our hospital started providing triple-drug therapy to those who can afford it. Since 1994, we've had more than 12,000 HIV/AIDS outpatient registrations and 2342 in-patients. Of these, only 72 patients have been able to afford to buy even generic drugs' (Gurusamy 2003). Hence the reality is that people lack access to ARV and other medical resources in India.

Additionally, given the large amount of funding for AIDS by international organisations some problems are to be expected. The lack of co-operation between government and NGOs has been criticised (Chatterjee and Sahgal 2002; Sethi 2002). AIDS prevention programmes in India have been criticised for being highly politically contested, resulting in ineffective and counter-productive use of international donor funds (Ramasubban 1998; TimesNewsNetwork 2004). It has also been observed that the bureaucracy and corruption accompanying donor funding further impedes the efficient progress of prevention programs (TimesofIndia 2003).

### 3.2.3 *State Responses*

We describe responses by TN and AP states to HIV/AIDS in this section. The TN experience of HIV/AIDS in India had been recognised as a successful model in a global context in its attempts to combat the infection (Ramasundaram 2001). TN is also listed among UNAIDS country claims of success in bringing down HIV risk in males through education programs resulting in halving of casual sex and increases in condom use with casual partners (UNAIDS 2001a). The TN model is considered cost effective and timely in implementation of its programmes in an Indian context (Ramasubban 1998).

### ***Tamil Nadu State AIDS Control Society (TNSACS)***

NACO operated centrally but devolved power to autonomous state AIDS control cells for efficient co-ordination and management of programs. Tamil Nadu (TN), Maharashtra and Kerala were the first to establish empowered committees and AIDS control cells at the state level in 1993 (UNAIDS-India 2000). Tamil Nadu AIDS cell was the first to be transformed into a Society in 1994 to enable greater autonomy for state AIDS cells (TNSACS 2002). Tamil Nadu State AIDS Control Society put together policies and programs for risk behaviour assessment, primary prevention and organisational and managerial reforms co-ordinated with NGOs and PLWHA. There was a large increase in funding from NACO to TNSACS in 1996, which resulted in an intensification of its programs in order to shift from awareness to intervention (90% of total funds) and care (10%).

Non-Government Organisations (NGOs) in India have played a key role in HIV/AIDS interventions, and government organisations channel their targeted programmes through NGOs (Hawkes and Santhya 2001). TNSACS collaborated closely with NGOs and provided them with financial assistance to implement its projects. With 338 NGOs involved in HIV prevention and intervention programmes in TN (of who 200 were supported by TNSACS), the state had the highest NGO participation in the country. AIDS Research Foundation of India; YRG Care; PRAKRITI; Media Foundation; Indian Network of People living with HIV/AIDS; DESH and Reaching the Unreached Trust are some of the major NGOs contributing significantly to the prevention of HIV/AIDS in TN (TNSACS 2002). The AIDS Prevention and Control Project (APAC), established in Chennai in 1995, via a tripartite agreement between the Government of India, United States Agency for International Development (USAID), and Voluntary Health Services (VHS) aims to build the capacity of NGOs to ensure quality intervention programs; increase awareness of STD/HIV/AIDS preventive measures; conduct behavioural and epidemiological research, and encourage modifications in program direction for

Government and voluntary agencies. APAC has also been responsible for conducting Behaviour Surveillance Surveys (BSS) in TN with support from USAID.

Two special projects supported by TNSACS are GHTM in Tambaram offering hospice type care for HIV/AIDS patients, and the Community Health Education Society (CHES) in Chennai providing care, particularly to women living with HIV/AIDS. Also called the Ashram, CHES started as a home for AIDS orphans and has become a refuge for women including CSWs, many of who have left the sex trade and work as care-givers for the orphans at this home (TNSACS 2002).

### ***Indigenous Treatments***

India has a variety of systems of medical practice and it is common for people with symptoms of sexually transmitted diseases including HIV/AIDS to seek treatment from indigenous practitioners (Hawkes and Santhya 2001). In 1993 TNSACS set up an AIDS Research Unit at GHTM to investigate the utility of siddah, an indigenous Tamil system of medicine. By January 2003, GHTM had administered 35,000 patients with siddah drugs together with opportunistic infection controlling drugs (no antiretroviral) and reportedly demonstrated a decrease in viral load and increase in CD4 and CD8 cell counts besides symptoms control and increase in body weight (GHTM 2003; Paramesh 2001). Approximately twenty other siddah drugs and the Ice Bucket method, and the benefits of yoga for the well being of HIV patients were also being examined. However, the researcher observed that these indigenous treatments were administered in combination with opportunistic infection (OI) controlling drugs and data might not substantiate such conclusions.

Independent indigenous medicine practitioners also offer “cures”, none of which have been properly tested or researched. Such claims were misleading and a cause of confusion and further distress among PLWHA (Kattumuri 2003). The researcher met HIV positive people at GHTM and CMC who had tried such ‘cures’ who said that

after an initial feeling of well being, they got worse and had to return to the hospital for treatment having exhausted their savings.

### ***Andhra Pradesh State AIDS Control Society (APSACS)***

Andhra Pradesh (AP) was defined as a state with a concentrated epidemic (HIV prevalence of more than 1% among women attending antenatal clinics) as late as 1998 (NACO 1999). By end of 2002 AP had recorded 30% HIV prevalence among STD clinic attendees and over 2% in antenatal clinics. High prevalence was detected in nine (mainly in the south and east of the state) of its 23 districts.

AP had the advantage of learning from the experience of other states, particularly neighbouring TN and modelled its programmes accordingly. Then Chief Minister of AP, Mr Chandrababu Naidu, had expressed strong political commitment to HIV/AIDS prevention. For example, he was the first politician in India to publicly display a large condom to confront reservations about using condoms (AIDS-INDIA 2002). In the words of Mr Chandramouli, first director of APSACS (25<sup>th</sup> September 2001),

"AP state initiated an intensive programme based on TN's experience. Accelerated awareness programmes have been initiated in the state through television, radio, and folk arts. The National Service Scheme is involved in creating awareness in schools and colleges. We hold a two-day program in colleges, which is attended by 70% of pupils. We have opened at least one VCT centre in each of the 23 districts, which are attended by 15-20 people every day. We found about 60% prevalence rate among high-risk groups. Each centre is equipped with two counsellors. We also have information centres and provide toll free telephone counselling, in September 2001 alone we had 1097 calls. The state has initiated 114 targeted interventions, which is the highest for any state (Maharashtra has 47 and TN 73). We support several NGOs who are involved in counselling programs. We take the help of religious leaders, which helps reduce stigma associated with the disease. Since AP has a popular cinema culture, we take the help of interested movie stars to advertise awareness programs through television".



However, Chandramouli also stated that stigma and discrimination were a problem and that well known film stars were afraid to participate in media campaigns. While Chandramouli's report sounded enthusiastic and optimistic, AP was in its early stages of interventions and the described efforts were concentrated mainly in Hyderabad, the capital of AP. The initiatives were mostly being adopted from the TN model and had not been monitored or evaluated for their implementation or effectiveness in AP where the needs might be different.

### *3.2.4 Response by the Indian Corporate Sector*

NACO promotes inter-sectoral collaboration with private, public and voluntary sectors (NACO 2002). Some corporate sector organisations in collaboration with NACO have incorporated HIV/AIDS education and information into their ongoing health care and family welfare programs (NACO 2000). 'AIDS and the Workplace' advocacy and IEC package was developed by Confederation of India Industry (CII) with support from WHO/UNAIDS/USAID for promotion of industry action of HIV/AIDS prevention policies (UNAIDS-India 2003). The Trucking Corporation of India (TCI) actively participates in a national network of NGO service providers of HIV/STD interventions for truck drivers. Tata Iron and Steel Corporation is involved in HIV prevention and care programmes including media promotion, installation of condom vending machines, work with NGOs, training and awareness programs at Tata's Main Hospital through counselling and help-lines (AIDS-INDIA 2003b).

The involvement of the corporate sector is essential and the efforts of CII, Tata and TCI are important. These efforts alone are inadequate and much greater involvement by the corporate is essential. Further, all interventions would be handicapped by stigma and discrimination at the work place, which requires to be addressed.

### 3.3 Study of HIV/AIDS patients at Two Hospitals

This section provides background information on the study sites. In 1999 there were two hospitals that were exceptional in terms of HIV/AIDS care in Tamil Nadu - the Government Hospital for Thoracic Medicine (GHTM) and Christian Medical College and Hospital (CMC). These two hospitals comprised the fieldwork sites for this sample survey.

#### 3.3.1 *History of HIV/AIDS treatment at GHTM and CMC*

The data below had been collated by the researcher from rough, poorly maintained and incomplete hospital records. Both GHTM and CMC were themselves just beginning to collate their records, since in the past they had not considered it important and are resource constrained for trained personnel to maintain detailed records of HIV positive patients. The data from early 1990's were insufficient and incomplete and any estimation based on such data would be unrepresentative. The quality of record keeping was deficient during the time of the researcher's survey of PLWHA in 1999. In presenting some of the data below, the attempt is to provide indicative rather than exhaustive evidence.

#### ***Government Hospital for Thoracic Medicine (GHTM)***

GHTM is located in a suburb of Chennai. It was founded by Dr. *Muthu* based on experience gained in the treatment of tuberculosis (TB) at Mendip Hills Sanatorium near London (GHTM 2003). Dr *Muthu* purchased 250 acres in 1928, and started a TB Sanatorium with 12 beds (see also Rajalakshmi 1998). The foot of *Pachamalai* (i.e. 'green hill' in Tamil) was chosen since its atmosphere was deemed to be conducive to the recovery of TB patients. However, Dr. *Muthu's* English wife could not survive the heat of Madras so they sold the hospital to government of TN (then Madras Presidency) in March 1937 and returned to England.

By 1952-53 the government had upgraded the hospital to accommodate 700 beds for TB patients. Until 1970 it only accommodated in-patients. Thereafter, further advancements in medicine made it possible to provide treatment to outpatients too. The authorities felt TB was on the decline in the early 80s and decided to extend the scope of the hospital and named it Government Hospital for Thoracic Medicine (GHTM) in late 1980s. There had been an upsurge of TB cases since the '90s and had more than tripled in eight years, which might be indicative of HIV-TB co-infection. In 1992 GHTM took 10306 inpatients and treated a total of 120811 patients (Tab. 3.5). It had a death rate of 3.2% in that year (i.e. the number of inpatient deaths as a proportion of the total number of inpatients). By 1999 it accommodated a total of 27916 inpatients, treated 456376 outpatients. The death rate declined to 1.5% in 1995 but rose again to 1.7% in 1999 mainly due to AIDS as reported.

**Tab. 3.5 Trends in HIV+ patient treatments and Death Rates at GHTM, 1992 - 2000**

Description	1992	1993	1994	1995	1996	1997	1998	1999	2000
Outpatients	120811	176222	276645	303376	375504	360052	407152	456376	443254
Inpatients	10306	15831	18225	21056	21996	23147	24715	27916	27215
Avg. length of stay	27	24	22	18	16	17	15	13	13
Deaths in Hosp.	327	304	326	308	361	397	447	475	481
Death Rate%	3.2	1.9	1.8	1.5	1.6	1.7	1.8	1.7	1.8

**Source: GHTM Hospital records**

The first blood sample that tested HIV positive, in 1986, was sent from Madras Medical College Hospital (MMC). As more samples tested positive for HIV, the microbiology department at MMC began to accommodate HIV patients in its wards for treatment. However, fear and stigma associated with HIV, both among other patients and doctors, necessitated moving HIV/AIDS patients to a smaller, but more specialised hospital such as GHTM. GHTM provided an appropriate environment and the hospital was extended as a HIV care and training centre in 1993, under the guidance of Dr. C. N. Deivanayagam. Indeed, GHTM accommodated the largest number of HIV inpatients (approximately 300 patients at any given time), allocated

to eight special wards (three for women and five for men). It continues to be the largest AIDS care centre in India (Steinbrook 2007).

Increasing numbers of HIV positive inpatients have been recorded at GHTM since 1993 (Tab. 3.6), partly attributable to increased reporting and testing as awareness of HIV increased. The sex ratio of HIV+ inpatients increased from 0.6 in 1998 to 4.9 by 2003. Records relating to children were incomplete and inadequate for study. Most recent HIV statistics from GHTM (2006) show that new HIV cases being reported have fallen from 14969 cases in 2004 to 10126 cases in 2006.

Facilities for HIV positive inpatients are getting better but are still inadequate. For example, during this study, HIV wards were always filled to 150% capacity (40 bed wards had at least 60 patients in them with the extra patients lying on straw mats on the floor between beds).

**Tab. 3.6 Cummulative number of HIV/AIDS inpatients treated at GHTM, 1993-98**

Year	Male	Female	M:F Ratio	Children	Total (M+F)	Cum. Tot.
1993	2	3	0.6	0	5	5
1994	31	8	3.9	0	39	44
1995	69	20	3.5	0	89	133
1996	278	87	3.2	0	365	498
1997	813	181	4.5	11	1005	1503
1998	1882	388	4.9	42	2302	3805

**Source: GHTM hospital records**

In a country with virtually no social support system, hospitals and families have to provide all the necessary support. The family members (occasionally friends) were the primary carers since GHTM was overburdened and hospital staff could only provide medical advice and attention. CSWs, destitutes, widows and HIV orphans were given vocational training and rehabilitated with help from old age homes and orphanages run by NGOs (including Missionaries of Charity, Relief Foundation and World Vision of India).

### ***Christian Medical College and Hospital (CMC)***

CMC at Vellore had an interesting beginning. As a young girl Ida Sophia Scudder was visiting her missionary parents in south India. One night she was asked to help three women struggling with difficult childbirth. Custom prevented the husbands allowing any male doctor, even Ida Scudder's medical missionary father, to help their wives. Ida Scudder was without training at that time and could not help. The next morning she was shocked to learn that all three women had died. She took this as a calling and embarked upon a ministry to meet the health needs of people in India and went to Cornell University Medical College, among its first group of women. Dr. Ida Scudder returned and started CMC as a one-bed clinic in her parents' home at Vellore in 1900.

Today CMC is recognised among the premier medical institutions in Asia (CMC 2003). The emphasis on research, technical competence and a focus on being relevant to the needs of the regional environment have enabled it to provide advanced medical care. Among its collaborators are NACO, ICMR, Ministry of Health and Family Welfare; CMC also has ongoing projects with international organisations such as Rockefeller Foundation, Ford Foundation, WHO, Yale, USAID, National Institute of Health (USA), European Union, British Heart Foundation, PFIZER, University of North Carolina and University of Southampton.

The National AIDS Reference and Surveillance Centre was established at CMC in 1986, and CMC has been in the forefront of HIV/AIDS treatment and research since February 1986 when Dr T Jacob John tested the first positive sample in India. The hospital was equipped to conduct Rapid test, ELISA and Western blot tests (Rajesh 1999). Patients were charged INR 140 (£2) for ELISA and INR 1400 (£20) for Western blot. Approximately 3500 samples a month had been sent for analysis since 1997 of which approximately 80% turned out to be HIV positive. To support the need for training doctors particularly in the care of PLWHA, under a new initiative

CMC was conducting HIV/AIDS training courses for hospital-based physicians in collaboration with the Population Council (CMC 2002).

In order to avoid discrimination, the hospital did not have a separate department for HIV/AIDS patients. Instead patients were referred from various departments, chiefly from the departments of medicine, dermatology and obstetrics and gynaecology, to the HIV clinic conducted twice a week, which was started in 1988 under the auspices of Medicine Unit-I. All patients attending antenatal clinics were automatically recommended for HIV/AIDS testing. The HIV clinic offered psychosocial support to patients as well as treatment for any sexually transmitted diseases. It also diagnosed and treated opportunistic infections in AIDS patients and provided retroviral therapy for patients who could afford it. Seventy seven percent of the hospital's beds were in general wards, where the cost was subsidised. The remaining patients were housed in private wards.

CMC's reputation, together with its location in Vellore on the northern border of TN, attracted many patients from AP. Vellore is a satellite town of Chennai and is an important commercial centre, connecting with north-eastern TN. High quality care was provided by CMC at a subsidised cost, made possible through fund raising efforts. Up to 15% of all in-patients were treated completely free of charge and many others were granted significant cost reductions. A daily outpatient clinic was held in Vellore town where the majority of attendees were from disadvantaged groups. From the beginning, CMC had provided counselling services to those who tested positive. However, doctors themselves admitted, in conversation that, demand for counselling was far greater than what was being provided.

CMC records showed an increasing trend of HIV/AIDS patients (Tab. 3.7). Fluctuations in numbers might be explained in part by errors in recording and delays in updating computer records. On the contrary, a doctor at the HIV clinic stated that HIV cases had been decreasing (20<sup>th</sup> September 2001): 'The number of HIV patients coming to the hospital has gone down'. It might be that other hospitals such as

GHTM were becoming more widely popular, (as they provided free treatment or were locally available), and some patients might be able to get affordable treatment from private doctors within proximity. 'We went to CMC but could not afford to pay for treatment and hence we came here' was mentioned by atleast 5% of patients interviewed at GHTM (April 1999).

**Tab. 3.7 Cummulative Number of HIV/AIDS patients treated at CMC, 1990-2000**

Year	Inpatients			Outpatients				
	Male	Female	M:F Ratio	Children <15yrs	Total	Cum. Tot.	Total	Cum. Total
1990	12	5	2.4		17	17		
1991	25	7	3.6	1	33	50		
1992	39	12	3.3	1	52	102		
1993	51	12	4.3	3	66	168		
1994	84	12	7.0		96	264		
1995	95	16	5.9	3	114	378		
1996	222	48	4.6	16	286	664	949	949
1997	181	67	2.7	9	257	921	1018	1967
1998	261	92	2.8	19	372	1293	1035	3002
1999	239	77	3.1	16	332	1625	1111	4113
2000							1268	5381

Source: CMC Hospital Records, 2001

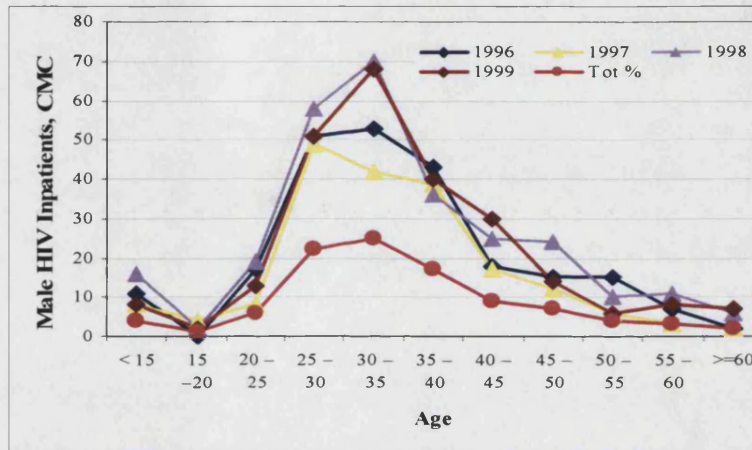
The male to female ratio of HIV patients was very high in the mid-1990's but it subsequently declined to approximately three males for every female, which could be indicative of the narrowing of gap between male and female HIV/AIDS patients (Tab. 3.7).

Fig. 3.8 and Fig. 3.9 based on HIV inpatients at CMC clearly showed that women were infected at younger ages compared to men, as in other countries (Nzyuko *et al.* 1997). This reflected the general pattern for TN (Fig. 3.5).

The age-distribution of all recorded HIV/AIDS inpatients at CMC showed that a majority had been infected between 20-44 years (79% men and 76% women) (Fig. 3.8). There were some patients reported as aged over 60 years. This might be the result of age misreporting in India, where once the couple has had the required number of children, they perceive themselves to be old. There was also evidence of

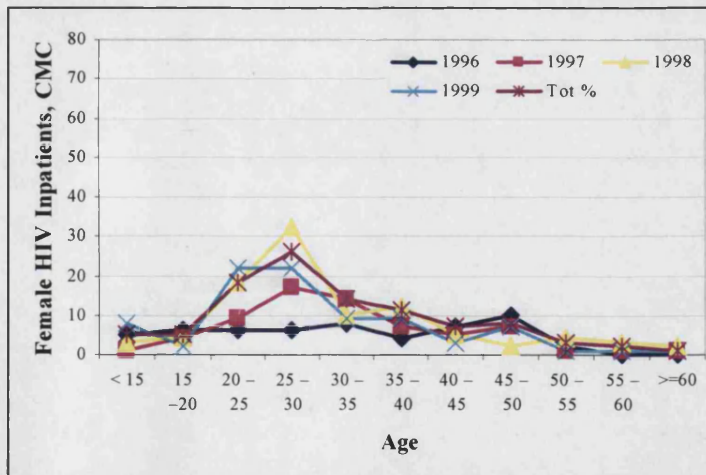
age heaping. If we allow for these errors we might find that the age profile of patients shifted down further.

**Fig. 3.8 Age distributions of All Male HIV inpatients, CMC, 1996-1999**



Source: Data from CMC Hospital Records

**Fig. 3.9 Age distributions of All Female HIV inpatients, CMC, 1996-1999**



Source: Based on data from CMC Hospital Records



### ***Issues of data and reporting at GHTM and CMC***

HIV/AIDS mortality drawn from CMC hospital records showed increases (see Appendix C.4). The increase in AIDS mortality may be attributed to improvements in detection and recording apart from expected increases as a consequence of increase in number of patients suffering from the disease. Gender differences in AIDS deaths at GHTM illustrated that men constituted 80% of the deaths, unsurprising since 82% of HIV/AIDS patients being treated at the hospital were male in 1998. Both GHTM and CMC had made improvements in keeping records of HIV patients and mortality due to AIDS. However recorded HIV/AIDS mortality data are questionable since these were a record of deaths of patients while in hospital and therefore incomplete and underestimates. Thus recording was incomplete and systems for efficient and regular updates of patient data were poorly developed, even though accurate collection would be useful for health education.

## **3.4 Summary**

India has been behind by a decade in detecting HIV/AIDS in the country. There are still controversies over HIV/AIDS prevalence estimates in the country. Infection levels are reportedly different across regions - TN and AP are high prevalence states. Sero-surveillance is not uniform across the country. Where cases are reported in India, Barnett and Whiteside (2002) suggest that the process of data collating can take so long that the prevalence of an epidemic like HIV will be progressing faster than published records. Thus delays in processes in India could be a cause for inaccuracies that estimates produced in India may be inaccurate both due to non-reporting, and reported estimates are likely to be outdated.

Tamil Nadu has been leading in prevention efforts. A recent study based on an analysis of the prevalence of HIV among pregnant women aged 15 to 24 in four southern Indian states found that the rate of infection within this group fell from 1.7 percent to 1.1 percent in TN (Kumar *et al.* 2006). Studies from AP show cases of

pregnant women testing HIV positive and their husbands testing negative in a government hospital in Hyderabad (AIDS-INDIA 2007b).

Some authors (Mills Stephen *et al.* 2006) suggest that extrapolations from ANC data should be made with caution. Because of the large denominator used (general population of women), even a small percentage difference in HIV prevalence between pregnant women and women in the general population could potentially result in an over- or underestimation of the total number of women infected. Further these authors suggest that, ANC sentinel data also are subject to selection biases related to convenience sampling and also that ANC women may under represent HIV levels in the general female because of lower fertility among HIV positive women. Hence while reports of decline in prevalence of HIV in TN are encouraging for prevention efforts in the state, they should be treated with caution not complacency.

The government had been slow to make ARVs available and they are still unavailable and unaffordable to a majority of PLWHA. Further counselling facilities are limited. Stronger political commitment and willingness to see the real situation is important for implementing effective intervention policies.

# Chapter 4      METHODOLOGY

This chapter firstly discusses general methodological issues related to social research on HIV/AIDS in India. Secondary data sources used to contextualise the current study and for comparative analyses are discussed. This is followed by research methods and field work, wherein the questionnaire design and data collection are discussed. Finally, the analysis techniques applied in this empirical study are set out.

## 4.1      General Methodological Issues for Social Science Research in India

In 1999, when this research was conducted, the paucity of both data and literature was a major handicap for social research on HIV/AIDS in India (Miller 2002; Sethi 2002). A wide range of government and non-government organisations such as APAC (1996), NACO (1998) and others were involved in organising and implementing intervention programs, but there was little emphasis on evaluation and scientific documentation (Murthy *et al.* 1999; ORG 1998; TNSACS 2003; TNSACS and ORG 1998). This was a ‘circular problem’ wherein research was urgently needed because so little was known, but there was very little information available for project planning and implementation (Bulmer and Warwick 1993). Since the early 2000s, increasing numbers of studies have been conducted and the literature is growing (Collumbien and Das 2004; Lakhani *et al.* 2001; Verma and Roy 2002).

### ***Secondary data sources for knowledge and behavioural HIV/AIDS research in India***

This section outlines the sources of secondary data on HIV-related behaviour, and addresses their strengths and weaknesses. Secondary data are used in this study as context for the research, and for the purposes of results comparison. The scale and diversity of India leads to sampling problems for survey data. Sample sizes may be large by international standards but they are not reliable and according to Srinivasa Roa (2003) data currently available in India are inadequate to estimate the number of HIV infected people accurately (Dandona, L. *et al.* 2006). Data collection has been further compromised by a tendency to use large-scale survey instruments, often developed elsewhere.

The secondary data sources are summarised in Tab. 4.1. At the time of this study in 1999, access to secondary data sources was considerably more difficult than it is now. For example, NFHS-1998 was subject to time delays and frequent follow-up requests for data were necessary until data was made available during the writing stages of this thesis. NFHS data was limited to only among ever-married women in selected states. Further, the questions related to NFHS were very few, NFHS 1998 has been improved from NFHS 1992 but is still limited in scope for information on HIV/AIDS. NFHS included questions related to contraception but did not have any questions related to sexual behaviours. The latest round of NFHS, in 2006, had included testing an all India sample for HIV (conversation with Director, International Institute for Population Studies, who co-ordinate NFHS in India). Results have not yet been published to assess this exercise and might be constrained by the limitations of large-scale surveys.

**Tab. 4.1 Secondary Data Sources**

Survey	Year(s)	Sample size	Sample population	Knowledge data	Behavioural data
NFHS-1	1992	88,562  89,777  (HIV data collected from ever-married women from 13 states including TN but not AP. AP was not included as it was not thought to be at risk for HIV/AIDS)	Households  Ever-married women aged 13-49	<ul style="list-style-type: none"> <li>• Ever heard of AIDS?</li> <li>• Source of HIV knowledge</li> <li>• Reported as 'Misconceptions' of acquiring HIV (shaking hands, mosquito bite, hugging, kissing, wearing clothes, stepping on urine/stool, sharing utensils). See (NFHSTN-1992 1994)</li> <li>• Is AIDS curable?</li> <li>• Does AIDS vaccine exist?</li> <li>• Knowledge of contraceptive methods (including condoms) Since not AIDS related, this question was asked in all state including AP. See (NFHS 1995)</li> </ul>	<ul style="list-style-type: none"> <li>• Current use of modern contraceptive method (including condoms). See (NFHSTN-1992 1994)</li> </ul>
NFHS-2  (National Family Health Surveys were collaborated by International Institute of Population Studies (IIPS) in Mumbai; Ministry of Health and Family Welfare, Govt of India; ORC Macro and USAID)	1998-2000	92,486  90,303  (HIV data collected from ever-married women from all 26 states)	Households  ever-married women aged 15-49	<ul style="list-style-type: none"> <li>• Ever heard of AIDS?</li> <li>• Source of HIV knowledge</li> <li>• Knowledge of ways in which AIDS can be avoided (abstain from sex, using condoms, single partner, avoid prostitutes, avoid blood transfusions, using clean injections avoid homosexuals, avoid IV drugs). (NFHSTN-1998 2001)</li> <li>• Knowledge of contraceptive methods (including condoms) (NFHS 2000)</li> </ul>	<ul style="list-style-type: none"> <li>• Current use of modern contraceptive method (including condoms). See (NFHS 2000)</li> </ul>

Table continued...

<p>BSS (Behaviour Surveillance Surveys) Conducted by AIDS Prevention and Control (APAC) administered by Voluntary Health Services (VHS) They were developed by Family Health International (FHI) and funded by USAID.</p>	<p>1996-2000</p>	<p>13700  (total sample size selected from 12 towns in TN)</p>	<ul style="list-style-type: none"> <li>• female commercial sex workers</li> <li>• truckers and helpers</li> <li>• male patients attending STD clinics</li> <li>• male and female factor workers</li> </ul>	<ul style="list-style-type: none"> <li>• know that condoms prevent STD;</li> <li>• cite two acceptable ways of preventing HIV/AIDS</li> <li>• know that condoms prevent HIV/AIDS</li> </ul> <p>See (NACO 2001)</p>	<ul style="list-style-type: none"> <li>• heterosexual intercourse with a non-regular partner in the last year</li> <li>• condom use during last sexual intercourse with a non-regular partner in the last year.</li> </ul>
<p>GBSS  (General Population Behaviour Surveillance Survey) Conducted by APAC, administered by (VHS), developed by FHI and funded by USAID</p>	<p>2000-2001</p>	<p>1920 (960 men and 960 women)  (sample size selected from each of 21 states including TN and AP; with 40 from each of 48 villages and 48 urban blocks)</p>	<ul style="list-style-type: none"> <li>• High Risk groups</li> <li>• Bridge population</li> <li>• General Population</li> </ul>	<ul style="list-style-type: none"> <li>• Awareness of anyone infected with HIV</li> <li>• Ever heard or seen a condom</li> <li>• Awareness of condom availability</li> <li>• Know that HIV can be prevented by having one faithful uninfected partner</li> <li>• Know that HIV can be prevented through sexual abstinence</li> <li>• Know HIV can be prevented through consistent condom use</li> <li>• No incorrect knowledge about HIV transmission</li> </ul>	<ul style="list-style-type: none"> <li>• Reported consistent condom use with all non-regular sex partners within last 12 months</li> <li>• Reported condom use during last sexual intercourse with non-regular sex partner</li> </ul> <p>See (NACO 2001a)</p>

The data collected from such large-scale studies in the general population included only limited information on sexual behaviours. Behaviour surveillance surveys such as BSS (1996-2000) and GBSS (2000/2001) were quantitative studies of the general population and only limited details could be collected (Tab. 4.1). BSS was among high-risk groups; GBSS was among high-risk groups and general population but were limited in scope about the data collected on sexual behaviours. Nevertheless they were the only data available at the time and have been used for comparison after taking account of their limitations.

The population surveys conducted by NFHS were patterned after the WHO model and examined knowledge of transmission and prevention but not in depth (Meda *et al.* 1998; Morisky *et al.* 2002; Rahman *et al.* 1999; Vinh *et al.* 2003). They focused only on blood and sex-related knowledge of HIV transmission and knowledge of two methods of prevention. These constituted only a first line of knowledge and did not cover a full range. As Cleland (1995) and others argue, these models relatively neglect the powerful impact of wider social contexts (Organista *et al.* 1996; Poddar 1995). One reason for the neglect of social contexts was attributed to the lack of access to such data (Knox *et al.* 1993).

## 4.2 Research Methods

The aim of this empirical research was to examine knowledge, attitudes, behaviours and sexual practices (KABP) of HIV/AIDS patients as far as possible in their social contexts. The original WHO conceptual framework was incomplete in that it ignored the fact that KABP in developing countries could not be seen in isolation as 'scientific truth', since they were shaped by social, economic and cultural issues with manifestations of decisions concerning marriage, children and sexual practices being responses to societal constraints rather than 'rational' choices (Lugalla *et al.* 2004; Maticka-Tyndale *et al.* 1994; Mukherjee and Sikdar 2005; O'Neil *et al.* 2004; Roberts *et al.* 2004). Population surveys conducted after the late 1990s, such as the

NFHS and BSS had modified the WHO model and examined KABP in more culturally appropriate ways but they were still limited to quantitative survey data (Morisky *et al.* 2002). A growing recognition of the limitations of survey data alone for collecting fully textured data of social reality has generated interest in research methods, which combine quantitative and qualitative techniques universally (Caldwell *et al.* 1998; Hogle and Sweat 2001; Oppenheim 1992; Scheper-Hughes 1997; Todd *et al.* 1997).

We therefore collected structured information based on an adaptation of the WHO questionnaire available at the time, adapted for suitability in the socio-cultural context of PLWHA in India. The aim here was to improve the validity of data and to gain a better understanding of knowledge and attitudes of the study population in a socio-cultural context (Rubin *et al.* 1995). The patient survey aimed not only to produce factual, reliable data on knowledge, but also to elicit rich descriptions and explanations of processes occurring in local contexts (Carey 1993; Miles and Huberman 1994; Ulin *et al.* 2002; Whyte and Alberti 1993; Wolff *et al.* 1991). As exploratory research (Robson 1993), our survey combined quantitative and qualitative techniques to investigate KABP of PLWHA and to better understand socio-economic and demographic interactions where applicable. We utilized qualitative methods to investigate complex cultural issues in a regional context. Additionally, we have examined possible quantitative analyses to increase the trustworthiness of our qualitative findings and vice versa.

KABP research in a developing country like India was a problem. Personal experience in developing countries suggested that standardised questionnaires such as those described above were not fulfilling socio-cultural requirements (Bulmer and Warwick 1993). Hence we added open-ended, probe questions, to obtain in-depth qualitative data for exploratory research.

Details about the questionnaire content used in our survey and comparisons with other surveys are discussed in section 4.3.2. An assessment of these secondary data



sources provides context for the research instrument used in the current study. Firstly, they served as comparator for the research instrument used in this study. Secondly, wherever relevant, the results from secondary sources were compared with the patient survey to examine how closely the patient survey results matched those from population surveys.

### 4.3 Fieldwork

This section outlines the processes of conducting this study. The first phase of fieldwork was conducted between August and September of 1997. This visit was for following up contacts established earlier during past work and also establishing new contacts among those working on HIV/AIDS issues broadly in India and particularly in TN and AP (see Appendix A2 for contacts made at this stage). Building partnerships through discussions with others working on HIV/AIDS issues was an important step for developing this study.

Networking with relevant organisations and practitioners in India and Geneva provided professional guidance on related ongoing HIV/AIDS research due to the lack of literature. The few reports pertaining to HIV/AIDS work in India were available with greater ease at the WHO offices in Geneva than within country. Key informant interviews (including Joint director of NACO, Special Secretary for HIV/AIDS of TNSACS, Joint Director of ICMR) facilitated the implementation of this study. Further contacts were established during fieldwork in 1999 (including NACO, ICMR, UNFPA, UNAIDS, Population Council, Christian AIDS/HIV National Alliance) (see Appendix A3). A post-fieldwork visit to India in September 2001 was used to update reports and collect any newly available documentation for TN and AP (see Appendix A4).

Obtaining permission for access to secondary data sources and primary research in India was difficult and time consuming (Robson 1993; Ulin *et al.* 2002). The process and time taken to obtain permission was in some ways more difficult than

conducting our patients' interviews. Thus bureaucracy comprises a major hurdle in conducting such studies and additional time needs to be built in for such processes (Tully 2004).

Permission to access TNSACS published data took three months and was finally granted as a White Paper. The white paper although granted for the purpose of the study, was not honoured for the entire duration of this research. The white paper was honoured only during the data collection period, when the document had been given, thereafter permission had to be sought each time for obtaining updates. Frequent transfers of HIV/AIDS program managers caused additional problems with obtaining permission afresh each time. This meant additional time delays for obtaining a government order (GO) to access published statistics each time.

In terms of primary data collection, even if permission had been granted, it did not guarantee that it would be honoured. For example, an NGO in Chennai working with HIV/AIDS patients, had granted email permission in advance of commencing the fieldwork, to contact PLWHA via their organisation and access to any relevant data. On reaching the site for data collection in January 1999 it became evident, through repeated visits spanning a month that ground realities had changed and the chairperson withdrew her earlier promise to the researcher. This resulted in additional constraints, unanticipated time delays and a fresh start to the whole process of finding an institution within which to conduct the fieldwork.

There was a range of other organizations based in Chennai dealing with PLWHA (see Appendix A3), however they had only about five HIV patients a month at that time and were therefore not appropriate as sources of interviewees for this research. However they were all explored before choosing GHTM and CMC, the two most important hospitals involved in treating the largest number of HIV/AIDS patients in India at that time.

The research and ethics committees at both GHTM and CMC had to formally approve this research proposal before the interviews could be undertaken (Green and Thorogood 1998). As a research oriented academic hospital CMC had an established, professional procedure for granting permission. The research proposal, endorsed by heads of relevant departments treating HIV/AIDS patients (medicine, dermatology and obstetrics and gynaecology), was submitted beforehand. It then had to be presented to the hospital review committee at their monthly meeting and was duly approved. By contrast, obtaining permission from GHTM was based on the superintendent's personal discretion, which was granted within two weeks of application.

#### 4.3.1 *Sample*

Data were collected from a purposive sample of PLWHA and aimed to be a complete enumeration at the time of HIV/AIDS patients at two hospitals, GHTM and CMC located in Tamil Nadu. The advantage of a sample of PLWHA was that they possessed concentrated knowledge on such a sensitive topic as HIV/AIDS and sexual behaviours. Further, in a hospital environment they were more accessible and willing to talk freely and it provided a reliable and safe atmosphere conducive to developing an easy rapport with patients, essential to such a study. This therefore had the added advantages of greater reliability of data. Another advantage was that HIV status was known without having to organise testing of blood samples.

PLWHA in the sample were similar to the general population except for some biases in favour of lower class, men and those in their reproductive years (see section 5.2.7). However, their greater experience of the spread of AIDS outweighed the disadvantage of having a sample, which was not strictly representative of the general population.

HIV/AIDS patients who were able, and who consented, were interviewed at GHTM during March-April 1999 and at CMC during May-June 1999 and numbered a

total of 292 respondents (Tab. 4.2). TN patients (242) comprised 1.7% of the total (13846) reported HIV positive cases in the state according to June 1999 records (TNSACS 1999).

**Tab. 4.2 Interview sample description**

<b>Description</b>	<b>Numbers</b>
Patient interviews	
GHTM	143 (2 refusals)
CMC	149 (5 refusals)
Total patients interviewed	292
Patients too ill to be interviewed	15
Voice Recorded Interviews, GHTM	20
Supplementary interviews	
Doctors	
<i>Siddah</i> specialists	10 (2 hours each)
Social workers	2 (90 minutes each)
Family members	3 (regular contact)
	150 (30 minutes each)
Policy makers	
	See Appendices A.2 – A.4

### ***Response Rate***

The response level was high (7 refusals and 15 too ill to be interviewed). There had been 4 patients at the hospitals who said they were not HIV positive, although the hospital records showed them as HIV positive. Due to the confusion involved with this situation and although they had been questioned in part, we have eliminated these persons from analysis. The main reason for reluctance to participate immediately in the survey, as described by patients, was the fear of publicity resulting in discrimination and rejection by friends/neighbours/relatives. Some mentioned unhappy experiences resulting from unauthorised articles published in newspapers and magazines naming the patients, in spite of being assured of confidentiality at the time, which had caused them great grief. In particular, women patients explained that they had been unwilling to be interviewed until they had gained confidence in the researcher by observing her in the hospital wards.

$$\begin{aligned}
 \text{Overall Response rate} &= \frac{\text{Number interviewed}}{\text{No. interviewed} + \text{No. refused} + \text{No. too ill to be interviewed} \\
 &\quad + \text{patient said they were HIV negative, thereby removed from analysis}} \\
 &= \frac{292}{292 + 7 + 15 + 4} = 92\%
 \end{aligned}$$

### 4.3.2 *Questionnaire Design*

In the preliminary planning stages, academics and professionals in government, non-government and international organisations that were working on HIV/AIDS were interviewed to define and develop the questionnaire.

Knowledge in our patients' survey meant health prevention knowledge, which required deeper knowledge, and ideally would include a full range of information, education and communication (IEC) and behaviour change communication (BCC) related to HIV transmission and prevention. To examine in-depth knowledge in our patients' survey, we included in our questionnaire additional levels of knowledge such as transmission through physical contact and additional miscellaneous modes relevant in the south Indian socio-cultural context, for example, using public water sources. Open-ended questions with probes were incorporated for in-depth qualitative analysis, especially on sexual behaviour.

The survey instrument for this research was questionnaire (see Appendix B) related to HIV/AIDS knowledge, attitudes, behaviours and practices. The structured questions provided a format, which helped in guiding the direction of our interviews. Open-ended questions provided freedom of expression to respondents while capturing their experiences more completely (Kvale 1996; Moser and Kalton 1971; Oppenheim 1992). The following KABP studies provided templates for constructing our questionnaire:

1. Joint United Nations Programme on HIV/AIDS Questionnaire used for tracing Sexual Networks (UNAIDS 1998).
2. WHO's Global Programme on AIDS (WHO 1994) questionnaire was used together with its combined partner relations (PR)/KABP questionnaire (1990).
3. The questionnaire used in studies of sexual behaviour and AIDS in the developing world by Carael, Cleland and Ferry (1995).
4. National Family Health Survey (NFHS) questionnaire used in TN (1994).
5. Hospitals questionnaire used in Tamil Nadu (NGO, unpublished)

The basic WHO's (1994) knowledge, attitudes, behaviours and practices/partner relations (KABP) questionnaire was being widely used at the time of this study, especially in countries in the early stages of HIV/AIDS. KABP studies have evolved since 1998 with greater emphasis on adapting the questionnaire based on local needs and experience. Our questionnaire was developed using those listed above as templates and modified to be relevant to respondents who were HIV positive and in the local cultural context. The questionnaire was reassessed and further modified following the pilot study in January/February 1999. For example, open-ended questions were added to get more detail and allow free expression. The overall design of the questionnaire was a balance between sufficient comparability with extant secondary data sources and appropriateness in the light of the sample and socio-cultural setting. In designing and administering the questionnaire our aim was to preserve sensitivity to customs, cultures and sentiments of the respondents.

The HIV/AIDS section from NFHS questionnaire was used as the template for our survey. Second round of NFHS 1998 was still being conducted at the time of our fieldwork, which was published only in 2000, hence we had to use NFHS 1992 questionnaire for our template. It is important to note that most of the NFHS questions themselves originated from WHO. Additionally, we developed and included questions in response to issues which were being raised in the local culture and media at the time. BSS and GBSS were developed by Family Health International and, in common with the NFHS, were based on other existing international models. Results from BSS and GBSS (Tab. 4.1) which became

available after 2001 hence they could not be used as templates but have been used for comparison of analyses wherever appropriate.

There were no other studies based specifically on PLWHA at the time of our study, so comparability was difficult per se. Extant KABP surveys had very different samples (Tab. 4.1). One difficulty was in comparing small and large-scale surveys. Additionally behaviour studies, such as GBSS, were limited in scope since they were based on standard models without much detail about socio-economic or cultural issues. Thus, comparability of the current study with existing sources of secondary data is limited. Hence large-scale data had to be treated with extreme caution. Tab. 4.3 lists sections where some comparisons could be made with other surveys.

**Tab. 4.3 Sections comparable with other surveys**

<b>Section</b>	<b>Survey</b>
Socio-economic and demographic (see sec 5.2)	NFHS
Source of HIV/AIDS Knowledge (see sec. 6.2)	NFHS
Knowledge of HIV transmission (see sec 6.1.1)	NFHS
Knowledge of Condoms (see sec. 6.3)	BSS, GBSS
Sexual Behaviours (sec. 7.2)	BSS, GBSS

The questionnaire was developed in English and translated into Tamil (see Appendix B). In translating, priority was given to conceptual equivalence (Bulmer and Warwick 1993). The questionnaire was independently translated into Tamil by a translator and verified for inconsistencies. Further, since written language was often different from spoken dialects, it was important to ensure that the respondents understood correctly what was being asked. The researcher's knowledge and experience of local languages was essential in conducting interviews to ensure that respondents understood the questions as intended.

### ***Critique of Questionnaire:***

Questionnaires for KABP studies have been improving in recent years (UNAIDS/WHO 2002). The international method of recording sexual behaviour are fast being revised particularly in the global context of HIV/AIDS (FHI 2000; Rehle

*et al.* 2006). If we were to conduct another study, we would modify some of the procedural and design aspects, including: questionnaire modification in keeping with recent research and developments; a greater emphasis on qualitative data collection; and, incorporate formal validation of the questionnaire by independent experts.

With hindsight we should not have depended on WHO questionnaire as heavily as we did, but did so because at the time of the study it was the accepted international standard. In part, this was also due to the constraint of limited resources. Using a standard questionnaire based on what existed at that time led to several problems which were not immediately obvious. Some of the questions were revealed to be flawed while administering the interviews and these are addressed in detail below. We had to explain the meanings in detail while administering some questions to PLWHA to help them understand the questions.

One structural issue that could have been better dealt with was the issue of question order as related to knowledge hierarchies. According to Tuomi (1999), data are simple facts that become information as they are combined into meaningful structures, which subsequently become knowledge as meaningful information is put into a context. Robert Gagné (1985), suggests that knowledge hierarchy is a ranked list of all knowledge, and, therefore, all intellectual skills and learning progresses from the simplest to the most complex (LinguaLinks 1999). Therefore the order in which questions are administered is important. It would have been best practise to test for ordering the questions. We did not test for the order but we did give considerable thought to it and the questions were administered according to the best possible order under the circumstances, guided by question order in the template WHO and NFHS questionnaire available at the time.

Tab. 4.4 summarises what was deemed 'correct' knowledge of HIV transmission according to the surveys which formed our template. The researcher had also validated what was deemed correct knowledge from doctors at GHTM, CMC and others in Chennai working with PLWHA at that time. Our measures of 'correct'



knowledge were same as that used according to NFHS for all questions which were same.

**Tab. 4.4 Knowledge deemed Correct**

<b>HIV can be transmitted</b>	<b>HIV cannot be transmitted</b>
<ul style="list-style-type: none"> <li>• Unsterilized needles/ injections</li> <li>• IV Drugs (Sharing needles)</li> <li>• blood transfusion (referred in our survey to receiving blood)</li> <li>• unclean barber blades</li> <li>• Dental clinics</li> <li>• sexual intercourse with HIV positive person</li> <li>• deep kissing</li> <li>• healthy looking HIV positive person</li> <li>• Mother to child transmission (33% chance)</li> </ul>	<ul style="list-style-type: none"> <li>• shaking hands</li> <li>• playing with child</li> <li>• using public toilets</li> <li>• using public bathing places</li> <li>• using public water sources</li> <li>• mosquito bites</li> <li>• kissing on cheek</li> <li>• streets and public transports</li> <li>• public hospitals and health centres used by HIV positive people</li> </ul>

**Source: (NFHSTN-1992 1994; WHO 1994)**

Knowledge questions in surveys were primarily developed for the evaluation of health education interventions based on the prevailing biomedical model at the time. The evidence in which these questions are rooted is also subject to change over time. Some answers that were thought to be correct at the time of the survey, with new research have a different thinking and no longer thought to be correct. For instance, when we designed the questionnaire, it was thought that HIV could not be transmitted through deep kissing (Q529), when we finished the field work it was being debated and the current thinking is that deep kissing can transmit HIV through any cuts or blood that might get exchanged.

Knowledge in a cultural context did not mean scientific knowledge that asked correct and incorrect questions but what had been communicated and what had been heard. Answers appeared to indicate weaknesses in the questionnaire related to wording and showed that respondents understood differently from what was intended by the questions for example, Q525, HIV transmission at a dental clinic.

The following section outlines the key elements of the questionnaire. Where appropriate, we identify commonalities with other standardised questionnaires in usage at the time of the fieldwork, highlighting drawbacks and improvements. The questionnaire was pre-tested in March 1999 on ten HIV/AIDS patients at GHTM. Changes made to the questionnaire following the pre-test are also highlighted below. Tab. 4.5 details the questionnaire sources and whether they were adapted or modified.

### **Section 1 – Socio-demographic characteristics of PLWHA**

This section included questions on age, sex, region of residence, education, occupation, religion and media exposure, and was based on the WHO questionnaire (WHO 1994). We adapted the questions to fit the cultural context and categorised these according to NFHS categories to facilitate comparison.

Respondent's sex (Q103) may seem straightforward, but in a cultural context it became clear that the patient sample included *hijra* who were HIV positive. *Hijra* are attributed with a third gender role in India, serve as commercial sex workers and comprise an important high-risk group. In some of our analyses, such as questions related to media exposure, they have been counted as women in accordance with their self-definition. In other analyses, however, they have been considered separately on the grounds that their gendered lifestyles were atypical of Indian women in general.

Q104 (Name of place) asked about an individual's place of residence. Individuals who had migrated for employment reported their place of residence to be where their family lived (permanent residence). We used probes to determine where the individual currently lived and recorded both current and permanent address if different. Lorry drivers were on the move and returned home to their families for between 15-60 days in a year. Hence in their case we had to record where their family lived as their place of residence. Some people were homeless or had recently

been made homeless as a result of being found to be HIV positive. In all such cases, their last permanent address was recorded since their displacement might have been temporary.

The region of residence was classified as those from rural or urban areas. However, the city of Chennai had expanded fast and respondents from *peri*-urban areas reported themselves to be from rural areas as recognised by the administrative definitions.

Q106 (What is your mother tongue?) listed the local language that the respondent spoke. Q108 (What was your medium of instruction at school?) was added by the researcher since the medium of instruction at schools could be any of those listed; this was not necessary since we have not used this for any analysis. Q110 (Can you read a letter or newspaper?) was modified to suit local social and literacy levels where people might be keen to read letter from children/family even if they could not read a newspaper; Q111 (During the past month how often have you read/listened to reading a newspaper?) was modified to include 'listened to reading a newspaper' from researcher's observations during past fieldwork experience, that in towns and villages, men sit round with their morning tea in a shop and listen to newspaper being read aloud by one man. Questions about literacy were elaborated with additional clarification over whether the respondent could sign his/her name. Some respondents reported that they listened to tape recorders rather than radio (Q112). Accordingly this was noted when indicated. It was essential to record radio listeners separately as this could provide an important source of public awareness that the tape recorder did not.

Questions of occupation and income (Q117 and Q118) were difficult for the case of PLWHA due to their circumstances. The respondent was prompted to elaborate if she/he had not been able to work due to illness (section 5.2.6).

**Tab. 4.5 Questionnaire Source**

Q No	Question	Source and whether adapted
<i>Section 1</i>	<p>Q103 Record the sex of the respondent            Q108 What was your medium of instruction at school?            Q110 Can you read a newspaper or letter?              Q111 During the past month how often have you read/listened to reading a newspaper?              Q112 During the past month how often have you listened to the radio?            Q117 What is your usual occupation?            Q118 Can you tell me your monthly income from your usual occupation            Other questions in this section unchanged from WHO and/or NFHS</p>	<p><b>WHO + NFHS</b>            Recorded Hijra as a third gender            Added by researcher            Modified for examining regional literacy levels            Modified to suit regional social situation where people listen to one person reading newspaper in a tea shop            Recorded 'tape recorder' if mentioned            Modified to open-ended for descriptions            Modified to open-ended for descriptions</p>
<i>Section 2</i>	<p>Q204 What type of house do you live in?            Other questions were unchanged</p>	<p><b>NFHS</b>            Modified to open-ended for descriptions</p>
<i>Section 3</i>	<p>Q302 How and why did you first come here (hospital)?            Q307 Who in your family knows you are HIV positive? &amp; Q308 What is their attitude?            Q310 How do you feel now?            Q311 &amp; 312 related to study if practising safe sex due to being HIV positive</p>	<p><b>Hospital questions</b>            Added by researcher            Added by researcher to study attitudes            Added by researcher            Added by researcher</p>
<i>Section 4A</i>	<p>Q401 Are you a regular smoker?            Q403 – 408 related to drinking and taking drugs</p>	<p><b>WHO</b>            Added by researcher            Modified for regional relevance</p>
<i>Section 4B</i>	<p>Q410 &amp; 411 Age at marriage of respondent &amp; spouse            Q413 Currently how often do you have sex with your spouse in a month?            Q417, 421, 427, &amp; 428, 435 are open-ended questions related to sexual practices outside marriage            Q418, 425, 426 questions related to sexual practices in a regional context            Q430-431 questions related to frequency of sex</p>	<p><b>WHO + UNAIDS</b>            Modified to open ended            Modified to open-ended for descriptions            Added by researcher for descriptions              Added by researcher            Modified to open-ended for descriptions</p>

<p><i>Section 5A</i></p>	<p>Q432 related to last sexual contact</p> <p>Q501 Do you know anything about HIV/AIDS?</p> <p>Q502 If Yes, What do you know about it? (record verbatim what respondent says, prompt using questions such as; What do you think causes HIV/AIDS? How is it transmitted? Who is most likely to get it?)</p> <p>Q503 Do you think that HIV/AIDS is prevalent in Tamil Nadu?</p> <p>Q504 Do you know if HIV/AIDS is prevalent in your neighbourhood?</p> <p>Q505 Do you know anyone personally who has HIV/AIDS?</p> <p>Q506 How many people do you know? How are they related to you?</p> <p>Q507 Can you tell by looking at a person if they have HIV/AIDS?</p> <p>Q508 Can a person who looks healthy but has the HIV virus pass it to other people?</p> <p>Q509 Is there a difference between HIV &amp; AIDS? If Yes, what do you think is the difference?</p> <p>Q510 Do you think that a person who has HIV/AIDS can be cured? If No, What will happen to the person?</p> <p>Q511 Do you think that a couple should be tested for HIV/AIDS before they get married?</p> <p>Q512 Do you think that a couple should take a HIV test before your marriage? Would you attempt to ensure that your son/daughter/sibling was tested before marriage?</p> <p>Q513 Do you think there is any risk of your getting HIV? If Yes, what are the reasons? Can you do anything to protect yourself? What can you do? What have you done? (ask only if patient does not know HIV test result)</p> <p>Q514 Shaking hands with someone who has HIV/AIDS?</p> <p>Q515 Playing with a child who has HIV/AIDS</p> <p>Q516 Using public toilets?</p> <p>Q517 Using public bathing places?</p> <p>Q518 Using public water sources?</p> <p>Q519 Mosquito/bug bite anywhere?</p> <p>Q520 Mosquito/bug bite when sitting in the same room with someone who has HIV/AIDS?</p> <p>Q521 If the barber does not clean his blades properly?</p> <p>Q522 Over a year ago, there were stories of strangers injecting people on the streets/public</p>	<p>Modified to open-ended for description</p> <p><b>WHO + NFHS</b> NFHS, we made it open-ended to get description Added for additional description</p> <p>WHO; replaced country with TN Adapted for regional knowledge WHO Adapted for additional description WHO WHO NFHS, expanded for description NFHS, expanded for description</p> <p>Researcher included based on questions being raised socially and in media at the time in a context of arranged marriages Researcher expanded Q511</p> <p>WHO, expanded for description</p> <p>WHO/NFHS WHO/NFHS WHO/NFHS Adapted WHO/NFHS Researcher included based on questions being raised socially and in media NFHS Expanded for description WHO, adapted for region Researcher included based on questions being raised socially and media at the time</p>
--------------------------	--	---

<p><i>Section 5B</i></p>	<p>transports with the HIV virus, can one get HIV this way?  Q523 Taking an injection without sterilizing the needle?  Q524 Receiving or donating blood?</p> <p>Q525 At a dental clinic?  Q526 Going to a health centre used by people with HIV/AIDS?</p> <p>Q527 Sharing needles with IV drug users?  Q528 Kissing a person who is HIV+ on the cheek?  Q529 Deep kissing a person who is HIV+?  Q530 Casual sex with someone who is HIV+?  Q531 Sexual intercourse with someone who is HIV+?  Q532 What do you think is the risk of acquiring HIV/AIDS through sexual intercourse with commercial sex workers? What can one do to safeguard oneself?  Q533 What is the risk of transmitting HIV/AIDS to one's spouse if one is infected? What can be done to safeguard from spreading the infection to one's spouse?  Q534 What do you think is the risk of a pregnant woman who is HIV+ passing on the infection to the baby?  Q535 Do you think that a couple should have a child if either of them are HIV+?</p> <p>Q536 What are the sources through which you have acquired your knowledge about HIV/AIDS?  Q537 If a person wants to know more about HIV/AIDS where should one go? Which are the places that one can go to test for HIV?</p> <p>Q538 – 540 Question related to family planning and methods of contraception  Q541- 552 Questions related to knowledge and attitudes toward condoms</p>	<p>NFHS, elaborated  NFHS (research interview only asked about receiving blood)  WHO  Researcher included based on questions being raised socially and media at the time  WHO, adapted for region  WHO/NFHS, elaborated  WHO  WHO  WHO/UNAIDS  NFHS, expanded</p> <p>Researcher included based on questions being raised socially and media at the time  WHO</p> <p>Researcher included based on questions being raised socially and media at the time  WHO/NFHS</p> <p>NFHS, expanded</p> <p><b>WHO + UNAIDS + NFHS</b>  NFHS  NFHS + WHO + UNAIDS</p>
--------------------------	---	---

## **Section 2 – Household information of PLWHA**

Questions in this section were based on NFHS questionnaire for data comparability with available secondary data. Data included number of people living together, household socio-economic status, amenities and access to health care.

Our sample comprised of PLWHA currently living in an institutional setting, rather than their household of origin, which caused problems in collecting these data. Family size (Q201-203), posed some problems due to issues of migration mentioned above. Further some were estranged from their family after being diagnosed as HIV positive. Hence the usefulness of data from this section was limited since its relevance is debatable.

In circumstances where PLWHA had to move or had been evicted, data on family size was fluid and merely provided a rough estimate. For related reasons, therefore, household income calculated from Q203, was problematic, and is treated only as a rough estimate of wealth and cannot be used for sophisticated analysis.

Sections 1 and 2 were instrumental in building rapport with respondents before going into more sensitive topics.

## **Section 3 – HIV stigma and discrimination**

Background history of patient's HIV infection, including partners' HIV status if applicable and where known, were covered in this section. The WHO (1994) questionnaire did not cover such topics, therefore for this study the questions were patterned on a questionnaire developed by an NGO working with PLWHA in TN. In particular, questions relating to discrimination and psychosocial struggles in coming to terms with being positive were included.

Q301 (when did you first come to this hospital) and Q302 (how and why did you come here) gave an opportunity for patients to introduce their HIV positive status.

Q303 (when did you find out that you are HIV positive) was introduced carefully so as to not offend the patients. Four patients responded that they were not HIV positive in response to Q303. Patients had been selected for interviews based on hospital records that they were HIV positive. However it appeared that these patients were not aware of their HIV status, which had ethical implications. One among these 4 respondents had been recorded to have been HIV positive for 4 years, however, he strongly denied that he was HIV positive. In all these cases, we had to be careful not to offend them and because we had already started the interview, continued with a few questions without asking anything related to HIV positive status. And since our research focus is PLWHA, we did not include respondents who said they were not HIV positive in our analyses.

Q's 305 to 310 addressed issues related to stigma and discrimination faced by PLWHA, Q's 311 and 312 were an introduction to changes in sexual behaviour since being diagnosed with HIV. 'Don't know' (DK) option was missed out in Q312 due to typo error. In general if patients responded with DK for any question, we recorded the response as DK together with the reason if specified while administering the questions.

#### **Section 4A – reported personal habits**

Reported smoking, drinking and drug-taking behaviours were recorded in this section. It was patterned after WHO (1994), which had these questions on drinking and drug-taking as an optional section. Some of the response categories in our survey were modified to suit regional and cultural circumstances, for example, Toddy/Arrack in Q404. The question on smoking was added by the researcher since WHO did not have a question on smoking. This section was included for the purpose of examining any relationship that might exist between smoking, drinking and high-risk sexual relations in the context of HIV/AIDS.



Some questions had choices that were not very precise, which was a problem with the questionnaire. This was realised at the time of administration and the researcher explained the meanings of options to all respondents (example, Q403, 404, 407 - 'occasionally', was explained as during special occasions such as festivals or weddings; 'couple of times a month' referred to 2 or 3 times a month; and 'couple of times a week' referred to 2 or 3 times a week). However, problems might remain.

#### **Section 4B – reported sexual behaviours**

Globally developed questions are useful for comparison purposes, however when they do not incorporate local issues, they do not easily translate to regional context. For example using the word 'sex' in 'have you had sex' (ex. Qs 412, 416) was not appropriate usage in a socio-cultural context and were translated into local language during administration as 'have you had 'contact' ('*thodarbu*' in Tamil, meaning sexual contact) with someone'.

It is important to remember that NFHS did not include questions on sexual behaviour in 1998, and that BSS and GBSS had not formally published their report. This section in our questionnaire included several open-ended questions and covered pre-marital, marital and extra-marital sexual behaviours. Questions were formulated with specific reference to the socio-cultural context. For example, Q418 (Do you have a 'chinna veedu'/do you have one regular partner other than your spouse?), was included. "Chinna veedu" (meaning 'small house in the Tamil language) is a term for a regular extra-marital partner in the region. The WHO questionnaire used only closed questions for such topics, we adapted WHO questions on sexual behaviour and introduced several open-ended questions. Open-ended questions allowed respondents to speak freely and openly in order to get as much detail as possible about their sexual practices. We also had to use probes to prompt for details (example Q417). Thus this section from our patient survey produced rich qualitative data about sexual relations and sexual episodes.

In all these questions the aim was to minimize reporting errors by considering more recent events (such as practices in the past month rather than past year). In the case of events, which required longer recall, we asked about frequency of sexual relations rather than actual dates in order to minimise problems of memory bias. Q413 (currently how often do you have sex with your spouse in a month?) was imprecise' in the sense that it assumed regularity, which was in many cases interrupted by sickness, so we asked all patients about how often they had sex with their spouse before they knew of their HIV positive status. Q430 (approximately how often do you have sex in a month?), also Q431, referred to frequency of sex prior to HIV diagnosis. Q432 (when was the last time you had sex?) was also asked of all patients for last sexual contact prior to diagnosis. Responses were affected by length of hospitalisation and date of diagnosis and recall.

We had asked the patients if they could recall when they had their last sexual contact and noted what they mentioned. Because of recall problems, the answers were of the form 'over a year ago', 'over six months ago', 'within the last six months' or 'within the last one month'. Some of the questions resulted in issues of response censoring. The issues of censored data on the results are addressed in the analyses (section 4.4.1). The scaling used was in terms of broad averages rather than actual numbers in order to accommodate semi-literate respondents in our survey.

### **Section 5A – Knowledge and attitudes of HIV/AIDS**

In studying KABP, there was the difficulty of knowledge overlapping with attitudes. Questions pertaining to health prevention knowledge in terms of what was known to be true were taken to represent knowledge and questions dealing with expression of social, personal and public expression which could change as a function of experience were taken to represent attitudes (section 2.2).

Knowledge in this socio-cultural context meant prevalent attitudes at the time of the survey. Hence this section deals with popular attitudes comprising knowledge,

and can be used as a proxy for the level of HIV/AIDS health education among PLWHA. These questions were drawn from WHO (1994) questionnaire. De Vaus (2002) points out that in KABP surveys in developing countries the respondent often lacks an adequate frame of reference for answering questions, as evidenced by the inappropriateness in an Indian setting of questions in the WHO questionnaires about deep kissing (Q529). Such questions were not culturally appropriate since people rarely kiss in public and kissing was not permitted by the Indian film censor board at the time. Hence, 'don't know (DK)' responses were high for such questions. For the same reason, Q528 (kissing a person who is HIV positive on the cheek) was also not appropriate in a cultural context. Considering these problems, we have not included Q528 and Q529 in our analysis.

Q501 was the first question to start the discussion with the respondent about HIV and formed a polite and sensitive translation of asking if they had heard about HIV. The responses to Q503 (do you think HIV is prevalent in TN?) were mostly missing and hence we have not analysed this question. For Q504 (do you know if HIV is prevalent in your neighbourhood?), we had written down what the respondents described and based on their responses, we classified the categories as high (knowing 10 or more people), moderate (knowing 2 – 9 people), low (knowing 1 positive person other than oneself).

Several questions (509, 511, 512, 535) were used to obtain additional information pertaining to local cultural issues. For example Q511 (do you think a couple should be tested for HIV/AIDS before they get married?) deals with whether a couple should be tested for HIV before marriage, a problematic issue in a setting where an arranged marriage system prevails. Q512 (do you think that a couple should take a HIV test before marriage? would you attempt to ensure that your son/daughter/sibling was tested before marriage?) was a typo error since the first part is a repetition of Q511. Thereby the first part was not asked but only the respondent's

personal attitude to HIV testing in the second part was asked, that is, whether respondent would be willing to have son/daughter/siblings tested for HIV.

Q513 (Do you think there is a risk of your getting HIV?) from WHO questionnaire was retained because nothing was known about the extent of awareness and knowledge among PLWHA in India. Since all respondents were HIV positive, even if they had not been told their test result by the time of interview, this question was asked only of those who said they were not HIV positive at the time of interview.

Q514 – 535 in our survey represent knowledge of HIV/AIDS transmission, and were based on what was considered correct knowledge of HIV transmission in India at the time of our survey (Tab. 4.4). The responses to these questions as in the original WHO questionnaire which had asked for different levels of risk was problematic. It was evident from patient's responses that the levels of risk were difficult to classify and resulted in heaping of responses under 'high risk' and 'no risk'. Therefore these responses have been collapsed in our analysis. Other specific problems with these questions were as follows.

In Q517, it was uncommon for our respondents to go to swimming pools, however people bathe in common places such as by the well side or other public water sources. Hence the question was translated to 'public bathing places' which was relevant in the social and cultural context. Socio-economic conditions entail people depending on public water supply sources to meet their requirement and concerns were being expressed at the time about whether there was any risk of acquiring HIV from collecting water from public supply sources and Q518 was included to address that. Whether HIV could be transmitted by mosquito bites was another concern and has been included (Q519 & Q520). Regional bio-medical knowledge prevalent at the time was that HIV could not be transmitted through being bitten by a mosquito even if in the same room with PLWHA (Tab. 4.4).

Q521 was adapted for regional conditions where men go to roadside barbers and asked if HIV could be transmitted if the barber did not use clean blades. Although culturally relevant, respondents found it difficult to understand the meaning of this question. Q522 was included based on questions raised by respondents during the pilot survey as they represented local stories. There were rumours spread about getting HIV through being injected by strangers in streets and public transports. However, doctors and experts were disseminating the message through media and other sources that HIV could not be transmitted through this mode since blood would get coagulated in the syringe and it would not be possible to inject the blood. Q525 about HIV transmission from a dental clinic was also ambiguous and the meaning was difficult for the patients to understand. Hence Q521 and Q525 have been removed from our analysis (section 6.1.1).

In an Indian context, with a large and at the time unregulated blood donor supply, HIV could be transmitted not only through receiving infected blood but also through donating blood using unsterilized needles. For our survey we interpreted blood transfusions as receiving blood. Q526 represents local fears that HIV was air borne and could be acquired through breathing the same air at health centres or public hospitals where other HIV positive people might be present. Q528 (kissing a person on the cheek who is HIV positive) and Q529 (deep kissing a person who is HIV positive) were not culturally relevant since people rarely express such gestures in public.

Q530 was problematic in meaning since it had a different meaning in a cultural context. 'Casual sex' as understood in the west is equated with commercial sex in India (even when it is unpaid). Since other questions in our questionnaire pertained to commercial sex, 'casual sex' in Q530 was interpreted by the researcher as 'petting, referring to touching and feeling without penetrative sex' and was understood as such in the regional culture. Q531 was translated as 'sexual intercourse with a positive person without a condom'. It was believed that sexual intercourse with a commercial

sex worker (CSW) without a condom comprised a high risk for HIV since the CSW might already be infected (Q532). Condom use was addressed separately in section 5B. Q534, risk of HIV transmission from positive mother-to-child was estimated to be 33% in India at the time, hence 'not 100%' was considered correct knowledge. Q535 represent local attitudes in a social context where having children soon after marriage is highly desirable.

### **Section 5B – Condom knowledge and attitudes**

This section focused on knowledge and attitudes about condoms and their use, and was adapted from WHO (1994) and NFHS questionnaires. Responses to these questions highlighted the issue that there was a conflict between the intentions of the KABP questions on the efficacy of condom use in general and local perceptions that *nirodh* (locally produced condom) tore frequently in use. We asked about knowledge and attitudes to 'condom' during the interviews. However, sometimes patients did not understand the word 'condom', in which case we had to use alternative words that they understood, these were 'nirodh' or 'rubber'. Therefore it is possible that responses might have implications for 'nirodh' in particular rather than 'condom' in general.

Q538 to Q540 about contraception were included for comparability with NFHS. However only questions (Q540.4 and 540.5) pertaining to knowledge of male and female condoms were used in our analyses as relevant in the context of HIV/AIDS. Language and vernacular were carefully considered throughout these questions. For example, '*Nirodh*', the brand of condoms supplied for free by the Indian government, was more commonly used to refer to condoms rather than the word "condom" per se.

Prior to pre-testing, Q540 had included questions of associated cost and source of supply of the listed items of contraception. During the pilot study it was found that people only mentioned the free condom (*nirodh*) obtainable at health centres, thereafter questions related to cost and supply were removed.

Questions (541-552) about condom use revealed respondent courtesy bias during the pre-test. For example, for Q552 (One should not have sex with a casual partner if they do not have a condom) revealed that respondents were giving what they thought was an expected answer rather than their opinion, possibly because the question was hypothetical and might imply moral judgement. To minimise this effect, we used probes (for example, Q551, 'I would use condom if my partner asked me to') in an attempt to get a more accurate measure of their attitude. Responses to Q551 revealed social and cultural sensitivity to condom use.

### 4.3.3 *Data collection*

Experience of local survey research, knowledge of regional languages, sensitivity to the local context, and having an established network of contacts were important in planning and implementing this study (Basu and Aaby 1998; Hogle and Sweat 2001). According to Bulmer and Warwick (1993) the most essential element for dealing with bias and error is the awareness that they exist. Thus unreliability of data due to biases and errors was anticipated from past experience and it was possible to counter and reduce it as far as possible but not eliminate completely. Not only was the questionnaire modified to take account of cultural sensitivities, but it was also important to allow adequate time to gain the confidence of the respondents and factor in an appropriate length of time for individual interviews.

Knowledge and experience of local culture was very helpful in data collection, observation and reporting (Makkar 2002). For example, I did not need to learn the local languages, I could walk into the ward and communicate with the respondents and also understand their social, cultural and psychological structures more easily. A foreigner may more often be treated with curiosity even in urban areas, so may need to overcome some barriers and/or require the assistance of local interpreters, both to communicate and to understand social structures.

In administering questions pertaining to sexual behaviour it was considered appropriate to capture the answers to open-ended questions verbatim, as far as possible (Hogle and Sweat 2001). Responses to descriptive questions were voice recorded with consent from patients. In the case of those who did not consent, we wrote down their detailed descriptions. This increased the time taken for the interviews and was necessary to allow for the extra time.

Physical conditions were often unfavourable for conducting interviews and maintaining confidentiality. At GHTM, each ward had only one room for examination and a smaller one for storing medicines. A storeroom was allocated for interviews, which meant constant interruptions by staff to collect medicines. Since rooms did not have doors, curious relatives and other patients would often stand around to observe. Several times the interview had to be paused mid-sentence until the relatives and/or onlookers left voluntarily. While this had the advantage of assuring the respondent of confidentiality, it took longer to complete the questionnaire. At CMC, sometimes the room allocated for interviews had to be shared with other staff. Additionally, the patients at CMC were outpatients and might have found money just to visit for the day and had time constraints amidst the long queues to complete all required tasks. However they willingly agreed to fit in the interview. Five in-patients were in the general wards at CMC and had to be interviewed very quietly in a room full of patients, as they could not be moved from their beds. Under these circumstances, the questions and answers had to be memorised and the interview had to be interspersed with several general questions and administered softly so as not to be overheard. At both hospitals, it was necessary to make sure that anxious relatives were not present during interviewing. The need for privacy is considered relevant in a culture where an average family of 4 members lives in very basic accommodation comprising of only 1-2 rooms. Besides, relatives wanted to stay in order to talk/hear/understand more about this new disease, which was causing them great distress. A few patients (3) were too ill to talk and even to sit on hard wooden stools (the only seats available in the room). In such cases I stopped



the interview on observing their inconvenience; their questionnaires were completed at another time (Weiss 1994).

On an average, 12 hours a day, were spent at GHTM during March-April 1999 and another two months (May-June) were spent at CMC for data collection. CMC respondents were mainly outpatients, so that interactions with them were limited to the time of interview and follow up discussions for advice and counselling as needed. Hence CMC patients could not be observed in-depth as had been possible with the in-patients at GHTM.

Some errors due to difference in status between researcher and respondents were inevitable but all efforts were made to reduce prestige bias and minimise them (Oppenheim 1992). Indian culture requires deference toward anyone older than oneself and greater sensitivity was required in administering personal questions on sexual behaviours (Ward 1993). All efforts were made to be non-judgemental (Morton-Williams 1993). This had benefits, since patients talked among themselves and reported that they had heard of the non-judgmental and sympathetic attitude of the researcher as different from other professionals; this also helped to boost the response rate.

In a population with low education levels, self-administration of questionnaire was not an option, so face-to-face interviews was the main mode of collecting information (De Vaus 2002). In countries like India non-sampling errors are likely to be higher than sampling errors; for example, age reporting is a generic problem (Anderson 1992; Jones 1993; Pearson *et al.* 1992). Some errors can be avoided in these circumstances if the researchers have knowledge and understanding of the social, economic, psychological, cultural and behavioural structures of the research region (Miles and Huberman 1994; William 1993).

I administered the interviews personally since I had extensive experience of conducting survey research in the region. This had the advantage of saving in cost,

effort, and time and ensured a high response rate (92%). By conducting interviews oneself it was possible to reduce sampling bias and response errors resulting from misunderstood questions by interviewers and respondents (Oppenheim 1992). If needed, respondents were asked simple additional probes in their own language to ensure they understood questions as intended (Moser and Kalton 1971; Suchman and Jordan 1992). Further, problems of employing, training and motivating interviewers were avoided and ensured greater confidentiality by reducing the numbers of people involved.

The critical problems with questions adopted from standard questionnaire were addressed by the researcher in as far as possible while administering the questions. However, the problem with this is that while it is convenient that the researcher can translate the wording to communicate intended meanings verbally, this process cannot be entirely standardised across all the interviews or for large surveys which will require more researchers.

Interviews were mainly conducted in Tamil (and in Telugu for patients from AP). The responses were simultaneously translated into English and recorded on the questionnaire. The minimum length of time taken to interview a patient who did not elaborate on his/her responses was one hour, and the maximum time with someone who elaborated was 3 hours. Responses to open-ended questions were tape recorded with patients' permission (Ulin *et al.* 2002; Weiss 1994). Twenty patients at GHTM consented to in-depth voice-recorded interviews, which were transcribed. None at CMC consented to voice recording due to fear of publicity but they agreed for us to write down their detailed descriptions.

Daily communication during the interview period with doctors and social workers provided useful supplementary information about the range of experiences, perspectives, and relevant behaviours of patients as seen from a professional perspective. Interviews with *siddah* doctors (providing alternative treatments) helped to understand the nature of their contribution to HIV treatment. Family members

attending/accompanying patients provided useful information about the impact of HIV on the wider family, the type of care and support available, and concerns about how to prevent infection among other family members. Patients in India are usually accompanied by family members/friends when seeing a doctor. Patients in hospitals are required to have an attendant family member/friend since hospitals lack the resources to provide complete care. The information gathered from these supplementary primary sources was collected in note form and used as supporting data for the qualitative analysis.

### ***Limitations***

It is important to recognise the limitations of survey data, particularly when collecting information on sensitive topics such as sexual behaviour and HIV. Dare and Cleland (1994) in a review of reliability and validity of survey data on sexual behaviour in developing countries, recognise the difficulty in obtaining trustworthy data (Nag 1996). Problems arise because retrospective data suffer from recall errors (increased with remoteness of event) and desirability biases, and these affect reported sexual behaviours (Asiimwe-Okiror *et al.* 1997; Loftus *et al.* 1992; White *et al.* 2000). Men tend to exaggerate levels of sexual activity while women tend to under-report as they face greater stigma associated with extramarital behaviours in India (Bulmer and Warwick 1993). Some reports suggest that data on sexual behaviours can be subject to underestimation overall (Selvan *et al.* 2001; Usmani 1999). It has also to be remembered when studying knowledge and sexual behaviours that data are as reported by patients surveyed and cannot be verified. However growing experience in collecting data on sexual behaviour indicates, as also evident in this survey, that people report more accurately if they are assured of confidentiality and if the interviewer's attitude is sympathetic and sensitive to local psychological and behavioural factors (Barnett and Whiteside 2002).

Methodological problems resulting from standard survey questionnaires mainly result in non-sampling errors, although many of these can be addressed through

researcher knowledge and experience of regional languages, cultures and psychology (Blacker and Brass 1993; Ward 1993). Non-sampling errors have been minimised as far as possible, aided by the researcher's awareness and experience of survey research in the region, and familiarity with sociological structures of the population. Moreover the purpose of open-ended questions was to provide greater understanding without putting too much strain on respondents (Oppenheim 1992; William 1993). Thus the weaknesses of getting large-scale survey data on sensitive topics have been reduced by the use of open-ended questions. Efforts were made through probes to ensure understanding, however it might yet have resulted in reporting errors.

A limitation of surveys is the gap between reported and actual behaviours (Hauser 1993). Hence in framing questions we have considered the extent to which attitudes and opinions were present, rather than assuming they existed. More recent research has cast doubt on the link between knowledge and behaviour in developing countries (Maticka-Tyndale *et al.* 1994; Vinh *et al.* 2003). Two other biases are worth mentioning. Firstly, respondents had a tendency to understate their income because of their expectations of financial assistance and support wherever possible. Secondly, respondents often did not know their date of birth hence it was easier to ask for their age, which also might have only been approximate.

### ***Don't Know (DK) Responses***

Mathiowetz (1998) suggests that people who do not provide an answer to a particular question are most similar to those who did provide a response but were very uncertain. He concluded that it reflected a response style "both are uncertain, but some opt to report a count accompanied by a disclaimer, while others who are more cautious report a possible range answer or say they don't know". Bauer and Joffe (1996) refer to DK-responses as self-attributed ignorance of knowledge. They suggest that DK responses may indicate factors other than ignorance, such as lack of interest, irrelevance, exclusion, fear or some other state of affairs. Secondly, if they do indicate ignorance, it may be related to shame, opposition and challenge,

irrelevance, division of labour, confidence or refusal. People may actively and intentionally ignore certain information that was at their disposal perhaps due to ambivalent or inaccessible attitudes (William 1993). In an Indian context, the first time people encountered a disease such as HIV that they had heard kills, they were often engulfed in dread. Consequently they may have set up mental blocks such as self-attributed ignorance. They either deliberately did not want to know, or even if they had been exposed to some information, they did not want to acknowledge it, let alone voice opinions. For example, some respondents reported ignoring television information on the AIDS epidemic and some lorry drivers said they refused to listen to health workers, and that they (and their colleagues) ran away when they heard that health workers had come to meet them.

There are also gendered aspects to DK responses, with women reporting higher levels of DK responses than men. This might reflect lower levels of knowledge, but also a wish to avoid the moral judgement that might follow from expressing knowledge of sexual or other “shameful” matters. Thus, DK responses by women could stand for ‘I am a respectable woman and will not talk about such matters’. Sometimes it was perceived that they simply nodded their head out of politeness in compliance with anything that was asked, whether they understood it or not, although probes aimed to minimise these responses. Thus, a DK response by our survey patients may have been an indication of unresponsiveness resulting from fear, stigma, raw feelings, irrelevance or ignorance; and may have resulted in some non-response errors. On the other hand ignoring DK responses could lead to selection bias and affect statistical conclusions, hence we presented DK responses as such for reference.

### ***Potential Bias***

Other reasons for bias were as follows. Respondents had a tendency to understate their income because of their expectations of financial assistance and support wherever possible. Respondents often did not know their date of birth hence it was

easier to ask for their age, which also might have only been approximate. However errors in age reporting did not appear to have seriously affected the accuracy of our results since the majority (84%) of patients surveyed were aged between 21 and 40 years (Bulmer and Warwick 1993).

#### 4.3.4 *Ethical Issues*

Ethical issues are not neutral principles but rooted in socio-cultural and political contexts (Green and Thorogood 1998). In as far as possible within the cultural limitations of India, the researcher adhered to international ethical principles for conducting research with human participants (Robson 1993). At the start of each interview, informed oral consent was obtained in fulfilment of ethical aspects of any survey on sexual behaviour and HIV (De Vaus 2002; WHO 1994). It was very important that patients were assured that treatment at hospital was not conditional on their consent to be interviewed and that participation was for purposes of research. Confidentiality and privacy was ensured as far as possible to avoid problems associated with the presence of others when talking about sensitive issues such as sexual behaviour (Weiss 1994). Interviews were interrupted if relatives or bystanders refused to leave when sensitive sections of the questionnaire were being covered. All names of patients surveyed were changed in recording and presenting the qualitative data.

Participation by respondents was voluntary and the high response rate indicated their confidence in the researcher. Two women (grandparents attending to HIV patients at GHTM), were very keen to be interviewed but had to be respectfully refused, as they were not HIV positive and only carers who were HIV positive themselves had been included in our sample. Thus contrary to assumptions that people would be unwilling to talk about their sexual behaviour, with sensitive administration of interviews and sympathetic listening, they were willing to do so. The study was dealing with people in stressful circumstances. They were short of

information on their condition and very rarely had the chance to talk to their doctors or other professionals. In such circumstances it was ethical to spend time after the interview giving information and listening to problems. This applied both to patients and their friends/relatives who were anxious to discuss their doubts and fears (Lee 1993; Morton-Williams 1993).

## 4.4 Analyses

The quantitative data from hospital interviews were entered in SPSS and verified. Verification detected errors during an initial run of frequency tables and they were corrected. *Stat Transfer* was used to transfer data from SPSS to *Stata* for quantitative analysis. The descriptive responses of all respondents were typed verbatim into Word; and voice-recorded interviews were transcribed and typed into Word. These were processed by searching for key words and topics. Detailed case studies were developed from long interviews where appropriate.

### 4.4.1 *Quantitative analysis*

A descriptive analysis of socio-demographic and economic characteristics of HIV-infected people at the two hospitals was performed. Bi-variate analysis was conducted to study associations using Chi-Square test. Fisher's exact test was used to study the significance of associations when cell frequencies were less than five. Fisher's test is similar to Chi-Square except that the probability of the observed outcome or an outcome more extreme is calculated exactly when a table that does not result from missing rows or columns in a larger table has cell frequencies of less than five. To improve the power of the test, we have attempted to reduce Type II error by considering 1% significance level where appropriate.

There was no point in testing the associations between occupation and gender using Chi-square/Fisher's exact test because there is bound to be an association between sex and occupation. This is because we know in advance that the category

‘housewife’ does not have men at all, therefore the association for this category would be perfect. However, we were able to examine the significance of occupation using logistic regression models. Using occupation as categorical explanatory variable we get estimates for effects comparing each category to a reference category, as usual. We however had to take into account that ‘housewife’ referred only to women. We also made sure that the reference category included both men and women. Here the difference to a normal situation is that for category of ‘housewife’ all the respondents have value for women only, that however, does not affect estimation (unless we wanted to include interaction between sex and occupation, which we have not been able to do because of small numbers).

Multivariate analysis, logistic regression and latent class analysis have been performed where appropriate. Some results from logistic regressions are inconclusive because of insufficient sample size, large differences between categories and high DK responses. To improve accuracy and address problems related to data censoring, maximum likelihood ratio tests have been used for testing the significance of a variable when observations were inadequate.

Three-way association of knowledge for different modes of HIV transmission was examined across explanatory variables; four-way associations and other complex models provided could not be computed due to insufficient cell sizes. Associations with socio-economic characteristics such as age, region of residence, media exposure, education, and household were examined within genders.

There were some problems with coding and grouping knowledge variables. For example, Q514 - 532 covering knowledge of HIV transmission were originally coded as high, medium, low or no risk (Appendix B). Following WHO/NFHS categories, we attempted to analyse patient answers in these ways. However patients were unable to discriminate between levels of risk as indicated by heaped responses under high risk and no risk, hence we collapsed these into two categories as ‘no risk’ and ‘risk’.



It would have been ideal to control for time since diagnosis in the analyses however, limitations of recall from retrospective data from patients who were ill raised issues relating to the reliability of time since diagnosis data. We wanted to triangulate responses with medical notes, but although we had access to medical records they were limited and incomplete and hence it was not possible to do this. Evidence from India suggests that HIV diagnosis is not key point in sex life and reported sex and reported date of diagnosis are not related (Rogers *et al.* 2006). For example, patients surveyed said that they might go to CSWs or have sex with wife when not having symptomatic illness. Thus time since diagnosis does not affect sexual behaviour as the cultural imperative was to have sex if free from symptomatic illnesses. Hence we have not been able to control for time since diagnosis.

### ***Latent Class Analysis (LCA)***

Knowledge could not be determined by a single question, it was necessary to ask a series of questions. A simple approach to combining knowledge responses would have been to take the sum of overall scores. However, latent variable models provide a useful method of analysis to classify cases to most likely latent class. LCA defines latent classes by the criterion of "conditional independence." That is, within each latent class, each variable is treated as statistically independent of every other variable. Thus, latent classes are defined such that, if one removes the effect of latent class membership on the data, all that remains is randomness or complete independence among measures.

Latent class analysis is a simplifying device and allows to identify broad regularities in a group of variables to look at systematic features. It allows to look at all items together and provides a simpler method to describe them all together. Testing in latent class analysis is based on observed and expected frequencies and it picks the smallest number of classes that work. We can call the classes low and high based on results in the fact that the codes are 0,1, so probabilities indicate low level of knowledge. Low probability indicates variables for which knowledge was not

made available. Therefore LCA was performed to classify HIV/AIDS knowledge levels.

All variables were treated equally for latent class analysis of knowledge. We did not apply knowledge hierarchy in latent class analysis, therefore treating knowledge variables as mutually independent whilst acknowledging that, in reality, they might not be.

### ***Latent variable models***

Latent variable models were used for multivariate analysis of knowledge variables. A statistical model specifies the joint distribution of a set of random variables and becomes a latent variable model when some of these variables are unobservable (Bartholomew 2002; Bartholomew and Knott 1999). One reason for using this technique is to reduce dimensionality. That is, to convey the information contained in interrelationships of many variables, to a good approximation, in a smaller set. This improves our ability to see the data structure. Latent variable models provide one way to condense many variables with which we start into a smaller number of indices with as little loss of information as possible. In practice one chooses a variety of indicators that can be measured, such as answers to a set of yes/no questions, and then an attempt is made to extract commonalities.

Variables that are directly observed are known as manifest variables (denoted by  $x$ ) and unobserved variables are called latent variables (denoted by  $y$ ). Two models described below are applicable to our survey data.

### ***Latent Trait Models***

The latent variables are conceived as 'traits'. The response variables  $x_i$ 's are binary or ordinal. If dependence among  $x$ 's is wholly explained by  $y$  they may be regarded as mutually independent random variables with

$$P = p_i(y) \quad (x_i = 0, 1; i = 1, 2, \dots, p),$$

where  $p_i(y)$  is called the response function. Since it is a probability,  $0 \leq p_i(y) \leq 1$ . In test theory, where  $y$  is usually a scalar,  $p_i(y)$  is known as the item response function or item characteristic curve. In that context  $y$  represents an ability of some kind, in which case one would expect  $p_i(y)$  to be a monotonic function.

The conditional distribution of  $x_i$  given  $y$  is thus

$$g_i(x_i|y) = \{p_i(y)\}^{x_i} \{1 - p_i(y)\}^{1-x_i} \quad (x_i = 0, 1; i = 1, 2, \dots, p).$$

This distribution is a member of the exponential family; hence the general linear latent variable model for  $q$  latent variables takes the form:

$$\text{logit } p_i(y) = a_{i0} + \sum_{j=1}^q a_{ij} y_j \quad (i = 1..p)$$

It is assumed that the prior distribution of  $y$  is standard normal with correlation matrix  $I$ , then we have the logit/normit model. The parameter  $a_{i0}$  is the intercept in the linear plot of  $\text{logit } p_i(y)$  against  $y$ . The parameter  $a_{ij}$  governs the steepness of the curve; it is known as the discrimination parameter because the bigger the  $a_{ij}$  the easier it will be to discriminate between a pair of individuals a given distance apart on the latent scale. From the fitted model expected latent scores may be calculated from any given combination of  $x$  values.

### ***Latent class models***

The latent class model is a special case of latent trait model in which the prior distribution consists of discrete probability masses. That is, it treats latent space as categorical. All general results, which do not depend on the prior distribution, will apply equally to both models. A further insight into their relationship can be considered with a case of two latent classes ( $k=2$ ). We start with a logit/normit model with a single latent variable,

$$\text{logit } p_i(y) = a_{i0} + a_{i1} y \quad (i = 1, 2, \dots, p),$$

where  $y$  has zero mean and unit standard deviation. Suppose that  $y$  takes two values  $v(1-\eta)/\eta$  and  $-v(\eta)/(1-\eta)$  with probabilities  $\eta$  and  $(1-\eta)$  respectively. It follows that  $E(y) = 0$  and  $\text{var}(y) = 1$  as required. We then have a latent class model with

$$\text{logit } p_{i0} = a_{i0} - a_{i1} v(\eta)/(1-\eta) \quad \text{and} \quad \text{logit } p_{i1} = a_{i0} + a_{i1} v(\eta)/(1-\eta)$$

For class 1, corresponding to  $y = v(1-\eta)/\eta$ ,

$$p_{i1} = \frac{1}{1 + \exp \{-a_{i0} - a_{i1} v(\eta)/(1-\eta)\}}$$

and for class 0,

$$p_{i0} = \frac{1}{1 + \exp \{-a_{i0} + a_{i1} v(1-\eta)/\eta\}}$$

These equations relate the class-specific response probabilities of the latent class model to the intercept and slope parameters of the latent trait model. If, for example, we estimate  $p_{i0}$ ,  $p_{i1}$  and  $\eta$  using a latent class model, we could express them as latent trait parameters. How close they turn out to be will give some indication of how sensitive the estimates are to the choice of prior distribution. From the fitted model posterior probability of class membership given  $x$  may be calculated.

The package TWOMISS, developed by the Statistics Department at London School of Economics, has been used to reduce the dimensionality of observed items and allocate individuals to exhaustive and mutually exclusive classes based on their responses to observed items. The package is suitable for one or more latent variables. It can also handle missing data. The individuals here have been allocated to low,

medium or high classes of knowledge based on their responses to whether or not HIV could be transmitted through various modes.

We obtained estimated probabilities,  $E(y)$  from the model, of belonging to a certain class for each individual. The goodness-of-fit for the models has been evaluated using log-likelihood ratio statistic ( $G^2$ ) and, when this alone could not be relied on, the observed and expected margins of individuals with each response pattern were compared. Estimated probabilities have been used to determine the association between knowledge categories and selected socio-demographic characteristics.

#### 4.4.2 *Qualitative Analysis and Case Studies*

Qualitative data collection and analysis were a secondary focus of this research project. We used qualitative analysis to add depth and meaning to results of the quantitative analysis, especially in understanding the intricacies of sexual behaviours (Carey 1993; Kvale 1996; Steckler *et al.* 1992; Thomas *et al.* 2004; Whyte and Alberti 1993; Wolff *et al.* 1991). Open-ended answers and spontaneous comments were helpful to investigate the complex cultural issues in a regional context and for interpretation. The longer interviews were coded to establish links between the quantitative and qualitative data (Robson 1993). Additionally, we have examined possible quantitative analyses to increase the trustworthiness of our qualitative findings and vice versa.

A summary sheet was recorded for each of our 292 respondents in a Word document. The transcribed text of voice-recorded answers and all responses to open ended questions were analysed by classifying the data into themes and sub-themes in order to understand the range of meanings attached to different attitudes and practices, such as condom use or attitudes about HIV/AIDS infection (Miles and Huberman 1994; Tesch 1990; Ulin *et al.* 2002). Eighty seven among the 292 respondents provided in-depth descriptions to open-ended questions and have

comprised key informants for quantitative analyses and to build case histories (Mills *et al.* 1998). Key quotations were selected to illustrate themes and behaviours related to our research questions. Further, case studies of lorry drivers, female sex workers, *hijra*, construction workers and hotel workers presented detailed data on their high-risk practices, and they were representative as key informants (Robson 1993). A limited amount of participant observation in the hospitals was instrumental in understanding and interpreting patients' behaviours. Responses to open-ended questions were coded for quantitative analysis but also analysed qualitatively to supplement the quantitative data (Moser and Kalton 1971).

Qualitative analysis was instrumental in effectively utilising the abundant information provided by respondents through their responses to open-ended questions on sexual behaviour. The combination of the two methods highlighted the discrepancies between the underlying assumptions of the survey questionnaire and those of the respondents, which neither method could have produced alone (Holstein and Gubrium 1999; Miles 1985; Rossman and Rallis 1998; Sieber 1973). The flexibility was possible since all interviews were conducted by the researcher.

We followed the method suggested by Ulin *et al.* (2002) and Robson (1993) for analysis of exploratory and descriptive case study frameworks by developing case descriptions and working toward an *issue analysis*. That is, to look for a set of themes or areas, linked to the research questions. For example, to understand why our respondents did not use condoms, we had to collect together all references to condoms and to set them in their different contexts in order to give a balanced and varied description of condom use and the physical and cultural barriers that were limiting preventive behaviours.

In-depth interviews with members of groups where infection rates were high were analysed separately. The most forthcoming patient in each group was treated as a key informant (Yin 1989) and presented as a case study. These in-depth interviews provided explanatory details supporting our research questions. Much of the

information provided was replicated by those who gave less detailed interviews, and by other members of the group. These case studies were therefore representative of each of the sub-groups.

The decision to use qualitative data had its share of problems and weaknesses. Collecting and analysing qualitative data was highly labour-intensive, demanding and stressful (Miles and Huberman 1994; Van Maanen 1985). Sometimes respondents might have left something unsaid due to cultural biases. For example, after over an hour of interviewing a 59-year-old lady, I discovered that she had refrained from saying that she was a CSW but reported herself to be a housewife. In this case a longer in depth interview allowed survey data to be corrected but other inaccuracies may have remained.

## 4.5 Summary

The study was based on a purposive sample of PLWHA (Scheper-Hughes 1997), most easily identified in hospitals and clinics testing for HIV and/or treating it. Hence face-to-face exploratory long interviews of 292 HIV/AIDS patients at GHTM and CMC between March-June 1999 comprised our primary data. For this purpose our survey instrument was a questionnaire containing intensive closed and open-ended questions, which replicated existing large-scale survey instruments wherever possible.

The questionnaires used as templates for this study were, in parts, insensitive to country-specific social and cultural context. Hence our survey suffered from the inadequacies caused by reliance on such questionnaires. We should not have depended on WHO questionnaire as heavily as we did on this occasion deeming it to be the accepted international standard. Some problems were addressed during face-to-face interviews and questions which could not be resolved have been eliminated from analyses.

Secondary sources were difficult to acquire and those available were not free from weaknesses. Large-scale studies were useful for some information, but in-depth studies among smaller groups, such as this, were essential to produce knowledge of behaviours that could be used to assist in intervention programs among PLWHA. NFHS and NACO surveys of the general population were the best available background studies and were useful for comparisons with our survey results.

This research used data and methodological triangulation to improve validity and reliability. Both quantitative and qualitative analysis techniques were used to study levels of knowledge, attitudes and reported sexual practices among PLWHA. Studying sexual behaviours in a social and cultural context was challenging for collecting information. Stigma associated with HIV/AIDS in India only added to the complications of such a study (Mawar *et al.* 2005).



# Chapter 5      CHARACTERISTICS OF SAMPLE SURVEYED OF PLWHA

The importance of estimating HIV prevalence levels and the associated limitations in India are firstly discussed in this chapter. This is followed by detailed analyses of the socio-demographic and economic characteristics of our survey of PLWHA. The two hospitals, namely GHTM and CMC in Tamil Nadu are described and compared.

## 5.1      HIV Prevalence

Estimating the prevalence levels is helpful for not only knowing the extent of the epidemic but also to plan prevention strategies. Hence in this section we examine issues related to HIV prevalence in India. Some studies show declining trends in HIV cases in some parts of south India. However, prevalence estimates in India are based on sero-surveillance reports, and studies have often raised concerns about accuracy of these estimates.

When first confronted with the presence of the HIV/AIDS virus, almost every community in the world has reacted by denying the problem (MAP 1997). Denial together with neglect results in time delays for implementing preventive action, while the epidemic gains in intensity in a short period. India was no exception in typically showing complacency and denial (Ammann and Nogueira 2002; UNAIDS 2000d). When HIV was first detected in a patient from Mumbai in 1986, delays in

combating the problem followed, with officials trying to blame it on foreign origin. The source for the early infections were blamed on sexual contact with foreigners (Pavri 1990; Ramachandran 1992; Simoes *et al.* 1987). However one study providing evidence of infection showed that 61 patients diagnosed to have AIDS in Vellore during 1992 had no experience of foreign contact indicating that the infection was prevalent in the region (John 1993).

One weakness of official statistics arises because the generalised HIV/AIDS epidemic in India is measured by Sentinel Surveillance sites with prevalence reported at selected STD and antenatal clinics (NACO 2002) and based on only a limited number of specified sites in each state (only 10 such sites in TN according to NACO (2000)) and limited in scope (Hawkes and Santhya 2001; Kadiyala and Barnett 2004; Rowley and Berkley 1998; WHO 1998). The number of sites have been increased, however, biases arise because the sites were confined solely to major government run hospitals and do not include primary health care centres in rural areas or private medical practitioners, used widely by those who can afford to see private practitioners (Barnett and Whiteside 2006; Chandrasekaran *et al.* 2006).

In the Indian context people may resort to self-treatments and do not go to a clinic/hospital in the first instance. For example, NACO (2002) estimated that only 5-10% of patients, both poor and wealthy, with STDs sought public sector care. Hence reported cases of HIV/AIDS/STD caused by sexual activities might have been grossly underreported (Mudur 2000). NACO (2002) itself admitted that it was difficult to estimate the exact prevalence of HIV given the varied cultural characteristics, traditions and values surrounding sexual behaviours in India, as they stated in June 2001:

Data on HIV sero-surveillance has been withdrawn because of gross underreporting. Further, based on scientifically valid HIV sentinel surveillance in place in 232 sites in the country, which provide insight on total disease burden in the country from time to time, the sero-surveillance data has limited value.

In India AIDS is not a notifiable disease, so that medical staff are not legally required to report cases. Further, problems associated with cultural attitudes when studying sensitive topics, such as sexual behaviour, could result in inaccuracies. Stigma associated with the disease increases unwillingness, by patients, their families and medical staff, to report cases (Barnett and Whiteside 2002; Lee 1993). The statistics collected are socially and geographically limited to certain groups and areas. For example, younger women will be over represented at antenatal clinics as they are more sexually active and more likely to become pregnant, and HIV positive women will be underrepresented as HIV infection reduces fertility and could be under-representative (Barnett and Whiteside 2002; UNAIDS 2000b). On the other hand, a population based study in Andhra Pradesh, suggested that the official sentinel surveillance based methods lead to overestimation of the HIV estimates due to extra HIV estimates from STI clinics, common practise of referral of people in lower socio-economic strata (Dandona, L *et al.* 2006; Dandona, L. *et al.* 2006). Barnett & Whiteside (2002) suggest that NACO data included people who were tested more than once and/or in different localities and resulted in double counting. This further contributes to the problems of estimating the level of the epidemic, and the lack of knowledge about the real number of HIV positive cases is a deterrent to analysis of the demographic implications of the epidemic (Elliot 1998).

India's AIDS case surveillance system attributes 86% of HIV infections to sexual risks, 2.4% to injection drug use, 2.0% to blood transfusions, 3.6% to *peri*-natal transmission, and 6.0% to others or not specified. To assess the reliability of this information, Correa and Gisselquist (2006) examined the process of AIDS case surveillance in four high HIV-prevalence districts in southern India. They reviewed forms and interviewed doctors, counsellors, officials of State AIDS Control Societies, and a convenience sample of people living with HIV/AIDS. Their findings suggest that surveillance practices were not sensitive to parental exposures; forms had no space to report blood exposures other than transfusions and injections, and counsellors ignored *peri*-natal risks. The system did not distinguish high from lower

risk sexual behaviours; all cases with sexual risks were reported in one category. These authors therefore propose changes in forms and practices to improve the reliability and usefulness of information on risks from AIDS case reporting.

According to Rao (2003) projecting HIV cases on the annual NACO estimates is not reliable, because such predictions are based on no more than a simple trend analysis and does not contain biological and epidemiological information. He suggests that the spread of HIV may be modelled by considering behavioural changes among the population at risk. However, in the absence of well-quantified behavioural parameters from various parts of India, these models will not account for HIV spread adequately. Cultural diversity and geographical variations introduce uncertainty into the estimation, making prediction a challenging task. Behaviour surveillance surveys by NACO in 2002 reported reductions in risk behaviours of high-risk groups in some parts of the country. Decreases in risk behaviours would further invalidate projections. The problem of estimating the sizes of high-risk groups remains. All these contribute to the problems of collecting reliable HIV/AIDS data in India.

## 5.2 Socio-Demographic and Economic characteristics of HIV/AIDS patients surveyed

In this chapter we describe the socio-demographic and economic characteristics of HIV/AIDS patients. Such information is important if we are to understand the differing impact of the disease according to socio-economic status. The socio-demographic characteristics, such as age, sex, marital status, education and occupation, of all the 292 patients surveyed have been consolidated. Where appropriate, patient characteristics were compared with data from the state of Tamil Nadu (TN) from the census and National Family Health Survey (NFHSTN-1998 2001). Only total population and rural/urban population results from Census 2001 were available during the time of this analysis. For all other comparisons with census

we used the data from TN census n 1991. Fifty among the 292 patients surveyed travelled from AP, but we have not disaggregated them for our analysis. Data from all patients surveyed in TN, represented 8% of total registered AIDS cases in TN in 1999. The socio-economic status from our survey is compared with census data.

### 5.2.1 Sex ratios

The survey of PLWHA was not representative of the gender structure in the population of TN (Tab. 5.1). The survey of HIV patients at the two hospitals showed that over twice as many men as women were HIV positive. On the other hand, the population in TN according to Census and NSHS-1998 exhibited near equal sex ratios.

**Tab. 5.1 Sex structure of PLWHA, patients survey, compared with TN Census and NFHS**

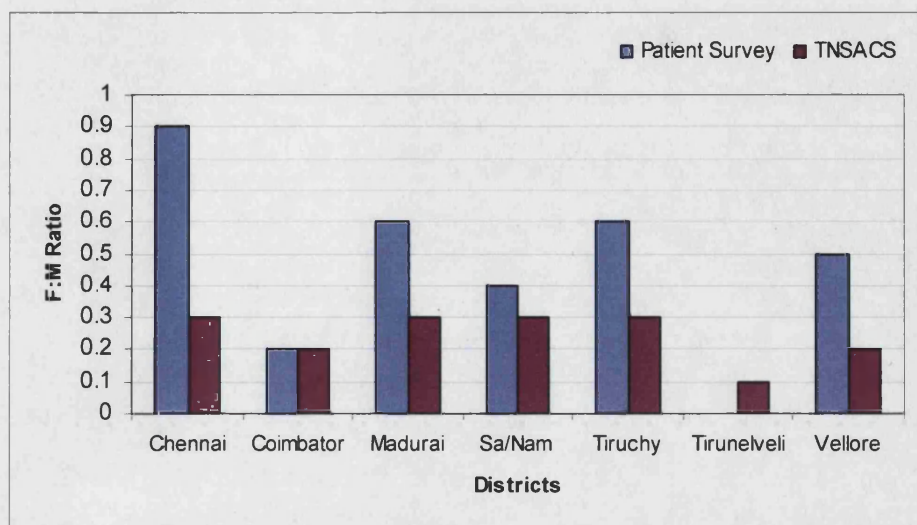
	TN Census			NFHS (TN)-1998			HIV patients 1999		
	M	F	Ratio	M	F	Ratio	M	F	Ratio
<b>Total</b>	17246805	17062087	1.01	6505	7015	0.93	198	94	2.11

**Source: Population from Census 2001; NFHS (TN)-1998**

Fig. 5.1 below compares sex ratios for patient survey with unpublished data made available with permission for research purpose to the author by Tamil Nadu State AIDS control society (TNSACS). In 1999, TNSACS had not counted PLWHA at GHTM or CMC in this surveillance, which was part of the methodological problems with their estimates.

The sex ratio of HIV patients was not unexpected since the prevalence data indicated higher HIV prevalence among males, and might also be indicative of better access to treatment for men. In terms of place of origin of surveyed HIV patients, the near unity of female: male ratios among patients from Chennai can be explained in part to the fact that GHTM is located in Chennai and hence might have been more accessible for women.

**Fig. 5.1 Female to Male ratios by District of origin: Patient Survey compared with TNSACS data**



**Source: Patients – own PLWHA survey; TNSACS: unpublished report TNSACS (1999)**

The female: male ratio for patients from AP was low (0.2). This bias against women was not surprising since travelling to these specialised hospitals in TN has a high cost (both financial and opportunity), which is more accessible in favour of men. Men, who tend to be household income providers, tend to have priority in seeking treatment in an Indian setting. It was observed at least 10 times during fieldwork that HIV positive wives attending their husbands at GHTM would not be registered for treatment although they were staying in the hospital. Further, men stated that they chose not to tell their wives or families about their HIV status so there were almost certainly women who were HIV positive but did not know their status.

Our patient survey includes *hijra* (6), who are treated as a third gender in India. *Hijra* were admitted to women's ward at GHTM and we have counted them among women in deference to their request, except when studying details about knowledge and behaviours for better understanding since they were of different scales.

### 5.2.2 Rural – Urban distribution

The population of TN is predominantly rural, while HIV patients surveyed were overwhelmingly urban (Tab. 5.2). Testing the association of total population in rural and urban compared with total patients in rural and urban areas showed that patients surveyed were significantly more urban ( $\chi^2_1 = 27.6 > \chi^2_1(\alpha=0.05) = 3.84$ ) compared to the population. In reality it is likely that an even higher proportion of male patients originated from urban settings, since many came from *peri*-urban areas (small satellite towns between urban and rural areas) but were recorded in the survey as rural (AIDS-INDIA 2004c). This was a shortcoming of the survey data. On the other hand, patients from rural areas could be under-represented in the survey. This introduces caution to interpretations of analyses by place of residence.

**Tab. 5.2 Place of Residence of PLWHA compared with TN Census and NFHS**

Region	TN Census				NFHS (TN)-1998				HIV patients 1999			
	Male		Female		Male		Female		Mal=198		Fem=94	
	n	%	n	%	n	%	n	%	n	%	n	%
Rural	11041638	64	11133707	65	4228	65	4630	66	94	48	40	43
Urban	6205167	36	5928380	35	2277	35	2385	34	104	52	54	57

Source: Population from Census 2001; NFHS (TN)-1998

A higher proportion of HIV positive women were from urban areas due to easier accessibility to a hospital and partly to the fact that all surveyed female commercial sex workers and *hijra* were urban.

### 5.2.3 Age distribution

A higher proportion of HIV positive patients surveyed belonged to the 25-44 year age group compared to the population (Tab. 5.3). The test for association between total population according to age groups with the number of patients in the corresponding age groups showed this difference in age structure between population and HIV patients to be significant ( $\chi^2 = 114.3 > \chi^2_2(\alpha=0.05) = 5.99$ ). The majority of

HIV patients (83% men and 72% women) were aged between 25 and 44 years, which is typical of the nature of HIV infection.

**Tab. 5.3 Age distribution of PLWHA compared with TN Census and NFHS**

Age	TN Census		NFHS (TN) -1998		HIV patients 1999	
	M%	F%	M%	F%	M%	F%
15-24	31	32	28	31	7	20
25-44	47	47	52	48	83	72
45-59	22	21	20	21	10	8

Source: Population from Census 1991; NFHS(TN)-1998

In keeping with national age distribution of infection, female HIV positive patients surveyed were infected at younger ages compared to men, with 68% of women infected by age 30 (see section 3.1.1). There was a significant difference between the ages of male and female patients ( $\chi^2_2=22$ ,  $p=0.005$ ). The mean age of female patients (29 years) was lower than that of males (33 years) by four years. This is due in part to earlier sexual debut as a result of younger age at first marriage for women compared to men (Tab. 5.5).

#### 5.2.4 Marital Status

Comparison of marital status of all HIV positive patients surveyed originating with total population from TN census showed significant ( $\chi^2=139.0 > \chi^2_3(\alpha=0.05) = 7.82$ ) differences in marital structure (Tab. 5.4). This was partly because the rates of separation and divorce were higher among patients because it was common for a woman's parents to take her and any children, to live with them if a husband was HIV positive, especially within the first couple of years of marriage.

**Tab. 5.4 Marital Status of PLWHA compared with TN Census and NFHS**

Marital Status	TN Census		NFHS(TN)-1998		HIV patients 1999	
	M %	F %	M %	F %	M %	F %
Never Married	36	20	44	32	32	11
Married	62	72	53	53	64	49
Separated/Divorced	<1	1	<1	2	3	9
Widowed	2	7	3	13	1	31

Source: Population from Census 1991 (15-59 years); NFHS(TN)-1998 (all ages)



The major difference in marital status between female patients and the state level population was the high levels of widowhood (31%) among the HIV positive sample, unsurprising given the expected mortality differentials of their husbands. In fact if we eliminated the difference between observed and expected frequencies among widows, the proportion of married women was found to be identical to the state-level population.

**Tab. 5.5 Marital Status of PLWHA by Gender, patient survey, 1999**

Marital Characteristics	HIV patients 1999					
	Male		Female		Total	
	n	%	n	%	n	%
<b>Marital Status**</b>						
Never Married	64	32	10	11	74	25
Married	127	64	46	49	173	59
Separated/Divorced	5	3	9	9	14	5
Widowed	2	1	29	31	31	11
<b>Age at marriage**</b>						
<18	0	0	28	33	28	13
18 – 21	25	18	42	50	67	31
22 – 25	52	39	12	14	64	29
26 – 30	44	33	2	3	46	21
>30	13	10	0	0	13	6
<b>Age of Spouse at marriage**</b>						
<18	23	17	0	0	23	11
18 – 21	35	26	12	16	47	23
22 – 25	31	23	17	23	48	23
26 – 30	22	17	16	22	38	18
>30	23	17	29	39	52	25

\*\*p<0.05

Women were married at significantly younger ages compared to men (Fisher's Exact test (4df)=115.12, p<0.001) (Tab. 5.5). Almost all women had married by 25 years compared to just over half the men, likely in part to be an outcome of women's lower education level and economic status (see Tab. 5.7 and Tab. 5.12).

The lower age at marriage of women was also reflected in 'Age of spouse at marriage' and age at marriage of women were significantly lower for women compared to men as reported by their spouses (Fisher's Exact test(4df)=28.4, p<0.001). The proportions for 'age at marriage' and 'age of spouse at marriage' were

asked of all patients who were married. Fourteen percent of married women said that they did not know the age of their husbands.

A fifth of the women and a third of the men surveyed were unmarried (Tab. 5.5). This might have been aided by the fact that TN is one of the more urbanised and educationally advanced states (NFHS 2000). In a few cases delayed marriage among men could imply homosexual behaviour, which was admitted to being practised by 5% of the male patients.

Unmarried patients often said 'I will not marry until I am cured'. While this was good, it also caused concern that infection levels could be escalated through having multiple sex partners or getting married under personal or social pressure, when they were in remission symptomatically. A case in point was *Subbu*, a 26-year-old lorry driver from Trichy (3<sup>rd</sup> April 1999):

He said his cousin sister and he liked each other and were considering marriage. Awareness of HIV among his colleagues caused him to go for a HIV test and he was found to be positive. Due to the stigma associated with the disease he was unable to tell his cousin and severed all contact with her instead. Only his parents knew about it and were abiding by his decision to put off marriage 'until he was cured'. He went back to driving a lorry and got admitted at GHTM for treatment as and when required. When he was not seen in the village for a long time rumours spread that Subbu had gone to see another girl for marriage. His cousin on hearing this consumed poison and was taken to hospital. Subbu was at GHTM when he was told this news.

All patients (n=14) who reported being separated had become so as a result of HIV/AIDS. It was either because men continued being promiscuous with more than one regular partner, 'he is a *pombalai poruki* (female picker)' as *Pavai*, a 32-year-old woman said about her husband (19<sup>th</sup> May 1999); or that the woman's parent's had taken her back to their home for her protection. Thus *Mala*, aged 28, originally from Vellore town, had lived with her husband for four years in Mumbai. She said (28<sup>th</sup> May 1999): 'He used to drink too much, take drugs and go to CSWs hence my

mother brought me and my three daughters to live with her'. Women faced greater social disadvantages due to HIV/AIDS.

### 5.2.5 Education Levels

As in the general population, male HIV positive patients had considerably higher literacy compared to women (Tab. 5.6). HIV patients reported higher literacy rates compared to the state-level population however these data were not strictly comparable but provide broad indicators, because census and NFHS-1998 measured illiteracy as those who could neither read nor write while the HIV positive patients survey classified literates as those who could sign their name.

**Tab. 5.6 Education levels of PLWHA compared with TN census and NFHS**

Education	TN Census		NFHS(TN)-1998		HIV patients 1999	
	M %	F %	M %	F %	M %	F %
Literacy rate	82	65	80	58	96	75
Education						
Below Primary	23	28	20	41	8	31
Primary	49	51	39	32	49	42
Secondary	21	17	30	20	35	22
Higher	7	4	11	7	8	5

Source: TN Population from Census 2001 and NFHS(TN)-1998

The higher education level of men according to NFHS and patient survey, compared to census, could be a consequence of rapid improvements in recent years with regard to educational attainments in TN. However the improvements among women were still unsatisfactory. The association between all patients surveyed compared to TN census showed education levels of patients to be significantly higher than that of the population ( $\chi^2_3 = 2.81 < \chi^2_3(\alpha=0.05) = 7.82$ ). Patients showed evidence of a higher average educational level compared to the general population and twice as many patients reported secondary or higher schooling compared to data on population at the state level (Tab. 5.7).

**Tab. 5.7 Education levels of PLWHA, patient survey, 1999**

Education	HIV patients 1999					
	Male=198		Female=94		Total=292	
	n	%	n	%	n	%
<b>Literacy- Can Resp. sign? **</b>						
Yes	191	96	70	75	261	89
No	7	4	24	25	31	11
<b>Education**</b>						
Below Primary	20	10	30	32	50	17
Primary	89	45	40	43	129	44
Secondary	66	33	19	20	85	29
Higher	23	12	5	5	28	10

\*\*p<0.05

Women patients surveyed reported significantly lower education levels compared to their male counterparts (Fishers Exact Test (3df)= 22.85, p<.001). Although the majority (90%) of HIV positive patients surveyed had completed only up to secondary schooling, it cannot be assumed that HIV was restricted to people with low to medium schooling. Analyses elsewhere in India of *sero*-status and educational level among STD clinic and ANC attendees indicated high HIV prevalence (8.0%) among those with graduate level education compared with prevalence rates of 2.2% for illiterates (NACO 1999).

### 5.2.6 Occupation

The occupational categories (Tab. 5.8) were constructed based on those in TN census to make our data easily comparable. Commercial sex workers from patients sample were included among labourers, as was the practise for census. In comparing occupational categories of all HIV positive patients surveyed with the total state population, we found that they were significantly different ( $\chi^2_5 = 62.8 < \chi^2_5(\alpha=0.05) = 11.07$ ) (Tab. 5.8). The differences in the two groups were mainly because of the higher representation of occupational groups considered to be at higher risk of HIV infection (for example lorry drivers, commercial sex workers) among the HIV/AIDS patients.

**Tab. 5.8 Occupation by Gender of PLWHA compared with TN Census**

Occupation	TN Census			HIV Patients 1999		
	M%	F%	T%	M%	F%	T%
Farmer/Cultivation	29	21	27	10	3	9
Labourer	26	54	35	40	63	45
Trade & Commerce	11	3	9	5	19	8
Construction	3	1	3	7	7	7
Transport/Storage	4	<1	3	16	0	12
Prof/Office/Students	27	20	23	22	8	19

**Source: Population from Census 1991. 'Housewife' from PLWHA, patient survey not included for comparability since they were treated as non-workers in Census.**

The detailed distribution of patients' occupational groups giving their usual occupation before being tested HIV positive is presented below. They not only represent the main groups but also provide evidence from the survey of those who were likely to be at high risk of acquiring HIV/AIDS (Tab. 5.9). Labourer included agriculture, weavers and tailors in rural areas, while in urban areas they comprised of *coolies*, auto-rickshaw drivers and housemaids. Although representing different categories in rural and urban areas, 'labourer' was classified to represent a similar socio-economic and occupational category. Women traders included those who sold products at train station platforms, slept rough and were exposed to high-risk sexual behaviour. It was evident from our group of HIV positive patients that there was high representation of certain kinds of occupation categories such as lorry drivers and CSW. HIV infection was reportedly high among lorry drivers, construction workers and labourers.

Over a third of female HIV positive patients surveyed were labourers and more than one in ten were CSWs. Apart from the well known high-risk groups of lorry drivers and CSWs (which included *hijra*), a significant number of construction workers (19) and hotel workers (11) were among the HIV positive patients surveyed.

Among all patients surveyed, over a third of the women were housewives (Tab. 5.9). They typically represented the spread of HIV through unprotected marital sex as a result of the culturally vulnerable status of women. Spousal occupation was also

recorded, and a fifth of all ever-married female HIV positive patients surveyed had husbands who were lorry drivers, in the army or police force, and in the hotel trade, all of who lived away from their wives for prolonged periods.

**Tab. 5.9 Usual occupation of PLWHA before being tested HIV positive, patient survey, 1999**

Occupation	HIV patients 1999					
	Male=198		Female=94		Total=292	
	n	%	n	%	n	%
Housewife	0	0	35	37	35	12
Labourer/Trader	80	40	35	37	115	39
Office/Prof/Business	42	21	5	6	47	16
Farmer	20	10	2	2	22	7
Construction	15	8	4	4	19	7
Lorry Driver	32	16	0	0	32	11
Hotel Worker	9	5	2	2	11	4
CSW	0	0	11	12	11	4

**Table Note: 'Occupation' for men did not include the category 'housewife' hence there was no point in testing this using chi-square statistic. There is bound to be an association between sex and occupation since the association is perfect for the category of housewife.**

A fourth of HIV patients surveyed said they could not continue their former occupations since being diagnosed as HIV positive (Tab. 5.10). A majority of men were still registered employed and either worked off and on (47%) or were on prolonged leave without pay. Some others were on daily wages, which meant no pay without work.

**Tab. 5.10 Current Occupational Status of PLWHA after being tested HIV positive**

Are you able to do normal work?	HIV patients 1999					
	Male=198		Female=94		Total=292	
	n	%	n	%	n	%
Unable to work since HIV+	52	26	24	25	76	26
Unchanged employment situation	122	62	27	29	149	51
Farm/Trade being managed by Family	16	8	1	1	17	6
Housewife/Dependent	3	1	40	43	43	15
Changed to less tiring work	5	3	2	2	7	2

**Not tested for association due to big differences between categories for men and women**

### 5.2.7 Household composition and living standard

The average reported household size before being tested HIV positive was 4.8 members (std. dev. 2.5), which compared with the mean household size for TN of 4.3 persons (NFHSTN-1998 2001) (Tab. 5.11). In the absence of any social support larger household size could have the advantage, although by no means guaranteed, that larger numbers of family members might provide care, both financial and social to HIV positive patients.

**Tab. 5.11 Household composition prior to HIV diagnosis, Patients surveyed, 1999**

	HIV patients					
	Male=198		Female=94		Total=292	
	n	%	n	%	n	%
<b>Family Type§</b>						
Joint	129	65	63	67	192	66
Nuclear	69	35	31	33	100	34
<b>Number of family members living together</b>						
1 – 2	21	11	23	25	44	15
3 – 4	75	38	35	37	110	38
5 – 6	65	33	19	20	84	29
7 – 9	26	13	15	16	41	14
>= 10	11	5	2	2	13	4

§ Joint - living with extended family; Nuclear – couple and children only living together

There was evidence of lowering of income levels as a result of HIV (Tab. 5.12). This was particularly evident among men, where a majority reported medium income levels before they became ill, compared to low-income level at the time of the survey representing their income after they had been tested HIV positive. Household income is a function of household composition and would vary by household size. However the circumstances of PLWHA had changed since being tested positive as they had to move out due to stigma etc and family size was unclear under the circumstances and could not be used meaningfully for this purpose.

**Tab. 5.12 Household income, by sex, PLWHA**

	HIV patients 1999					
	Male=198		Female=94		Total=292	
	n	%	n	%	n	%
<b>Household income** ^</b>						
Low	107	54	73	78	180	62
Medium	64	32	19	20	83	28
High	27	14	2	2	29	10
<b>Income before testing HIV+ (Rs.)**</b>						
Low	54	27	73	78	127	44
Medium	101	51	19	20	120	41
High	43	22	2	2	45	15
<b>Current source of Income</b>						
Personal savings/property	12	6	6	6	18	6
Depend on spouse/children	9	5	20	21	29	10
Depend on parents/relatives	42	21	30	33	72	25
Continuing in work	116	59	20	21	136	47
Employer supports	1	<1	0	0	1	<1
Social worker supports	0	0	6	6	6	2
Nothing to depend on	17	9	12	13	29	10

**\*\*p<0.05. Fisher's exact test used to test association between men and women for Household income and Income when working.**

**Did not test association for Current source of income due to big differences between men and women**

**^: Income levels were categorized as follows - Low (below INR4000); Medium (4000-10000) & High (above 10000). These categories were based on objective official income categories at the time.**

Comparison of household standard of living indicators between population and patient's surveyed indicated HIV positive sample to have lower levels compared to household standard of living indicators according to NFHS-1998 (Tab. 5.13). Indicators for type of house and amenities were same for our patient's survey and NFHS-1998. Indicator for standard of living index (STI) in NFHS was calculated based on house type, toilet facility, source of lighting, main fuel for cooking, source of drinking water, whether respondent had separate kitchen, ownership of house, ownership of agricultural land, ownership of irrigated land, ownership of livestock and ownership of durable goods. Data related to household characteristics was incomplete in our patient survey because the sample of PLWHA was of people in unusual circumstances. Hence we have been able to categorise income levels as - Low (below INR4000); Medium (4000-10000) & High (above 10000), based on



official income categories at the time. Thus STI from NFHS and household income from patient survey were calculated differently and can only be compared broadly.

**Tab. 5.13 Household standard of living indicators, by place of residence, PLWHA patient survey data compared with state-level data**

	NFHS(TN)-1998		HIV patients 1999	
	Urban %	Rural %	Urban %	Rural %
<b>STI/Household Income+</b>				
Low	23	51	63	61
Medium	51	40	26	31
High	25	8	11	8
<b>Type of House<sup>‡</sup></b>				
<i>Kachha</i>	17	43	25	42
<i>Semi-Pucca</i>	39	38	36	39
<i>Pucca</i>	44	19	39	19
<b>Amenities</b>				
Electricity	91	73	90	82
Safe drinking water	89	83	88	80

Source: NFHS(TN)-1998

+ STI (Standard of Living Index from NFHS was classified as 0-14 =Low, 15-24=Medium, 25-67=High according to NFHS). Household income from our survey of PLWHA was classified as - Low (below INR4000); Medium (4000-10000) & High (above 10000).

‡ Pucca – concrete roof and walls, Kachha-thatched roof and mud walls, Semi-Pucca-titled roof and stone walls

**Tab. 5.14 Household Amenities & Possessions, by sex of PLWHA**

	HIV patients 1999					
	Male=198		Female=94		Total=292	
	n	%	n	%	n	%
<b>Type of House</b>						
<i>Kachha</i>	52	26	40	42	92	32
<i>Semi-Pucca</i>	77	39	28	30	105	36
<i>Pucca</i>	69	35	26	28	95	32
<b>Amenities &amp; Possessions</b>	179	90	74	79	253	87
Electricity	174	88	85	90	259	89
Safe drinking water	146	74	55	59	201	69
Electric Fan	120	61	38	40	158	54
Radio/Tape recorder	122	62	34	36	156	53
Bicycle	117	59	39	41	156	54
Television	50	25	10	11	60	21
Scooter/Motorcycle	114	58	38	40	152	52
Furniture (Cot, wardrobe)	14	7	7	7	21	7
Fridge	4	2	2	2	6	2
Washing machine	9	5	2	2	11	4
Video Cassette Recorder	7	4	1	1	8	3
Car						

The HIV patients surveyed were poorer compared to state-level population wealth, regardless of indicator – STI/household income, type of house and household amenities (Tab. 5.13). Ownership of amenities and possessions of HIV positive sample was consistent with the fact that overall only 10% was from high income group. Hence only 16% of overall patients surveyed reported owning a fridge/washing machine/video cassette recorder or car (Tab. 5.14). There was no significant difference between genders.

### 5.2.8 Religion

The majority of all patients surveyed were Hindus (Tab. 5.15). The distribution of HIV patients from TN across the three religious categories were representative of the corresponding proportions in the population.

**Tab. 5.15 Religion of PLWHA compared with TN Census and NFHS**

Religion	TN Census		NFHS(TN)-1998		HIV patients 1999	
	M%	F%	M%	F%	M%	F%
Hindu	89	89	87	89	88	93
Muslim	5	5	7	5	6	0
Christian	6	6	6	6	68	7

Source: Census 1991; NFHS(TN)-1998

Religion and faith in God was found to be important to patients for their psychological comfort when confronted with a diagnosis of HIV/AIDS. A case in point was *Mala* aged 25 (19th May 1999),

“My husband had fever and rashes and went to CMC. He was tested HIV positive. I was then tested and the result was negative. I did not know anything about HIV, and did not follow any advice they gave at the hospital. I had contact with my husband, got pregnant and went to antenatal clinic at CMC. When they tested me, I was found to be HIV positive. I could not stop crying and did not know what to do. The social worker spent time talking to me and encouraging me. We desperately wanted to have the baby and the social worker said that it is not 100% chance that the baby would be HIV positive and she prayed for me. I am a Hindu but I thank Jesus that our child is born without HIV.”

There were no Muslim HIV positive women among patients surveyed and we also found that Muslims were rarely reported in the high-risk occupation categories. This could mean that infection rates were lower among Muslims and hence women belonging to this faith had been largely spared HIV until 1999. However we do not have enough evidence to be conclusive either way since the number of Muslims represented here were few and this requires further investigation.

### 5.2.9 Medical Care facilities

Available medical care was important to study in the context of HIV/AIDS. For this we examined the distance to the nearest health care facility they used and the type of most used health care facility as reported by HIV positive patients. Most HIV positive patients (70%) reported that they used government hospitals together with private clinics (used for as first stop for any ad hoc complaints) (Tab. 5.16). Private clinics were usually small, mainly single doctor clinics in local neighbourhoods. Urban patients had better options in terms of available health care (Fishers exact test (4df)=25.04,  $p<0.001$ ) and better access (Fishers exact test (3df) =14.12,  $p=0.003$ ). However as reported by patients, while they had access to medical care, they were often refused care for HIV/AIDS.

**Tab. 5.16 Health care facilities by place of residence, PLWHA, patient survey, 1999**

	HIV patients 1999					
	Rural		Urban		Total	
	n	%	n	%	n	%
<b>Most used health care facility**</b>						
Primary Health Centre	4	3	n/a		4	1
Mainly Govt. Hospital	39	29	15	10	54	19
Govt. Hosp& Private clinic	79	59	125	80	204	70
Govt. Hosp & Private Hosp	11	8	13	8	24	8
Mainly Private Hospital	1	1	4	2	5	2
<b>Distance to health care**</b>						
< 1 km	29	22	56	36	85	29
1 – 5 km	73	54	85	54	158	54
5 – 10 km	21	16	13	8	34	12
> 10 km	11	8	3	2	14	5

\*\* $p<0.05$

### 5.2.10 *The Distribution of HIV/AIDS patients surveyed by Districts*

Consistent with overall state results, HIV patients surveyed were mainly from Chennai, Coimbatore, Madurai, Salem/Namakkal, Tiruchy and Tirunelveli districts in TN (Fig. 5.1). Chennai is the capital of TN with a population of 4.2 million (CensusIndiaTN 2002). It had been most targeted for IEC and other prevention and care programs, which has almost certainly resulted in greater detection and reporting of cases. The districts of Salem and Namakkal (with population of 3 million between them) were *peri-urban* and housed major transport companies and hence there was a concentration of lorry drivers from these two districts. Studies have demonstrated lorry drivers in India to be a high-risk group in the dissemination of HIV/AIDS to the general population (Lacerda *et al.* 1997; Rao *et al.* 1994; Thakur 1998).

Vellore (sixth largest town in TN) is an important market town where people from neighbouring villages went regularly to sell their products and used the services of the well-established CSWs in the city. For example *Raju*, a 30-year old farmer from a village near Salem said (12 May 1999),

‘I started having sexual relations from the age of 15 years. I tried to stop after I was married at age 22. But during the period of my wife’s pregnancy, she went to live at her mother’s house, at that time I went to ‘other women’ 2-3 times a month during my visits to town on business’.

Further CMC was located in Vellore and hence understandably over a quarter of the patients (28%) in our survey were from this district. Altogether it was significant that Vellore might be a high prevalence district and requires further investigation (Srikanth *et al.* 1997). 17% (50) of the patients surveyed were from neighbouring AP, and two thirds of AP patients were from three districts (Chittoor (26%), Cuddapah (22%) and Nellore (18%)).

Both GHTM and CMC are in northern TN and conveniently located for patients from southern AP to use them. This was also indicative of the lack of hospitals for

HIV care and treatment within AP. According to *Venu*, a 28 year old man from Nellore (15<sup>th</sup> June 1999):

“I had a skin problem and went to hospital in Nellore, they tested and found I was HIV positive. They do not have the facility to treat here and referred me to CMC. I was afraid of this disease, I am not afraid to die but the disgrace is unbearable. My wife is afraid and has gone away to her mother’s house. My friends ridicule me. The problem is quite severe in Nellore, at least 2-3 cases are being found everyday and newspapers say that there are over 8000 cases of HIV here. People are now scared of the disease, most do not want to go for a test. Unless it comes out some other way no one will know, because people prefer not to know than get tested and die of fear. I only went to hospital for my skin rash”.

Guntur (6%), Kurnool (6%), Godavari (6%) and Visakhapatnam (2%) were other districts in AP from which HIV patients were represented. It is important to note that 40% of the AP patients surveyed were from the districts of Cuddapah and Nellore. These two districts have not been detected by NACO to have high prevalence in AP, which needs further investigation (NACO 2004). Patients from these two districts had said that they found it easier to consult in hospitals in Chennai and Vellore and hence they might be getting recorded at hospitals in Tamil Nadu rather than in Andhra Pradesh.

### 5.3 Comparison between GHTM and CMC

The majority of HIV/AIDS patients at GHTM were from TN (63%), about a third were from neighbouring AP (35%), with the remainder from several other states (GHTM 2003). Over the years GHTM has attained a reputation for providing a haven for HIV/AIDS patients, as opposed to the stigma they faced at other hospitals. The following were some examples of patients’ relief at finding care at GHTM. All the names of patients in this thesis have been changed to provide anonymity to PLWHA.

*Subbu*, a 28 year unmarried man who worked as a supervisor for an export garment factory in Mumbai went to a well known hospital for treating HIV

patients in that city. He said, “They would not take me in as I was not very seriously ill. I heard of GHTM through an advertisement in a Tamil magazine and came here.” (20<sup>th</sup> April 1999).

*Andi*, a 32-year bus driver was tested HIV positive at a hospital in Coimbatore. He said, “when I was tested positive the doctors came to me and said I had to leave immediately. They said, ‘we put *vamakkam* (traditional greeting in Tamil) to you, please leave immediately, we do not care if you do not pay your hospital bills, but please leave’ ” (19<sup>th</sup> March 1999).

*Venky*, a 24-year farm worker went to a well-known private hospital (Vijaya Hospital) in Chennai. When he tested positive they immediately discharged him and suggested that he went to GHTM.

The majority of patients at GHTM were from poorer economic backgrounds, as treatment was free to those from low income background (below INR 5000 (£62) per month according to our classification of income levels above) (GHTM 2003). Less than five HIV patients a month were from what might be considered as better-off backgrounds. Such people normally chose to be accommodated in private rooms, and paid INR 100 (£1.50) a day. Medicines administered were charged according to cost. Anti-retroviral treatment was not available at the hospital but those who could afford to pay were given prescriptions to buy ARVs in the open market. All HIV in-patients were provided with *siddha* drugs and nutritious meals free of charge.

CMC had been providing ARV from the beginning. Women attending antenatal clinics at CMC were routinely tested for HIV and when found to be positive, they were counselled, encouraged and given antiretroviral drugs if affordable by the patients. In the words of *Sundari* aged 25 (23<sup>rd</sup> June 1999),

“I was tested HIV positive when I went to the antenatal clinic at CMC. My husband was then tested and found to be HIV positive. I had already lost my twins. When we heard about our positive status we were devastated and attempted suicide. But we survived through the encouragement and support of the hospital and our parents. We are so happy that this son is born HIV negative.”

Cost was subsidised by income levels and was less than other hospitals which charged. Some patients went to CMC because they could not afford treatment at

other private hospitals, as was illustrated by *Krishna*, a 33-year-old labourer making *beedi's* (tobacco rolled in a leaf). He said (13<sup>th</sup> May 1999): 'I was admitted at YRG (well known NGO for HIV care in Chennai) but could not afford it and hence came to CMC'. Others trusted CMC's reputation to provide relief and treatment for HIV. According to *Kanda*, a 27-year-old lorry owner-driver from Namakkal (3rd June 1999), 'I was tested HIV positive in Namakkal. But it is a big racket there, so I decided to come to CMC for a reliable report.'

### ***Patient experience of study hospitals***

GHTM attempted to assist patients according to their social circumstances, and destitute women who had nowhere else to go upon discharge were allowed to stay on until an alternative arrangement could be made. In some cases, the hospital social workers succeeded in arranging alternative care homes.

*Padma* aged 28 years. Her husband had been a lorry driver and died of AIDS in January 1999. She had had a love marriage with her husband and had been ostracised by both their families. She said (14<sup>th</sup> April 1999): 'my first daughter died of AIDS. I have given my second daughter up for adoption. The social worker from GHTM has arranged for me to work and live at ACT (a home for destitute and/or HIV+ women)'.

The HIV patients interviewed were satisfied with the treatment they received at CMC. In their words (May 1999), 'when the doctor tested our blood and found mistake in it, he referred us to CMC. He said that they will be able to treat us here' and again 'we feel much better health-wise since coming here', and 'we are encouraged through the counselling we receive here'. A testimony to CMC's efforts in meeting the needs of HIV patients,

*Dhana*, a widow aged 30 (17<sup>th</sup> May 1999) "My husband was a farm worker and died of AIDS. He used to go to Madras for treatment. I ignored my health and did not even bother to get tested for HIV. Recently some people came from CMC to the village and counselled me and persuaded me to get tested. They offered to help me with treatment and finding work to look after my children if I was tested

positive and had no other help. They were true to their word and I am encouraged by their support”.

## 5.4 Comparison of HIV positive patients surveyed from TN and AP

Here we compared some socio-demographic and economic characteristics of patients from TN and AP. About one-fifth of the patients were from AP and there were socio-demographic differences between them and the patients from TN (Tab. 5.17). There was no significant difference between AP and TN in terms of gender ( $\chi^2_1=2.87$ ,  $p=0.09$ ) and age ( $\chi^2_2=2.71$ ,  $p=0.26$ ) of HIV patients.

**Tab. 5.17 Socio-demographic characteristics of survey respondents, by State of origin, PLWHA, 1999**

Background characteristics	HIV patients 1999					
	AP=50		TN=242		Total=292	
	n	%	n	%	n	%
<b>Gender</b>						
Male	39	78	159	66	198	68
Female	11	22	83	34	94	32
<b>Place of Residence**</b>						
Rural	16	32	118	49	134	46
Urban	34	68	124	51	158	54
<b>Education level**</b>						
Below Primary	12	24	38	16	50	17
Primary	16	32	113	47	129	44
Secondary & Higher	22	44	91	38	113	39
<b>Household Income</b>						
Low	27	54	153	63	180	62
Medium	15	30	68	28	83	28
High	8	16	21	9	29	10
<b>Marital status**</b>						
Never married	15	30	59	24	74	25
Married	31	62	142	59	173	59
Separate/Div/Widowed	4	8	41	17	45	16

\*\*p<0.05

Patients from AP reported significantly lower education levels compared to those from TN ( $\chi^2_2=14.4$ ,  $p<0.001$ ) (Tab. 5.17). In general, AP was more agrarian and behind TN in education levels (NFHSAP-1998 2000; NFHSTN-1998 2001). On an



average, AP patients were economically better off than those from TN. This could also presumably be because people with greater economic resources would attempt to seek treatment away from their home state. However there was no significant difference between patients from the two states in household income ( $\chi^2_2=2.86$ ,  $p=0.24$ ). Significantly more patients from AP were married (Fishers exact test (2df)=8.52,  $p=0.010$ ).

## 5.5 Discussion and Summary

The comparison between patients surveyed and Census (and/or NFHS) showed that HIV patients formed a subset of the population but differed from the average in important ways. The majority of patients surveyed belonged to the prime reproductive years of 25-44, with women being about five years younger compared to men. *Hijra* were present in women's ward at GHTM, they have been counted as women, as per their request, and comprise an important group in studying PLWHA.

Another socio-economic survey of HIV and non-HIV households in 6 high prevalence states in India found 43% of PLWHA were women (Bery 2006). This study found that households generally belonged to poor economic status, and poor educational background (24% men and 30% women were illiterate). The impact on household income was through loss of employment of PLWHA and leave/absence from work of PLWHA and their caregivers. The survey showed that women faced greater discrimination within the family. These findings were similar to our sample of PLWHA.

Apart from the higher prevalence among men, there was evidence of cultural male bias in providing treatment for HIV. Women appeared to be less likely to avail of hospital treatment compared to their male counterparts. Often it was only after the death of the husband that women visited the hospital for treatment in order to enable them to care for their children or because their parents brought them. Women patients also reported lower education and significantly lower economic status

compared to male patients. Women from urban areas had easier access to hospital compared to women from rural areas.

There was evidence of high proportion of HIV/AIDS cases from Vellore in TN; Cuddapah and Nellore in AP, not represented in state level data, which requires further investigation. GHTM attracted more patients from south of TN while CMC had patients from northern districts and from AP. Together they represented 8% of the recorded HIV/AIDS cases in the state. The key differences between GHTM and CMC were that CMC was more research oriented; it required patients to pay at least partly for treatment and care. Thus CMC was a type of private (mission hence self funded) hospital while GHTM was a government run hospital providing basic treatment and care without any charge. GHTM had mainly inpatients while majority from CMC were outpatients. Thus patients at GHTM were poorer compared to CMC. However the socio-demographic differences among patients between the two hospitals were negligible and hence it was not necessary to differentiate by hospitals for further analysis.

Patients from AP had lower education levels but higher economic status compared to TN patients. The socio-demographic differences between patients from the states of AP and TN were relatively small. This combined with the large difference in sample sizes from the two states meant that it was not appropriate to do state level analysis in further results.

The patient survey showed evidence of lowering of income levels and household standard of living as a result of HIV although they had education levels, which were higher than the average for the state. However, even allowing for current low income, attendance at hospitals was not confined to low education and income groups alone, indicating that AIDS had spread to all sections of the population.

The socio-demographic consequences of HIV revealed were early widowhood, and higher levels of separation/divorce. One third of the women patients were

housewives who had been infected by their husbands. Almost a third of the female patients were widowed women, mostly as a result of their husbands having died of AIDS. The high proportion of unmarried HIV positive men was a cause for concern since they were likely to spread the infection through multiple sex partners or marriage after being symptomatically cured.

PLWHA from all religions at GHTM and CMC expressed the psychological support and care they received from Christians visiting them in hospitals. The Indian government and United Nations praised the Christian community for its dedicated care for PLWHA at a recent conference in Delhi (Ekklesia 2007). Indeed religion appeared to be important for their psychological support when personally confronted with HIV/AIDS. Muslim patients were under-represented in our patient survey, in particular, there were no Muslim women in the sample and requires further investigation. However, the numbers of patients from Muslim were too few for performing additional analysis using religion. Hence we have removed religion from further analyses.

The survey reinforced previous findings that high-risk behaviours were common not only among lorry drivers and CSWs, but also indicated that construction workers and hotel workers should be further investigated to see if the findings reported in the patient survey are replicated. Army and police personnel also need to be further investigated. If they are found to be high-risk groups then HIV/AIDS prevention and care policies need to be targeted accordingly.

The patients surveyed were more urban or *peri*-urban than the average. Although it is well known that HIV patients tend to be more urban, here we cannot say whether it reflects the nature of the infection or nature of hospital attendees. TN has a well-developed transport system, and people who lived in satellite villages frequently visited towns for business and pleasure. Although *de-jure* rural, many HIV positive patients surveyed lived within commuting distance of towns, were well connected by public transport, and were frequently exposed to an urban environment. Thus urban

count of HIV positive patients might be higher than that reported. Additionally, PLWHA may be under-represented in the patients' survey and requires further research to establish. Thus clear cut classification of respondents according to rural or urban as their region of residence are becoming increasingly problematic in modern India and is a shortcoming of state and national level data. This requires further research to establish.

In 1999, Tamil Nadu State AIDS Control Society had not counted PLWHA at GHTM or CMC in this surveillance, which was indicative of existing methodological problems with their estimates. Our overt reliance on government and programmatic data and documentation was an inherent weakness. However, these were the only source of information available to the researcher at the time.

# Chapter 6      KNOWLEDGE AND ATTITUDES OF PLWHA

In this chapter we discuss knowledge of HIV/AIDS among hospital patients separately from their reported behaviours. The associations between knowledge and socio-demographic and economic characteristics have been examined. This is followed by an analysis of media exposure and sources of knowledge. Attitudes concerning HIV/AIDS have also been analysed in terms of socio-demographic associations. Where possible we have compared results from patient survey with results from larger population surveys conducted by NFHS and NACO. The final section pertains to knowledge and attitudes about condoms in the context of HIV prevention messages.

## 6.1      Awareness and Knowledge of HIV/AIDS

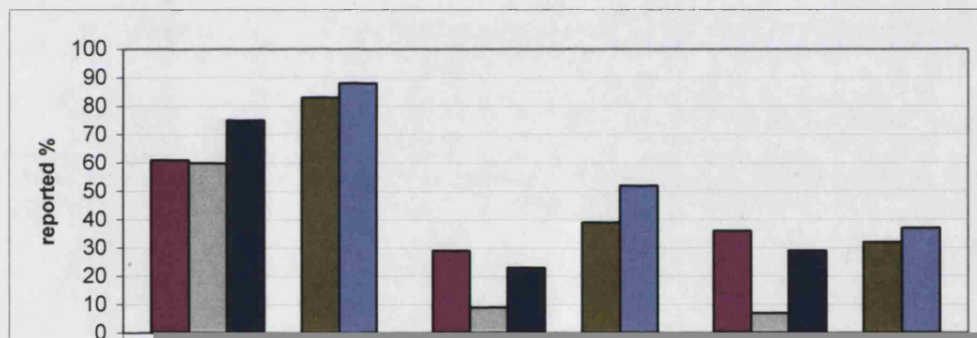
This section is composed of both descriptive and analytic elements. The descriptive results are presented first based on knowledge about different modes of HIV transmission. High proportions of don't know (DK) responses (Tab. 6.4) to questions about HIV transmission through kissing (both on cheek and deep kissing) confirmed that these questions were culturally inappropriate. Knowledge of HIV transmission at dental clinics was unclear in meaning and resulted in high proportion of DK responses. Knowledge of HIV transmission if barber did not clean his blades properly, albeit culturally relevant, was also not very clear in meaning particularly

for women and also resulted in high proportion of DK responses. Hence all these have been removed from further analyses.

### 6.1.1 Knowledge of HIV transmission

An understanding of HIV transmission is important for planning effective intervention programs. In Fig. 6.1 we compare results from the patient survey with secondary data sources (Tamil Nadu Family Health Survey - TNFHS and National Family Health Survey -NFHS) survey. Secondary data sources had been conducted among the general population and are grouped together in the graph. Our patient survey was conducted among PLWHA.

**Fig. 6.1** Percentage distribution of reported source of HIV infection, patient survey data compared with secondary data sources



to the fact that these were HIV positive women in hospitals. Knowledge of HIV transmission across all modes was higher among male patients compared to women patients. The following sections focus in detail on results from patient surveyed.

### ***Knowledge of blood related HIV transmission***

This section focused on whether HIV could be transmitted through unsterilized injections, blood transfusions (receiving blood) and IV drugs. Awareness was widespread among both men and women patients with regard to HIV transmission through injections and blood transfusions (Tab. 6.1). Education was significant among men ( $\chi^2=5.94$ ,  $p=0.050$ ) and women (Fishers exact test (2df)=33.75,  $p<0.001$ ) for knowledge of transmission from blood transfusions. Education was significant among women (Fishers exact test (2df)=11.02,  $p=0.004$ ) for knowledge of transmission through unsterilized injections. Household income was not significant for knowledge pertaining to any blood related HIV transmission and might have been confounded with education and occupation.

**Tab. 6.1 Percentage distribution of "Yes" responses to questions on blood-related HIV transmission, PLWHA, 1999**

Background Characteristics	Unsterilized injections		Blood Transfusions		IV drugs	
	M%	F%	M%	F%	M%	F%
<b>Sex</b>	78	70	77	68	54	35**
<b>Age</b>						
15-24	93	74	79	74	79*	42
25-34	78	67	77	67	56	33
35-49	74	74	75	65	45	35
<b>Education</b>						
No schooling	60	47**	55**	27**	50	23
Primary	80	83	79	85	47	45
Secondary	80	79	80	92	62	33
<b>Occupation</b>						
Housewife	-	66	-	69	-	20
Skill/Unskilled Labour	74	73	71	65	51	41
Prof./Business	83	80	79	80	67	80
High-risk group	80	71	86	71	50	41

**Table Note:** \* $p<0.10$ ; \*\* $p<0.05$ , indicate effects are significant. Significance for 'Sex' represents differences in knowledge between genders. Significance across all other characteristics represents association within genders. Don't Know (DK) responses taken as missing. Totals are different in each case since missing values are different.

Patients' knowledge of transmission through IV drugs was low, consistent with general population surveys. For example, knowledge of HIV transmission through IV drugs as reported in secondary data sources (TNFHS and NFHS) is negligible (Balk and Lahiri 1997; Sambamoorthi *et al.* 2001). Women patients surveyed had significantly lower knowledge of IV drugs compared to men ( $\chi^2_1=9.16$ ,  $p=0.003$ ). Younger men had significantly (Fishers exact test(2df)=5.88,  $p=0.055$ ) higher knowledge of IV drugs compared to older men. Housewives had significantly (Fishers exact test(3df)=8.46,  $p=0.033$ ) lower knowledge on IV drugs compared to women in other occupation groups. 'Don't know' (DK) responses for transmission through IV drugs were high among men (41%) and women (62%) (Tab. 6.4).

### ***Knowledge of sex-related HIV transmission***

Knowledge of sex-related HIV transmission was examined among patients surveyed using four questions on transmission through sex with a positive person, sex with a positive spouse, sex with a CSW, and petting a HIV positive partner (Tab. 6.2). Knowledge was widespread among men and women on HIV transmission through sex with positive person, sex with positive spouse and sex with CSW. These three questions elicited the lowest DK responses (Tab. 6.4).

Significantly more male patients from high-risk groups (Fishers exact test(3df)=11.43,  $p=0.004$ ) reported that sex with CSWs comprised a high risk for HIV transmission (Tab. 6.2). All 56 men from high-risk groups (lorry drivers-32, construction workers-15 and hotel workers-19) had reported having sex with CSWs.



**Tab. 6.2 Percentage distribution of “Yes” responses to questions on knowledge of sex-related HIV transmission, PLWHA, 1999**

Background Characteristics	Male				Female			
	Sex with HIV+ person	Sex with HIV+ spouse	Sex with CSW	Pet HIV+ Person	Sex with HIV+ person	Sex with HIV+ spouse	Sex with CSW	Pet HIV+ person
<b>Sex</b>	87	88	89	29	86	88	87	37
<b>Education</b>								
No schooling	75	75	75	40	70**	73**	73**	57**
Primary	90	90	91	33	93	95	93	38
Secondary	88	89	91	24	96	96	96	13
<b>Household Income</b>								
Low	87	87	89	30	90**	92*	92**	34
Medium	86	88	89	33	74	79	74	42
High	93	93	93	19	50	50	50	50
<b>Occupation</b>								
Housewife	-	-	-	-	86	86	86	43*
Skill/Unskilled Labour	85	85	87**	33	84	89	87	43
Prof./Business	83	86	86	29	80	80	80	40
High-risk group	95	95	96	23	94	94	94	12

\*p<0.10; \*\*p<0.05, indicate effects are significant. Significance for ‘Sex’ represents differences in knowledge between genders. Significance across all other characteristics represents association within genders. Don’t Know (DK) responses taken as missing. Totals are different for each knowledge question since missing values are different in each case.

Education was significant among women for knowledge of transmission from sex with a positive person (Fishers exact test(2df)=8.43,  $p=0.02$ ), sex with a positive spouse (Fishers exact test(2df)=8.03,  $p=0.01$ ) and sex with a CSW (Fishers exact test(2df)=6.67,  $p=0.04$ ). Women from lower income households had higher knowledge compared to women from higher income households for transmission from sex with positive person (Fishers exact test (2df)=5.94,  $p=0.05$ ), sex with positive spouse (Fishers exact test(2df)=5.39,  $p=0.06$ ) and sex with CSW (Fishers exact test(3df)=6.92,  $p=0.03$ ). Age was not significant for any knowledge pertaining to sex related transmission and could have been confounded with education.

On HIV transmission from petting a positive person, educated women reported significantly (Fishers exact test(2df)=11.43,  $p=0.004$ ) higher knowledge compared to women with lower education and women from high-risk groups reported significantly (Fishers exact test(3df)=6.17,  $p=0.09$ ) higher knowledge compared to women from other occupation categories.

### ***Knowledge of other methods of HIV transmission***

The socio-cultural setting of this study is reflected in the distribution of knowledge about HIV transmission through physical contact and public places. Tab. 6.3 reports the distribution of “No” responses to questions about other modes of transmission, and can be interpreted as correct knowledge about HIV transmission. In the study areas, people commonly use the outdoors as toilets rather than public toilets which are considered unhygienic and used less often, and 14% of the patients thought that HIV could be transmitted through using public toilets. It is useful to examine in detail the verbatim responses relating to these modes of transmission. For example, ten patients reported that spirits could be responsible for incurable and unknown diseases such as HIV/AIDS, for example, “breathing the air in a toilet used by a HIV positive person could induce the HIV-spirit to pass into someone”. Household income was significantly (Fishers exact test (2df)=6.91,  $p=0.03$ ) positively associated with knowledge of HIV transmission from public toilets among men. A significantly

higher ( $\chi^2_{23}=4.78$ ,  $p=0.09$ ) proportion of professional men reported that HIV could not be transmitted from public toilets compared to men from other occupation groups. A significantly ( $\chi^2_{22}=5.55$ ,  $p<0.10$ ) higher proportion of women aged 25-34 reported that HIV could not be transmitted from public toilets compared to women from other age groups.

Public bathing places are commonly used, especially by men and children, and 10% of patients surveyed reported that they believed that HIV could be transmitted through this route. Women were significantly ( $\chi^2_1=3.51$ ,  $p<0.10$ ) less likely than men to report HIV transmission from public bathing places. Household income was significantly (Fishers exact test (2df)=6.6,  $p=0.04$ ) positively associated with knowledge of transmission from bathing places among men. Education was significantly ( $\chi^2_2=11.36$ ,  $p=0.003$ ) positively associated with knowledge of transmission from bathing places among women. Significantly ( $\chi^2_2=9.88$ ,  $p=0.007$ ) higher proportion of women aged 25-34 reported HIV could not be transmitted through this mode compared to women from other age groups.

People in Tamil Nadu depend on state-provided public water sources (wells, bore pumps, street taps), but they are rarely subject to purification procedures and are often the cause of water borne illnesses. However, experience of other water borne diseases spread through public water sources was not reflected in the responses pertaining to HIV infection from these sources. Only 4% said that HIV could be transmitted through public water sources. It is worth noting that 15 respondents who expressed concern about water as a source of infection did not want their response to be recorded as 'yes' because they were not absolutely sure, hence we recorded their responses as DK.

**Tab. 6.3 Percentage distribution, by sex, of “No” responses to question on modes of HIV transmission, PLWHA, 1999**

Background Characteristics	MALE								FEMALE							
	Shake hands with HIV+ M%	Play with HIV+ child M%	Public toilets M%	Shared bathing places M%	Public water source M%	Public Hosp's M%	Mosq. bite M%	Public Transport M%	Shake hands with HIV+ F%	Play with HIV+ child F%	Public toilets F%	Shared bathing places F%	Public water source F%	Public Hosp's F%	Mosq. bite F%	Public Transport F%
<b>Sex</b>	79	75	59	65*	26**	59	40	32**	75	73	50	50*	37**	55	32	18**
<b>Age</b>																
15-24	79	86	64	86	93	64	50	29	79	68	32*	42**	58**	37	16	21
25-34	81	77	60	66	75	60	42	31	79	79	60	67	73	64	39	15
35-49	77	71	56	59	69	57	34	35	61	65	39	30	44	52	30	22
<b>Education</b>																
No Schooling	65	50**	45	55	60*	45	35**	25	53**	50**	33	30**	37**	23**	20	10
Primary	80	76	60	61	71	65	32	29	80	78	55	58	68	63	38	20
Secondary	82	80	62	71	81	56	49	37	92	96	58	75	88	83	38	25
<b>Household Income</b>																
Low	77**	69**	54**	64**	73	55	33**	31	75	75	51	55	62	55	33	19
Medium	75	75	58	58	70	61	42	31	68	63	42	47	63	58	26	11
High	100	100	82	85	89	70	63	41	100	100	50	50	100	50	50	50
<b>Occupation</b>																
Housewife	-	-	-	-	-	-	-	-	66*	69*	54	57	69	51	20	20
Skill/Unskilled Labour	76	69	55*	62	73	54	33**	33	70	65	43	49	54	51	38	14
Prof./Business	83	81	74	74	79	64	60	33	100	100	40	80	100	60	60	40
High-risk group	82	82	55	63	73	64	38	30	94	84	53	47	59	71	35	18

\*p<0.10; \*\*p<0.05, indicate effects are significant. Significance for ‘Sex’ represents differences in knowledge between genders. Significance across all other characteristics represents association within genders. ‘public hospitals’ meant general issues related to hospitals (transmission through needles was considered under ‘unsterilized injections’ in Tab. 6.1). Don’t Know (DK) responses taken as missing. Totals are different for each knowledge question since missing values are different in each case.

In general, women brought water for the family's need from public places. Women were more knowledgeable than men about this mode of transmission and significantly ( $\chi^2_1=4.04$ ,  $p=0.05$ ) more women said HIV could not be transmitted from public water sources. Education was significantly positively associated with knowledge of transmission from public water sources among men ( $\chi^2_2=4.74$ ,  $p<0.10$ ) and women (Fishers exact test(2df)=15.41,  $p<0.001$ ). A significantly ( $\chi^2_2=6.22$ ,  $p=0.04$ ) higher proportion of women aged 25-34 reported HIV could not be transmitted through this mode compared to women from other age groups.

Knowledge of HIV transmission through shaking hands (3% men and 3% women said 'yes') or playing with a HIV positive child (7% men and 3% women said 'yes') was widespread as indicated by the majority who reported that HIV could not be transmitted through these modes (Tab. 6.3). Household income was significantly (Fishers exact test(2df)=10.57,  $p=0.005$ ) positively associated with knowledge of transmission from shaking hands among men. Education was significantly (Fishers exact test(2df)=10.85,  $p=0.003$ ) positively associated for knowledge of transmission from shaking hands among women. Significantly (Fishers exact test(3df)=6.59,  $p=0.07$ ) more women from high-risk groups and professional categories reported that HIV could not be transmitted from shaking hands with a positive person. Education ( $\chi^2_2=7.89$ ,  $p=0.02$ ) and household income (Fishers exact test(2df)=14.09,  $p=0.001$ ) were significantly positively associated for knowledge of transmission from playing with a positive child among men. Education was significantly (Fishers exact test(2df)=15.07,  $p=0.001$ ) positively associated for knowledge of transmission from playing with positive child among women. Significantly (Fishers exact test(3df)=7.10,  $p=0.06$ ) more women from high-risk groups and professional categories reported that HIV could not be transmitted from playing with positive child.

Knowledge of HIV transmission from hospitals was significantly (Fishers exact test(2df)=21.22,  $p<0.001$ ) positively associated with education among women.

Knowledge of HIV transmission from mosquito bites was significantly positively associated with education ( $\chi^2_2=6.22$ ,  $p=0.045$ ) and household income ( $\chi^2_2=8.43$ ,  $p=0.015$ ) among men. A significantly ( $\chi^2_3=8.87$ ,  $p=0.012$ ) higher proportion of professional men reported HIV could not be transmitted from mosquito bites compared to men from other occupation categories.

Over a third of patients reported that HIV could be acquired after using public transport. It is important to contextualize these results in order to explain them. In late 1997 a major news story gave rise to what became a very popular “urban myth”. A young man had given a lift on his motorbike to a stranger in Chennai. When he reached home, he supposedly found a sticker on his shirt saying ‘welcome to the AIDS club’. On being tested for HIV, he turned out to be positive. The story received wide publicity in Chennai and worldwide via the internet. As a result many feared that they could be inconspicuously injected with HIV at bus stops or when travelling by auto rickshaws, over-crowded buses or other public transport. Significantly ( $\chi^2_1=6.45$ ,  $p=0.012$ ) more men reported HIV could be transmitted through this mode compared to women.

### ***Don't Know (DK) responses to questions on HIV transmission***

In examining knowledge of HIV transmission among our respondents the DK responses were important. The only interpretation that one can make of a DK response is that the respondent does not, in fact, know the response. It is possible, however, that this response category is used when a respondent would prefer not to give a “Yes” or “No” response. The distribution of DK responses is useful in exploring whether some questions were, in fact, meaningless for the respondents. For example, questions related to knowledge of HIV transmission through kissing (both deep and cheek) were revealed to be culturally inappropriate, as evidenced by the high proportion of DK responses, and have not been included in detailed analyses (Tab. 6.4). Questions pertaining to HIV transmission through mosquito bite, unclean

barber blades and dental clinics, albeit culturally relevant issues also resulted in high ‘don’t know’ responses. Hence, in the analyses of the variables, we have taken DK responses as missing.

**Tab. 6.4 Percentage distribution of “Don’t Know” (DK) Responses to HIV transmission knowledge questions, PLWHA**

Knowledge Variables	HIV Patients	
	Male % (n=198)	Female% (n=94)
<b>Blood related modes of transmission</b>		
<i>Injections</i>	18	27
<i>Blood transfusion</i>	20	31
<i>IV Drugs</i>	41	62
<i>Unclean barber blades</i>	22	46
<b>Sex related modes of transmission</b>		
<i>Sex with positive person</i>	13	14
<i>Sex with positive spouse</i>	12	12
<i>Sex with CSW</i>	11	13
<i>Deep kissing with positive person</i>	28	40
<i>Petting with positive person</i>	25	30
<b>Other modes of transmission</b>		
<i>Kissing on cheek of positive person</i>	26	32
<i>Shaking hands of positive person</i>	18	22
<i>Playing with a positive child</i>	18	23
<i>Public Toilets</i>	26	39
<i>Public places</i>	24	42
<i>Public water sources</i>	22	33
<i>Public Hospitals</i>	24	32
<i>Mosquito bite</i>	27	42
<i>Public Transport</i>	30	47
<i>Dental clinics</i>	43	65

The high proportion of DK responses might also be due, in part, to the ambiguity of the wording of the question, particularly for the question relating to dental clinics and unclean barber blades. Therefore, although we administered all questions as included in the questionnaire, we have eliminated these questions which were ambiguous and problematic from analyses.

### 6.1.2 *Latent Class Analysis of Knowledge*

Latent class analysis was used to identify distinct diagnostic categories (levels) of knowledge for groups of blood-related, sex-related and other modes of HIV transmission variables from patient responses. Latent class allows the identification of broad regularities in a group of variables to look at systematic features. Latent class analysis identified the level of knowledge an individual possessed based on the estimated probability of an individual being in a class based on correct knowledge when categories of knowledge variables were taken together in a model. We could not take all knowledge variables together in one model due to small numbers. We have taken three models; one for blood-related transmission which included three knowledge variables (injection, blood transfusion, IVDU); another model for sex-related transmission which included four variables; and another model for “other” modes of HIV transmission which included eight variables. Additionally, we have examined associations between the latent classes (low and high knowledge) and explanatory socio-economic and demographic characteristics. DKs were taken as missing values throughout.

HIV can be transmitted through the three blood-related modes considered, hence an affirmative response by patients was coded as correct answer. For sex related variables, HIV can be transmitted through sex with HIV positive person, sex with positive spouse and through sex with CSWs and an affirmative response was coded as correct. HIV cannot be transmitted through petting and a negative response was taken as correct answer.

Knowledge of transmission from unsterilized injections, blood transfusions and sharing needles for IV drugs altogether were classified into low and high classes of knowledge based on estimated probabilities. On blood related modes of transmission, 76% of respondents scored as high knowledge and 24% scored as low knowledge (Tab. 6.5). Knowledge of transmission through IV drugs (only 63% scored high; in comparison with injections where 98% scored high knowledge; and 96% scored high



on blood transfusions) shows to have been more difficult for respondents to answer. This is indicative of the fact that dissemination of knowledge of HIV transmission through IV drugs had not been widespread.

**Tab. 6.5 Latent Class Model for Knowledge of blood and sex related HIV transmission, PLWHA**

Knowledge Variable	Class	
	Low	High
<i>Estimated probabilities of belonging to a class and overall estimated proportions of belonging to each class based on correct responses to blood related modes of HIV transmission.</i>		
Injections	0.0604	0.9754
Blood Transfusion	0.0567	0.9585
IV drugs	0.0144	0.6284
<b>Estimated proportions</b>	<b>0.2426</b>	<b>0.7574</b>
<i>Estimated probabilities of belonging to a class and overall estimated proportions of belonging to each class based on correct responses to sex related modes of HIV transmission.</i>		
Sex with HIV+ person	0.0511	1.0000
Sex with HIV+ spouse	0.1260	1.0000
Sex with CSW	0.1759	1.0000
Petting HIV + person	0.0000	0.7898
<b>Estimated proportions</b>	<b>0.1371</b>	<b>0.8629</b>

Comparison of observed (292) and expected (291) frequencies evidenced that the sample data provided a good fit on knowledge of blood-related transmission. Association of latent classes with socio-economic and demographic characteristics showed that high risk groups reported higher blood-related transmission knowledge compared to those from other occupation categories.

Knowledge of transmission from sex-related source of infection was classified into low and high classes of knowledge based on estimated probabilities. On sex related HIV transmission, 86% scored as high knowledge and 14% scored as low knowledge (Tab. 6.5). The probability of knowledge of transmission from petting being high was only 79% compared to 100% high knowledge for other sex related modes of transmission. The results pertaining to petting might reveal confusion,

either in terms of whether petting was a source of infection, or indeed, in understanding its meaning.

The observed (292) and expected frequencies (290) evidenced that the sample data provided a good fit. The association of the two latent classes with socio-demographic characteristics showed sex ( $\chi^2_1=6.73$ ,  $p=0.01$ ) and age ( $\chi^2_2=4.7$ ,  $p<0.10$ ) of patients to be significantly positively associated with levels of knowledge. A higher proportion of older patients reported 'high' knowledge on this group of sex related HIV transmission compared to younger patients. Men reported higher knowledge compared to women. High-risk groups and professional patients reported higher knowledge compared to other occupation groups.

Knowledge of transmission from other modes included shaking hands with HIV positive person, playing with a positive child, using public toilets, using public bathing places, using public water sources, using public hospitals, mosquito bite and from streets and public transport (Tab. 6.6). A negative answer was taken as the correct response.

**Tab. 6.6 Latent Class Model for Knowledge of HIV transmission through other modes of infection, patient survey, PLWHA**

<b>Knowledge Variable</b>	<b>Low</b>	<b>Medium</b>	<b>High</b>
<i>Estimated probabilities of belonging to a class and overall estimated proportions of belonging to each class based on correct responses to HIV transmission through physical contact and other modes of HIV transmission</i>			
Shaking hands of HIV+ person	0.0149	0.9274	0.9901
Playing with HIV+ child	0.0000	0.8072	1.0000
Public toilets	0.0168	0.2048	0.9502
Public baths	0.0000	0.3088	1.0000
Public water sources	0.0316	0.6347	1.0000
Public hospitals	0.0670	0.5024	0.8143
Mosquito bite	0.0000	0.1142	0.6516
Streets and public transport	0.0000	0.1990	0.4244
<b>Estimated proportions</b>	<b>0.2004</b>	<b>0.2748</b>	<b>0.5247</b>

Observed (292) and expected frequencies (261) for three classes provided a good fit compared with two classes (observed responses 292, expected responses 213). Therefore, knowledge based on these seven variables was classified into three classes of low, medium and high classes of knowledge based on estimated probabilities. Latent class analysis of knowledge of HIV transmission pertaining to all these modes of transmission included together in the model showed 52% to have high knowledge, 28% to have medium knowledge and 20% to have low knowledge. Knowledge about HIV transmission from mosquito bites and street and public transport appears to have been difficult for respondents to answer, since only 65% and 42% respectively belonged to high class of knowledge, which are lower than that for each of the other modes of transmission included in this model (Tab. 6.6).

The association of latent classes with socio-economic and demographic characteristics showed that experiential knowledge (knowing other positive people) was significantly (Fishers exact test(2df)=4.95, p=0.09) positively associated with higher knowledge. Patients with higher household incomes had significantly (Fishers exact test(4df)=8.95, p=0.06) higher knowledge.

## 6.2 Media as a source of HIV information

Media has been used for creating HIV/AIDS awareness among the general population in India. Data from the 1998 NFHS in TN and AP are used to provide context for the sources of HIV information in India at the time of the patient survey (Tab. 6.7). The majority of women (92% in TN and 67% in AP), with any exposure to media, had heard of AIDS. According to these surveys, newspapers and magazines were the most commonly reported sources of information about HIV in the general population, followed by TV.

**Tab. 6.7** Percentage distribution of ever-married women who had heard of HIV/AIDS by media exposure, secondary data sources, 1998.

Media Exposure	NFHS-AP	NFHS-TN
	% Heard of HIV	% Heard of HIV
Exposed to any media	67	92
Listen to Radio weekly	68	93
Watch TV weekly	74	94
Cinema monthly	67	92
Read News./Mag. wkly	92	99
No exposure, any media	21	67

Source: NFHS-AP & TN -1998

Tab. 6.8 presents a comparison between proportions of those who had heard of HIV/AIDS according to TNFHS (1995), NFHS (1992, 1998) and PLWHA from our patient survey (1999). The comparison should be interpreted with some caution as the comparator surveys only include ever-married women, and all respondents in the patient survey had heard of HIV. Trend data showed that awareness of HIV/AIDS among ever-married women in TN doubled between 1992 and 1995. Awareness of HIV/AIDS among ever-married women in AP was low compared to TN in 1998.

**Tab. 6.8** Percentage distribution of sources of HIV/AIDS knowledge among those who had heard about HIV/AIDS

Source of knowledge of those who had heard of HIV/AIDS	NFHS(W)-TN, 1992 %	TNFHS(W) 1995 %	NFHS(W)-TN, 1998 %	NFHS(W)-AP, 1998 %	PLWHA(W) 1999 %	PLWHA(M) 1999 %
<b>Sources</b>						
Radio	50	65	52	34	5	11
Television*	64	74	75	74	40	53
Newspapers/ Mag.**	37	n/a	19	16	14	38
Posters	31	n/a	14	7	19	23
Meetings			5	4	9	5
Experiential/ community	14	n/a	51	41	79	80
Others	8	n/a	9	8	n/a	n/a

Source: Tamil Nadu Family Health Survey (TNFHS) among ever married women (Population Research Centre, Madurai, TN, 1995); National Family Health Surveys, TN (1994&2000) and AP (2000).

n/a- not available (or not applicable). W = women; M indicates men. Numbers in brackets provide numbers of patients. \*p<0.10; \*\*p<0.05, indicates significance between genders in our survey of PLWHA.

Across all population surveys TV constituted the most often reported source for HIV knowledge. The second most important source of knowledge was discussions with others in the community or friends (NFHS 2000).

The reported sources of HIV/AIDS knowledge were different among the patients surveyed compared to that reported by ever-married women in the general population. The main difference was that experiential knowledge was the most important source among patients surveyed (79% among women and 80% among men) (see section 6.3.3).

TV was reported as the second most important source of information among patients surveyed. Qualitative data shed light on the timing of patients' watching of HIV/AIDS information on the television. In the words of *Mani*, (aged 29 years, dated April 23, 1999),

'before I was diagnosed with HIV, I did not pay any attention to AIDS material when it was shown on TV because I thought it had nothing to do with me. And now that I have HIV, I find such material frightening and depressing and avoid looking at it. On the other hand, I want to know more so I do look at them'.

Examples of HIV/AIDS-related messages, were observed by the author painted on lorries in TN, June 1999; 'A for AIDS, D for Death' and 'AIDS countdown to death'. In the words of *Subbu* (aged 25, dated April 20, 1999), a lorry driver,

'we have such messages painted at the back of our lorries but we do not pay attention to it, until we find out about other colleagues who become victims to AIDS'.

Patients, especially women (50%), reported that they heard about HIV only after they had been diagnosed as sero-positive. Before which even if they had come across the disease anywhere, it had not registered, as stated by *Kamala* (aged 22, dated April 23, 1999),

'I thought that it did not concern me and never paid any attention or switched off the TV but now I need to know more than what they show.'

Levels of newspapers/Magazines readership in our study were considerably lower than the levels reported elsewhere (Tab. 6.8). Posters were reported by 14% of our patients surveyed and communication from professionals was very low (health workers – 3.4%, teachers and education programs -1.3%). Meetings were rarely reported as a source of HIV/AIDS awareness according to NFHS as well as our patients' survey.

A comparison of media exposure with reported sources of HIV awareness, revealed TV viewing as most important, particularly for men. Of those men and women who reported watching TV at least once a week, 63% and 46% respectively, reported TV as a source of HIV information. These results might show that men are more likely to watch TV programs that include HIV/AIDS awareness issues. Gender differentials persist for other, less reported, media sources of HIV information for men and women, including radio (16% and 9% respectively) and newspapers (43% and 39%, respectively).

The high level of 'don't know' (DK) responses, over one-fourth (26%) said DK, when asked where they would go to find out more about HIV/AIDS, indicated gaps in knowledge dissemination. Women reported significantly higher (41%) DK's compared to men (19%) ( $\chi^2_1=18.5$ ,  $p=0.001$ ). This might partly reflect their unmet needs at hospitals (Laukamm-Josten *et al.* 2000) and partly anxiety over their situation. In the words of *Rama*, a 25-year old soon after she had been informed of her HIV positive status,

'I have enough worries with the news I have received and I cannot think about anything else right now'.

The high level of DK's is an indication that further research is needed to understand the socio-cultural context of differentials in access to IEC/BCC. Patients surveyed were asked to report their exposure to media prior to being tested HIV positive, although it is recognised that differences in length of time since diagnosis might confound these results. The question asked patients to report media exposure

prior to being tested HIV positive as it was assumed that post-diagnosis, people's routines would have changed significantly. Logistic regression provides the odds ratios for a minimum of weekly media exposure by media type and background characteristics. Over three-quarters of respondents reported weekly exposure to television (Tab. 6.9). Those who said that they never watched TV included people 'preoccupied with their problems' and women who were 'too busy with housework to think of watching TV'. The majority (54%) reported having access to TV at home followed by, in the neighbourhood (37%) or at a community centre (7%). It is common practise, especially in suburbs, towns and villages, for people who owned a television, to provide an 'open house' for neighbours. It is normal for neighbouring women, children and occasionally men to watch TV in the house of those who owned one, even while the family members were otherwise busy.

Sixty-nine percent of men reported being able to read newspapers easily themselves and 13% said they listened to newspapers being read. A common sight in suburbs and small towns is to see men sitting in a teashop while one of them reads the newspaper aloud. Thus exposure to newspapers was high among men even if they could not read themselves. However women were less likely to listen to newspaper reading and only twenty-eight percent reported weekly exposure to newspapers and magazines. Education was a significant predictor (95% CI did not include 1 in logistic regression) for exposure to media. Cinema viewing was reported significantly (95% CI did not include 1 in logistic regression) more often by younger patients compared to older. Exposure to TV was the highest among all media considered, followed by newspapers/magazines and radio. Television had reportedly overtaken both radio and cinema, as patients said "we rarely go to cinema since the arrival of TV as we can see films on TV at home".

**Tab. 6.9 Exposure to Media: Proportion of PLWHA reporting at least weekly exposure by media type prior to diagnosis, and Logistic regression of reports of exposure by socio-demographic characteristics, PLWHA, 1999**

Background Characteristics	TV		Logistic Reg. Odds	95% CI	Radio		Logistic Reg. Odds	95% CI	Newspaper/Mags			Logistic Reg. Odds	95% CI	Cinema		Logistic Reg. Odds	95% CI
	M%	F%			M%	F%			M%	F%	M%			F%			
<b>Sex</b>	77	79	N.S.		57	37	2.41 (1.19, 4.87)		82	28	25.9 <sup>a</sup> (9.43, 71.32)		32	10	4.27 (1.71, 10.66)		
<b>Age</b>			N.S.				N.S.				N.S.						
15-24	86	68			64	42			71	26			71	5	9.95 <sup>a</sup> (3.16, 31.33)		
25-34	75	85			56	39			83	29			39	14	5.76 (2.53, 13.12)		
35-49 <sup>R</sup>	77	74			54	30			80	26			11	4	-		
<b>Education</b>																	
No Schooling	45	63	0.17 (0.07, 0.43)		40	13	0.21 (0.09, 0.48)		55	13	0.09 (0.03, 0.25)		40	7		N.S.	
Primary	73	83	0.49 (0.23, 0.94)		55	28	0.40 (0.22, 0.73)		74	15	0.13 (0.05, 0.31)		34	8			
Secondary <sup>R</sup>	88	92	-		62	83	-		96	67	-		29	17			
<b>Household Income</b>			N.S.				N.S.				N.S.					N.S.	
Low	71	75			56	33			77	22			36	12			
Medium	75	19			53	47			84	42			31	0			
High <sup>R</sup>	100	100			63	100			96	100			19	0			
<b>Occupation</b>			N.S.				N.S.				N.S.					N.S.	
Housewife	-	94			-	40			-	37			-	3			
Skilled/Unskilled Labour	75	70			58	22			77	14	98		36	5			
Professional/Business	88	100			55	100			80	79	24		31	20			
High-risk group <sup>R</sup>	71	59			55	47							27	29			

<sup>R</sup>-Reference category; Effects taken as significant by logistic regression if 95% CI does not contain 1. <sup>a</sup> wide CI indicates that there is clearly a strong positive effect, but the data are not sufficient to conclude very precisely what the magnitude of it is.

Occupation as categorical variable in logistic regression gives estimate for effects comparing each category to a reference category as usual. Thus even though there were no men for the category 'housewife' it does not affect estimation and we have taken a reference category which includes both men and women as we have done here.

Don't Know (DK) responses taken as missing. Totals are different in each case since missing values are different.



## 6.3 Knowledge in the context of HIV prevention

This section examines knowledge with reference to HIV/AIDS prevention. Using secondary data sources we first examined awareness of condoms in the general population for comparison with our patient survey. This is followed by analysis of results about knowledge and attitudes about condoms as reported by PLWHA in our patient survey. The role of experiential knowledge and knowing other PLWHA for HIV prevention is described. We then examine the association of time since diagnosis on knowledge of HIV/AIDS. Thirdly we report the relationships between time since diagnosis and knowledge of, and attitudes towards, HIV. Finally, issues surrounding stigma and discrimination are discussed.

### 6.3.1 *Condom awareness in general population*

Condom awareness was widespread in both TN and AP (GBSS, 2001) (Tab. 6.10). A high proportion (94% in AP and 86% in TN) reported easy access to condoms in their area (meaning that they could get one if they wanted to), although only 50% in both states reported that they could obtain a condom in under half-an-hour from their place of residence. Thus while awareness of condoms was high, availability was much lower. Levels of awareness and availability were consistently higher in urban compared with rural areas.

According to GBSS (2001), higher proportion of people had heard of condoms compared to those who were aware that condoms could prevent HIV/AIDS (59% in TN and 62% in AP) (Tab. 6.11). Again, men scored higher than women and urban inhabitants higher than rural on knowledge of condoms for HIV prevention.

Knowledge that using condoms could prevent HIV/AIDS, compared to GBSS, was much lower according to NFHS-1998 in both TN and AP for ever-married women mentioning condoms (11% and 16% respectively), and many reporting DK

any method at all (12% and 37%, respectively) (NFHSAP-1998 2000; NFHSTN-1998 2001).

**Tab. 6.10 Percentage distribution, by sex and place of residence, of awareness and availability of condoms, secondary data (GBSS)**

State	Urban			Rural			Combined		
	M	F	T	M	F	T	M	F	T
<i>Ever heard of, or seen, a Condom</i>									
AP	92	81	86	85	83	84	87	83	85
TN	92	69	81	82	53	68	86	58	72
All India	95	86	90	84	69	77	87	73	80
<i>Reporting easy availability of Condoms in their area</i>									
AP	97	94	96	94	94	94	95	94	94
TN	95	91	93	81	83	82	86	87	86
All India	98	94	96	89	85	87	91	88	90
<i>Reported that it takes less than 30 minutes to obtain a condom from their place of residence</i>									
AP	78	59	69	47	41	44	55	46	51
TN	83	61	72	47	31	39	59	41	50
All India	86	65	77	48	35	41	57	43	50

**Source: NACO (2001a).** It should be noted that these data refer to 2 years after our patient survey, and it is likely that general condom awareness and availability had increased between 1999 and 2001.

**Tab. 6.11 Percentage distribution, by sex, place of residence and state, of knowledge of condoms for HIV/AIDS prevention, GBSS, 2001**

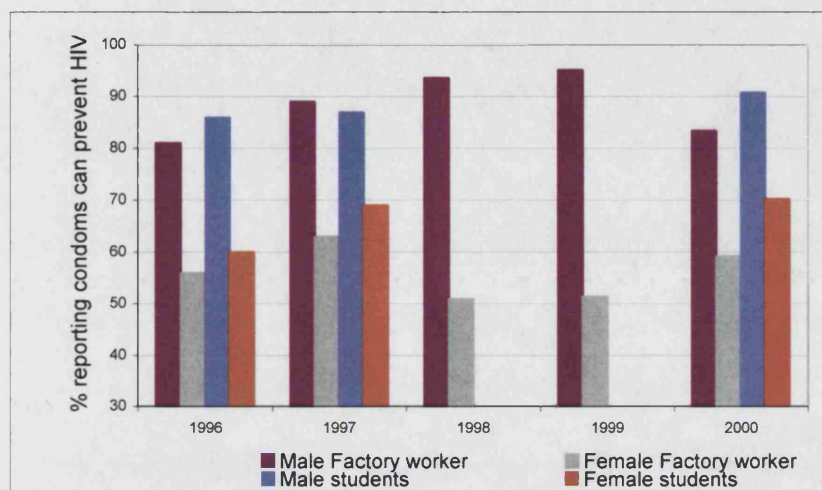
State	Urban			Rural			Combined		
	M	F	T	M	F	T	M	F	T
<i>HIV/AIDS can be prevented through consistent condom use</i>									
AP	76	60	68	62	56	59	66	57	61
TN	77	56	66	70	41	56	72	46	59
All India	83	64	73	66	43	54	70	48	59
<i>Having an uninfected faithful partner and consistent condom use can prevent HIV/AIDS</i>									
AP	61	46	54	50	48	49	53	48	51
TN	66	50	58	59	35	47	62	40	51
All India	65	51	59	52	34	43	55	38	47

**Source: NACO (2001a)**

BSS reported that knowledge that condoms can prevent HIV/AIDS was high among male factory workers and male students in TN (Fig. 6.2). Thus knowledge

showed improvements between the first survey in 1996 compared to that in 2000 among female students.

**Fig. 6.2 Percentage distribution, by sex and occupational categories, knowledge that condoms can prevent HIV infection, BSS surveys in TN, 1996-2000.**



**Source: BSSTN, APAC (2001)**

**Note- Male and Female student's data was not recorded for 1998 & 1999**

These results from secondary sources show improvements in knowledge that condoms prevent HIV in TN, particularly among men. NFHS was earlier than GBSS and shows much lower levels compared to GBSS. NFHS was also only among ever-married women and knowledge is reportedly lower among women compared to men in all the above secondary sources. BSS was conducted among target groups and hence showed highest levels of this knowledge.

The next section reports the results from PLWHA in our patient survey relating to condom knowledge and attitudes.

### 6.3.2 *Knowledge and Attitudes about Condom, Patient survey*

Awareness of condoms was high among patients surveyed. Issues surrounding the terminology used in the interviews are dealt with in section 4.3.2, p. 71. Most men and women had heard of condoms (94% and 81%, respectively), although only (57%) reported unprompted that condom could safeguard against HIV infection. In the analysis that follows we considered only those patients who had heard of condoms and HIV (n=263; 76 women and 187 men). The proportions that mentioned condoms to safeguard against HIV/AIDS were consistent with GBSS data, and a significantly (Fishers exact test(1df)= 21.1,  $p < 0.001$ ) higher proportion of men reported having heard of condoms compared to women. Awareness of female condoms was negligible, only 3 men and 4 women had ever heard of them.

The quantitative analyses of knowledge and attitudes about condoms in this section include all PLWHA who said they had heard about condoms regardless of their experience of having ever-used them. Thus some of the opinions expressed are attitudes rather than based on actual experience.

A majority of patients (81% men and 68% women) reported when prompted that condoms could prevent HIV, and awareness that condoms could prevent STDs was lower (71% men and 47% women) (Tab. 6.12). A higher proportion (87% men and 72% women) reported that condoms could be used as a type of contraception. Respondents with secondary education, exposure to one or more media and those who had been HIV positive for more than one year were significantly more likely to report that HIV could be prevented through using condoms. Those from high risk occupational category reported this more often than those from other occupations.

**Tab. 6.12 Percentage distribution, by sex and selected socio-demographic characteristics and Logistic regression by socio-demographic characteristics of “Yes” responses to knowledge and attitudes about Condoms, PLWHA, 1999**

Background characteristics	Condoms are easy to use				Condoms can prevent HIV/AIDS				Condoms make sex less enjoyable			
	M%	F%	Logistic Regn.		M%	F%	Logistic Regn.		M%	F%	Logistic Regn.	
			Odds	95%CI			Odds	95%CI			Odds	95%CI
<b>Sex (Female<sup>R</sup>)</b>	60	24**	3.2	(1.76, 8.6)	81	68**	1.7	(0.7,0.94)	67	26**	3.4	(2.1, 9.2)
<b>Age</b>							N.S.				N.S.	
15-24	50	8	-		86	31**			50	15		
25-34	66	28	1.8	(1.1, 3.4)	81	77			67	28		
35-49 <sup>R</sup>	53	25			80	75			71	31		
<b>Education</b>											N.S.	
No Schooling	50**	21	0.5	(0.2, 0.7)	67**	53	0.34	(0.1, 0.98)	78	16**		
Primary	54	21	0.56	(0.3, 0.98)	76	74	0.45	(0.2, 0.99)	65	32		
Secondary <sup>R</sup>	70	30			90	74			66	26		
<b>Household Income</b>							N.S.				N.S.	
Low	56**	17**	0.3	(0.1, 0.93)	81**	67			67	22		
Medium	58	53	-		74	73			66	47		
High <sup>R</sup>	84	0			100	50			68	0		
<b>Marital Status</b>				N.S.				N.S.				
Never married	61	50**			82	67			57**	17	2.1	(2.1, 4.0)
Ever married <sup>R</sup>	60	19			81	69			72	28		
<b>Occupation</b>							N.S.					
Housewife	-	20	0.4	(0.1,0.8)	-	67			-	20	2.3	(0.2, 0.8)
Skill/Unskilled Labour	53	12	0.5	(0.3,0.9)	77	65			62	31	-	
Prof./Business	72	50	0.8	(0.3,0.8)	87	50			72	50	-	
High-risk group <sup>R</sup>	64	44			84	81			71	25		
<b>Time since Diagnosis</b>				N.S.							N.S.	
<=1year	57**	22			78*	61**	0.7	(1.1, 5.1)	67	26		
>1year <sup>R</sup>	68	28			89	84			66	28		
<b>Media Exposure</b>				N.S.							N.S.	
None	41*	20			53**	40**	0.5	(1.3, 9.2)	71	30		
One or more <sup>R</sup>	62	24			84	73			67	26		

**Table Note: \*p<0.10; \*\*p<0.05. Significance for ‘Sex’ represents differences between genders. Significance across all other characteristics represents association within genders. Effects are significant by logistic regression if 95% CI does not contain 1. <sup>R</sup> represents Reference category. Occupation as categorical variable in logistic regression gives estimate for effects comparing each category to a reference category as usual. Thus even though there were no men for the category ‘housewife’ it does not affect estimation and we have taken a reference category which includes both men and women as we have done here. Don’t Know (DK) responses taken as missing. Totals are different in each case since missing values are different.**

When asked whether they had heard about condoms, 25% of male patients added spontaneously, based on experiential knowledge of having used condoms, that condoms did not provide adequate protection against HIV/AIDS as they tore during intercourse. Qualitative analysis showed that PLWHA having used condoms, had reservations about the effectiveness of condoms to protect against HIV because they tore or broke:

‘I have used a nirodh it does not give full protection, there is breakage and leakage. It only gives 10% protection’ (*Subbu*, 33 year old teacher).

‘Nirodh might help only to a small extent as breakage is very common.’ (*Ashokan*, 34-year-old lorry driver).

‘nirodh can be used to safeguard, but it is not very useful as it often tears’. (*Arumugam*, 27-year-old construction worker).

‘I went only once before marriage to a CSW. I used nirodh but it tore. I did not like the experience and never went back. I wish I had known before marriage, then I should not have married and could have avoided this suffering’. (*Ravi*, a 31-year married businessman).

‘nirodh is advisable to use with spouse only because of HIV or STD. Otherwise it is like using an artificial item foreign to the body’. (*Ramu*, a 46-year-old unskilled labourer).

Over two-thirds of men reported, ‘condoms make sex less enjoyable’ (Tab. 6.12). Over one-fifth women reported that ‘condoms make sex less enjoyable’, however ten of them said that was their perception rather than based on experience. Housewives reported this significantly (based on odds and confidence interval) more often than women from high occupational risk groups. A majority of men (60%) said ‘condoms are easy to use’ compared with 24% of women. Those with higher levels of education, high occupational risk groups and 25-34 year olds were more likely to report ease of condom use compared to their reference categories.

As *nirodh* is supplied free of cost by government health centres, only a minority reported them to be expensive (12% men and 5% women-CSWs). The men who reported condoms to be expensive were those who paid to buy condoms from outside, the following is one such case in point:

*Govind*, 26 year old from Visakapatnam in AP said, 'I am tempted to go to a CSW when I abstain from my wife, so I did go (to a CSW) when she [my wife] was pregnant. I have used condoms with CSWs to avoid STDs. I have used condom with wife after child was born, but we do not like it, even she does not like it. So I will abstain from her. When I am tempted, I will go to CSWs instead. Good quality condoms have to be bought from outside and are expensive but what to do? *Nirodh* is not good and it tears easily'.

A majority of men did not consider that one should avoid sex with a casual partner if a condom is not available. The reservation for this was expressed in terms of the impossibility of thinking about condoms 'when overtaken by passion'. Patients aged 25-39 were twice as likely; and those with no schooling and those who had been diagnosed as HIV positive for under a year were less likely to say they would use condoms with a partner (Tab. 6.13). Higher proportions from high-income groups compared to other occupation groups; those with exposure to one or more media compared to those with no exposure, reported that they might use condoms with a partner.

Only half the patients (55% men and 43% women) reported that it was appropriate to use condoms with a spouse (Tab. 6.13). The categories of older, urban, higher educational level, higher income, married, professionals and those with media exposure were more favourable to this. Those who had been HIV positive for over a year were significantly (based on odds and confidence interval) more likely to express agreement. And half of all men (41% women) who had heard of condoms reported that their spouse would get suspicious if their husband insisted on condom use. A majority of respondents (85% men and 61% women) reported it was better to use condoms with casual partners. Education, marital status and time since diagnosis were significant predictors of those who reported that it was appropriate to use condoms with a spouse.

**Tab. 6.13 Percentage distribution by sex and socio-demographic characteristics and logistic regression by socio-demographic characteristics of “Yes” responses to attitudes about condom use with partner, PLWHA, 1999**

Background Characteristics	Appropriate to use with spouse				Condom use better with casual partner				Reported “I might use a condom with a partner”			
	M%	F%	Logistic Regn. Odds	95% CI	M%	F%	Logistic Regn. Odds	95%CI	M%	F%	Logistic Regn. Odds	95%CI
<b>Sex (Female<sup>R</sup>)</b>	55	43	1.6	(2.1, 3.0)	85	61**	2.9	(1.7, 6.3)	82	59**	2.3	(2.6, 7.1)
<b>Age</b>			N.S.				N.S.					
15-24	43	23			79	31**			79	23**	1.8	(2.1, 3.7)
25-34	55	47			86	70			87	68	1.3	(1.1, 5.0)
35-49 <sup>R</sup>	56	50			84	56			74	63		
<b>Education</b>			N.S.									
No Schooling	50	42			78	32**	0.3	(0.1, 0.7)	78	37**	0.4	(0.1, 0.8)
Primary	51	41			83	65	0.5	(0.3, 0.8)	80	62	0.7	(0.4, 0.7)
Secondary <sup>R</sup>	59	48			88	78			84	74		
<b>Household Income</b>			N.S.				N.S.				N.S.	
Low	57	40			84	53**			80	55		
Medium	50	60			81	87			79	73		
High <sup>R</sup>	56	nil			96	100			96	100		
<b>Marital Status</b>			N.S.								N.S.	
Never married <sup>R</sup>	50	58			84	50	0.84	(1.1, 4.3)	81	67		
Ever married	57	41			85	63			82	58		
<b>Occupation</b>			N.S.								N.S.	
Housewife	0	37			-	63	-		-	67		
Skill/Unskilled Labour	51	42			78	54	0.3	(0.1, 0.7)	78	46		
Prof./Business	64	50			87	75			92	50		
High-risk group <sup>R</sup>	54	56			93	63			80	69		
<b>Time since Diagnosis</b>												
<=1year	50**	39	0.8	(1.6, 3.2)	81**	55	0.7	(2.1, 4.6)	79	49**	0.6	(3.1, 4.6)
>1year <sup>R</sup>	66	52			93	72			88	80		
<b>Media Exposure</b>			N.S.				N.S.				N.S.	
None	29**	50			82	20**			77	50		
One or more <sup>R</sup>	57	42			85	67			82	61		

\*p<0.10; \*\*p<0.05. Significance for Sex represents differences between genders. Significance across all other characteristics represents association within genders. Effects are significant by logistic regression if CI does not contain 1. <sup>R</sup> represents Reference category.

Occupation as categorical variable in logistic regression gives estimate for effects comparing each category to a reference category as usual. Thus even though there were no men for the category ‘housewife’ it does not affect estimation and we have taken a reference category which includes both men and women as we have done here.

Don’t Know (DK) responses taken as missing. Totals are different in each case since missing values are different.



In examining attitudes about condoms in associations with socio-demographic characteristics, it is important to note that DK responses were high, particularly from women (Tab. 6.14). DK responses were highest for 'condoms are easy to use' both among men (32%) and women (72%), reflecting lack of personal experience of condoms. One-third of women reported DK for whether condoms could prevent HIV.

**Tab. 6.14 Percentage distribution, by sex, of 'Don't Know' responses by PLWHA for knowledge and attitudes about condoms**

Knowledge & Attitudes	HIV patients	
	Male % (n=187)	Female % (n=76)
Condoms prevent HIV/AIDS	14	32
Condoms make sex less enjoyable	17	59
I would use condoms with a partner	8	18
Appropriate to use condoms with spouse	9	22
Better to use condoms with casual partners	10	30
Condoms are easy to use	32	72
Condoms are expensive	26	68
Condoms are good at preventing pregnancy	10	25
Condoms are good at preventing STDs	25	53
Spouse would get suspicious if I insist condom use	18	32
Condom use is against my religion	3	11
Should not have sex with casual partner if no condom	11	36

Basic knowledge of condoms was widespread, but this did not necessarily translate into attitudes associated with lower risk of HIV infection. Qualitative analyses revealed cultural (for example, the need for childbearing within marriage) and environmental (for example, availability) constraints that appeared to form barriers to condom use. These constraints are discussed further in chapter VII.

### 6.3.3 *Experiential knowledge*

Experiential knowledge is defined as a persons' knowledge through personal experience of being HIV positive themselves and/or knowing other people (family members or friends) who are HIV positive. It included discussions with PLWHA and peers at the hospital and the broader community members/friends. Among women

and men who reported experiential knowledge, 21% and 42% respectively, reported that such discussions had been very helpful to them. For example, discussions with more experienced patients in hospitals were also helpful for new patients, when confronted with the shock of their HIV positive status.

#### 6.3.4 *Knowledge of other PLWHA*

In this section we have examined awareness of other HIV positive persons as reported by patients surveyed. Ingham (1995) proposed that perceived severity predicted the likelihood of behaviour change in a health preserving direction. It is important to note that in reporting knowledge of HIV prevalence in the neighbourhood and awareness of other positive persons, the answers could be based on beliefs rather than epidemiological evidence. This was also true among patients surveyed, as we found that 15 women and 19 men who said they knew a positive person other than themselves also said that one could identify a HIV positive person simply by looking at them. Patients from groups where high-risk behaviours were common were highly likely to know more HIV positive people compared to those who were not from high-risk groups. Hence they have not been included in reporting knowledge in this section, and have been reported separately in chapter VIII.

We have examined responses of prevalence in the neighbourhood as perceived by our patient sample and are therefore subject to individual bias and inaccuracies (Tab. 6.15). Awareness of HIV/AIDS in the neighbourhood was significantly (Fishers exact test(1df)=9.54, p=0.02) higher among men compared to women. In reporting knowledge of positive persons, patients did not count themselves or other patients in the hospital but tended to refer to HIV positive people they knew outside the hospital, and questionnaire response categories were based on the standard WHO (1994) questionnaire.

A majority of our respondents (48% women and 59% men) reported that HIV was prevalent in their neighbourhood (Tab. 6.15) A significantly ( $\chi^2_1=14.35$ , p<0.001)

higher proportion of women (66%) compared to men (39%), reported knowing HIV positive person(s) other than themselves, usually their husbands. Some patients (5%) reported knowing ten or more HIV positive persons other than themselves. NACO data showed that 21% men and 14% women in Tamil Nadu reported being aware of someone who is HIV positive, the proportions are understandably lower since they represented the general population.

**Tab. 6.15 Percentgae distribution of awareness of HIV/AIDS prevalence, PLWHA, patient survey, 1999**

Awareness of prevalence	HIV patients					
	Male =142		Female=77		Total =219	
	N	%	N	%	N	%
<b>Prevalence in Neighbourhood**</b>						
High	60	42	19	25	79	36
Moderate	19	13	11	14	30	14
Low	5	4	7	9	11	5
Don't Know	58	41	40	52	98	45
<b>Know positive person**</b>						
No	86	61	26	34	112	51
Yes	56	39	51	66	106	49
<b>Number of positive people known**</b>						
0	86	61	26	34	112	51
1	22	15	26	34	47	22
2 - 9	26	18	21	27	47	22
>= 10	8	6	4	5	12	5
<b>Relationship to known positive person**</b>						
Spouse	4	3	43	56	47	22
Sibling	1	1	0	0	1	1
Neighbour/Colleague/Friend	51	35	8	10	58	26
Don't Know positive person	86	61	26	34	112	51

\*\*p<0.05

Logistic regression was used to determine socio-economic and demographic variables, which predict variations in knowing one or more positive persons (Tab. 6.16). Gender and age were significant predictors; women (example their husband) were more likely to know an HIV positive person compared to men; those aged 25-34 were more likely to know an HIV positive person compared to 35-49 year olds. Time since diagnosis was also a significant predictor; those who had been sero-positive for over one year were twice as likely to know an HIV positive person other than themselves, compared to those who had been sero-positive for less than or equal

to a year. Education, household income and occupation were not significant predictors of knowledge of other PLWHA.

**Tab. 6.16 Logistic regression of Knowledge of HIV positive persons other than oneself, PLWHA, patient survey, 1999.**

Background Characteristics	Logistic Regression	
	Odds Ratios	95% CI
Sex (Female <sup>R</sup> )	0.23	(0.09, 0.55)
Age		
15-24	1.20	(1.30, 1.92)
25-34	2.00	(1.09, 3.32)
35-49 <sup>R</sup>	--	
Time since Diagnosis		
>1yr	1.9	(1.04, 3.79)
<1yr <sup>R</sup>		

<sup>R</sup>-Reference category; Effects are significant by logistic regression if CI does not contain 1.

### 6.3.5 *Time since diagnosis and knowledge of, and attitudes towards, HIV.*

Here we specifically examine the importance of time since diagnosis, which in the regression analyses appeared to contribute to experiential knowledge among our patients. Patients who had been sero-positive for over a year reported knowing a higher number of other HIV positive people compared to those who had been sero-positive for one year or less (Tab. 6.17). Time since diagnosis was significantly associated with number of positive people known both among men (Fishers exact test(3df)=21.5, p=0.004) and women (Fishers exact test(3df)=18.7, p=0.012).

Thus time since diagnosis could be considered to be a proxy measure for experience with the disease. People with over one year experience of being positive had higher scores for knowledge variables, compared to those who had been sero-positive for less than a year. Thus experiential knowledge appeared to improve comprehensive knowledge on various aspects of HIV transmission knowledge. The

importance of experiential knowledge and many (10+) HIV positive people is examined further in the subsequent knowledge sections.

**Tab. 6.17 Percentgae distribution of HIV/AIDS knowledge by time since diagnosis, PLWHA, patient survey, 1999.**

Awareness of prevalence	HIV patients			
	<=1 year		>1 yr.	
	M%	F%	M%	F%
<b>Number of positive people known**</b>				
0	66	37	45	22
1	13	39	24	17
2 – 9	16	20	23	50
>= 10	5	4	8	11
<b>Knowledge of Possibility of infection</b>				
Through reusing syringes(M**)				
Through blood transfusions(M&F**)	74	66	88	81
Sharing needles for IV drugs	71	59	91	92
Sex with HIV+ person(M&F**)	51	31	62	46
Sex with HIV+ spouse(M**)	84	82	97	96
Sex with CSWs(M**)	84	85	97	96
Petting HIV+ person(M&F**)	85	84	97	96
Shaking hanks with HIV+ person(M&F**)	64	53	88	89
Playing with HIV+ child(M&F**)	72	66	97	96
Using public toilets(M&F**)	69	63	90	100
Using public bathing places(M&F**)	50	40	81	73
Through public water sources(M&F**)	59	40	79	89
Through public hospitals <sup>§</sup> (M&F**)	69	52	88	92
Can be injected with virus in public transport(F**)	52	44	76	85
Knowledge of Prevalence in neighbourhood(M&F**)	32	12	33	35
Know positive persons other than spouse(M**)	54	44	81	73
	38	62	59	81

\*\*p<0.05. Significance represents association within genders. M\*\* means significant association within Males; M&F\*\* means significant association within Males and within Females.

§ By public hospitals we meant general issues and not through needles since that was taken care of by injections.

Don't Know (DK) responses taken as missing.

The following section discusses attitudes related to HIV/AIDS. In particular, attitudes pertaining to testing for HIV, childbearing by positive women, mother-to-child transmission, willingness to talk to others about HIV/AIDS (and sero-status disclosure), physical appearance, and the use of alternative therapies.

### *Testing*

In our study a majority of women reported that they had acquired HIV through marital sex (section 5.2.6), hence, whether a couple should be tested for HIV before marriage is an important issue (although it would not capture post-marital infection). A majority (66% men and 59% women) supported pre-marital testing, an attitude that was positively correlated with education and media exposure for women (Tab. 6.18). Younger patients were more likely to support pre-marital HIV testing than older age groups. Unmarried men supported pre-marital testing significantly more often than married men, and many described their struggle between their awareness of their positive status and pressure from their parents to marry in accordance with traditional social norms. Thus these results can be interpreted as indicative of experiential knowledge having influenced their attitudes.

Patients from groups with high occupational risk, particularly lorry drivers, favoured testing for HIV before marriage more than other occupational groups. The DK responses were high among women (20%) for this question, but this was explained typically because

‘while testing is good, it is not practical to implement in our culture and experience’. (*Meena*, 38 year old from Salem)

The governments of some high prevalence states have been attempting to introduce HIV/AIDS testing before marriage (AIDS-INDIA 2007a; Tanga 2004). However the ruling suffers from difficulties associated with implementation since registration of marriages is not mandatory and it has not been attempted in TN. Patients surveyed could be expected to be more supportive of HIV testing before marriage compared to the general population. However cultural barriers were immediately evident. Thus although support for HIV testing before marriage was high in theory, all (except three) of those that supported it typically reported that it would be difficult to implement,

'it is good to have test conducted but how can we ask that it be done when we are arranging a marriage? They will think we are suspecting their child and this will cause serious misunderstandings' (*Rajan*, 39 year old father of 2 daughters)

'they will tell us to keep our daughter with us and they will look for someone else, what will happen to our daughter then'? (*Saroja*, 32 years old mother)

Respondents were asked whether they would be willing to test children or siblings for HIV before marriage. Forty-two percent were totally opposed to the idea and 8% reported DK. About one third of the men (35%) and a fourth of women supported such testing in theory; these figures are not small in the cultural context. Their views were based on experiential knowledge, as expressed strongly by *Kanni*, widowed at 40 years:

'it was bad enough that my husband had HIV, he also ruined my life and my two son's lives. Who will look after them when I die? I will have my sons tested for HIV before getting them married. I will also ask my brother to get his daughter tested for HIV before getting her married to my son. He will be willing to do it'.

It was evident that even if respondents supported testing in theory, the actual practise of testing was restricted by the cultural context, even when it concerned testing their spouse, particularly their wives and children. A majority of the married male patients (57%) reported that they would not get their spouse tested for HIV, despite repeated advice from physicians. About a fourth of the married male patients reported that their wives had tested HIV positive and 19% reported that their wives had tested negative. Two-thirds of the married women reported that their husbands were, or had been, HIV positive, while one third reported 'DK'.

**Tab. 6.18 Percentage distribution by Gender and socio-demographic characteristics and logistic regression by socio-demographic characteristics of “Yes” responses to attitudes towards HIV Testing, childbearing and disclosure, PLWHA, patient survey, 1999**

Background Characteristics	Test for HIV before marriage		HIV+ couple should have child		Mother to child transmission		Willing to tell others about HIV					
	M%	F%	Logistic Regn.		M%	F%	Logistic Regn.		M%	F%	Logistic Regn.	
			Odds	95% CI	M%	F%	Odds	95%CI	M%	F%	Odds	95%CI
Sex (Female R)	66	59**	N.S.		34	31	1.78 (1.1, 3.4)		14	15	N.S.	
Age							N.S.				N.S.	
15-24	86	47	0.9 (0.9, 0.98)		21	26			14	16	43** 11	
25-34	70	64			32	37			13	17	49 35	
35-49 <sup>R</sup>	55	57			40	22			14	9	25 30	
Education							N.S.					
No Schooling	55	33**	0.7 (0.2, 0.80)		40	37**	3.27 (1.3, 8.3)		10	10**	25 13** 0.40 (0.2, 0.9)	
Primary	70	68	0.8 (0.2, 0.72)		39	33	1.48 (0.8, 2.8)		16	20	43 43 1.06 (0.6, 0.8)	
Secondary <sup>R</sup>	65	75			27	21			12	13	42 25	
Household Income			N.S.				N.S.				N.S.	
Low	65	62			39	29			13	14	38 30	
Medium	66	53			27	42			11	21	44 26	
High <sup>R</sup>	74	0			30	0			22	0	41 0	
Marital Status			N.S.				N.S.				N.S.	
Never married <sup>R</sup>	83**	46			16**	23	3.57 (1.7, 7.6)		16	15	44 39	
Ever married	58	61			43	32			13	15	39 27	
Occupation			N.S.				N.S.					
Housewife	0	51			0	29			0	11	0 17 0.2 (0.1, 0.7)	
Skill/Unskilled Labour	65	65			36	30			12	19	40 32 0.6 (0.3, 0.6)	
Prof./Business	55	60			21	20			19	20	29 20 0.3 (0.2, 0.8)	
High-risk group <sup>R</sup>	77	59			39	41			13	12	50 47	
Time since Diagnosis			N.S.				N.S.				N.S.	
<=1year	62	53			35**	31			11**	10**	39 22**	
>1year <sup>R</sup>	76	73			31	31			19	27	43 46	
Media Exposure			N.S.				N.S.				N.S.	
None	47	33*	0.2 (2.1, 8.6)		53	27			6**	7*	18** 27	
One or more per week? <sup>R</sup>	68	63			32	32			14	17	43 29	

\*p<0.10; \*\*p<0.05; Significance for ‘Sex’ represents difference between genders.

Significance across all other characteristics represents association within genders.

Effects are significant by logistic regression if 95% CI does not contain 1. <sup>R</sup> represents Reference category.

Occupation as categorical variable in logistic regression gives estimate for effects comparing each category to a reference category as usual. Thus even though there were no men for the category ‘housewife’ it does not affect estimation and we have taken a reference category which includes both men and women as we have done here.

Don’t Know (DK) responses taken as missing. Totals are different in each case since missing values are different.



### ***Childbearing and Mother to Child Transmission***

Knowledge of mother-to-child transmission, and infection through IVDU was negligible according to TNFHS and NFHS (Balk and Lahiri 1997; Sambamoorthi *et al.* 2001). In a culture with social pressures for a couple to have a child within a year of marriage, giving birth to a child can be perceived to be more important than the health and well-being of the woman. Coping not only with their HIV positive status, but also the resulting uncertainties caused by social pressures combined with their own desire to have a child, was the cause of great distress among patients surveyed. About a third of the patients reported that an HIV positive couple should have a child, and many further suggested that 'they should get cleaned and have a child'. Several respondents reported that they had observed friends or neighbours struggling with a positive child, and was therefore a perspective based on experiential knowledge. A higher proportion of women aged 15-34 (mean age at first birth in Tamil Nadu is 21 years), supported childbearing by a positive couple compared to their male counterparts. Some women stated 'I want a child' or they queried 'how can a married couple possibly not have a child?' and insisted that they would have one. This may be a consequence of family pressure on a woman to have children in a cultural context where the entire blame for not giving birth to a child is attributed to the woman. Women with no schooling, in particular, appeared more affected by cultural pressure, and were more than three times more likely to support having a child compared to women with secondary schooling.

The majority (58%) of respondents reported that there was a 100% risk of HIV positive mother-to-child transmission (Tab. 6.18). Three (2 men and 1 woman) reported that there was 'no risk'. Just 14% of respondents reported that a HIV positive mother would not necessarily give birth to an HIV positive infant. This again was based on experiential knowledge and comprised of those who knew of a HIV positive woman who had given birth to a child who was HIV negative. This was particularly evident at CMC where AZT was administered to women patients

attending antenatal clinics for a fee, but it could be afforded only by a few. People had to pay for AZT in India during the time of this survey, consequently it was unaffordable to the vast majority. Very few places such as CMC provided it to pregnant women but even there the doctors reported that hardly 10% of such people had provision for the complete course due to shortage of supply. Although Cipla (an Indian pharmaceutical company) was able to provide generic drugs at a low cost for distribution in developing countries, these were not generally available for PLWHA in India (Jyothi 2003). The free ARV program was launched in April 2004 by the Government of India (Johnson 2004). This program provides free ARVs only in states with high HIV prevalence and is limited mainly to pregnant women (Abhijit 2004; Kumar 2004). The programme continues to have significant administration and logistical problems (AIDS-INDIA 2004d).

### ***Talking about HIV/AIDS and status disclosure***

A majority (63%) of patients reported their unwillingness to tell others about HIV/AIDS (Tab. 6.18). The main reason given for not wanting to tell others about HIV/AIDS was fear of ridicule/disgrace/alienation. A majority (90%) of those who said they were willing to tell others about HIV would not, however, be willing to disclose their own status. Socio-demographic variables associated with a greater reported willingness to talk to others about HIV included, income (high), education (high), media exposure and length of time since diagnosis (more than one year).

Women were generally more reluctant to talk about their HIV positive status, which may have been a cultural consequence of greater discrimination against them. Female in-patients initially refused to be interviewed since they thought 'here is yet another person wanting to publicise our story in the press and disgrace us before family and friends'. But when they were convinced that there was no need to feel threatened, they were usually anxious to talk to someone about their fears and worries.

*Mahalingam*, a 28-year-old businessman was an interesting case about disclosure and consequences of being HIV positive. He married six months before the interview and was tested HIV positive a week before the interviews.

‘Wish I had done test before marriage’, he wept. ‘I picked a fight with my wife when I heard I had HIV and sent her to her parent’s house. I have had contact with her only five times altogether and hope she is negative. I have not told her yet that I have HIV. I have spoken to a lawyer about getting a divorce, at least then she can make something of her life’.

### ***HIV and physical appearance***

Given that all of the respondents in the patient survey were HIV positive, it is important to examine their perceptions regarding HIV risks and physical appearance (Tab. 6.19). Responses to this set of questions revealed dissonance between their own experience of living with HIV/AIDS and that portrayed in the media. About one-fifth who said that one could tell a HIV positive person simply by looking at them were referring to people with full-blown AIDS as reported in the media, with impressions of HIV/AIDS patients based on emaciated images presented on TV and posters. There appeared to be some confusion about this issue. The images they had seen were different from their own experience of not feeling very ill in the early stages. A higher proportion of those who had been ill for more than a year said they could tell a positive person simply by looking at them, possibly referring to greater experiential knowledge of people in the later stages of AIDS. All patients who reported that one could not tell a HIV positive person simply by looking at them, additionally commented that they were glad, in the face of stigma and discrimination, that there were no immediate outward signs to tell a HIV positive person simply by looking at them.

**Tab. 6.19 Percentage distribution, by sex and other socio-demographic characteristics and logistic regression by socio-demographic characteristics of attitudes about HIV/AIDS and physical appearance, PLWHA, 1999**

Background Characteristics	Tell HIV+ by looking at person				Healthy looking HIV+ person can infect				HIV/AIDS can be cured			
	M%	F%	Logistic Regn.		M%	F%	Logistic Regn.		M%	F%	Logistic Regn.	
			Odds	95%CI			Odds	95%CI			Odds	95% CI
<b>Sex (Female<sup>R</sup>)</b>	16	17	N.S.		74	64*	N.S.		35	29	N.S.	
<b>Age</b>			N.S.				N.S.				N.S.	
15-24	14	11			71	53**			50	42		
25-34	15	15			77	75			36	21		
35-49 <sup>R</sup>	17	26			69	48			29	35		
<b>Education</b>			N.S.				N.S.				N.S.	
No Schooling	5	10**			40**	33**			25**	23**		
Primary	19	28			73	75			42	30		
Secondary <sup>R</sup>	15	8			83	83			30	33		
<b>Household Income</b>			N.S.				N.S.				N.S.	
Low	16	19			70	63			36	30		
Medium	19	11			74	63			34	21		
High <sup>R</sup>	7	0			89	100			30	50		
<b>Marital Status</b>			N.S.				N.S.				N.S.	
Never married <sup>R</sup>	17	31			80**	85			31	31		
Ever married	15	15			71	61			36	28		
<b>Occupation</b>			N.S.				N.S.				N.S.	
Housewife	0	14			0	60			0	23		
Skill/Unskilled Labour	15	14			69	54			31	32		
Prof./Business	12	20			81	100			38	60		
High-risk group <sup>R</sup>	20	29			79	82			38	24		
<b>Time since Diagnosis</b>							N.S.					
<=1year	12*	9**	2.76	(1.4, 5.4)	73**	54**			37**	27**	1.59	(0.3, 0.9)
>1year <sup>R</sup>	25	39			77	86			28	35		
<b>Media Exposure</b>			N.S.				N.S.					
None	0	27			29**	40*			24**	47**	0.39	(0.2, 0.9)
One or more <sup>R</sup>	17	15			78	68			36	25		

\*p<0.10; \*\*p<0.05. Significance for 'Sex' represents differences between genders. Significance across all other characteristics represents association within genders.

Effects are significant by logistic regression if 95% CI does not contain 1. <sup>R</sup> represents Reference category. 'Mother-to-child transmission' represents percent who said '<100% risk'. Occupation as categorical variable in logistic regression gives estimate for effects comparing each category to a reference category as usual. Thus even though there were no men for the category 'housewife' it does not affect estimation and we have taken a reference category which includes both men and women as we have done here. Don't Know responses taken as missing. Totals are different in each case since missing values are different.

A majority of patients (74% men and 64% women) believed that a healthy looking HIV positive person could transmit the infection, again based on experiential knowledge,

‘I felt normal and did not know I had HIV. I just had fever and went to hospital, it was then I tested positive and by then my wife had already got infected’.  
(*Sampath*, 28 year old)

A third of the patients believed that AIDS could be cured, which may have indicated that they did not want to believe that they could not be cured. Some respondents reported that they were willing to try anything that was marketed, even if it made them bankrupt, and frequent reference was made to media reports of cures, which have ethical implications. Following this question, several respondents asked whether a cure had, indeed, been found. We had to give them an honest answer that great progress was being made in research to find a cure but there was no cure yet.

GHTM offered alternative therapies such as *siddah* and yoga for HIV positive patients (GHTM 2003). Although GHTM officially stated that these therapies could not cure HIV, the practitioners of *siddah* marketed them as a cure, and it resulted in misunderstandings and confusions about treatment and cure for HIV/AIDS.

### ***Indigenous medicines***

Indigenous medicines for the treatment of HIV/AIDS are aggressively marketed in TN, often referred to as ‘Kerala medicines’. We asked PLWHA about their perception of whether any therapy to cure HIV existed (Tab. 6.20). Thirty-six percent reported that medicines existed that could cure people of the virus, and 2% reported that ‘HIV can be cured, it is only AIDS that has no cure’. One in eight of unmarried respondents believed that they would get cured and then marry, and about 6% of married respondents said ‘we will get cleaned and have children’. About a tenth believed that biomedical therapy to cure HIV/AIDS existed, which they referred to as ‘English medicine’.

**Tab. 6.20** Distribution of perception that therapy to cure HIV existed, PLWHA

Treatment	HIV patients					
	Male =198		Female=94		Total =292	
	n	%	n	%	n	%
Indigenouse/ <i>Siddha</i> /etc.	53	27	21	22	74	25
English Medicine	25	13	7	8	32	11
Painkillers for temporary relief	15	7	5	5	20	7
No cure	85	43	45	48	130	45
Don't Know	20	10	16	17	36	12

Respondents were asked whether they had tried any indigenous treatments. Altogether one-fourth of the patients said that they had tried homeopathy, *siddah* or 'Kerala treatment'. Thus patients from TN with exposure to one or more media and who had been sero-positive for longer (one year or more) were reportedly more likely to have used alternative therapies. Those who had been HIV positive for over a year and had tried alternative therapies said for example 'we tried them but after the initial well-being our condition deteriorated and we had to return to English medicine'.

### ***DK responses on some aspects of HIV transmission***

DK responses were consistently higher for women compared to men, and were particularly high for questions related to positive childbearing and mother to child transmission, probably reflecting respondent's own uncertainty about this issue (Tab. 6.21).

**Tab. 6.21** Percentage distribution, by sex, of Don't Know responses for questions on some aspects of HIV transmission, PLWHA, patient survey.

Aspects of HIV transmission	HIV patients	
	Male % (n=198)	Female % (n=94)
Test HIV before marriage	7	20
HIV+ couple should have child	19	22
Tell HIV+ by looking at person	4	9
Healthy looking HIV+ person can infect	23	35
HIV/AIDS can be cured	13	20
Mother to child transmission is 100%	25	30

### 6.3.6 *Stigma, discrimination, coping and support*

It is important to understand issues related to discrimination of PLWHA, not only to help them to live with the disease, but also encourage acceptance of PLWHA by society in general. This section presents thematic qualitative analysis from PLWHA, who not only have to deal with their own trauma related to the illness but are also faced with stigma and discrimination by governments, health care systems, society and other individuals. Qualitative analyses revealed frequent use of metaphors referring to HIV/AIDS as death, punishment, a badge of shame or sin, and crime. The result can be isolation and exclusion of PLWHA, sometimes leading to suicide.

Discrimination against HIV positive women is particularly acute. Women were blamed and rejected by husbands and wider family members, either directly as the perceived sources of infection, or indirectly through failing to 'satisfy' their husbands. A case in point is *Susi* who was 26 years old:

'I get saamy [possessed by gods] ... the gods told me that my husband has HIV. My husband also did tell me that he is HIV positive. He ill-treats me all the time, so my parents have brought me back to live with them. I was worried about my daughter, I am relieved that she tested negative for HIV, but my husband has taken her away from me. All I am concerned about now is the welfare of my daughter.'

In the early stages of this research some (ten) women patients were afraid to be interviewed because they had already suffered discrimination. Their names and photographs had been published by the media without their permission (see section 4.3.1).

The psycho-social impacts of being HIV positive manifested in many different ways. For example, one man said that he took alcohol to forget about his illness. Twenty-four men said they had been depressed, of who 16 said they had attempted suicide. Ten of the respondents reported that they had suffered severe psychological breakdown.

[I am] 'depressed, I am the only son, what will my mother and sisters do if I die' (*Murali*, 26 year old).

[I am] 'suicidal, I tried to kill myself and my children' (*Samy*, 30 year old father of 2 children).

Patients reported having been treated with contempt by their neighbours and the proportion was higher among those who had been positive for more than one year. Shame associated with HIV infection made them reluctant to inform friends or neighbours of their status. Stigma and discrimination only compounded the struggles of PLWHA, not least because fear of stigmatisation made people initially reluctant to be tested for HIV. Spouses of respondents were reportedly reluctant to be tested, and about half of the HIV positive married men interviewed were not aware of their partners' HIV status.

In some instances PLWHA were in denial about their sero-status. Twelve respondents denied their HIV positive status even though their test results had proved it, and they had been informed of the results. The implications for transmission risks to others are therefore large.

There appeared to be many socio-cultural factors that compounded discrimination and interfered with the extent of effective support that could be provided by family/friends and others, more so with reference to support for positive women. Addressing discrimination in a socio-cultural context is most important in preventing isolation of PLWHA.

Patients reported that religion and faith had helped them sustain themselves, particularly in this crisis. Faith in God, particularly for women, was reported as having helped them to come to terms with their situation, and meditation was also used as a coping strategy.

In the absence of a welfare system in TN and AP, and a culture where families are close knit (66% of respondents lived in multi-generation households), relatives were essential as carer. A majority (70%) of patients said that their immediate family



knew that they were HIV positive and provided valuable support for them. Typical responses of family members were reported as: 'angry, but caring', 'crying, upset I will die, but caring', 'my family is worried, but they are loving and caring towards me', 'mother has only me to depend on, she is terribly upset and spends her nights and days caring for me', and 'my wife is worried and upset, but she is trying to be brave and caring very much for my health'.

Overcrowded hospitals and overburdened staff required a member of the family to stay at the hospital to assist in looking after the patient. Married men were looked after by their wives while unmarried men were looked after by other relatives. Qualitative analysis showed men seemed to take it for granted that their wife or parents would not reject them,

'husband and wife have to share all problems together, so she looks after me well'  
(*Sekar*, 33 year old)

'my wife does not believe I could have done anything like that so she says I cannot have HIV' (*Kumar*, 35 year old)

[my] 'wife is afraid to have physical contact but takes very good care of me'  
(*Suresh*, 33 year old)

'my parents are angry with me but they will not reject their son' (*Somu*, 28 year old)

'my parents are angry with me, they scold me all the time but they cannot reject me' (*Kuppu*, 24 year old)

Women on the other hand, had to support themselves and their children after all their resources had been spent on their husband's care. *Rani*, a 35-year-old widow's statement was illustrative 'We do not have money even for one meal a day, what will happen to my children when I die'? The following example is illustrative of a wife's dependence on her husband and her struggle to come to terms with the possibility of his premature death:

'my wife is crying all the time as she is upset that I will die soon, it is only 3 months since we married' (*Murali*, 31 year old)

Only seven men (5%) had been totally rejected by all family members (wives and/or parents). For example, *Ramesh*, a 25-year unmarried man said 'I was sent out of the house by my parents as I am HIV positive'. While *Somu*, a 30-year old could not believe that his wife deserted him, 'my wife says I am a disgrace and she has left with the children to her parents'. The cases below show the rejection by parents, children, siblings or other relatives and friends:

'my wife is loving to me, but my in-laws want to take her away' (*Kumar*, 29 year old)

'my wife and I live with my brother's family and they give us food but treat us as outcasts' (*Kanda*, 34 year old)

'my family takes care of me, but my relatives snigger at me' (*Ramesh*, 24 year old)

'our son and daughter-in-law treat us as outcasts and don't even let the grandchildren come near us' (couple in their 50's)

'friends are afraid and don't come to see us anymore' (*Suresh*, 32 year old)

One-fourth of the men said that they had confided only in their friends, because they could not confide in their parents or wife. In *Sunil's* words, 'my friend is the only one who knows my HIV positive status and comes with me to hospital as my family would panic, rant and rave and put me to further tension if they came to know'. Others who had not informed their family said 'my mother will die if she knows', or [my] 'wife does not know I am HIV positive, she thinks that I have fever and STD and I will be cured soon'.

Another aspect of family life was the pressure from parents to marry in spite of their being HIV positive, for example:

'my parents insist that I should marry, I have managed to evade them so far by saying that I must clean the mistake in my blood first, but I don't know how long I can manage to keep up that excuse'. (*Krishna*, 28 year old)

Support from employers, when HIV positive, was forthcoming only up to a certain point and did not appear to be sustained. For example, one man reported that

his employer continued to support him when he had not gone to work for up to three months. However, when his employer realised that the illness was going to be sustained, his visits and financial support had dwindled.

## 6.4 Discussion and Summary

Knowledge by itself is rarely enough to change behaviour. However knowledge that a disease exists, in this case HIV/AIDS, an understanding of how it is transmitted and how it can be prevented is a basic starting point for health promotion.

Studies have shown low levels of comprehensive biomedical knowledge in India (Bharat and Aggleton 2002; Ponnuraj and Sankarapandian 1994; Rangaiyan 1998; Sehgal 1994; Sethi 2002) . According to the latest NFHS survey only 57% of women in India have heard of HIV/AIDS (NFHS-3 2007). Our survey findings showed that knowledge was relatively high among PLWHA. Knowledge of HIV transmission and prevention was higher among patients compared to the general population and could be attributed to experiential knowledge. However, comprehensive knowledge (meaning high knowledge on all relevant modes) of HIV transmission is difficult to achieve. For example, Organista and colleagues (1996) studied Mexican migrant workers in the US and found that although respondents were highly knowledgeable about major modes of HIV transmission, one-third to one-half believed that HIV could be contracted from mosquito bites, public bathrooms, kissing, and the HIV test itself. We found that comprehensive knowledge of HIV/AIDS was low among our survey of PLWHA.

Our research indicated some critical issues that acted as constraints on the comprehension, absorption and adoption of HIV transmission reduction information and behaviour. Health-related knowledge is built up from exposure to information combined with what people learn from personal experience. IEC and BCC, using mass media, help to place issues on the public agenda, legitimate local efforts, raise consciousness about health issues, and convey information. Therefore we have

examined exposure to media and reported sources of HIV/AIDS knowledge. What the mass media do less effectively, according to Wellings and Macdowall (2000), is to convey complex information, teach skills, shift attitudes and change behaviour in the absence of other enabling factors (see also section 3.2, p. 43).

The limitations of media to communicate complex information are well known (Wellings and Macdowall 2000). While TV provided a good basis for primary knowledge of transmission and prevention, it was apparent in our survey that it had not been adequate to provide a full range of knowledge. PLWHA wanted to know more, and for this they turned to their community and peers, irrespective of the accuracy of knowledge so acquired. Across all population surveys in India, TV constituted the most often reported source for HIV knowledge (NFHSAP-1998 2000; NFHSTN-1992 1994; NFHSTN-1998 2001; TNSACS 1999), also access and exposure to TV among patients was widespread.

Newspapers as a source of HIV/AIDS knowledge were significantly higher among men compared to women; but only a minority of men and women reported radio. Knowledge from posters was reportedly low, which raises questions of the extent to which people read (or notice) advertisements or posters, regardless of whether they absorb and retain the messaging.

Men were more likely to watch TV programs that include HIV/AIDS awareness issues, supporting findings from elsewhere that TV can be used for targeted HIV awareness for men. Further research would be useful to design and implement HIV awareness TV programs to targeted audiences. Among women, education was an important predictor for IEC exposure. Overall, men had higher knowledge on all measured variable, had higher exposure to health education and messages were getting through better than for women. The data collected in this research were not adequate to examine these questions in depth and they require further research.

The second most important source of information in India (NFHSTN-1998 (2001)) was discussions with others (family, community, and friends). According to Campbell (2003) understanding what constitutes a health-enhancing community is still in its infancy. However, the ability of peer education to promote the development of 'health-enabling community contexts' that support and enable the processes of individual and social change necessary for safer sexual behaviour has been recognised. Hence Campbell suggests that in Africa the focus is shifting toward facilitating community-led peer education for affecting behaviour changes in the context of HIV/AIDS. Sivaram and colleagues (2005) found that information about sex and sexual health is exchanged within and between married women, married men, unmarried men and unmarried women in a study of low-income communities in Chennai. They found that spousal communication about sexual behaviour or sexual health was minimal. Findings from our patients survey was similar where their main source of HIV/AIDS knowledge was reported to be discussions with other PLWHA, community members and friends.

Patel and colleagues (2006) in their focus group study of first year college students in the US about high-risk behaviour related to HIV transmission, reported the use of concrete experiential examples to illustrate their responses. In our study, discussions with experienced patients in hospitals were very helpful for new patients, when confronted with the shock of their HIV positive status. This information has useful policy implications of community- or hospital-based care and support by other PLWHA.

Patients had assimilated knowledge based on what was directly relevant to them, such as sex-related HIV transmission and blood-related transmission through injections and blood transfusions. Knowledge of sex related HIV transmission was higher than blood related transmission, and it had greater relevance in their lives. In India, HIV transmission through IV drugs was mainly found in the north-eastern region. Hence this practice was reportedly an uncommon source of infection among

patients surveyed and the high proportion of 'don't knows' (DK) to this question was to be expected. Latent class analysis showed that knowledge on HIV transmission through IV drugs was low in comparison with other blood-related modes of transmission.

Analyses revealed that levels of knowledge were low, and there was confusion about questions relating to practices, which would be considered culturally inappropriate, such as kissing. In addition, questions relating to transmission from sources such as dental clinics produced high DK responses, highlighting the low level of familiarity of the respondents with such services. It is interesting to note that questions related to kissing are still being used in the NFHS, which raises questions about the quality of such information.

The association between knowledge and socio-demographic characteristics showed that education, occupation, age, media exposure, time since diagnosis and experiential knowledge were important predictors for knowledge of HIV transmission. Education was an important predictor for knowledge in our study but did not always show up to be significant and could have been due to small numbers and might have been confounded with age. Other studies in India have found the significance of education on HIV awareness and knowledge (Mukherjee and Sikdar 2005; Sudha *et al.* 2005). As in our study, Pallikadavath and colleagues (2005) in a focus group study of 19 PLWHA in rural India found that misconceptions co-existed with correct knowledge of HIV transmission; they also reported inadequate counselling.

Other studies have shown that knowing people with HIV/AIDS is associated with safer sex (Caron-Flinterman *et al.* 2005; Gerbert *et al.* 1991; Kelly *et al.* 1991; Lugalla *et al.* 2004; Mansergh *et al.* 2000). In our survey of PLWHA it was evident that experiential knowledge was a positive predictor associated with higher levels of knowledge. Additionally, such experiential knowledge influenced attitudes favourably toward possible future behaviour changes. People with occupations where

high-risk behaviours were common were exposed to more PLWHA and greater experiential knowledge and consequently better knowledge.

The knowledge requirements for PLWHA are different to the general population. PLWHA reported that before they had tested *sero*-positive, they had looked but not watched, listened but not heard the HIV messages. Once they were diagnosed with HIV, they required greater knowledge. For this they were turning to others who had the experience, or greater knowledge, in their community. While it is encouraging that media have been useful for communicating basic information, the finding from our sample is that the community was a more important source of knowledge. Salunke and colleagues (2001) emphasise the importance of empowered opinion leaders in India was effective communication for PLWHA.

IEC/BCC comprises an important component of HIV/AIDS prevention through creating knowledge which is culturally sensitive and influencing attitudes (Rogers *et al.* 2006). Our research identified that targeted interventions need to take into account gendered differences in knowledge and access to sources of knowledge. For example, programmes could target specific communities, such as Salem/Namakkal where the majority of truck-drivers and their families lived. Housewives were identified in this study as a sub-group with very low levels of access to sources of information, and would benefit from programmes which could reach them at a time when they might be free from their household chores. The high level of 'don't know' responses, over one-fourth (26%) said DK, when asked where they would go to find out more about HIV/AIDS, indicated a gap that current IEC was not filling. Considering this was a group of PLWHA in hospitals, it indicates not only the gaps in knowledge but also of available support and services.

Our findings also suggest that community networks may be used to disseminate knowledge of HIV transmission and prevention. Additional research pertaining to issues of culturally sensitive experiential knowledge would provide additional value.

More than 80% of patients surveyed had heard about condoms, and the knowledge that condoms can prevent HIV/AIDS was high (over 70%). A majority of men (82%) reported willingness, in theory, to use them with a partner, although two thirds reported that condoms made sex less enjoyable and only about half reported it was appropriate to use condoms with their wives. What was very important, in terms of positive prevention, was the issue of the contraceptive effect of condoms in a setting with strong societal and individual pressures to marry and have children. Thus, our survey showed that there were critical cultural and environmental constraints that influenced their knowledge and attitudes, which appeared to form barriers against using condoms (see section 7.3). Additionally, experiential knowledge of poor quality condoms combined with low levels of easy access to condoms suggest that, even with high levels of condom knowledge, behaviour change would be more difficult to achieve. The fact that knowing other HIV positive persons and time since diagnosis were significant predictors indicates that experiential knowledge was important. If these issues were addressed by IEC/BCC, they might constitute successful interventions leading to behaviour change. Also more research pertaining to issues of culturally sensitive experiential knowledge would provide additional value to our findings.

Data relating to stigma and discrimination are poorly developed in India (Godbole and Mehendale 2005; Pallikadavath *et al.* 2005). HIV positive women in particular face high levels of stigma and discrimination (Bharat and Aggleton 1999; Elford and Bor 1998; UNAIDS 2000c). The issue of initial reluctance to be involved in the research as a result of previous involuntary status disclosure has been noted elsewhere (Panos 1990; Singh 1991).

Rogers and colleagues (2006) in a study of HIV-related knowledge, attitudes, perceived benefits, and risks of HIV testing among pregnant women in rural Southern India found 60% had good knowledge regarding risk factors for HIV transmission. Although 85% of women expressed their willingness to be tested, most



were concerned about confidentiality and disclosing HIV sero-status because of fear of negative reactions from their husbands, parents, and community. These authors report that social and cultural barriers confront pregnant women when they decide to opt for HIV testing and suggest that urgent attention be focused on education, development of innovative culturally appropriate interventions that empower women to make decisions about HIV testing, involvement of men, and addressing stigma and discriminatory attitudes toward people living with HIV/AIDS.

One-fourth of the male PLWHA said that they had confided only in their friends, because they could not confide in their parents or wife. A Ugandan study of 22 families with one or more adult member with AIDS studied in Uganda, found non-disclosure of status in the majority of cases for reasons of fear of stigma and discrimination (Lie and Biswala, 1998). In our study of PLWHA, an important finding was the non-rejection of the PLWHA by their family following disclosure. Instead, PLWHA and their families expressed fear of rejection from those outside the household, similar findings were noted in Uganda by McGrath and colleagues (1993).

Elford and colleagues (1999) showed that nearly half the gay men in London were unaware of their own HIV status and also that of their partners. If this was the case among people with access to resources; it is not surprising in the context of resource poor setting for HIV testing, counselling and treatment in our study, that half the positive men were not aware of their partners' HIV status.

In India, childbearing soon after marriage is considered essential (Sambamoorthi *et al.* 2001), which has major implications for positive prevention for those couples whose serostatus is known. The prevention of MTCT is therefore a major concern, not least because of issues of ART availability. This was particularly evident at CMC where AZT was available for a fee to HIV positive women attending antenatal clinics. The fee could only be afforded by a small proportion of those women who needed it. Indigenous medicines promising a cure are aggressively marketed in TN.

Importantly, from the perspective of formal health service providers, the fact that practitioners of *siddah* at GHTM marketed their therapies as a cure is a policy issue that needs to be addressed. And hospitals should be able to provide unambiguous information for HIV positive people about what these therapies could do for them in order to avoid their hopes of having complete cures.

In general there is a widespread culture of close-knit multi-generational household in India. When combined with an absence of a formal welfare system, relatives of PLWHA are essential carers, both in and out of hospital (Foley *et al.* 1995; Mansergh *et al.* 2000). Our research revealed, however, important gendered differences, with HIV positive women having to support themselves and their children after all their resources had been spent on their husband's care. There is an urgent need to develop systems of support and care for carers themselves (Joseph and Bhatti 2004; Kennedy *et al.* 1999).

## Chapter 7 Behaviour

The primary mode of HIV transmission in India is through heterosexual sex (Chatterjee and Hosain 2006; Narain *et al.* 1994). This chapter describes the profile of sexual behaviours as reported by PLWHA in India. In particular we consider sexual debut, frequency of sex, number of sexual partners, other sexual risk behaviours and condom use, all of which have important implications for HIV infection and prevention (FHI 2000; Thomas *et al.* 2004).

We examine in-depth HIV risk related habits of PLWHA, both before and after diagnosis. We present reported source of HIV infection, age at sexual debut, premarital and extra marital sex and other sexual behaviours of PLWHA. It should be noted here that reported sexual behaviours are subject to biases such as misreporting and recall errors, apart from dilemmas of reporting more likely for a sub-group of sero-positive people (Kerrigan *et al.* 2006) (see section 4.3.2). Some limitations in the questionnaire, related to descriptions of sexual behaviour, safe sex practices and HIV status, were encountered when administering the interviews. Sexual behaviours were studied with respect to sexual relations (meaning regular sexual practices) and sexual episodes (meaning sexual incidents, for example, sexual debut). Detailed descriptions of sexual relations and behaviour changes including condom use were noted through verbal probes during qualitative questioning and discussions. This in-depth qualitative information is reported, where appropriate, alongside the quantitative results from the survey.

We have examined reported behaviour change with particular reference to condom use, as a measure of HIV prevention. Studying behaviour change was problematic as reported by PLWHA not least because of respondents not knowing when they might have become infected prior to testing. Analyses in this chapter did not include “high-risk groups” (lorry drivers, hotel workers, construction workers, female sex workers (FSW) and *hijra*). Reports of sexual behaviour from high-risk groups are examined separately in chapter VIII. The current chapter aims to produce descriptions of sexual behaviour that more closely represents the situations of the general population, to the extent possible, based on description by PLWHA and eliminate bias related to behaviours and practices of high-risk groups.

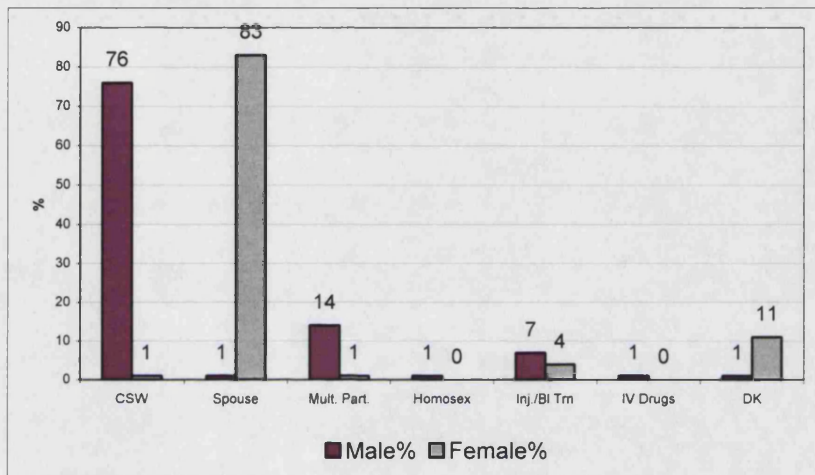
The concept of ‘positive prevention’, namely prevention directed toward improving the health of PLWHA and reducing transmission is a recent development and had not existed when this study was initially researched. A weakness of prevention strategies in many countries has been the failure to target intensive prevention efforts toward people who have been diagnosed with HIV (InternationalHIV/AIDSAlliance 2003). Positive prevention is currently a major issue and includes the role of HIV positive people in preventing new infections, particularly among persons at risk such as their spouses and/or other sexual partners. This research provides important evidence about behaviours and practices of PLWHA and contributes toward understanding positive prevention in general and in India in particular.

This study has a relatively small sample size, which limits the power of the statistical tests. However, these findings from PLWHA have important contributions and implications for the control of HIV-1 epidemic in India. Throughout this chapter, Fisher’s exact test has been used instead of Chi-Square test for computing associations between variables when a cell count was less than five. The effects in logistic regression model were considered significant if the confidence interval did not include ‘1’.

## 7.1 Reported source of HIV infection

In the absence of detailed, retrospective behavioural and serostatus data, we asked PLWHA how they thought they had become infected. Heterosexual transmission was the dominant mode reported among patients surveyed at the two hospitals (Fig. 7.1).

**Fig. 7.1** Percentage distribution, reported source of HIV infection by Gender: Reports from Patient survey (n=292)



A majority (65%) believed they had acquired HIV through heterosexual relations (CSWs, multiple partners, spouse). Transmission through blood and blood products

## 7.2 Sexual Behaviours

### 7.2.1 *Sexual debut*

The reported mean age at sexual debut (18 years) for women patients in our survey was the same as their mean age at marriage. The mean age at sexual debut for men (19 years) was comparatively lower than their mean age at marriage (26 years). The mean age at sexual debut was calculated by treating 'don't know' responses as missing. It should be noted, however, that DK responses for men accounted for more than a third of the responses. Women were initiated to sex at significantly (Fishers exact test (3df)=110,  $p<0.001$ ) younger ages compared to men, explained by their earlier age at marriage (Tab. 7.1). Median age (calculated for comparison with general population) at sexual debut was lower among male patients surveyed (19 years) compared to that of the general population in TN (24 years) as reported by NACO (2001a).

**Tab. 7.1 Percentgae distribution of age at sexual debut, by sex, PLWHA, patient survey, 1999.**

Age at sexual debut	HIV patients			
	Men =142		Women=77	
	n	%	n	%
=< 19 years	29	20	67	87
20-24	42	30	10	13
25+	18	13	0	0
DK	53	37	0	0

**Fishers exact test (3df)=110,  $p<0.001$**

Education and household income showed positive, but non-significant, association with age at sexual debut for both men (18 years among low income and 20 years among middle and high income) and women (16 years among low income and 18 years among middle and high income).

### 7.2.2 *Smoking, alcohol and drug consumption behaviour*

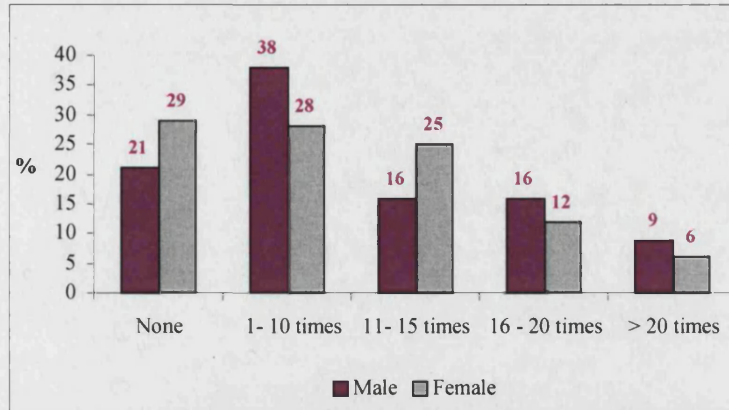
A majority (58%) of male patients reported having smoked; and a higher proportion (71%) reported alcohol consumption. About a fifth (22%) said that they had given up smoking since having tested sero-positive as smoking made them feel ill; and a little over half of them had given up drinking. Substance use is uncommon among women in this region so that all answered 'no' to smoking, alcohol and drug consumption. The women who reported smoking or drinking were female sex workers and have been studied separately (see section 8.4). Taking drugs was reportedly uncommon among respondents. Seven men and one woman reported smoking Gaanja, similar to Cannabis, and none reported use of drugs intravenously. The data showed a positive, though non-significant, association between substance use and less safe sexual behaviour among male PLWHA.

### 7.2.3 *Frequency of Sex*

Here, we present data on frequency of sex prior to diagnosis, data which have implications for HIV spread and prevention (Q430). We have examined reported sexual episodes prior to HIV diagnosis since data on sexual episodes after people had been diagnosed was of very small sample size and post-diagnosis reports of sex were subject to biases resulting from symptomatic illness. We found that males consistently reported higher sexual frequency compared to females, both before and after diagnosis (Fig. 7.2).

Men reported significantly ( $\chi^2_4 = 12.3$ ,  $p=0.014$ ) more episodes of coital frequency per month with their spouse. 46% reported more than 15 sex acts per month prior to diagnosis, which was about twice that reported by women (Tab. 7.2). There was a significant difference in coital frequency with spouse between age groups (Fishers exact test(8df)= 36.2,  $p<0.001$ ), with reported coital frequency decreasing with age.

**Fig. 7.2** Frequency of sex per month, prior to diagnosis, by gender, PLWHA.



**Tab. 7.2** Frequency of marital sex per month prior to diagnosis, by sex and age, PLWHA

HIV patients	Frequency of Sex with Spouse per month prior to diagnosis									
	<= 3 times		4-9 times		10-15 times		16-20 times		>20 times	
	n	%	n	%	n	%	n	%	n	%
<b>Gender**</b>										
Men	15	15	18	18	21	21	28	29	17	17
Women	17	23	14	19	28	37	10	13	6	8
<b>Age**</b>										
15-24	1	5	1	5	5	26	9	48	3	16
25-34	9	9	17	18	37	39	18	19	14	15
35-39	22	37	14	23	7	12	11	18	6	10
<b>Total</b>	<b>32</b>	<b>18</b>	<b>32</b>	<b>18</b>	<b>49</b>	<b>29</b>	<b>38</b>	<b>22</b>	<b>23</b>	<b>13</b>

\*\*p<0.05, Total responses of married patients=174 (75 women +99 men)

**Fig. 7.3** Frequency of sex per month, prior to HIV diagnosis by occupation, PLWHA.





A majority of housewives reported lower frequency of sex per month compared to other occupation groups, while 41% of farmers reported sex between 16 and 20 times per month prior to diagnosis (Fig. 7.3). Education and household income did not appear to be significant in relation to frequency of sex.

Reported frequency of sex per month before HIV diagnosis was significantly (Fishers exact test (4df)=9.29,  $p=0.047$ ) negatively associated with length of time since diagnosis (Tab. 7.3). This could be attributed to reduction in frequency of sexual episodes resulting from symptomatic illnesses prior to diagnosis.

**Tab. 7.3** Frequency of sex per month prior to HIV diagnosis by time since diagnosis, PLWHA

Frequency of sex	Time since diagnosis			
	<= 1 year		> 1 year	
	n	%	n	%
None	36	22	19	34
1-10 times	50	31	22	40
11-15 times	31	19	9	16
16-20 times	30	18	3	5
> 20 times	16	10	3	5
<b>Total</b>	<b>163</b>	<b>100</b>	<b>56</b>	<b>100</b>

**Fishers exact test (4df)=9.29,  $p=0.047$**

Controlling for time since HIV diagnosis in analyses of frequency of sexual episodes by gender resulted in very small cell numbers and was not significant. It has to be noted that HIV patients interviewed might have been living with the virus for some time before they had been diagnosed. As described by *Murali* 'I had been ill with fever continuously for 3 months, tablets were not curing me. I consulted few doctors, until the last doctor tested my blood and said I had this virus and referred me to GHTM'. The data were inadequate for additional statistical analyses and subject to problems of censoring for people diagnosed over a year ago.

#### 7.2.4 Premarital Sexual behaviour

A majority of male patients (80%) reported pre-marital sex (PMS). Only two women in our survey reported that their first sex partner was not their spouse at the time,

although both went on to marry their PMS partner. This was significantly different from married men ( $\chi^2_2=91.8$ ,  $p<0.001$ ) where only one-fourth said that their spouse was the first person they had sex with. Given the small numbers of women reporting PMS, the following analyses of PMS behaviours pertained to men only. The sex partners of sexually active men prior to marriage are therefore an important group to identify, and the majority reported here were either CSWs or older, married women. Logistic regression of factors associated with PMS was performed based on reports from ever-married men (Tab. 7.4)

**Tab. 7.4 Percent distribution and Logistic Regression by socio-demographic characteristics for reported premarital sex, ever-married male PLWHA, patient survey, 1999.**

Background Characteristics	Premarital Sex (Yes)		Logistic Regression	
	No.	%	Odds	Confidence Interval
<b>Age</b>			1.04	(0.87, 0.93)
15 - 24	9	90		
25 - 34	68	80		
35 - 49	37	77		
<b>Age at marriage</b>			2.37	(1.14, 4.92)
16 - 20	7	64		
21 - 25	30	67		
26 - 30	32	89		
31 - 39	7	88		
<b>Ever consumption of Alcohol</b>				
No				
Yes <sup>R</sup>	45	40	0.67	(0.04, 0.56)
<b>Knowledge of blood related HIV transmission</b>	69	61		
Low				
High <sup>R</sup>	25	22	3.15	(1.19, 8.34)
	89	78		

<sup>R</sup> – Reference Category. Effects are significant by logistic regression if 95% CI does not contain 1. Knowledge of blood related HIV transmission is based on Latent classes of this knowledge. Age and age at marriage are in years (not groups) for logistic regression.

The logistic regression model for premarital sex among men showed age; age at marriage; alcohol consumption; and, knowledge of blood related HIV transmission to be significant (Tab. 7.4). These associations were significant only when this logistic model included education and smoking. This could indicate that education and smoking were confounded with age and alcohol consumption in this model although they did not show up as significant on their own because of small numbers. Younger

men were more likely to report pre-marital sex compared to older men, and the chance of engaging in premarital sex increased with every additional year of age at marriage among men. Men who reportedly did not ever consume alcohol had less chance of engaging in PMS compared to those who had ever consumed alcohol. Those with lower knowledge of blood related transmission were more likely to engage in PMS, knowledge of sex related transmission did not show up as being significant, which could have been due to small numbers in the analysis.

It is possible that reporting or recall errors are introduced, suggested by the fact that currently married men were less likely to report PMS (78%) compared with never married men (94%). For all men, both ever- and never-married, household income, occupation, media exposure and smoking were not significantly associated with PMS. Education was positively associated with PMS, but was not significant, although it could have been confounded with age and occupation, but small numbers of cases preclude further analysis for additional associations or interactions.

A majority of men (55%) had an interval of six or more years between their sexual debut and marriage and the median was eight years (Tab. 7.5). Premarital sex was significantly ( $\chi^2=18.2$ ,  $p<0.0005$ ) positively associated with interval between sexual debut and age at marriage.

**Tab. 7.5 Report of PMS by length of time between sexual debut and marriage, ever married male PLWHA**

Interval between sexual debut and marriage	PMS	
	n	%
<=1 year	10	10
2-5 years	37	36
>=6 years	57	55
<b>Total</b>	<b>104</b>	<b>100</b>

$$\chi^2=18.2, p<0.0005$$

The qualitative data supported reports that substantial proportions of men (46%) have regular PMS, with an average of 2-3 sexual episodes per month pre-marriage. Three quarters of ever-married men reported that their spouse was not the first person

they had sex with, and men frequently reported use of CSWs if they had had a successful day of trading in an urban area, for example. Another feature of PMS with CSWs was the peer group involvement:

‘friends got together from when we were 15 years old, watched blue films, got drunk and went to CSWs. Once 5 of us went to the same woman’ (*Raman*, 24 year old)

‘went to CSW before marriage, less often after marriage’ (*Kishore*, 28 year old)

‘women are brought to the check post regularly when I am on duty’ (*Sudhir*, 33 year old working in state border security force)

‘colleagues forced me to go with them to *Hijra*’ (*Senthil*, 27 year old)

Delayed entry into marriage was another reason reported for PMS;

‘family responsibility [meant I] could not marry until I settled siblings, so from 25 years of age I went to CSWs because I got married very late’. (*Kumar*, aged 38)

Regardless of the actual source of HIV infection, eleven respondents reported that they believed that a single premarital sexual contact with a CSW had been the cause of infection. This is an important insight into men’s construction of attitudes, and possibly blame, surrounding HIV infection.

### 7.2.5 *Extramarital sex (EMS)*

In this section, analyses are limited to ever-married men only. Only two ever-married women reported EMS and it should be noted that the same two women who reported PMS also reported EMS, and that the reason for EMS was unspecified problems with their husbands. Importantly, one third of men reported that their EMS partner(s) were themselves married. This is an important methodological finding, as it suggests that EMS was not uncommon among married women and was probably under-reported here, and is likely to be under-reported in other surveys of sexual partners for married women in India.

Overall, EMS among ever-married men was reported by a smaller proportion (49%) compared to PMS (80%). Logistic regression showed that older men reported significantly higher EMS compared to their younger counterparts (Tab. 7.6).

**Tab. 7.6 Percent distribution and Logistic Regression by socio-demographic characteristics of Extramarital Sex among ever-married male PLWHA**

Background Characteristics	Extramarital Sex (Yes)		Logistic Regression	
	No.	%	Odds	Confidence Interval
<b>Age</b>			1.10	(1.03, 1.18)
15 - 24	2	4		
25 - 34	22	45		
35 - 49	25	51		
<b>Ever Smoked</b>				
No	21	43	0.51	(0.95, 0.99)
Yes <sup>R</sup>	28	57		
<b>Age at marriage</b>			0.87	(0.76, 0.99)
16 - 20	7	14		
21 - 25	27	55		
26 - 30	12	24		
31 - 39	3	6		
<b>Ever consumption of Alcohol</b>				
No	19	39	0.45	(0.19, 0.83)
Yes <sup>R</sup>	30	61		
<b>Knowledge of blood related HIV transmission</b>				
Low	6	12	5.36	(1.34, 21.48)
High <sup>R</sup>	43	88		

<sup>R</sup> – Reference Category. Effects are significant by logistic regression if 95% CI does not contain 1. Knowledge of blood related HIV transmission is based on Latent classes of this knowledge.

Age and age at marriage are in years (not groups) for logistic regression.

Men with a younger age at marriage were significantly more likely to report EMS than men who married late. Those who smoked and consumed alcohol were more likely to practise EMS. Men with lower knowledge of blood related HIV transmission were more likely to practise EMS; knowledge of sex related transmission did not show to be significant but could have been confounded. Education was negatively associated with EMS, while household income was positively associated, although non-significant. It is possible that education and household income were confounded with age and small sample sizes precluded further statistical analyses. Occupation and media exposure were not significantly associated with EMS.

We found a significant (Fishers exact test (4df) =23.89, p=0.001) positive association between EMS and PMS among men. In addition, men reporting a younger sexual debut practised EMS significantly (Fishers exact test (4df)=22.46, p=0.003) more often (Tab. 7.7).

**Tab. 7.7 Percentage distribution of pre-marital sex, ever-married male PLWHA, patient survey, 1999.**

Pre-marital sexual relations	Ever-married male PLWHA	
	No.	%
<b>Age at premarital sexual debut</b>		
No premarital contacts	15	31
15-19 years	16	33
20-24 years	15	31
25+years	3	5
<b>Number of premarital sex partners</b>		
None	15	31
2-9	3	6
10-20	4	9
> 20	27	54

Reports of EMS were highest (41%) among those men whose sexual debut had been before 20 years of age. There was evidence of a positive association between EMS and the interval between sexual debut and marriage but the numbers were too small to establish the significance of this association.

Qualitative responses from forty percent of men gave 'wife reasons' as an explanation for EMS, including reasons such as: 'she was pregnant'; 'my wife went to her parents house for delivery'; 'my wife was out of house' [i.e. menstruating]; 'my wife fought with me and went away to her parents place so I went to CSWs'; 'my wife is busy looking after children and gets very tired to have sex with me'; 'my wife is mentally ill'. Interestingly, two patients referred to the need to limit their fertility as a reason for EMS with CSWs. Finally, analysis of verbatim responses revealed another sub-group of men who explained EMS with CSWs as a result of absence from home due to migratory employment (for example, traders, police, army personnel).

Eleven (16%) men reported that they had a '*chinna veedu*'. This directly translates as "small house", and is a vernacular expression used to describe a regular female sex partner in addition to a wife. Four men reported having a 'second wife', acquired through a simple ceremony between the couple and a few friends at a local temple while continuing to be married to the first wife. This *de facto* polygamy practise is customary among Hindus and Muslims although polygamy is not legal in India. In general marriages are not registered and a Hindu priest would perform a simple prayer without asking questions if a couple went to a temple for marriage. Sometimes a couple might simple exchange garlands in a temple on their own and consider themselves married irrespective of whether they were already married to other partners.

### 7.2.6 *Brothel visits*

In general commercial sex work could mean any source such as street walkers, red light areas and/or brothels. However, this section focused on men visting brothels (that provide commercial sex from more than one woman), in particular, as a source for commercial sex. This is with reference to men alone as no women reported ever having visited a brothel for commercial sex. Again high-rigk groups are not included in the analyses here. Nearly three quarters (72%) of all male respondents reporteded having ever visited a brothel. The modal age of first brothel visit was 20 years. Muslims reported visiting brothels least often (50%); while levels of reports from Hindus (74%) and Christians (73%) were similar.

Logistic regression of reports of ever visiting a brothel was performed (Tab. 7.8). Education was not significant, although it could have been confounded with age and age at marriage, since age at marriage was significant only when education was included in the logistic model.

**Tab. 7.8 Percent distribution and Logistic Regression by socio-demographic characteristics of brothel visits by male PLWHA, patient survey, 1999.**

Background Characteristics	Extramarital Sex (Yes)		Logistic Regression	
	No.	%	Odds	Confidence Interval
<b>Age at marriage</b>			1.12	(1.09, 1.26)
16 - 20	5	8		
21 - 25	29	44		
26 - 30	26	39		
31 - 39	6	9		
<b>Knowledge of blood related HIV transmission</b>				
Low	19	19	4.08	(1.33, 12.59)
High <sup>R</sup>	83	81		

<sup>R</sup> – Reference Category. Effects are significant by logistic regression if 95% CI does not contains 1. Knowledge of blood related HIV transmission is based on Latent classes of this knowledge.

Age and age at marriage are in years (not groups) for logistic regression.

Age at marriage was a significant (based on confidence interval using logistic regression) and positive predictor for brothel visits with 84% of those who married after age 30 reporting a brothel visit. Thirty-eight of the 102 men (37%) who reported ever using a brothel said they had used a condom in a brothel. And 71% of these reported that condom use was insisted on by the CSW.

Qualitative descriptions of reasons for brothel visits revealed similar explanations as those reported for EMS, including: peer pressure (particularly for men aged under 21) and mobility of work "I was lonely and lived away from my family so I went to CSWs".

### 7.2.7 Men having sex with men (MSM)

Indian penal code 377 criminalises 'sexual behaviour against the order of nature', which include sodomy (anal sex), oral sex and masturbation. Hence MSM is socially considered to be deviant (more so compared to CSWs) in India (Khan 2004). This has methodological implications for quality of reporting because men having sex with men keep it secret.



Of the 198 male PLWHA interviewed here, 12 men reported ever having had sex with another man. Men reporting ever having sex with another man or boy all described their orientation as heterosexual, even if they were married and continued to have sexual relations with men. Reported low MSM in our sample, is not an indication of numbers being low but could be a factor of under-reporting due to stigma associated with it (Safren *et al.* 2006).

Two of the twelve men who reported having sex with other men said that they had had anal intercourse with *hijra* partners. While *hijra* consider themselves to be women, and dress as women, they are a category of CSW for MSM.

Eleven of the twelve men who reported sex with another man were aged below 35, which suggests under-reporting of MSM among older men. Numbers of men reporting MSM were too small for statistical analyses, but it is interesting to note that men reporting MSM had a later reported age at first marriage (29 years) compared to men that did not report MSM (25 years). The following three case studies highlight some of the difficult issues involved in reporting of MSM, including reports of childhood sexual abuse by an older male partner, and also abusive behaviour on the part of the respondents.

*Mohan* was 32 years and had worked in the navy as a wireless operator. At the time of the interview (April 1999) he worked in a hotel as a server and was admitted in the hospital for treatment of symptomatic illnesses, he was married but his wife lived in his native village while he worked in Chennai, 'I used to get drunk in the evenings and go back to the hotel to sleep. All the boys would be lying around me and I was tempted to have sex with them. I then started changing hotels regularly to find younger boys'.

*Ramu*, a 29-year skilled labourer reported, 'when I was 14-15 years old, a neighbour, a single man in his 30s used to talk to me nicely. One day he called me to his house, I just went there and could not do anything to stop him when he locked the door and had anal sex with me. I have avoided him like the plague since then. Then when I was 25, my cousin who is 3 years younger came to stay

with us. I was attracted to her and we used to have sex 3-4 times a week. After a year, she returned to her parents' home and was later married'.

*Kanna* (aged 22, married) reported that he was 17 when a friend of his, a hijra, invited him to his house. He reported that he was plied with alcohol, and that when he was sleeping, his friend forcibly had anal sex with him.

### 7.2.8 *Ever use of Condoms*

This section deals with ever use of condoms as reported by all patients surveyed (not including high-risk groups). Knowledge of condoms was high among surveyed PLWHA (see section 6.3.2). However, high knowledge was not accompanied by high usage of condoms. Twenty six percent of all PLWHA, not including high-risk groups, reported ever using condoms. There was a significant ( $\chi^2_1=17.7$ ,  $p<0.0005$ ) difference between men (35%) and women (9%) for ever use (Tab. 7.9), and consistent use of condoms post-diagnosis was reported by only 7 respondents. Prior to diagnosis, one-fifth of men (and three women) reported that they had used condoms occasionally with their spouse. While two men reported having heard of female condoms, no one had ever used them. Thirty-nine men said that they had used condoms occasionally at brothels; five of them specifically reported it was because of HIV; two said it was because they were forced by CSWs; 30 of these 39 (77%) men said there was no point in using condoms because they tore.

Those with higher education ( $\chi^2_2=7.9$ ,  $p=0.02$ ), higher income ( $\chi^2_2=10.4$ ,  $p=0.005$ ), or with more than one year post-diagnosis ( $\chi^2_1=3.7$ ,  $p=0.05$ ) reported significantly more ever-use of condoms (Tab. 7.9).

Other factors, including age, marital status, and knowledge of other HIV positive people did not show up as significant. Logistic regression for ever use of condoms showed that gender, time since diagnosis and knowledge of sex related transmission were all significant predictors (Tab. 7.10).

**Tab. 7.9 Percentgae distribution of ever-use of condoms by respondent characteristics, PLWHA, patient survey, 1999.**

Respondent characteristics	Condom use			
	Ever used		Never used	
	No.	%	No.	%
<b>Gender**</b>				
Male	50	35	92	65
Female	7	9	70	91
<b>Education**</b>				
No Schooling	4	10	34	90
Primary	22	24	68	76
Secondary	31	34	60	66
<b>Household Income**</b>				
Low	25	18	110	82
Medium	23	37	39	63
High	9	41	13	59
<b>Occupation</b>				
Housewife	3	9	32	91
Skilled/Unskilled labour	31	23	106	77
Professionals	23	49	24	51
<b>Time since diagnosis**</b>				
<= 1 year	37	23	126	77
> 1 year	20	36	36	64

\*\*p<0.05.

**Tab. 7.10 Logistic Regression, ever use of condoms, PLWHA, patient survey, 1999**

Background Characteristics	Logistic Regression	
	Odds	Confidence Interval
<b>Gender</b>		
Male	2.3	(0.09, 0.49)
Female <sup>R</sup>		
<b>Time since diagnosis**</b>		
<= 1 year	0.4	(1.03, 5.02)
> 1 year <sup>R</sup>		
<b>Knowledge of sex related HIV transmission</b>		
Low	0.6	(1.04, 6.07)
High <sup>R</sup>		

Table Note: <sup>R</sup> – Reference Category. Effects are significant by logistic regression if 95% CI does not contain 1.

Knowledge of sex related HIV transmission is based on Latent classes of this knowledge.

Education and other socio-demographic variables were not significant predictors of ever use of condoms. Those with high knowledge of sexual transmission (based on latent class analysis) reported ever use of condoms more often than those with low knowledge of sexual transmission of HIV. Knowledge of blood related transmission and other miscellaneous modes of transmission were not significant.

Those who had known their HIV positive status for over a year were more likely to report ever use of condoms compared with respondents with less than one year since diagnosis.

### 7.3 Attitudes about Condom Use

Knowledge of attitudes towards condom use is essential for planning effective prevention programs. Here, we are dealing with condom attitudes of a specific group of people, PLWHA, and describe attitudes regardless of ever-use of condoms. A majority of men (54%), and relatively fewer (14%) women, agreed with the statement that 'condoms are easy to use'. The verbatim responses, however, probably provided the most informative insight into locally constructed attitudes about condom use, including their associated health beliefs.

*Shanmugam* (29 year old, trader) reported having used *nirodh* with his wife a few times after the birth of their first child. However, he went on to say,

'it is difficult to use it each time because it might cause trouble for the wife (he mentioned the problem that condoms slip and go inside a woman and are difficult to get out), but it can be used occasionally'.

'it is dangerous for women, if I use *nirodh*, it could go inside and cause problems' (*Rama*, male, 32 year old, married, labourer)

Most patients (92%) did not agree with the statement 'condoms are expensive' since they could get 'nirodh' for free at health centres. Respondents did, however, express concern about knowledge of correct condom use. In this example his concerns extend beyond correct use to the issue of his image with sex partners, in particular EMS partners.

*Kanna* was 22-years-old and married. He reported, 'People do not know how to use *nirodh* properly, so they can get pregnant or get infected with HIV even when they use it. It is difficult to use a *nirodh* every time, it does not give the same feeling with *nirodh*. Also if I go to a casual partner and stop because there is no *nirodh*, she will think cheaply of me'.

Only five men (2 Hindus and 3 Muslims) reported that condom use was against their religion. These attitudes were not necessarily guided by what the religion said per se, but rather by the religious leaders they followed. One of them was Sadullah, a 33-year married man, 'Condom use is against my religion. We already have four children. I have to abstain from my wife. But I get tempted and go to a CSW so I don't have to use it.' Women were vocal in their attitudes against condom use for religious or ethical reasons:

*Jaya*, a 24-year-old was vehement,

'*nirodh* is all nonsense, it is not part of what God created, it is wrong to use it. I would abstain or even separate from my husband rather than use that thing'.

*Baghya* aged 35 said,

'I do not like using rubber. How can anyone use such things? Even the thought of it is repulsive. We are from the village, we do not have such practises, maybe town people get used to these things, but do not talk to us about it'.

*Neela* was 27-years-old and her husband died of HIV at GHTM. She said,

'How can a woman ask her husband to wear *nirodh*?...it is not right to suspect him'.

*Rukku*, a 26-year-old explained why she left her husband to live with her mother,

'I am so angry with him for putting me and my children into this trouble, I cannot bring myself to even look at him. He drinks a lot and goes to other women. I do not want to live with him. He will get drunk and force me to have contact and I do not like using *nirodh* so that will only increase my infection. Atleast this way I can live for a little longer to look after my son'.

More generally, women expressed their distaste at the mention of condoms, although some did report intermittent use:

*Shanti* aged 38, whose husband was a lorry driver said,

'we used *nirodh* a few times, but both of us did not like it. It is too much of a hindrance to use when we have children sleeping around us, so we stopped. Anyway, we are both positive, so now it does not matter. I only hope the children are free of it. If we can carry on like this until they are settled, I will be happy'.

*Shyamala* a 25-year-old narrated her experience:

‘My husband had fever and rashes and we went to the hospital where they tested him HIV positive. They tested me and said my blood was clean. I did not know anything about the disease and did not understand or believe anything they told us. We had contact without using a *nirodh*. Then we kept hearing more things about the disease and used *nirodh* occasionally but we did not like it. Anyway, I got pregnant and at the antenatal clinic I was tested as HIV positive. I was very upset and wanted to abort the baby. After counselling, I was encouraged and prayed that the baby should be spared. I am relieved that my child is negative. Since both my husband and I are positive now and I have been sterilized, we have contacts, but do not want to use a *nirodh*.’

*Selvi* was 27-years-old and her husband had died in 1996.

‘People will not use *nirodh*, they will abstain rather than use one. People don’t like it; it is like a foreign object and will be irritating inside. Why should a couple have indirect contact? They have promised to belong to each other, so when the husband looks all right, no one will think it necessary to use a *nirodh*. When we found out he had HIV, we abstained from sex’.

*Lakshmi*, a 29-year-old said,

‘There is no need to use a *nirodh* with my husband. I do not like such things. We have made no change since being tested HIV positive. But if we do we will abstain since we have two children already’.

*Prasanna*, a 25-year-old wife of a lorry driver said,

‘who wants those silly things, *chee* [word to express distaste]’

*Vijaya*, a 25-year-old married woman said,

‘we have no use for things like rubber. My husband too will not agree. What is the need for this between husband and wife?’

*Viola* a 28-year widow whose husband died of HIV said with hindsight,

‘even when my husband was tested positive, I was careless and we had sex without protection a few times since I did not know anything about the disease. After that the social worker counselled us and then we stopped having contact. We did not like to use a *nirodh*’.

*Anbu*, a 40-year lodge manager, reported his wife’s dislike of condoms,

‘my wife will not agree to using a condom. It is disgusting to her. Most of our women think it improper to engage with their bodies. We respect that and go to CSWs if we want to have fun.’

*Shanthi* was 17-years-old and had lost her first son within months of his birth. She said,

‘I was ill and was tested HIV positive, so I got my tubes tied in order not to have a child. It is very uncomfortable. I abstain from my husband. I don’t like using a *nirodh*, I don’t know why, but I simply don’t like the idea of using one’.

*Saroj*, a nurse aged 56, reported that she had used condoms regularly with her husband since she was tested HIV positive,

‘I have been using condoms each time I had contact with my husband since I was tested HIV positive and he is negative’

*Saroj* is a relatively unusual example of an educated, independent middle class woman in India who is able to change her sexual behaviour and practice safe sex in contrast with the less educated and poor women.

A strong perception was that condoms made sex less enjoyable (67% men and 26% women), cited as the main reason for not using them:

*Aadi* said, ‘*nirodh* cannot stop spreading HIV. Since it is not even effective, what is the point in using something that is uncomfortable and does not give satisfaction?’

*Venugopal*, a 30-year-old from Nellore in AP said,

‘I used *nirodh* three times when I had an STD, but it makes sex dull and uninteresting. There is no feeling of satisfaction when I use condoms so I will abstain with my wife instead. I can go to CSWs if I cannot control’.

*Vijayan*, a 38-year-old trader said

‘I do not like using *nirodh* because it is like eating a banana with the skin - does not give satisfaction. I have contact with my wife occasionally but do not use *nirodh*’.

*Sudhakar*, a 40-year-old was a married man from Vijayawada in AP. He said

‘I am a respected leader in my community. I cannot even tell my wife I have HIV. She would not be able to keep quiet about it and everyone will come to

know. I do not want to be looked down upon. I had an HIV test before marriage as I went to so many women, but I was tested negative. I went to other women even after marriage. Only now I am HIV positive. I have reduced frequency with my wife. I used *nirodh* with her just after marriage a few times, but I do not like it as it feels like drinking water without having your thirst quenched’.

*Venkatesh*, aged 32-years said

‘They [doctors] consoled me. They said I would be fine for ten years maybe, now I feel brave to handle it. We want children, so my wife and I have contact without *nirodh* but we have reduced frequency. She was tested negative one year ago.’

*Moorthy*, a 26-year-old businessman said,

‘*nirodh* does not give 100% protection, they are not enjoyable and also a man’s strength will go. So I will not marry until I am fully cured’.

PLWHA reported sex without condoms, irrespective of their partner’s serostatus. In some cases, for example, *Venkatesh*, for reasons associated with desired fertility. Women reported strong reservations against using condoms, and only one third agreed that it was appropriate to use condoms with their husband. Men expressed greater willingness (55%) to use condoms with their wives. However, men went to great lengths to avoid actual use of condoms with their wives as illustrated by the following examples:

*Muthu* aged 26, was not married but had a regular partner who was married. He used to tell her before he became positive

‘if I have to get HIV from you, let me get it, but please do not force me to use *nirodh*’.

*Mani* was a 32-year-old skilled labourer. When he was 23, he went to CSWs for the first time, and in total visited 4 or 5, and never used a condom. When he married he stopped going to CSWs. However he then began to suspect that he had HIV, and reported that he knew that he should stop having unprotected sex with his wife,

‘I pretended to get *saamy* (meaning god, refers to being possessed by gods, a normal phenomenon in rural and peri-urban regions) and told her that the god I am possessed with says we should not touch one another. She respected that, so I



put *vibudhi* (holy ash) and abstain from her. I will abstain, but I cannot use *nirodh*, it is not a thing nature created’.

Men (43%) and women (31%) thought that a spouse would become suspicious if condom use was insisted upon. However, a higher proportion of men (82%) and women (45%) agreed that ‘it is good to use condom with casual partners’. This response might have been biased by the hospital atmosphere but it was also a positive indication that proper counselling might encourage people to try to use condoms. Their positive attitudes towards condoms were possibly related to their own experience with HIV. The following cases were illustrative:

*Raju* was 30-years-old and married with three children. His wife was not HIV positive,

‘I have not had contact with my wife for some time...if I get the feeling, I take a bath in cold water. Then the doctor said that I could have sex with my wife sometimes if I used a *nirodh*. So we have had contact 6-7 times in the last 6 months. I used a *nirodh* each time’.

*Kumar*, a 32-year supervisor was married and had a child. His wife was angry with him for having been to CSWs and getting infected with HIV. So she left him and went to live with her parents, but she still wanted to have another child.

‘I tell her that there is a risk of the child being born with HIV, and then she hesitates. I go there to see her. I was tested positive in 1994. But thank God my wife and child are negative. I abstained for two years. But now I have contact with my wife about once a month, but I use a condom each time. I do not have any outside contact’.

*Krishna* was 33-years-old, and married for the second time:

‘I married again and since then stopped visiting CSWs. I abstained for a while after being tested HIV positive, now I feel better so I have contact sometimes, but use a *nirodh* each time since she is HIV negative’.

A majority (54%) of male respondents did not agree that one should refrain from having sex with casual partners/commercial sex workers if a condom was unavailable. In this context *Ayyah*, a 25-year-old pointed out practical difficulties involved,

‘when a man goes for sex he goes with only one thing on his mind. So it is difficult not to have sex with a woman simply because there is no *nirodh* available’.

A majority of respondents reported that condoms could prevent HIV, STDs (66% men and 31% women) and pregnancy (78% men and 55% women) (Tab. 7.11).

**Tab. 7.11 Percentage distribution of attitudes towards condoms, by gender, PLWHA, patient survey, 1999.**

Attitudes	Male (142)		Female (77)	
	No.	%	No.	%
Condoms can prevent HIV	115	81	52	68
Willing to use condoms with spouse	78	55	33	43
Agreed ‘Good to use condoms with casual partners	116	82	34	45
Reported condom reduces sexual pleasure	95	67	20	26

However, a combination of dissatisfaction in sexual pleasure, lack of knowledge and confidence in the ability of condoms to provide adequate protection against HIV (mainly due to tearing) were deterrents against use. Some respondents reported a preference to abstain from sex with their spouse rather than use condoms. In addition, male respondents reported using CSWs for sex rather than using a condom with their spouse.

## 7.4 Sexual Behaviours and Practices in relation to Positive Prevention Reported

Sexual behaviours among PLWHA are an important indicator for HIV prevention. Understanding attitudes to safer sexual practices, such as using condoms, is important for planning HIV interventions. However, studying sexual behaviours and practices among PLWHA is difficult in general. For example, the date of diagnosis is not the same as date of infection. Using cross-sectional retrospective reports from a survey makes it impossible to differentiate between behaviours that resulted in HIV transmission. Analyses are restricted to reports of behaviours before and after diagnosis, not actual serostatus. Together with small sample sizes these are the data

limitations of this study. Nevertheless, we can glean some valuable information about PLWHA from this data. High-risk groups have not been included in the analyses and are dealt with in chapter VIII. In this section we consider last sexual contact prior to diagnosis and reported preventive actions taken in relation to positive prevention post-diagnosis. In particular we examine attitudes to, and reported use of condoms.

An important finding of post-diagnosis behaviour is that some respondents (not including high-risk groups) reported continued sex (23%), and entry into marriage (8 patients), post-diagnosis. Respondents reported that sex, and entry to marriage, were associated with post-diagnosis recovery from symptomatic illnesses. Because of issues of censoring, the descriptive analyses reported here are limited to reports of sex in the last year from those people who had been diagnosed as HIV positive more than a year prior to interview.

Among those who had been positive for over one year, 25% of unmarried and 62% of married PLWHA reported at least one sexual contact in the last year. Sex within the last year was reported by one-third of married women who had been positive for over a year. Respondents who reported sex post-diagnosis were asked probing questions, and women tended to report, “we have to share difficulties with a husband”. Where both partners were sero-positive, respondents reported that sex under such circumstances “did not matter”. Some (12%) unmarried men who had been diagnosed for more than a year reported reduction, but not cessation, of sex post-diagnosis.

### ***Post-diagnosis positive prevention***

A majority (84%) of patients reported that they had taken preventive action post-diagnosis. It should be noted that results here are based on reduced (n=176) responses due to high levels (20%) of non-response to questions about post-diagnosis sex. The majority of respondents reported abstinence as positive prevention, and

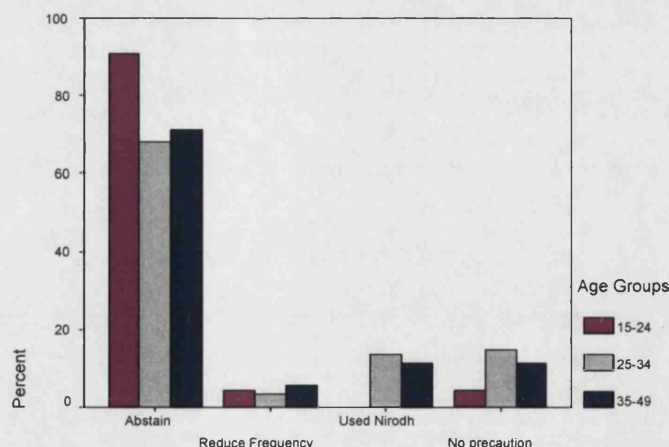
reported condom use was low, particularly for women (14% of men, 6% of women). Overall, however, there was no significant difference between men and women in the nature of preventive action taken since being diagnosed with HIV. Logistic regression showed only age and marital status to be significant for whether patients reported preventive action post-diagnosis (Tab. 7.12). Gender, education, media exposure, and levels of knowledge of HIV/AIDS were not significant.

**Tab. 7.12 Percent distribution and Logistic Regression by socio-demographic characteristics of reported post-diagnosis preventive prevention, PLWHA, patient survey, 1999.**

Background Characteristics	Preventive action taken		Logistic Regression	
	No.	%	Odds	Confidence Interval
<b>Age</b>			0.96	(0.91, 0.99)
15 - 24	19	79		
25 - 34	82	86		
35 - 49	46	81		
<b>Marital Status</b>				
Never Married	7	50	8.05	(2.67, 13.63)
Ever Married <sup>R</sup>	140	86		

<sup>R</sup> - reference category. Effects are significant by logistic regression if 95% CI does not contain 1. Age is in years (not groups) for logistic regression

**Fig. 7.4 Reported post-diagnosis positive prevention by age group**



Never-married respondents were eight times more likely to report post-diagnosis preventive action compared to ever-married PLWHA. Abstinence was reportedly higher among 15-24 year olds compared to older age groups (Fig. 7.4).

Levels of knowledge about a partner's (spouse or regular partner) serostatus were low, particularly among men. 60% of men and 32% of women reported that they did not know their partner's HIV status.

**Tab. 7.13 Distribution of reported positive prevention with spouse or regular partner, by sex and partner's serostatus, PLWHA who knew their partner's status, 1999**

Reported positive prevention	Partner's HIV status	
	Positive	Negative
<b>Female</b>		n/a
Abstain	28 (80%)	
Reduce Frequency	1 (3%)	
Used condom	3 (9%)	
No precaution	3 (9%)	
<b>Male</b>		
Abstain	17 (85%)	12 (60%)
Reduce Frequency	1 (5%)	0
Used condom	2 (10%)	7 (35%)
No precaution	0	1 (5%)

**Data only refer to respondents who knew their partner's HIV status.**

**All female PLWHA who knew their spouse/partner's serostatus reported that them to be positive.**

Abstinence was the main reported precaution taken with spouse/regular partner post-diagnosis (Tab. 7.13). Nine men (two of them only occasionally) and three women (two of them only occasionally) said that they had ever used condom after being tested positive. Condom use was also low among the twenty men who reported their wife to be HIV negative, with six men reporting consistent condom use and one man reporting inconsistent condom use post-diagnosis.

In our study, 25% (56 out of 219) of respondents had been diagnosed as HIV positive over one year prior to interview. Analysis of this sub-group provides an in-depth examination of sexual behaviour for longer term PLWHA. Based on reports of sex in the last year, there is clear evidence of PLWHA having sex: 9% reported sex in the preceding 6-12 months; 29% reported having sex in 2-6 months prior to the interview; and, 14% reported having had sex within one month prior to the interview. Qualitative analysis provided further information on the attitudes and behaviour of this sub-group of PLWHA, with more than one year since diagnosis.

*Senthil* was a 42-year farmer near Salem was married with a daughter. He had been diagnosed as HIV positive over a year before the interview but his wife had not been tested for HIV. 'Nirodh can be used to prevent pregnancy' he said, 'but it is not really working. It usually tears or there is leakage'. He had not abstained from having sex with her, but he had reduced his frequency of sexual intercourse with her. He had never used condoms, although he said, 'if a husband knows he has HIV, he should use a nirodh'. *Senthil's* case is illustrative of the paradox between what one says and actually does in relation to using condoms.

*Kandaswamy*, a 27-year skilled labourer, diagnosed as HIV positive for over a year said,

'since 1995 when we all got scared about HIV, I have used *nirodh* each time, but you know how they do not give 100% protection? They tear and leak often. Anyway, it is impossible to use it with my wife each time.'

The case of *Kandaswamy* showed that even when someone reported that they used condoms regularly, it did not mean every single time. When probed for why he thought it was impossible to use condoms each time, he responded with 'my wife and I do not like such things, they are for the educated people', which relates to cultural attitudes toward condoms.

## 7.5 Discussion and Summary

Studies have stressed that a greater knowledge of sexual behaviours in different socio-cultural contexts has important implications for designing and evaluating efforts to encourage self-protective behaviours (Brummelhuis and Herdt 1995; Farmer 1999; Gausset 2002; Obbo 1995; Orubuloye et al. 1997; Schoepf 1995). The data presented here contribute to the knowledge base of sexual behaviours and attitudes of PLWHA in India.

Doubts about whether respondents would answer questions on sexual behaviour were dispelled early on in the survey. Indeed, because this research reports on a group of people who already knew their HIV status and were seropositive, it was observed that people were eager to discuss their concerns. Caldwell and his colleagues (1998) reported similar responses in West Africa.

A survey among the general population showed reported sexual intercourse with non-regular partners in the last 12 months among men in Tamil Nadu to be 12% (NACO 2001a). Reported sexual intercourse with non-regular partners among women in TN was negligible (<1%). A survey conducted by APAC (2001) among various groups in TN showed that about 17% of male youth in slums reported sexual intercourse with non-regular partners in the behaviour surveillance survey conducted in 2000 (APAC 2001). Sexual intercourse with non-regular partners was reported at 15% among male factory workers and 3% among female factory workers in the first round in 1996 and at 9% and 2% correspondingly in 2001. It was reported at 5% among male students. Reported sexual intercourse with non-regular partners among female students showed an increase from 1% in 1996 to 3% in the latest round in 2000. Thus sexual intercourse with non-regular partners is not negligible for men, in the context of exposure to HIV in TN, even allowing for possible under reporting.

Our study of sexual behaviour produced reports of pre- and extra-marital sex, use of CSWs (including at brothels) and men having sex with men (MSM). These findings confound the traditionally held perception of India as a heterosexual and monogamous society (Sethi 2002; Solomon *et al.* 1997; TNSACS and ORG 1998). Heterosexual transmission accounts for the major route of HIV transmission in India. Cultural roles, and the position of married women in the Indian society present challenges for the development of effective prevention programs. Research elsewhere in India shows that monogamous married women are increasingly exposed to the risk of acquiring HIV/AIDS from their husbands (Gangakhedkar *et al.* 1997; George *et al.* 1997; Narain *et al.* 1994; Panda *et al.* 2000). While norms of pre-

marital chastity and marital fidelity continue to be imposed strictly on women, they are lenient in relation to men. It is possible that these strong norms may have led to under reporting of extra-marital sex among women. This is suggested by the reports from men that some of their sexual partners are women married to other men.

Women, excluding high-risk groups (studied separately in chapter VIII), reported earlier sexual debut compared to men but it was synonymous with marital sex. Age at first sexual intercourse was the same as age at marriage among all but two women, consistent with other findings (Carael 1995; Nag 1996). Infection of women after marriage, resulting from infection from their husbands was evident, and 83% of married women reported that they believed they had acquired the infection from their husbands.

In India, urbanisation and increasing pursuit of education in the last couple of decades, for both men and women, have resulted in a gradual increase in Singulate Mean Age at Marriage (SMAM) consequently extending the gap between puberty and marital sex (CensusIndiaTN 2002; NFHS 2000). It has been hypothesised that this shift, coupled with increased exposure to different sexual norms through mass media could be contributing to rising levels of PMS (SifyNews 2002).

The interval between age at sexual debut and age at marriage is a predictor of potential exposure to HIV (Carael 1995). In the current study, the likelihood of PMS for men was positively associated with the length of interval between sexual debut and age at marriage. This study corroborates other reports from India that the PMS partners of men include older, married women (Jejeebhoy 1998; Nag 1996), together with CSWs, friends, relatives and future spouses (Abraham *et al.* 2000).

Commercial Sex Workers (CSWs) were the main reported sources of infection reported by men (90%). PMS was reported by the majority of men (80%), and a common feature was the visiting of CSWs with groups of friends or peers, also noted in other studies (Pelto *et al.* 2000).



Studies of attitudes and practises related to EMS are far fewer than those related to PMS (Nag 1996). Sanctions for women practising EMS in India are again stricter than those for men. In general studies have found that reported levels of EMS are very low, probably due to underreporting (Hawkes and Santhya 2001). EMS among men was reported by approximately half (49%) of all men, and the length of time between sexual debut and age at marriage was an important predictor for subsequent EMS. Men reporting an early sexual debut were more likely to report EMS. Qualitative analysis identified that reasons associated with a wife (for example, pregnancy) were most frequently cited as an explanation for EMS. As other authors too have suggested, the need for anonymity might be the reason for EMS partners being CSWs more often than friends or relatives (Srikanth *et al.* 1997).

The twelve men in our survey who reported MSM self-reported themselves as heterosexual (and most were married and had children), in keeping with findings elsewhere in India (Pradeep 2002).

With regards to potential interplays between religion and risk of HIV infection, studies elsewhere in South Asia (Muslims in Bangladesh) have shown behavioural risk factors for HIV/AIDS to be low (Gibney *et al.* 2003; Gibney *et al.* 1999). Muslims were least likely in this study to report visiting brothels, but additional research into relationships between religion and HIV risk in India is required. Studies have shown substance use (smoking, alcohol and drugs) to be important predictors for unsafe sexual behaviour, which was also indicated in our study of PLWHA (NIMH 1997; Prabha *et al.* 2003; Selvan *et al.* 2001).

### ***Positive Prevention***

It is important to understand the sexual behaviours of HIV infected persons but the area has been under researched for a range of reasons (Schiltz and Sandfort 2000). Safe-sex practices from our study, such as condom use by PLWHA, adds value to

information related to positive prevention. Socio-cultural issues influenced attitudes associated with sexual behaviours.

Strategies for positive prevention should aim to support people with HIV to protect their sexual health, to delay HIV/AIDS disease progression and to avoid passing their infection to others (InternationalHIV/AIDSAlliance 2003). Comprehensive intervention programmes aimed at PLWHA need to take account of social and individual factors in helping them maintain long term and consistent safe sex practices. Individualized interventions are recommended to increase both knowledge of how to use condoms, and self-efficacy for condom use among men, and also among women at risk of acquiring HIV (Agha *et al.* 2001; Kanya *et al.* 1997; Lindberg 2000; Roth *et al.* 2001).

Reported behaviour changes evident in parts of Africa included use of condoms, a reduced number of sexual partners, reduction in extramarital sex, a trend towards monogamy and respect for people with HIV/AIDS as a consequence of many HIV/AIDS related deaths in the community (Asiimwe-Okiror *et al.* 1997; Ntozi and Kirunga 1997). According to Amuyunzu-Nyamongo (1999) behaviour change required a minimum of 10 years to start showing in East Africa.

India now has two-decades of HIV/AIDS experience. However it has only recently accelerated programs to encourage condom use and it could be a while before a majority of people adopt safe sexual practises. The evidence generated by systematic reviews alone may not provide a clear answer as to whether social interventions shown to be effective in one setting, place or moment in time can be replicated in another (Elford and Hart 2003; Elford *et al.* 2004). Thus it is essential for India to develop suitable prevention programs appropriate to socio-cultural and economic context.

Studies have indicated increase in reported ever-use of condoms in urban south India (Thomas *et al.* 2004). TNSACS (1998) had reported ever-use of condom to be

7% in a large-scale population survey in TN. A later study by NACO (2001a) reported even higher levels of ever-use of condoms (22% in TN) in the general population. However, awareness of condoms was higher (section 6.3.1) than reported usage of condoms in the general population. The levels of reported ever-use of condoms in our patient survey are consistent with findings from elsewhere, but our findings are based on small numbers from PLWHA and may be overstated. The important message is the majority of respondent PLWHA report that they have never used a condom.

The majority (84%) of PLWHA reported changes in sexual behaviours with their spouse or regular partner since being tested HIV positive. However, the main reported behaviour change was abstinence (72%), but it is important to examine in more detail this response through qualitative analysis of verbatim quotes. Many men reported an intention of abstinence, but qualitative analysis revealed that this did not refer to total abstinence. It might be that, in keeping with evidence from elsewhere, respondents may be merely giving a verbal acquiescence to the desirability or need for change (Cleland 1995). The sexual behaviour reported by PLWHA showed that, especially for those who had met their familial and societal expectations, married and had children, were unlikely to abstain totally from sex. This finding has important implications for positive prevention and associated policies and programmes.

Reported knowledge, attitudes and behaviours were not congruent with regard to condoms. We saw that knowledge of condoms was high (94% men and 81% women had heard of condoms). However, this high knowledge was not accompanied by high usage of condoms, with 35% of men and 9% of women (excluding high-risk groups), reporting ever use of condoms. Consistent condom use was reported by only 6 men and 1 woman. Only six men (out of 20), who reported that they knew their wife to be HIV negative, said they had used condoms consistently since being tested positive themselves. Qualitative evidence further suggested that those that reported they used

condom each time might not mean every single time in actual fact (Cleland 1995). Thus high-risk sexual behaviours continued post-diagnosis.

Condom use was higher among those patients who were younger, *peri-urban*, unmarried, had higher levels of education, income and exposure to media, and longer time since diagnosis. Hernandez-Giron and colleagues (1999) identified age, education and type of sexual partner as important characteristics for use of condoms among males in Mexico city. About 10% of patients surveyed reported that fear of HIV had made them 'more careful', even though they were not practising abstinence or using condoms on a regular basis.

A combination of socio-cultural and environmental factors contributed to low condom use. First the perceived poor quality of condoms had led to a lack of confidence in their ability to provide adequate protection against HIV. A quarter of men spontaneously said that *nirodh* (government brand condoms) were liable to tear during use, and a tenth of men reported that they did not know how to use a condom correctly. It is possible that the lack of practical knowledge contributed to condom failure and so to the perception that they were unreliable as a means of preventing HIV infection. Thirty percent of men also reported problems of access to condoms. *Nirodh* are distributed for free and were widely available, but imported condoms are perceived to be of higher quality, are more expensive and more difficult to buy. Regardless of condom type, men reported that there was often no time to acquire a condom in a sexual encounter, a common finding (Amuyunzu-Nyamongo *et al.* 1999; Caldwell *et al.* 1999a; Orubuloye *et al.* 1997).

Other studies have suggested that belief in the effectiveness of condoms to protect against HIV transmission is important to encourage people to use them (Irwin *et al.* 1991). Controlled clinical trials (Frezieres *et al.* 1998; Rosenberg and Waugh 1997) and studies in France (Messiah 1997) and Australia (Smith *et al.* 1998) showed that condom breakage and slippage was about 5% in the west. Condom failure was reportedly higher in India (15%) (Sharma 2001, 2001a). Condom failure was

reportedly even higher (21%) as reported by male patients surveyed (Table 7.19). Condoms at best are preventive, however if the failure rate is high then they are worse than nothing as people will become reluctant to use them. In order to achieve behaviour change through effective interventions, key barriers such as the attitude that condoms reduce sexual pleasure, and access to good quality condoms that do not tear, have to be addressed.

Other widely mentioned barriers to using condoms were that they interfered with sexual pleasure, the belief that they were unnatural and even dangerous and that nothing should come between husband and wife. This last belief was reinforced by culture and religion for many, particularly women, and was a frequent theme in the qualitative analyses. As reported by our respondents in conversation, both a lack of privacy at home and while buying them in local stores in an environment of social stigma associated with condoms added to the difficulties of using them (Roth *et al.* 2001).

Recent (2006) research based on an interview survey of 350 married women in Mumbai reported that of the 67% who were aware of HIV/AIDS: less than two thirds (59%) mentioned unsafe sexual activity as increasing risk of HIV; two in five women perceived HIV as a threat to the community; one in eight perceived personal risk of getting infected as high; and, only 7% (17) reported behaviour change to avoid infection (Chatterjee and Hosain 2006). When probed for reasons for not changing behaviour, most women cited their personal behaviour of monogamy which, when combined with trust in their husbands, placed them in a group that was not at risk of infection.

Qualitative analysis of responses underlined that condom use with regular partners and spouses was much more difficult than with casual partners. In general, knowledge about condoms was lower among women, which when combined with the lack of power that women experience in relation to men, make it difficult for women to negotiate protection against infection (for example, condom use) with their

husband. In a culture where fertility is extremely important, as in India, it is difficult for either partner but especially the woman, to insist on condoms if that means controlling fertility (Obbo 1995; Schoepf 1995). We found evidence from our patients surveyed that they were willing to take the risk of getting HIV because the desire for children was greater. Social and culture issues combine with low levels of knowledge to reduce the likelihood of the adoption of safer sexual practices (Gausset 2002; Giffin 1998; Macdonald 1996).

Sexual risk behaviours within a relationship have many interrelated determinants, including an individual's characteristics (age, marital status, ethnicity), length of relationship, already established behaviour patterns, level of emotional and sexual intimacy, satisfaction with the relationship and communication patterns. There are both HIV-infected people and people with unknown *sero*-status who have unprotected sex, just as there are HIV-negative people or people with unknown *sero*-status who take precautions. Among *sero*-positive people, sex also involves dilemmas over disclosing their *sero*-status to potential sex partners, and their motivation to protect their partners as well as themselves against repeated infection by HIV and STDs. Furthermore, having to cope with a serious disease induces negative mood states (particularly depression) and may compromise sexual functioning (Schiltz and Sandfort 2000).

Although it was impossible to gather full data on the HIV status of partners in the patient survey, it emerged from the qualitative data that unsafe sexual behaviour continued in many *sero*-discordant couples. Without a clearer understanding of the dynamics of heterosexual relationships in which one or both persons are at risk of HIV, interventions are unlikely to be sufficiently sensitive or targeted to produce meaningful behaviour change. Interventions, such as couple counselling, that target couples rather than individuals might help improve communication within relationships, focusing on protecting those who are at high risk and may well have the most direct benefit. Lurie (2003) suggests that including *sero*-negative partners in

counselling interventions may decrease sexual risk-taking among *sero*-discordant couples. Interventions aimed at couples could help improve communication within relationships, focusing on protecting those who are at high risk. This however poses difficulties for behaviour change communications (BCC) in a cultural context where women are committed to share their husbands' pain, are economically dependent on them, and many men do not tell their wives of their positive status.

## Chapter 8 HIGH-RISK SUB-GROUPS

Research on sexual behaviour and the risk of HIV infection among people where high-risk behaviours were common, requires focusing on the specific social and cultural interactions that influence individual behaviour and provide important implications for designing and evaluating efforts to encourage self-protective behaviours (Brummelhuis and Herdt 1995; Cleland 1995; Gausset 2002; Huygens *et al.* 1996; Macdonald 1996; O'Neil *et al.* 2004; Orubuloye *et al.* 1997; Schiller *et al.* 1994; van Kerkwijk 1995) According to Hubert (1990), histories of sexual practices are difficult to obtain from people where high-risk behaviours were common. However, it is important to understand this since their high-risk behaviours expose them to the risk of acquiring HIV/AIDS.

Groups where high-risk behaviours were common, when infected with HIV, can comprise channels for disseminating infection to the general population. Studies have shown that certain occupations could be significant risk factors for HIV/AIDS (George *et al.* 1997; Morris *et al.* 2000; Nagelkerke 2002). Morris and colleagues (2000), suggest that workers who were migratory were more likely to have higher levels of sexual risk behaviour, and the risk could be offset by greater knowledge, acceptance and use of condoms. According to these authors the sexual risk differential for migratory workers was explained by occupational exposure and higher socio-economic status. They also recorded that condom use with non-spousal partners was three times higher among migratory workers than among those whose work did not involve travelling.



In this chapter we focused specially on those PLWHA in our survey among whom high-risk sexual behaviours were common. We examined whether higher knowledge of HIV/AIDS among these groups was accompanied by behaviour change. Analyses of data from these high-risk groups allow a detailed appraisal of the critical social and cultural issues that constrain behaviour change.

A considerable numbers of lorry drivers (32), Female Sex Workers (FSW) (5), *Hijra* (6), construction workers (19) and hotel workers (11) were present in our survey of PLWHA at GHTM and CMC. Commercial sex workers by the nature of their occupation were exposed to HIV infection. Lorry drivers, construction workers and hotel workers might be classified as migratory workers. Construction workers moved between sites with or without their families; hotel workers reported living away from their families depending on employment opportunities, which were to be found in urban or *peri*-urban areas and/or not within commutable distances from their family homes. Thus frequent absences from the family made exposure to HIV/AIDS infection an occupational hazard among these groups.

Research suggests that power in sexual relationships is unevenly distributed by gender (Rhodes *et al.* 2001). Seidel (1993) argues that a new focus on development, empowerment and human rights has emerged that provides a more positive and hopeful message for women at risk for HIV/AIDS. According to Jana *et al.* (2002), imbalance in power and ability to negotiate condom use, results in low condom use among CSWs in India. A study in India reported condom use to be less than 25% even among CSWs (AIDS-INDIA 2004a). As was evident among our patients surveyed, Irwin and colleagues (1991) argued that many participants did not believe that condom use would consistently prevent infection through sexual intercourse. This was true even though they had fairly accurate understanding of HIV transmission and prevention. The main reason reported by men in these groups was lack of motivation due to poor quality of condoms, which tore. FSWs reported lack

of autonomy as the main reason for not being able to use condoms. Condom use only meant ever-use of condoms and consistent condom use was non-existent.

In this chapter we have first performed an introductory analysis of knowledge and sexual behaviours among groups where high-risk behaviours were common. More importantly, we have conducted qualitative analysis of knowledge and sexual behaviours, based on qualitative analysis of answers to open ended questions, and spontaneous stories and comments provided by lorry drivers, construction workers, hotel workers, Female sex workers (FSWs) and *hijra*. These data have been examined in the context of greater vulnerability to HIV/AIDS. Knowledge and use of condoms in these groups have been examined separately to emphasize that, even when high-risk behaviours are common, knowing about condoms is often not accompanied by consistent use (Meda *et al.* 1998). Additionally some reasons for this have been highlighted.

## 8.1 Lorry drivers

Rao and others (1994) have established that lorry drivers in India are a high-risk group in disseminating HIV to the general population (Shanmuganandan *et al.* 1996). Lorry drivers are all male and are separated from their families for months at a time while they drive to various parts of the country. This occupational model generates the presence of commercial sex workers along lorry routes where drivers stop for breaks. Lorry drivers contract HIV through their high-risk behaviours and pass it on to other CSWs along their routes. Thus lorry drivers disseminate the infection to their wives who then infect up to one third of their children through vertical transmission (Singh and Malaviya 1994). Unsurprisingly therefore, lorry drivers were well represented in our survey, and over one-tenth (11%) of the sample were found to be lorry drivers. Their socio-demographic characteristics are summarised in Box 8.1.

**Box 8.1 Lorry Drivers****Sample size = 32**

(no women in this profession in India to date)

- The median age was 26 years.
- They originated from Salem/Namakkal (10), Trichy (4), Vellore (9), Chennai (3) and Andhra (6)
- Marital status – 22 were married & 10 were not married
- Educational level – 23 had completed primary education and 5 secondary; 4 no schooling.
- Reading newspapers - most days 15; at least once a week 9
- Watching TV – Once a week (16), less often (16) [Overall media exposure=26]
- Low Income Group (16); Middle Income Group (14) i.e. total family income under Rs. 10000/- (£150) pm
- Period of illness: 24 for less than 1 year; 8 between 1-5 years
- Financial resources since being ill – 8 depended on relatives; 20 continued to work.

**Knowledge of HIV/AIDS**

- Main source of knowledge: Hospitals- 24; TV- 15; Newspapers-7; Radio & posters- 3 each.
- Correct knowledge on acquiring HIV was high on these:- CSWs(97%), positive partner(97%). Fairly good on blood transfusion (84%), playing with children (81%), handshake (80%), petting (75%), public water source(69%), common hospitals (66%), common baths(66%) and toilets(62%).  
And low on these: - IV drugs (44%), mosquito bite (38%), and public transport(25%)
- Can one tell HIV+ person by sight? – 4 said 'yes, since an infected person becomes lean'.
- Can HIV/AIDS be cured? – 15 said 'Yes'
- Mother-to-child transmission – 4 said 'not 100% chance' of passing it on
- Should a couple either of who is HIV+ have a child? – 17 said 'No'
- Should a man be tested before marriage? – 25 said 'Yes'

**Reported Risky Behaviours**

- Smoking – 16 still smoked while 11 had given up
- Drinking – 10 still consumed alcohol while 17 claimed to have given up
- Pre-marital sex – 28; Median age for first sexual intercourse – 20 years

*(3 lorry drivers mentioned occasional sex with male cleaners who travelled with them in the lorry)*

- Extra-marital sex – (10/22)
- Source of infection – 100% from CSWs
- Frequency of sex before HIV: – 18 married men had sex up to 15 times/month remaining had more often, unmarried men (4) have had less than 5 contacts with CSWs while (6) reported going up to 15 times a month
- Frequency of sex among married men since being diagnosed as HIV positive:- Abstain from spouse (14); Use *nirodh* sometimes (6); No change (4)
- Frequency of sex among unmarried men since being diagnosed as HIV positive: - Stopped CSW 90%, No change 10%
- Last sexual contact – 20 had at least one contact within the last six months.
- STD infections – 11 (a third)

**Knowledge & Use of condoms**

- Heard of Condoms – 100%; Heard of female condoms – 2
- Beliefs about condoms: (percent who said 'Yes')  
Make sex less enjoyable – 25; Easy to use – 23; Not expensive – 19; Prevent pregnancy – 29; Prevent STDs – 20; Prevent HIV – 27; Better to use with casual partner – 29; Should not have sex with casual partner if no condom – 23; Would use with regular partner – 28  
Spouse would get suspicious – 16; Appropriate to use with wife – 15
- Ever used Condoms – 21(two-thirds); Condom use with spouse occasionally – (6/22)  
Relevant quotes:

*'Used Nirodh occasionally in recent years due to fear of acquiring HIV'**'Used Nirodh each time recently, but it tore about 5 times'*

### ***Occupational Exposure to HIV/AIDS***

The 32 lorry drivers in our survey were all HIV positive and reported high-risk sexual behaviours with CSWs. Three lorry drivers also reported occasional sexual contact with the young men who accompanied them as cleaners. It appeared that they acquired the habit of visiting FSWs as a matter of course from colleagues. They might visit between 50-100 FSWs a year and possibly pass on the infection to other FSWs (Nag 1996). Lorry drivers explained that they could visit their homes only once a year and spent only 1-2 months with their wife and children; one man said that his little son did not even recognise him and called him 'uncle'. The stated reasons for sexual contact with FSWs were peer pressure; being away from home/wives for long periods and the belief that sex would reduce body heat, which was increased by long distance driving (Barnett and Whiteside 2002). The following examples were illustrative:

*Ramu*, a 30-year-old from Namakkal said, 'we travel all over the country, my colleagues and I often go as a group to CSWs in Mumbai, both before and after marriage'.

*Ganesh* was a 50-year-old lorry driver from Trichy. He started as a cleaner and graduated to driving the lorry. He was married with 2 daughters and a son. He said, 'we are away from our wives for at least 8 months in a year. We drive in the vehicles for such long periods at a time, going all over the country, and our bodies get heated up and it is essential to find relief through going to the women who are readily available at the places where we stop for breaks'.

*Vijayan*, a 38-year-old similarly believed, 'our body gets heated up sitting behind the wheel for so many hours at a time. So we have to go to CSWs to get some relief'.

Most (28) reported pre-marital sex with FSWs. The median age for first sexual intercourse was 20 years. Extra-marital sex was reported less often (10 out of the 22 married men). Lorry drivers also reported bisexual habits, three said that they sometimes had sex with their male assistants/or cleaners who travel with them in the lorry but went to FSWs at lorry stops. Similar behaviours among lorry drivers, were also reported by Verma and Roy (2002).

### ***Knowledge and Attitudes about HIV/AIDS***

As noted the transport industry in TN is mainly concentrated in Salem/Namakkal and Tiruchy (see section 5.2.10) where large numbers of lorry drivers live. The overall knowledge level of HIV among lorry drivers was high or fairly high on most aspects (Box 8.1). Although lorry drivers in general had been targeted with intervention programs, three-quarters of those interviewed in our survey reported that their source of information about HIV infection had been only at the hospital. One reason in the words of *Narayan*, aged 28 could be 'we never pay any attention to what is being told to us when these people come and give advice since we thought that it would not happen to us'. Targeted interventions could also encourage discrimination against them as a group (Thomas and Bandyopadhyay 2003). Thus it seemed that targeted intervention to prevent HIV/AIDS among lorry drivers needed to be reassessed and renewed (Chatterjee and Sahgal 2002). A case in point was *Ashok*, a 34 year married man:

'To abstain is the only method to avoid spreading HIV. Nirodh might help only to a small extent, as breakage is very common. I have been to several meetings regularly, even the noon meal scheme where my wife works, organises meetings for people in the village about HIV. But the villagers feel shy to talk about these matters, or even to be seen hearing about these things. They react saying, 'go away, do you not have anything else to do? Or those people who talk those shameless things are here, let us escape'. In fact, hardly anyone attends when someone comes to talk about HIV in the village'.

There was evidence of lorry drivers in Salem and Namakkal being particularly asked for HIV test results by prospective brides' parents. On the other hand their personal struggles with problems involved in being HIV positive might be responsible for their strong support of HIV testing before marriage (25 agreed). They reportedly went voluntarily (and often without informing their parents) for HIV testing before their families fixed their marriage. Indeed three said that they had cancelled marriage arrangements that had been initiated by their parents, since they

independently decided to be tested for HIV and were found to be positive. Thus (dated April 1999):

*Sarkil* who was 25 years said, 'it is better to commit suicide than to get married and spoil a girl's life'.

*Murali* suspected that he might be HIV positive and came voluntarily to get tested. He had decided to put off marriage for two years. He hoped to get better, and then get married.

Since marriage is a social and cultural norm in India, they had difficulties in convincing their parents to put off marriage; however they managed to buy time suggesting that they would marry when they were cured. Since their parents were uninformed about HIV they accepted the suggestion, and some might not have believed that their son could die shortly when he seemed perfectly healthy. Parents had consented to wait for a short while but continued to solicit marriage brokers. These young people said that they would be compelled to marry without informing the girl or her family when they recovered (from symptomatic illness).

There were some who did not understand the seriousness of the situation and not only gave in to family pressure but their own wish to be married. Two such lorry drivers vowed to go ahead with marriage to the girl they were engaged to even without informing her or her parents about their positive status. *Umapathy* (below) was willing to stop going to CSWs but could not give up his marriage as stated:

*Umapathy* a 28 year lorry driver from Vellore said (April 1999), 'all plans have been made for my marriage. We cannot cancel it now. I want to get married, I will stop going to CSWs'.

*Sudhakar*, a 26-year old lorry driver from Tiruchy, was illustrative of some social complications associated with marriage and HIV/AIDS in India. In his words:

'My cousin and I were looking forward to getting married' he said, 'on hearing all these scary things about HIV, I got tested without telling anyone. I was totally devastated when the result came as HIV positive. I only told my parents and they

were supportive of my decision not to spoil another girl's life. However we did not want to tell others about my status, as we would be disgraced. Instead we conveyed to the girl's parents that I have stomach ulcers and do not want to think about marriage for some time. I came to GHTM and my health improved, I also saw other guys like myself here and felt encouraged. Meanwhile, someone had told my cousin's family that my parents were arranging my marriage with somewhere else. On hearing this, she consumed hibiscus leaf paste to commit suicide but was found in time and has been taken to hospital. My father called today and wants me to return home immediately; since they are our close relatives I might be forced to marry her. I am so confused, I do not know what to do, I simply cannot tell her I am HIV positive'.

Awareness among lorry drivers (13%) that mother-to-child transmission (MTCT) was not 100% was similar to the average for men in our survey. HIV positive lorry drivers (perhaps because they were still young, median age=26 years) were willing to grasp any straw to believe that they could be cured and live a normal life. About ten men in this group reported having tried indigenous treatments advertised by private individuals who claimed they would cure. These were often at unaffordable costs to their families who might have sacrificed all their savings with the hope of getting them cured and being available to support their family. Twelve women in our sample of patients were widows of lorry drivers and reported that they and their children were left more or less destitute with no savings, income or employment. The following narrations show that greater awareness and knowledge was needed to prevent unscrupulous practitioners exploiting the situation. These were some mixed reactions to indigenous treatments (May – June 1999),

*Sivakumar* said, 'I have seen advertisements showing people being cured after taking Kerala medicine, they also showed a lady who became HIV negative and had a child who is HIV negative'.

*Mohan* said, 'TV advertisements say we can be cured through Ayurveda medicines in Kerala'.

*Elumalai* had difficulty with its restrictions, 'I tried Kerala medicine for a while, they said I should give up smoking totally. So I gave up smoking and tried their medicines but they did not help so I gave up on them and came back to this hospital'.

*Mani* narrated his experience, 'the doctor in my town told me I had little mistake in blood, it has just started and if I try Kerala medicine I will be cured. I went to Kerala Ayurveda place, they asked for Rs. 10,000/- (£143). But I do not have that much money, then I heard about CMC and came here'.

*Kanda* a 27-year-old from Namakkal expressed doubts about its claims, 'My mother has been pestering me to get married, one girl's family was interested but because of the fear about lorry drivers having AIDS in our town, they insisted on my having a HIV test. I got it done, and was found HIV positive. I have not told anyone, but came to CMC for confirmation, as it is all a big racket in Namakkal. People are misleading with promises of cures for Rs. 5000/- (£72). Every other place claims that they can conduct the HIV test, but one cannot rely on them. People say *Siddah* and *Ayurveda* medicines can provide a cure. However some have taken these medicine and died suddenly'.

Some lorry driver patients resorted to invoking their gods for a cure, as was evident from these examples:

*Arumugam* a 44 year old from a village reported, 'this drama with AIDS is going on for a while. My family and neighbours get-together in the village to sacrifice goats; offer rice etc. to appease the gods. They chant manthras to remove the curse and black magic from me'.

*Murugadas* who was 34 said, 'I must have got it through a mosquito bite. When I was first not well, I went to my village and they performed all kinds of prayers to drive out the evil spirits of HIV'.

Lack of in depth knowledge was evident among those patients who believed that simply going to a hospital would cure them. The professionals they encountered did not always provide useful information or support. For example:

*Murthy*, 'doctor in Chittoor gave injections, said I will be fine and I can get married'!

*Murali* 'doctor said it is a dangerous disease, you will die, only God should help you'.

*Roshan*, 'when the hospital staff in Andhra knew I had HIV, they would not come near me'.

*Mahalingam*, 'Coimbatore doctors said my HIV can be cured at CMC or if I took *Siddah*.'

*Vijay* 'a hospital in Chittoor did compulsory AIDS test for all patients. When the patients came to know it was this test, they got frightened and tried to run away.'



They tested me but did not tell me the result even though I wanted to know the result. I later found out through testing at another place’.

Four of them said that they learnt on reaching the ward that something was seriously wrong with them and everyone there suffered from HIV, which they had heard their colleagues had died of.

Although a majority of lorry drivers were aware of the infection among their colleagues (18 knew someone with HIV), they had lived under the misapprehension that it would not happen to them (Majumdar 2004). Attitudes like ‘it won’t happen to me’ and ‘she (meaning FSW) looked fine, so I did not think it would happen to me’, were expressed by 10 lorry drivers (Hubert 1990; Moatti and Souteyrand 2000). *Arun* who had been married less than a month before the interview:

‘I dare not tell anyone at home just now, I am trying to abstain with my wife but I cannot bring myself to tell her. I had gone for voluntary HIV testing in 1997 and the result was negative. I assumed that result was valid when I got married a month ago. How could I know that I might have acquired HIV meanwhile? If only I had known I would not have got married and ruin another girls’ life. I am so frightened, I feel haunted and cannot think straight. People used to come to our offices to talk about AIDS, but I thought that it only happened to others. Even my colleagues used to think I was such a nice guy that I am not at risk and do not need to attend these meetings. If people come to know about this it will ruin the chances of my sister’s marriage, so I will have to keep this to myself’.

This is a clear example of the way that infection could bring shame on other members of the family.

Three quarters of lorry drivers surveyed had been aware of their HIV positive status for less than a year, and the remaining for up to 5 years. Although they were aware of colleagues who had died of HIV, it had been taboo to talk about the disease with them except to hear rumours of colleagues who had died. This induced greater fear, depression and often-suicidal tendencies when they first learnt of their positive status. However on reflection, most developed resilience, which was reportedly aided through sharing experiences with peers in hospital.

Nearly all (30) of the lorry drivers belonged to the lower-middle class and could afford the commercial sex workers specially catering to their needs. However their social status could not survive the consequences of HIV/AIDS so that they suffered downward economic and social mobility. Only two-thirds (21) reported being able to continue their regular work, a quarter depended on their parents or relatives for financial support, while the rest had only limited resources.

Not all of the lorry drivers had informed their families about their HIV status (less than three-quarters both married and unmarried said that their families knew). It was evident on the hospital wards (and reported at interview) that their wives, who were socially and economically dependent on them, spent time caring for their husbands with the hope that they would be cured. Family support is essential in hospitals since hospital professionals cannot cope with the workload. Family support is also essential for sick people when not in hospital in the absence of any social support system in the country.

Not all married lorry drivers had had their wives tested for HIV (8 out of 22 said they did not because they were afraid in case they tested positive). Among the 14 who had had their wives tested, only one man's wife was negative and all others reported their wives to be HIV positive.

### ***Knowledge and Use of Condoms***

A behaviour surveillance survey (BSS) by APAC (2001) in Tamil Nadu showed that knowledge of AIDS prevention was high among lorry drivers – 97% interviewed were aware of two acceptable ways of HIV/AIDS prevention and 96% knew that condoms could prevent AIDS. However, only 43% had knowledge of two methods of prevention of HIV/AIDS according to this study. According to this study sexual intercourse with non-regular partners had declined (from 50% in 1996 to 25% in 2000). And reported condom usage with non-regular partners was reported to be increasing, but was still low (44% in 1996 to 67% in 1999). This evidences that

targeted interventions alone were not adequate to achieve behaviour change among groups where high-risk behaviours were common. Intercourse with multiple partners continued and condoms were reported to be unreliable. Another study also has reported about the unreliability of condoms in India (Amin 2004).

All the lorry drivers in our patient survey had knowledge of condoms. Two of them mentioned rather innovative ways in which they had used the condoms that had been given to them (Case study 8.1). However, the motivation for and actual use of condoms among lorry drivers was low and were expressive of socio-cultural barriers for condom use (only two-thirds had ever used condoms –similar to the level reported by APAC in BSS-1999) (IMRB 2000). The following were some common sentiments expressed by lorry drivers ‘we usually have *nirodh* in the vehicle, but when one gets the mood to go to a woman, and cannot find the *nirodh*, who cares’. ‘We are drunk and all we can think of is going to a woman’. Or ‘people will use *nirodh* only if they know that the woman has HIV, but we found only after becoming positive that we cannot know that and by then the damage is done. And we have passed it on to our wives as well’. Or again ‘if a couple is faithful to each other, there is no need to use *nirodh*’. Also ‘if both are HIV positive there is no need to use *nirodh*’. ‘Why spend money on something which does not give any pleasure when it does not even serve the purpose properly since it breaks often?’ was another frequently expressed frustration about using condoms related to their poor quality. Twenty-one lorry drivers reported ever use of condoms with multiple partners/CSWs. Of these 21 lorry drivers, ten reported that condoms were unreliable because they tore, the case of a 30 year old *Nagaraj* below is illustrative:

Nagaraj, a 30-year-old unmarried man said (April 1999), ‘I went with colleagues to CSWs 10 to 15 times, I used *nirodh* each time, but it tore at least one-third of the time’.

Case study 8.1 further illustrates aspects of lorry drivers' lives in relation to HIV/AIDS, namely their high-risk sexual activities and inconsistent condom use in spite of knowing that condoms could protect against AIDS.

### Case study 8.1 Lorry Driver

#### Raju

Raju was a 31-year-old lorry driver (April 1999), married with a son. He belonged to Paramathivelur near Namakkal. He lived with his wife, son, mother and brother. He had completed 5 years of schooling.

From 16 years of age he had sexual contact with both married and unmarried women from his village almost every day. At 22 years when he went to Mumbai, he went to the red light area. 'There are many girls from Tamil Nadu there, I had money, I used to drink and go to many girls. I also started going regularly to one 19-year-old girl from Salem in the red light area whenever I went to Mumbai', he said.

At age 27 he married a girl who was his relative (his aunt's granddaughter). 'Her family was well off, and they objected to our marriage, so I brought her out of the house and took her to Coimbatore where we were married secretly. I have not gone to any other girl since then'. 'I have never used nirodh with my wife or any other women'. He continued 'condoms are very good for repair works like tying some things together in the lorry, they hold fast and act like welding for tubes. This way they get used if nothing else, since we get them in bulk for free'.

When he heard about his being HIV positive he reacted thus, 'I was very upset when I heard that I had HIV, I tried a natural treatment that was advertised. It seemed to help other colleagues, but it did not help me. Then another colleague who got treated here recommended GHTM. My wife, mother and brother are very worried about me. I was very worried and upset about how I was going to look after my family. However since being here, and seeing other patients in a similar situation getting better and going home, I feel encouraged. I hope to feel better and go back to work. I am relieved that my wife and child have tested negative for HIV. I will totally abstain from my wife. I have hope that siddah treatment here can cure me'. He strongly supported testing for HIV before marriage, 'I did get tested, but the result showed negative at that time'. His view on whether a couple, either of whom was HIV positive should have a child was, 'A couple will definitely want at least one child, even if they have HIV, they can have the pleasure of that child, at least for some time'. This attitude might have been influenced by the fact that although he was positive his son had tested negative.

## 8.2 Construction workers

Construction workers were representative of migrant workers who moved according to where they were able to find work in the region. There were 19 construction workers among patients surveyed (15 men and 4 women). All women were married and three of them had had husbands who had also been construction workers. A summary of characteristics of this occupation group is given in Box 8.2. Construction workers had fairly accurate knowledge on sex and blood-related HIV transmission. However, their knowledge on other modes of transmission was relatively low. They reported watching television more than they read newspapers.

**Box 8.2 Construction workers****Sample size n=19***(percentages represent – 5(26%), 10(53%), 14(74%) 17(90%)*

- Number of women – 4 (3 had husbands who were construction workers); Number of men - 15
- Tamil Nadu – 15 patients, Andhra Pradesh – 4 patients
- The median age - 32 years
- Marital status – 13 ever married & 6 men not married
- Educational level – 3 men had no schooling; 9 (6 men + 3 women) had primary schooling & 7 (6 men + 1 woman) had secondary schooling
- Reading newspapers - most days (6); once a week or less (13)
- Watching TV – Most days (13), Sometimes – (6) [Overall no media exposure among 10%]
- Income was between Rs. 500/- (£7) and Rs. 2500/- (£36) per month; All women earned less than Rs. 1000/- (£14); only two who are the supervisors earn up to about £150

[Overall – Low income families (12), Medium (4) and High income (3)]

- Period of illness – 12 < 1 year; 6 for 1-5 years; 1 for > 5 years
- Financial resource since being ill – depended on relatives – 8; continued to work – 8

**Knowledge of HIV/AIDS**

- Source of knowledge: Hospital (14); TV (12); Newspapers & Posters (8) each
- Correct knowledge on acquiring HIV was almost universal on these: sex with CSW(100%), positive partner(95%), handshake(90%), playing with children(90%). Fairly good on blood transfusions (84%), common hospitals & public water source (74%). And low on these:- public toilets and common baths (47%), IV drugs, public transport & mosquito bite(32%).
- Can one tell HIV+ person by sight? – 5 said 'yes, as person becomes lean'
- Can HIV/AIDS be cured? – 6 (third) said 'Yes'
- Mother-to-child transmission – 13 said '100% risk', 3 said 'not 100%'
- Should a couple either of who is HIV+ have a child? – 6 said 'Yes'
- Should a couple be tested before marriage? – 13 (nearly two-thirds) said 'Yes'

**Reported Risky Behaviours**

- Smoking – 8 men did and 7 did not; none of the women smoked
- Drinking – all men consumed alcohol often; none of the women did
- Median age at sexual debut among men – 17 years; among women – 16 years
- Pre-marital sex – 100% among men & 1/4 women; Extra-marital sex – 50% men; ¼ women
- Source of infection – 14 (most) men through multiple partners other than spouse; 1 said man injections. 2 women from husband & 2 from multiple partners
- Frequency of sex before HIV positive: married men (4) had sex >15 times/month, others less often single men (4) said 3-4 times/m, one went only once, one unmarried man said he acquired HIV through blood splashing during an accident; women reported up to 10times/month
- Behaviour change after HIV positive: All women had abstained. Unmarried men- (4) stopped CSW, (2) reduced frequency; Married men – (1) no change, (1) reduced frequency, (7) abstained.
- Last sexual contact: over 3 years ago (1); 1-3 years (8) and majority within the year (10)
- Have never had STDs – 15

**Knowledge & Use of condoms**

- Heard of Condoms – 17 (90%)
- Beliefs about condoms:

*Make sex less enjoyable – 14 (three-quarters) agreed, others 'don't know'; Easy to use – 9 said 'don't know' & 8 agreed; Prevent pregnancy – 16 agreed; Prevent STDs – 13 agreed; Prevent HIV- 15 agreed; Expensive to use – 9 disagreed, 7 said 'don't know'; Better to use with casual partner – 16 agreed; Not have sex with casual partner if no condom – 12 (nearly two-thirds) disagreed; Appropriate to use with wife – 10 agreed; Spouse would get suspicious – 12 agreed; Would use with regular partner – 11 agree*

- Ever used Condoms – 4 men have used; Only one married man had used condom with his wife

### ***Occupational Exposure to HIV/AIDS***

All male construction workers reported pre-marital sex, and half of them reported extra-marital sex. *Gopal*, a 23-year-old man said (April 1999), 'when I was 18 years old, I went with friends to a CSW. Since then I got into the habit and went to CSWs about 2-3 times a month. However, I have not been able to go to them after my marriage, since now I do not have the money to spare.' No cases of same sex relations, or child abuse or sexual relations with *hijra* were reported.

Their occupation was migratory in nature and men usually lived on site in temporary shelters without their wives wherever they found work and were exposed to high-risk sexual behaviours. Again according to *Gopal*,

'my wife is staying with her parents, since I have to go to different places for work. I visit her perhaps once a month. Often even when I go to see my wife, I cannot stay the night at her parents home.'

Another example was *Anbu* aged 43-years 'I go out of town for work. I have gone to women for 23 years. Some were married neighbours. I go to prostitutes 1-2 times a month. I sometimes go with lorry drivers to the prostitutes when I get a lift in their lorry for a low fare. When my wife was pregnant I used to go to prostitutes 4-5 times a month.'

Sexual activity had commenced early among the female construction workers (2 reported age at marriage as 13 years). One among the 4 female construction workers reported premarital and extra-marital sex. Some women working on construction sites had more than one partner. A case in point was *Usha*, aged 33-years.

'My husband left me and went away with another woman who used to work on the same construction site. I then went out with 3 men. After that I lived with a man from Kerala for 2 years. Somehow his family found out and took him back. Since then I have been on my own. Now I have this dreadful disease and I am afraid of what is going to happen to me.'

### ***Knowledge and Attitudes to HIV/AIDS***

Overall HIV/AIDS knowledge was fairly high among construction workers, though lower than that of lorry drivers. Apart from hospitals (73%), they reported TV as a main source (63%) of HIV/AIDS information. This suggests that communicating information through TV was fairly effective. It also seemed that once a community became conscious of HIV/AIDS they began to exchange knowledge among themselves.

Nine construction workers knew of colleagues and friends, who were HIV positive, and although this was less than that reported by lorry drivers in our sample, it was still high. A majority (12) had been diagnosed with HIV within the last year, and a third (7) had been HIV positive for over one year. Only half (10) of them had informed their family of their HIV status (four of these men said that their wives had returned to live with their parents). Over half the married men (7) had not had their wives tested, two men said their wives had tested positive and two had tested negative. One woman's husband had died of HIV and the other three did not know what their husband had died of, they said it might have been HIV but they had not known about it at that time. As with lorry drivers, it appeared that knowing people who were or had been HIV positive increased awareness and knowledge.

### ***Knowledge and Use of Condoms***

While 90% were aware of condoms, their attitudes were unfavourable to using them. Consequently condom use proved to be very low (only one fifth (4 out of 19) reported ever using condoms). Only one of the nine married men reported that he had used condoms with his wife, but that had been occasionally. None of the female construction workers reported use of condoms. Somu's narration is further illustrative (Case study 8.2).

**Case study 8.2 Construction workers****Somu**

Somu was 29-years-old (May 1999). He had been married one month before the interview. He earned about Rs. 1500/- (£21) p/m. He had sexual intercourse with his wife only on the first night after their marriage. He had been ill soon after and refrained from sex with his wife. He went to the doctor in Chittoor and as he was not getting better, they referred him to CMC. He was tested HIV positive at CMC. He had a history of visiting CSWs since the age of 18 years. He had used condoms occasionally.

He agonised over his HIV positive status as follows:

'I stopped going to CSWs in the last 4 years since I heard about HIV and got scared. I was shocked to know that I have this dangerous disease. How can I tell my wife? I was counselled that it is only the beginning stages. I will live for some years if I am careful, so I feel encouraged now. But I cannot even tell my wife that I have to use condoms with her. She will get upset and probably leave me. Maybe I should tell her that a doctor advised me to use condoms. It is not good to build a barrier between husband and wife by using condoms. But because of HIV it is necessary'.

'I will take medicines regularly, so that I can get better and then we can have children'.  
'I had not imagined that I had the slightest chance of getting HIV, otherwise I would have got tested before marriage. Then I would not be in such a dilemma'.

**8.3 Hotel Workers**

This occupational group appeared to practise high-risk sexual behaviour, as was revealed by relatively high numbers of hotel workers in our survey. Among patients interviewed, there were 11 such workers, of whom two were women. The median age of this group (32 years) was higher than that of the lorry drivers or male construction workers. A majority (6) belonged to the low-income groups (Box 8.3).

***Occupational Exposure to HIV/AIDS***

The median age at sexual debut was 17 years (earlier than that of lorry drivers), the lowering of age of debut may also be attributed to men having sex with men. Both women were married and a majority (6 out of 9) of the men were unmarried. All men in this group reported premarital sex, and extramarital sex had been practised by two thirds of the men (see below for women).



**Box 8.3 Hotel workers****Sample size n=11**

(percentages represent – 3(27%), 6(55%), 8(73%) 10(91%))

- 9 were men and 2 were women.
- The median age of the respondents was 32 years (Mean=35, std. dev.= 9.4).
- Marital status: both women were married. 3 men were married, 6 were not married.
- Educational level was high – 4 had primary; 6 secondary education (1 missing).
- Reading Newspapers: 7 read Most days;
- Watching TV: 6 watched most days and 4 sometimes. [Overall media exposure =100%]
- Total family Income: 9 earned only up to Rs. 4000/- (£57); 8 still continued in work.
- [Overall - Low income families (6), Medium (3) and High income (2)]
- Period of illness – 4 for < 1 year; 7 for 1-5 years

**Knowledge of HIV/AIDS**

- Source of knowledge: TV – 80%; Hospital – 60%; Newspapers - 30%; others – 20%
- High knowledge on acquiring HIV through these: sex with CSW (91%), Positive person (91%), blood transfusions (91%) and handshake (91%). Fairly good on playing with child (82%), and public water sources (73%). And low on these:- Common hospitals and baths (56%), common toilets, mosquito bite and IV Drugs (46%), and public transport (36%).
- Can one tell HIV positive person by sight? – 4 (36%) said ‘Yes’
- Can HIV/AIDS be cured? – 8 said ‘Yes’
- Mother-to-child transmission – 2 said ‘<100%’; 7 said ‘100%’ & 2 said ‘don’t know’
- Should a couple either of who is HIV positive have a child? – 4 said ‘Yes’
- Should a couple be tested before marriage? – 9 said ‘Yes’

**Reported Risky behaviours**

- Smoking – 5 men did, none of the women did.
- Drinking - 6 men did, none of the women did.
- Median age at sexual debut - 17 years.
- Premarital sex – 100% among men; Extramarital among 2 of the 3 married men.
- Source of infection – Both women from husbands. All men from CSWs and/or multiple partners.
- Frequency of sex before HIV positive – 4 reported > 15 times/month, others less than that.
- Behaviour change since HIV –  
All unmarried men and both women abstained.  
Among the three married men, 1 used condoms sometimes & 2 made no change.
- Last sexual contact – over 3 years ago (1); 1-3 years (4); less than a year (6)
- Had other STDs – 5

**Knowledge & Use of condoms**

- Heard of Condoms – 100%
- Beliefs about condoms:  
Make sex less enjoyable – 6  
Easy to use - 4; Prevent pregnancy – 10; Prevent HIV – 9;  
Expensive – 1; Prevent STDs – 9; Appropriate to use with spouse – 5;  
Better to use with casual partner – 10; spouse would get suspicious if insist use of condom – 8; would use condom with regular partner – 9;  
Should not have sex with casual partner if no condom – 8
- Ever used condoms – Only one married man did.

It was exceptional that with a median age of 32 years, two-thirds of the men were not married. Postponing marriage may be attributed to men having sex with other men. Vikram, aged 33, reported how he had sex with boys/men, he said ‘all men hang out together and at night slept together on the floor in one room in the hotel.

This encouraged male sex with males even after marriage especially since we are living apart from our wives'. He reported that he constantly changed hotels to find younger boys to have sex. Another case was *Hari* (man aged 39 years) from Andhra Pradesh who said he was unmarried because he had the responsibility of getting his sisters married first. He said that he had not had sexual relations and wondered about the cause of his infection.

Working in lodges and residential hotels gave men access to female commercial sex workers between serving hotel guests. One example was that of *Srini* (24-years), a lodge worker, who had a stroke (resulted in speech impairment). He swore that he had no sexual relations while his father stayed in the room even after repeated polite requests to 'come back' later. So while his father stood there, the discussion centred on general background information. But when his father finally left, he related how he often had sex with prostitutes who were hired to serve guests at the lodge where he worked. Again *Krishna* (36 years), a married man worked in a lodge. He fell in love with a CSW working at the same lodge. He then tried to stop her from commercial sex work, and kept her instead as '*chinna veedu*' (regular partner apart from wife), and was willing to support her financially. However, he suspected that she was not satisfied with his support alone and was involved in commercial sex work surreptitiously. These cases indicate that hotel workers were exposed to high-risk sexual behaviour (Case study 8.3).

Both women working in hotels denied any premarital or extramarital relations and reported their source of HIV infection to be their husbands. It was not clear whether their reports were completely reliable.

### ***Knowledge and Attitudes to HIV/AIDS***

The knowledge level of hotel workers was higher than that of lorry drivers and constructions workers (Box 8.3). Media exposure was high (100%) among hotel workers, which might be responsible for higher knowledge although they had not

been targeted for intervention programs. However, they also scored highest in terms of knowing other HIV positive persons (73% knew another positive person compared to 56% among lorry drivers). It seems reasonable to assume that hotel workers had greater exposure to commercial sex and were more likely to access knowledge of sexual issues through discussions with colleagues as well as media exposure. In this group also, media exposure together with peer communication seemed effective in creating greater awareness of HIV/AIDS.

### ***Knowledge and Use of Condoms***

All hotel workers had heard of condoms however, only one of the three married men had ever used a condom and neither of the women had used a condom (Box 8.3). None of the unmarried men had used a condom. This man said that initially he abstained from sex but 'it was not possible after I felt better. There was nothing to show I was sick so I started going to CSWs. I tried to use condoms but it is not possible always when one gets carried away to have sex with a woman in the hotel. It is not possible to carry condoms with me all the time'. Others reported that they abstained after they were tested positive for HIV because they were worried and did not feel well enough to think about sex for sometime.

#### **Case study 8.3 Hotel workers**

##### **Srini**

Srini was a 40-year-old lodge manager in Tirunelveli (May 1999).

He had visited CSWs several times.

He was married himself 'but she left me and took our daughter with her. I have to give her Rs. 450/ (£7) per month as settlement. I then got married to my cousin at a temple in front of some friends (as witnesses)'. He also had another regular partner, a 23-year-old woman who had been separated from her husband.

'I cannot use condom as it is disgusting', he said.

## **8.4 Female Sex Workers (FSW)**

Accurate information on current numbers of sex workers is impossible to find (Huber and Schneider 1992). Nag (1996) and Weeramunda (1996) reported 'guesstimates'

provided by NGOs working with commercial sex workers (CSW) to be between 100,000 and 150,000 Female Sex Workers (FSW) and 2,000 *hijra* in Mumbai, and 6,000 FSWs in Chennai. A comparison of results from a study among 269 non-brothel based FSWs in TN (NACO 2001) with that of FSWs in the patient survey showed them to be fairly similar in socio-demographic characteristics and also in terms of HIV/AIDS knowledge and sexual behaviour (Box 8.4 and Box 8.5).

**Box 8.4 Female Sex Workers in Tamil Nadu, GBSS**

<ul style="list-style-type: none"> <li>➤ Age: Median = 33 years (mean =33)</li> <li>➤ Education: None – 22%, Primary 45%, Higher – 33%</li> <li>➤ Currently married: 32%</li> <li>➤ Additional work: 37% (20% as maid, 5% as factory worker, 4% as trader, 2% in office, 2% in bar)</li> <li>➤ Ever drinking: 68%; Ever use drugs: 6%</li> </ul> <p><b>Knowledge</b></p> <ul style="list-style-type: none"> <li>➤ Ever heard of HIV/AIDS: 99%; Know two methods of prevention: 78%</li> <li>➤ Proportion aware that HIV cannot be transmitted through sharing meal with infected person: 84%</li> <li style="padding-left: 20px;">mosquito bites: 93%</li> <li>➤ Proportion aware that healthy looking person could be suffering from HIV: 71%</li> </ul> <p><b>Behaviour</b></p> <ul style="list-style-type: none"> <li>➤ Age at first sex: Median = 18 (Mean =19)</li> <li>➤ Age when first started sex work: Median = 25 (Mean =26)</li> <li>➤ Mean number of paying clients in the last seven days before survey: 6.8</li> <li>➤ Mean number of clients on the last working day: 2.5</li> <li>➤ Last time used condom with: paying clients 83%; non-paying clients 25%</li> <li>➤ Consistent condom use in last 30 days: paying clients 54%; non-paying clients 9%</li> </ul>
---

Source: NACO (2001a)

***Occupational Exposure to HIV/AIDS***

FSWs reportedly entertained around 3-10 clients a day (APAC 2001; Chakraborty *et al.* 1994; NACO 1997). The sex workers in India are classified into the following categories: brothel-based female sex workers (FSWs) in red-light areas and elsewhere; FSWs of *devadasi* origin; floating FSWs (non-brothel based); call-girls; *hijra* (see p. 285 below); and male sex workers (MSWs) other than *hijra* (Amin 2004). Those who operate as call girls, are professionals and economically well off, *hijra* have some advantages from belonging to an organised community but others had very little protection from sexual exploitation (Bhave *et al.* 1995).

Mumbai, Kolkata (formerly Calcutta) and Delhi have demarcated red-light areas that make it easier to target them for intervention programmes. But in Chennai (formerly Madras) there are no such demarcated areas and this has caused the sex trade to operate underground. Consequently it was difficult to implement targeted interventions among CSWs; and it appeared that they were subject to greater victimisation. A study reported that under the official prevention of immoral traffic act (PITA), out of about 3,000 women estimated to work as sex workers in Chennai, 1,500 cases were registered annually under PITA (Asthana and Oostvogels 1996). Asthana and Oostvogels estimated numbers of different categories of sex workers in TN: street workers 700; brothel-based workers 400; 'family girls' or housemaids 1,700-1,800; *ali/hijra* 200-250; and call girls 200. They estimated the numbers of sexual partners among FSWs to average at 2-3 clients a night in Chennai and 5-8 clients in Coimbatore (APAC 2001). Thirty percent of brothel based FSWs in Chennai were reportedly from Andhra.

FSWs (except those in brothels) in TN rarely reported their occupation to be commercial sex work; they lived with their husbands and children and might be known among their neighbours only to be working as housemaids (Amin 2004; APAC 2001). All FSWs in this study were from GHTM since those from CMC did not consent to talk about their commercial sex work.

The FSWs interviewed in the patient survey were both brothel-based (1); and floating (4), meaning they usually waited in certain streets and public places and attracted the attention of potential clients. They were all reportedly driven into the profession through poverty and desertion. Such FSWs were particularly vulnerable to HIV/AIDS. All five FSWs were from urban areas with a median age of 27 years. Two had been married, one woman's husband had died and another said her husband was HIV positive. All reported their source of infection as commercial sex work. Their education level was low. Their individual earnings alone determined their economic status and all of them reported low income. Their earnings gave them

independence but at a price. Other socio-demographic characteristics are described in Box 8.5. Smoking and drinking among women is generally considered taboo in India, but one FSW said she smoked occasionally and four reported consuming alcohol but none reported use of drugs.

**Box 8.5 Female sex workers, Patients survey, 1999**

**Sample size n=5**

(percentages represent – 1(20%), 2(40%), 3 (60%) 4 (80%)

- Median age: 27 years (mean age= 30 years, std. dev. = 9.3)
- They have worked in Mumbai (1), Namakkal (1), Chennai (2), Vijayawada –Andhra Pradesh (1)
- Marital status: Married - 2; Never married – 3
- Schooling: None 3; Primary 2
- Reading Newspapers – ‘Rarely’ 4, Watching TV – Once a week (2), Less often (2)

[Overall media exposure – None (2), One or more media (3)]

- Income per month: Between Rs. 1000/- & Rs. 1500/- (£21) (all reported Low income level)
- Period of illness – less than a year (3), 1- 5 years (2)
- Financial resources since becoming ill: (4) continued in commercial sex work, (1) supported by a social worker

**Knowledge of HIV/AIDS**

- Knowledge of acquiring HIV high on the commonest modes: - sex with CSW (100%) and positive person (100%). Fairly high knowledge on the following: handshake (80%) and playing with children (80%).

All others had low knowledge: - blood transfusions (60%), injections and common hospitals (60%), public water sources (60%), public toilets and common baths (40%), mosquito bites (40%), IV drugs (40%); and public transport (20%)

- Can someone tell an HIV positive person by sight? – (2) said ‘No’
- Can HIV/AIDS be cured? – 2 said ‘Yes’
- Mother-to-child transmission – (1) said ‘not 100%’; (3) said ‘100% chance’
- Should a couple either of who is HIV+ have a child? – (2) said ‘Yes they should, how can they not have’
- Should a couple be tested before marriage? – (2) said ‘Yes’; (1) ‘No’; (2) said ‘don’t know’

**Reported Risky Behaviours**

- Smoking: One said ‘Yes’
- Drinking: (4) women said ‘Yes’ of whom (1) woman had given up. None had tried drugs.
- Experience of sexual abuse as children: (3). Median age at sexual debut: 12 years
- Frequency of sex in the last 3 months: up to 15 times/month (4); almost daily (1)
- Last sexual contact – last 6-3 months (3); less than 3 months (1); less than a week (1)
- If has STDs – 100% said ‘yes’

**Knowledge & Use of condoms**

- Heard of Condoms – 100% (5); Heard of female condoms – (1)
- Beliefs about condoms: (percent who said ‘Yes’)
  - Make sex less enjoyable – (2)
  - Easy to use - (3); Prevent pregnancy – (4); Prevent STDs – (4); Prevent HIV – (4)
  - Better to use with casual partner – (3); not have sex with casual partner if no condom – (5)
  - Appropriate to use with spouse – (4); Spouse would get suspicious – (2)
  - Would use with regular partner – (2)
- Ever used Condoms – (3); Condom use with spouse occasionally – (1 of the 2 married women)

*‘Don’t like it’, ‘Dependent on client’*

All but one FSW had been initiated into sex before the age of fifteen. Their frequency of sex with 1-2 clients a day seemed underreported in comparison with figures from previous studies or might have decreased due to their illness. The last sexual contact for all FSWs in our survey was as recent as the week previous to the interview. Three reported sexual harassment at ages twelve to thirteen and one said she had sex with a *hijra*.

### ***Knowledge and Attitudes to HIV/AIDS***

Peer-education of FSWs has been reported to be successful in India. An example is the Sonagachi project in Calcutta. It has been successful in ensuring low HIV prevalence among CSWs (less than 6%) while it was 25% or above among CSWs in other parts of India (Cohen 2004). This project trained some FSWs as HIV/AIDS educators who then formed peer educators among other FSWs to both distribute and demonstrate the use of condoms. However since commercial sex work is not legalised in TN, sex workers are forced to operate independently and clandestinely. Consequently it is very hard to target them for interventions or to train peer-educators. Thus a majority of surveyed patients had not been exposed to any kind of targeted interventions (only two said they had attended some meetings). All five FSWs in our study reported their main source of HIV knowledge as radio or newspapers; four each, reported TV or doctors as a source of knowledge; and posters were not important (2). A majority seemed unclear as to where they could go to learn more about HIV (only two women said doctors, remaining said 'don't know').

Knowledge of HIV/AIDS among FSWs surveyed was high on sexual modes of transmission but not on other modes (Verma 1999). Four of these women said that they knew other colleagues who were HIV positive (one said she knew 25 HIV positive CSWs and another reported knowledge of 300 (possibly over reported)). Brothel based FSW said that the 'madam' (the lady who ran the brothel) they worked for knew they were HIV positive and helped them to find treatment. They also reported that they drew comfort from knowing others who were HIV positive. Two

believed they might be cured of HIV; and three had tried indigenous medicines hoping to be healed. One of them served as a peer educator to other colleagues and campaigned for condom use, and one other woman was willing to campaign (both these women were brothel based); while those who were not brothel based did not want to get involved due to social stigma.

### ***Knowledge and Use of Condoms***

AIDS Prevention and Control (APAC) studies (2001) were conducted in Tamil Nadu in five waves during 1996 and 2000; they had included FSWs in their sample. These studies reported that knowledge of prevention of AIDS among FSWs was high (98% in 1999 knew two acceptable ways of prevention) and 96% were aware that condoms could prevent AIDS. About half (51% in 1999 and 53% in 2000) reported basic knowledge of HIV/AIDS prevention. Their reported condom use with non-regular sexual partners had increased from 56% in 1996 to 91% in 2000 (was 88% in 1999) although voluntary condom procurement was reported as only increasing from 12% in 1996 to 25% in 2000. According to APAC, FSWs reported improvements in the following condom negotiation practices; negotiate condom use for commercial sex – 48% in 1999 (58% in 2000), refuse to have sex – 54% in 1999 (56% in 2000), have sex without condom – 17% in 1999 (16% in 2000), refuse to have sex sometimes – 16% in 1999 (20% in 2000) and increase fees to have sex without condoms – 7% in 1999 (16% in 2000), refuse to have sex sometimes – 16% in 1999 (20% in 2000) and increase fees to have sex without condoms – 7% in 1999 (16% in 2000).

Despite the above optimistic reports, the risk of acquiring HIV through being unable to use condoms was reported to be high by FSWs in the patient survey. They belonged to the low-income category and were dependent on clients for their income. They appeared to have little scope for practising safer sexual behaviour or negotiating condom use. One informant, *Valli*, said ‘my parents arranged my marriage to a married man as his second wife when I was 12 years old. When I was unhappy and wanted to return to my parents, they would not have me back, so I



ended up working in commercial sex work in Pondicherry'. She continued, 'the men usually refuse to wear a *nirodh*. They say 'it is my problem, I am the one who could get HIV, so they could not be bothered to wear *nirodh*'. She said 'as a CSW I cannot force men to wear a condom. If I try to do that, I am the one who will starve'. Then again, *Martha* reported that she went to help her sister and was raped by her brother-in-law when she was 13-years-old. When she escaped from the house, people who offered to befriend her and promised to take her back to her parents sold her into commercial sex work instead. At 25 years of age she was married to a man who was living with six other wives (multiple partners) and she lacked the autonomy to use condoms with him. It was reportedly harder to use condoms with regular partners (Amin 2004).

Only three among the five FSWs in the patient survey reported having used *nirodh* sometimes. Only one among the two married FSW said she had used condoms with her husband occasionally and the other married woman reported that she had abstained. They talked of their powerlessness to practise safer sex, or to stop commercial sex work even after they had been tested HIV positive. The reasons were threat of destitution and lack of autonomy (Bhave *et al.* 1995).

Case study 8.4 conveyed a classic story of a commercial sex worker from Tamil Nadu. Even though these FSW reported high levels of relevant knowledge on HIV/AIDS they were not normally successful in negotiating use of condoms with their clients (Amin 2004; Asthana and Oostvogels 1996; Gangakhedkar *et al.* 1997).

**Case study 8.4 Female sex worker****Rani**

Rani was a 27-year-old female commercial sex worker (April 1999). She was not married and had studied up to VIII standard. She grew up in a hostel in Chennai. She did not know who her parents were since someone had looked after her until she was a year old and left her at a hostel. They had told her that her mother had given her to their care and left with no trace of her whereabouts. Although they cared for her, they were poor themselves and could not afford to look after her, and consequently left her at the hostel but visited her regularly until they died.

At the age of 12, before she had attained puberty, when she was with a man called Das, two other men at the beach beat up Das, pulled her away from him and raped her. When she tried to go back to the hostel the next day, they would not take her in. Some nuns found her and left her in a house to work as a maid where she was paid INR 200/-(£3) a month. The family ill-treated her and she left them. She continued as housemaid with other families during the day and also continued with commercial sex work from the age of 15.

She lived with a man for a year. He sold '*gaanja*' (a non-injecting drug like cannabis) and used IV drugs himself. She used to drink when she was with him. They did not have a house, so they would sleep in a school at night, clean themselves at some public well or street taps in the morning and were out and about during the day. She told a friend who used to lend her partner money regularly to stop it as he was wasting it on drinks and drugs. Her partner got suspicious of her and ill-treated her so she left him.

She then went to a Catholic priest who admitted her to a convent, which provided refuge for destitute women. She remained there for 2 years, learnt tailoring and they even tried to arrange a marriage for her. The man they suggested had a government job. He was dumb, she liked him, but he wanted a dowry. She was unable to provide the dowry and so he did not marry her. She had given up commercial sex work during this period, but after this incident she started again.

Rani was caught by the police for her commercial sex work, which is illegal to practise in Chennai, and was admitted into a vigilance home. While there she was tested for HIV and was found to be positive. She had gone out to 'Anna Samadhi' (a well known tourist spot near the beach) one day. She met a lady there who promised to find her work as a housemaid and landed her in the Mumbai red light area instead. She was exposed to 10-20 men a night, mostly just 10 minutes with each person. Sometimes even hijra would have sex with her during the day. She was paid INR 500/- (£7) a month. She became very ill and they sent her back to Chennai. She was first sent to a general government hospital and then to GHTM; this was in 1996. She was in the hospital for 6 months, got well and a doctor arranged for her to stay at a hostel. Since then her life had followed a routine of working as housemaid, combined with commercial sex work, (sometimes she found regular partners, she lived with a man, (she met through rag picking) for 3 months) and returned to GHTM when she got very ill. At the time of interview, she had returned to the hospital in March 1999. She hoped to work for Dr Manoramma who ran a home for children in Kodambakkam (she also ran a home for destitute HIV positive women and gave them work). Rani was hoping to look after the children in that home.

Rani had used condoms in Mumbai only when the men who came to her brought one with them. 'In Chennai, 20-25 men come to me everyday. Some men who come to me ask if I have a condom, since I do not keep condoms with me we are not able to use it if we had already started having sex. A few ask if they can buy a condom before we start sex, then we try to find a shop and buy the deluxe variety as the others often tear. This is possible as I usually pick them up from the streets and we go to marina beach to have sex', she said.

**8.5 Hijra**

Hijra is an Urdu word which means hermaphrodite (intersexed) and its closest English translation is taken to mean eunuch (Nag 1996; Nanda 1990). Hermaphrodite refers to a person whose genitals are ambiguously male-like while eunuchs are castrated males. Both are associated with impotence. In India *hijra* connote a

cultural, institutionalised third gender and impotence is a necessary but not sufficient condition. According to Nag (1996), only a small proportion of *hijra* are hermaphrodites and there might be some who are neither castrated nor hermaphrodite but identify themselves as *hijra*. On the other hand Nanda (1990) reported on persons she met who had been raised as women but had failed to develop secondary female sexual characteristics (breasts and menarche) at puberty and became a *hijra* (one person among the patients surveyed was of this kind). The exact number of *hijra* in India are not known since they are counted as women in census, but unofficial estimates state about 50,000 (Nag 1996).

A *hijra* household is organised as a commune of 5-15 members. Some might choose to live alone but each belonged to one of seven named 'houses' that were symbolic descent groups. According to Nanda (1990), persons of any caste and religion could be initiated into the *hijra* community. The initiation implied renunciation of male sexuality through surgical removal of male sexual organ and was essential to the cultural role and identity of *hijra*. Emasculation was considered to be a *dharma* (religious obligation) and was performed to attain *nirvana* (calm and absence of desire). The people who seek ritual services in marriage and childbirth do not accept non-emasculated *hijra*. The *hijra* themselves take pride in their emasculation and readily lift their skirts during ritual dancing (with or without instigation) to display their emasculation to alleviate people's doubts. The ritual of emasculation is performed by a *dai-ma* (a guru bestowed with special powers by *Bahuchara Mata* to perform the operation) in secret and is in theory punishable under section 326 of the Indian Penal Code for 'abduction and grievous injury with a sharp weapon'.

An initiate becomes a member of the house of her guru after she is approved by representatives of all seven houses and is expected to adopt the values and organisational principles of the community, with sanctions for misbehaviour. The guru-chela relationship while providing social nexus required economic obligations

in favour of the guru. Procedures have been developed to change one's guru (and consequently one's house) but these procedures ensured that the guru would have the economic advantage (Nanda 1990). Apart from the guru, they had a regular establishment of family relations; members of the household were referred to as *chelas* (sisters), guru's guru was granny, guru's chela was an aunt etc. The hijra patients interviewed in our survey referred to their guru as mother and said that she knew all about them, even all their sexually transmitted infections and provided them opportunities for care. Thus their strong dependence on guru and community was obvious.

*Hijra* are concentrated more in north Indian cities where they are paid to perform at weddings, the birth of a male child and other festivals. At these functions their traditional role is to sing, dance and bestow blessings of prosperity, health and fertility on male children and newly wed couples. The paradox of impotent and emasculated men conferring blessings of fertility is resolved by the fact that they are held in awe as they are perceived to be bearers of divine power bestowed on them by a female deity, *Bahuchara Mata* who transforms their impotence into the power of generativity (Nanda 1990). Their traditional role is not as significant in south India so that an estimate for the number of *hijra* in Chennai was only between 75 and 150 (Khan 2001). In fact they are derided by derogatory names such as *kojja* in Telugu (native language in Andhra) and *pottai, ali, or onbadu* in Tamil (native language in TN).

### ***Occupational Exposure to HIV/AIDS***

There were six *hijra* in the women's ward at GHTM. Their general characteristics are described in Box 8.6. They dress and act like women hence they were admitted in Female wards. In adherence to their preference, they were treated as women in this study. They were all from urban areas with a median age of 28-years and had never married. A majority (4) had completed secondary education but all reported low-income level. Four reported that they were exposed to at least one media. The

median age of first sexual activity (15 years) for *hijra* was higher than that of FSWs. All except one reported practising sexual intercourse with males and referred to homosexual activity, before they were castrated. The exception was *Mala* (aged 25) who was born a female but did not develop secondary female characteristics and hence joined the *hijra* community. She was gentle, soft-spoken and very feminine.

### Box 8.6 *Hijra*

**Sample size n=6** (Percentages represent – 1(17%), 2(33%), 3(50%), 4(67%), 5 (83%))

- Median age: 28 years (Mean = 31 years, std. dev.=8)
- All *hijra* interviewed at GHTM were born in Tamil Nadu, but lived in the Mumbai red light area
- They all had never been married
- Schooling: None (1); Primary (1); Secondary (4)
- Reading Newspapers – ‘Rarely’ (4); Watching TV – Once a week (3), Less often (3)  
[Overall media exposure – none (2); one or more (4)]
- Income per month: Between Rs. 2000/- (£28) & Rs. 3000/- (£43)
- Period of illness – less than a year (2), 1-5 years (4)
- Financial resources since becoming ill: (4) continued commercial sex work, (2) supported by social worker

#### Knowledge of HIV/AIDS

- Knowledge level high on common modes: - sex with CSW (100%), sex with positive person, and petting (100%), handshake & playing with children (100%).  
Fairly good on these: - blood transfusion (83%); public toilets, common bathing places, common hospitals, and public water places (67%).  
And low knowledge on these: - IV drugs (50%); mosquito bites (33%); and public transport travel (17%).
- Can one tell HIV+ person by sight? – (5) say ‘No’
- Can HIV/AIDS be cured? – (2) say ‘Yes’
- Mother-to-child transmission – (4) say ‘100% chance’; the rest ‘no risk’
- Should a couple either of who is HIV positive have a child? – (4) said ‘No’
- Should a couple be tested before marriage? – (3) said ‘Yes’

#### Reported Risky Behaviours

- Smoking: None
- Drinking: (5) of them said ‘Yes’ of whom (1) woman had given up.
- Experience of sexual abuse as children (1); Median age at first homosexual activity – 15 years
- Experience of homosexuality: 100% ((1) started at 13 years of age, (5) started at age 15. One person has not had the castration operation yet)
- Frequency of sex in the last 3 months: Not at all (3); more than once daily (3)
- Last sexual contact – over 3 years ago (1), 1-3 years (1), 6mnths-1 year (1), 6-3 months (1), less than a week (2)
- Has never had STDs – 100%

#### Knowledge & Use of condoms

- Heard of Condoms – 100%; Heard of female condoms – (2)
- Beliefs about condoms: (percent who said ‘Yes’)  
Make sex less enjoyable – (1) said ‘Yes’; (2) said ‘No’ and (3) said ‘don’t know’  
Easy to use - (3); Prevent pregnancy – (4); Prevent STDs – (5); Prevent HIV – (4)  
Better to use with casual partner – (3); not have sex with casual partner if no condom – (2)  
Would use with regular partner – (4)
- Ever used Condoms – (2)

*‘Depends on the client’*

The other *hijra* patients surveyed said that they had been born as males but had been inclined to dress, talk and behave as females from their childhood. They possessed feminine mannerisms, which they reported had attracted their elder male relatives/friends/neighbours to practice male-to-male sex with them during their early teens or earlier. *Amudha*, aged 25-years said, 'When I was 10-years-old, my uncle first had sex with me. At age 12, my male cousin had sex with me. I then had a regular male partner with whom I used to have sex 2-3 times a week before I went to Mumbai at the age of 15'.

Some patients reported being targeted as children by other *hijra*, who watched them and waited outside their schools in order to recruit them into their community saying 'come with us and you will be happy, you can dress, live and even sing and dance like a woman and you will be protected in our community by our unity and nobody can hurt you'. Such persuasion, offering freedom and independence to follow their inclinations, had been compelling and they had chosen to leave their homes and joined the *hijra* community. To quote *Suni*, 'when I was 18, as I came out of school one day, a man tempted me and said if I went with him I would be very happy as I could live like a girl and no one would scold me or stop me behaving like a girl. I was tempted by his offer and he took me to the Mumbai red-light area'. She continued 'I left without telling my parents because they would not have permitted me. I could not be like other boys and some men in the neighbourhood had already had sex with me so I had to go and find my own life'. These interviewees reported that they had joined the community voluntarily (Nanda 1990). Other studies report that infants and children were believed to have been sold by poor parents or kidnapped to join the *hijra* community (Nag 1996).

Studies have shown that *hijra* engage in sexual activities with men for money or for personal sexual gratification (Nag 1996; Nanda 1990). According to Pradeep (Pradeep 2002), *hijra* form key sex providers for between 5,000 – 6,000 men having sex with men in Chennai. Some *hijra* who were castrated said that they had a canal

fixed which enabled them to have vaginal type sex while others said they did it between the thighs and the drunken men did not realise it.

*Hijra* in our sample too reported that men came to them for alternative techniques of sexual gratification, thus they were providers of commercial sex. They said that some men went to them specifically for male-to-male sex, while other men, especially when drunk, assumed they were women. Two of the six *hijra* in our sample said that they had taken on a 'husband'/regular partner and become involved in a long-term relationship while also continuing with commercial sex work. They said that they did not use condoms with their 'husband'/regular partners.

The *hijra* in the patients sample had all been born in TN but had gone to Mumbai for commercial sex work. When they were ill or older (around 30 years), and not able to continue in commercial sex work as profitably, they were inclined to return to their home state. Reports of good care provided at GHTM for HIV patients were reported to be a catalyst to try returning to their home state. According to *Rajathi*, a *hijra* aged 25,

'There are nearly 2,000 CSWs from Tamil Nadu in Golivada, a red-light area in Mumbai'. 'I used to work as a typist. At 15-years I started having sex with men. I used to fall in love with them and believed they were my husbands. They would talk to me very sweetly and I would fall for it and think they loved me but the next day, the same guys would be going to other commercial sex workers. So I got very upset and angry and learnt to treat them as they deserved. Since then when someone came to me I would first get INR 300/- (£4) from them in the hotel room. After having sex I would extract all the money from their wallets and pockets and leave them with nothing. I am quite strong physically so they could not do anything to me and even if they threatened me, I would call the police who would take my side and have the man beaten up. The police were my friends as they too took sexual favours from me. I used to tell them that they can get HIV from me and forced them to wear *nirodh*. I have some regular partners who are nice to me so I treat them well. Since they are so nice to me I cannot force these men who are nice to me to wear *nirodh* and they mostly do not want to'.

The sexual contacts of *hijra* were reportedly less frequent than FSWs. About a third had their last sexual contact over a year before the survey. They seemed less vulnerable to STDs, which might be attributable to anatomical reasons together with lower frequency of sexual contacts (none of them reported infections, while all FSWs surveyed did, see Box 8.5 and Box 8.6).

### ***Knowledge and Attitudes to HIV/AIDS***

The red light area in Mumbai has legal permission for commercial sex work and much of the commercial sex work is concentrated in one area, consequently it is easier to target these *hijra* for intervention programs. The *hijra* lived together so that they had an identity, were better organised as a community and could be more professional with their customers. They had better knowledge of HIV/AIDS compared to the FSW patients interviewed. *Hijra* had high or fairly high knowledge of HIV/AIDS (Box 8.6). Even so two of them thought that they could be cured because they had been told so by those who treated them with indigenous medicines. Hospital was their major source of HIV information (5 of the 6 said they learnt most of what they knew from hospitals and health workers). Other sources were posters (4); television (3), radio (2), newspapers (2) and meetings (2). Two *hijra* said that they did not know where to get more information about HIV and two each mentioned they could get information from hospitals and TNSACS.

Thus *hijra* had greater awareness of HIV compared to female sex workers. They practised high-risk behaviours but their sexual activity was less intense or demanding than that of FSWs. They had greater autonomy and were better able to ensure condom use with their clients compared to FSWs.

All said that they had been shocked and very upset when they first tested sero-positive but seemed to acquire resilience very soon and said 'we take life one day at a time, it is not so bad for us because we do not have children or families who depend on us, besides we are used to a tough life'.



As with FSWs all except one knew other colleagues who were also HIV positive. One *hijra* said she was aware of about 40 others. However, this was less than the numbers reported by some female CSWs. Half said they would like to be peer educators and tell others to take precautions against HIV by following the 'one man, one woman' policy and also by using condoms every time they had sex (the ABC message).

### Case study 8.5 *Hijra*

#### Mina

*Mina* was a 45-year-old *hijra* (March 1999). Her family had moved from Burma to Tiruchy (TN) in 1964. She herself had gone to work in the red-light area of Mumbai at 20 years of age. She had completed 8 years of schooling in Tamil. 'When at school we boys would go for late films and later sleep beside each other in someone's house. We would get feelings and then have sex with other boys. But the first time for me was when my uncle forced me to have sex with him when I was 15 years old. From the age of six I wanted to be like a girl, my mannerisms were very feminine and that tempted my uncle. He continued having sex with me about twice a month. I also liked to have sex with other boys. I was the only son for my parents and they were very upset, but they could not stop me. They still care for me and come to see me when I go to Villupuram in Tamil Nadu for the annual festival of the *hijra*'s. When I wrote to them that I was ill and at GHTM, they came to see me, gave me money, and even asked me to go to a private doctor.

I went with another woman who was like me to the red-light area in Mumbai. I could stay there without being ostracized as we have an established community. I used to get Rs 8/- a day initially. I also had a regular partner who would give me Rs.50/- whenever he came to me. I started dressing like a woman. I rented a house and would wait outside, men would desire me and come in. My earnings went up. Then I decided to have the operation (castration and vaginal reconstruction) 13 years ago in Dindigul (TN)'.

Her first visit to GHTM was in May 1998. Someone from the Mumbai red-light area had been there for treatment and mentioned it to others. 'The news spread quickly about GHTM being good and some of us, especially those from TN origin, started coming to GHTM' she said. When she returned to Mumbai in 1998, she gave up commercial sex since she was not well. But continued having sex with her regular partners. One regular partner had been like a husband to her for the past 5 years. He was a married man. When she returned from her first visit to GHTM, she would have about 2-4 men a day. About 10 of her regular men continued going to her and she earned about Rs 2000/- a month.

She said, 'I insist that men should use condoms, but it is not always possible to get one. If they do not have one, I send them out to get a condom from the shop. Sometimes the shops would be closed and it would not be possible to get condoms. In that case, nothing can be done. Sometimes I might try to cheat by doing between the thighs and I can get away with it when they are drunk, but other times I have no choice but to have sex without condoms even after I was tested HIV positive'. Her last sexual contact was with one regular partner using *nirodh*. She had about 5 contacts with him in the first week of March '99. She deceived him sometimes by pretending it was penetrative sex while just doing it between the thighs but she could not persuade him to wear condoms. (Since the men were mostly drunk she often got away with it!). If customers told her that they did not want to use *nirodh* because they were not HIV positive, she would advice them to use one. She would persuade them saying that they could get it if she was positive, so it was better for them to use a condom to protect themselves (without revealing her own HIV status, so that she did not loose her custom).

She was reluctant to return to Mumbai and commercial sex when she would be discharged from GHTM. 'I can go singing and dancing *gummi* (a form of begging by *hijra*'s) with others or I could go to *udavum karangal* (a social organization)'.

### ***Knowledge and Use of Condoms***

*Hijra* have a reputation for being aggressive and getting what they want. Greater autonomy, compared to FSWs, is also facilitated through their functioning in a network under protection from their community. Hence they could be forceful about imposing the use of condoms. However, even they did not have absolute control in the matter because of their dependence on their customers for income. Thus only two *hijra* reported having used condoms and only one among them said that she had used *nirodh* each time; while the remaining four *hijra* reported abstinence since being tested HIV positive. Two said that there was nothing to safeguard against HIV because, to quote, ‘even condoms tear all the time and do not provide any protection’.

*Mina* described her initiation into male-to-male sex and was representative of a typical *hijra* (Case study 8.5). She reported continuing in high-risk sexual activity even after she was diagnosed with HIV and described her inability to use a condom during every episode of sex.

## **8.6 Discussion and Summary**

Lorry drivers, FSWs, *hijra*, construction workers and hotel workers studied here reported occupational exposure to high-risk sexual behaviours, which made them vulnerable to HIV/AIDS (Bharat and Aggleton 2002; Gupta and Panda 2002; Verma and Roy 2002). Our survey also included some police and army personnel (5), enough to infer that they too might be among those where high-risk behaviours were common, partly because of the migratory nature of their occupation. However their numbers were not sufficient for representative in-depth interviews. More recent reports have also indicated that police and army personnel are among those with high levels of HIV infection, and it would be useful to investigate these groups further (AIDS-INDIA 2004a).

These groups had higher knowledge compared to other patients. We found that sex-related knowledge of transmission was high among these groups where high-risk sexual behaviours were common. A majority (52%) had low scores for knowledge of blood-related HIV transmission. Only 53% had high scores on knowledge of transmission through miscellaneous modes. Knowing other sero-positive persons was significantly associated with knowledge of HIV transmission among women (FSWs and two construction workers) but not for men (see Box 8.5 and Box 8.2). Media exposure was significantly associated with knowledge of HIV transmission among men (lorry drivers, construction workers and hotel workers). Younger men (15-24 compared to other age groups) and women aged 25-34 (compared to those younger or older) in these groups had significantly higher knowledge.

Knowing other sero-positive persons was a significant predictor for condom use among these women (CSWs, two construction workers). Women from urban areas reported condom use significantly more than those from rural areas. Men who had been diagnosed as HIV positive for more than a year (4) reported condom use significantly more often than those who had been ill for one year or less (3). Ever-use of condoms among all these high risk groups put together was higher (42%) compared to other people living with HIV/AIDS (PLWHA) we surveyed (26% - 45 out of 176 patients who responded). Among these groups condom use was reported most by lorry drivers (21 out of 32 –66%); followed by FSWs (3 out of 5), *hijra* (2 out of 6), construction workers (4 out of 19) and lowest among hotel workers (1 out of 11). These analyses are based on very small numbers and would require further research.

A study of sexual risk behaviour of men attending sexually transmitted infection (STI) clinics in Mumbai, India found that a high proportion of men who were behaviorally bi- or tri-sexual and have multiple partners with whom they engage in risky sex (Hernandez *et al.* 2006). Almost all men reported sex with women; additionally, 13% also reported having sex with other men, 13% reported sex with

*hijras* (male-to-female transgenders), and 11% had sex with all 3 genders (men, women and *hijra*). Men who had sex with men and/or *hijra* as well as women, reported having greater numbers of partners, including female sex workers (FSW), and were more likely to engage in insertive anal and oral sex with women. The prevalence of HIV was higher among men having sex with *hijra* (14%) or with all 3 genders (13%) compared to prevalence among men having sex with men and women (8%). Another study found HIV prevalence to be high among men practising same-sex and high-risk behaviours in India, also highlighting the importance of additional targeted efforts to reduce HIV risk among men having sex with men (MSM) (Gupta *et al.* 2006).

Asthana and Oostvogels (2001) based on an ethnographic study of MSMs in Chennai highlight the importance of studying homosexual groups as a HIV prevention strategy. Another study among MSM surveyed 62 MSM outreach workers from three non governmental organizations in Chennai (Safren *et al.* 2006). Although 92% reported having sex with men, only 74% identified as gay and 27% were married. Only half of these men reported having been tested for HIV. More than half of the sample reported that they would rather not know they had HIV until they were sick, and almost half indicated that they would rather end their life than live with the disease. Eighty-five percent reported harassment and discrimination from others. Homosexuality continues to have limited focus in India and more research and interventions targeting this group are essential.

This chapter showed that when infection rates are high, knowledge appears to increase relatively fast. Possibly more importantly, there was more evidence of behaviour change among these groups where high-risk behaviours were common, than among the rest of the patients surveyed. These groups reported knowing more sero-positive people (18 % of patients from groups where high-risk behaviours were common reported knowing ten or more other sero-positive people compared to 11% of other patients who said this). There was a significant positive association between

knowing other sero-positive people and behaviour change among these groups. Social position appeared to be related to the ability to adopt safer sexual practices, but occupational cultures were also important.

Overall knowledge of HIV/AIDS was high among lorry drivers. CSWs and *hijra* were well informed about HIV/AIDS in the context of sexual behaviours but lacked broader knowledge. Construction workers and hotel workers demonstrated that they were relatively well informed through watching TV and peer discussions. The nature of occupations among lorry drivers, *hijra* and CSWs had limitations for media exposure, particularly TV.

An inherent concern among lorry drivers is that of marriage and children. Since they are young and eligible among the lower-middle classes, there is the social and cultural compulsion to marry and have children which results in painful complications not only to themselves but also to their wives and children who get infected through them. This also caused dilemmas associated with disclosing their sero-status to potential sex partners (Schiltz and Sandfort 2000). On the other hand, publicity resulting from targeted interventions about high levels of HIV/AIDS among them was exacerbating stigma and discrimination against them. Hence this important issue requires to be addressed with great socio-cultural sensitivity.

As evidenced by the patient survey, targeted interventions and peer-education among lorry drivers and licensed CSWs appeared successful in creating awareness about HIV/AIDS (Asthana and Oostvogels 1996). However they had not been very successful in influencing safe sexual behaviours. Lorry drivers reportedly did not pay attention to targeted intervention. Thus it seemed that interventions to prevent HIV/AIDS among lorry drivers needed to be reassessed (since they reported not paying attention to health messages until they tested positive). However, they had all heard about other colleagues dying due to AIDS. The shock from hearing/observing other colleagues suddenly die due to HIV/AIDS caused fear and an increased perception of personal risk and seemed most effective in reducing high-risk sexual

behaviour and induced condom use to some extent among lorry drivers in the patient survey (Moatti and Souteyrand 2000). As reported, they did not listen to educators and hid from them, hence targeted interventions that firstly make them listen, pay attention to the fact that it could happen to them and practise safe sexual behaviours have to be developed (Amin 2004; Barnett and Whiteside 2002; Campbell 2003; McKeganey 1994). The bigger challenge appeared to be to develop and implement prevention programs that were culturally sensitive and resulted in safe sexual practices.

An information-motivation-behavioral skills (IMB) model-based HIV prevention intervention for truck drivers in India compared to an information only control condition in a randomised trial showed that there was an effect of the IMB intervention on attitudes, norms, behavioral skills, and intentions specific to condom use with marital partners, but no effects on constructs related to non-marital partners (Cornman *et al.* 2007). There was some evidence of greater condom use with marital and non-marital partners at behavioral follow-up for participants in the IMB condition, and effects on condom use with marital partners were mediated by changes in IMB constructs. These findings provide initial evidence for the effectiveness of theoretically-based approaches to HIV prevention in India.

The importance of this chapter is that although these groups had high levels of knowledge they still reported low condom use. These groups had been targeted for distribution of condoms and had used them more than other patients surveyed. These people having used condoms expressed their experiential knowledge of the unreliability of condoms. The attitudes about condoms among people where high-risk behaviours were common were also influenced by gender imbalances in power, personal pleasure, religion and family life.

Lorry drivers had considerable personal autonomy but a combination of long term separation from their wives and health beliefs that encouraged sex with CSWs, made them vulnerable to infection. Qualitative data from their interviews suggests that if

reliable condoms were available lorry drivers might be one of the groups most likely to use them.

While lorry drivers reported greater acceptance of condoms and change towards safer sex, actual ever use of condoms reported was low (only 21 out of 32 reported ever-use of condoms), and none reported consistent condom use. Lorry drivers reported practicing abstinence to prevent infection. The main reason stated for lacking motivation to use condoms was the poor quality (Irwin *et al.* 1991). The fact that they exposed themselves to risk of HIV infection means they need greater protection that could be provided by more reliable condoms. To enable this, it is important firstly that the need for reliable condoms be met.

Results from a study among lorry drivers and FSWs in Uganda indicate that despite the HIV/AIDS epidemic, these groups had only changed their sexual behaviour a little, and they reported to be continuing with multiple sexual partners (Ntozi *et al.* 2003). In a study of HIV/AIDS knowledge and frequency of and influences on condom use with clients and regular, non-client partners among female sex workers (FSWs) in Vietnam where sex work is common, condom use was found to be low and the authors recommend the need to improve the rate of condom use among FSWs in Vietnam (Rosenthal and Oanha 2006). On the other hand, Joesoef and colleagues (2000) report the successful implementation of condom only brothels in Thailand.

Longer duration in brothels was associated with greater likelihood of HIV infection; findings demonstrate the need for increased attention to HIV among young victims of sex trafficking in research and practice, and to the rescue of sex trafficking victims as a form of HIV prevention (Silverman *et al.* 2006). Another study among brothel-based sex workers in India suggests that their behavioural factors increase a young sex worker's risk of acquiring HIV infection (Sarkar *et al.* 2006). A study of CSWs in India suggests they are disempowered and socioeconomically marginalized, which does not allow them to insist on condom use by the client, especially in

absence of governmental structural support (Chattopadhyay and McKaig 2004). These authors argue that CSWs need to be empowered and emancipated for effective HIV/AIDS control and prevention efforts in India and that ad hoc promotion of condom alone will not be effective to control HIV/AIDS. The authors suggest that more extensive developmental work aimed at betterment of living conditions of CSWs is required for effective HIV/AIDS prevention.

Dandona and colleagues (2005a) in a study of 6648 FSWs in Andhra Pradesh found that the risk of HIV infection as a result of the non-use of condoms was higher among FSW who reported not having been tested and were also unwilling to get tested, and they held significantly more negative beliefs about HIV/AIDS. In another study of non-brothel-based FSWs, who form the majority of sex workers in Andhra Pradesh, Dandona and colleagues (2005b) found them to be at a significantly higher risk of HIV infection as compared with brothel-based FSWs. They found that about half of FSWs did not use condoms. They recommend that the success of expansion of HIV prevention efforts will depend on achieving and sustaining an environment that enables HIV prevention with the non-brothel based FSWs. In an earlier study Bhawe and others (1995) showed that targeted intervention among CSWs to improve levels of condom use have achieved only limited success in India.

FSW in our patient survey, who combined the low status of women with illegal work were very disadvantaged. The lower social position of CSWs not only made them vulnerable to HIV infection but unable to practise safe sex. They were dependent on clients for income and were not in a position to insist on condom use. Even though this group of FSW, because all but one had been non-brothel based, had not been targeted for KABP, they were well informed about the risks of HIV/AIDS but unable to put the health prevention message into effect. Their work exposed members of these groups to great risk of contracting HIV than the majority of patients, but there is no reason to suppose that the attitudes that made them unwilling



to use condoms or take advantage of tests was different from the rest of the patient sample.

According to O'Neil and colleagues (2004), 'collectivization' (referring to collective action) is a powerful force for reform to empower sex workers in India to take greater control over their health risks associated with their occupation (Giffin 1998; Majumdar 2004; Narashimhan 1999; Oldenberg 1990). Thus CSWs who operated in brothels under supervision by a madam (or *hijra* who operated as a community) may be successful in negotiating condom use. However in TN and Andhra, few brothels are tolerated and are operated against the law, other CSWs had to be clandestine and operated independently and were additionally vulnerable to exploitation from police and others. Consequently it is difficult to implement targeted interventions among CSWs in these states, or support compulsory use of condoms with their clients. On the other hand, implementing licensing laws appears to be an uphill task due to strong opposition, especially in an Indian socio-cultural context. A recent move to licence commercial sex work in Andhra is facing staunch opposition even by NGOs operating to safeguard the interest of commercial sex workers (Mohan 2004).

Social exclusion, economically and otherwise, destitution and lack of autonomy made CSWs powerless to insist on condom use or to practise health-promoting behaviours with their clients (Jana *et al.* 2002; Rhodes *et al.* 2001). Studies also reported acute shortage of condoms in Indian brothels (BBC 2003; Deutsche-Press-Agentur 2002). The problem of poor quality condoms that tore, as reported by patients surveyed, remained a barrier to elaborating a credible safe sex message or behaviour. Making good quality condoms available and affordable might be helpful in persuading men to use them at least during commercial sexual relations (Bhave *et al.* 1995; Garside 1999). More importantly educating people about correct ways of using condoms might minimize tearing or slippage.

Ubaidullah (2004) recommends the best vaccine to be 'social vaccine' (referring to education on how to protect oneself, hundred percent condom use, and changing sexual behaviour). He refers to the example of an action research study conducted in Chittoor District of Andhra Pradesh among truck drivers. As part of this study, different strategies, namely mass media, personal contact, group discussion, folk media, and counselling, were adopted to provide AIDS education, to encourage increase in condom use for safer sex, and bring changes in their sexual behaviour. The strategies adopted in this study greatly enhanced the knowledge of the truck drivers on AIDS, changed their attitudes on sex, increased the use of condoms, and modified their sexual behaviour. Ubaidullah suggests that the 'social vaccine' can be extended to all the high risk group population for successful HIV prevention.

Stigma and discrimination also hinders targeted interventions among lorry drivers who do not want to be seen together with people who are talking about HIV and run away from them; it restrains positive people from volunteering to be peer educators for communicating effectively to caution others from acquiring the infection. Those groups who are supported by social networks might be able to cope with stigma but others face even greater difficulties. Addressing issues of stigma and discrimination is essential, which will enable high-risk groups to discuss problems openly and help HIV prevention program to be successful.

Further research into the socio-economic and cultural aspects of sexual behaviours among groups where high-risk behaviours are common is important for understanding related issues and ways to support them to practise safe behaviours and help to control HIV infections among them.

## Chapter 9      Conclusions

This research aimed to investigate HIV/AIDS knowledge and behaviours among people living with HIV/AIDS (PLWHA), its context and correlates of factors associated with HIV sero-positivity. This hospital-based study of PLWHA was the first of its kind to be conducted in India at the time (1999), and respondents' personal experience of HIV/AIDS outweighed any potential drawbacks of a sample that was not strictly representative of the general population. The study was located in the two main hospitals dealing with HIV/AIDS in Tamil Nadu between March-June 1999. A 92% completion rate was achieved, resulting in a sample size of 292 PLWHA.

In this chapter we outline first the limitations to the conclusions that can be drawn from the research. We then consider the research findings in terms of the original research questions. We dealt with the following objectives in this study:

- To describe the levels, types and sources of HIV/AIDS knowledge and attitudes among PLWHA, and their socio-demographic correlates.
- To describe the sexual behaviour, and analyse its socio-demographic correlates, of PLWHA.
- To describe the extent of knowledge and practice of safe sexual practices, in particular condom use, of PLWHA.

- To understand the context of HIV risk for PLWHA identified as having high risk sexual behaviour (for example, CSWs).

The chapter concludes with an outline of the contributions of this research and reflections on the contributions to knowledge for Behaviour Change Communication (BCC) and positive prevention. Future avenues for research on PLWHA in India are then discussed.

The patients surveyed formed a subset of the general population but differed from the average in important ways. A male bias was evident among those seeking treatment for HIV at hospitals, explained by a combination of higher disease prevalence among men relative to women, and men's greater socio-economic accessibility to treatment. The proportions of rural and urban respondents are not significantly different from the general population.

## 9.1 Limitations of the research

The paucity of India-specific data and literature were a limiting factor for the design and conceptualisation of this research. Available HIV-related data from large-scale Indian surveys (for example, general population Behaviour Surveillance Surveys (BSS)) were cursory (see section 3.2, p. 43). Where appropriate we have compared analyses of patients' survey data with existing large-scale secondary survey data, where available. However the limited scope and doubtful accuracy of some of the general population surveys was a major constraint (see section 4.1).

This study used a WHO-based survey instrument to collect information on knowledge of modes of HIV transmission and methods of prevention. While globally developed questions are useful for comparison purposes, they are developed non-locally, and if applied verbatim, often do not easily translate accurately to local contexts, nor do they take account of local sensitivities. In developing countries the respondent often lacks an adequate frame of reference for answering questions in

KABP surveys (De Vaus 2002). This was evident in our survey, for example, although the WHO questionnaire had questions on knowledge of HIV transmission through petting and deep kissing, these questions were not relevant in the local cultural context. For example, people rarely kiss in public and the censor board of Indian films permitted limited kissing scenes only since 2006. Hence 'don't know' (DK) responses for these questions were high (over 30%) and these have been removed from multivariate analyses. However, DK responses were retained in bivariate analyses as their exclusion could lead to selection bias and affect statistical conclusions, hence we are justified in retaining them.

At the time of the study, the WHO questionnaire was the accepted international standard, although retrospectively it is acknowledged that this standard should have been adapted more fully for the present study. Resource limitations constrained us to use the standard questionnaire, and limited changes were made to the questionnaire (chapter IV, section 4.3.2). For example, questions specific to the south Indian context were added to the main survey. Importantly open-ended and probing questions were inserted to supplement and add depth to the questionnaire-derived data. Some answers to these questions were coded and quantified, but the main body of qualitative data was written down in verbatim translation. The strength of this method is that it allows the integration of quantitative and qualitative methods and data to capture a more complete, holistic, and contextual portrayal of knowledge, attitudes, behaviours and practices (KABP) as reported by PLWHA. Open-ended questions and spontaneous patient contributions are placed alongside more standardised questionnaire responses. Qualitative data were particularly useful for studying behavioural aspects of premarital and extramarital sex and condom use.

Conceptualisation of KABP research in India was a problem as has been discussed in chapter II (section 2.3). Analysis of the correlates of HIV/AIDS knowledge among PLWHA revealed gaps between knowledge and safe sexual practices that went beyond the need for biomedical knowledge of HIV/AIDS. To

understand these gaps it was important to examine the cultural dynamics that influenced knowledge, attitudes, behaviours and practices (Gausset 2002; Kalichman *et al.* 2006; Lugalla *et al.* 2004; Roberts *et al.* 2004; Smyth 1998; Sudha *et al.* 2005).

Problems with retrospective data were evident due to recall errors (increased with remoteness of event) and desirability biases, and these may have affected reported sexual behaviours. In any survey of sexual behaviours it is difficult to verify responses. However people tend to report more accurately if they are assured of confidentiality and if the interviewer's attitude is sympathetic and sensitive to local psychological and behavioural factors (Barnett and Whiteside 2002). The author's initial apprehension associated with discussing sexual matters was rapidly overcome. During the patient survey it was evident that there was an urgent need among PLWHA to discuss HIV related behaviours and practices, even if it did mean divulging their high-risk sexual behaviours. Further, in a hospital environment, patients were very keen to discuss sensitive issues surrounding their infection. On occasion their ability to talk freely was inhibited by the very public nature of hospital life in India, where relatives are likely to be present, providing food and care to patients. Some respondents did not disclose aspects of their sex lives at first interview or denied behaviours such as premarital sex (PSM) while their relatives were present.

The combination of patient's desire for more information and discussion of their condition, the lack of privacy, and perceptions of the stigma associated with risky and stigmatised sexual behaviours, highlights the ethical issues surrounding study of HIV/AIDS in India. All patients were assured of confidentiality, but it took some days in each hospital before the author was widely accepted as a trustworthy person, (this was particularly true among women respondents), since some patients had been betrayed by journalists and others who had named them, despite promising anonymity. Lack of space in the hospitals made private interviews difficult, and interviews often had to be stopped until staff or relatives had moved away (see

sections 4.3.2, p. 71 and 4.3.4, p. 96 for fuller discussion of ethical and methodological problems). It is not possible to know how much information was withheld or inaccurately supplied due to these conditions. However, comments from patients indicated that the ethical standing of the researcher was accepted, and we are confident that the data are of robust quality.

Above and beyond data collection, the interviews highlighted PLWHA's need to talk about their problems, and was considered by the author as essential to the ethics of interviewing. This meant that many interviews were long (in-depth interviews on average three hours each) and the progress of data collection was correspondingly slowed. Future research on cultural and socio-economic aspects of behaviour change communication and positive prevention would have to allow for extra time at the interview stage.

Methodological problems resulting from standard survey questionnaire are discussed in detail in chapter IV. We have considered Fisher's exact tests where necessary. To improve the power of the test we have considered 1% level of significance where appropriate (section 4.4.1). Maximum likelihood estimates have been used to improve accuracy arising from problems resulting from data censoring. Non-sampling errors from problems with questionnaire were addressed in as far as possible through researcher's knowledge and experience of the region, and socio-cultural understanding of respondents; and by personally conducting all the interviews (section 4.3.3, p. 89).

## 9.2 Research Findings

In general, PLWHA were more knowledgeable about HIV, reported more sources of knowledge dissemination, and more likely to report acceptance of behaviour change messages than the general population, outcomes to be expected given their personal experience of HIV/AIDS (sections 6.1, p. 135; 6.2, p. 149; section 6.3.1, p. 155; section 7.4, p. 212).

In terms of the factors associated with reported sexual behaviour, structural socio-economic (poverty, occupation) and cultural (pressure to marry and have children) factors far outweighed reported biomedical knowledge. There are important gendered aspects of the results that need to be highlighted. The patients surveyed formed a subset of the general population but differed from the average in important ways. A male bias was evident among those seeking treatment for HIV at hospitals, explained by a combination of higher disease prevalence among men relative to women, and men's greater socio-economic accessibility to treatment. Early infection among women (mean age of female patients five years lower than that of male patients) resulted from earlier sexual initiation through marriage and was supported by gender differences between age at marriage and age of husband at marriage. Married women rarely perceived themselves to be at risk of STD and/or HIV infection from their husband. Despite having educational levels comparable to the general population, PLWHA were generally poorer than the general population, suggesting downward social and economic mobility as a result of HIV infection. Women faced greater social disadvantages due to HIV/AIDS.

The nuptiality consequences of HIV revealed by this research were early widowhood and increased rates of separation/divorce. The major differences in marital status between female patients and the general population were due to high widowhood, as 97% of female respondents reported death of a spouse due to AIDS. A third of the male PLWHA surveyed were not married, and ninety-nine per cent of these unmarried HIV positive men reported that they would be under social pressure to marry and have children after the remission of symptomatic illness, with implications for future infections.

As HIV/AIDS patients all of the respondents had heard of the disease, and even though the sample as a whole had very high levels of exposure to biomedical knowledge from various media, the main source of HIV knowledge was reported to



be discussions with peers, members of their communities, other patients at the hospital, and/or friends, for both men and women (79% of women; 80% of men).

Television was reported as an important medium for communicating basic knowledge of HIV/AIDS transmission and prevention, although men were significantly more likely to report knowledge derived from print media. PLWHA reported that prior to testing they were too scared to watch television programs about HIV.

Knowledge of basic modes of transmission via sex and blood was high and a range of factors (age, media exposure, experiential knowledge, and time since diagnosis) were important predictors for knowledge of HIV transmission processes, findings which support conclusions from work elsewhere (Goodwin *et al.* 2003; Ingham 1995; Maticka-Tyndale *et al.* 1994). Knowledge developed through their personal experience of living with HIV infection (referred to here as experiential knowledge) influenced attitudes favourably toward possible behaviour changes. Culturally, experiential knowledge among PLWHA appeared to be enabling the development of less restrictive attitudes. Education was an important predictor of knowledge for women. Urban-rural differences were not apparent, partly attributable to the *peri*-urban nature of the sample, whose characteristics were urban due to their living in suburbs that were still officially classified as rural.

Culture was intricately interwoven in many of the attitudes and behaviours reported by PLWHA. For example, reports of support for HIV testing before marriage were high, although many of the same respondents typically went on to say that it would be difficult to implement. Cultural pressure for a couple to have a child within a year of marriage, can make reproduction more important than the health and well-being of the woman or the child. Married women tended to give priority to their husbands' health and were less likely to seek treatment, with household income and resources likely to be spent on a HIV positive male household head. During the data collection it became apparent, for example, that at least 10 HIV positive wives

of male respondents were staying at the hospital to care for their HIV positive husband, but were not receiving any treatment themselves.

As opposed to popular beliefs that Indian society is monogamous, and chaste before marriage, male respondents reported premarital sex (PMS 80%) and extra marital sex (EMS 49%). In addition, qualitative data describing how and when such behaviours take place indicated established cultural practices that evidenced such behaviour to be widespread (see sections 7.2.4, p. 195 and 7.2.5, p. 198). Sexual transmission was the most frequently reported source of infection. Women reported infection via their husbands, unless they themselves were CSWs.

Given that the consistent use of condoms reduces HIV transmission, it forms the main focus of positive prevention (UNAIDS 1998). It follows that it is extremely important to understand behaviour changes in the context of HIV/AIDS, particularly with reference to condoms, when attempting to design successful prevention strategies. The evidence generated by systematic reviews alone may not provide a clear answer as to whether social interventions shown to be effective in one setting, place or moment in time can be replicated in another (Elford *et al.* 2004). Different settings have different cultural and socio-economic realities, and data collected locally is needed to design and evaluate preventive activities. Hence it was important to study aspects of HIV/AIDS prevention specifically in a south Indian context.

Methodologically the measurement of behaviour change is fraught with problems, as people may validly report changes in their sexual behaviour even though these changes do not amount to safer sexual practices. For instance they may only occasionally abstain from their regular partner or use condoms sporadically. They would be correct in reporting behaviour change but they might not be doing what was required to protect their partners from HIV infection or themselves from co-infections.

This research examined reported behaviour changes with a positive prevention focus with particular reference to condoms. The quantitative and qualitative data both highlighted the confusion that can accompany new knowledge and the gaps between what is 'known' and what is deemed relevant to behaviour change (InternationalHIV/AIDSAlliance 2003; McFarland *et al.* 2002; Shoveller and Pietersma 2002; UNPD 2002). These showed that the culture of a community is an important issue in the context of HIV/AIDS prevention, since it can work with or against health prevention messages (Baban *et al.* 2006; Cowley 2003; Khan 2001; Trostle 2005). When international agencies began with a reliance on making the technology available – the male condom - and with little else to offer, they soon became aware of problems in sexual negotiations and social organization, which made the distribution and acceptance of the male condom more difficult than they had expected (Chimbiri 2007; Godbole and Mehendale 2005; IANS 2004; Meekers and Van Rossem 2005).

In our survey, knowledge, attitudes and behaviours were not congruent with regard to condom use. A large majority of PLWHA had heard about condoms (94% of men and 81% of women) (section 6.3.2, p. 158) and their use as a prophylaxis for HIV/AIDS. However, this knowledge did not translate into ever-use of condoms. Only 35% of men (excluding high risk occupation groups) reported ever-use of condoms. Ever-use of condoms with spouse was even lower (20% among men and 4% among women). Consistent condom use was reported, but the qualitative evidence revealed that even the small number of people that reported they used condom use each time did not, in fact, mean every single time they had sex (see section 7.4, p. 212). Eighty two percent of men reported willingness, in theory, to use condoms with casual partners (see Tab. 6.13, p. 162), but none reported regular use with CSWs or other extra marital partners.

Willingness to use condoms with spouse was considerably lower (55% men and 43% women) than with casual partners. Among married respondents, only 9 men

and 3 women reported ever-use of condoms with their spouse after being tested HIV positive and only one HIV positive woman reported consistent condom use with her husband since being tested positive. Societal and individual pressure to have children is another reason for low condom use among couples, which has implications for positive prevention.

Even those who had never used condoms reported perceptions that condoms made sex less enjoyable (67% men and 26% women), were unpleasant to use, were difficult to access easily and were ineffective. The perceived ineffectiveness of condoms was reinforced by high reports of condom breakage. Spontaneous comments on condoms indicated that *nirodh*, the locally produced condom, was widely perceived to tear in use. Overall, 21% of all men (not including those from groups where high-risk behaviours were common) reported that condoms tear/break, which is higher than the failure rate of 15% reported by Sharma (2001). These were based on their own experiential knowledge and what they had heard from discussions with others, was in direct conflict with the biomedical message that condoms prevent HIV/AIDS. Women PLWHA perceived themselves to not be at risk because of their own monogamous behaviour combined with trust in their husbands.

Spontaneous observations by patients indicated that promotion of condom use within marriage was opposed by social pressures and gendered power relations. In a culture where fertility is highly regarded it is difficult for either partner, but especially the woman, to insist on a practice that will prevent procreation, and condom use within marriage was reported to be extremely difficult due to the strong social pressure to have children. There was also the stigma associated with use of condoms, which implied extramarital activity. Wives who were at risk of infection from HIV positive husbands lacked the power to enforce or even suggest condom use, and this powerlessness was reinforced by the cultural attitude that wives should share the fate of their husbands. Condom use outside marriage was more acceptable but no one reported regular use with CSWs or other extra marital partners. In sum,

the PLWHA surveyed here appeared to act on locally constructed information and attitudes with regards to condom use rather than biomedical messaging, a finding reported elsewhere in community-based studies (Lugalla *et al.* 2004; Mansergh *et al.* 2000).

Despite the programmatic importance given to condoms, abstinence was reported as the most common behaviour to reduce the risk of infection. Qualitative data indicated that, as with condom use, it was sporadic unless the respondent was too ill to think about sex. Eighty four percent of patients reported change in sexual behaviour since being tested HIV positive, with 72% of these respondents reporting abstinence with their spouse/regular partner since being tested HIV positive. However, this finding cannot be relied upon. Reported abstinence might indicate an intention to abstain, rather than its practise and was not necessarily consistently practised. Qualitative evidence showed that respondents tended to discount occasional sex with their partners after they had tested positive.

Members of certain occupational groups had very high levels of basic knowledge about HIV/AIDS and knew significantly more people with the disease than members of other occupational groups. These were lorry drivers, construction workers, hotel workers, and CSW's. Some police and armed forces were represented in our survey. These groups too might fall into the high-risk category, further research into HIV/AIDS and security in India would be beneficial in this regard (AIDS-INDIA 2004a). Data from these occupational groups highlighted occupation-specific barriers to behaviour change. Lorry drivers spent long periods away from home and believed that frequent sex was necessary for their health. Construction workers often worked away from home, living on construction sites in a mixed community and had access to sex with colleagues. Hotel workers who lived on site reported sex with other members of staff, (men and boys) and women entertaining guests. CSWs could be divided into FSWs and *hijra* (a third gender who are enumerated in India as women but are usually physiologically male). All FSWs were powerless to use condoms

unless their customers agreed, but *hijra* reported greater ability to negotiate condom use. Even when knowledge levels were high, these groups were still subject to cultural and socio-economic constraints to positive prevention.

In our study reports of condom use were more likely when personal perception of risk was higher. Thomas and colleagues (2004), in a study of condom acceptability among HIV positive and negative urban men in south India, reported reasons for condom use to be protection from AIDS and partner insistence. Patients who knew more sero-positive people were significantly more likely to report changes in behaviour. However they were in a minority and further research is needed to explore the pathways to behaviour change.

The combination of biomedical and experiential knowledge found in these occupational groups exposed to high-risk practices was accompanied by the greatest willingness (though still very limited) to accept voluntary testing for HIV/AIDS (for example 78% of all lorry drivers said that a man should be tested for HIV before marriage) and to reduce unsafe sexual behaviours, (for example, two-thirds of all lorry drivers reported ever use of condoms and 27% reported having used condoms with their spouse) (Box 8.1). These groups were more positively inclined toward behaviour change compared to other PLWHA surveyed because of their greater experience in that they knew of many others who had died of HIV/AIDS and also perceived themselves to be at risk.

### 9.3 Contributions of the study

This study comprises a rare contribution to the knowledge of PLWHA in India. Analyses of knowledge, attitudes, sexual behaviours and practices of PLWHA provide valuable insight into positive prevention in the region. This research contributes to the body of knowledge needed to place behaviour change in context and shows the importance of the shift in dominance of prevention models from earlier biological, technical models to an understanding of the need to place

behaviour change in a socio-economic and cultural context over time for information, education and communication (IEC) and behaviour change communication (BCC) to be successful in India.

The patient survey illustrates the very wide gap between knowledge, attitudes and behaviour change in one region in India. There is no reason to suggest that the results would not be relevant in other geographic locations in India. Our research findings suggest that peers, community and TV were the main sources of HIV knowledge. Overall knowledge was low even though these were a group of PLWHA. Knowledge was higher among groups where high-risk behaviours were common (FSWs, *hijra*, lorry drivers, construction workers and hotel workers). Higher knowledge among high-risk groups was not accompanied by safe sexual practices.

We identified risk sexual behaviours as reported by PLWHA were visiting commercial sex workers, premarital sex, extra marital sex, MSM (were bisexual and married due to social pressure) and low condom use. Lack of female autonomy, low education, limited media exposure, inconsistent condom use, environmental factors (for example, poor quality condoms and poor access to condoms; lack of access to medicines), and stigma and discrimination comprised socio-economic and cultural constraints for behaviour change.

Therefore knowledge on its own cannot greatly influence behaviour change (see also Huber and Schneider 1992). Intervention programs, which are culturally sensitive and support people's experiences, may encourage favourable changes in sexual practices. For example, even if individuals are known to be HIV positive, their families would expect them to get married, and a married couple would be under pressure to produce children within a couple of years of their marriage. Even though lorry drivers reported that they went to be tested for HIV before marriage, they also said that if they tested positive, they could only buy time and found themselves powerless to resist family and social pressure to marry.

Qualitative data discredits BCC model that condoms prevent AIDS in the regional and cultural context of poor quality condoms/nirodh and poor access to supplies. BCC models could be improved when they address cultural, structural and environmental constraints. Further culturally sensitive knowledge that is based on experiential knowledge could be more helpful in enabling behaviour change.

The cultural environment in India is among the more stringent in relation to 'sexual wrongdoings'. Accurate information for all and improved facilities for counselling HIV patients might be helpful in providing support, and most importantly in addressing issues of stigma and discrimination. According to Cowley (2003) attitudes are changing, albeit slowly, and India needs to utilise its existing strengths such as a pharmaceutical industry that is producing cheaper anti-retroviral drugs, a scientific community working on vaccine trials, and a strong network of NGOs in order to avoid a catastrophe.

Studies in Asia and India highlight the importance of programs to reduce stigma in order for HIV prevention programs to be effective (Mawar *et al.* 2005; Reidpath *et al.* 2005). We briefly considered patients' ways of coping with stigma and discrimination (Gerbert *et al.* 1991; Green 1995). Stigma and discrimination against people living with HIV/AIDS has been attributed to ignorance, lack of knowledge, fear, moralistic assumptions of guilt, perceived incurability of HIV/AIDS and denial by government and health officials (Blendon and Donelan 1988; Cole *et al.* 1993; Kegeles *et al.* 1989; UNAIDS 2000). The qualitative data relating to stigma and discrimination in this research revealed that suicide attempts are relatively common, echoing findings elsewhere (Gilmore and Somerville 1994; Rajarethinam 2002; Sherr and Strace 1998).

Our patients' surveyed had received HIV prevention messages but, as might be the case in the general population, they could be perceived as people who had not made the best use of IEC/BCC programmes.



Use of condoms was shown to be problematic, not least because they require partner compliance and the policy implications of these results are far-reaching (Barnett and Whiteside 2006; Hunter 2005; Susser 2001). Firstly, there is a need to address the perceptions of condom unreliability. Secondly, interventions need to target changes in the normative social meanings of the condom as a symbol of non-commitment in relationships. Thirdly, there is a need for information that addresses people as members of families and as members of a relationship, not only as individuals, as units of sexual behaviour change (Huber and Schneider 1992).

Through exploring the correlates of AIDS knowledge among patients surveyed using both quantitative and qualitative methods, it was evident that there existed gaps between knowledge and safe sexual practices governed not only by cultural issues but also by wider social and economic structures. The conclusion from this research is that a more comprehensive model for IEC/BCC must start from the knowledge that any efforts to inculcate biomedical knowledge will fail unless the widely perceived problems of quality and access to condoms are overcome, and local socio-economic and cultural limitations are incorporated into the health prevention message. Thus the need is for more socially situated health prevention campaigns and more understanding of how to fit health messages to people's attitudes. This has echoes of a shift in the dominant model of HIV/AIDS prevention from biomedical to a more social approach that might result in the beginnings of a culture of safer sex.

## 9.4 Recommendations for future work on HIV/AIDS prevention

The most recent UNAIDS (2006) report suggests that access to existing prevention strategies could avert an estimated 28 million new infections by 2015. Infections could be further prevented by the introduction of new prevention strategies currently under development, including: topical microbicides; new treatments for other sexually transmitted diseases; male circumcision; female diaphragms; and a

preventive vaccine. Expanded access to prevention is also critical for sustaining the important progress being made in providing antiretroviral therapy to people living with HIV. As HIV prevention programs are scaled up, it is essential that they make use of the full range of available prevention options, and that prevention programs are closely integrated with treatment services. Additionally understanding environmental constraints, e.g. lack of access to treatment, are invaluable if interventions are to be successful.

There is a need to increase research and accelerate the development of new technologies for HIV prevention (Gayle 2006). Research and data that embraces social relationships from a broader perspective by logically addressing the cultural, environmental and structural factors which directly or indirectly influence the dynamics of the AIDS epidemics and of the societal responses to it, would provide valuable input for socio-culturally relevant IEC/BCC interventions (Booyesen and Arntz 2003). Perret (2000) suggests converging attention of different theoretical approaches resulting in a more holistic study of HIV/AIDS, and argues for taking into account that individual preferences are relational, social and endogenous to interactions with others and the global social environment. The range of attitudes, behaviours and relevant cultural and socioeconomic factors among patients surveyed was found to be wide and additional research would undoubtedly discover greater complexity in the model.

In India, the scope remains for more socio-economic and cultural impact studies related to HIV/AIDS to be conducted. The numbers in our survey were limited and additional research would be beneficial to understand the complexity of lack of condom use and other behaviour change issues related to HIV prevention in the region. Also more research pertaining to issues of culturally sensitive experiential knowledge would provide additional value to our findings.

Speakers at the 16th international AIDS conference in Toronto claimed that until women take control of HIV prevention, it will be impossible to halt the global spread

of HIV/AIDS (Clark 2006). Scholes and colleagues (2003) in a tailored minimal self help intervention to promote condom use among young women in the US showed that condom use had increased. Participants in this study had been given computer-generated self help magazine, individually tailored items including stage of readiness to use condoms, partner type, barriers to condom use, condom sample and a condom carrying case. Elford and colleagues (2004) determine the potential for using the internet for HIV prevention in a study of London gay men recruited and interviewed both online and offline. Such schemes may not easily be transferable to resource-poor countries such as India (Williams *et al.* 2006). However, it might be possible to develop tailor made programs suitable to specific target groups. The Government of India has a commitment to e-governance, with a goal of internet access in each of 600,000 villages (Anand 2002; Hermida Alfred 2002), and this medium might be used for communicating risk reduction strategies.

Even if people have relevant knowledge about condoms, they may not have the incentive or the power to change their behaviour, due to socio-economic and cultural factors (O'Neil *et al.* 2004). This is particularly so for women, and lack of autonomy in the use of condoms was evident among FSWs (Jana *et al.* 2002; Kamya *et al.* 1997). Collecting survey data on the number of sex acts and the number of condoms used in a fixed time period may enable the calculation of more reliable estimates of the number of sex acts and condoms used (Meekers and Van Rossem 2005).

Individualized interventions are recommended to increase both knowledge of how to use condoms and self-efficacy for condom use among men and women at risk of acquiring HIV (Agha *et al.* 2001; Lindberg 2000; Roth *et al.* 2001). Godbole and Mehendale (2005) recommend a multi-disciplinary approach combining targeted interventions like early identification and treatment of STDs, condom promotion, blood safety, drug de-addiction programs and expanding and strengthening VCTCs combined with broader development strategies.

Condoms have been distributed through the family welfare programme in India since 1970s but the challenge currently faced by National AIDS Control Organisation (NACO) is to promote condoms as dual use for contraception and disease prevention. However the condoms being supplied were reported as perceived to be not suitable for HIV prevention, due to their lack of size differences, making them uncomfortable, lack of lubrication, and high breakage rate. This is another area of challenge for NACO. The successful promotion of condoms will be influenced by the quality of condoms that are distributed (Garside 1999; Smith *et al.* 1999).

According to the latest National Family Health Survey (NFHS) (2007), two-thirds of married women reported that they did not know that condoms could prevent HIV infection. Only 80% of men and 57% of women have ever heard of AIDS. Further, only 68% of men and 35% of women know that consistent condom use can reduce the chances of getting HIV. A report suggests that the cases of HIV positive wives, where husbands were negative was increasing (AIDS-INDIA 2007b). These results underscore the need for targeted IEC/BCC in India. Political commitment is key for HIV/AIDS prevention programs and promoting condoms use (Sethi 2002). However, attempts to publicly create awareness of condoms for HIV prevention in India have regularly met with opposition (Correspondent 2003; Farooq 2002). In India there is a need at the highest political level to deal with HIV/AIDS multi-sectorally.

For HIV/AIDS prevention messages to be successful socio-economic and cultural factors must be taken into account (Gupta and Panda 2002). If sexual behaviour is to change, much more information is needed on cultural and socio-economic barriers to change (Pickett 2003). This study goes some way to addressing gaps in knowledge about the socio-cultural context of HIV/AIDS transmission in India. India is a diverse country with varied agendas. While some Indian villages are forcing couples to be tested for HIV before marriage (AIDS-INDIA 2007a), some Indian states ban sex education in schools (Chadha 2007) and a case of HIV patient setting an AIDS

counsellor on fire was reported from another state (AIDS-INDIA 2007c). Thus there is a need for greater regional and culturally sensitive research for developing a greater understanding of HIV prevention in India (Tricoles 2007).

Recent research indicates increasing prevalence levels in rural India could be attributed to data becoming available (Dandona, L. *et al.* 2006; Rogers *et al.* 2006). In this study the official rural-urban boundary has not kept pace with the development of the city of Chennai, so many *peri*-urban areas were still classified as rural. Future research would need to take into account the rapidly expanding influence of India's urban and peri-urban areas, regardless of official demarcation of what is urban and what is rural.

Salomon and colleagues (2005) used an epidemiological model of HIV/AIDS, calibrated to sub-Saharan Africa, to investigate a range of possible positive and negative health outcomes under alternative scenarios that reflect varying implementation of prevention and treatment. Their analyses demonstrate the importance of integrating expanded treatment and care activities with prevention activities if there are to be long-term reductions in the number of new HIV infections and significant declines in AIDS mortality. Treatment can enable more effective prevention, and prevention makes treatment affordable. Sustained progress in the global fight against HIV/AIDS will be attained only through a comprehensive response.

There is an unmet need for HIV treatment in India. Cipla, an Indian pharmaceutical company, is a major supplier of low-cost generic antiretroviral drugs, and exports 18 times as many antiretroviral drugs as it sells domestically, in part because retail drug prices are high in India. Thus controlling HIV/AIDS in India, with over one billion vastly heterogeneous population and social and cultural difference, comprises a major challenge (Tricoles 2007). The dynamic economic growth being experienced in India, benefiting from its young population, might

struggle owing to the socio-economic and demographic consequences of HIV/AIDS among the sexually active age group.

It may be some years until a vaccine against HIV/AIDS becomes available and affordable by the majority of people (Calarota and Weiner 2003). Only 7% of people who need antiretroviral (ARV) treatment in developing countries have access to ARVs (UNAIDS 2004). And only one in ten pregnant women were offered services for preventing mother-to-child transmission in 2003. Out of pocket expenses, evidence from UNDP India, that district level free ARV being used less than locally available private ARV because of the transport and opportunity costs. Booyesen and Arntz (2003) in their review of studies on the socio-economic impact of HIV/AIDS shows that diversity in methodological design, which often is a result of practical considerations and resource constraints rather than of poor design, is the norm. Scope remains for more impact studies to be conducted in developing countries in general and in certain high prevalence countries such as India in particular.

The challenges to HIV control in India includes increasing the number of patients receiving treatment, making additional antiretroviral medications available, improving the monitoring of therapy, training physicians and other health care workers, caring for patients with tuberculosis co-infection and reducing stigma and discrimination (Steinbrook 2007).

# Bibliography

Abhijit, B. (2004) 'More Indians are living on HIV than dying of it', *British Medical Journal*, vol. 328.

Abraham, S., Prasad, J., Joseph, A. and Jacob, K. S. (2000) 'Confidentiality, partner notification and HIV infection: issues related to community health programmes', *Natl Med J India*, vol. 13, 4, pp. 207-211.

Agha, S., Karlyn, A. and Meekers, D. (2001) 'The promotion of condom use in non-regular sexual partnerships in urban Mozambique', *Health Policy and Planning*, vol. 16, 2, pp. 144-151.

Agoramoorthy, G. and Hsu, M. J. (2006) 'Keeping the promise in stopping HIV/AIDS: can India succeed?' *Indian J Med Res*, vol. 123, 6, pp. 830-832.

Aguilera, S. and Plasencia, A. V. (2005) 'Culturally appropriate HIV/AIDS and substance abuse prevention programs for urban Native youth', *J Psychoactive Drugs*, vol. 37, 3, pp. 299-304.

Ahmed, S. I. (1992) *Truck Drivers as a vulnerable group in North East India*, The Second International Congress on AIDS in Asia and the Pacific, New Delhi, India.

AIDS-INDIA (2002) *Sex on the move: 'Mobile' brothels a huge hit in Chennai*, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/1517>.

AIDS-INDIA (2003a) *Andhra Pradesh: HIV positive patient ends life at hospital*, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/2976>.

AIDS-INDIA (2003b) *Tata Steels to offer its facilities for HIV/AIDS programmes*, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/3011>.

AIDS-INDIA (2004a) *450 Bombay police test positive for HIV*, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/3080>.

AIDS-INDIA (2004b) *ARV Drug Procurement: Letter to Minister of Health and Family Welfare*, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/3611>.

AIDS-INDIA (2004c) *AIDS has struck the hardest in India's villages*, AIDS-India Yahoo Group, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/4121>.

AIDS-INDIA (2004d) *Disparity in ARV distribution*, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/3484>.

AIDS-INDIA (2007a) *Indian village forces couples to take HIV tests*, AIDS-INDIA Yahoo Groups, Available at: [AIDS-INDIA@yahoogroups.com](mailto:AIDS-INDIA@yahoogroups.com).

AIDS-INDIA (2007b) *Cases of HIV+ wives rising*, AIDS-INDIA Yahoo Groups, Available at: [AIDS-INDIA@yahoogroups.com](mailto:AIDS-INDIA@yahoogroups.com).

AIDS-INDIA (2007c) *Patient sets AIDS counsellor on fire in Jabalpur*, AIDS-INDIA Yahoo Groups, Available at: [AIDS-INDIA@yahoogroups.com](mailto:AIDS-INDIA@yahoogroups.com).

Amin, A. (2004) *Risk, Mortality, and Blame: A Critical Analysis of Government and US Donor Responses to HIV infections among sex workers in India*, Center for Health and Gender Equity (CHANGE).

Ammann, A. J. and Nogueira, S. (2002) 'Governments as facilitators or obstacles in the HIV epidemic - If governments do not act the epidemic will spread relentlessly', *British Medical Journal*, vol. 7331.

Amuyunzu-Nyamongo, M., Tendo-Wambua, L., Babishangire, B., Nyagero, J., Yitbarek, N., M Matasha and Omurwa, T. (1999) 'Barriers to behaviour change as a response to STD including HIV/AIDS: the East African



experience', *Resistances to Behavioural Change to Reduce HIV/AIDS Infections*, pp. 1-11.

Anand, C. (2002) *Rural India On-line*, (e-journal), <http://in3.org/articles/IIT.htm>.

Anand, K., Pandav, C. S. and Nath, L. M. (1999) 'Impact of HIV/AIDS on the national economy of India', *Health Policy and Planning*, vol. 47, pp. 195-205.

Ananth, P. and Koopman, C. (2003) 'HIV/AIDS knowledge, beliefs, and behavior among women of childbearing age in India', *AIDS Educ Prev*, vol. 15, 6, pp. 529-546.

Anderson, R. M. (1992) 'Some Aspects of Sexual Behaviour and the Potential Demographic Impact of AIDS in Developing Countries', *Social Science & Medicine*, vol. 34, 3, pp. 271-280.

Anderson, R. M., Ray, R. M., Boily, M. C., Garnett, G. P. and Rowley, J. T. (1991) 'The spread of HIV-1 in Africa: sexual contact patterns and the predicted demographic impact of AIDS', *Nature*, vol. 352, pp. 581-589.

APAC (1996) *HIV Risk Behaviour Sentinel Surveillance Survey in Tamil Nadu*, AIDS Prevention and Control unit of the Voluntary Health Services, Chennai, India.

APAC (2001) *HIV Risk Behaviour Surveillance Survey in Tamil Nadu*, VHS/USAID, Chennai, p. 56.

Asiimwe-Okiror, G., Opio, A. A., Musinguzi, J., Madraa, E., Tembo, G. and Crael, M. (1997) 'Change in sexual behaviour and decline in HIV infection among young pregnant women in urban Uganda', *AIDS*, vol. 11, 14, pp. 1757-1763.

Asthana, S. and Oostvogels, R. (1996) 'Community participation in HIV prevention: Problems and prospects for community-based strategies among sex workers in Madras', *Social Science and Medicine*, vol. 43, 2, pp. 133-148.

Asthana, S. and Oostvogels, R. (2001) 'The social construction of male 'homosexuality' in India: implications for HIV transmission and prevention', *Soc Sci Med*, vol. 52, 5, pp. 707-721.

- Auerbach, J. D. (1998) 'The Role of Behavioural Research in HIV/AIDS Prevention', *Current Opinion in Infectious Diseases*, vol. 11, pp. 3-7.
- Baban, K., Ikeda, S., Pooran, D., Hennig, N., Indyk, D., Sacks, H. and Carter, G. (2006) 'Culture, community networks, and HIV/AIDS outreach opportunities in a south Indian Siddha organization', *Soc Work Health Care*, vol. 42, 3-4, pp. 77-92.
- Babu, P. G., Saraswathi, N. K., Devapriya, F. and John, J. T. (1993) 'The detection of HIV-2 infection in southern India', *AIDS*, vol. 7, pp. 421-423.
- Bajos, N. and Marquet, J. (2000) 'Research on HIV sexual risk: social relations-based approach in a cross-cultural perspective', *Social Science and Medicine*, vol. 50, 11, pp. 1533-1546.
- Balk, D. and Lahiri, S. (1997) 'Awareness and knowledge of AIDS among Indian women: evidence from 13 states', *Health Transition Review*, Supplement to Volume 7, pp. 421-465.
- Bansal, I., Kaushal and Aggarwal (2001) 'Malignancy in AIDS: institutional management or home care?' *Indian J Med Sci*, vol. 55, 3, pp. 159-164.
- Barnett, T. and Whiteside, A. (2002) *AIDS in the Twenty-First Century - Disease and Globalization*, Palgrave Macmillan, Great Britain.
- Barnett, T. and Whiteside, A. (2006) *AIDS in the Twenty-First Century: Disease and Globalisation*, Palgrave Macmillan Great Britain.
- Barnett, T., Whiteside, A. and Desmond, C. (2001) 'The social and economic impact of HIV/AIDS in poor countries: a review of studies and lessons', *Progress in Development Studies*, vol. 1, 2, pp. 151-170.
- Bartholomew, D. J. (2002) *The analysis and interpretation of multivariate data for social scientists*, Chapman & Hall/CRC, Boca Raton, Florida ; London.
- Bartholomew, D. J. and Knott, M. (1999) *Latent Variable Models and Factor Analysis*, Arnold, London.

- Basu, A. M. and Aaby, P. (1998) *Introduction: Approaches to Anthropological Demography*, The Methods and Uses of Anthropological Demography, Oxford University Press Inc., New York.
- Bauer, M. and Joffe, H. (1996) 'Meanings of self-attributed ignorance: an introduction to the Symposium', *Social Science Information*, vol. 35, 1, pp. 5-13.
- BBC (2003) *South Asia AIDS warning*, British Broadcasting Corporation, Available at: [http://news.bbc.co.uk/1/hi/world/south\\_asia/2726373.stm](http://news.bbc.co.uk/1/hi/world/south_asia/2726373.stm).
- Berer, M. and Ray, S. (1993) *Women and HIV/AIDS*, Pandora Press of Harper Collins, London.
- Bery, S. (2006) *Socio-Economic Impact of HIV/AIDS on Households: A Study of Six High Prevalence States of India*, National Council of Applied Economic Research, (Presentation at CII Workshop).
- Bharat, S. and Aggleton, P. (1999) 'Facing the challenge: household responses to HIV/AIDS in Mumbai, India', *AIDS Care*, vol. 11, 1, pp. 31-44.
- Bharat, S. and Aggleton, P. (2002) 'Community Responses to HIV/AIDS in Mumbai City', in *Living with the AIDS virus: The Epidemic and the response in India*, ed. A. C. Samiran Panda, Abu S Abdul-Quader, Sage, New Delhi.
- Bhattacharjee, J., Gupta, R. S., Kumar, A. and C, J. D. (2000) 'Pre-and extra-marital heterosexual behaviour of an urban community in Rajasthan, India', *Journal of Communicable Diseases*, vol. 32, 1, pp. 33-39.
- Bhattacharjee, J., Gupta, R. S., Kumar, A. and Jain, D. C. (2000) 'Pre- and extra-marital heterosexual behaviour of an urban community in Rajasthan, India', *J Commun Dis*, vol. 32, 1, pp. 33-39.
- Bhave, G., Lindan, C. P., Hudes, E. S., Desai, S., Wagle, U., Tripathi, S. P. and Mandel, J. S. (1995) 'Impact of an Intervention on HIV, sexually transmitted diseases, and condom use among sex workers in Bombay, India', *AIDS*, vol. 9, Suppl 1, pp. S21-S30.

Bhushan, B. (2003) *Bill heads to Delhi, for AIDS and Atal*, Available at: [http://www.telegraphindia.com/1031118/asp/nation/story\\_2584283.asp](http://www.telegraphindia.com/1031118/asp/nation/story_2584283.asp).

Blacker and Brass (1993) 'Chapter XVI', in *Social Research in Developing Countries: Surveys and Censuses in the Third World*, eds M. Bulmer and D. P. Warwick, p. 383, UCL Press, London.

Blendon, R. J. and Donelan, K. (1988) 'Discrimination against people with AIDS', *American Journal of Public Health*, vol. 319, pp. 1022-1026.

Booyesen, F. I. R. and Arntz, T. (2003) 'The methodology of HIV/AIDS impact studies: a review of current practices', *Social Science & Medicine*, vol. 56, 12, pp. 2391-2405.

Brenny, P. J. (1998) International Efforts Counter HIV Infection in India, paper presented to Symposium on AIDS in India, Pune, India, Harvard AIDS Institute.

Brummelhuis, H., ten and Herdt, G. (1995) *Culture and sexual risk: anthropological perspectives on AIDS*, Gordon and Breach, Amsterdam.

Bulmer, M. and Warwick, D. P. (eds) (1993) *Social Research in Developing Countries: Surveys and Censuses in the Third World*, UCL Press, London.

Burton, A., Thierry, E. and Lal, S. (1995) 'Estimation of Adult HIV Prevalence as of the end of 1994 in India', *Indian Journal of Public Health*, vol. 39, pp. 79-85.

Calarota, S. A. and Weiner, D. B. (2003) 'Present status of human HIV vaccine development', *AIDS*, vol. 17, Suppl 4, pp. S73-S84.

Caldwell, J., Orubuloye, I. O. and Caldwell, P. (1998) 'Methodological Advances in Studying the Social Context of AIDS in West Africa', in *The Methods and Uses of Anthropological Demography*, eds A. M. Basu and P. Aaby, pp. 22-38, Oxford University Press Inc., New York.

Caldwell, J. C., Caldwell, P., Amarfi, J., Awusabo-Asare, K., Ntozi, J., Orubuloye, I. O., Marck, J., Cosford, W., Colombo, R. and Hollings, E. (1999a) 'Resistance to Behavioural Change to reduce HIV/AIDS Infection in Predominantly Heterosexual Epidemics in Third World Countries', *Health Transition Centre*.

Camara, B. (2006) *The Third Generation HIV/AIDS/STI Surveillance: A summary presentation of guidelines*, WHO, Available at: [http://www.who.int/hiv/strategic/surveillance/en/pres\\_paho.pdf](http://www.who.int/hiv/strategic/surveillance/en/pres_paho.pdf).

Campbell, C. (2003) *African Issues: 'Letting them Die' Why HIV/AIDS Prevention Programmes Fail*, The International African Institute in association with James Currey, Cape Town edn, Indiana University Press, Bloomington and Indianapolis.

Carael, M. (1995) 'Sexual Behaviour', in *Sexual Behaviour and AIDS in the Developing World*, eds J. Cleland and B. Ferry, Social Aspects of AIDS, pp. 75-123, Taylor and Francis, London.

Carey, J. (1993) 'Linking qualitative and quantitative methods: integrating cultural factors into public health', *Qualitative Health Res*, vol. 3, 3, pp. 298-318.

Caron-Flinterman, J. F., Broerse, J. E. and Bunders, J. F. (2005) 'The experiential knowledge of patients: a new resource for biomedical research?' *Soc Sci Med*, vol. 60, 11, pp. 2575-2584.

CensusIndiaTN (2002) *Population estimates, TN*, Available at: [http://www.censusindia.net/cendata1/show\\_data52.php3?j=120&j2=1&j1=33&j3=Tamil%20Nadu](http://www.censusindia.net/cendata1/show_data52.php3?j=120&j2=1&j1=33&j3=Tamil%20Nadu).

Chadha, M. (2007) 'Indian state bans sex education', *BBC News*, p. 2.

Chakraborty, A. K., Jana, S., Das, A., Khodakevich, L., Chakraborty, M. S. and Pal, N. K. (1994) 'Community Based Survey of STD/HIV Infection Among Commercial Sex Workers in Calcutta (India): Part I - Some Social Features of Commercial Sex Workers', *Journal of Communicable Diseases*, vol. 26, 3, pp. 161-167.

Chan R, Khoo, L., Goh, C. L. and Lam, M. S. (1997) 'A knowledge, attitudes, beliefs and practices (KABP) survey on HIV infection and AIDS among doctors and dental surgeons in Singapore', *Ann Acad Med Singapore*, vol. 26, 5, pp. 581-587.

- Chandrasekaran, P., Dallabetta, G., Loo, V., Rao, S., Gayle, H. and Alexander, A. (2006) 'Containing HIV/AIDS in India: the unfinished agenda', *Lancet Infect Dis*, vol. 6, 8, pp. 508-521.
- Chatterjee, A. and Sahgal, K. (2002) 'HIV/AIDS Awareness and Control: The Role of Non-governmental Organisations in the Country', in *Living with the AIDS Virus: the Epidemic and the Response in India*, ed. A. C. Samiran Panda, Abu S Abdul-Quader, Sage, New Delhi.
- Chatterjee, N. (1999) 'AIDS-related information exposure in the mass media and discussion within social networks among married women in Bombay, India', *AIDS Care*, vol. 11, 4, pp. 443-446.
- Chatterjee, N. and Hosain, G. M. (2006) 'Perceptions of risk and behaviour change for prevention of HIV among married women in Mumbai, India', *J Health Popul Nutr*, vol. 24, 1, pp. 81-88.
- Chattopadhyay, A. and McKaig, R. G. (2004) 'Social development of commercial sex workers in India: an essential step in HIV/AIDS prevention', *AIDS Patient Care STDS*, vol. 18, 3, pp. 159-168.
- Chimbiri, A. M. (2007) 'The condom is an 'intruder' in marriage: Evidence from rural Malawi', *Soc Sci Med*, vol. 64, 5, pp. 1102-1115.
- Clark, J. (2006) 'Women must take control of HIV prevention to curb spread of infection', *BMJ*, vol. 333, 370, p. 1136.
- Cleland, J. (1995) 'Risk Perception and Behavioural Change', in *Sexual Behaviour and AIDS in the Developing World*, eds J. Cleland and B. Ferry, Social Aspects of AIDS, pp. 157-192, Taylor and Francis for WHO.
- Cleland, J., Ferry, B. and Crael, M. (1995a) 'Summary and Conclusions', in *Sexual Behaviour and AIDS in the Developing World*, eds J. Cleland and B. Ferry, Social Aspects of AIDS, pp. 208-228.
- CMC (2002) *HIV/AIDS Training Course for Hospital Based Physicians*, Available at: [http://cmch-vellore.edu/HIV\\_AIDS.htm](http://cmch-vellore.edu/HIV_AIDS.htm).

CMC (2003) *The Official Guide*, Available at: <http://cmch-vellore.edu/guide/guide2002.pdf>.

Cohen, J. (2004) 'HIV/AIDS in India. Sonagachi sex workers stymie HIV', *Science*, vol. 304, 5670, p. 506.

Cole, B. L., Zhang, Z. and Chen, C. Z. (1993) 'HIV-related knowledge and attitudes among medical students in China', *AIDS Care*, vol. 5, 3, pp. 305-312.

Collumbien, M. and Das, B. (2004) 'Sexual risk behaviour and condom use in Orissa', in *Sexuality in the time of AIDS*, eds Verma Ravi K, P. Pelto and S. Schensul.

Cornman, D. H., Schmiede, S. J., Bryan, A., Joseph Benziger, T. and Fisher, J. D. (2007) 'An information-motivation-behavioral skills (IMB) model-based HIV prevention intervention for truck drivers in India', *Soc Sci Med*.

Correa, M. and Gisselquist, D. (2006) 'Routes of HIV transmission in India: assessing the reliability of information from AIDS case surveillance', *Int J STD AIDS*, vol. 17, 11, pp. 731-735.

Correspondent (2003) 'AIDS campaign not to be condom-centric: Sushma', *Express News Service*, 31 Jan.

Cowley, G. (2003) 'AIDS in India, a Culture Shock', *New Scientist*, vol. 177, 2379, p. 42.

Dandona, L., Lakshmi, V., Kumar, G. A. and Dandona, R. (2006) 'Is the HIV burden in India being overestimated?' *BMC Public Health*, vol. 6, p. 308.

Dandona, L., Sivan, Y. S., Jyothi, M. N., Bhaskar, V. S. and Dandona, R. (2004) 'The lack of public health research output from India', *BMC Public Health*, vol. 4, p. 55.

Dandona, L., Lakshmi, V., Sudha, T., Kumar, G. A. and Dandona, R. (2006) 'A population-based study of human immunodeficiency virus in south India reveals major differences from sentinel surveillance-based estimates', *BMC Med*, vol. 4, p. 31.

Dandona, R., Dandona, L., Kumar, G. A., Gutierrez, J. P., McPherson, S. and Bertozzi, S. M. (2005a) 'HIV testing among female sex workers in Andhra Pradesh, India', *AIDS*, vol. 19, 17, pp. 2033-2036.

Dandona, R., Dandona, L., Gutierrez, J. P., Kumar, A. G., McPherson, S., Samuels, F. and Bertozzi, S. M. (2005b) 'High risk of HIV in non-brothel based female sex workers in India', *BMC Public Health*, vol. 5, p. 87.

Dandona, R., Dandona, L., Kumar, G. A., Gutierrez, J. P., McPherson, S., Samuels, F. and Bertozzi, S. M. (2006) 'Demography and sex work characteristics of female sex workers in India', *BMC Int Health Hum Rights*, vol. 6, p. 5.

Dare, O. O. and Cleland, J. G. (1994) 'Reliability and validity of survey data on sexual behaviour', *Health Transition Review*, vol. 4, Suppl, pp. 93-110.

Dasgupta, P. R., Jain, M. K. and John, T. J. (1994) 'Government response to HIV/AIDS in India', *AIDS*, vol. 8 Suppl 2, pp. S83-90.

De Vaus, D. (2002) *Surveys in Social Research*, Routledge, London.

Deutsche-Press-Agentur (2002) *Chronic Condom Shortage Could Trigger AIDS in Indian Brothels*, Center for Disease Control & Prevention News Updates, Available at: [http://www.thebody.com/cdc/news\\_updates\\_archive/aug7\\_02/india\\_condoms.html](http://www.thebody.com/cdc/news_updates_archive/aug7_02/india_condoms.html).

DFID-India (2004) *UK Minister Launches UKs new global AIDS Strategy in India*, Department for International Development, Available at: [http://www.dfidindia.org/news/news/2004/2004\\_10\\_05.htm](http://www.dfidindia.org/news/news/2004/2004_10_05.htm).

Divekar, A. A. and Gogate, A. S., Shivkar, L.K., Gogate, S. and Badhwar, V.R. (2000) 'Disease prevalence in women attending the STD clinic in Mumbai, India', *International Journal of STD & AIDS*, vol. 11, 1, pp. 45-48.

Earickson, R. J. (1990) 'International behavioral responses to a health hazard: AIDS', *Social Science & Medicine*, vol. 31, 9, pp. 951-962.

Ekklesia (2007) 'Indian churches praised for role in HIV-AIDS struggle', *Ecumenical News International*, April 2007.



Elamon, J. (2005) 'A situational analysis of HIV/AIDS-related discrimination in Kerala, India', *AIDS Care*, vol. 17 Suppl 2, pp. S141-151.

Elford, J. and Bor, R. (1998) *The family and HIV today: recent research and practice*, Cassell, London.

Elford, J. and Hart, G. (2003) 'If HIV prevention works, why are rates of high-risk sexual behaviour increasing among MSM?' *AIDS Education Prevention*, vol. 15, 4, pp. 294-308.

Elford, J., Sherr, L., Bolding, G. and Maguire, M. (1999) 'Sexual risk behaviour among gay men in a relationship', *AIDS*, vol. 13, pp. 1407-1411.

Elford, J., Bolding, G., Davis, M., Sherr, L. and Hart, G. (2004) 'Trends in sexual behaviour among London homosexual men 1998-2003: implications for HIV prevention and sexual health promotion', *Sex Transm Infect*, vol. 80, 6, pp. 451-454.

Elliot, E. (1998) 'Changes in Mortality in Mumbai: Monitoring Mortality to Analyse the Spread of HIV', in *The Looming Epidemic: The Impact of HIV & AIDS in India*, ed. P. Godwin, pp. 62-93, Hurst & Company, London.

Farmer, P. (1999) *Infections and inequalities. The modern plagues*, University of California Press, Berkeley.

Farooq, O. (2002) *Condom uproar in India assembly*, BBC, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/1955>.

FHI (2000) *Behaviour Surveillance Surveys*, Family Health International/Impact/UNIADS/DIFD, NC, p. 350.

Fishbein, M. (2000) 'The role of theory in HIV prevention', *AIDSCare*, vol. 12, 3, pp. 273-278.

Foley, M. E., Fahs M C and Eisenhandler J, e. a. (1995) 'Satisfaction with home healthcare services for clients with HIV: preliminary findings', *J Assoc Nurses in AIDS Care*, vol. 6, pp. 20-25.

- Ford, N. and Koetsawang, S. (1991) 'The socio-cultural context of the transmission of HIV in Thailand', *Social Science & Medicine*, vol. 33, 4, pp. 405-414.
- Frezieres, R. G., Walsh, T. L., Nelson, A. L., Clark, V. A. and Coulson, A. H. (1998) 'Breakage and Acceptability of a Polyurethane Condom: A Randomized, Controlled Study', *Family Planning Perspectives*, vol. 30, pp. 73-78.
- Gagné, R. M. (1985) *The conditions of learning and theory of instruction*, vol. xv, 4th edn, Holt, Rinehart, and Winston, New York.
- Gangakhedkar, R. R., Bentley, M. E., Divekar, A. D., Gadkari, D., Mehendale, S. M., Shepherd, M. E., Bollinger, R. C. and Quinn, T. C. (1997) 'Spread of HIV Infection in Married Monogamous Women in India', *Journal of American Medical Association*, vol. 278, Dec 17, pp. 2090-2092.
- Garnett, G. P. and Anderson, R. M. (1993) 'No reason for complacency about the potential demographic impact of AIDS in Africa', *Transactions of the Royal Society of Tropical Medicine and Hygiene*, vol. 87.
- Garside, R. (1999) 'Condom shape: a neglected factor influencing use and acceptability', *International Journal of STD & AIDS*, vol. 10, 12, pp. 785-790.
- Gausset, Q. (2002) *A plague of paradoxes. Aids, culture, and demography in Northern Tanzania*, The University of Chicago Press, Chicago.
- Gayle, H. (2006) 'Expanding access to HIV prevention', *AIDS Research and Therapy*, vol. 3, 1, p. 2.
- George, S., Jacob, M., John, T. J., Jain, M. K., Nathan, N., Rao, P. S. S., Richard, J. and Antonisamy, B. (1997) 'A Case-Control Analysis of Risk Factors in HIV Transmission in South India', *Journal of Acquired Immune Deficiency Syndrome and Human Retrovirology*, vol. 14, pp. 290-293.
- Gerbert, B., Sumser, J. and Maguire, B. T. (1991) 'The impact of who you know and where you live on opinions about aids and health care', *Social Science & Medicine*, vol. 32, 6, pp. 677-681.

GHTM (2003) *Historical Background*, Government Hospital for Thoracic Medicine, Available at: <http://education.vsnl.com/thoracic/brief.html>.

GHTM (2006) *HIV statistics*, Available at: [http://education.vsnl.com/thoracic/hiv\\_stats.htm](http://education.vsnl.com/thoracic/hiv_stats.htm).

Gibney, L., Saquib, N. and Metzger, J. (2003) 'Behavioral risk factors for STD/HIV transmission in Bangladesh's trucking industry', *Social Science & Medicine*, vol. 56, 7, pp. 1411-1424.

Gibney, L., Choudhury, P., Khawaja, Z., Sarker, M. and Vermund, S. H. (1999) 'Behavioural risk factors for HIV/AIDS in a low-HIV prevalence Muslim nation: Bangladesh', *Int J STD AIDS*, vol. 10, 3, pp. 186-194.

Giffin, K. (1998) 'Beyond empowerment: Heterosexualities and the prevention of AIDS', *Social Science & Medicine*, vol. 46, 2, pp. 151-156.

Gilmore, N. and Somerville, M. A. (1994) 'Stigmatization, scapegoating and discrimination in sexually transmitted diseases, overcoming 'them' and 'us'', *Social Science and Medicine*, vol. 39, pp. 1339-1358.

Godbole, S. and Mehendale, S. (2005) 'HIV/AIDS epidemic in India: risk factors, risk behaviour & strategies for prevention & control', *Indian J Med Res*, vol. 121, 4, pp. 356-368.

Godwin, P. (1998) *The Looming Epidemic: The Impact of HIV & AIDS in India*, Hurst & Company, London.

Goodwin, R., Alexandra Kozlovab, Anna Kwiatkowskac, Lan Anh Nguyen Luud, George Nizharadzee, Anu Realof and Rämmerf, A. K. a. A. (2003) 'Social representations of HIV/AIDS in Central and Eastern Europe', *Social Science & Medicine*, vol. 56, 7, pp. 1373-1384.

Green, G. (1995) 'Attitudes towards people with HIV: Are they as stigmatizing as people with HIV perceive them to be?' *Social Science & Medicine*, vol. 41, 4, pp. 557-568.

Green, J. and Thorogood, N. (1998) *Analysing Health Policy - A Sociological Approach*, Longman, London & NY.

Gregson, S. (1996) The Early Socio-Demographic Impact of the HIV-1 Epidemic in Rural Zimbabwe, PhD thesis, University of London.

Gupta, A., Mehta, S., Godbole, S. V., Sahay, S., Walshe, L., Reynolds, S. J., Ghate, M., Gangakhedkar, R. R., Divekar, A. D., Risbud, A. R., Mehendale, S. M. and Bollinger, R. C. (2006) 'Same-sex behavior and high rates of HIV among men attending sexually transmitted infection clinics in Pune, India (1993-2002)', *J Acquir Immune Defic Syndr*, vol. 43, 4, pp. 483-490.

Gupta, I. and Panda, S. (2002) 'The HIV/AIDS Epidemic in India: Looking Ahead', in *Living with the AIDS Virus: The Epidemic and the response in India*, ed. A. C. Samiran Panda, Abu S Abdul-Quader, Sage, New Delhi.

Gupta, K. and Klasse, P. J. (2006) 'How do viral and host factors modulate the sexual transmission of HIV? Can transmission be blocked?' *PLoS Med*, vol. 3, 2, p. e79.

Gurusamy, M. (2003) 'News Features', *AIDS*, vol. 17, Suppl 4, p. S6.

Hauser (1993) 'Chapter V', in *Social Research in Developing Countries: Surveys and Censuses in the Third World*, eds M. Bulmer and D. P. Warwick, p. 383, UCL Press, London.

Hawkes, S. and Santhya, K. G. (2001) *Diverse Realities: Understanding Sexually Transmitted Infections in India*, Population Council, New Delhi, 15.

Hermida Alfred (2002) 'Villagers try our net on wheats', *BBC online*.

Hernandez-Giron, C. A., Cruz-Valdez, A., Quiterio-Trenado, M., Uribe-Salas, F., Peruga, A. and Hernandez-Avila, M. (1999) 'Factors associated with condom use in the male population of Mexico City', *Int J STD AIDS*, vol. 10, 2, pp. 112-117.

Hernandez, A. L., Lindan, C. P., Mathur, M., Ekstrand, M., Madhivanan, P., Stein, E. S., Gregorich, S., Kundu, S., Gogate, A. and Jerajani, H. R. (2006) 'Sexual behavior among men who have sex with women, men, and Hijras in Mumbai, India--multiple sexual risks', *AIDS Behav*, vol. 10, 4 Suppl, pp. S5-16.

- Hogle, J. and Sweat, M. (2001) 'The Role of Qualitative data in evaluating HIV programs', in *Evaluating programs for HIV/AIDS prevention and care in developing countries*, ed. T. S. Thomas Rehle, Stephen Mills and Robert Magnani, pp. 175-194, Family Health International, 2001, funded by USAID.
- Holstein, J. and Gubrium, J. (1999) 'Active interviewing', in *Qualitative Research. Vol II, Methods of qualitative research*, eds A. Bryman and R. Burgess, pp. 105-121, Sage, London.
- Huang, J., Bova, C., Fennie, K. P., Rogers, A. and Williams, A. B. (2005) 'Knowledge, attitudes, behaviors, and perceptions of risk related to HIV/AIDS among Chinese university students in Hunan, China', *AIDS Patient Care STDS*, vol. 19, 11, pp. 769-777.
- Huber, J. and Schneider, B. E. (1992) *The Social Context of AIDS*, American Sociological Association Presidential Series, Sage Publications, London, New Delhi.
- Hubert, M. (1990) *Sexual Behaviour and Risks of HIV Infection.*, Proceedings of an international workshop supported by the European Communities, Publications des Facultes universitaires Saint-Louis., Bruxelles. Boulevard du Jardin botanique 43, p. 149.
- Hubert, M., Bajos, N. and Sandfort, T. (1998) *Sexual Behaviour and HIV/AIDS in Europe*, Taylor & Francis, London.
- Hunter, S. (2005) *AIDS in Asia: A Continent in Peril*, Palgrave Macmillan, London.
- Huygens, P., Kajura, E., Seeley, J. and Barton, T. (1996) 'Rethinking methods for the study of sexual behaviour', *Social Science & Medicine*, vol. 42, 2, pp. 221-231.
- IANS (2004) *Is India about to throw away the condom?*, Available at: <http://timesofindia.indiatimes.com/articleshow/909167.cms>.
- ICMR (1998) *Changing trends in sero-surveillance of HIV infection*, Indian Council of Medical Research, New Delhi.
- IDF (1997) *HIV/AIDS in India: A Status Report*, India Development Forum, Paris.

IMPACT/FHI/UNAIDS (1998) *Meeting the behavioural Data Collection Needs of National HIV/AIDS and STD programmes*, Calverton, MD, p. 40.

IMRB (2000) *Healthy Highway Project*, Indian Market Research Bureau (IMRB) conducted project for Family Health International and DFID, India.

Ingham, R. (1995) 'AIDS: Knowledge, Awareness and Attitudes', in *Sexual Behaviour and AIDS in the Developing World*, eds J. Cleland and B. Ferry, Social Aspects of AIDS, pp. 43-74.

InternationalHIV/AIDSAlliance (2003) *Positive Prevention: Prevention Strategies for people with HIV/AIDS*, Emerging Practice Series, International HIV/AIDS Alliance, Brighton, p. 94.

Irwin, K., Bertrand, J., Mibandumba, N., Mbuyi, K., Muremeri, C., Mukoka, M., Munkolenkole, K., Nzilambi, N., Bosenge, N., Ryder, R., Peterson, H., Lee, N. C., Wingo, P., O'Reilly, K. and Rufo, K. (1991) 'Knowledge, attitudes and beliefs about HIV infection and AIDS among healthy factory workers and their wives, Kinshasa, Zaire', *Social Science & Medicine*, vol. 32, 8, pp. 917-930.

Jain, M. K., John, J. T. and Keusch, G. T. (1994a) 'A Review of Human Immunodeficiency Virus Infection in India', *Journal of Acquired Immune Deficiency Syndrome*, vol. 7, 11, pp. 1185-1194.

Jana, S., Ghosh, S., Bose, D., Chowdhury, S. and Mukherjee, K. (2002) 'Female Commercial Sex Workers: An innovative Intervention from West Bengal', in *Living with the AIDS Virus: The Epidemic and the response in India*, ed. A. C. Samiran Panda, Abu S Abdul-Quader, Sage, New Delhi.

Jana, S., Chakraborty, A. K., Das, A., Khodakevich, L., Chakraborty, M. S. and Pal, N. K. (1994) 'Community Based Survey of STD/HIV Infection Among Commercial Sex Workers in Calcutta (India), Part II - Sexual Behaviour, Knowledge and Attitude Towards STD', *Journal of Communicable Diseases*, vol. 26, 3, pp. 168-171.

Jejeebhoy, S. J. (1998) 'Adolescent Sexual and Reproductive Behaviour: A Review of the evidence from India', *Social Science and Medicine*, vol. 46, 10, pp. 1275-1290.

- Joesoef, M. R., Linnan, M., Kamboji, A., Barakbah, Y. and Idajadi, A. (2000) 'Determinants of condom use in female sex workers in Surabaya', *International Journal of STD & AIDS*, vol. 11, 4, pp. 262-265.
- John, J. T. (1993) 'The epidemiology of AIDS in the Vellore region, Southern India', *AIDS*, vol. 7, 3, pp. 421-424.
- John, J. T. and Babu, G. P. (1995) *The epidemiology of Retroviruses in India*, Symposium on AIDS in India, Harvard Institute of AIDS, Pune, India.
- John, J. T., P George Babu, Jeyakumari, H. M. and Simoes, E. A. F. (1987) 'Prevalence of HIV infection in risk groups in Tamil Nadu, India (a letter)', *The Lancet*, vol. i, pp. 160 - 161.
- John, J. T., P George Babu, R Pulimod and Jeyakumari, H. (1989) 'Prevalence of Human Immuno-deficiency Virus infection among voluntary blood donors', *Indian Journal of Medical Research*, vol. 8, pp. 1-3.
- John, T. J. and Nisha Bhushan, P. G. B., Lakshmi Seshadri, N Balasubramaniam and Padmini Jasper (1993) 'Prevalence of HIV infection in Pregnant Women in Vellore Region', *The Indian Journal of Medical Research [A]*, vol. 97, pp. 227-230.
- Johnson, T. (2004) *AIDS treatment programme to be launched on April 1*, Times News Network, Available at: <http://timesofindia.indiatimes.com/articleshow/591765.cms>.
- Jones (1993) 'Chapter XX', in *Social Research in Developing Countries: Surveys and Censuses in the Third World*, eds M. Bulmer and D. P. Warwick, p. 383, UCL Press, London.
- Joseph, E. B. and Bhatti, R. S. (2004) 'Psychosocial problems and coping patterns of HIV seropositive wives of men with HIV/AIDS', *Soc Work Health Care*, vol. 39, 1-2, pp. 29-47.
- Jyothi, D. (2003) *Make AIDS drugs affordable at home first*, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/2911>.

- Kadiyala, S. and Barnett, T. (2004) 'AIDS in India: Disaster in the Making', *EPW Perspectives*, vol. 39, no. 19.
- Kalichman, S. C., Eaton, L., Cain, D., Cherry, C., Pope, H. and Kalichman, M. (2006) 'HIV treatment beliefs and sexual transmission risk behaviors among HIV positive men and women', *J Behav Med*, vol. 29, 5, pp. 401-410.
- Kamya, M., McFarland, W., Hudes, E., Ssali, A., Busuulwa, R. and Hearst, N. (1997) 'Condom use with casual partners by men in Kampala, Uganda', *AIDS*, vol. 11, Suppl 1, pp. S61-66.
- Kar, H. K., Jain, R. K., Sharma, P. K., Gautam, R. K., Gupta, A. K., Sharma, S. K., Hans, C. and Doda, V. (2001) 'Increasing HIV prevalence in STD clinic attendees in Delhi, India: 6 year (1995-2000) hospital based study results', *Sex Transm Infect*, vol. 77, 5, p. 393.
- Kattumuri, R. (2003) 'One-and-a-half decades of HIV/AIDS in Tamil Nadu: how much do patients know now?' *Int J STD AIDS*, vol. 14, 8, pp. 552-559.
- Kaushalendra, K. S., Bloom, S. S. and Tsui, A. O. (1998) *Husbands' Reproductive Health Knowledge, Attitudes, and Behaviour in Uttar Pradesh, India*, Studies in Family Planning, pp. 388-399.
- Kegeles, S. M., Coates, T. J., Christopher, T. A. and 1989, J. L. L. (1989) 'Perceptions of AIDS, the continuing saga of AIDS-related stigma', *AIDS*, vol. 3, Suppl. 1, pp. S253 - S258.
- Kelly, R. B., Zyzanski, S. J. and Alemagno, S. A. (1991) 'Prediction of motivation and behavior change following health promotion: Role of health beliefs, social support, and self-efficacy', *Social Science & Medicine*, vol. 32, 3, pp. 311-320.
- Kennedy, G., Rutherford GW and KA, F. (1999) *Three- or four- versus two-drug antiretroviral maintenance regimens for HIV infection – a meta-analysis*, Cochrane Library publication, Univeristy of California, San Francisco.
- Kerrigan, D., Bastos, F. I., Malta, M., Carneiro-da-Cunha, C., Pilotto, J. H. and Strathdee, S. A. (2006) 'The search for social validation and the sexual behavior of people living with HIV in Rio de Janeiro, Brazil: understanding



- the role of treatment optimism in context', *Soc Sci Med*, vol. 62, 10, pp. 2386-2396.
- Khan, A. (2006) *STIs and Prevention in Pakistan*, WHO, Available at: [http://www.emro.who.int/asd/Media/PowerPoint/6%20Pakistan%20STIs%20situation%20analysis%20in%20Pakistan%20\(WHO%20EMRO%202006\).pps#274,44,Thanks](http://www.emro.who.int/asd/Media/PowerPoint/6%20Pakistan%20STIs%20situation%20analysis%20in%20Pakistan%20(WHO%20EMRO%202006).pps#274,44,Thanks)
- Khan, S. (1993) Cultural Contexts of Sexual Behaviours and Identities and their Impact upon HIV Prevention Models, paper presented to Workshop on Sexual Aspects of AIDS/STD Prevention in India, Tata Institute of Social Sciences, Bombay.
- Khan, S. (2001) 'Culture, Sexualities, and Identities: Men Who Have Sex with Men in India', *Journal of Homosexuality*, vol. 10, pp. 99-115.
- Khan, S. (2004) *MSM and HIV/AIDS in India*, Naz Foundation International, p. 23.
- Khanna S.A and D.N Lanjewar, P. G. S., A B Shinde (1993) 'Paediatric HIV infection: Recent Advances in Perinatally Acquired AIDS', *Indian Paediatrician*, vol. 30, 508-510.
- Knodel, J., Van Lan Dingham, M., Saengtienchai, C. and Pramualratana, A. (1996) 'Thai Views on Sexuality and Sexual Behaviour', *Health Transition Review*, vol. 6, pp. 179 - 201.
- Knox, E., MacArthur, C. and Simons, K. (1993) *Sexual Behaviour and AIDS in Britain*, HMSO, University of Birmingham, London.
- Kraft, P. and Rise, J. (1995) 'Prediction of attitudes towards restrictive aids policies: A structural equation modelling approach', *Social Science & Medicine*, vol. 40, 5, pp. 711-718.
- Kumar, A., Mehra, M., Badhan, S. K. and Gulati, N. (1997) 'Heterosexual behaviour and condom usage in an urban population of Delhi, India', *AIDS Care*, vol. 9, 3, pp. 311-318.
- Kumar, R., Jha, P., Arora, P., Mony, P., Bhatia, P., Millson, P., Dhingra, N., Bhattacharya, M., Remis, R. S. and Nagelkerke, N. (2006) 'Trends in HIV-1 in young adults in south India from 2000 to 2004: a prevalence study', *Lancet*, vol. 367, 9517, pp. 1164-1172.

Kumar, S. (1999) 'India has the largest number of people infected with HIV', *The Lancet*, vol. 353, 9146, p. 48.

Kumar, S. (2004) 'India's treatment programme for AIDS is premature', *British Medical Journal*, vol. 328, 70.

Kvale, S. (1996) *Interviews: An introduction to Qualitative interviewing*, Sage publications, Thousand Oaks, California, London, New Delhi.

Lacerda, R., Gravato, N., McFarland, W., Rutherford, G., Iskrant, K., Stall, R. and Hearst, N. (1997) 'Truck drivers in Brazil: prevalence of HIV and other sexually transmitted diseases, risk behaviour and potential for spread of infection', *AIDS*, vol. 11, supplement 1, pp. S15-S19.

Lakhani, A., Gandhi, K. and Collumbien, M. (2001) 'Addressing semen loss concerns: towards culturally appropriate HIV/AIDS interventions in Gujarat, India', *Reprod Health Matters*, vol. 9, 18, pp. 49-59.

Lal, P., Kumar, A., Ingle, G. K. and Gulati, N. (1994) 'Knowledge and attitudes of university students regarding HIV/AIDS: an urban--rural difference', *J Commun Dis*, vol. 26, 4, pp. 186-191.

Lal, S. and Thakur, B. B. (1993) 'Proposed National HIV Testing Policy', *Indian Journal of Medical Research*, vol. 97, pp. 223-224.

Lambert, H. and Wood, K. (2005) 'A comparative analysis of communication about sex, health and sexual health in India and South Africa: Implications for HIV prevention', *Cult Health Sex*, vol. 7, 6, pp. 527-541.

Lampthey, P. R. and Gayle, H. D. (2001) *HIV/AIDS Prevention and Care in Resource-Constrained Settings: A handbook for the design and management of programs*, Family Health International, p. 695.

Laukamm-Josten, U., B K Mwizarubi, A Outwater, C L Mwaijonga, J J Valadez, D Nyamwaya, R Swai, T Saidel and Nyamuryekung'e, K. (2000) 'Preventing HIV infection through peer education and condom promotion among truck drivers and their sexual partners in Tanzania, 1990-1993', *AIDS Care*, vol. 12, 1, pp. 27-40.

Lazarus, J. V., Bollerup, A. and Matic, S. (2006) 'HIV/AIDS in eastern Europe: more than a sexual health crisis', *Cent Eur J Public Health*, vol. 14, 2, pp. 55-58.

Lee, R. (1993) *Doing Research on Sensitive Topics*, Sage, London.

Lie, G. T. and Biswala, P. M. (1998) 'Exploring Sustainable Responses to the HIV Epidemic: Grounding Responses in People's Realities - a cross cultural study of responses', *Institute of African Studies: Research Reveiwer*, vol. 17, 1, pp. 14-27.

Lindberg, C. E. (2000) 'Knowledge, self-efficacy, coping, and condom use among urban women', *Journal of Association of Nurses*, vol. 11, 5, pp. 80-90.

LinguaLinks (1999) *What is knowledge hierarchy?*, SIL International, Available at: <http://www.sil.org/lingualinks/literacy/referencematerials/glossaryofliteracyterms/WhatIsAKnowledgeHierarchy.htm>.

Loftus, E. F., Smith, K. D., Klinger, M. R. and Fiedler, J. (1992) 'Memory and Mismemory for Health Events', in *Questions about Questions: Inquiries into the Cognitive Bases of Surveys*, ed. J. M. Tanur, pp. 102-137, Russell Sage Foundation, NY.

Lugalla, J., Maria Emmelin, Aldin Mutembei, Mwiru Sima, Gideon Kwesigabo, Killewo, J. and Dahlgren, L. (2004) 'Social, cultural and sexual behavioral determinants of observed decline in HIV infection trends: lessons from the Kagera Region, Tanzania', *Social Science & Medicine*, vol. 59, 1, pp. 185-198.

Lurie, M. N., Williams, B. G., Zuma, K., Mkaya-Mwamburi, D., Garnett, G. P., Sweat, M. D., Gittelsohn, J. and Karim, S. S. A. (2003) 'Who infects whom? HIV-1 concordance and discordance among mirgrant and non-migrant couples in South Africa', *AIDS*, vol. 17, pp. 2245-2252.

Macdonald, D. S. (1996) 'Notes on the socio-economic and cultural factors influencing the transmission of HIV in Botswana', *Social Science & Medicine*, vol. 42, 9, pp. 1325-1333.

- MacNeil, J. M. and Hogle, J. (1998) 'Applying social, behavioral and evaluation research to developing country HIV prevention programs', *AIDS*, vol. 12, Suppl. 2, pp. S99-S108.
- Majumdar, S. (2004) *Fighting India's AIDS Apathy*, BBC online, Available at: [http://news.bbc.co.uk/1/hi/world/south\\_asia/3886883.stm](http://news.bbc.co.uk/1/hi/world/south_asia/3886883.stm).
- Makkar, B. D. (2002) 'Roles and responsibilities in researching poor women in Brazil', in *Ethical Dilemmas in Qualitative Research*, eds T. Welland and L. Pugsley, Cardiff Papers in Qualitative Research, pp. 75-93, Ashgate Publishing Company, Burlington, VT USA.
- Malhotra, V. N. and P Seth, D. T., R M Pandey (2000) 'HIV seropositivity in women with syphilis in Delhi, India', *Sexually Transmitted Infections*, vol. 76, pp. 59-60.
- Mann, J. M., Daniel J M Tarantola (1996) *AIDS in the World II*, Oxford University Press, New York.
- Mansergh, G., Marks, G., Miller, L., Appleby, P. R. and Murphy, S. (2000) 'Is 'knowing people with HIV/AIDS' associated with safer sex in men who have sex with men?' *AIDS*, vol. 14, 12, pp. 1845-1851.
- MAP (1997) The Status and Trends of the HIV/AIDS/STD Epidemic in Asia and the Pacific, paper presented to Official Symposium of the IV International Conference on AIDS in Asia and the Pacific, Manila, Philippines.
- Mathiowetz, N. A. (1998) 'Respondent uncertainty as indicator of response quality', *International Journal of Public Opinion Research*, vol. 11, 3, pp. 289-296.
- Maticka-Tyndale, E., Kiewying, M., Haswell-Elkins, M. and Kuyyakanond T, A. S., Chantapreeda N, Choosathan R, Sornchai S, Theerasobhon P, Supornpun A (1994) 'Knowledge, attitudes and beliefs about HIV/AIDS among women in northeastern Thailand', *AIDS Educ Prev.*, vol. 6, 3, pp. 205-218.
- Mawar, N., Saha, S., Pandit, A. and Mahajan, U. (2005) 'The third phase of HIV pandemic: social consequences of HIV/AIDS stigma & discrimination & future needs', *Indian J Med Res*, vol. 122, 6, pp. 471-484.

- Mawar, N., S Mehendale, S Thilakavathi, M Shepherd, J Rodrigues, R Bollinger, M Bentley (1997) 'Awareness & knowledge of AIDS & HIV risk among women attending STD clinics in Pune, India', *Indian Journal Medical Research*, vol. 106, pp. 212-222.
- McFarland, W. C., Lindan, C. P., Mandel, J. and Rutherford, G. (2002) 'HIV Prevention in the Developing World: Training Researchers for the Long Haul', *AIDS and Behaviour*, vol. 6, 3, pp. 207-209.
- McGrath, J. W., Ankrah, E. M., Schumann, D. A., Nkumbi, S. and Lubega, M. (1993) 'AIDS and the urban family: its impact in Kampala, Uganda', *AIDS Care*, vol. 5, 1, pp. 55-70.
- McKeganey, N. P. (1994) 'Prostitution and HIV: What do we know and where might research be targeted in the future?' *AIDS*, vol. 8, pp. 1215 - 1226.
- Meda, N., Sangare, L., Lankoande, S. and Compaore I P, C. J., Sanou PT, Van Dyck E, Cartoux M, Soudre RB (1998) 'The HIV epidemic in Burkina Faso: current status and the knowledge level of the population about AIDS, 1994-1995', *Rev Epidemiol Sante Publique*, vol. 46, 1, pp. 3-4.
- Meekers, D. and Van Rossem, R. (2005) 'Explaining inconsistencies between data on condom use and condom sales', *BMC Health Serv Res*, vol. 5, 1, p. 5.
- Mehendale, S. M. and Shepherd, M. E., Divekar, A.D., Gangakhedkar, R.R., Kamble, S.S., Menon, P.A., Yadav, R., Risbud, A.R., Paranjape, R.S., Gadkari, D.A., Quinn, T.C., Bollinger, R.C., Rodrigues, J.J. (1996) 'Evidence for high prevalence and rapid transmission of HIV among individuals attending STD clinics in Pune, India', *Indian Journal of Medical Research*, vol. 104, pp. 327-335.
- Mehendale, S. M., Ghate, M. V., Kishore Kumar, B., Sahay, S., Gamble, T. R., Godbole, S. V., Thakar, M. R., Kulkarni, S. S., Gupta, A., Gangakhedkar, R. R., Divekar, A. D., Risbud, A. R., Paranjape, R. S. and Bollinger, R. C. (2006) 'Low HIV-1 incidence among married serodiscordant couples in Pune, India', *J Acquir Immune Defic Syndr*, vol. 41, 3, pp. 371-373.
- Mehta, S. H., Gupta, A., Sahay, S., Godbole, S. V., Joshi, S. N., Reynolds, S. J., Celentano, D. D., Risbud, A., Mehendale, S. M. and Bollinger, R. C. (2006) 'High HIV prevalence among a high-risk subgroup of women attending

- sexually transmitted infection clinics in Pune, India', *J Acquir Immune Defic Syndr*, vol. 41, 1, pp. 75-80.
- Messiah, A. (1997) 'Condom breakage and slippage during heterosexual intercourse: a French national survey.' *American Journal of Public Health*, vol. 87, pp. 421-424.
- Miles, M. B. (1985) 'Qualitative Data as an Attractive Nuisance: The Problem of Analysis', in *Qualitative Methodology*, ed. J. V. Maanen, pp. 117-134, Sage Publication, Beverly Hills, London, New Delhi.
- Miles, M. B. and Huberman, A. M. (1994) *Qualitative data analysis: an expanded source book*, 2nd edn, Sage publications, Thousand Oaks.
- Miller, D. (2002) 'Foreword', in *Living with the AIDS Virus: The Epidemic and the response in India*, ed. A. C. Samiran Panda, Abu S Abdul-Quader, Sage, New Delhi.
- Mills, S., Saidel, T., Bennett, A., Rehle, T., Hogle, J., and, T. B. and Magnani, R. (1998) 'HIV risk behavioural surveillance: a methodology for monitoring behavioural trends', *AIDS*, vol. 12, Suppl. 2, pp. S37-S46.
- Mills Stephen, Rehle, T. and Schwartländer, B. (2006) 'Understanding HIV Epidemics And The Response To Them: Linking Data On Behavior Change And HIV Decline', in *Evaluating Programs for HIV/AIDS Prevention and Care in Developing Countries*, eds Thomas Rehle, Tobi Saidel, Stephen Mills, R. Magnani and A. B. Rodgers, p. 274, FHI, Impact and USAID, NC.
- Moatti, J.-P. and Souteyrand, Y. (2000) 'HIV/AIDS social and behavioural research: past advances and thoughts about the future', *Social Science & Medicine*, vol. 50, 11, pp. 1519-1532.
- Mohan, R. (2004) *Protest against the proposed legalization of prostitution in India*, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/3630>.
- Morisky, D. E., Stein, J. A., Sneed, C. D., Tiglaio, T. V., Liu, K., Detels, R., Temponko, S. B. and Baltazar, J. C. (2002) 'Modeling Personal and Situational Influences on Condom Use Among establishment-based CSWs in the Phillippines', *AIDS and Behaviour*, vol. 6, 2, pp. 163-171.

- Morris, M., Wawer, M. J., Makumbi F, Zavisca J R and N, S. (2000) 'Condom acceptance is higher among travelers in Uganda', *AIDS*, vol. 14, 6, pp. 733-741.
- Morton-Williams, J. (1993) *Interviewer Approaches*, Dartmouth Publishing Company, England, USA.
- Moser, C. A. and Kalton, G. (1971) *Survey Methods in Social Investigation*, Heinemann Educational Books Limited, London.
- Mudur, G. (2000) 'Indian agency admits publishing 'wrong' HIV figures', *British Medical Journal*, vol. 321, p. 402.
- Mukherjee, S. and Sikdar, D. P. (2005) 'Impact of educational status on AIDS awareness and attitude: a micro study of Krishnanagar City', *Indian J Public Health*, vol. 49, 2, pp. 97-98.
- Mulder, D. (1996) 'Disease progression and mortality following HIV-1 infection', in *AIDS in the World II*, ed. J. M. M. a. D. J. M. Tarantola, pp. 15-16, Oxford University Press, New York.
- Murthy, K., Mills, S., Srinivasan, V. and Bai, L. (1999) 'An Innovative Methodology of Monitoring AIDS/STD Intervention Project', in *Health Education in South East Asia*, vol. XIII, pp. 70-78, IUHPE - SEARB, Chennai, India.
- Muthuswamy, V. (2001) *Interview*, Senior Secretary, Indian Council of Medical Research, June 15.
- NACO (1995) *National AIDS Control Program:Country Scenario Update*, National AIDS Control Organisation, New Delhi, India.
- NACO (1997) *A summary of the Findings of the High Risk Behaviour Study from 18 Cities*, National AIDS Control Organisation, Government of India, Ministry of Health and Family Welfare, New Delhi.
- NACO (1998) *A Summary of findings of the high-risk behaviour study for 18 cities*, National AIDS Control Organisation, Ministry of Health, India, New Delhi.

NACO (1999) *Country Scenario 1997-98*, National AIDS Control Organisation, Ministry of Health, India, New Delhi.

NACO (2000) *Combating HIV/AIDS in India 1999-2000*, Ministry of Health and Family Welfare, Govt. of India, New Delhi, p. 164.

NACO (2001) *National Baseline High Risk and Bridge Population Behavioural Surveillance Survey - Female Sex Workers and their Clients*, National AIDS Control Organisation, New Delhi, p. 101.

NACO (2001a) *National Baseline General Population Behavioural Surveillance Survey*, National AIDS Control Organisation, p. 40.

NACO (2002) *National AIDS Control Organisation*, Ministry of Health and Family Welfare, Available at: [www.nacoonline.org](http://www.nacoonline.org).

NACO (2003) *HIV estimates*, Ministry of Health and Family Welfare, Govt. of India, Available at: [http://www.nacoonline.org/facts\\_hivestimates.htm](http://www.nacoonline.org/facts_hivestimates.htm).

NACO (2004) *Annual Report*, National AIDS Control Organisation, Government of India, New Delhi.

NACO (2006) *HIV estimates*, Ministry of Health and Family Welfare, Govt. of India, Available at: [http://www.nacoonline.org/facts\\_hivestimates.htm](http://www.nacoonline.org/facts_hivestimates.htm).

Nag, M. (1995) 'Sexual behaviour in India with risk of HIV/AIDS transmission', *Health Transition Review*, vol. 5, Supplement, pp. 293-305.

Nag, M. (1996) *Sexual Behaviour and AIDS in India*, Vikas Publishing House, New Delhi, India.

Nagelkerke, N. J. D., Jha, P., de Vlas, S.J. et al. (2002) 'Modelling the HIV epidemics in India and Botswana: The impact of interventions to prevent transmission', *Bulletin of the World Health Organization*, vol. 80, 2, pp. 89-96.

Nanda, S. (1990) *Neither Man nor Woman: The Hijras of India*, Wadsworth Publishing Co.



Narain, J. P., Jha, A., Lal, S. and Salunke, S. (1994) 'Risk factors for HIV transmission in India', *AIDS*, vol. 8 Suppl 2, pp. S77-82.

Narashimhan, S. (1999) *Empowering women. An alternative strategy from rural India*, SAGE Publications, New Delhi.

Newman, S., P. S., Kumarasamy, N., Amalraj, E., Rogers, M., Madhivanan, P., Flanigan, T. P., Cu-Uvin, S., McGarvey, S., Mayer, K. H. and Solomon, S. (2000) 'Marriage, Monogamy and HIV: a profile of HIV infected women in South India', *International Journal of STD & AIDS*, vol. 11, pp. 250-253.

NFHS-3 (2007) *National Family Health Survey*, <http://www.nfhsindia.org/summary.html>.

NFHS (1995) *National Family Health Survey (1992-93) - India*, International Institute of Population Studies, Bombay, India, p. 402.

NFHS (2000) *National Family Health Survey (NFHS-2) - India*, International Institute of Population Studies, ORC Macro, Maryland, Mumbai, India, p. 443.

NFHSAP-1998 (2000) *National Family Health Survey - Andhra Pradesh*, Indian Institute of Population Studies and MEASURE DHS+, ORC Macro, Mumbai, India.

NFHSTN-1992 (1994) *National Family Health Survey - Tamil Nadu*, Population Research Centre and Indian Institute for Population Sciences, Mumbai, India.

NFHSTN-1998 (2001) *National Family Health Survey - Tamil Nadu*, Indian Institute of Population Studies and MEASURE DHS+, ORC Macro, Mumbai, India.

Niccolai, L. M., D'Entremont, D., Pritchett, E. N. and Wagner, K. (2006) 'Unprotected intercourse among people living with HIV/AIDS: The importance of partnership characteristics', *AIDS Care*, vol. 18, 7, pp. 801-807.

NIMH (1997) 'Demographic and behavioral predictors of sexual risk in a multisite HIV prevention trial', *AIDS*, vol. 11, Suppl. 2, pp. S21-S27.

- Ntozi, J. P. and Kirunga, C. T. (1997) 'HIV/AIDS, change in sexual behaviour and community attitudes in Uganda', *Health Transit Rev*, vol. 7 Suppl, pp. 157-174.
- Ntozi, J. P., Najjumba, I. M., Ahimbisibwe, F., Ayiga, N. and Odwee, J. (2003) 'Has the HIV/AIDS epidemic changed sexual behaviour of high risk groups in Uganda?' *Afr Health Sci*, vol. 3, 3, pp. 107-116.
- Nzyuko, S., Lurie, P., McFarland, W., Leyden, W., Nyamwaya, D. and mandel, J. S. (1997) 'Adolescent Sexual Behaviour along the Trans-Africa Highway in Kenya', *AIDS*, vol. 11, Suppl. 1, pp. S21-S26.
- O'Neil, J., Orchard, T., Swarankar, R. C., Blanchard, J. F., Gurav, K. and Moses, S. (2004) 'Dhandha, dharma and disease: traditional sex work and HIV/AIDS in rural India', *Soc Sci Med*, vol. 59, 4, pp. 851-860.
- Obbo, C. (1995) 'Gender, age and class: discourses on HIV transmission and control in Uganda', in *Culture and sexual risk: anthropological perspectives on AIDS*, eds H. T. BRUMMELHUIS and G. HERDT, pp. 79-98, Gordon and Breach, Amsterdam.
- Oldenberg, V. T. (1990) 'Lifestyle as resistance: The case of the courtesans of Lucknow, India', *Feminist Studies*, vol. 16, 2, pp. 259-287.
- Oppenheim, A. N. (1992) *Questionnaire Design, Interviewing and attitude measurement*, 2nd edn, Printer publishers, NY, London.
- ORG (1998) *Special Behaviour Study in Tamil Nadu*, Operations Research Group for Tamil Nadu State AIDS Control Society, Chennai.
- Organista, K. C., Organista, P. B. and Garcia De Alba J E, C. M. M., Carrillo H (1996) 'AIDS and condom-related knowledge, beliefs, and behaviors in Mexican migrant laborers', *Hispanic Journal of Behaviour Science*, vol. 18, 3, pp. 392-406.
- Orubuloye, I. O., Caldwell, J. C. and Caldwell, P. (1997) 'Perceived male sexual needs and male sexual behaviour in southwest Nigeria', *Social Science & Medicine*, vol. 44, 8, pp. 1195-1207.

- Pais, P. (1996) 'HIV and India: looking into the abyss', *Tropical Medicine and International Health*, vol. 1, 3, pp. 295-304.
- Pallikadavath, S., Garda, L., Apte, H., Freedman, J. and Stones, R. W. (2005) 'HIV/AIDS in rural India: context and health care needs', *J Biosoc Sci*, vol. 37, 5, pp. 641-655.
- Panda, S., Chatterjee, A., Bhattacharya, S. K., Manna, B., Singh, P. N., Sarkar, S., Naik, T. N., Chakrabarti, S. and Detels, R. (2000) 'Transmission of HIV from injecting drug users to their wives in India', *International Journal of STD & AIDS*, vol. 11, pp. 468-473.
- Panos (1990) *The 3rd epidemic, repercussions of the fear of AIDS*, Panos Institute, London.
- Paramesh, P. (2001) *About GHTM*, Government Hospital for Thoracic Medicine, Available at: <http://education.vsnl.com/thoracic/brief.html>.
- Patel, V. L., Branch, T., Gutnik, L. and Arocha, J. F. (2006) 'Shaping understanding of HIV through negotiation and conflict resolution during peer group discussion', *Adv Health Sci Educ Theory Pract*, vol. 11, 2, pp. 185-207.
- Pavri, K. (1990) 'HIV disease in India : an update', *Centre AIDS Research Control*, vol. 3, pp. 30-34.
- Pearson, R. W., Ross, M. and Dawes, R. M. (1992) 'Personal Recall and the Limits of Retrospective Questions in Surveys', in *Questions about Questions: Inquiries into the Cognitive Bases of Surveys*, ed. J. M. Tanur, pp. 65-94, Russell Sage Foundation, NY.
- Pelto, P. J., Joshi, A. and Verma, R. (2000) *Development of Sexuality and Sexual Behaviour among Indian Males: Implications for the Reproductive Health Programme*, Population Council, New Delhi.
- Peruga, A. and Celentano, D. D. (1993) 'Correlates of AIDS knowledge in samples of the general population', *Social Science & Medicine*, vol. 36, 4, pp. 509-524.

- Pickett, J. (2003) 'News Features', *AIDS*, vol. 17, Suppl 4, p. S22.
- Pierret, J. (2000) 'Everyday life with AIDS/HIV', *Social Science & Medicine*, vol. 50, pp. 1589-1598.
- Pinkerton, S. D. and Holtgrave, D. R. (1999) 'Combination Antiretroviral Therapies for HIV - Some Economic Considerations', pp. 83-112.
- Piot, P. (2000) *Monitoring AIDS Pandemic*, UNAIDS, Vancouver.
- Piot, P., Zewdie, D. and Turmen, T. (2002) 'HIV/AIDS prevention and treatment', *The Lancet*, vol. 360, p. 86.
- Poddar, D. P. (1995) 'Country watch: India', *AIDS STD Health Promot Exch.*, 2, p. 9.
- Ponnuraj, S. and Sankarapandian (1994) 'Analysis and Assessment of Knowledge about AIDS among Students of Gandhigram Rural University', *Health and Population Perspectives and Issues*, vol. 17, pp. 45-65.
- Prabha, S. C., Michael P Carey, Kate B Carey, PSDV Prasada Rao, Jairam, K. R. and Thomas, T. (2003) 'HIV risk behaviour among psychiatric inpatients: results from a hospital-wide screening study in southern India', *International Journal of STD and AIDS*, vol. 14, 8, pp. 532-538.
- Pradeep, K. (2002) 'Interventions among Men who have sex with Men', in *Living with the AIDS Virus: The Epidemic and the response in India*, ed. A. C. Samiran Panda, Abu S Abdul-Quader, Sage, New Delhi.
- Rabori, E. D., Gupta, P., Pandey, R. M., Chattopadhaya, D., Lal, S. and Baveja, U. K. (2005) 'Sexual risk behaviors in HIV positive individuals in north India', *J Commun Dis*, vol. 37, 3, pp. 249-253.
- Radley, A. and Billig, M. (1996) 'Accounts of health and illness: dilemmas and representations', *Sociology of Health and Illness*, vol. 18, pp. 220-240.
- Rahman, M., Shimu, T. A. and Fukui, T., Shimbo T, Yamamoto W (1999) 'Knowledge, attitudes, beliefs and practices about HIV/AIDS among the overseas job seekers in Bangladesh', *Public Health Reports*, vol. 113, 1, pp. 35-38.

Rajarethinam, E. (2002) *Suicide Series at The AIDS Ward Of A South Indian Hospital*, Global Citizens, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/1694>.

Rajesh, D. (1999) *Department of Clinical Virology, CMC*, 27 May, (interview).

Ramachandran, P. (1992) 'Women's Vulnerability', *Seminar*, vol. 396, pp. 21-25.

Ramasubban, R. (1990) Sexual Behaviour and Conditions of Health Care: Potential Risks for HIV Transmission in India, paper presented to Seminar on Anthropological Studies Relevant to the Sexual Transmission of HIV. IUSSP Committee on Anthropological Demography and DANIDA, Sonderberg, Denmark.

Ramasubban, R. (1995) Sexual Behaviour and Conditions of Health Care: Potential Risks for HIV Transmission in India, paper presented to Seminar on Anthropological Studies Relevant to the Sexual Transmission of HIV. IUSSP Committee on Anthropological Demography and DANIDA, Sonderberg, Denmark.

Ramasubban, R. (1998) Politics Behind HIV/AIDS Policies: The Case of India, paper presented to 12th World AIDS Conference, Geneva.

Ramasundaram, S., K Allaudin, B Charles, K Gopal, P Krishnamurthy, R Poornalingam and D Warren (2001) *HIV/AIDS control in India - Lessons learned from Tamil Nadu.*, Working Paper Series, WG5:25.

Rangaiyan, G. and Verma, R. K. (2001) *A study of Sexual Behaviour among College Students in Mumbai*, International Institute of Population Studies, Mumbai.

Rangaiyan, G., N Phanindra Babu and S Sureender (1998) 'HIV/AIDS in the north eastern states of India: Knowledge and misconceptions regarding its transmission', *The Journal of Family Welfare*, vol. 44, 1, pp. 24-31.

Rao, A., Mishra, S. D. and Dey, A. (1993) A Study on Sexual Behaviour Patterns of Truck Drivers and helpers, paper presented to Workshop on Sexual Aspects of AIDS/STD Prevention in India, Tata Institute of Social Sciences, Bombay.

- Rao, A., Nag, M., Mishra, K. and Dey, A. (1994) 'Sexual Behaviour Pattern of Truck Drivers and their helpers in relation to Female Sex Workers', *Indian Journal of Social Work*, vol. 55, pp. 603-616.
- Rao, A. S. R. S. (2003) 'Can we obtain realistic HIV/AIDS estimates for India?' *Journal of Biological Sciences*, vol. 28, 4.
- Rawlings, M. K., Graff, R. J., Calderon, R., Casey-Bailey, S. and Pasley, M. V. (2006) 'Differences in perceptions of what constitutes having "had sex" in a population of people living with HIV/AIDS', *J Natl Med Assoc*, vol. 98, 6, pp. 845-850.
- Rehle, T., Saidel Tobi, Stephen Mills, Magnani, R. and Rodgers, A. B. (eds) (2006) *Evaluating Programs for HIV/AIDS Prevention and Care in Developing Countries*, Family Health International, Impact and USAID, NC.
- Rehle Thomas, Saidel Tobi, Stephen Mills, Magnani, R. and Rodgers, A. B. (eds) (2006) *Evaluating Programs for HIV/AIDS Prevention and Care in Developing Countries*, Family Health International, Impact and USAID, NC.
- Reidpath, D. D., Brijnath, B. and Chan, K. Y. (2005) 'An Asia Pacific six-country study on HIV-related discrimination: introduction', *AIDS Care*, vol. 17 Suppl 2, pp. S117-127.
- Rhodes, T., Gloria Greenwood and Robertson, K. (2001) *INSIGHTS: Injecting drug use, risk behaviour and qualitative research in the time of AIDS*.
- Roberts, A. B., Oyun, C., Batnasan, E. and Laing, L. (2004) 'Exploring the social and cultural context of sexual health for young people in Mongolia: implications for health promotion', *Social Science & Medicine*, vol. 59, 4, pp. 851-860.
- Robson, C. (1993) *Real World Research - A Resource for Social Scientists and Practitioner - Researchers*, Blackwell Publishers Ltd, Oxford UK and Cambridge USA.
- Rogers, A., Meundi, A., Amma, A., Rao, A., Shetty, P., Antony, J., Sebastian, D., Shetty, P. and Shetty, A. K. (2006) 'HIV-related knowledge, attitudes, perceived benefits, and risks of HIV testing among pregnant women in rural Southern India', *AIDS Patient Care STDS*, vol. 20, 11, pp. 803-811.

- Rosenberg, M. and Waugh, M. (1997) 'Latex condom breakage and slippage in a controlled clinical trial', *Contraception*, vol. 56, pp. 17-21.
- Rosenthal, D. and Oanh, T. T. (2006) 'Listening to female sex workers in Vietnam: influences on safe-sex practices with clients and partners', *Sex Health*, vol. 3, 1, pp. 21-32.
- Rossmann, G. and Rallis, F. (1998) *Learning in the field: an introduction to qualitative research*, Sage, Thousand Oaks, CA.
- Roth, J., Krishnan, S. P. and Bunch, E. (2001) 'Barriers to condom use: results from a study in Mumbai (Bombay), India', *AIDS Educ Prev*, vol. 13, 1, pp. 65-77.
- Rowley, J. and Berkley, S. (1998) 'Sexually transmitted diseases', in *Health Dimensions of Sex and Reproduction - The Global Burden of Sexually Transmitted Diseases, HIV, Maternal Conditions, Perinatal Disorders, and Congenital Anomalies*, eds C. J. L. Murray and A. D. Lopez, pp. 19-110, Harvard University Press.
- Rubin, M. Q. and Patton, M. Q. (1995) *Qualitative Evaluation and Research Methods*, 2nd edn, Sage, Newbury Park, CA.
- Rubsamen-Waigmann, H., Briesen, H. V. and Maniar, J. K. (1991) 'Spread of HIV-2 in India', *The Lancet*, vol. 337, pp. 550-551.
- Safren, S. A., Martin, C., Menon, S., Greer, J., Solomon, S., Mimiaga, M. J. and Mayer, K. H. (2006) 'A survey of MSM HIV prevention outreach workers in Chennai, India', *AIDS Educ Prev*, vol. 18, 4, pp. 323-332.
- Salomon, J., Hogan DR, Stover J, Stanek KA, Walker N, Ghys PD and B, S. (2005) 'Integrating HIV prevention and treatment: from slogans to impact', *PLoS Med*, vol. 2, 1, p. e16.
- Salunke, D., Sapalya, R. and Hira, S. (2001) 'Empowered opinion leaders in India and the HIV/AIDS programme', *Natl Med J India*, vol. 14, 2, pp. 99-102.
- Sambamoorthi, U., Crystal, S., Moynihan, P. and McSpirt, E. (2001) 'Initiation and continuation of newer antiretroviral treatments among medicaid recipients with AIDS.' *J Gen Intern Med*, vol. 16, 12, pp. 850-859.

- Sankaranarayan, S., Naik, E., Reddy, P. S., Gurunani, G., Ganesh, K., Gandewar, K., Singh, K. P. and Vermund, S. H. (1996) 'Impact of school-based HIV and AIDS education for adolescents in Bombay, India', *Southeast Asian J Trop Med Public Health*, vol. 27, 4, pp. 692-695.
- Sarkar, K., Bal, B., Mukherjee, R., Saha, M. K., Chakraborty, S., Niyogi, S. K. and Bhattacharya, S. K. (2006) 'Young age is a risk factor for HIV among female sex workers--an experience from India', *J Infect*, vol. 53, 4, pp. 255-259.
- Scheper-Hughes, N. (1997) 'Demography without Numbers', in *Anthropological Demography - Toward a New Synthesis*, eds D. I. Kertzer and T. Fricke, pp. 201-222, The University of Chicago Press Ltd., Chicago, London.
- Schiller, N. G., Crystal, S. and Lewellen, D. (1994) 'Risky business: The cultural construction of AIDS risk groups', *Social Science & Medicine*, vol. 38, 10, pp. 1337-1346.
- Schiltz, M. A. and Sandfort, T. G. (2000) 'HIV-positive people, risk and sexual behaviour', *Soc Sci Med*, vol. 50, 11, pp. 1571-1588.
- Schoepf, B. G. (1995) 'Culture, sex research and AIDS in Africa', in *Culture and sexual risk: anthropological perspectives on AIDS*, eds H. t. BRUMMELHUIS and G. HERDT, pp. 29-51, Gordon and Breach, Amsterdam.
- Scholes, D., McBride, C. M., Grothaus, L., Civic, D., Ichikawa, L. E., Fish, L. J. and Yarnall, K. S. (2003) 'A tailored minimal self-help intervention to promote condom use in young women: results from a randomized trial', *Aids*, vol. 17, 10, pp. 1547-1556.
- Sehgal, P. N., Saulina Arnold (1994) *Knowledge, Attitude, Beliefs and Practices (KABP) study related to AIDS in Tamil Nadu, India and Intervention Strategies*, Voluntary Health Association of India, New Delhi, p. 71.
- Seidel, G. (1993) 'The competing discourses of HIV/AIDS in sub-Saharan Africa: Discourses of rights and empowerment vs discourses of control and exclusion', *Social Science & Medicine*, vol. 36, 3, pp. 175-194.



- Selvan, M. S., Ross, M. W., Kapadia, A. S., Mathai, R. and Hira, S. (2001) 'Study of perceived norms, beliefs and intended sexual behaviour among higher secondary school students in India', *AIDS Care*, vol. 13, 6, pp. 779-788.
- Sen, S. (1995) 'Campaign Against HIV/AIDS: Youth as Force for Change', *Indian Paediatrician*, vol. 32, pp. 519-527.
- Setel, P. W. (1999) *A plague of paradoxes : AIDS, culture, and demography in northern Tanzania*, University of Chicago Press.
- Sethi, G. (2002) 'AIDS in India: The Government's Response', in *Living with the AIDS Virus: The Epidemic and the response in India*, eds Samiran Panda, Anindya Chatterjee and A. S. Abdul-Quader, Sage, New Delhi.
- Shaikh, J. S. (2004) *Are the tech savvy wired for infidelity?*, Times News Network, Available at: <http://economictimes.indiatimes.com/articleshow/642417.cms>.
- Shanmuganandan, S., A Uma and R Maniyosai (1996) HIV Infection and HIV Risk Behaviour among Truck Drivers in Tamil Nadu, India: An attempt at modelling the Risk Factors, paper presented to XI International Conference on AIDS, Vancouver.
- Sharma, A. (2003) *Gates Foundation Doubles India AIDS Grant*, AIDS-INDIA yahoo group, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/2840>.
- Sharma, A. K. (2006) 'HIV and law in India: Need for an Act of Parliament to Protect the Vulnerable and Related Issues', *Population Review*, vol. 45, 2, pp. 72-84.
- Sharma, D. C. (1999) 'Indian government re-evaluates AIDS control', *The Lancet*, vol. 354, 9183, p. 1010.
- Sharma, R. (2001) 'Project launched in India to measure the size of men's penises', *British Medical Journal*, vol. 323, p. 826.
- Sharma, R. (2001a) 'Condom use seems to be reducing number of new HIV/AIDS cases', *British Medical Journal*, vol. 323, p. 417.

- Sherman, S. G., Celentano, D. A., McGrath, J. W., Chard, S. E., Gangakhedkar, R. R., Joglekar, N., Malhotra-Kohli, R., Kanya, M. and Fullem, A. (2003) 'The reliability and validity of the Modified Condom Outcome Expectancy Scale (MCOES) among an international sample of HIV-negative partners of people living with HIV/AIDS', *AIDS Care*, vol. 15, 3, pp. 359-366.
- Sherr, L. and Strace, F. (1998) 'Suicidal behaviours, euthanasia and AIDS', *AIDS*, vol. 12, pp. 339-347.
- Shoveller, J. A. and Pietersma, W. A. W. (2002) 'Preventing HIV/AIDS Risk Behavior Among Youth', *AIDS and Behaviour*, vol. 6, 2, pp. 123-129.
- Sieber, S. D. (1973) 'The integration of field work and survey methods', *American Journal of Sociology*, vol. 78, pp. 1335-1359.
- SifyNews (2002) 'Let's watch hard porn, says Indian Censor Board chief', *SifyNews*, 25 June.
- Silverman, J. G., Decker, M. R., Gupta, J., Maheshwari, A., Patel, V. and Raj, A. (2006) 'HIV prevalence and predictors among rescued sex-trafficked women and girls in Mumbai, India', *J Acquir Immune Defic Syndr*, vol. 43, 5, pp. 588-593.
- Simoes, E. A. F., Babu, P. G. and John, J. T. (1987) 'Evidence for HTLV - III infection in prostitutes in Tamil Nadu', *Indian Journal of Medical Research*, vol. 85, pp. 335-338.
- Simoes, E. A. F., Babu, P. G., Jeyakumari, H. M. and John, J. T. (1993) 'The initial detection of Human Immunodeficiency Virus - I and its subsequent spread in prostitutes in Tamil Nadu, India', *Journal of Acquired Immune Deficiency Syndrome*, vol. 6, 9, pp. 1030-1034.
- Singh, N. K. (1991) 'Health for the millions', *AIDS and Society*, vol. 17, pp. 29-30.
- Singh, Y. N. and Malaviya, A. N. (1994) 'Long distance truck drivers in India: HIV infection and their possible role in disseminating HIV into rural areas', *Int J STD AIDS*, vol. 5, 2, pp. 137-138.

- Singh, Y. N. and Malaviya, A. N. (1994a) 'Experience of HIV prevention interventions among female sex workers in Delhi, India', *International Journal of STD & AIDS*, vol. 5, pp. 56-57.
- Sivaram, S., Johnson, S., Bentley, M. E., Go, V. F., Latkin, C., Srikrishnan, A. K., Celentano, D. D. and Solomon, S. (2005) 'Sexual health promotion in Chennai, India: key role of communication among social networks', *Health Promot Int*, vol. 20, 4, pp. 327-333.
- Smith, A. M. A., Jolley, D., Hocking, J., Benton, K. and Gerofi, J. (1998) 'Does penis size influence condom slippage and breakage?' *International Journal of STD & AIDS*, vol. 9, 8, pp. 444-447.
- Smith, A. M. A., Jolley, D., Hocking, J., Benton, K. and Gerofi, J. (1999) 'Factors affecting men's liking of condoms they have used', *International Journal of STD & AIDS*, vol. 10, 4, pp. 258-262.
- Smyth, F. (1998) 'Cultural constraints on the delivery of HIV/AIDS prevention in Ireland', *Social Science & Medicine*, vol. 46, 6, pp. 661-672.
- Solomon, S., Kumarasamy, N., Ganesh, A. K. and Amalraj, R. E. (1997) 'Prevalence and risk factors of HIV-1 and HIV-2 infection in urban and rural areas in Tamil Nadu, India', *International Journal of STD & AIDS*, vol. 8, pp. A1025.1021-1026.
- Srikanth, P., John, T. J., Jeyakumari, H., Babu, P. G., Mathai, D., Jacob, M., Cherian, A. M., Ganesh, A. and Zachariah, A. (1997) 'Epidemiological features of acquired immunodeficiency syndrome in southern India', *Indian Journal of Medical Research*, vol. 105, pp. 191-197.
- Srinivasa Rao, A. S. (2003) 'Can we obtain realistic HIV/AIDS estimates for India?' *J Biosci*, vol. 28, 4, pp. 367-369.
- Steckler, A., McLeroy, K. and Goodman, R. (1992) 'Toward integrating qualitative and quantitative methods: an introduction', *Health Educ Q*, vol. 19, 1, pp. 1-8.
- Steinbrook, R. (2007) 'HIV in India - The Challenges Ahead', *The New England Journal of Medicine*, vol. 356, 12, pp. 1197-1201.

- Stevens, P. E. (1994) 'HIV prevention education for lesbians and bisexual women: A cultural analysis of a community intervention', *Social Science & Medicine*, vol. 39, 11, pp. 1565-1578.
- Stover, J., Walker, N., Garnett, G. P., Saolomon, J. A., Stanecki, K. A., Ghys, P. D., Grassly, N. C., Anderson, R. M. and Schwartlander, B. (1999) 'Can we reverse the HIV/AIDS pandemic with an expanded response?' *The Lancet*, vol. 360, pp. 73-77.
- Suchman, L. and Jordan, B. (1992) 'Validity and the collaborative construction of meaning in face-to-face surveys', in *Questions about Questions: Inquiries into the Cognitive Bases of Surveys*, ed. J. M. Tanur, pp. 241-267, Russell Sage Foundation, NY.
- Sudha, R. T., Vijay, D. T. and Lakshmi, V. (2005) 'Awareness, attitudes, and beliefs of the general public towards HIV/AIDS in Hyderabad, a capital city from South India', *Indian J Med Sci*, vol. 59, 7, pp. 307-316.
- Susser, I. (2001) 'Sexual Negotiations in Relation to Political Mobilization: The prevention of HIV in a comparative context', *AIDS and Behaviour*, vol. 5, 2, pp. 163-172.
- Taghizade, M. (2005) 'Attitude and knowledge of adolescent girls about prevention of HIV/AIDS', *Nurs J India*, vol. 96, 2, pp. 40-42.
- Tanga, S. M. (2004) *Karnataka to enact law to make pre-marital HIV test mandatory*, AIDS-INDIS yahoo group, Available at: <http://health.groups.yahoo.com/group/AIDS-INDIA/message/3139>.
- Tesch, R. (1990) *Qualitative Research: analysis types and software tools*, Falmer, London.
- Thakur, B. B. (1998) Epidemiology of HIV/AIDS in India, paper presented to Symposium on AIDS in India, Pune, Harvard AIDS Institute.
- Thomas, B. E., Rehman, F., Malaisamy, M., Dilip, M., Suhadev, M., Priyadarsini, P., Purushotham, N. K. and Swaminathan, S. (2004) 'A study of condom acceptability among men in an urban population in South India', *AIDS Behav*, vol. 8, 2, pp. 215-220.

Thomas, J. and Bandyopadhyay, M. (2003) 'Why India should disregard the advise of Potts and Walsh', *British Medcial Journal*, vol. 326, 7403.

Tibdewel, S. S. and Wadhva, S. K. (2001) 'HIV/AIDS awareness among hospital employees', *Indian J Med Sci*, vol. 55, 2, pp. 69-72.

TimesNewsNetwork (2004) *Programme to prevent spread of AIDS on the cards*, Available at: <http://timesofindia.indiatimes.com/articleshow/480589.cms>.

TimesofIndia (2003) 'Bill Gates Million: Grant Dependency Will Drag Us Down', *Times of India*, Oct. 27.

TNSACS (1999) *Meeting the Challenge in Tamil Nadu State, India*, Tamil Nadu State AIDS Control Society, Chennai, India.

TNSACS (2002) *History of TNSACS*, Available at: <http://tnsacs.tn.nic.in/>.

TNSACS (2003) *Sero-surveillance of HIV/AIDS in Tamil Nadu*, Tamil Nadu State AIDS Control Organisation, Chennai.

TNSACS and ORG (1998) *Special Behaviour study in TN - a dissemination seminar*, TNSACS, ORG, 1998, Tamil Nadu State AIDS Control Society.

Todd, J., Balira, R., Grosskruth, H., Mayaud, P., Mosha, F., Ka-Gina, G., Klokke, A., Gabone, R., Gavyole, A., Mabey, D. and Hayes, R. (1997) 'HIV-associated adult mortality in a rural Tanzanian population', *AIDS*, vol. 11, 801-807.

Tricoles, R. (2007) 'HIV/AIDS conference focuses on Indian cultural challenges', *Emory Report*, vol. 59, 21, p. 1.

Trostle, J. A. (2005) *Epidemiology and Culture*, Cambridge University Press, NY.

Tully, M. (2004) *India's struggle to befriend investors*, Available at: <http://news.bbc.co.uk/1/hi/business/3720852.stm>.

Tuomi, I. (1999) Data is more than knowledge: implications of the reversed knowledgehierarchy for knowledge management and organizational memory, paper presented to HICSS-32. Proceedings of the 32nd Annual Hawaii

International Conference on Volume Track1, Maui, HI, USA, vol. HICSS-32, p. 12.

Turner, C. F., Miller, H. G. and Moses, L. E. (1989) *AIDS Sexual Behaviour and Intravenous Drug Use*, Committee on AIDS Research and the Behavioural, Social and Statistical Sciences, National Research Council, National Academy Press, Washington DC.

Ubaidullah, M. (2004) 'Social vaccine for HIV prevention: a study on truck drivers in South India', *Soc Work Health Care*, vol. 39, 3-4, pp. 399-414.

Ulin, P. R., Elizabeth T Robinson, Elizabeth E Tolley and McNeill, E. T. (2002) *Qualitative Methods: A field guide for applied research in sexual and reproductive health*, Family Health International, North Carolina, USA.

UNAIDS-India (2000) *Annual Report*, New Delhi.

UNAIDS-India (2003) *India announces 4.58 million Indians are living with HIV/AIDS*, Available at: <http://www.youandaids.org/News/Headlines.asp?ID=84EA56E6BE8411D786CC00508B6D18B8#>.

UNAIDS (1998) *Looking Deeper into the HIV Epidemic: A Questionnaire for Tracing Sexual Networks*, Best Practise Collection, Joint United Nations Programme on HIV/AIDS.

UNAIDS (2000) *A measure of success: changing behaviour in Tamil Nadu*, Report on Global HIV/AIDS epidemic, Geneva.

UNAIDS (2000b) *How reliable are estimates of HIV infection and AIDS deaths*, Report on the global HIV/AIDS epidemic, UNAIDS, Geneva, Switzerland.

UNAIDS (2000c) *HIV and AIDS-related stigmatization, discrimination and denial: forms, contexts and determinants*, Research studies from Uganda and India, Best Practice Collection, UNAIDS, Geneva, p. 40.

UNAIDS (2000d) *India Responds to HIV/AIDS - A strategic response to the HIV epidemic by the Government of India, the UN and its development partners in India*.

UNAIDS (2001) *Twenty years of HIV/AIDS*, Available at:  
[www.unaids.org/fact\\_sheets/files/AIDStwenty\\_en.html](http://www.unaids.org/fact_sheets/files/AIDStwenty_en.html).

UNAIDS (2001a) *Country Success*, Available at:  
[www.unaids.org/fact\\_sheets/files/successes\\_Eng.html](http://www.unaids.org/fact_sheets/files/successes_Eng.html).

UNAIDS (2002) *Report on the global HIV/AIDS*, UNAIDS/02.26E, ISBN 92-1973-185-4.

UNAIDS (2002b) *Monitoring & Evaluation in UNAIDS*, UNAIDS, Available at:  
<http://elink.unaids.org/menew/default.asp>.

UNAIDS (2004) *Report on the Global AIDS Epidemic*, Joint United Nations Programme on HIV/AIDS, Geneva, p. 236.

UNAIDS (2006) *Report on the global AIDS epidemic*, Geneva, p. 629.

UNAIDS/WHO (2002) *AIDS epidemic update*, UNAIDS/WHO, Geneva, p. 45, UNAIDS/02.46E.

UNAIDS/WHO (2002a) *Report of the global HIV/AIDS epidemic 2002: Table of country-specific HIV estimates and data end 2001*.

UNPD (2002) *AIDS Awareness High, but Behaviour remains risky*, UN Population Division, NY.

USBureauofCensus (2002) *HIV/AIDS Surveillance Data Base*, International Programs Center, Population Division, Available at:  
<http://www.census.gov/ipc/hiv/India.pdf>.

Usmani, F. (1999) *Sexual Behaviour linked to HIV/AIDS*, UNFPA, New Delhi, pp. 1-8.

van Kerkwijk, C. (1995) 'The Dynamics of Condom Use in Thai Sex Work with Farang Clients', in *Culture and Sexual Risk: Anthropological Perspectives on AIDS*, eds Han ten Brummelhuis and G. Herdt, pp. 115-134, Gordon and Breach Publishers, New York, Amsterdam.

- Van Maanen, J. (ed.) (1985) *Qualitative Methodology*, Sage, Beverly Hills, London, New Delhi.
- Verma, R. K. (1999) *A study of commercial sex workers at Bhiwandi and Vashi*, IIPS, Mumbai.
- Verma, R. K. and Roy, T. K. (2002) 'HIV Risk Behaviour and the Sociocultural Environment in India', in *Living with the AIDS Virus: The Epidemic and the response in India.*, ed. A. C. Samiran Panda, Abu S Abdul-Quader, Sage, New Delhi.
- Vinh, D., Raguin, G., Thebaud, Y., Semaille, C. and Tri, L. (2003) 'Knowledge, attitudes, belief and practice related to HIV/AIDS among young people in Ho Chi Minh City, Vietnam', *European Journal of Epidemiology*, vol. 18, 8, pp. 835-836.
- Vivian, F. G., C Johnson Sethulakshmi, Margaret E Bentley, Sudha Sivaram, AK Srikrishnan, Suniti Solomon and Celentano, D. D. (2003) 'When HIV-Prevention Messages and Gender Norms Clash: the Impact of domestic violence on Women's HIV Risk in Slums of Chennai, India', *AIDS and Behaviour*, vol. 17, 3.
- Walker, N., Stanecki, K. A., Brown, T., Stover, J., Lazzari, S., Farcia-Celleja, J. M., Schwartlander, B. and Ghys, P. D. (2003) 'Methods and procedures for estimating HIV/AIDS and its impact: the UNAIDS/WHO estimates for the end of 2001', *AIDS*, vol. 17, pp. 2215-2225.
- Ward, M. (1993) 'Chapter X', in *Social Research in Developing Countries: Surveys and Censuses in the Third World*, eds M. Bulmer and D. P. Warwick, p. 383, UCL Press, London.
- Weeramunda, A. J. (1996) *NGOs working with Sex Workers - A Personal Perspective*, UNDP Regional Project on HIV and Development, New Delhi.
- Weiss, R. S. (1994) *Learning from strangers: the art and method of qualitative interview studies*, The free press, a division of Macmillan Inc., NY, Toronto, Oxford, Singapore, Sydney.



Wellings, K. and Macdowall, W. (2000) 'Evaluating Mass media approaches', in *Evaluating Health Promotion- Practice and Methods*, ed. M. T. Y. Coombes, pp. 113-128, Oxford University Press, Oxford.

White, R., Cleland, J. and Carael, M. (2000) 'Links between premarital sexual behaviour and extramarital intercourse: a multi-site analysis', *AIDS*, vol. 14, pp. 2323-2331.

WHO (1994) *Evaluation of a National AIDS Programme: A Methods Package*, Global Programme on AIDS, World Health Organisation, Geneva.

WHO (1998) *Demographic Data for Health Situation Assessment and Projections*, Division of Health Situation and Trend Assessment, World Health Organisation, Geneva.

WHO (2006) *HIV/AIDS: Information, Education and Communication*, Available at: [http://www.searo.who.int/en/Section10/Section18/Section356/Section424\\_16\\_12.htm](http://www.searo.who.int/en/Section10/Section18/Section356/Section424_16_12.htm).

Whyte and Alberti (1993) 'Chapter XXIII', in *Social Research in Developing Countries: Surveys and Censuses in the Third World*, eds M. Bulmer and D. P. Warwick, p. 383, UCL Press, London.

William, F. (1993) *Constructing questions for interviews and questionnaires: Theory and practice in social research*, Cambridge University Press.

Williams, J. R., Foss, A. M., Vickerman, P., Watts, C., Ramesh, B. M., Reza-Paul, S., Washington, R. G., Moses, S., Blanchard, J., Lowndes, C. M., Alary, M. and Boily, M. C. (2006) 'What is the achievable effectiveness of the India AIDS Initiative intervention among female sex workers under target coverage? Model projections from southern India', *Sex Transm Infect*, vol. 82, 5, pp. 372-380.

Wolff, B., Knodel, J. and Sittitrai, W. (1991) *Focus groups and surveys as complementary methods: examples from a study of the consequences of family size in Thailand*, Population Studies Center, University of Michigan, Ann Arbor, MI, Research report no. 91-213.

Yin, R. K. (1989) *Case Study Research: Design and Methods*, 2nd edn, Sage, London.

# Appendix A: History of HIV/AIDS in India and Organisations working on related issues

## A.1 Chronological History of HIV/AIDS in India, 1999

Month/Year	Program
Oct 1985	Screening for HIV initiated at the Christian Medical College, Vellore and the National Institute of Virology, Pune
Feb 1986	First cases of serologically identified HIV in CSWs (n=10) in Madras, TN
April 1986	National AIDS Surveillance Program initiated by the ICMR
May 1986	First patient with end-stage AIDS detected, in Bombay (Mumbai), recipient of unscreened blood in USA
Dec 1986	First seropositive man detected, at an STD clinic in Tamil Nadu
July 1987	First seropositive blood donor detected, in Vellore, Tamil Nadu
July 1987	First case of spouse-to-spouse transmission recorded
Oct 1987	First seropositive infant detected
April 1988	First case of AIDS acquired in India
Jan 1989	Evidence of HIV antibodies in indigenously produced blood products
1986 - 1990	602,096 samples tested for HIV by the ICMR. A total of 4,515 found to be HIV positive
By 1990	Government set up surveillance centres in 23 states and union territories equipped to conduct the ELISA test. Four centres set up for Western Blot testing. 128 Blood Banks set up for HIV screening
Jan 1990	Cluster of seropositives found among IVDUs in north-east India
Dec 1990	HIV-2 first reported from Mumbai. Cases also detected in Madras and Visakhapatnam.
1990 - 1992	Medium-Term Plan formulated for Manipur, Maharashtra, Tamil Nadu, West Bengal and the union territory of Delhi
July 1992	NACO formed for the control and prevention of HIV/AIDS
July 1992	National AIDS Research Institute formed for co-ordination and evaluation of HIV research
Dec 1994	Reports of HIV & AIDS from all but two of the 32 states and union territories
1996	Supreme Court directive making HIV screening mandatory in all blood banks

## A.2 Networking during preliminary feasibility work: Aug. – Sept. 1997

1. **Tamil Nadu State AIDS Control Society:**  
Mr Ramasundaram, Director  
Mr P K Palanisamy, Deputy Director  
Dr V Rajalakshmi, Chairperson, Women's Ad-hoc Committee  
Dr Vimala Ramalingam, & Mrs Usha Raghavan, Project Co-ordinator
2. **Tuberculosis Research Centre (Indian Council of Medical Research), Chennai:**  
Dr Thilakavathy, Projects on AIDS & Women,
3. **Government hospitals in Madras:**  
Dr Jeyakar Paul, Madra Medical College, Head of Microbiology, In-charge of HIV/AIDS patients  
Dr Shameem Banu, Head of Microbiology, Madras Medical College  
Ms Adeline Francis, Dept. of Experimental Medicine, Tamil Nadu Dr MGR Medical University
4. **Government Hospital for Thoracic Medicine:**  
Dr C N Theivanayagam, Superintendent
5. **Department of Social Defence:**  
Tirumati. Kannagi Packianathan, Director, Projects for PLWHA & homes for CSWs
6. **Non-Governmental Organisations:**  
YRG Care, Chennai: Dr Suniti Solomon, Director  
Dr Kumarasamy-Medical Assistants & Project Officers  
Voluntary Health Services:  
Dr Krishnamoorthy, Director  
Dr Lakshmi Bai, Women's Sexual & Reproductive Health  
Dr Vijaya Srinivasan, TTR Foundation:  
Mr Anand Kumar, expert on *Siddah* Medicines
7. **Department of Health & Family Welfare**  
Mrs Kasturi Thangaivanan, Joint Director of Women & Health Statistical Officers
8. **J J Hospital in Mumbai:**  
Dr Subash Hira, AIDS Research & Control Programme (ARCON)
9. **Other organisations in Mumbai:**  
Indian/People's Health Organisation, Mr Srinivasa Rao  
Centre for Social and Technological Change: Dr Radhika Ramasubban
10. **Tata Institute of Social Sciences, Mumbai: Dr Vimala Nadkarni, Professor**
11. **National Institute of Mental Health and Neuro Sciences: Bangalore**  
Dr Jeyashree Ramakrishnan, Department of Health Education,

### In Geneva: July 1998

1. **World Health Organisation:**  
Dr Michael Carael, HIV/AIDS Division  
Ms Odile Frank, Reproductive Health Division;
2. **World Council of Churches: Mrs Aruna Gnanadasan, International Projects**

## A.3 Networking during fieldwork: Jan. – July, 1999

1. ***Government Hospital for Thoracic Medicine***  
Dr C N Theivanayagam, Superintendent  
Registered Medical Officer & doctors in wards  
*Siddah* doctors  
Social workers; Mrs. Rita, Mrs Seline and Mrs Devika – dietician
2. ***Christian Medical College & Hospital:***  
Dr O C Abraham, Head of Department of Medicine- Unit I  
Dr J Richard, Professor & Head of Department of Biostatistics  
Dr Anand Zachariah, Department of Medicine, Unit I  
Dr Padmini Jasper, Professor & Head Obstetrics & Gynaecology  
Dr Renu George, Professor of Dermatology  
Dr Susan Pulimood, Department of Dermatology  
Mrs Joyce Rajan, Social Worker  
Dr Vijay Aruldas, Head of Department of Medical Records  
Dr Chellam Kirubakaran, Head of Pediatrics  
Dr Shanthi Dhani Minz, Social Research Project.
3. ***Tamil Nadu State AIDS Control Society***  
Mr K Allaudin, Special Secretary for HIV/AIDS, Health & Family Welfare
4. ***National AIDS Control Organisation***  
Dr Joshi, Joint Director, New Delhi
5. ***Indian Council of Medical Research***  
Dr Padam Singh, Joint Director – Statistics, New Delhi  
Dr Yadav, Statistical Officer, New Delhi  
Dr Thilakavathy, Tuberculosis Research Centre, Project officer for HIV/AIDS, Chennai
6. ***Tamil Nadu Dr MGR Medical University***  
Dr Mini Jacob, HIV/AIDS research and testing centre.
7. ***Ramachandra Medical College & Research Institute***  
Dr Ramasubramanian, Infectious Diseases, *through* Dr M Venkataramana
8. ***AIDS Research Foundation of India, Chennai***  
Mr R Gunasekaran, Director
9. ***Church of South India Rainy Hospital, Chennai***  
Dr Shyam Prasad, Director  
Dr Sheila Prasad, HIV/AIDS, *through* Dr Percy Sumithran
10. ***International Organisations at New Delhi***  
Dr Farah Usmani, UNFPA  
Mr Amit Sharma, UNAIDS  
Population Council
11. ***Christian AIDS/HIV National Alliance, New Delhi***  
Mr Eddie Mall, Director
12. ***Vijaya Health Centre***
13. ***Madras Medical College, Voluntary Health Services and YRG Care.***

## A.4 Meetings during visit to update data, Sept. 2001

1. Indian Council of Medical Research, New Delhi  
Dr Deepali Mukherji
2. Population Foundation of India, New Delhi  
Dr Shantannu Dutta, Joint Director (Programmes)
3. Participated in a one-day conference organised by an NGO, Deepak Charitable Trust on  
'Male Sexuality: A Key to HIV/AIDS at New Delhi on 4<sup>th</sup> September.
4. Population Council, New Delhi  
Dr Rangaiya Gurumurthy, Project Director, HIV/STI Programme
5. World Bank, New Delhi  
Mr Peter Heywood
6. Department of Health and Family Welfare, New Delhi  
Dr Lalrintluangi
7. UNAIDS, New Delhi  
Dr David Miller
8. Registrar General of Census, New Delhi  
Mr Jayanth Bhantia
9. National Institute of Health and Family Welfare, New Delhi  
Dr M Bhattacharya, Head of Com. Health
10. National AIDS Control Organisation, New Delhi  
Dr Prasada Rao, Director and Dr P L Joshi
11. Tamil Nadu State AIDS Control Society, Chennai  
Mr Christudas Gandhi, Project Director
12. Madras Institute of Development Studies, Chennai  
Dr C T Kurien
13. AIDS Prevention and Control, Chennai  
Dr Bimal Charles, Project Director
14. Government Hospital for Thoracic Medicine, Chennai  
Dr Rajasekar, Dep. Supt. & Dr. N Ravichandran
15. Directorate of Family Welfare  
Ms S Kasthuri, Joint Director
16. Christian Medical College, Vellore  
Dr Dilip Mathia Head of Medicine -I  
Dr John Muthuswamy, Medical Records
17. Family Health International, Hyderabad  
Dr B Gangaiya, Director for Healthy Highway Project
18. Andhra Pradesh State AIDS Control Society, Hyderabad  
Mr K. Chandramouli, Joint Secretary
19. Directorate of Family Welfare, Hyderabad  
Dr Prasad
20. State Census Office, Hyderabad
21. Indian Institute of Population Studies, Mumbai
22. Tata Institute of Social Services, Mumbai

## Appendix B: Questionnaire

## B.1 English Questionnaire

**Appendix B: Questionnaire**

**Section 1: Individual's Information**

I would first like to obtain some background information from you.

<b>Q #</b>	<b>Questions &amp; filters &amp; Coding Categories: Socio-Economic Background</b>	<b>Skip to</b>
101	Questionnaire identification number & Date of interview	
102	Do you know your Date of Birth/ Can you tell me how old you are? (probe for best estimate & also check with hospital records)	DD/MM/YR <input type="text"/> <input type="text"/> Yrs
103	Record the sex of the respondent	Male 1      Female 2
104	Name of place	Rural 1      Urban 2
105	How many years have you lived at this address? If moved from home town, reason:	
106	What is your mother tongue? Tamil 1      Telugu 2      Malayalam 3      Kannada 4      Others (specify)..... 5	
107	Have you ever attended school? If YES, how many years of full time education did you have?	Yes 1      No 2 <input type="text"/> <input type="text"/> Yrs      (no school code 00) → 110
108	What was your medium of instruction at school? English 1      Tamil 2      Telugu 3      Hindi 4      Others (specify)..... 5	
109	What is the highest level of education that you have completed? Secondary 2      Tech./dip./voc. 3      Undergraduate 4      Post-graduate 5      Primary 1      Professional 6      any of these cases → 111 Others (specify) ..... 7	
110	Can you read a letter or newspaper? Yes, easily 1      Yes, with difficulty 2      No, but listen to newspaper being read at home 3 No, but listen to newspaper being read in the tea shop 4      No, neither listen nor read 5      if 5 → 112 (If 3-5, also ask) Can you sign your name? Yes 1      No, use thumb impression 2	



Q #	Questions & filters & Coding Categories	Skip to
111	During the past month how often have you read/listened to reading a newspaper? Everyday 1    Most days 2    At least once a week 3    Less often 4    Not even once 5	
112	During the past month how often have you listened to the radio? Everyday 1    Most days 2    At least once a week 3    Less often 4    Never 5	
113	Do you have access to a television? Yes, at home 1    Yes, neighbour's house 2    Yes, village community 3    No access 4	if 4 → 114
	In the past month how often have you watched TV? Everyday 1    Most days 2    Atleast once a week 3    Less often 4    Never 5	
114	How often do you go to the cinema? Everyday 1    Most days 2    Atleast once a week 3    Less often 4    Never 5	
115	What religion do you practise? Hindu 1    Muslim 2    Christian 3    No religion 4    Other (specify) ..... 5	if 4 → 117
116	How important is religion to you in dealing with your daily life? Very important 1    Somewhat important 2    Not important at all 3	
117	What is your usual occupation? Are you now employed? What work do you do?	
118	Can you tell me your monthly income from your usual occupation? What is your current source of income?	

**Section 2: Household Information**

I would now like to find out some information about your family and your housing.

**Q # Questions & filters & Coding categories**

201 How many members live in your house? No.

202 Do you live in a joint family or a nuclear family? Joint 1 Nuclear 2

203 I would like to get some information regarding the other members of your family:  
 Relationship to Respondent Sex Age Education Occupation Income Marital status

204 What type of house do you live in?

205 Do you have electricity at home? Yes 1 No 2  
 If No, what is your main source of lighting?

206 What is the main source of water in your household?  
 What is the source of your drinking water?

207 Does your household own any of the following?  
 1 Y 2 N      1 Y 2 N      1 Y 2 N      1 Y 2 N      1 Y 2 N  
 electric fan      sofa set      radio      television      vcr/vcp  
 refrigerator      washing machine      bicycle      scooter/motorcycle      car

208 What is the health care facility that you and your family normally use? (This refers to hospital used prior to being detected to be HIV+)

209 How accessible is your most frequented health care facility for you?

### Section 3: Patient's HIV background

#### Q# Questions & filters & Coding Categories

301 When did you first come to this hospital?

302 How and why did you first come here?

303 When did you find out that you are HIV positive?

304 What is the source of your infection?

305 Do your family members know about your being HIV positive?

Yes 1 No 2

306 Do your friends know about your being HIV positive?

Yes 1 No 2

307 Who in your family knows about it?

308 What is their attitude to it?

309 What was your first reaction when you heard that you were HIV positive?

310 How do you feel now?

311 Have you had to make any changes in your life since you were detected to be HIV+?  
If Yes, what are the changes?

Yes 1 No 2

312 If married, is your spouse also infected?

Yes 1 No 2

If No, are you taking precautions to prevent your spouse from being infected?

Yes 1 No 2

If Yes, what do you do?

**Section 4A: Personal habits**

(The questions in the following sections are to be administered after ensuring total confidentiality)  
 These questions are mainly meant to be asked of men. However, use discretion to try the question on women.

Q#	Questions & filters & Coding categories					Skip to Q			
401	Are you a regular smoker?	Yes	1	No	2				
402	Do you take alcoholic drinks?	Yes	1	No	2	if 2 → 406			
403	How often do you have alcoholic drinks in a month? (or ask how often did you take alcoholic drinks last month)	Occasionally	1	Few times a month	2	Couple of times a week	3		
		Few times a week	4	Daily	5				
404	What do you drink and how regularly do you drink it?	Often	Occasionally	No		Often	Occasionally	No	
		Toddy/Arrack			Whisky/Rum				
		Beer			Others(specify).....				
		Wine							
405	Where do you drink?	Often	Occasionally	Never		Often	Occasionally	Never	
		Home			Bar				
		Friend's place			Toddy shop				
		College/Hostel			Others (specify).....				
		Restaurant/Hotel							
406	Have you ever taken any drugs/dope?	Yes	1	No	2		if 2 → 409		
407	How often do you take drugs?	Just few times out of curiosity	1	Occasionally	2				
		Couple of times a month	3	Couple of times a week	4	Daily	5		
408	What drugs do you take?			IVD's	Y	N	Others (specify).....	Y	N
	<i>Ganja</i> (similar to Cannabis)	Y	N						

**Section 4B: Partner Relations**

**Q# Questions & filters & Coding categories**

**Skip to Q**

- 409 What is your marital status?  
 Single 1 Married 2 Separated 3 Divorced 4 Widowed 5 Others (spe.)..... 6 if 1 → 420
- 410 How old were you when you first married?   years
- 411 What was the age of your spouse you first married?   years
- 412 Was your spouse the first person you had sex with? Yes 1 No 2
- 413 Currently how often do you have sex with your spouse in a month?
- 414 Have you ever used condom with your spouse?  
 Yes, always 1 Yes, occasionally 2 Never 3
- 415 Did you use a condom with your spouse in the last one month?  
 Yes, each time 1 Yes, a few times 2 Not even once 3
- 416 Since you were first married, have you had sex with anyone other than your spouse? Yes 1 No 2 if 2 → 423
- 417 Can you tell me who it was with? When was it and how did it happen? How long did you know the person before you had sex? Was it petting or penetrative sex? How often did you have sex with the person? When was the last time? Was it just one person Or have there been others? Have you used a condom during these times? Did you use a condom the last time?

Q#	Questions & filters & Coding categories					Skip to Q
418	Do you have a 'chinna veedu' / do you have one regular partner other than your spouse?	Yes	1	No	2	
419	Do you have more than one spouse? If yes, how many?	Yes	1 (# )	No	2	
420	(Omit this & next question if answer to Q412 is Yes) Have you ever had sex before marriage?	Yes	1	No	2	if 2 → 428
421	Can you tell me how old you were? What was the relationship with the person you had sex with? How old was your partner? How did it happen? How long did you know the person before you had sex? Was it casual sex or penetrative sex? When was the last time with that person? Have you had other partners since the first one? How many? Do you use a condom? Did you use a condom the last time you had sex with someone who is not your spouse?					
422	Have you ever had penetrative sex with a partner married to someone else?	Yes	1	No	2	
423	Can you tell me if you have ever been to a brothel/red light area for sex? (This applied mainly to men, except few women who were CSW's)	Yes	1	No	2	if 2 → 426
424	When was the first time you went there? Who did you have sex with (same sex/opposite sex)? How many times (on an average) would have gone to a brothel? When was the last time?					
425	Do you take care to protect yourself against any infection when you go to the red light area for sex? If Yes, what did you do?					

**Q# Questions & filters & Coding Categories**

426	Have you ever had penetrative sex with a hijra/kojja/ombodu? (ask men only) If Yes, how often? When was the last time? Do you use condoms? Did you use condom the last time?	Yes	1	No	2
427	Have you ever had penetrative sex with a person of your own sex? (mainly for men) If Yes, how often? When was the last time? Do you use a condom each time? Did you use a condom the last time?	Yes	1	No	2
428	Have you ever had an experience of someone getting sexual with you when you were a child? If Yes, can you tell me how old you were and what happened? (If respondent is Single & has no sexual experience before marriage & No to this Q then Skip to Section 5)	Yes	1	No	2
429	Ask this question only if marital status is separated/divorced/widowed: Do you have someone who is your regular partner?	Yes	1	No	2
430	Approximately how often do you have sex in a month?			#	
431	Approximately how often do you have sex in a week?			#	
432	When was the last time you had sex?				
433	In the last twelve months, have you had any infection in your private parts? If Yes, what kind of problem do you have?	Yes	1	No	2
434	If you have a regular partner: Have you done anything to prevent spread the infection to your partner?	Yes	1	No	2
435	What have you done?				

**Section 5A: Knowledge, Attitudes & Beliefs of HIV/AIDS**

**Q# Questions & filters & Coding Categories**

501	Do you know anything about HIV/AIDS?	Yes	1	No	2						
502	If Yes, What do you know about it? (record verbatim what the respondent says, prompt using questions such as; What do you think causes HIV/AIDS? How is it transmitted? Who is most likely to get it?)										
503	Do you think that HIV/AIDS is prevalent in Tamil Nadu?	Highly	1	Moderately	2	Hardly	3	Not at all	4	Don't know	5
504	Do you know if HIV/AIDS is prevalent in your neighbourhood?										
505	Do you know anyone personally who has HIV/AIDS?	Yes	1	No	2	if 2 →	507				
506	How many people do you know? How are they related to you?	#		Relationship							
507	Can you tell by looking at a person if they have HIV/AIDS?	Yes	1	No	2						
508	Can a person who looks healthy but has the HIV virus pass it to other people?	Yes	1	No	2	Don't Know	3				
509	Is there a difference between HIV & AIDS? If Yes, what do you think is the difference?	Yes	1	No	2						
510	Do you think that a person who has HIV/AIDS can be cured? If No, What will happen to the person?	Yes	1	No	2	Don't Know	3				
511	Do you think that a couple should be tested for HIV/AIDS before they get married?	Yes	1	No	2						
512	Do you think that a couple should take a HIV test before your marriage? Would you attempt to ensure that your son/daughter/sibling was tested before marriage?	Yes	1	No	2						
513	Do you think there is any risk of your getting HIV? If Yes, what are the reasons? Can you do anything to protect yourself? What can you do? What have you done?(ask only if patient does not know HIV test result)	Yes	1	No	2						



I will now ask you some specific questions regarding HIV/AIDS. Please listen carefully to each activity being mentioned and then tell me whether you think that the activity is associated with:  
High Risk (HR); Moderate Risk (MR); Low Risk (LR); No Risk at all(NR)

**Q# Questions & filters & Coding Categories**

- 514 Shaking hands with someone who has HIV/AIDS?
- 515 Playing with a child who has HIV/AIDS
- 516 Using public toilets?
- 517 Using public swimming pools?
- 518 Using public water sources?
- 519 Mosquito/bug bite anywhere?
- 520 Mosquito/bug bite when sitting in the same room with someone who has HIV/AIDS?
- 521 If the barber does not clean his blades properly?
- 522 Over a year ago, there were stories of strangers injecting people on the streets/public transports with the HIV virus, can one get HIV this way?
- 523 Taking an injection without sterilizing the needle?
- 524 Receiving or donating blood?
- 525 At a dental clinic?
- 526 Going to a health centre used by people with HIV/AIDS?
- 527 Sharing needles with IV drug users?
- 528 Kissing a person who is HIV+ on the cheek?
- 529 Deep kissing a person who is HIV+?
- 530 Casual sex with someone who is HIV+?
- 531 Sexual intercourse with someone who is HIV+?
- 532 What do you think is the risk of acquiring HIV/AIDS through sexual intercourse with commercial sex workers?  
What can one do to safeguard oneself?
  
- 533 What is the risk of transmitting HIV/AIDS to one's spouse if one is infected?  
What can be done to safeguard from spreading the infection to one's spouse?
  
- 534 What do you think is the risk of a pregnant woman who is HIV+ passing on the infection to the baby?
  
- 535 Do you think that a couple should have a child if either of them are HIV+?
  
- 536 What are the sources through which you have acquired your knowledge about HIV/AIDS?
  
- 537 If a person wants to know more about HIV/AIDS where should one go?  
Which are the places that one can go to test for HIV?

**Section 5B: Knowledge, Attitudes & Use of Condoms**

Q#	Questions & filters & Coding Categories					Skip to Q
538	Do you think that family planning/birth control/contraception should be practiced?	Yes	1	No	2	
539	Can you tell me the family planning measures that you are aware of? (write down all that the respondent mentions)					
540	I would now like to ask you specifically about some birth control measures, kindly tell me what you know about them. (The question, 'have you used (a method of contraception)' should be asked only if the person has had sexual relations)					
1.	Pill					
	Have you heard about pills for contraception?	Yes	1	No	2	if 2 → 540- 2
	(Do not ask if no history of partner) Have you/partner (if male) used any pills for contraception?	Yes	1	No	2	
2.	IUD/Loop/Copper T					
	Have you heard about it?	Yes	1	No	2	if 2 → 540- 3
	(Do not ask if no history of partner) Have you/partner (if male) used it?	Yes	1	No	2	
3.	Injections					
	Have you heard about injections for birth control?	Yes	1	No	2	if 2 → 540-4
	(Do not ask if no history of partner) Have you/partner (if male) used any injections for contraception?	Yes	1	No	2	
4.	Male condoms/ Nirodh					
	Have you heard about male condoms/ nirodh/rubber?	Yes	1	No	2	if 2 → 540-5
	(Do not ask if no history of partner) Have you/partner (if female) used them?	Yes	1	No	2	
5.	Female condoms					
	Have you heard about female condoms?	Yes	1	No	2	if 2 → 540- 6
	(Do not ask if no history of partner) Have you/partner (if male) used them?	Yes	1	No	2	
6.	Female sterilization					
	Have you heard about it?	Yes	1	No	2	if 2 → 540-7
	(Do not ask if no history of partner) Have you/partner (if male) been sterilized?	Yes	1	No	2	

Q#	Questions & filters & Coding Categories					Skip to Q
540 -	7. Male sterilization					
	Have you heard about it? (Do not ask if no history of partner) Have you/partner(if female) been sterilized?	Yes	1	No	2	if 2 → 540- 8
	8. Rhythm method					
	Have you heard about it? (Do not ask if no history of partner) Have you used it?	Yes	1	No	2	if 2 → 540- 9
	9. Abstinence					
	Have you heard about it? (Do not ask if no history of partner) Have you practised it?	Yes	1	No	2	if 2 → 540-10
	10. Withdrawal					
	Have you heard about it? (Do not ask if no history of partner) Have you/partner(if female) practised it?	Yes	1	No	2	if 2 → 540-11
	11. Foam/ Jelly/ Foaming tablets					
	Have you heard about them? (Do not ask if no history of partner) Have you ever used them?	Yes	1	No	2	if 2 → 541

(If the respondent has not heard of condoms skip the following Q's)

I am going to read some ideas that people have about condoms. Kindly tell me whether you agree or disagree with each of the statements. (Read out each of the questions and ask whether they agree or disagree)

		Agree	Disagree	Don't know
541	Condoms are easy to use			
542	If used properly, condoms are good at preventing pregnancy. If they disagree, ask why?			
543	Condoms are too expensive to use regularly			
544	Condoms can prevent STDs if used properly			
545	Condoms are most appropriate to use with a spouse or regular partner. If they disagree, ask why?			
546	Condom use is against my religion			
547	Condoms make sex less enjoyable			
548	It is advisable to always use a condom with casual partners. Ask why if they agree or disagree.			
549	A spouse could get suspicious that I was visiting a CSW or that I was not being faithful, if I were to insist on the use of a condom			
550	Condoms can prevent HIV/AIDS if used properly			
551	I would use a condom if my partner asked me to			
552	One should not have sex with a casual partner if they do not have a condom. If disagree, ask why?			

## B.2 Tamil Questionnaire

## இணைப்பு

### பகுதி 1

#### தனிநபரின் தகவல்கள்

முதலாவது உங்கள் பின்னணியைக் குறித்து சில தகவல்கள் அறிய விரும்புகிறேன்.

101. வினாப்படிவக் குறியீட்டு எண் மற்றும் நேரிடை பேட்டி நடைபெற்ற நாள்
102. உங்கள் பிறந்த தேதி தெரியுமா? உங்கள் வயது என்ன? நாள் மாதம் வருடம்
103. உங்கள் பாலினம் ஆண் 1 பெண் 2
104. தங்கும் இடம் கிராமம் 1 நகரம் 2
105. இந்த இடத்தில் வாழ்ந்த ஆண்டுகளின் எண்ணிக்கை  
1 வருடம் 1 1-5 வருடங்கள் 5-10 வருடங்கள் 3 10 வருடங்கள் 4
106. உங்கள் தாய்மொழி என்ன?  
தமிழ் 1 தெலுங்கு 2 மலையாளம் 3 கன்னடம் 4 வேறு ஏதாவது 5
107. பள்ளிக்கூடம் சென்றிருக்கிறீர்களா?  
ஆம் 1 இல்லை 2  
(ஆம் என்றால் எத்தனை ஆண்டுகள் கல்வி முடித்திருக்கிறீர்கள்? வருடங்கள்)
108. பள்ளிக் கூடத்தில் கல்வி கற்றமொழி  
ஆங்கிலம் 1. தமிழ் 2 தெலுங்கு 3 உறிந்தி 4 வேறு 5
109. நீங்கள் கற்று முடித்த உயர்கல்வி தகுதி என்ன?  
துவக்க நிலை 1 உயர்நிலை 2 தொழிற் பயிற்சி 3 இளங்கலை 4  
முதுகலை 5 உத்தியோக வாய்ப்புக் கல்வி 6 இவைகளில் ஏதாவது 7  
வேறு ஏதாவது
110. ஒரு கடித்தத்தையோ. நாளிதழையோ வாசிக்க முடியுமா?  
ஆம். சுலபமாக 1 ஆம் கடினத்ததுடன் 2 இல்லை வீட்டில் வாசிப்பதைக்  
கேட்பேன் 3 இல்லை தேநீர் கடையில் வாசிப்பதைக் கேட்பேன் 4  
வாசிக்கவும் தெரியாது கேட்கவும் மாட்டேன் 5 ( 5 என்றால் 112)(3-5 என்றால்  
உங்களுக்கு கையெழுத்து போடத் தெரியுமா?  
ஆம் 1 இல்லை விரல் அச்சிடுவேன் 2
111. கடந்த ஒரு மாதத்தில் எத்தனை முறை செய்தித்தாளை வாசித்தீர்கள் ?  
பிறர் வாசிக்கக் கேட்டீர்கள்?  
தினமும் 1 அநேக நாட்கள் 2 ஒரு வாரத்தில் ஒரு நாளாவது 3

மிக்க குறைவாக 4 வாசிப்பதே இல்லை 5

112. கடந்த மாதத்தில் நீங்கள் எத்தனை முறை வானொலியை கேட்டீர்கள் ?

113. உங்களிடம் தொலைக் காட்சி வசதி உண்டா?

ஆம் வீட்டில் 1 ஆம் அடுத்த வீட்டில் 2 ஆம். கிராம சமுதாயம் 3  
இல்லை 4 4 என்றால் 114

கடந்த மாதம் எத்தனை தடவை தொலைக் காட்சி நிகழ்ச்சிகளைப் பார்த்தீர்கள்?  
தினமும் 1 அநேக நாட்கள் 2 வாரத்திற்கு ஒரு நாளாவது 3  
மிகவும் குறைவாக 4 இல்லை 5

114. சாதாரணமாக எத்தனை நாட்களுக்கு ஒருமுறை திரைப்படம் பார்ப்பீர்கள்?

115. நீங்கள் எந்த மதத்தைச் சார்ந்தவர்கள்?

இந்து 1 முஸ்லீம் 2 கிறிஸ்துவர் 3 எதுவும் இல்லை 4

116. உங்கள் தினசரி வாழ்க்கையில் மதம் எவ்வளவு முக்கியத்துவம் வாய்ந்தது?  
மிகவும் முக்கியம் 1 சுமாராக முக்கியம் 2 முக்கியமே இல்லை 3

117. உங்கள் வேலை என்ன? (முன்பும் இப்போதும் )

தன்வீட்டுப் பணி 1 உத்தியோகம் 2 மேற்பார்வை 3 அலுவலகப் பணி 4  
C.S.W. 5 கூலி 6 பிறர் வீட்டு வேலை 7 ஆட்டோ ஓட்டுநர் 8  
ஓட்டுநர் 9 வேலை இல்லை 10 விவசாயி 11 வேறு ஏதாவது 12

118. உங்கள் பணியில் மாத சம்பளம் என்ன?

20000 க்குமேல் (1) 10001 - 20000 (2) 5001- 10000 (3) 1001 - 5000 (4)  
1000க்கும்குறைவாக (5) சம்பாதிக்கவில்லை (6) சொல்லமுடியாது (7)

## பகுதி 2

உங்கள் குடும்பம் மற்றும் வீடு குறித்து சில தகவல்கள் அறிய விரும்புகிறேன்

201. உங்கள் குடும்பத்தில் எத்தனை பேர் உள்ளனர்?  
எண்ணிக்கை
202. நீங்கள் வாழ்வது எத்தகைய குடும்பம்?  
கூட்டுக் குடும்பம் 1 தனிக் குடும்பம் 2
203. உங்கள் குடும்பத்திலுள்ள நபர்களைக் குறித்த சில தகவல்களை அறிய விரும்புகிறேன்.  
உங்களுடன் தொடர்புடைய நபருடன் உறவு பாலினம் வயது கல்வி வேலை வருவாய் திருமணமான நிலை
204. நீங்கள் வாழ்கிற வீடு எத்தகையது?  
சுவர்: கான்கிரீட் 1 செங்கல் 2 மண் 3  
கூரை: கான்கிரீட் 1 ஓடு 2 ஆஸ்பெஸ்டாஸ் 3 ஓலை 4
205. உங்களது வீட்டில் மின்வசதி உண்டா? ஆம் 1 இல்லை 2  
இல்லையெனில் வெளிச்சத்திற்காக எதைப் பயன்படுத்துகிறீர்கள்?
206. உங்களது குடிநீர் எங்கிருந்து பெறப்படுகிறது?  
வீட்டில் - வீட்டில் குழாய் 1 தெருக்குழாய் 2 அடிகுழாய் 3  
கிணறு ஏரி முதலியன 4
207. கீழ்க்கண்டவைகளில் ஏதாவது உங்களிடம் இருக்கிறதா?  
மின்விசிறி .  
சோபா இருக்கை  
வானொலி தொலைக்காட்சி வீடியோ ரெக்கார்டு  
குளிர்சாதன்பெட்டி  
துவைக்கும் இயந்திரம்  
மிதிவண்டி ஸ்கூட்டர்  
மோட்டார் சைக்கிள் கார்
208. சரீர் ஆரோக்கியத்திற்காக நீங்களும் உங்கள் குடும்பமும் சாதாரணமாக என்ன உபயோகிக்கிறீர்கள்?  
சொந்த சிகிச்சை 1 உறாமியோபதி ஆயுர்வேதம் 2 ஆரம்பசுகாதார நிலையம் 3  
அரசு நகராட்சி மருத்துவமனை 4 தனியார் மருத்துவமனை 5 வேறுஏதாவது 6
209. இந்த சுகாதார கவனிப்பு வசதி எவ்வளவு தூரத்தில் உள்ளது?  
1கி.மீ.க்குள் (1) 1-5 கி.மீ. (2) 5-10 கி.மீ. (3) 10கி.மீ.க்கு மேல் (4)

நோயாளியின் எச்.ஐ.வி. பின்னணி

301. எப்போது முதலாவது இந்த மருத்துவமனைக்கு வந்தீர்கள்?  
மாதம் வருடம் (மருத்துவமனை குறிப்பேட்டின்படி)
302. எப்படி? மற்றும் ஏன்? இங்கு முதலாவது வந்தீர்கள். விவரிக்கவும்.
303. நீங்கள் ஒரு எச்.ஐ.வி. நோயாளி என்று எப்போது கண்டுபிடித்தீர்கள்?
304. இந்தத் தாக்குதலுக்குக் காரணம் என்ன?
305. நீங்கள் ஒரு எச்.ஐ.வி. நோயாளி என்பது உங்கள் குடும்பத்தினருக்கு தெரியுமா?  
ஆம் 1 இல்லை 2
306. நீங்கள் எச்.ஐ.வி. நோயாளி என்பது உங்கள் நண்பர்களுக்குத் தெரியுமா?  
ஆம் 1 இல்லை 2
307. உங்கள் குடும்பத்தில் யாருக்கு இதுபற்றித் தெரியும்?
308. உங்கள்பேரில் அவர்களின் மனப்பான்மை எப்படியுள்ளது?
309. நீங்கள் எச்.ஐ.வி.நோயாளி என்று முதன்முதல் அறிந்தவுடன் அதை எவ்விதம் ஏற்றுக் கொண்டீர்கள்?
310. இப்போது எப்படி நினைக்கிறீர்கள்?
311. நீங்கள் எச்.ஐ.வி.நோயாளி என்பது தெரிந்ததிலிருந்து உங்கள் வாழ்க்கையில் ஏதேனும் மாறுதல் செய்ய நினைக்கிறீர்களா?  
ஆம் 1 இல்லை 2  
ஆம் என்றால் என்ன மாறுதல்?
312. நீங்கள் திருமணமானவராக இருந்தால் உங்கள் துணைவர் தாக்கப்பட்டுள்ளார்களா?  
ஆம். 1 இல்லை 2.  
இல்லையென்றால் அது உங்கள் துணைவரை தாக்காமலிருக்க முன்னெச்சரிக்கை மேற்கொண்டிருக்கிறீர்கள்?  
ஆம் என்றால் நீங்கள் என்னென்ன முன்னெச்சரிக்கையை மேற்கொண்டிருக்கிறீர்கள்.



பகுதி 4 அ

சொந்தப் பழக்க வழக்கங்கள்

கீழே குறிப்பிடப்பட்டுள்ள கேள்விகளை பதிலுரைப்பவரின் நம்பிக்கையைப் பெற்ற பின்பு கேட்கவேண்டும்.

401. நீங்கள் வழக்கமாக புகை பிடிப்பவரா?  
ஆம் 1 இல்லை 2
402. நீங்கள் மதுபானம் அருந்துகிறவரா?  
ஆம் 1 இல்லை 2 இல்லை என்றால் 406.
403. ஒரு மாதத்தில் எத்தனை தடவை மதுபானம் அருந்துவீர்கள்? (அல்லது கடந்த மாதத்தில் எத்தனை தடவை மதுபானம் அருந்தினீர்கள்?)  
எப்போதாவது 1 ஒரு மாதத்தில் சில நாட்கள் 2 ஒரு வாரத்தில் 2 தடவை 3 ஒரு சில நாட்கள் 4 தினமும் 5
404. என்ன அருந்துவீர்கள்? அதை எத்தனை முறை அருந்துவீர்கள்?  
கள் விஸ்கி ரம் பீர் மற்றவை(குறிப்பிடுக)  
அடிக்கடி 1 எப்போதாவது 2 அடிக்கடி அல்ல
405. எங்கே அருந்துவீர்கள்? அதை எத்தனை முறை அருந்துவீர்கள் ?  
வீட்டில் நண்பர்களுடன் சாராயக்கடை கல்லூரி விடுதி மற்றவை(குறிப்பிடுக)  
விடுதி உணவகங்கள் (தங்குமிடம்)
406. போதை மருந்து எடுத்துள்ளீர்களா?  
ஆம் 1 இல்லை 2 இல்லை என்றால் 409
407. எப்போதெல்லாம் போதை மருந்து எடுப்பீர்கள்?  
ஆர்வத்தினால் ஒரு சில நேரங்களில் 1 எப்போதாவது 2 ஒருமாதத்தில் இருமுறை 3 ஒரு வாரத்தில் இருமுறை 4 தினமும் 5
408. நீங்கள் எடுக்கும் போதை மருந்து எத்தகையது?  
புகைக்கும் பொருளா? ஆம் 1 இல்லை 2  
கஞ்சா ஊசிமருந்து மற்றவை (குறிப்பிடுக)

பகுதி 4ஆ : உறவு முறைகள்

409. நீங்கள் திருமணமானவரா? ஆம் 1 இல்லை 2  
தனி நபர் பிரிந்து வாழ்பவர் விவாகரத்து பெற்றவர் துணைவரை இழந்தவர்  
மற்றவர்கள் தனிநபர் என்றால் 420க்கு செல்க
410. நீங்கள் திருமணமானபோது உங்கள் வயது என்ன? வருடங்கள்
411. நீங்கள் திருமணமானபோது உங்கள் துணைவரின் வயது என்ன? வருடங்கள்
412. நீங்கள் முதன்முதல் பாலுறவு கொண்டவர் உங்கள் துணைவர்தானா?  
ஆம் 1 இல்லை 2
413. ஒரு மாதத்தில் உங்கள் துணைவருடன் எத்தனை முறை பாலுறவு கொண்டீர்கள்?
414. உங்கள் துணைவருடன் கருத்தடை முறைகள் பயன்படுத்தியதுண்டா?  
ஆம். எப்போதும் 1 ஆம். எப்போதாவது 2. இல்லை 3
415. கடந்த ஒரு மாதமாக உங்கள் துணைவருடன் கருத்தடை முறைகள் பயன்படுத்தப்  
பட்டதா?  
ஆம். ஒவ்வொரு நாளும்1 ஆம். ஒருசில சமயங்களில் 2 ஒருதடவைகூடஇல்லை3
416. நீங்கள் திருமணமான போதிலிருந்து உங்கள் துணைவர் தவிர வேறொருவரிடமாவது  
பாலுறவு கொண்டீர்களா?,  
ஆம் 1 இல்லை 2  
இல்லை என்றால் 423  
ஆம் என்றால் கேள்வி 416ன்
- சரியான விவரத்திற்கு கீழ்க்கண்ட கேள்விகளைக் கேட்கவும்.
- .. நீங்கள் யாருடன் பாலுறவு கொண்டீர்கள்? என்று சொல்ல முடியுமா?  
.. அது எப்பொழுது நடந்தது?  
.. எப்படி நடந்தது?  
.. பாலுறவுக்கு முன் அந்த நபரை எத்தனை காலம் தெரியும்?  
.. அது தழுவிய பாலுறவா? அல்லது உட்செலுத்திய பாலுறவா?  
.. அந்த நபருடன் எத்தனை முறை பாலுறவு கொண்டீர்கள்?  
.. கடைசியாக எப்போது அவருடன் பாலுறவு கொண்டீர்கள்?  
.. அந்த ஒரு நபரிடம் மட்டும்தானா?  
.. வேறு நபர்கள் உண்டா?  
.. கருத்தடை முறைகளை அந்நேரங்களில் உபயோகித்தீர்களா?  
.. கடைசி முறையில் கருத்தடை முறை உபயோகிக்கப்பட்டதா?
417. நீங்கள் பாலுறவு கொண்ட நபர் உறவினர் நண்பர் அயலார் அந்நியர்  
C.S.W.  
காரணம் - நோன்பு மனைவி கர்ப்பினி ஆவல் மது  
போதை மருந்து

418. உங்களுக்கு சின்ன வீடு உண்டா?  
உங்கள் துணைவர் தவிர வேறு எவருடனாவது பாலுறவு உண்டா?  
ஆம் 1 இல்லை 2
419. உங்களுக்கு ஒன்றுக்குமேல் துணைவர் உண்டா? ஆம் என்றால் எத்தனை பேர்?  
ஆம். ( ) 1 இல்லை 2  
இந்தக் கேள்வியையும் அடுத்த கேள்வியையும் கேள்வி 412க்கான பதில் ஆம் என்றால் தவிர்க்க.
420. திருமணத்திற்கு முன் பாலுறவு கொண்டுள்ளீர்களா?  
ஆம் 1 இல்லை 2 எண் 2 என்றால் 428 ஆம் என்றால் சரியான விபரங்களுக்கு கீழ்க்கண்ட கேள்விகளைப் பயன்படுத்துக.
- .. அப்பொழுது உங்கள் வயது என்ன?  
.. நீங்கள் உறவு கொண்டவர் எந்தவகையில் சொந்தம்/ உறவு?  
.. அந்த பங்காளருக்கு அப்போது வயது என்ன?
421. இது எப்படி நிகழ்ந்தது?  
நீங்கள் பாலுறவு கொள்ளும் முன் எவ்வளவு காலமாய் அவரைத் தெரியும்?  
அது சாதாரண பாலுறவா? அல்லது ஊடுருவும் பாலுறவா?  
அந்த நபருடன் கடைசியாக எப்போது பாலுறவு கொண்டீர்கள்?  
அந்த முதல் நபரைத் தவிர வேறு நபர்கள் உள்ளனரா? எத்தனை பேர்?  
கருத்தடைமுறைகளை உபயோகித்தீர்களா?  
உங்கள் துணைவர் அல்லாமல் வேறொருவருடன் நீங்கள் பாலுறவு கொண்டபோது கருத்தடை முறைகளை உபயோகித்தீர்களா?
422. வேறொருவருடைய துணைவருடன் நீங்கள் எப்போதாவது ஊடுருவும் பாலுறவு கொண்டதுண்டா? ஆம் 1 இல்லை 2
423. விபசார விடுதிக்கோ சிவப்பு விளக்குப் பகுதிக்கோ பாலுறவுக்காக நீங்கள் எப்போதாவது சென்றுள்ளீர்களா?  
ஆம் 1 இல்லை 2 எண் 2 என்றால் 426 (இது பெரும்பாலும் ஆண்களுக்கே. C.S.W பெண்கள் இதற்கு தவிப்பானவர்கள்)
424. முதல் தடவையாக எப்போது அங்கு போனீர்கள்? யாருடன் பாலுறவு கொண்டீர்கள்? (ஒரே பாலினமா? எதிர் பாலினமா?)  
விபச்சார விடுதிக்கு எத்தனை தடவை சென்றுள்ளீர்கள்?  
கடைசியாக எப்போது சென்றீர்கள்?
424. நீங்கள் பாலுறவு கொள்ள சிவப்புவிளக்கு பகுதிக்கு சென்றபோது ஏதாவது தொற்றுவின்று உங்களை பாதுகாக்கும் கவனமுறைகளை எடுத்தீர்களா?  
ஆம் என்றால் என்ன முறைகள்
425. அலிகள் போன்றவர்களுடன் ஊடுருவும் பாலுறவு எப்போதாவது கொண்டுள்ளீர்களா?(ஆண்களுக்கு மட்டும்) ஆம் 1 இல்லை 2  
ஆம் என்றால் எத்தனை தடவை? கடைசியாக எப்போது?  
ஆணுறைகளை பயன்படுத்தினீர்களா? கடைசியாக நீங்கள் பாலுறவு கொண்டபோது ஆணுறைகளை பயன்படுத்தினீர்களா?

427. உங்கள் பாலின நபருடன் எப்போதாவது ஊடுருவு பாலுறவு கொண்டுள்ளீர்களா?  
(ஆண்களிடம் கேட்கவும்) ஆம் 1 இல்லை 2  
ஆம் என்றால் எத்தனை தடவை? கடைசியாக எப்போது?  
ஒவ்வொரு தடவையும் ஆணுறைகளை உபயோகித்தீர்களா?  
கடைசிமுறை ஆணுறைகளை பயன்படுத்தினீர்களா?
428. நீங்கள் சிறு பிள்ளையாக இருக்கும்போது யாரோ ஒருவர் பாலுறவுக்காக உங்களை  
அணுகிய அனுபவம் உண்டா? ஆம் 1 இல்லை 2  
ஆம் என்றால் அப்போது உங்கள் வயது என்ன? என்ன நடந்தது?  
(பதில் கூறுபவர் தனிநபர் ஆனாலும் அவருக்கு திருமணத்திற்கு முன் இத்தகைய  
பாலுறவு இல்லை என்றாலும் இந்தக் கேள்விகளுக்கு இல்லை என்று பதில்  
கூறினாலும் பகுதி 5க்கு போய்விடவும்)
429. உங்களுக்கு குறிப்பிட்ட ஒரு நபருடன் பாலுறவு உண்டா? (இக்கேள்வியை  
திருமணமாகி பிரிந்தவர் விவாக ரத்து செய்தவர் கணவர் மனைவியை  
இழந்தவர் ஆகியவரிடம் மட்டுமே கேட்கவும்)  
ஆம் 1 இல்லை 2
430. ஒரு மாதத்தில் சுமாராக எத்தனை தடவை பாலுறவு கொள்கிறீர்கள்?
431. ஒரு வாரத்தில் எத்தனை தடவை பாலுறவு கொள்கிறீர்கள்?
432. கடைசியாக எப்பொழுது பாலுறவு கொண்டீர்கள்?
433. கடந்த 12 மாதங்களில் உங்கள் அந்தரங்க ( ) உறுப்புகளில்  
ஏதாவது தொற்று நோய் பாதிப்பு இருந்ததா? ஆம்.1 இல்லை 2  
ஆம் என்றால் உங்களுக்குள்ள பிரச்சனை என்ன?
434. உங்களுக்கு ஒரு குறிப்பிட்ட நபருடன் பாலுறவு இருந்தால் எச்.ஐ.வி.  
தொற்றுதல் அவருக்கு பரவாமலிருக்க ஏதாவது செய்தீர்களா? நீங்கள்  
என்ன செய்தீர்கள்?

பகுதி 5 அ

எச்.ஐ.வி.மற்றும் எய்ட்ஸ்-ஐக் குறித்த அறிவு. மனப்பான்மை மற்றும் நம்பிக்கை

500. எச்.ஐ.வி. / எய்ட்ஸ் பற்றி உங்களுக்கு என்ன தெரியும்?
501. இதை ஏற்படுத்துவது எது? இது எவ்வாறு பரவுகிறது? அதிகமாக யாருக்கு இந்நோய் ஏற்படுகிறது?
502. தமிழ்நாட்டில் எச்ஐவி/ எய்ட்ஸ் அதிகம் உண்டா ?  
மிக அதிகமாக 1 சுமாராக 2 இல்லை 3 இல்லவே இல்லை 4 தெரியாது 5
- 503 நீங்கள் வாழும் பகுதியில் எச்ஐவி/எய்ட்ஸ் அதிகம் உண்டா?
504. எச்ஐவி/எய்ட்ஸ் உள்ள யாரையாவது உங்களுக்கு நன்றாகத் தெரியுமா?  
ஆம் 1 இல்லை 2 2என்றால் 506.
505. எத்தனை பேரைத் தெரியும்? அவர்களுக்கு உங்களுக்கு எப்படி சொந்தம்?  
உறவுமுறை .
506. ஒரு நபரை பார்த்த மாத்திரத்தில் அவருக்கு எச்ஐவி/ எய்ட்ஸ் உண்டா என்று சொல்லமுடியுமா?  
ஆம்.1 இல்லை 2.
507. ஆரோக்கியமுடையவராய் தோற்றமளிக்கும் ஒருவர் எச்ஐவி. உடையவராயிருப்பின் மற்றவர்களுக்கு அதைக் கடத்தக் கூடுமா?  
ஆம்.1 இல்லை 2. தெரியாது 3.
508. எச்ஐவி.-க்கும் எய்ட்ஸ்-க்கும் வேறுபாடு உண்டா? ஆம்.1 இல்லை.2  
ஆம் என்றால் என்ன வேறுபாடு?
509. எச்ஐவி/எய்ட்ஸ் உள்ள நபர் ஒருவர் குணமடைய முடியுமா?  
ஆம்.1 இல்லை 2. தெரியாது 3.
510. திருமணத்திற்கு முன் ஒரு தம்பதியினர் எச்ஐவி/ எய்ட்ஸ் -க்காக சோதிக்கப்பட வேண்டும் என்று எண்ணுகிறீர்களா?  
ஆம் 1. இல்லை 2 இல்லை என்றால் என்ன நேரிடும்?
511. உங்கள் திருமணத்திற்கு முன் தம்பதியினர் எச்ஐவி. பரிசோதனை எடுக்க வேண்டும் என்று எண்ணுகிறீர்களா?  
ஆம்.1 இல்லை 2.

512. நீங்கள் எச்ஐவி. அடைவதற்கான ஆபத்து இருப்பதாக நினைக்கிறீர்களா?  
ஆம். 1 இல்லை 2. ஆம். என்றால் காரணங்கள் என்ன?

512. உங்களை பாதுகாக்க ஏதேனும் செய்யமுடியுமா? நீங்கள் என்ன செய்ய முடியும்? நீங்கள் என்ன செய்துள்ளீர்கள்?

(எச்ஐவி. சோதனையின் முடிவு (results) தெரியாதவரிடம் மட்டும் கேளுங்கள்) எச்ஐவி எய்ட்ஸ் குறித்து ஒரு சில குறிப்பிட்ட கேள்விகளை இப்போது கேட்க போகிறேன். குறிப்பிடப்பட்டுள்ள செயல்களை மட்டும் மிக கவனமாக கவனித்து இதனுடன் தொடர்புள்ளதா என்று சொல்லுங்கள்.

.. பெரும் அபாயம் (1) சுமாரான அபாயம் (2) குறைந்த அபாயம் (3) அபாயமில்லை.(4)  
.. எச்ஐவி. எய்ட்ஸ் உள்ள ஒருவருடன் கை குலுக்குதல்

.. எச்ஐவி. எய்ட்ஸ் உள்ள குழந்தையுடன் விளையாடுதல்

.. பொது கழிப்பறைகளை பயன்படுத்துதல்

.. பொது நீச்சல் குளங்களைப் பயன்படுத்துதல்

.. பொது நீர் நிலைகளை பயன்படுத்துதல்.

.. எங்கேயாவது கொசு அல்லது மூட்டை கடித்தல்

.. எச்ஐவி. எய்ட்ஸ் உள்ளவரின் அறையில் உங்களை கொசு அல்லது மூட்டை கடித்தல்

.. முடிவெட்டுவர் சவரக் கத்தியை சரியாக சுத்தம் பண்ணாதிருத்தல்

.. ஒரு வருடத்திற்கு முன்பு வீதிகளில் பொது பேருந்து நிலையங்களில் தெரியாத நபர்கள் மக்களை எச்ஐவி-யை ஊசி மூலம் குத்த செய்தல் போன்ற கதைகள் இருந்தன. அவற்றின் மூலம் எச்ஐவி. பரவுமா?

.. எச்ஐவி.-ஐ அடையும் ஆபத்து எவ்விதத்தில் உள்ளது?

.. இரத்தத்தை கொடுத்தல் பெறுதல்

.. பல் மருத்துவ மனையில்

.. எச்ஐவி. எய்ட்ஸ் உடைய மக்கள் பயன்படுத்தும் ஆரோக்கிய மையங்களுக்கு செல்லுதல்.

.. நரம்பு ஊசி மருந்து பயன்படுத்துபவர்களுடன் ஊசியை பகிர்ந்து கொள்ளுதல்

.. எச்ஐவி உள்ள நபரின் கன்னத்தில் முத்தமிடுதல்

- .. எச்ஐவி. உள்ள நபரை அழுத்தமாக முத்தமிடுதல்
- .. எச்ஐவி. உள்ள ஒரு நபரிடம் எதேச்சையாக பாலுறவு கொள்ளுதல்

**C.S.W.** நபர்களுடன் இணையும் பாலுறவு கொள்ளுவதினால் எச்ஐவி அல்லது எய்ட்ஸ்-ஐ அடையும் ஆபத்தைக் குறித்து நீங்கள் என்ன நினைக்கிறீர்கள்?

- .. ஒருவர் தன்னை பாதுகாத்துக் கொள்ள என்ன செய்ய முடியும்?
- .. தம்பதியரில் ஒருவர் எச்ஐவி. எய்ட்ஸ்-னால் பாதிக்கப்பட்டால் அதை மற்றவருக்கு கடத்துவதினால் ஏற்படும் ஆபத்து என்ன?
- .. எச்ஐவி-னால் பாதிக்கப்பட்ட ஒரு கர்ப்பிணி அதை குழந்தைக்கு கடத்துவதினால் உள்ள ஆபத்தைப் பற்றி என்ன நினைக்கிறீர்கள்?
- .. எச்ஐவி./ எய்ட்ஸ் குறித்த அறிவை எவற்றின் மூலம் பெற்றுக் கொண்டீர்கள்?
- .. எச்ஐவி/எய்ட்ஸ் குறித்து மேலும் விபரம் அறிய விரும்பினால் எங்கு போகவேண்டும்?
- .. எச்ஐவி-க்கு பரிசோதனை செய்ய எந்தெந்த இடங்களுக்கு செல்லலாம்?

## பகுதி 5-ஆ

(கருத்தடை முறைகளைப் பற்றிய அறிவும், மனப்பான்மையும், கருத்தடை முறைகளை பயன்படுத்துதலும்)

537. குடும்பக் கட்டுப்பாடு திட்டமிட்ட குடும்பம் கருத்தடை முறைகள் இவற்றை கடைப்பிடிக்க வேண்டும் என்று நினைக்கிறீர்களா?  
ஆம். 1 இல்லை 2.

538. உங்களுக்குத் தெரிந்த திட்டமிட்ட குடும்ப நடவடிக்கைகள் சில கூறமுடியுமா?  
(சொல்லும் முறைகளை எழுதுக)

சில குறிப்பிட்ட குடும்பக் கட்டுப்பாட்டு முறைகளை நான் கேட்கிறேன். அவைகளைக் குறித்து உங்களுக்கு என்ன தெரியும் என்று தயவு செய்து கூறுங்கள்.

கருத்தடை முறையை நீங்கள் உபயோகித்துள்ளீர்களா?  
(பாலுறவுடன் கொண்டவருடன் மட்டும் கேட்கவும்)

1. மாத்திரை

கருத்தடை மாத்திரைகளைக் குறித்து கேள்விப்பட்டுள்ளீர்களா?

ஆம். 1 இல்லை 2. 2 என்றால் 539-2

(துணைவர் இல்லாதவரிடம் கேட்க வேண்டாம்)

நீங்களாவது உங்கள் துணைவராவது ஏதாவது கருத்தடை மாத்திரைகள் உபயோகித்துள்ளீர்களா?

ஆம். 1 இல்லை 2.

2. IUD வளையம் காப்பர் 'T'

இவைகளைப் பற்றி கேள்விப் பட்டிருக்கிறீர்களா?

ஆம் 1 இல்லை 2.. 2 என்றால் 539-3

(துணைவர் இல்லாதவரிடம் கேட்க வேண்டாம்)

நீங்களாவது உங்கள் துணைவராவது உபயோகித்துள்ளீர்களா? ஆம்.1 இல்லை 2.

3. ஊசி

குடும்பக் கட்டுப்பாட்டிற்கான ஊசியை குறித்து கேள்விப் பட்டுள்ளீர்களா?

ஆம் 1 இல்லை 2 2 என்றால் 539-4

(துணைவர் இல்லாதவரிடம் கேட்க வேண்டாம்)

நீங்களாவது உங்கள் துணைவராவது ஏதாவது ஊசி போட்டுள்ளீர்களா?

ஆம்.1 இல்லை 2

4. ஆண்களின் கருத்தடை முறைகள்- நிரோத்

ஆண்களின் கருத்தடை முறைகள் நிரோத் ரப்பர் குறித்து கேள்விப்பட்டுள்ளீர்களா?

ஆம் 1 இல்லை 2 ஆம் என்றால் 539-5

(துணைவர் இல்லாதவரிடம் கேட்க வேண்டாம்)

நீங்களாவது உங்கள் துணைவராவது உபயோகித்துள்ளீர்களா,

ஆம் 1 இல்லை 2



5. பெண்களின் கருத்தடை முறைகள்  
பெண்களின் கருத்தடை முறைகள் குறித்து கேள்விப் பட்டுள்ளீர்களா?  
ஆம் 1 இல்லை 2 ஆம் என்றால் 539-6  
(துணைவர் இல்லாதவரிடம் கேட்க வேண்டாம்)  
நீங்களாவது உங்கள் துணைவராவது உபயோகித்துள்ளீர்களா?  
ஆம் 1 இல்லை 2
6. பெண்களுக்கான அறுவை சிகிச்சை  
இதைக் குறித்து கேள்விப்பட்டுள்ளீர்களா? ஆம்.1 இல்லை 2. ஆம் என்றால் 539-7  
(துணைவர் இல்லாதவரிடம் கேட்க வேண்டாம்)  
நீங்களாவது உங்கள் துணைவராவது அறுவை சிகிச்சை மேற்க்கொண்டுள்ளீர்களா?  
ஆம். 1 இல்லை 2
7. ஆண்களுக்கான அறுவை சிகிச்சை  
இதைக் குறித்து கேள்விப்பட்டுள்ளீர்களா? ஆம்.1 இல்லை 2. ஆம் என்றால் 539-8  
(துணைவர் இல்லாதவரிடம் கேட்க வேண்டாம்)  
நீங்களாவது உங்கள் துணைவராவது அறுவை சிகிச்சை மேற்க்கொண்டுள்ளீர்களா?  
ஆம். 1 இல்லை 2
8. ரிதம் (rhythm) முறை  
இதைக் குறித்து கேள்விப்பட்டுள்ளீர்களா? ஆம்.1 இல்லை 2. ஆம் என்றால் 539-9  
(துணைவர் இல்லாதவரிடம் கேட்க வேண்டாம்)  
நீங்களாவது உங்கள் துணைவராவது அறுவை சிகிச்சை மேற்க்கொண்டுள்ளீர்களா?  
ஆம். 1 இல்லை 2
9. நோன்பு ( abstinence) முறை  
இதைக் குறித்து கேள்விப்பட்டுள்ளீர்களா? ஆம்.1 இல்லை 2. ஆம் என்றால் 539-10  
(துணைவர் இல்லாதவரிடம் கேட்க வேண்டாம்)  
நீங்களாவது உங்கள் துணைவராவது அறுவை சிகிச்சை மேற்க்கொண்டுள்ளீர்களா?  
ஆம். 1 இல்லை 2
10. பின் வாங்குதல் (WITHDRAWAL)  
இதைக் குறித்து கேள்விப்பட்டுள்ளீர்களா? ஆம்.1 இல்லை 2. ஆம் என்றால் 539-11  
(துணைவர் இல்லாதவரிடம் கேட்க வேண்டாம்)  
நீங்களாவது உங்கள் துணைவராவது அறுவை சிகிச்சை மேற்க்கொண்டுள்ளீர்களா?  
ஆம். 1 இல்லை 2
11. FOAM/JELLY/FOAMING மாத்திரை  
இவைகளைக் குறித்து கேள்விப் பட்டுள்ளீர்களா? ஆம் 1 இல்லை 2  
ஆம் என்றால் 540  
(துணைவர் இல்லாதவரிடம் கேட்க வேண்டாம்)  
நீங்களாவது உங்கள் துணைவராவது பயன்படுத்தியது உண்டா?  
ஆம் 1 இல்லை 2

540. கருத்தடை முறைகளை எங்கு பெறலாம்?
- .. ஆரம்ப சுகாதார நிலையம் 01
  - .. குடும்பக் கட்டுப்பாடு மருத்துவமனை 02
  - .. அரசு மருத்துவமனை 03
  - .. சமுதாய பணியாளர் சமூகநல பணியாளர் 04
  - .. பாரம்பரிய மருத்துவர் 05
  - .. நண்பர் உறவினர் 06
  - .. எந்த கடையிலும் 07
  - .. தனியார் மருத்துவர் 08
  - .. மருந்துக்கடை 09
  - .. எங்கும் கிடைக்காது 10
  - .. தெரியாது 98

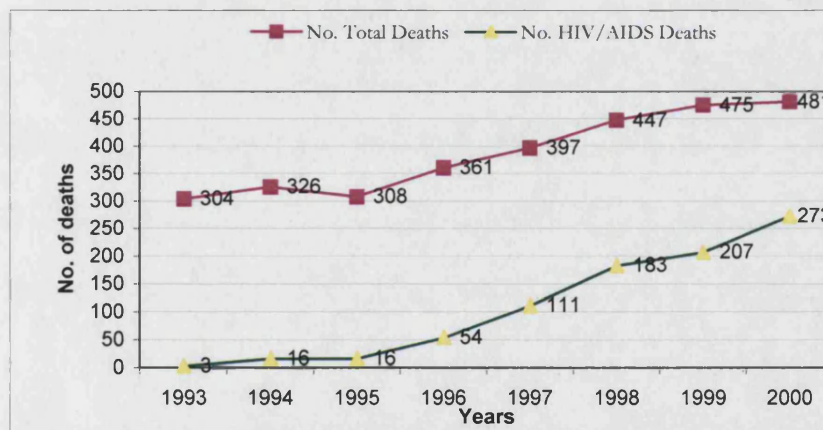
பதிலரைப்பவர் இக்கருத்தடை முறைகளைக் குறித்து கேள்விப்படாதவராயின் கீழ்க்கண்ட கூற்றுக்களுக்கு ஒப்புக் கொள்ளுகிறேன்/ மறுக்கிறேன்/ எனக்குத் தெரியாது என்று பதில் கூறச் செய்யுங்கள்.  
ஒவ்வொன்றாக வாசிப்புகள்:

541. கருத்தடை முறைகள் பயன்படுத்துவது இலகுவானது.
542. சரியாக உபயோகித்தால், ஆணுறை கார்ப்பம் அடைவதை தடுக்கும். (மறுத்தால் ஏன் என்று கேட்கவும்)
543. ஆணுறை மிகவும் விலைஅதிகம். எனவே ஒழுங்காக பயன்படுத்த என்னால் இயலாது
544. சரியாக உபயோகித்தால் இவை S.T.D.ஐத் தடுக்கும்
545. ஒரு துணைவர் அல்லது வழக்கமாக பாலுறவு கொள்பவருடன் பயன்படுத்துவதற்கு சரியானது இல்லை(மறுத்தால் ஏன்? என்று கேட்கவும்)
546. இவைகளை பயன்படுத்துவது என் மத நெறிமுறைகளுக்கு எதிரானது.
547. இவை பாலுறவின் இனிமையைக் குறைக்கிறது.
548. எதேச்சையாக பாலுறவு கொள்வருடன் எப்போதும் ஒரு கருத்தடை முறையை பயன்படுத்துவது நல்லது (ஒப்புக் கொண்டாலும் மறுத்தாலும் ஏன்? என்றுகேட்கவும்)
549. ஆணுறையை பயன்படுத்த வேண்டும் என்று நான் வற்புறுத்தினால் என் துணைவர் என்மேல் சந்தேகப்பட்டு நான் C.S.W.ஐ சந்திப்பதாகவும் அல்லது நான் நம்பிக்கைக்கு பாத்திரமல்ல என்றும் கூறக்கூடும்.
550. சரியாக இவற்றை பயன்படுத்தினால் எச்ஐவி/எய்ட்ஸ்-ஐ தடுக்கலாம்.
551. என் துணைவர் விரும்பினால் நான் ஒரு ஆணுறையை பயன்படுத்துவேன்
552. ஆணுறையை இல்லாமல் எதேச்சையாக ஒருவருடனும் பாலுறவு கொள்ளக்கூடாது. (மறுத்தால் ஏன்? என கேட்கவும்)

## Appendix C: HIV/AIDS Mortality trends based on Hospital's records

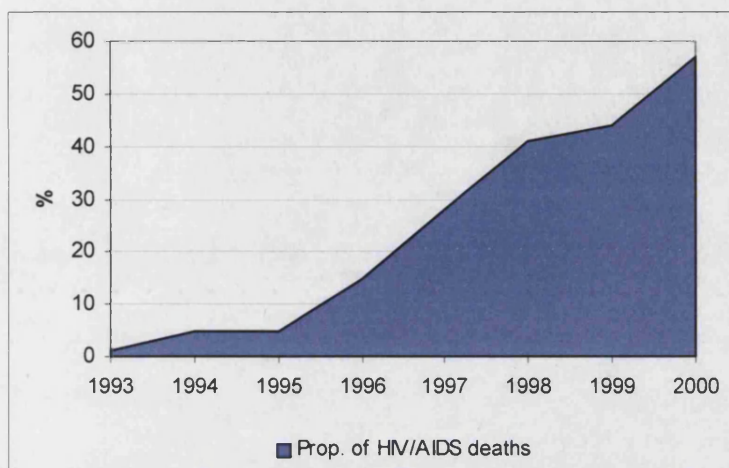
Government hospital for thoracic medicine (GHTM) had recorded HIV patients who had died at the hospital. These records were very basic, not tabulated and in Tamil, which we translated and recorded into tables. This had the advantage of being able to record wherever was available and hence we have been able to develop more estimates with this data. Christian Medical college (CMC) records very available electronically and we were able to get printouts and these estimates were limited to data made available.

### C.1 Total Deaths due to all causes and due to HIV/AIDS, GHTM, 1993-2000



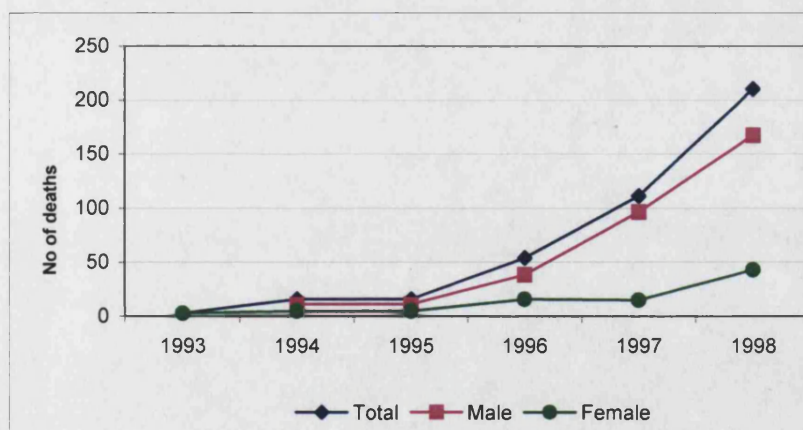
Source: Based on data from GHTM hospital records

## C.2 HIV/AIDS deaths as proportion of total deaths, GHTM, 1993-2000



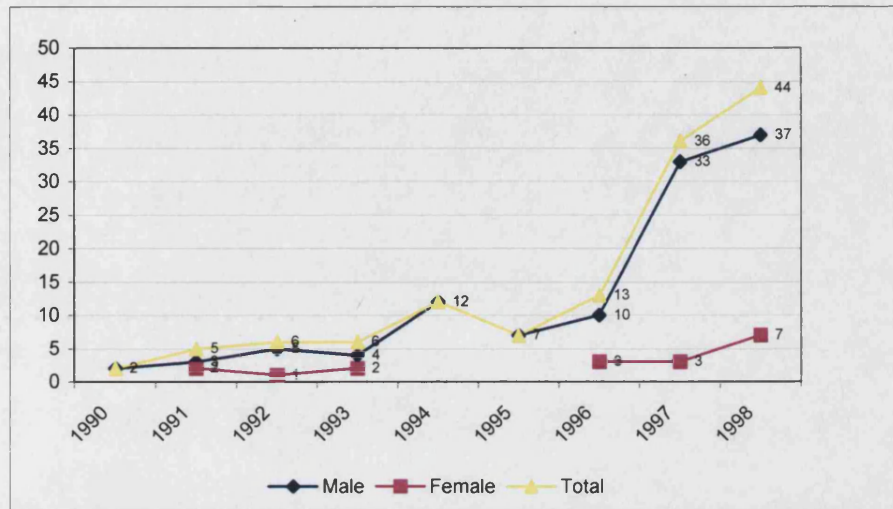
Source: Based on data from GHTM hospital records

## C.3 HIV/AIDS deaths by Gender, GHTM, 1993-1998



Source: Based on data from GHTM hospital records

#### C.4 Deaths due to HIV/AIDS by Gender, CMC, 1990-1998



Source: CMC records, female deaths missing for 1994 & 1995